Building bridges over troubled water

A qualitative evaluation of an implementation study on family involvement in the treatment of persons with psychotic disorders

Kristiane M. Hansson

Dissertation for the Degree of PhD
Centre for Medical Ethics
Institute of Health and Society
Faculty of Medicine

UNIVERSITY OF OSLO
2023

Series of dissertations submitted to the
Faculty of Medicine, University of Oslo

ISBN 978-82-348-0212-6

Cover: UiO.
Print production: Graphic Center, University of Oslo.

Time to be together, to build relations,
is probably the most important ingredient in
good psychiatric treatment – time and continuity.
For the development of mental health care of the future
these two values must be the ones that show the way,
and the ones which our health care structures reflect.

Johannessen & Joa, 2021

Scientific environment

This thesis has been developed through extensive collaboration with several contributors involved in the "Implementation of family involvement for persons with psychotic disorders" (IFIP)-study, funded by the Research Council of Norway, from 2017–2023:

The IFIP research group

Main supervisor

Reidar Pedersen, PI and professor at the Centre for Medical Ethics, University of Oslo.

Co-supervisors

- *Maria Romøren,* Centre for Medical Ethics, University of Oslo; Department of General Practice, University of Oslo.
- *Kristin Sverdvik Heiervang*, Division of Mental Health Services, Akershus University Hospital; Center for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway; Centre for Medical Ethics, University of Oslo; Department of General Practice, University of Oslo.
- *Bente Weimand,* Center for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway; Division of Mental Health Services, Akershus University Hospital.

Co-researchers

- *Lars Hestmark,* Centre for Medical Ethics, University of Oslo.
- *Irene Norheim,* Division of Mental Health and Addiction, Vestre Viken Hospital Trust.
- *Torleif Ruud,* Institute of Clinical Medicine, University of Oslo.
- *Eline Aas,* Department of Health Management and Health Economics, University of Oslo.
- *Reidun Norvoll*, Work Research Institute, Oslo Metropolitan University.
- *Per Bonde Hansen,* Work Research Institute, Oslo Metropolitan University.

Collaborating institutions

- Division of Mental Health Services, Akershus University Hospital.
- Division of Mental Health and Addiction, Vestre Viken Hospital Trust.
- Centre for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway.
- Oslo Metropolitan University, Faculty of Health Sciences and Work Research Institute.
- Early Intervention in Psychosis Advisory Unit for South East Norway, Division of Mental Health and Addiction, Oslo University Hospital (TIPS Sør-Øst).

Acknowledgements

Being part of the IFIP study and writing up this thesis has been, to use a well-known metaphor, a profoundly meaningful journey, and I am thankful that I was given this once-in-a-lifetime opportunity. To me, it turned out to be a series of professional and personal journeys, and I would never have reached the final destination of these journeys without the support from my wonderful professional and social network. I therefore wish to express my sincere gratitude to all the people that have contributed towards making the IFIP study and this thesis a reality:

Reidar Pedersen: For being the main supervisor that one can only dream of. Under your supervision, I have felt secure from day one and confident that I would complete this task, even though I knew it would be challenging at times. You are as solid as a rock and especially gifted as a supervisor in finding the crucial balance between facilitating the necessary independence required as a PhD candidate and providing invaluable support. I am truly grateful for these five years of collaboration.

I also want to thank my wonderful co-supervisors, *Maria Romøren*, *Kristin S. Heiervang* and *Bente Weimand*, who have followed me closely all the way. I have learned a lot from you, and I really appreciate the patience and enthusiasm that you have showed during the whole project. Your professional skills and individual personalities have complemented each other perfectly and I was lucky to learn from these along the way.

I also want to thank *Lars Hestmark* and *Irene Norheim,* my colleagues and “PhD candidates in crime”. It has meant a lot to me to have you two as colleagues during these years, and I have learned a lot through our collaborations. This field needs professionals like you.

Thanks to the remaining IFIP research group, the participating clinical sites, and to our advisory board for your commitment and useful contributions during this study.

Thanks also to *Hilde N. Nymoen* and *Mia Iversen* at the Division of Mental Health and Addiction, Vestre Viken Hospital Trust, and *Inger Stølan Hymer* and her colleagues at TIPS Sør-Øst for our collaborations during the implementation.

Furthermore, I would like to thank our participants; the patients, health personnel, and leaders that participated in this study. A special thank you to the patients who shared with us their views and experiences with family involvement. By sharing small, yet crucial pieces of your life with us, you might have contributed to the improvement of other peoples’ lives.

I also wish to express my gratitude to my inspiring colleagues at the Centre for Medical Ethics who have contributed through professional input, practical tasks, and encouragement along the way.

In addition, I am grateful to the Norwegian Research Council for funding the IFIP study.

Monica: This thesis would never have been possible without you. You know all about it. I’m sure we will keep on having these life-changing conversations forever. Thanks also to my lovely friends, *Anette* and *Benedicte,* for your support.

My father, and my mother-in-law: For all the love and continuous help with kids, dogs and household during these busy years of our family’s life. You were the oil in the machinery.

Axel, Alexander and Sebastian: Among all the projects I have been doing these years, the three of you have always been the most important. The welcome home notes at the entrance door, the patience, the hugs, and everything that makes you as you are. Having you along the way has made all the difference.

CONTENTS

Summary in English

Background: Relatives of persons with psychotic disorders provide important informal care. Systematic family interventions have demonstrated positive patient outcomes concerning readmissions, relapses, medication and psychosocial functioning, and have also been found significant for the relatives themselves. Therefore, systematic family involvement is recommended as part of standard treatment. However, despite robust evidence, strong socio-economic arguments, and clear recommendations in guidelines, implementation is still poor.

This thesis is nested within a comprehensive cluster randomised research and implementation study - the IFIP study ("Implementation of family involvement in psychotic disorders" ["Bedre Pårørendesamarbeid" (BPS)]). The IFIP study has been conducted in Norwegian community mental health centres (CMHCs) from 2017 to 2023. An important aim is to implement the national guidelines on family involvement in the treatment of persons with psychotic disorders. Clinical interventions included a basic level of family involvement and support (BFIS) and a more advanced model of family intervention, Family psychoeducation (FPE). To foster the implementation of the clinical intervention, the IFIP study included an implementation intervention consisting of a comprehensive and tailored implementation support programme (ISP).

Aim: The purpose of this thesis was to evaluate the implementation strategy, and the experiences for persons with psychotic disorders with the clinical interventions. More specifically, the following areas were examined: barriers and facilitators to the implementation of systematic family involvement (article 1); ethical challenges related to the duty of confidentiality (article 2); and patient experiences with systematic family involvement (article 3).

Methods: We employed a qualitative and exploratory design. Data were generated through semi-structured focus group interviews with members of the implementation teams, leaders and other clinicians, and individual patient interviews. We also did a preliminary mapping of barriers and facilitators to implementing family involvement before the focus group interviews. This thesis includes both process and outcome evaluation, and preliminary results also served as formative evaluation in the IFIP-study. Content analysis guided the analytical processes.

Results: This thesis contributes to the research field with new and important knowledge about processes that may influence the implementation of systematic family involvement in mental health care for persons with psychotic disorders. This includes in-depth knowledge about barriers and facilitators to implementation of both basic and more advanced family involvement interventions, about ethical challenges related to the duty of confidentiality and how to handle them, and also knowledge about how patients with psychotic disorders experience participating in systematic family involvement.

We identified several barriers at the clinical and organisational level that were closely connected. At the clinical level, key provider related barriers included lack of competence and clinical experience with family involvement, lack of prioritisation and negative attitudes. A core finding across all three articles is that the engagement or start-up phase for family involvement should be subject to particular attention since various challenges may arise. In article 1, patient-related barriers concerned lack of consent, patient uncertainty and reluctance. In addition to the abovementioned provider-related barriers, lack of self-efficacy, and of experience and routines in how to invite patients to family involvement, were identified as important barriers. Article 2 indicates that the duty of confidentiality often hinders the start-up of family involvement, and that the professionals were uncertain about how to balance patients' and relatives' interests.

This thesis provides in depth knowledge on how to better deal with these challenges, that is facilitators or solutions to improve the implementation of family involvement. For instance, the findings indicate that implementation should take a whole-ward and multi-level approach where all mental health professionals should receive training and supervision in systematic family involvement and ethical and legal aspects and practice systematic family involvement. Furthermore, all patients with psychotic disorders and their relatives should be offered basic family involvement at an early phase of their illness trajectory. Furthermore, investing in the engagement phase is important. Other key facilitators seem to be organisational- and leadership commitment and flexible standardisation of family involvement, including flexible routines on how to invite and inform the patient and the relatives, how to carry out the first conversations and on documentation. Adequate information about family involvement is also a key to better deal with the duty of confidentiality. For example, there is often no need to share sensitive patient information to the relatives. With better routines and competence, it is easier to inform the patient and obtain a valid consent. Taken together, all the interviews indicate that a step-wise process to family involvement - starting with the most basic and then later introduce more advanced interventions - seems to be a wise strategy.

The IFIP implementation intervention seemed to create a shift in awareness, attitudes, understanding and clinical practices in favour of family involvement. When competence and experience increased, ethical dilemmas and other barriers became less demanding to handle. Through the implementation interventions, mutually reinforcing negative processes at the organisational and clinical level seemed to be transformed into mutually reinforcing positive processes. In the same way, the clinical interventions, according to the patients interviewed in article 3, seemed to change negative circles in the triadic collaboration to positive circles, for example through better understandings and awareness of each other’s situation, trust, support, and better coping with the illness. The adequately trained therapist seemed to constitute an important facilitator of these beneficial and transformative processes. Findings from the patient interviews also provide in-depth insight into possible mediators of positive outcomes for the patients and the relatives.

Conclusion: This thesis indicates that there are multiple barriers and facilitators for the implementation of systematic family involvement for patients with psychotic disorders and their relatives, both at the clinical and organizational level. Our findings indicate that the mental health professionals are often faced with unrealistic expectations, for example to offer systematic family involvement without adequate training, supervision, and routines. It also seems like the implementation resources and competence required to implement complex interventions, like systematic family involvement, are insufficient. This thesis provides in depth knowledge on possible solutions to improve the implementation of family involvement.

The key topics of this thesis – that is, facilitators in the implementation of systematic family involvement, ethical challenges related to the duty of confidentiality, and the patients’ perspectives on family involvement during psychotic illness – all represent under-researched areas. Furthermore, this is to our knowledge the first qualitative study of its kind taking place within a cluster randomised study that have successfully improved the implementation of systematic family involvement in long term mental health care services for patients with psychotic disorders in a large catchment area.

Findings in this thesis are likely to be relevant for future policy development, health education, implementation, health legislation, professional ethics and clinical practice when attempting to offer systematic family involvement and triadic collaboration in line with guidelines for the treatment for psychotic disorders and family involvement. Furthermore, the findings in this thesis may also be further investigated in future research in this field, for example in implementation and outcome research, and in similar research in other clinical settings or for other patient groups.

Summary in Norwegian

Bakgrunn: Pårørende til personer med psykoselidelser yter viktig uformell omsorg. Systematisk familiesamarbeid har godt dokumenterte og positive effekter på viktige pasientutfall som reinnleggelser, tilbakefall, bruk av medisiner og psykososial funksjon, og har også vist seg å ha positive effekter for de pårørende. Derfor anbefales systematisk familiesamarbeid som en del av standardbehandlingen. Til tross for solid evidens, gode samfunnsøkonomiske argumenter og klare anbefalinger i retningslinjer, er implementeringen fortsatt dårlig.

Denne avhandlingen er bygget inn i et omfattende klynge-randomisert forsknings- og forbedringsprosjekt – «Bedre Pårørendesamarbeid» (BPS). BPS er gjennomført i norske distriktspsykiatriske sentre (DPSer) fra 2017 til 2023. Et viktig mål har vært å implementere de nasjonale retningslinjene for familiesamarbeid i behandlingen til personer med psykoselidelser. Den kliniske intervensjonen inkluderte både et grunnleggende nivå av familiesamarbeid og støtte og en mer avansert modell for familiesamarbeid, familiepsykoedukasjon. For å styrke implementeringen av den kliniske intervensjonen, inkluderte BPS en implementeringsintervensjon med et omfattende og tilpasset implementeringsstøtteprogram.

Mål: Hensikten med denne avhandlingen var å evaluere implementeringsstrategien, og erfaringer som personer med psykoselidelser hadde med de kliniske intervensjonene. Mer spesifikt ble følgende områder undersøkt: Hemmere og fremmere for implementering av systematisk familiesamarbeid (artikkel 1); etiske utfordringer knyttet til taushetsplikten (artikkel 2); og pasienterfaringer med systematisk familiesamarbeid (artikkel 3).

Metoder: Vi benyttet et kvalitativt og utforskende design. Data ble samlet inn gjennom semistrukturerte fokusgruppeintervjuer med medlemmer av forbedringsteam, ledere og andre klinikere og gjennom individuelle pasientintervjuer. Vi gjorde også en foreløpig kartlegging av hemmere og fremmere for implementering av systematisk familiesamarbeid før fokusgruppeintervjuene. Denne avhandlingen inkluderer både prosess- og resultatevaluering, og foreløpige resultater fungerte også som formativ evaluering i BPS. Data ble analysert gjennom kvalitativ innholdsanalyse.

Resultater: Denne avhandlingen bidrar til forskningsfeltet med ny og viktig kunnskap om prosesser som kan påvirke implementeringen av systematisk familiesamarbeid i psykisk helsevern for personer med psykoselidelser. Dette inkluderer detaljert kunnskap om hemmere og fremmere for implementering av både grunnleggende og mer avansert familiesamarbeid, om etiske utfordringer knyttet til taushetsplikten og om hvordan de kan håndteres, og også kunnskap om hvordan pasienter med psykoselidelser erfarer å delta i systematisk familiesamarbeid.

Vi identifiserte flere hemmere på klinisk og organisatorisk nivå som var nært forbundet. På klinisk nivå inkluderte sentrale helsepersonell-relaterte hemmere mangel på kompetanse og klinisk erfaring med familiesamarbeid, manglende prioritering og negative holdninger. Et hovedfunn på tvers av alle tre artiklene er at engasjerings- eller oppstartfasen for familiesamarbeidet bør vies spesiell oppmerksomhet siden flere viktige utfordringer kan oppstå der. Artikkel 1 rapporterte om pasientrelaterte hemmere som manglende samtykke, usikkerhet og skepsis til pårørendesamarbeid. I tillegg til de ovennevnte helsepersonellrelaterte hemmerne, ble mangel på mestringstro, erfaring og rutiner for hvordan invitere pasienter til familiesamarbeid identifisert som viktige hemmere. Artikkel 2 indikerer at taushetsplikten ofte hindrer oppstart av familiesamarbeid, og at helsepersonell var usikre på hvordan de skulle balansere interessene til pasienten og pårørende.

Denne avhandlingen gir detaljert kunnskap om hvordan man bedre kan håndtere disse utfordringene, det vil si fremmere eller løsninger for å forbedre implementeringen av familiesamarbeid.

For eksempel tyder funnene på at implementeringsstøtten bør omfatte hele enheten og flere nivåer samtidig, for eksempel bør alle ansatte få opplæring og veiledning i systematisk familiesamarbeid, og

relevant etikk og juss, og praktisere systematisk familiesamarbeid. Videre bør alle pasienter med psykoselidelser og deres pårørende tilbys grunnleggende familiesamarbeid i en tidlig fase av sykdomsforløpet. Videre er det viktig å investere i engasjeringsfasen.

Andre sentrale fremmere synes å være forankring i organisasjonen, ledernes engasjement og fleksibel standardisering av familiesamarbeid, inkludert fleksible rutiner for hvordan man inviterer og informerer pasient og pårørende, hvordan man gjennomfører de første samtalene og for dokumentasjon. Tilstrekkelig informasjon om familiesamarbeid er også en nøkkel for å håndtere taushetsplikten bedre. For eksempel er det ofte ikke behov for å dele sensitiv pasientinformasjon til de pårørende. Med bedre rutiner og kompetanse er det lettere å informere pasienten og innhente et gyldig samtykke. Samlet tyder alle intervjuene på at en trinnvis prosess til familiesamarbeid – og å starte med det mest grunnleggende og så senere introdusere mer avanserte intervensjoner – ser ut til å være en klok strategi.

Implementeringsintervensjonen i BPS så ut til å skape en endret bevissthet, holdninger, forståelse og klinisk praksis til fordel for familiesamarbeidet. Når kompetansen og erfaringen økte, ble etiske dilemmaer og andre hemmere mindre krevende å håndtere. Gjennom implementeringsintervensjonene syntes gjensidig forsterkende negative prosesser på organisatorisk og klinisk nivå å bli omdannet til gjensidig forsterkende positive prosesser. På samme måte syntes den kliniske intervensjonen, ifølge de intervjuede pasientene i artikkel 3, å endre negative sirkler i det triadiske samarbeidet til positive sirkler, for eksempel gjennom bedre forståelse og bevissthet om hverandres situasjon, tillit, støtte og bedre mestring av sykdommen. Behandlere med god opplæring så ut til å være en viktig fremmer for disse gunstige endringsprosessene. Funn fra pasientintervjuene gir også detaljert innsikt i mulige mediatorer for positive utfall for pasientene og de pårørende.

Konklusjon: Denne avhandlingen indikerer at det er flere hemmere og fremmere for implementering av systematisk familiesamarbeid for pasienter med psykoselidelser og deres pårørende, både på klinisk og organisatorisk nivå. Våre funn tyder på at psykisk helsepersonell ofte står ovenfor urealistiske forventninger, for eksempel å skulle tilby systematisk familiesamarbeid uten tilstrekkelig opplæring, veiledning og rutiner. Det virker også som om ressursene og kompetansen som kreves for å implementere komplekse intervensjoner, som systematisk familiesamarbeid, er utilstrekkelig. Denne avhandlingen gir samtidig inngående kunnskap om mulige løsninger for å forbedre implementeringen av familiesamarbeid.

Hovedtemaene i denne avhandlingen – det vil si fremmere for implementering av systematisk familiesamarbeid, etiske utfordringer knyttet til taushetsplikten, og pasientenes perspektiv på familiesamarbeid ved psykoselidelse – representerer alle områder som er underutforsket. Videre er dette så vidt vi vet den første kvalitative studien av sitt slag som er gjennomført innenfor rammen av en klynge-randomisert studie som har lykkes med å forbedre implementeringen av systematisk familiesamarbeid i psykiske helsetjenester med hovedansvar for langtidsbehandling av pasienter med psykoselidelser i et stort opptaksområde.

Funnene i denne avhandlingen vil sannsynligvis være relevante for fremtidig helsepolitikkutforming, implementering, helseutdanningene, helselovgivningen, profesjonsetikken og klinisk praksis hvis man ønsker å tilby systematisk og triadisk familiesamarbeid i tråd med retningslinjene for behandling for psykoselidelser og familiesamarbeid. Videre kan funnene i denne avhandlingen også undersøkes videre i fremtidig forskning på dette feltet, for eksempel i implementerings- og effektforskning, og i lignende forskning i andre deler av helsetjenesten eller for andre pasientgrupper.

Publications

This thesis is based on the following articles, which will be referred to by their numerals:

Article 1
Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, Ruud T, Stølan Hymer I, Heiervang KS. *Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres – a nested qualitative study.* BMC Health Services Research. 2022; 22:1153. doi: 10.1186/s12913-022-08489-y

Article 2
Hansson KM, Romøren M, Weimand B, Heiervang KS, Hestmark L, Landeweer EGM, Pedersen R. *The duty of confidentiality during family involvement: ethical challenges and possible solutions in the treatment of persons with psychotic disorders.* BMC Psychiatry. 2022; 22:812. doi: 10.1186/s12888-022-04461-6

Article 3
Hansson KM, Romøren M, Hestmark L, Heiervang KS, Weimand B, Norheim I, Pedersen R. *"The most important thing is that those closest to you, understand you". A nested qualitative study of persons with psychotic disorders' experiences with family involvement*. Manuscript submitted for publication. 2022.

The articles are attached in "Appendices and publications" (p. 59).

List of figures and tables

Abbreviations

BFIS	Basic Family Involvement and Support
BPS	Bedre Pårørendesamarbeid (Norwegian acronym [Improved family collaboration])
CMHC	Community Mental Health Centre (in Norwegian “Distriktpsykiatrisk Senter”, DPS)
FPE	Family psychoeducation
HPA	Health Personnel Act
IFIP	Implementation of Family Involvement for Persons with Psychotic Disorders
ISP	Implementation Support Programme
MRC	Medical Research Council
REC	Regional Committee for Medical and Health Research Ethics
TSD	Tjenester for Sensitive Data (Norwegian acronym [Services for Sensitive Data])

1. Introduction

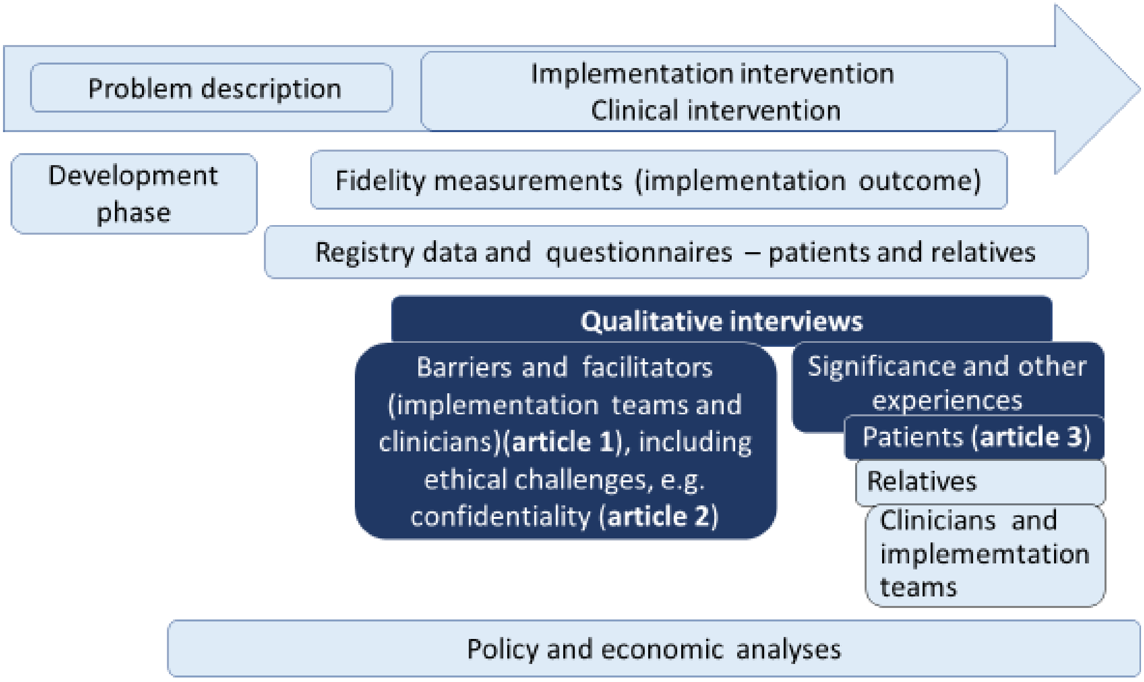
1.1. Outline of thesis and problem statement

The IFIP study, established to implement the national guidelines on family involvement in the treatment of persons with psychotic disorders, has been conducted in Norwegian mental health-care services from 2017–2023. National and international guidelines recommend family interventions as a first-line treatment of persons with psychotic disorders. Nevertheless, family involvement is currently not an integrated part of clinical practice. This study contributes to narrowing this theory–practice gap that deprives individuals with psychotic disorders and their families from appropriate treatment and care.

Nested within the IFIP study, this thesis addresses various challenges and fills several knowledge gaps in the intersection between the fields of psychiatric care, implementation science, family involvement and biomedical ethics. Our findings highlight the importance of supporting this patient group in sustaining and strengthening their social relations, and how this can be achieved. Both articles 1 and 2 provide knowledge about factors that promote and hinder involvement and support to the family, with a main focus on facilitators and possible solutions. Article 1 addresses this through an extensive exploration of barriers and facilitators as experienced by health professionals, while article 2 is composed of a more specific investigation of how the duty of confidentiality is experienced as an ethical challenge, and measures to improve the handling of such issues. Finally, the article 3 explores experiences with family involvement from the perspective of the patients.

Figure 1 details the contribution of this thesis to the overall IFIP study (dark-coloured boxes). Other results from the IFIP study (e.g., baseline measurements, fidelity evaluation, qualitative evaluation of clinicians' and relatives' experiences, and outcome evaluations) are published elsewhere (1, 2), or will be published in subsequent articles.

FIGURE 1 OUTLINE OF THE CONTRIBUTION OF THIS THESIS TO THE IFIP STUDY



As shown in Figure 1, the IFIP study is an ambitious and complex study including various methods, stakeholders and levels. The focus in this thesis is on qualitative data generated through qualitative interviews with some of the stakeholders (implementation teams, clinicians and patients) with a main focus on process evaluation, but also some qualitative outcome evaluation (patient interviews). Preliminary results from these sub-studies were fed back into the implementation intervention and can thus also be described as formative evaluation.

1.2. Structure of this thesis

Chapter 1, the *Introduction*, presents the outline of the thesis and the structure of this report. Chapter 2, the *Background*, presents the rationale for family interventions as a treatment method for persons with psychotic disorders, introduces the challenges the field is facing, presents relevant ethical principles and legislation, and concludes by illuminating the knowledge gaps that this thesis is intended to cover. Chapter 3 presents the *Aims and research questions* which the thesis attempts to answer, followed by chapter 4, the *Theoretical framework*, which presents the theories that serve as a roadmap for the scientific reasoning. In chapter 5, *Research design and methods,* the ontological and epistemological underpinnings of the thesis and rationale for the use of the methodologies in the studies are presented, along with the ethical principles and considerations that guided the research design and practice, presented in chapter 6, *Ethical considerations.* Then, chapter 7 presents a synthesis of the results from all three studies. The *Discussion* in chapter 8 presents and discusses the red thread of main findings running through the three articles. Chapter 9, *Implications,* discusses the research impact of this work from the perspectives of clinical and organisational practice in the mental health services context, education, and academia. Chapter 10 presents the *Conclusion*, which outlines the essential findings and contributions of this work.

1.3. Key terms

Family involvement: Throughout the IFIP project, we used the overarching term “family involvement” to cover basic support, integration and follow-up of relatives, and family psychoeducation (FPE).

Relative/Family: The terms “relative” and “family” were used concurrently and referred to “anyone who provides substantial and unpaid support to a person with a psychotic disorder, including friends and other significant persons” (1).

Psychotic disorders: Psychotic disorders are defined in 2.2 and are used concurrently with the terms “psychosis”, “psychotic illness” and “severe mental illness”.

2. Background

2.1. Guidelines and recommendations

Today, nearly all mental health-care policies and guidelines suggest some degree of carer involvement in the health care provided to patients with mental illness (3). Systematic family interventions are considered as a key ingredient of mental health care throughout all stages of psychotic disorders and are thus recommended as a standard approach in clinical practice worldwide (4-6).

In Norway, two guidelines have been issued by the Directorate of Health in order to facilitate the use of family interventions in clinical practice. Both the national clinical guidelines for the assessment, treatment and follow-up of persons with psychosis (7), and the clinical pathways of care for psychosis ("Pakkeforløp" in Norwegian) (8), indicate that family interventions are recommended treatment together with pharmacological treatment and individual therapy. Additionally, the general national guidelines on family involvement and support in the health and care services that were issued in 2017 provide recommendations on good practice applied to all groups of relatives, regardless of the patient's or user's diagnosis or age (9). These guidelines emphasise the responsibilities of health-care trusts and municipalities towards relatives, provide information about how to clarify who the relatives are, and their role, and encourage health professionals to share information with families and involve them in the assessment, treatment and follow-up of patients. Moreover, this general guideline provides information on appropriate support for children as next of kin and family and other relatives and presents and discusses common ethical dilemmas when working with relatives.

In 2022, the Norwegian government launched a national strategy regarding relatives and an action plan for 2021–2025, "We – the relatives" ["Vi – de pårørende"] (10). The strategy summarises the status and development features of the field, together with common challenges and needs, and identifies how the government plans to handle these challenges. Three main goals are presented in the strategy: 1) recognising relatives as a resource; 2) ensuring good and comprehensive care for all relatives so that they can live good lives for their own part; and 3) that no child should need to take care responsibilities for family or others. The strategy builds on the principle that family members are important participants in patients' health care.

At the municipal level in Norway there is moreover an increasing focus on involvement and support for informal care providers. For example, the Oslo municipality recently launched "Oslostandard for pårørendesamarbeid [The Oslo Standard for Family Collaboration] (11), a strategy founded on the basic view that relatives are an important and necessary resource in the municipality. The purpose of the standard is to ensure that co-operation with relatives is systematic and not random, and that it addresses all employees in all the municipality's health-care and welfare services.

2.2. Psychotic disorders

Psychotic disorders represent a cluster of severe mental disorders characterised by significantly altered perception, thoughts, mood and behaviour (12). Psychotic disorders are categorised in sections F20–F29 (schizophrenia, schizotypal and delusional disorder) under "Mental and behavioural disorders" in The International Classification of Diseases (ICD-10) (13). The symptoms of psychosis are commonly described in terms of "positive symptoms" and "negative symptoms". Positive symptoms include hallucinations, which means having a sensory experience in the absence of any stimulus, and delusions, which represent fixed or falsely held beliefs. Negative symptoms may include lack of drive, poverty of speech, emotional apathy, withdrawal and self-neglect (12). Psychotic disorders may have severe impact on psychosocial functioning, quality of life and life expectancy. However, there is a high variability in the quality and severity of psychotic disorders across individuals (14), and each person will have a unique combination of symptoms and experiences.

For the relatives of persons with psychosis, burdens associated with care are reported frequently in the literature (15). The potential impact of psychotic disorders on family dynamics may include dysfunctional communication patterns, high levels of expressed emotions and family disruptions (16-18).

Psychotic disorders also have an economic and wider societal impact. In Norway, for example, a relatively large part of the mental health-care resources is spent on psychosis treatment, although the prevalence of psychosis is relatively low (19). Furthermore, psychotic disorders may increase the need for other welfare services and reduce working capacity and income, both for the patient and the relatives.

How we understand psychosis and its likely causes and consequences is of the utmost importance, because this knowledge influences how we structure mental health services and which treatment approaches are given priority (19). Throughout history, the etiological understanding of psychosis has varied, and there are still some disagreements about what causes and affects the course of the disease. While some understand psychosis as a biomedical disease requiring solely pharmacological treatment, others believe the disease is mainly caused by environmental factors and hence requires psychological and psychosocial treatment modalities such as talking therapy and family intervention. The biopsychosocial model allows us to understand the cause and course of psychosis as a combination of several explanatory models, including psychological, social and biological models (20). The stress–vulnerability model (21) outlined in section 4.1 is an example of a model with a biopsychosocial foundation. Stressors combined with vulnerability are now widely recognised as risk factors for the development and subsequent course of psychotic disorders (19, 22).

2.3. Informal care in severe mental illness

Relatives play a vital role in supporting persons with severe mental illness. They hold a number of different roles in relation to the patient and the services and can be decisive in the patient's recovery (23, 24). Many relatives live with, and provide, daily care to persons with severe mental illness. They often have detailed knowledge of the patient and the illness, and can function as a source of information for the health professionals and messengers for the health-care services.

Additionally, relatives of persons with severe mental illness often have their own needs for support and care (9), and studies show that that experiences of caring are multidimensional and complex (15). Although providing informal care can be rewarding and meaningful, relatives of persons with severe mental illness often experience significant stresses and a high level of burden (25, 26) because the mental aspects of burden can be particularly demanding (27). These challenges have most likely increased with the advent of the deinstitutionalisation of mental health services. Living with a person with severe mental illness can be stressful, and today more patients share a household with their relatives in the community, implying heavier responsibility for daily care. Carer burden can lead to relatives developing health problems themselves (28).

In a historical perspective, the emphasis today is more on relatives' positive contributions to informal care and support for the patient, and the carers' burdens. This is in contrast with earlier theories of mental illness that focused more on the family as a cause of mental illness.

Relatives in Norway also have a legal right to general information when contacting the services, e.g. general information about psychosis if the diagnose is already known to the relatives and general information about rights and support services. To listen to, acknowledge and give support to the relatives is also in general possible without breaching the duty of confidentiality in cases where the patient has not consented to information sharing (9). Furthermore, Norwegian health legislation obliges the health services to provide training and supervision for relatives, especially if the relatives must perform extensive daily tasks (29). If the patient is not competent to consent to health care, the nearest relative should be informed to enable them to give the professionals information about what the patient would have wanted if competent (30).

To help the patient cope with their own situation, relatives need support from health-care and other welfare services. It has been established that relatives fulfil important roles in society and have certain legal rights. Moreover, despite robust evidence indicating that family interventions can improve a patient's health and alleviate carer burden, that there is a strong moral imperative to support relatives who assist the health-care system with important informal care (31), and that there is transference of patients and care responsibilities from inpatient care to the community, many relatives who provide informal care for severely ill persons continue to feel unsupported, devalued and excluded by mental health services (17, 23, 32-37). Moreover, from a socio-economic perspective, this is unfortunate. Due to poor involvement of, and support for relatives, e.g. being denied access to information, relatives may end up "fighting the health services" (32), and may experience the caring role as particularly burdensome. Furthermore, patients and society at large may forfeit the valuable care resources that relatives can provide if these resources are not used. Poor support for relatives can also impose further burdens on health-care and welfare services if the relatives themselves become ill due to the onerous nature of the carer role.

2.4. Family involvement in health care for persons with psychotic disorders

Family interventions constitute a key element in evidence-based treatment for persons with psychotic disorders. Numerous family models and interventions, such as family system theory (38), open dialogue (39), behavioural family therapy (40) and family psychoeducation (FPE) (41) have been developed to promote the integration of relatives into mental health services treatment. Although the theoretical background in these models differ, there are several similarities in their components. For example, a strong emphasis on information, communication, shared decision-making, triadic collaboration and psychosocial support are recurrent elements in several of these models (3).

Concerning efficacy, a robust evidence base demonstrates that working with families has a positive impact on relapse rates and re-hospitalisations, better compliance with medication, and improved social functioning (42-44). Generally speaking, the scientific literature demonstrates that persons with psychotic disorders who have well-functioning social support manage the disease and life better than those who lack the encouragement and support of their social surroundings. In addition to promoting patient recovery, family interventions are found to be beneficial to the relatives in the form of better experiences with caregiving and overall increased quality of life, together with lower levels of distress, better expressed emotions and lower carer burden (45-47).

2.5. Level of implementation

Although family interventions in psychotic disorders demonstrate significant positive outcomes, the implementation in clinical practice remains insufficient (3, 20, 48-51). The IFIP baseline measurements showed that this is also the case in Norway. Our fidelity measurements demonstrated that the level of implementation of the national guidelines on family involvement for persons with psychotic disorders is generally poor in the participating units. The fidelity measurements indicated the high quality of the FPE provided. However, less than 5% of the patients were offered this treatment at baseline (2).

These shortcomings with regard to family interventions also apply to other evidence-based interventions developed for use in mental health care, such as Assertive Community Teams (52) and Illness Management and Recovery (53). That is, while evidence has documented important and positive effects, implementation rates remain low. From a moral, economic and clinical point of view, this is problematic, as major resources invested in research to develop efficient treatment methods for severely ill patients are not used. When poor implementation of effective clinical interventions also negatively affects informal carers and may also increase the workload for health-care services, the stakes are even higher.

2.6. Barriers and facilitators to implementation

The initial mapping of barriers and facilitators of an intervention under investigation is crucial as it lays the foundation for well-considered implementation strategies, and increases the probability of succeeding (54). The scientific literature on barriers to the implementation of family involvement is quite substantial (31, 48, 55-57), and the health personnel perspective is the most explored. In general, there is more research on barriers than there is on facilitators. However, sometimes facilitators can be described as the opposite of barriers. To our knowledge, there are no previous studies of facilitators of systematic family involvement in services where implementation has been successful and measured with robust scientific methods as in the IFIP study. Furthermore, there are few in-depth studies on barriers and facilitators in services attempting to implement both basic family involvement interventions and more advanced models, such as FPE.

The research on barriers can broadly be divided into barriers to the implementation of evidence-based practices in health-care services in general, and barriers that are more specific to the implementation of family involvement practices in health-care services for patients with severe mental illness.

General barriers to implementation of evidence-based practices

The complexity of translating evidence-based practices into clinical practice has been repeatedly stressed within the field of health-care implementation science (31, 58, 59). Commonly reported barriers to implementation are lack of management leadership, of standardisation, of access to training and supervision, and of resources in terms of time and expense (31, 48, 55-57).

Specific barriers to the implementation of family involvement

Barriers concerning family involvement in particular are rooted in historical, cultural, ethical and clinical circumstances. Historical understandings of the aetiology of psychosis constituted a barrier, although this knowledge has now developed and the problem has been corrected. Former psychiatric and psychological theories believed that “bad mothers” and dysfunctional families were a major cause in the development of schizophrenia among young people (60). These misunderstandings were largely discarded in the 1970s and 80s. However, in the IFIP-study it became evident that mental health-care professionals sometimes still seem to undervalue positive effects and overemphasise risks when it comes to family involvement, for various reasons.

Furthermore, the biomedical paradigm can make implementation challenging, with its main focus on the individual patient, the dyadic relation between the patient and therapist and biological causes (e.g. genetics and neurotransmitters) and treatment (e.g. antipsychotic medication), while from triadic perspectives, the relatives as informal carers, and the patient’s everyday social life, network, support and functioning may receive less attention. As described in section 2.5, there has been increasing recognition of the utility of integrating the psychosocial aspects in the treatment of persons with severe mental illness. Nevertheless, these paradigms may still function as barriers to family involvement in mental health-care services for individuals with severe mental illness. Studies also demonstrate that organisational cultures and staff attitudes are barriers to implementation, and that health personnel feel they lack the necessary competence and skills to manage good family involvement (31). Another important barrier concerns the lack of trust and differences in normative understandings and perceptions among the participants in the triadic collaboration of what are the barriers to family involvement (57).

Furthermore, several barriers related to the organisation of care itself are documented (55, 57) – barriers that might further lead to low prioritisation of family involvement among staff, considering family involvement as secondary or optional. This could be for instance, lack of time and workforce to perform family involvement (55), or financial incentives. Inhibitors of a more practical and structural nature, such as logistical barriers (61, 62), and lack of systems in family involvement, or the FPE structure, can also hinder implementation. Studies reporting that clinicians who do not practice FPE after attending training are more likely not to conduct FPE indicate one example of such lack of good systems (63). Moreover, studies highlight that model elements and structure are not necessarily suitable for everyone (64, 65).

Some barriers to family involvement may best be described as ethical challenges. That is, situations where there is doubt or disagreement about what is right or good (66). For example, ethical challenges related to the duty of confidentiality, information sharing, and patient autonomy are barriers frequently described in the literature as hindering family involvement. Among such impediments, the research literature particularly points out confidentiality issues, which are portrayed as a complex and controversial area of clinical practice (15–18). The frequent "barrier metaphors" permeating the research literature, such as "wall of silence", "confidentiality smokescreens", "duty to remain silent", "a shield behind which services sometimes hide", and "perceived as a block to professionals", clearly illustrate the subtle yet crucial obstacle that the duty of confidentiality really represents (18, 19). Studies indicate that mental health professionals lack the necessary competence and training to deal with confidentiality issues (67, 68), that they fear that approaching relatives may threaten the therapeutical alliance (69), and that they struggle with understanding the nuances in what type of information is confidential and what is not (69). Research also demonstrates that professionals do not provide relatives with basic information to help them care for their loved one, and are prone to hide behind confidentiality (23). Furthermore, professionals may operate with seemingly different standards of confidentiality by disclosing information to patients that the relatives specifically have asked them not to (24). Professionals also find law, policy, and practice guidance ambiguous (23, 24, 32, 69), for example concerning who is responsible for initiating the consent process (70). Consequently, the absence of clear procedures in many mental health systems (69) and the overall lack of training in confidentiality barriers hinders meaningful engagement with relatives because professionals tend to refrain from disclosure or involve the relatives (23). This may lead to professionals not obtaining vital information from the relatives about the patient (71). This may also impact patients' attitudes towards family involvement and ultimately also relations within the family, because patients' willingness to consent to family involvement appears to be significantly associated with whether clinicians encourage them to involve the family in treatment (69). The quality of family involvement also needs to be considered. For example, the use of FPE may impact the relations between the patient and the relatives. Despite a certain amount of research indicating that the duty of confidentiality is an important barrier to family involvement, we have not been able to identify any study exploring ethical challenges in detail related to the duty of confidentiality in family involvement during severe mental illness, or how to deal with such challenges.

2.7. Professional codes of ethics and the duty of confidentiality

Professional codes of ethics

In the Norwegian physicians' codes of ethics, the responsibilities and obligations towards the patient and colleagues are described in detail. However, they do not include any descriptions of responsibilities or obligations towards the patient's relatives (72). This is also the case for the psychologists' code of ethics (73). In the nurses' code of ethics, obligations towards the relatives are also described explicitly, for instance that the nurse should show respect, consideration and include the relatives, and contribute to ensuring that the relatives' right to information and confidentiality is addressed. However, it also states that in case of conflict of interest between the patient and relative, the interests of the patient should be given priority.

The duty of confidentiality

In Norway, health professionals' duty to keep patient information confidential is regulated in the Health Personnel Act (HPA), Chapter 5 (74). The duty of confidentiality implies that professionals shall prevent others from gaining access to, or knowledge of, information about the patient's physical or medical conditions or other personal matters that they become aware of in their capacity as health professionals (HPA, § 21). Confidential information may only be shared with others if the patient consents (HPA, § 22), (The Patients' Rights Act, § 3-3) (30), or in emergency situations. Furthermore, as mentioned above (in section 2.3), if the patient is not competent to consent to health care, the nearest relative should be informed to enable them to give the professionals information about what the patient would have wanted if competent (30). This means that the duty of confidentiality does not apply in such situations in relation to the nearest relative. Finally, for patients admitted involuntarily or those subjected to coercive health-care interventions due to mental illness, the nearest relatives have a right to necessary information to be able to file a complaint on behalf of the patient (75). However, the relatives' right to information with regard to coercive measures only entail very limited information about the formal decisions on the use of coercion. Important criteria for the use of involuntary admissions and treatment is that the patient has a severe mental illness, that the involuntary health care is clearly in the best interest of the patient, and that the patient lacks competence to consent, except in situations that presents an immediate and severe risk to another person's life or health, or to the patient's own life.

In practice, this means that close relatives of patients above age 16 years with decision-making competence who refuse involvement/disclosure are not even entitled to receive any new information about the patient. Regardless of patient consent and without compromising the duty of confidentiality, professionals are allowed to share general information, e.g. about the unit's family work practices, inform in general terms about matters that are already known, e.g. treatment and prognosis if the diagnosis is known (HPA, § 23-1), and listen and provide support to relatives (9). In addition, the specialist health services have an obligation to provide relatives with training and support (29). However, even listening and providing support and supervision can be challenging if the relatives do not already know that the patient receives health care and from whom, due to the duty of confidentiality.

In addition, the professional code for physicians in Norway states that the ethical duty of confidentiality may be more extensive than the legal duty of confidentiality (74), § 4. As mentioned above, the Norwegian nurses' association emphasises the nurses' duty to safeguard the relatives' right to information. However, as indicated above, this right is both relatively weak and vague in Norwegian health legislation. Furthermore, also as mentioned above, nurses are required to give priority to the patient's interests in cases of conflict of interest. There is no discussion of possible exemptions, for instance if the privacy interests at stake are very limited, or the negative consequences of not giving minimal information to the relatives are severe. As mentioned above, the psychologists' code of ethics in Norway do not mention relatives or informal carers. Thus, the duty of confidentiality is equal, regardless of whether it is a complete stranger or the closest relative who is providing important informal care, as long as the patient is competent to consent.

2.8. Patients' experiences with family involvement

Few studies have qualitatively explored patients' experiences, views and benefits of FPE. To our knowledge, no investigation to date has explored patients' experiences with single-group FPE, combined with a basic family involvement practice. Nilsen and colleagues conducted two studies that examined experiences and benefits of participating in the McFarlane Psycho Education Multi Family Group treatment model (76, 77). This model was initially developed with a multi-family design but was further developed into a single-family intervention. A more recent study by Jensen and colleagues undertaken in an African–Caribbean context (78) explored patient and family perspectives and experiences of an adapted family intervention and perceived barriers and facilitators to implementation, Loh and colleagues (79) explored experiences with multi-family therapy in Singaporean families, while Allan and colleagues (80) investigated patients' experiences of an integrated family intervention in 2013 in England. Common findings across several of these studies was that the family interventions were significant in promoting shared understanding, fostering mutual support, as well as facilitating positive changes in family environment. The crucial role of the therapist in creating a safe and containing space for these processes to flourish was also a recurring theme. A few qualitative explorations of more basic family intervention practices have been performed in other service contexts, such as inpatient wards (81, 82).

2.9. The IFIP project

To meet the compelling need to scale up and investigate in detail the implementation of family involvement in severe mental illness, the project group established a large-scale cluster randomised controlled trial combined with extensive qualitative research (1) in Norwegian Community Mental Health Centres (CMHCs). The study was conducted from 2017 to 2023 with the aim of increasing the implementation of the national guidelines on family involvement for persons with psychotic disorders, and to investigate in detail how that could be done. The overarching aim was to improve the psychosocial health of patients and their families and improve mental health services. The project was funded by the Norwegian Research Council and was carried out at the Centre for Medical Ethics at the University of Oslo, in collaboration with several other parties (See Scientific environment).

The study setting constituted 15 clinical sites from 12 CMCHs responsible for inpatient and outpatient treatment of individuals with psychotic disorders in five counties in the South-Eastern Norway Regional Health Authority. There were major differences among the participating units in the character and level of family involvement, and there was also great variation in the population which the centres served. The trial study sites are further detailed at clinicaltrials.gov (Identifier NCT03869177).

The design and methodologies of the IFIP study are further described in chapter 5.

The primary outcome of the IFIP study was the level of fidelity to the intervention (1). Fidelity measures demonstrated a significant increase in fidelity in the intervention clusters compared to control clusters, allowing us to conclude that implementing guidelines on family involvement for persons with psychotic disorders in CMHCs is feasible (146). To understand the active characteristics that lead to such positive results, evaluation of the process is also required (83). Identification of the mediators of family interventions may inform future implementation and guide decision makers in the field.

2.10. Knowledge gaps that this thesis addresses

The following knowledge gaps constitute the rationale for this thesis.

Knowledge about facilitators of the implementation of family involvement in the treatment of psychotic disorders (articles 1–3).
There is ample evidence that family interventions are effective, but little evidence on how to make sure these interventions are used in accordance with evidence-based guidelines. In the context of implementation science and family interventions, fewer explorations have been conducted of facilitating factors than those of hindering factors. The kind of family involvement under investigation in the IFIP study also stands out from most other studies by exploring both basic family involvement and FPE, a more advanced model of family intervention.

Knowledge about process evaluations of family interventions (articles 1–3).
Efficacy studies of family involvement are numerous and robust. However, less is known about the processes and contextual factors that might lead to these outcomes.

Knowledge about ethical challenges related to the duty of confidentiality and how to handle them in family involvement during psychotic illness (article 2).
It is well known that the duty of confidentiality is a major barrier to family interventions. However, there is little research focusing on the ethical challenges related to the duty of confidentiality in this context and how to handle them.

Knowledge about patients' experiences with participation in family involvement (article 3).
In order to be able to develop services that are more successful in integrating the family on the patient's premises, we need information from the patients themselves about how they experience family involvement and recovery. Such interview studies are few, but important in order to go beyond the numbers and gain a deeper understanding of why family involvement is or is not successful, and the factors and processes that facilitate effective family involvement.

3. Theoretical framework

Various theoretical perspectives and approaches within the fields of implementation, family involvement and medical and health-care ethics formed a basis for the research questions and guided the research methodology used in this thesis, as well as the approaches to implementation support developed in the IFIP project.

3.1. Family involvement theory

The Pyramid of Family Care

The Pyramid of Family Care (84) is a general framework for family involvement assembled by Mottaghipour and Bickerton in order to strengthen mental health professionals in their desire to integrate family members of persons with severe mental illness into their services. This framework is based on the same theoretical base as Maslow's Hierarchy of Needs (85) and shows that working with families of patients involves a wide range of measures extending from the very basic of needs being met to receiving information and contact with the services leading to attending comprehensive and long-term interventions. Ideally, health-care services offer relatives of patients with psychotic disorders all the steps in the pyramid.

A valuable contribution of this model is the provision of a clear definition of what a minimum level of care for relatives should constitute. The model highlights how establishing contact with the family to create a strong partnership is the foundation upon which all further family interaction is built. Moreover, mental health professionals should provide relatives with general information about the illness, treatment and services, and where they can obtain support, an assessment of their needs, the establishment of "a system of safety", the development of a crisis/coping plan, and the provision of further education about important information such as patients' and relatives' rights. Defining such a minimum level of care can guide clinicians and ensure that basic-level tasks that are relevant when working with families are fulfilled before undertaking more specialised interventions. By breaking down the tasks, the model can empower health personnel in integrating the relatives into their everyday practice (84).

The stress–vulnerability model

The stress–vulnerability model (21), also referred to as the diathesis–stress model, is an exploratory model of the aetiology of psychosis, developed by Zurbin and Spring in the late 1970s. The model proposes that all individuals carry different levels of vulnerability that, in combination with stress, can lead to the development of a psychotic episode. What is of most importance to prevent new relapses is reducing the patients' internal and environmental stressors. This model has strongly impacted the current prevention and treatment of persons with psychosis.

Studies showed that families lacking the necessary understanding and skills to deal with the illness were vulnerable to developing behavioural patterns of critique, hostility and over-involvement, colloquially termed "expressed emotions". Expressed emotions have been shown to have a great impact on patients in the form of higher levels of stress, potentially resulting in relapse of psychosis. Reducing the levels of expressed emotions is therefore of high importance to reduce the stressors and improve the family environment.

Moving towards a more empathic approach to the families of persons suffering from psychosis, there has been an increasing awareness of the need for supporting them in order to reduce the stress and to disrupt circles of negative interplay and high levels of expressed emotions, thereby reducing the stress for the patient and rates of relapse and hospitalisations.

Family psychoeducation

Based on the stress–vulnerability model, FPE was developed as a response to recent scientific insights regarding stress and expressed emotions. During the 1970s, professional scientific environments in the field, led by McFarlane and Micklowith developed the FPE model (18), and it remains highly influential. FPE is an example of an advanced family involvement model, representing the higher levels of the Pyramid of Family Care. It is considered “best practice” for young adults with psychotic disorders and is supported by a large body of evidence (41).

The focus of FPE is to benefit patient outcomes. However, in order to achieve positive outcomes for patients, the FPE model emphasises that the families of persons with severe mental illness need professional support, information and specific skills training in order to deal sufficiently with the patients’ illnesses and being able to facilitate the patients’ recovery (18, 41). Thus, FPE is a structured approach to promote relative engagement in the treatment and rehabilitation of persons with psychosis.

The FPE model follows a structure in which one usually starts with separate alliance sessions with patient and relative(s), followed by joint sessions (41). The aim is to decrease expressed emotion levels and promote communication skills and problem-solving, establishing crisis/coping plans, and facilitating overall coping within the family through core FPE elements such as psychoeducation about the illness, medication and treatment, communication training, problem-solving, and recognition of warning signals (18). The sessions are based on facilitating trust, openness, proper communication, respect and a balanced relationship between the clinician, patient, and family member.

3.2. Implementation theory

An implementation strategy can be defined as “A systematic intervention process to adopt and integrate evidence-based health innovations into usual care” (86). In implementation science, the need for developing such strategies, as well as for proper theoretical foundations, has been increasingly recognised over recent decades. This has led to the emergence of an extensive range of various implementation theories, models and frameworks (87). The IFIP-study and this thesis has used this body of literature in an eclectic way. That is, we have not used one single theory or model, but rather been inspired by some models and concepts in this body of literature, such as process models (for instance ‘knowledge-to-action’ models), determinant frameworks (for instance the concepts ‘barriers’ and ‘facilitators’, distinguishing between various levels and perspectives, and detailed descriptions of the implementation object, context and implementation strategy), and more general theories emphasising for instance the motivation, competence, experience and operating conditions of those who are supposed to implement a new practice (87). We have also sought inspiration from the UK Medical Research Council (MRC) framework for design and evaluation of complex interventions (88) and a model developed to describe and evaluate different types of implementation outcomes at various levels (89).

Implementation of complex interventions

Translating evidence-based practices into clinical practice often constitutes complex assignments (31, 59) where the evaluators face a wide span of difficulties (88). To support researchers and research funders in navigating these challenging waters, the MRC constructed a framework for design and evaluation of complex interventions (90). The MRC framework offers a phased approach to the development and evaluation of complex interventions in order to differentiate the various phases of the research process. Since it was first issued, in 2000, the framework has been widely used and has undergone several updates (88, 91, 92).

Complex interventions can be defined as “interventions that contain several interacting components”. However, additional features that make interventions complex are described by the MRC framework, such as the number of groups or organisational levels targeted by the intervention, or the number and difficulty of behaviours required by the stakeholders of the intervention (88). With this framework as a starting point, the IFIP interventions – both the clinical interventions and the implementation intervention - can be considered complex in terms of containing several components that interact on various levels, the number of groups and individuals involved, and the fact that numerous and challenging behaviours are required both from those who deliver the intervention, and those who receive it. Since we planned to evaluate interventions at various levels, we found models and frameworks developed to describe and evaluate implementation outcomes at various levels particularly relevant (87, 89).

In 2021, an updated version of the MRC framework was issued (92) as a response to new developments in implementation methods and practice. One key point highlights that complex intervention research represents a broader range of activities than solely investigating whether the intervention produces its intended outcomes. Along with “pure” outcome evaluations, successful implementations require explorations of how the intervention interacts with the context, how it facilitates system change, and how the findings can facilitate real-life treatment (92).

Process evaluation of complex interventions

The purpose of process evaluation of complex interventions is to explain how the interventions work (93) and what factors influence the outcomes, to optimise the performance of the interventions (88). In many randomised controlled trials, undertaking process evaluations would improve the quality of the trials (94). However, the conceptual distinction between process evaluations and outcomes evaluations is not necessarily always clear. A distinct implementation measure for a given implementation outcome (e.g. fidelity) can, in some contexts also be considered a step or part of a process towards another outcome, e.g. patient or relative outcomes (95). For instance, in the IFIP study, family involvement is both part of the implementation outcome measurement for fidelity (penetrance) and may at the same time be described as a communicative and sometimes therapeutic process that may lead to positive outcomes for the patient and the relatives. For example, the number of alliance sessions in FPE or basic conversations with health personnel and relatives was measured as part of the fidelity measures which was our main implementation outcome and the primary outcome of the whole study. At the same time such conversations can be described and evaluated as processes that may lead to positive outcomes for both relatives and patients.

In complex interventions and health-care and implementation research, including at the clinical level, intermediate outcomes can also be part of a process leading to more ultimate outcomes (See Figure 1 “Conceptual model of implementation research” (95)). This is also the case in studies including both an implementation intervention and clinical intervention as in the IFIP study. Furthermore, this is also the case when studying complex clinical interventions where communication between several stakeholders is key element of the intervention, as in family involvement.

Qualitative research is often particularly suitable for the performance of process evaluation. However, qualitative research can also generate important knowledge about outcomes, including ultimate outcomes for patients and relatives. Typically, qualitative research can provide indications of possible outcomes at various levels that can generate hypotheses that can be tested in later quantitative research.

In evaluation research, many researchers often make a distinction between formative evaluation and summative evaluation, where formative evaluation is used before or during the evaluation and the results are used to make adjustments and improvements to the interventions (96). Summative evaluation evaluates the end results or final outcomes. Formative evaluation is often used in action research and in responsive evaluation: processes that have inspired the IFIP study (1). The IFIP study included both process and outcome research, formative and summative evaluation, and qualitative and quantitative research (see Figure 1).

In this thesis using qualitative methods, articles 1 and 2 mainly use process evaluation, while article 3 includes both a process and an outcome evaluation. Preliminary results from all articles were also used to inform the interventions in the IFIP study, thus functioning also as a formative evaluation.

3.3. Medical and health-care ethics

A fundamental ethical and legal norm in today's health care is the doctrine of informed consent (97). Thus, any kind of health care requires valid consent from the patient. This implies a right to relevant information and the right to consent to, or refuse, health care. This is also how the principle of autonomy, which means self-governing or self-legislating (98), has been operationalised in Norwegian health-care services, and those of many other countries.

Together with the principle of beneficence, non-maleficence and justice, autonomy represents four main ethical basic principles in medical and health-care ethics (99, 100). The duty of confidentiality is often described as deriving mainly from the principle of autonomy that often encompass the right to privacy. An important part of the principle of beneficence is that health-care professionals should consider what the best interest of the patient is. Thus, if family involvement is in the interest of the patient, the professionals should offer this as part of good treatment and care.

The four principles should be balanced and specified when facing ethical challenges. For example, if the patient lacks competence to consent, more emphasis is placed on the principles of beneficence and non-maleficence. However, even though the professionals consider a given treatment to be beneficial with no severe harm, they should still respect a competent refusal from the patient. On the other hand, a consent (or refusal) is only valid if the consent (or refusal) is competent, informed and voluntary.

If the patient lacks competence to consent, the professionals and representatives of the patient (e.g. a relative) in general get more responsibility for the decision on health care. In some countries, the patient's representative may consent on behalf of the patient. In other countries, like Norway, the patient's representative should, as mentioned above, be informed to be able to give the professionals information about what the patient would want if competent (30). Ideally any health care delivered to patients not competent to consent should be in accordance with the values and preferences of the individual patient. Furthermore, most countries also have legislation for the use of coercive health care. This kind of legislation, in particular in mental health care, often also includes the interests of other persons (e.g. harm to others, and not just in the patient's best interest).

Descriptions and discussions of the three first principles (autonomy, beneficence, non-maleficence) mostly focus on the patient and the health-care professionals. The interests of relatives, other stakeholders and society at large, e.g. the use of public resources, are generally introduced under discussions of the principle of justice.

In general, the attention given to relatives in medical and health-care ethics is similar to the situation described in professional codes of ethics (see section 2.7). That is, the focus is on the patients and the professionals.

The role of relatives and informal carers has received more systematic attention in ethical approaches focusing on family, relations, and relational autonomy (101, 102). However, in medical and health-care ethics and the health professionals' codes of ethics, such approaches have had far less influence than the "four principles" approach.

The "four" principles approach is largely influenced by deontology and utilitarianism, arguably the two most influential ethical theories in modern times. Neither of these theories has a focus on the family or social relations. Rather, both theories have inspired modern thinking about the individuals' right to freedom (e.g. in the human rights declarations). However, at least the principle of justice and utilitarianism can be used to argue that the relatives as informal carers have been relatively neglected. For example, as long as the relatives provide informal care and can be a resource for the patient, the services and society, it could be argued that they should be given other rights and responsibilities than other more remote persons, e.g. when it comes to information about the patient, supervision and support. Furthermore, if the relatives' burdens are high because of the carer role and if this may also generate other welfare costs, it seems reasonable to allocate support also to the relatives.

Furthermore, given the evidence about the benefits for the patient, the principle of beneficence may also be used as an argument for adequate family involvement. Finally, for the same reasons, the patient should receive adequate information about the benefits and possible side effects of family involvement. If the patient's competence to consent is reduced, e.g. due to psychotic symptoms, it becomes even more important to act on the professionals' judgement of the patient's best interest and to involve the relatives as the patient's representative (99).

A similar argument can be used when considering the duty of confidentiality. Interestingly, in the Hippocratic Oath (103), this duty implies not sharing private information outside the patient's house or family. Very few ethical theories, even non-deontological approaches, consider the duty of confidentiality as an absolute duty. Thus, we should also consider the pros and cons of this duty. For example, if the breach of privacy is minimal, and the positive effects are significant, this could in some circumstances be argued to be morally acceptable. Such a situation could be where the professionals want to establish contact with the relatives without the patient's consent, when the professionals have good reasons to believe that the relatives already know that the patient is severely mentally ill, but maybe do not know that the patient receives help or by whom.

Discourse ethics

Discourse ethics is a different type of ethical theory developed by the philosopher Jürgen Habermas (104), at least partly inspired by Immanuel Kant's deontological ethics. However, Habermas argues that is impossible to develop or agree on universal and substantial ethical approaches or principles, like Kantian deontology or utilitarianism. Instead, Habermas develops a procedure of ethics with universal norms for communication and discussions, or discourse ethics. One such norm is that all stakeholders affected by a decision must be heard and given an opportunity to participate in the decision-making. Thus, no stakeholder capable of making a relevant contribution should be excluded from the dialogue. Furthermore, Habermas argues that all voices, regardless of authority or social status, should be considered equal, that they should be given the opportunity to speak their honest opinion without deception or self-deception, and that the participants should not be subjected to any coercion or dominion (104). The discourse ethical theory further emphasises the importance of concrete experience, and that events or situations can have different meanings for different people because human beings understand and interpret situations differently (105). Finally, only those norms in which all involved parties agree, through an open, honest and free dialogue, are considered valid (99).

From a discourse ethical point of view, one can argue that relatives, as informal carers and legitimate stakeholders, are not always adequately involved in mental health care for severely mentally ill patients. The same is also sometimes the case for patients, and in research. As detailed in section 2.8, the patient perspective on experiences with family involvement is not sufficiently examined in the scientific literature, and as detailed in sections 2.3 and 2.6–2.7, relatives are not yet sufficiently integrated into the mental health services, hence several of the norms in Habermas' discourse ethics are not yet fully realised.

Thus, participants capable of making relevant and important contributions are often not included in clinical practice and research, and all voices are not equal. This lack of legitimate involvement in the mental health care context constitutes both direct and indirect barriers to family involvement. Discourse ethical principles can be used as an argument for emphasising both user participation and family involvement in research and service developments. Furthermore, most family involvement approaches emphasise involvement of both the patient and the relatives.

4. Aims and research questions

4.1. Aims

The purpose of the IFIP study was to improve the health services and psychosocial health of people with severe mental illness and their families through implementing well-researched interventions and good practices on family involvement in a mixed method and multidisciplinary study involving all stakeholders.

The aim of this thesis was to perform a qualitative evaluation of IFIP implementation.

The aim of article 1 was to explore what organisational and clinical barriers and facilitators local implementation teams and clinicians experience when implementing family involvement in mental health care for persons with psychotic disorders. The aim of article 2 was to explore ethical challenges related to the duty of confidentiality as experienced by health professionals, and to explore key measures that might contribute to improving the handling of such challenges. The aim of article 3 was to explore patients' experiences and significance of family involvement.

4.2. Research questions

The following research questions guided the studies included in this thesis.

1. What organisational and clinical barriers and facilitators do local implementation teams and clinicians in CMHCs experience when implementing family involvement for persons with psychotic disorders? (Article 1).

2. What ethical challenges do mental health professionals experience related to the duty of confidentiality in family involvement during the treatment of persons with psychotic disorders? What measures are experienced as helpful to improve the handling of such challenges? (Article 2).

3. How do patients with psychotic disorders experience systematic family involvement, and what significance does this family involvement have? (Article 3).

5. Research design and methods

The first part of this chapter describes the design, intervention and implementation strategy of the IFIP trial. The second part details the methodology of each individual article. The final section presents an elaboration on the reflexive process and trustworthiness of the findings of this thesis.

5.1. IFIP study design and methods

Section 5.1 is based on other IFIP publications, because the IFIP design, methods, intervention, and implementation strategy have been reported in detail in previous articles. This section refers to the study protocol (1), the baseline fidelity measurements (2), and the fidelity outcomes article (146). As part of the evaluation we also conducted individual interviews with relatives that had participated in family involvement. Findings from these sub-evaluations will be published in forthcoming articles.

Mixed-methods, cluster randomised research design

The trial had a cluster randomised design. Fourteen CMCH clusters were allocated to either the experimental (n = 7) or control (n = 7) arm. The recruitment of CMCH units took place in 2018 and the implementation period lasted for approximately 18 months from the beginning of 2019 until the end of 2020. During the implementation period, experimental clusters received an implementation support programme (ISP) to help them increase the implementation of the national guidelines on family involvement. The primary outcome of the IFIP trial was change in adherence to the national guidelines, measured through fidelity assessments.

In line with recommendations on how to perform complex interventions (92), the IFIP trial used a mixed-methods design. Both qualitative and quantitative methodologies in the form of process and outcome studies were used to capture different dimensions of the implementation process. We evaluated barriers and facilitators, and explored experiences, benefits, and challenges related to the intervention through qualitative interviews with members of implementation teams, leaders, clinicians, patients and relatives. Service outcomes were measured primarily through fidelity assessments and patient and relative outcomes were measured primarily through self-reported and clinician-reported questionnaires.

Responsive participatory research design and user involvement

Furthermore, the IFIP study was inspired by a responsive evaluation approach (106), which enabled continuous input from the involved parties throughout the various phases of research and implementation. The responsive evaluation approach acknowledges the plurality of interests and values, and aims at fostering genuine dialogue (107) (106). Through engagement with the stakeholders we were able to explore how they valued and gave meaning to the intervention while under development. During the initial phase of the project, the acceptability and feasibility of the IFIP intervention were assessed by receiving input from panel groups representing the project's main stakeholders, from the advisory board that collaborated with the project group throughout the project, and from representatives of the included CMHC units. This approach was continued throughout the project, by encouraging the CMHCs to include user representatives in the implementation teams, piloting questionnaires and interview guides with help from user representatives, receiving input from stakeholders, and extensive collaborative mapping of barriers and facilitators (see 5.2).

The IFIP intervention

A more in-depth presentation of the clinical intervention and the ISP has been published in the fidelity outcomes article (146). The IFIP intervention is a complex intervention, thus the MRC's framework (88) was used to guide its development and evaluation. The clinical intervention was developed by the project group through selecting recommendations in the national guidelines on family involvement for persons with psychotic disorders. The selections were based on the following non-ranked criteria.

- Scientific evidence of relevant and favourable outcomes for patients, relatives, or the public health and welfare services
- Legal regulations and requirements
- Feasibility for the mental health services
- Acceptability and relevance to patients, relatives and clinicians

Clinical interventions

Basic Family Involvement and Support (BFIS): BFIS includes conducting at least three conversations about family involvement with the patient and relative and together, providing written information, offering relatives psychoeducative seminars and establishing a crisis/coping plan.

FPE in single-family groups: FPE includes engagement and alliance sessions, psychoeducation, warning signals, crisis/coping plan, genogram, and treatment goals, communication skills and problem-solving. For a more detailed description of what the FPE elements entail, please see the introductory chapter of the method book for family psychoeducative single-family groups, developed by the Early Intervention in Psychosis Advisory Unit for Southeast Norway (TIPS Sør-Øst) (108). See also section 3.1 of this thesis.

Implementation interventions

Training and supervision: Training and supervision were offered to all staff through kick-off sessions at each site, a four-day FPE course and supervision every 6th week, feedback on fidelity results, and network conferences.

Family co-ordinator: Each unit appointed a family co-ordinator, a local health professional that contributed to the implementation and co-ordination of the practice. The family co-ordinator is intended to be a permanent position within the CMHC units, as recommended in the national guidelines.

Implementation team: The units also established a local team of four or five persons that included the family co-ordinator and preferably patient and/or relative representatives. This team worked closely with the unit leader, overseeing the implementation and acting as a link between the project group and the unit. These dedicated roles were intended to create awareness and motivation among staff, organise the various interventions, and contribute to the overall competence development in family involvement.

Fidelity measurements: Structured measurements of the implementation level of the guidelines at baseline, 6, 12, and 18 months, combined with providing the implementation teams with tailored feedback and on-site supervision to guide implementation.

Toolkit and shared resources: The units were provided with written and digital resources that were developed during the project, such as FPE manual, fidelity instruments, conversation guides, examples of procedures, documentation templates, a barriers and facilitators guide, and web resources.

Implementation support programme (ISP)

To support the implementation of the clinical interventions, an implementation support programme (ISP) (2) was established. The ISP applies to the various strategies and activities performed to foster the implementation of the clinical intervention. As implementation literature shows that barriers to implement family involvement exist on multiple levels and are associated with the implementation of evidence-based practices in general, but also with the implementation of family involvement in particular, the ISP addressed both the clinical and organisational level, and general and specific barriers. The units in the intervention arm were offered the following components as part of the ISP.

Implementation interventions

As described above.

Implementation strategies

Leadership commitment.

A whole-ward approach: As encouraged in previous research (31), the IFIP implementation strategy was performed by well-planned efforts to make the units embrace family involvement comprehensively. The implementation support programme employed a whole-ward approach that included the following key elements: that all clinicians practice BFIS; that all patients and relatives are offered BFIS; that all clinicians attend FPE courses; and that FPE is offered to as many patients and relatives as possible.

Responsive evaluation: Responsive evaluation was performed through pre-trial assessments of the intervention and outcome measures by panel groups of key stakeholders, continuous feedback from leaders, implementation teams, family co-ordinators, and clinicians. Qualitative interviews with key stakeholders, the mapping of barriers and ethical dilemmas, and measures to handle these were also a part of this evaluation. See also 5.1, Responsive participatory research design and user involvement.

5.2. Thesis design and methods

Qualitative exploratory design

The three articles in this thesis had an exploratory, qualitative design and were written in accordance with the "Standards for Reporting Qualitative Research" (SRQR) (109). Studies 1 and 2 present the perspective of the participating health personnel, while study 3 describes the perspective of the participating persons who have a psychotic disorder. Qualitative content analysis was selected as the analytical method. An overview of the studies is presented in Table 1.

TABLE 1. METHODOLOGICAL OVERVIEW OF THE STUDIES IN THE THESIS

Article	Design	Participants	Data collection	Analysis
1	Exploratory, qualitative	Health personnel and unit leaders. 21 focus groups	Focus group interviews of health personnel and leaders in the local implementation teams at the intervention units – at initial and middle phase of implementation. Focus group interviews of other clinicians – at late phase of implementation.	Qualitative content analysis
2	Exploratory, qualitative	Health personnel and unit leaders, 21 focus groups (same as study 1)	Focus group interviews of health personnel and leaders in the local implementation teams at the intervention units – at initial and middle phase of implementation. Focus group interviews of other clinicians – at late phase of implementation.	Qualitative content analysis
3	Exploratory, qualitative	Patients, 13 individual interviews	Individual interviews of patients who had participated in family involvement.	Qualitative content analysis

Process and formative evaluation

This thesis presents data from the qualitative process evaluation that aimed at exploring factors and processes that affected the implementation, and how the intervention was experienced by the participants. As outlined in 3.2, we consider study 3 as both a process and an outcome evaluation study, and preliminary findings in all articles also served as formative evaluation.

By undertaking such a study design, we were given the opportunity to explore several and parallel change processes at the units and among the participants (organisational/cultural and individual changes) over time. The formative evaluation design facilitated ongoing adjustments of the intervention according to stakeholders' feedback. The extensive mapping of potential barriers and facilitators to implementing family involvement that was completed before the main data collection became an essential part of this formative evaluation. Qualitative methods, focusing on open-ended questions and emergent discovery of knowledge, are particularly appropriate for this kind of evaluation (96).

Based on scientific literature and national guidelines, the research group developed an initial written summary of barriers and facilitators to provide information on the implementation. Through field notes from the fidelity measurements, and by engaging in a collaborative process with the panel groups, the implementation teams and the advisory board (in meetings and through written feedback), the research group received valuable input regarding what the stakeholders experienced as hindering and promoting factors, whereby the summary was accordingly adjusted. This “epistemic collaboration process” lasted for about one year and was crucial in preparing for the forthcoming data collection in studies 1, 2, (and 3). The summary was actively used to provide information for the interview guides, and it supported the researchers with initial knowledge of the topic under investigation. Furthermore, the summary was actively used during the focus group interviews, which enabled the health personnel to engage as “epistemic partners” (110).

5.3. Article 1

Study participants and data collection

In article 1, we aimed at increasing the understanding of hindering and promoting factors for the implementation of family involvement. As part of a purposive sampling strategy (111), focus group participants were recruited from each of the eight implementation teams and from clinicians with less engagement in the implementation process. Purposive sampling is a so-called non-probability sampling strategy, where non-random criteria are used to form the sample. Non-random criteria can be for instance a particular characteristic of the individuals, such as expert knowledge (112). Assuming that the implementation team members possessed expert knowledge of the family involvement implementation processes, participants were selected “on purpose” due to characteristics that made them suitable to contribute to the study’s research questions. This was also the case for the clinician focus group interviews; we assumed that these individuals could provide more varied perspectives and experiences, including perspectives of a more critical nature, regarding the implementation of family involvement in day-to-day clinical practice. Table 2, adapted from (113), presents an overview of the participants in the focus group interviews.

TABLE 2. KEY CHARACTERISTICS OF PARTICIPANTS IN THE FOCUS GROUP INTERVIEWS

	STUDY PARTICIPANTS					
	Members of implementation teams. Initial phase of intervention (N = 38, 8 focus groups)		Members of implementation teams Middle phase of intervention (N = 39, 8 focus groups)		Clinicians Late phase of intervention (N = 25, 5 focus groups)	
CHARACTERISTIC	**N**	**%**	**N**	**%**	**N**	**%**
Sex						
Male	6	16	5	13	5	20
Female	32	84	34	87	20	80
Age in years						
20–35	6	16	5	13	7	28
36–50	11	29	16	41	11	44
51–70	21	55	18	46	7	28
Prof. background /role						
Section/unit manager	6	16	5	13		
Physician	4	11	3	8	4	16
Psychologist	5	13	5	13	16	64
Psychiatric nurse	14	37	15	38	1	4
Other	9	24	11	28	4	16

Focus group interviews with the eight implementation teams and clinicians from five of the eight implementation sites comprise the data collection in both articles 1 and 2. The focus group interviews were carried out at the CMHCs and guided by two members of the research team. The interviews were audio recorded on dictation devices and lasted for 60–90 minutes. Written consent (Appendices 1-3) was obtained from all participants before the interviews started. The focus groups were guided by semi-structured interview guides (Appendices 5-7). The implementation teams were interviewed twice, at the initial and middle phase of implementation. In the first session, we introduced open-ended questions like “What have you experienced as the most important barriers to providing patients with family involvement?” and “What have you experienced as the most important success factors”? Participants were encouraged to share specific situations when family involvement was experienced as challenging, or when they felt that they had succeeded in the family work. They were also asked to reflect upon ethical dilemmas that typically arise during family involvement, what they needed as health professionals to provide appropriate family involvement, and were asked to give feedback on the implementation support provided by the project group. After being given the opportunity to speak freely, participants were introduced to the barrier and facilitator guide and encouraged to comment on the preliminary findings that had emerged through the initial phase of the implementation process. Providing the participants with the barrier document after allowing them to freely express themselves was a proven choice to avoid influencing their responses.

When attending the second round of focus group interviews with the implementation teams, we asked the participants how they related to the barriers previously identified, with particular attention to ethical dilemmas associated with patient confidentiality, patient refusal and documentation of family involvement. We also emphasised how they experienced the implementation process regarding the work in the implementation team, the role of the family co-ordinator, training and supervision, and the significance of family involvement. The third and last session of interviews explored clinicians’ experiences of how relatives of people with psychotic disorders were involved at their unit, and how they experienced the implementation measures and challenges that were raised in the previous interviews.

The following data collection procedure was applied in all the sub-studies in this thesis: To make data accessible to the research team and continue the analytical process (which started immediately at the onset of data collection), notes from each interview were summarised in a brief report. These reports highlighted topics and accounts of immediate interest and in addition, reinforced the researchers' reflections on the interview performance and ethical considerations. The interviews were then transcribed verbatim, and all data were stored in the University of Oslo's secure database (in Norwegian "Tjenester for Sensitive Data"–TSD). NVivo computer software package 12 was used for storage, search, and data coding.

Analysis

Elo and Kyngäs' approach to content analysis (114) guided the analytical process of exploring barriers, facilitators, and ethical challenges in family involvement. Qualitative content analysis can be structured in a preparation phase, an organising phase and a reporting phase (114), and the analytical work in articles 1 and 2 was performed according to this sequence. The preparation phase, including the above-mentioned mapping of barriers and facilitators, included verbatim transcription of audio files, and concerned the familiarisation of data by repeated readings of the transcripts. Moreover, the authors discussed initial themes and accounts of particular interest in depth. The organising phase pertained to the process of selecting, condensing and coding meaning units that were further organised into higher-level categories, sub-themes and main themes. The analysis elicited data on both barriers and facilitators; however, the focus was on the facilitators. The reporting phase concerned the presentation of numerous quotes in running text and in additional files. Although this analytical process can be described in separate phases, a core feature of qualitative content analysis is the non-linear processing of data (115), that is, the continuous shift back and forth among the transcripts, codes and categories. By repeatedly going back to the original data, the authors ensured that each category and theme covered the relevant content. The codes, categories and themes were adjusted, and restructured several times throughout the analysis before the final visual map (113) was completed.

5.4. Article 2

Study participants, data collection and analysis

Because article 1 and 2 use different data from the same focus group interviews, and the data was analysed by using the same analytical approach, the method section of article 2 is less detailed. Awareness of the duty of confidentiality and information sharing as an ethical challenge and barrier to implementation became increasingly evident during the implementation. While article 1 offers a broad and overall investigation of various barriers and facilitators, article 2 provides a more detailed investigation of one of the key barriers that was identified in the first study. The first round of focus group interviews typically involved data concerning the ethical challenges regarding confidentiality, while the second round to a greater extent addressed measures and developed strategies to deal with the challenges regarding the duty of confidentiality. In later phases of studies, focus groups are a suitable method to nuance, delve into, deepen, or challenge descriptions and analyses that was generated through earlier data collection (116).

5.5. Article 3

Study participants and data collection

In April-June 2020, we performed individual interviews with thirteen patients with psychotic disorders who had participated in family involvement. The participants were recruited through purposive sampling by the clinicians at the intervention units. Inclusion and exclusion criteria can be found in the protocol article (1). Their age ranged from 26–60 years, seven were female, time since they had been diagnosed with a F20–29 diagnosis ranged from 2–29 years, and all had recently participated in, or were part of, an ongoing FPE group (alliance or/and joint sessions), except for one.

A semi-structured interview guide, piloted by a user representative, guided the interviews (Appendix 8). One participant was interviewed face to face, whereas six participants were interviewed by phone, and six by Zoom, because of the coronavirus pandemic. Conducting interviews by Zoom and by phone may carry methodological advantages and disadvantages. A potential disadvantage was the risk of missing important nuances, e.g. body language or change in tone of voice, which weakened the data. Disadvantages of a more technical nature, for instance that the sound was not optimal or that the participants experienced technical problems with Zoom in some cases, led to loss of valuable time and was stressful for the participant and the interviewer. On the other hand, we know that some of the participants appreciated the distance that the screen/phone was providing. Ethical considerations and measures taken during the interviews to accommodate the participants is described in the article and in chapter 6 in this thesis.

Analysis

The analytical process in article 3 was inspired by Lindgren et al.'s analytical processes of abstraction and interpretation in qualitative research (115). The analysis of transcripts involved two main phases; decontexualisation and recontexualisation, and entailed analysis of both manifest and latent data.

The initial, decontexualisation phase entailed descriptions of the manifest content, and was characterised by a low level of abstraction and interpretation. It is a process of coding and categorisation that calls for the researchers' particular attention, as "portions of text and meaning are pulled loose from the totality of the interview (…) and from the more complete and complex situation of the person it derives from" (116). To reduce the probability of the fragments of data acquiring "a life of their own" (116) this part of the analysis therefore required a continuous movement back and forth between the codes/categories and the transcriptions. The analytical process further continued beyond the descriptive categories, towards constructing sub-themes and themes. This phase of recontexualisation entailed descriptions of the more latent content, which was characterised by a higher level of abstraction and interpretation. When handling rich data sets exploring lived experiences with complex phenomena, such an interpretative process is often suitable (115). In this phase, I was to a greater extent exploring the underlying meaning concealed in the descriptive categories.

5.6. Ontological and epistemological positions

Reliability is one of several criteria that may be useful for assessing quality in qualitative research (117). Reliability concerns the researcher's position(s) and how these positions might influence the research. How we regard the researcher position further depends on our ontological and epistemological assumptions. Ontology is the study of reality or "being", posing questions like "What is the nature of existence?" and "How do we understand reality?" Epistemology relates to theories of knowledge, and can be described as "the ideas of how we come to know the world and have faith in the truth, or validity of that knowledge" (118). Ontological and epistemological positions influence the choice of research design and methods.

This thesis, with its qualitative and explorative design, is anchored in the interpretative tradition, building upon philosophical hermeneutics and phenomenology. Unlike the positivist tradition whereby neutrality and objectivity are considered the gold standard, and the researchers' engagement with the topic is considered as "noise", the interpretative tradition claims, quite to the contrary, that full neutrality cannot exist (119). The researcher will engage in the topic of investigation and with the participants, and this interpretative approach is held as inevitable and as a strength of the epistemic process. According to phenomenological perspectives on intersubjectivity, by sharing the world with the other participants (120), I actively contributed to producing the knowledge that this thesis provides. Furthermore, I was concerned with how the participants *understand* the world, rather than *explaining* individuals and society (118). Absolute objectivity or neutrality is impossible according to the interpretive tradition (121). However, to achieve intersubjective and valid knowledge, and to avoid too subjective or biased interpretations, developing a “hermeneutic consciousness” or reflections on the interpretive processes is required (121).

5.7. Trustworthiness and reflexive process

Qualitative methods have several advantages when developing knowledge, yet such an epistemic position requires researcher reflexivity and sincere efforts to reduce bias. Inherent in the epistemological nature of qualitative research is that all parts of the analytical process will involve some degree of abstraction and interpretation (115). I shall now describe some of the strategies that I/we used to enhance the credibility of this thesis’ findings, such as accounting for personal biases and biases in sampling, ensuring interpretations of data are transparent through, for instance, the inclusion of rich and thick verbatim descriptions of participants’ accounts, and data and investigator triangulation (122). I will present relevant methodological pitfalls concerning the sub-studies in this thesis (which also involves the overarching IFIP trial), and elaborate on how I, and the research group, tried to alleviate these issues.

Reflexive process

“The pot carries its maker’s thoughts, feelings and spirit. To overlook this fact is to miss a crucial truth, whether in clay, story or science”, Krieger (123) states, stressing the significance of qualitative researchers being conscious of their own pre-understanding and roles. Ongoing reflections of how my background, previous experiences and position could influence the research process has been an important part of my doctoral work, because a researcher’s pre-understandings can influence the development of interview guides, how data is collected, how analysis is performed and the presentation of findings. When conducting interviews, there is a potential for this described “contamination”, “but through active reflexivity we should recognise that we are part of the social events and processes we observe and help to narrate” (124).

Kvale and Brinkmann (125) introduce the term “reflexive objectivity”, understood as reflecting on one’s own contribution to the knowledge production, that is, “striving for objectivity about subjectivity.” The term is rooted in the hermeneutic tradition, emphasising how our pre-understandings help us to make informed judgements, for example when authoring articles. Further, Kvale and Brinkmann encourage researchers to strive for insight into these unavoidable prejudices and write about them during the research project. I have written such reflection notes throughout my doctoral work, partly because this PhD project concerns topics related to my own subjective experiences. I hold a role as a researcher, but I am also, and inevitably, at the same time a woman, a mother, a wife, a person with higher education, a person who grew up with a family member having experienced mental illness, and thus also an author of books about related topics. These distinct roles make up who I am, shape my interpretations of the world, and affect the way I enter this field and how I am perceived by the research participants. I consider this broad, multifaceted competence a strength, if used accompanied with thorough reflexivity. For instance, thematising the first stage in the interviewing process means thinking about the topic of interest by the researcher (126). Which topics should be pursued, and which should not? For instance, if I decide to pay special attention to the attitudes of health professionals as a barrier to family involvement instead of structural or political barriers, why is that? Why do I want to probe into these specific topics at the expense of others? An important purpose of interviewing is often to understand others’ meaning making. Empathic appreciation of others’ meanings might be challenging when their own meanings and those of the participants’ intersect (126). Warren is also concerned about the fact that the interviewer participates in the interview from historically grounded perspectives with the following potential consequences: “Biographical perspectives may frame entire analyses or affect the selection of illustrative quotes” (126).

In sum, in the work involved in this thesis, reflexivity, openness about my position and being aware of how “the pot carries its maker’s thoughts, feelings and spirit”, contributed to reduce the risk of contamination throughout the process.

Potential sources of bias

Observer bias: A feature characterising a typical clinical research project is that the researchers have a personal interest in the success of the project (127). If researchers' prejudices, expectations, or opinions influence what they perceive or record in a study (112), there is a risk of observer bias. As researchers in an implementation study with the aim of implementing guidelines and recommendations for practice, the normative standing of the research team could possibly influence the questions we asked, the answers we received and how these were interpreted or highlighted. There is also a possibility that the researchers' standing may have influenced the participants to answer more positively. The focus group format also may have provoked difficulties in expressing one's honest opinion in front of the other participants if this opinion contrasted with that of the others or was critical to the intervention.

Recruitment bias: In study 3, sampling for the patient interviews was done by clinicians at the intervention units; this may have encouraged selection of the most well-functioning patients and also the patients that were most content with the treatment or had the most well-functioning families. There is also a risk that the clinicians that were most positive were those who accepted to participate in the focus group interviews.

Recall bias: The retrospective design of the studies can lead to recall bias. For example, the time from participating in family involvement until the interview varied among participants in the patient study. One of the patients said explicitly that because of cognitive impairment, she assumed she had forgotten aspects from the FPE sessions. There is also a risk that the researchers retrospectively highlighted positive perspectives from the interviews because they knew that the implementation was successful.

Measures to obtain trustworthiness

Plausibility of the scientific interpretations was strengthened through the following measures:

Data source triangulation: Triangulation in qualitative research can be described as a "tactic to bring the object of research more sharply into focus" (118). Trustworthiness of findings was strengthened by the IFIP study design, which allowed for all stakeholders' perspectives to come forth. Comparisons among the various sub-studies indicate that the findings were coherent. For instance, the importance of the initial phase of family involvement was revealed through both the health personnel and the patient interviews.

Evoking negative perspectives: To reduce observer bias, investigations of negative experiences, disadvantages, shortcomings and other critical perspectives regarding the implementation and the intervention were carried out throughout all sub-studies. Questions actively exploring negative perspectives were included in all interview guides.

Investigator triangulation: For each analytical process, the interpretations were discussed in depth among the co-authors. The fact that most of the researchers in our team have actively contributed to all the various implementation and research tasks in this project ensures an overall investigator triangulation.

Quotes: The articles provide numerous data extracts. Article 1 in particular provides many rich quotes pertaining to all categories and sub-categories regarding the identified facilitators. The inclusion of quotes provides the reader with a broader and contextualised understanding of the findings.

Formative evaluation/responsiveness: A methodological strength of this thesis is how the knowledge is generated through continuous collaboration with the stakeholders. Formative evaluation measures such as inviting stakeholder panel groups as part of the development process, piloting the patient interview guide, the barrier and facilitator guide process, and adjusting the interview guide after the baseline measurements when new insight was gained, also contribute to increase trustworthiness.

6. Ethical considerations

6.1. Research standards

All parts of the IFIP study have been conducted in accordance with the Helsinki Declaration (128), other international standards for research ethics (1), Norwegian research regulations (129, 130), and the research policies at the University of Oslo (131). Written and informed consent was obtained from all participants (Appendices 1-4). All data is treated confidentially and stored at the TSD secure database.

6.2. Ethical approvals

The study has been approved by the Regional Committee for Medical and Health Research Ethics (REC); reference: 2018/128 (first approval 29.05.2018). We also have ethical approvals from the local data protection officials (lokale personvernombud, PVO) at the University of Oslo, as well as local data protection officials at all participating CMHCs. On behalf of the University of Oslo, the project leader signed contracts on shared responsibility for data processing with each participating health-care trust. This was done in order to perform the study at each unit in accordance with the General Data Protection Regulation. After approval, the protocol (1) went through several modifications, for instance there was a need for adjusting the interview guides due to the corona pandemic. All major modifications were reported to REC, local data protection officials, and updated at clinicaltrials.gov.

6.3. Research on vulnerable groups

The third article in this thesis is based on data from individual interviews with patients with severe mental illness. Mental illness is one of several conditions that can make individuals or groups of individuals vulnerable (132). In most clinical research, there is by nature an asymmetry in power, and the participants contribute to research (and are in a sense “used”) to the benefit of others (127). Such an asymmetry will often be brought to the forefront when researching vulnerable groups, and thus requires particular ethical awareness. Therefore, this section focuses on ethical considerations concerning the research that was undertaken in article 3. However, undertaking research of a high ethical standard was of course equally relevant when researching the health personnel and unit leaders in study 1 and 2.

As described in previous chapters, experiences of family involvement from this patient group are insufficiently investigated. There may be various reasons why so few studies have been carried out in this area, for instance that recruitment can be challenging, due to difficulties in fulfilling the requirements of a valid consent form, assumptions that cognitive deficits may reduce the capability of patients speaking for themselves, that the patients can find it burdensome to participate, and uncertainty as to whether it is considered ethically justifiable to conduct research on persons who are characterised as vulnerable. Whether vulnerability is disqualifying for participating in research depends on the situation, the context, and thus the researcher’s ability to demonstrate moral sensitivity and self-reflexivity is crucial (132).

On the other hand, there is a risk that necessary and meaningful voices are deprived of the opportunity to consent to participation by underestimating their capacity, or by not being conscious of their needs for expressing themselves about prominent issues in their life. Several of the patients and relatives in the IFIP study noted how they truly appreciated having the opportunity to express their experiences of living with severe mental illness and how participating in family involvement made significant contributions to themselves and to their family. Additionally, a rich amount of valuable data was accumulated during the patient interviews. The patients provided the researchers with insightful, reflective narratives that contributed to broaden the understanding of key themes related to psychosis treatment: for instance why providing psychoeducation to their relatives could prevent new relapses, how the therapist could support them during the initial phase of family involvement to lower the threshold for giving consent, or the fact that FPE sessions made the participants more appreciative and understanding towards their family members. These are crucial findings that can guide implementation strategies and practice, hence demonstrating the significance of health services researchers including multiple perspectives when evaluating interventions.

Informed consent

The concept of informed consent operationalises the principle of respect for the patient's autonomy, stating that for a consent to be valid, the patient must have competence to consent, that the consent must be voluntary, and that sufficient information has been provided (133). A group might be defined as vulnerable because there is reason to assume that the individuals who form part of the group may have special challenges associated with giving a freely informed consent for research (134). This could be for instance due to cognitive impairment. In the IFIP study, recruitment was done by the clinicians, who provided proper information about what participating in the study entailed, and confirmed that they were entitled to withdraw from the study at any time without providing any reason and without consequences for their treatment (135). In a typical clinical research project, patients may depend on the researchers for receiving good clinical care if the researchers are also their physicians (127). Particular emphasis was placed on explaining to participants that a refusal to participate in the research study meant no exclusion from the family involvement intervention. Awareness of the power balance was also relevant in the IFIP study because the research was part of an implementation trial in which the patients were required for their participation in both the research trial and in the family intervention.

The principle of informed consent also applies to providing treatment such as family involvement or disclosure of information. Providing patients with treatment requires that consent is informed and is based on patients' free will. Reflections concerning the issue of informed consent to involve family members in treatment are discussed in depth in article 2 and discussed in this thesis.

Closeness and productive distance

The main principle of human biomedical research ethics is that potential harm should be minimised (127). Qualitative research in particular requires awareness of the researcher's role and how the human interaction in the interview situation affects the participants (125). Exercising "moral sensitivity" became an essential task during the interviews, described by Nordtvedt (98) as "the ability to pick up and recognise morally relevant features of a situation, being aware that important moral values are at stake". Considering qualitative research as travelling through landscapes with other travellers, in contrast to being a miner digging for knowledge (125) means that, through different methods of data collection, the researchers and study participants are brought into close proximity for a shorter or longer period. This closeness is essential "to get into a position from which discovery is possible" (116). During my doctoral work I have undertaken numerous individual interviews with patients, relatives and health-care personnel. Sometimes this resulted in high closeness as the participants occasionally disclosed highly sensitive information related to, for instance, severe illness, substance abuse, relational difficulties, grief and powerlessness. Others wept or displayed other emotional reactions, or expressed that they were nervous during the interviews. Consequently, the nature of the data and the setting in which they were acquired required high ethical awareness and moral sensitivity. I strove to meet the participants with empathy, sincere interest, and active listening to their stories, offering breaks if needed and avoiding the use of complex terms and language. I also tried to illuminate the significance of their attendance to our project and to the field as a whole. Taking such approaches was also important in order to optimise data collection. Creating a safe and caring atmosphere during the interviews may have facilitated the emergence of "true knowledge", as participants most likely dared to speak openly and honestly about topics that were important to them.

Kvale and Brinkmann (125) underline the importance of researchers having in-depth knowledge about the topic that is being researched. The quality of the data produced in a qualitative interview is highly dependent on the knowledge and methodological skill of the researcher. Complementary knowledge can make it easier to understand, grasp and relate to the stories being told by the participants. My own experience as a relative of a person with mental illness, and former worker with families in presumably difficult life situations was an advantage because it made it easier for me to ask relevant and adequate follow-up questions (117), to relate to the topic and the person telling their story, to recognise morally relevant features of the situation, and simply to get a grasp of "what's going on here".

Nevertheless, while this proximity provided insight and valuable data at the time, there was a need for what Moen and Middelthon (116) describe as a "productive distance". We need methods to come closer, but we must not get too close, at the risk of not seeing anything. Ongoing reflections on how my standing and previous experiences could possibly affect the research constituted an imperative task within my process of reflection (see also section 5.7). I was aware of the risk that my own pre-understandings could impact choices and performance during data collection and analysis. Maintaining a productive distance can be more challenging if one is highly engaged in the field that is being researched. Qualitative handcraft requires closeness and a productive distance at the same time (116). I am aware that personal knowledge and experience can be inconvenient, making the researcher "blind" or eroding a necessary critical distance, taking things for granted that do not correspond with reality or resulting in missed opportunities to ask follow-up questions, missing out on important information and findings, or becoming biased in the analyses. There is also a risk of becoming too emotionally involved when interacting with the participants. Being epistemic partners (116) does not mean sharing experiences equally but can be interpreted as creating knowledge together with the participants, grounded in *their* experiences, meanings and life worlds.

7. Summary of the scientific results

7.1. Article 1

Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, Ruud T, Stølan Hymer I, Heiervang KS. *Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres – a nested qualitative study.* BMC Health Services Research. 2022; 22:1153. doi: 10.1186/s12913-022-08489-y

We investigated barriers and facilitators to the implementation of family involvement in the treatment of persons with psychotic disorders, from the perspective of health professionals and unit leaders. The study had a particular focus on the facilitators.

Several barriers at the clinical and organisational level were identified. At the clinical level, we identified patient, relative and provider-related barriers that seemed to hinder implementation, such as patient confidentiality, lack of consent to involve the family, and lack of competence and experience in family involvement among the health professionals. Organisational barriers concerned the lack of shared knowledge, perceptions, and practice, the lack of routines and resources, and logistical barriers.

Important organisational facilitators to implementation were identified as taking a whole-ward approach including clear leadership and training for all staff in FPE, standardisation, routines and appointment of dedicated roles, in addition to access to external implementation support. The strategy of approaching the clinical and organisational level simultaneously contributed to building more family-friendly cultures and creating greater awareness among staff of the significance of family involvement. Implementing routines to ensure conversations with all patients about family involvement further strengthened the implementation. Additionally, implementing family intervention practices of various levels of comprehensiveness seemed to have mutual positive effects on both basic family involvement and performance of FPE. Furthermore, we found that clinicians practising family involvement became important promoters of it. After gaining their own clinical experience, motivation to continue this work rose, and the ethical challenges experienced were less challenging to deal with. This highlights the need for managers to ensure that professionals receive training and use the new knowledge in their clinical practice soon afterwards. Overall, the implementation was strengthened as the result of the professionals becoming more knowledgeable and experienced during the implementation. Several accounts demonstrate the emergence of a growing awareness and more positive attitudes towards relatives and family involvement among the participants, concomitant with increased understanding, skills and self-efficacy.

7.2. Article 2

Hansson KM, Romøren M, Weimand B, Heiervang KS, Hestmark L, Landeweer EGM, Pedersen R. *The duty of confidentiality during family involvement: ethical challenges and possible solutions in the treatment of persons with psychotic disorders.* BMC Psychiatry. 2022; 22:812. doi: 10.1186/s12888-022-04461-6

Findings from the first study revealed that confidentiality issues posed a core barrier to implementation. Participants were faced with uncertainty and various conflicts of interest when balancing confidentiality and information disclosure in family involvement. Therefore, the subsequent study focused on understanding the ethical dilemmas and concerns regarding the duty of confidentiality, as experienced by health professionals. As in article 1, we focused on the facilitators, and good solutions and practices to handle such ethical challenges. We attempted to obtain a broader understanding of how ethical dilemmas and challenges related to confidentiality could be best dealt with by each individual clinician, and through the organisation of the services.

Five themes or groups of ethical challenges related to the duty of confidentiality were emphasised by the study participants. First, the participants reported uncertainty in how to apply the legislation. Moreover, they expressed difficulties in balancing patient autonomy versus a less strict interpretation of the duty of confidentiality, and in balancing beneficence and the alliance with the patient versus a less strict interpretation of the duty of confidentiality. The fourth theme addressed uncertainty regarding what relatives already knew about the patients' illness and health care. Balancing relatives' interests versus the duty of confidentiality constituted the fifth and final theme illuminating the challenges. The interviews also demonstrated that before the implementation intervention in the IFIP study, understandings and practices regarding the duty of confidentiality varied considerably within the units and among individual clinicians.

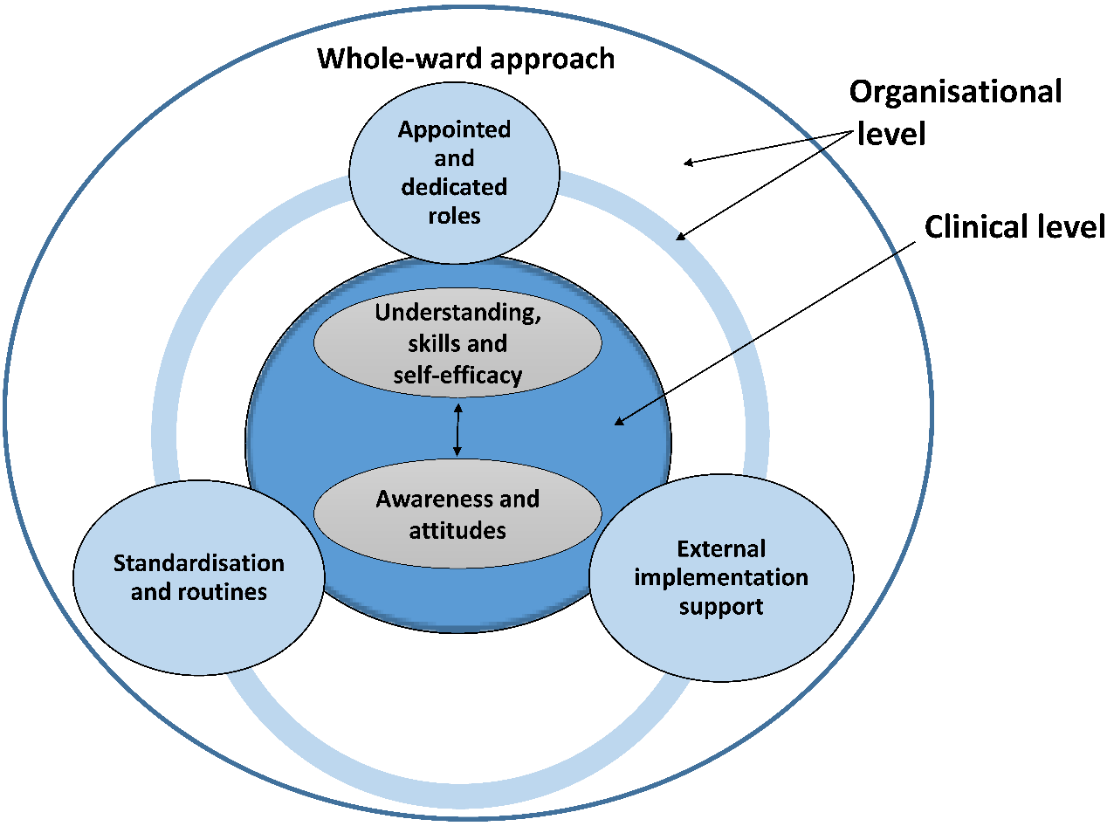
Two main themes or groups of measures that facilitated better handling of the duty of confidentiality were identified: 1) Training and practice in family involvement, and 2) Standardisation of family involvement practices. Throughout the study, we learned that the identified challenges at large can be handled suitably by improving competence and support to the professionals. As part of the IFIP implementation strategy, the project group provided staff and leaders at the intervention units with training in legal, ethical and clinical aspects of confidentiality in severe mental illness, in addition to the advanced FPE training programme. Increased knowledge seemed to facilitate a vital change in terms of how the participants understood and practised the duty of confidentiality. The situation before implementation was characterised by the following: The clinicians lacked competence and experience in family involvement, and the main focus was on the legislation and the question of information disclosure; patient autonomy triumphed over most other ethical principles. The result was that the units' confidentiality practices sometimes hindered family involvement, and in some cases there was no contact between the relatives and the services or the relatives did not receive any information.

The situation during and after implementation was characterised by the following: competence and experience in family involvement was improved among the clinicians, the main focus was on building relations and support, and other ethical principles such as beneficence and justice were more often considered and balanced with patient autonomy. The result was that the confidentiality practices became more nuanced and systematic and did, to a greater extent promote the integration of the family in the health-care provision. Contact was established with relatives through information and recommendations to patients, combined with minimal disclosure in the beginning and step-wise consent. The information flow thus became more appropriate without compromising patient autonomy. This process of change further seemed to decrease initial disagreements and variations among the units and the ethical challenges voiced by the clinicians were more often successfully addressed.

The main finding in article 2 is that providing the patients with sufficient information about family involvement and responding to minimal information-sharing needs during the engagement phase are imperative aspects for preventing concerns about confidentiality that unnecessarily erect a barrier to the involvement of the patients' social network. Findings demonstrate that how the professionals dealt with a lack of patient consent or explicit refusals to share information and/or participate in family involvement could lay the foundation for further collaboration and support.

Figure 2 outlines the main facilitators identified in studies 1 and 2.

FIGURE 2 FACILITATORS TO IMPLEMENTATION OF FAMILY INVOLVEMENT



7.3. Article 3

<u>Hansson KM,</u> Romøren M, Heiervang KS, Weimand B, Hestmark L, Norheim I, Pedersen R. *"The most important thing is that those closest to you, understand you". A nested qualitative study of persons with psychotic disorders' experiences with family involvement.* Manuscript submitted for publication. 2022.

The purpose of article 3 was to explore patients' experiences with family involvement and its significance for them and their relatives. We interviewed thirteen patients with psychotic disorders, of whom twelve had participated in FPE.

The participants were overall very content with participating in family involvement, and they reported immediate and long-term positive impacts for themselves, their relatives and the family environment in general. The most important finding that emerged in nearly all the interviews was the enhanced knowledge and mutual understanding that were achieved through the family work, and how these aspects became key mediators of triadic collaboration and support. It seemed imperative to the participants that those closest to them had knowledge about their illness and understood their situation, strains and needs. The participants' understanding and awareness regarding their family also increased during the family work: a mutuality that strongly benefitted them all. While a lack of understanding seemed to promote stress, conflicting communication, and worsening of disease, common therapeutic factors, education about the illness and problem-solving improved these situations by increasing knowledge and understanding of psychosis and of each other's situation and experiences. This new understanding and awareness of each other's situation reduced stress, stimulated a more caring family environment, and improved overall coping with the illness. The participants also reported that family involvement made the relatives better able to understand and help the patient, and they reported fewer feelings of being alone with a psychological burden.

Article 3 clearly demonstrate how “helping the helpers” is imperative to prevent relapse and promote health and wellbeing. The findings suggest that good family involvement is not only about support for family and better treatment effects for the patient, but also that the patients receive help that is better adapted to their own needs. The role of the therapist was found to be vital in order to facilitate patient–relative communication, to create a safe, containing space, and to provide continuous support to the relatives.

During the interviews, some of the participants shared honestly and openly how the illness had impacted them and their families over many years. Thus, the article provided further insight into participants’ long-term life experiences and illness trajectories. Several had wished for earlier help from the services to involve and relate to their family.

The most important challenge in family involvement seem to take place in the initial engagement phase. Some of the participants were reluctant and ambivalent to involving their family members, particularly in the beginning, and voiced a need for being well informed, reassured, and included in the planning of the coming FPE sessions. The therapist role was portrayed as particularly crucial in this phase in reducing tension and stress, and one of patiently paving the way for family involvement in the mental health care provided to the patient.

These findings are important supplements to the knowledge gained during studies 1 and 2 where health professionals reported that the initial phase was associated with several of the most prominent barriers to family involvement, such as lack of consent, the duty of confidentiality, and the fact that they felt uncertain and unskilled in this particular phase of family involvement.

8. Discussion of the findings

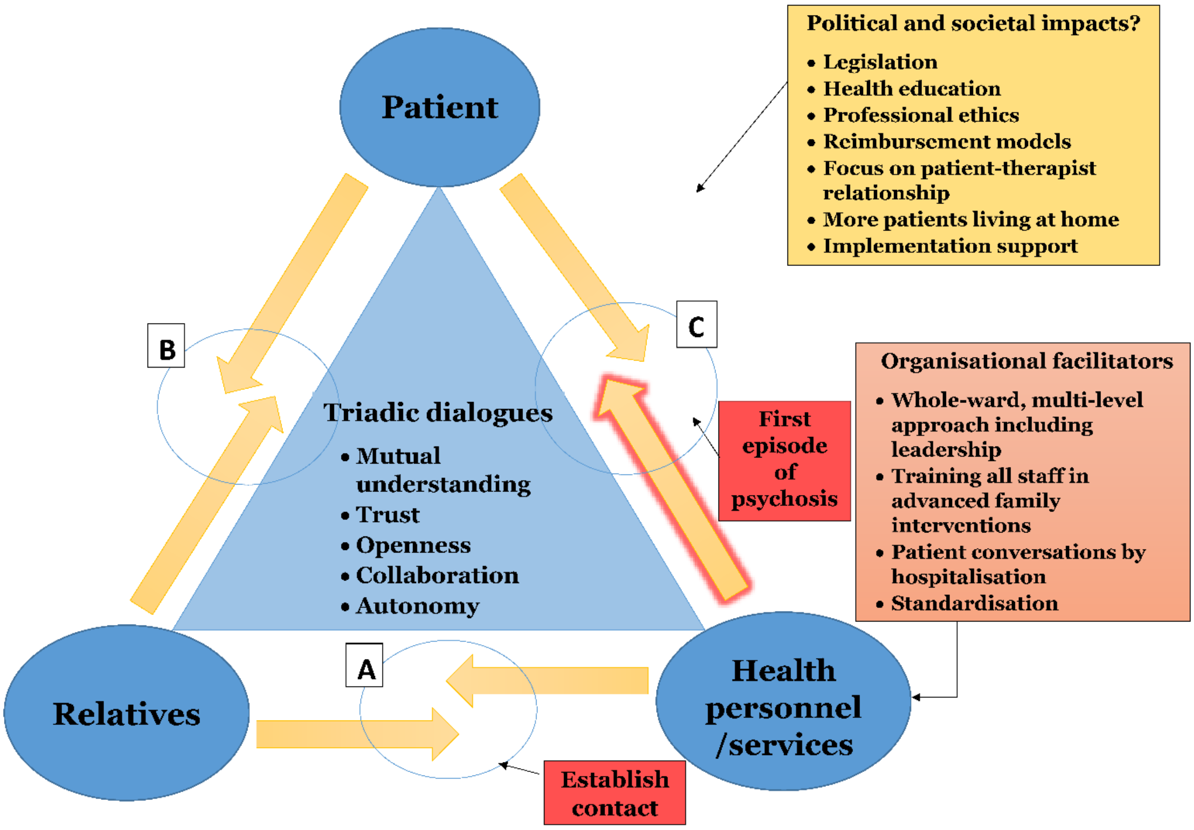
8.1. Summary of findings

Focus group interviews with health professionals suggest that the IFIP intervention and ISP contributed to alleviating several barriers to the implementation of family involvement in mental health care for patients with psychotic disorders. We identified organisational barriers as the lack of shared knowledge, perceptions, and practice, and furthermore the lack of standardisation, prioritisation and resources. Important clinical barriers concerned the lack of competence, skills, and experience in family involvement, and a lack of awareness and attitudes that were hindering among the professionals. Ethical challenges related to patient confidentiality and lack of patient consent were reinforced by provider-related barriers such as lack of skills and training in family involvement, which were core barriers to establishing contact with the patients' relatives and starting the triadic collaboration.

The whole-ward implementation approach was imperative for the beneficial changes that took place at the intervention units during implementation. Approaching the units synchronously and both top-down and bottom-up ensured that all staff members were offered relevant training in family involvement, promoted the implementation of conversations with all patients about family involvement as the default approach, encouraged strong leadership and prioritisation, and facilitated routines and standardisation that installed family involvement more as an integrated part of treatment and care. These achievements furthered crucial processes at the clinical level pertaining to health professionals gaining increased awareness, understanding, skills, experience, and more positive attitudes towards relatives and family involvement. Studies 1 and 2 also suggest that the external implementation support was invaluable to create awareness, maintain focus and ensure sustainability during the implementation period.

The individual interviews with patients revealed that family involvement overall increased the knowledge and mutual understanding among the family members, which further became mediators of triadic collaboration and support. Figure 3 illustrates how the IFIP intervention and the ISP directly and indirectly affected the triadic interplay. The focus of this thesis is at the clinical and organisational level. However, policy and societal impacts are included in Figure 3 as the findings must be seen in the broader context of mutual influences.

FIGURE 3. OVERVIEW OF THE FINDINGS OF THIS THESIS.



Despite continuous barriers, the IFIP study indicates it is achievable to integrate systematic family involvement practices in the treatment of persons with psychotic disorders (146). The results in this thesis indicate how this is possible, and possible benefits for the patients, as well as some important challenges. The discussion elaborates on key findings across articles 1-3 regarding critical implementation processes, and on the significance of family involvement. The first part discusses the implementation strategy and the measures that were identified as imperative to support the implementation. The second part unveils how the IFIP intervention and implementation strategy contributed to “build bridges” among the patients, their relatives, and the health professionals and why this bridging was momentous.

8.2. Key insights regarding implementation of family interventions

The IFIP evaluation clearly shows that translating family involvement into clinical practice required simultaneous engagement of several service levels as various minor and major factors and events possibly influenced implementation, service, and client outcomes (82). This interconnectedness of influencing factors became increasingly evident throughout the implementation, when we realised how intertwined the barriers and facilitators were, and how they played out across the clinical and organisational levels.

The barriers

Lack of patient consent to share information with their relatives, combined with the health personnel’s duty of confidentiality, was reported by the health personnel as robust barriers to establishing contact and involving the family in the treatment, as well as the importance of being able to provide support for the relatives. Study 3 adds to these findings through the patients’ narratives portraying how they felt particularly vulnerable and insecure in this initial phase. Some were reluctant to consent to family involvement, such as FPE sessions. The patients stated that during this phase, they needed the therapist to be particularly supportive and understanding, to provide relevant information, and to give them assurance that they would be involved in the process as an equal decision-maker. They felt a need to control what the family involvement should entail, and to understand what they could expect in the upcoming family involvement intervention.

Furthermore, the confidentiality barriers were closely linked to the fact that the clinicians felt uncertain, unskilled and inexperienced as to when they should inform the patient about family involvement and information disclosure and deal with possible reluctance from the patient, for example how to handle lack of consent, how to interpret the health legislation and how to balance professional codes of ethics.

An overall finding throughout the whole study is that the health personnel generally lacked sufficient competence and skills to work with relatives and to handle demanding ethical dilemmas. In some cases, this led to the rejection of relatives when they approached the services, or that no contact was made at all during the first psychotic episode, and sometimes also during later relapses. Relatives who experience exclusion from the services and have unmet needs for involvement, information and support when struggling with the burden of care, naturally may generate feelings of powerlessness and frustration towards the services, which is another barrier as expressed by the health personnel in this study. All these situations and consequences pertain to the identified barrier, “insufficient interaction with relatives”, by keeping relatives away and when mistrust is returned. Based on the research literature on expressed emotions and knowledge of how stressors are found to provoke psychotic relapses (18-19), there may also be consequences for the patients. For example, a participant valued the fact that her relatives could have an open line to the services when things became difficult and stated, "My husband and mother have my therapist’s phone number. Recently, they have been worried about my food intake, but then I find it better that they call my therapist rather than being frustrated with me” (Hansson, submitted 2022).

In other words, there seem to be many vicious circles or reinforcing feedback loops happening at the same time, and they sometimes even reinforce each other, although none of the participants want this to happen.

For example, we observed that many health professionals found it challenging to work with relatives. This was partly due to the relatives expressing critique, distrust and frustration, and a lack of mutual understanding, possibly as a consequence of being excluded or not involved from an early stage. This is natural and understandable, as such encounters, communication and relations can be demanding and demotivating for the professionals. Some of the participants shared their experiences of being criticised by frustrated and exhausted relatives due to previous distressing experiences with the services. The professionals knew this was not their fault, yet they had to accept the criticism and cope with the ongoing situation. Demanding interplay as described above may lead to health personnel not prioritising, or actively avoiding, family involvement, as shown in study 2, where some participants admitted they had been “hiding” behind the duty of confidentiality when challenging situations occurred. Challenging interplay, a strong focus on the patient–therapist relationship, historical understandings of the aetiology of psychosis, or simply that health personnel are not aware of the benefits of family involvement or not familiar with current clinical guidelines (lack of competence and experience), are all barriers identified in our study that may influence health personnel’s motivation and attitudes towards family involvement and towards relatives as a group. Lack of competence and experience with productive and efficient triadic collaboration make such encounters even more difficult. Furthermore, insufficient competence and experience among the professionals may also contribute to patients being more reluctant to involve the relatives, because it is difficult for the professionals to inform the patient about recommended family intervention and to obtain the patient’s valid consent. In the context of advanced care planning, Sævareid (136) writes that “Health care personnel may neglect a patient’s preferences or values when making decisions if they do not know them". In addition, it is difficult for the patient to express preferences if they are not informed adequately about possible benefits and risks with family involvement, or what kind of extra information sharing is needed to involve the relatives. These dynamics were something we learned in the IFIP study as described in article 2 as the duty of confidentiality-paradox.

At the organisational level, the greatest hindrance was that family involvement was not systematised and organised. Participants reported a lack of routine and structure for how to engage, inform, document and evaluate family involvement. This often led to deprioritisation of family involvement and great differences in approach and practices – dynamics that strongly reinforced the clinical barriers as described above. Lack of time and resources was also a recurring topic during the interviews.

Several of each of these barriers have previously been documented in the scientific literature. What this study adds is a deeper understanding of how these barriers work together. Furthermore, we have been investigating change processes over time in patients with various lengths of illness courses, from various stakeholder perspectives and organisational levels, and the barriers and facilitators involved. The IFIP study design provided a bird's eye view of these dynamics that made it possible to grasp what are the most important barriers and how they interact and reinforce each other.

What is more, because the IFIP study – to our knowledge – is the first to report significant improvement of systematic family involvement in health-care services for patients with psychotic disorders in a large catchment area, the findings about facilitators are probably the first of their kind. There are very limited empirical studies focusing on facilitators of family involvement, and probably none that are based on data from a study where the facilitators have most likely played an important role in achieving significant and positive family involvement implementation outcomes.

The facilitators

The whole-ward approach was significant in promoting the implementation by including all stakeholders and contributing to the "normalisation" of family involvement as an integrated approach in psychosis. This included training and supervision for all staff, inviting all patients and their relatives, and implementing standards to guide the staff in how to work with the families through shared practices.

Training and supervision of health personnel

Advanced family interventions for persons with psychotic disorders (7), and general family involvement and support for all patients and their families (9) are practices that health personnel are expected to offer and master as part of their clinical practice. However, the complexity of family involvement in severe mental illness has been repeatedly demonstrated in the IFIP study, as is the fact that the overall competences and skills in family involvement practices are insufficient. Thus, the five years of implementation research in this field has given rise to the question, can we expect health personnel to meet these requirements within the current framework and system in which they operate? It seems that the answer is no. That is, offering family involvement during severe mental illness according to the national guidelines is unrealistic without the professionals receiving necessary training, guidance and support, together with the other key facilitators.

Handling ethical dilemmas is one example of challenging situations that health personnel must master as part of their domain. Several of the barriers we found in this study are complex ethical challenges. A recurring challenge concerns the limits of the patient's self-determination. The principle of respect for autonomy holds a strong theoretical base in health care and research, and it is operationalised in the health legislation and professional codes of ethics. An overall finding in this thesis is that the organisation of mental health-care services and clinical practice largely echoes health legislation, as do the dominant approaches to medical and health-care ethics and the professional codes of ethics. That is, the focus is on the patient and the professionals, while the legitimate interests and important role of relatives as informal carers is relatively neglected. That is, before implementation support, the results reported in this thesis indicate that the identification and balancing of the interests of the relatives as well as of the benefits and risks related to family involvement for all stakeholders was in general largely underdeveloped. We found that ethical challenges often arise in mental health-care settings when the patient, health personnel and relatives have different wishes, needs, duties and rights.

For example, study 2 shows how the duty of confidentiality may constitute a significant barrier to involving significant helpers. That is, respecting patient's wishes not to involve or inform the relatives was seen as a self-evident action to safeguard the patient's autonomy and interests. However, this was sometimes done without informing the patient about the minimal or non-existent need to exchange new information, because close relatives often knew that the patient was both severely ill and was receiving help. Furthermore, patient refusal was often not valid because the patient did not receive adequate information about what systematic family involvement may entail, or the pros and cons involved. Thus, the patient may be deprived of appropriate treatment and care that the patient would want if adequately informed.

Such shortcomings in patient treatment can be considered as weaknesses related to those who perform the treatment, but it can also be seen as a systemic issue. Dealing properly with the above-mentioned issues requires that one has knowledge and experience with the intervention. Furthermore, knowledge about the limitations and possibilities within the health legislation and medical and health-care ethics, and how to adequately balance the interest of the various stakeholders, is needed. Finally, it requires that one receives professional support and guidance from managers, colleagues, and local policies and routines to stand firm in these situations. It also requires resources such as enough time to thoroughly elaborate on these issues, and adequate documentation systems. In the IFIP study, we found that all these conditions were lacking, which demonstrates the problems with issuing guidelines based on effective evidence-based practices if those who are supposed to offer these practices are lacking the basic prerequisites to follow the recommendations. However, despite all the possible barriers, the IFIP study indicates that this is still possible to remedy, thanks to large-scale and successful implementation, and that it is not necessary to wait for years until major reforms are made in health care, education and legislation. Furthermore, our findings indicate that some of the reported barriers and ethical challenges may be more frequent and more challenging if the relatives, as informal carers, are excluded. For example, in advance of the implementation, we expected that starting to work systematically with family involvement would increase the ethical challenges in the clinical sites. Quite surprisingly, the opposite happened. Several of the barriers seemed to dissolve throughout the implementation period. This striking effect can be due the increased knowledge and self-efficacy among the professionals, and the positive experiences that the health personnel gained when they first started the intervention. Experiencing the effects of involving the patients' close relatives in the treatment seemed to increase the clinicians' motivation and commitment to continue with these efforts. Further details of these findings are reported in another study from the IFIP project (Hestmark et al, accepted for publication 2023). These are key mediators to positive implementation outcomes, because ability, together with a motivation to facilitate family involvement, will most likely promote decision-making, health care and support in the best interests of all the stakeholders, despite sometimes conflicting ethical, medical and legal considerations.

Flexible standardisation and clear leadership

Standardisation became a mediating factor to implementation via various processes. The systematic uptake of conversations about family involvement strengthened implementation through routines that ensured family involvement was systematically offered to all patients, and not by coincidence. Standardising the initial phase also had a competence-enhancing effect; suddenly, when this was something all clinicians were obliged to do, turning to patient dialogues about involving their family became a more integrated part of the clinicians' regular practice. Pointing at another core facilitator identified in this study; when health personnel started to practice family involvement, awareness, motivation and self-efficacy were augmented. Another reason why standardisation promoted implementation was the indirect signalling of importance. Management anchoring and standardisation influenced the working culture, awareness of family involvement, and shared practices through directions for what to prioritise and how to do this through procedures, conversation guides and treatment plans.

The standardisation and the possibility to say, “This is how we usually do this” and to have standardised information internalised and easily available in written form, made it easier to introduce family involvement to the patient. Furthermore, the standardised approach made family involvement practices less vulnerable to high staff turnover, both among the staff and the leaders.

Allowing for flexibility in the implementation process was important. Welcoming local adjustments was done purposively to promote clinicians’ professional autonomy and positive attitudes towards the intervention. Flexibility was also significant when encountering users of the intervention. Although we aimed to implement family involvement as a standard approach, tailoring family practices to the needs of each patient and the relatives was important to ensure responsiveness and optimum treatment and care.

The managers were decisive in normalising and integrating family involvement. Fundamental tasks were to appoint dedicated positions such as the family co-ordinator and the local implementation team, allocate resources, ensure clinicians started with family involvement immediately after their training, and signalling that family involvement should be prioritised. Importantly, the family co-ordinators were reported as significant for the oversight of local implementation processes and to overcome resistance that the intervention provoked. Participants also reported that role clarification and dedicated time and space for staff to regularly exchange experiences regarding family involvement was important to guide the implementation. However, participants reported there was a tension between appointing personnel with dedicated responsibility and risking that clinicians without any particular roles in the implementation process did not engage sufficiently, considering family involvement to be the domain only of the specifically appointed personnel.

Timing: “Secure the beginnings of a collaborative relationship”

Several of the findings in this thesis point to accurate timing of the onset of family involvement as one of the most important measures to be implemented by the services. The two identified barriers, “long-term mental illness without relatives being involved” and “patient does not have relatives” pertain to this aspect and can be alleviated through facilitating early onset of family involvement. Several participants reported that the earlier they managed to establish a good triadic collaboration, the lower the barriers became, whereas in those patients who had been ill for many years without contact between the relatives and the services, the threshold was often higher, with conflicts and distance that had been allowed to take root. Establishing a “healthy” triadic relationship at an early phase can prevent the development of relational challenges and disruptions as repeatedly discussed in the scientific literature concerning psychosis. As described by McFarlane (16), psychosis is a young people’s disease. If intervention takes place at an early stage, the family members might still be motivated to support and engage in the patients’ life, and there is still the time and the opportunity to establish a supportive family environment. Health personnel not giving up on connecting with the families is significant, as Mottaghipour and Bickerton illustrate: “Persistent attempts at connection and the provision of practical resources to the family can often secure the beginnings of a collaborative relationship in those families in which connection initially is difficult.” Overcoming barriers that unfold in the early phase of family involvement can be decisive in promoting and maintaining lifelong and healthy relationships. On other hand, the alternative can be quite dismal and severe, and was described quite frequently by the professionals in this study: cases of patients living with no or very limited supporting relationships after many years with severe mental illness.

Implementing basic and advanced family involvement

The FPE training and supervision turned out to facilitate the more basic family involvement at the units. Providing training in FPE seemed to be a key contributor to establish a basic level of family involvement at the clinical sites. Most of the professionals found the FPE training valuable to achieve pivotal knowledge and to kick-start practising family involvement. While most participants had not conducted a full nine-month FPE course when interviewed, they expressed how they valued the model due to its flexibility and usefulness. It seems that learning about more extensive intervention “fuelled” the simpler interventions. The participants expressed how model elements could be successfully used through low-scale initiatives. By using “low thresholds” and “mini-family psychoeducation” (participants’ phrases), clinicians took advantage of the model whenever appropriate by selecting suitable elements such as the stress–vulnerability filter or the positive reformulation technique. We hope that units with restricted resources can find this motivating. Even though FPE is considered a complex and resource intensive intervention, implementing the model piecemeal may be feasible. Participants’ experiences with the intervention as permitting adaptation, tailoring and refining, lowered the threshold to a point where it could start. When first starting, both professionals and users gained positive experiences as previously elaborated, thus implementation was strengthened. This “step-by-step” approach as an effective strategy for scaling up the implementation of family involvement corresponds well with the dynamics of the Pyramid of Family Care (78). When the professionals were introduced to easily available basic concepts and measures, the threshold for working with the families was lowered, which further paved the way for introducing the more advanced FPE intervention.

A need to increase the implementation focus on all levels

The focus of this thesis is at the clinical and organisational level. However, the above-mentioned barriers and facilitators are interconnected and dependant on decision-making processes taking effect at the policy and societal level (Figure 3). This may apply to education, financial reimbursements, legislation, and how society relates to informal care. The role of implementation research in health and care services’ quality improvements is a persistent example. As highlighted in the implementation literature, to ensure that evidence-based family interventions transpire in clinical practice, there is a need for both effective interventions and carefully developed implementation strategies at all levels. The IFIP study and this thesis have provided further insight into the importance of such a dual approach to professional development in the mental health services. We have shown that overcoming barriers to family involvement in health care services for persons with psychotic disorders is possible. However, for these achievements to occur, they are probably dependent on being nested in the overarching IFIP ISP. On the other hand, if implementation strategies are strengthened at the policy and societal level, for example in health education and legislation, it is possible that the some of the current barriers and needs for implementation support at the lower levels may be reduced.

In health care, as in other welfare services, time and resources are limited. Implementation of complex interventions like systematic family involvement requires both resources and competence. However, it may also reduce costs. Furthermore, unsystematic, or ad hoc family involvement may also be time consuming and may generate even higher costs for society. Since complex interventions often require training and supervision for the professionals, it is important to discuss how the need for capacity building can be covered most efficiently and how to share responsibilities and further develop the collaboration between the health-care services and the health education institutions.

8.3. “Building bridges” – How the IFIP study changed the triadic interplay

Ahead of implementation, the triadic interplays (Figure 3, A-C) were to some extent characterised by *distance;* pertaining to lack of shared understandings and collaboration, poor communication patterns, avoidance, and distrust. The participants also expressed that all stakeholders were not included in the triadic interplay. This could be, for instance, patients reporting that their relatives had not been included in treatment or taken care of during times of illness, or health personnel voicing a need for integrating the relatives in treatment yet facing barriers that hindered such collaborations in their clinical practice. Preliminary findings from the relative sub-study add to these findings through the relatives’ accounts of being excluded from the triad.

Findings from articles 1-3 illuminate how these triadic interplays improved after implementation support in the IFIP study. That is, the unfortunate gaps between the individuals were narrowed.

Analysis of health personnel and patients' accounts show how the patients, the relatives and the health personnel in various ways were *brought closer to each other.*

A) Building bridges between the relatives and the health personnel

Challenging dynamics between the relatives and the health personnel were illustrated in this study, such as relatives experiencing not receiving information, lack of recognition of the care burden, or feeling neglected and unappreciated by the services (71). Previous historical understandings of psychosis, a one-sided focus on the therapist–patient relationship, lack of understanding and knowledge among professionals, low prestige in working with families and low prioritisation of family involvement add to this relational distance. Furthermore, relationship A, as shown in Figure 3, was characterised by the absence of proactive contact on the part of the health personnel with the relatives being "the active party" in approaching the services (23), often after negative experiences of being excluded. Consequently, this may negatively affect the relatives' commitment to caring (33), and the relationship with the professionals and services (137), while the professionals may lose the opportunity to gain collateral information and perceive the relatives as hostile or negative.

During the IFIP study, these dynamics were turned around. Suddenly, the services were seeking out the relatives through FPE and basic family involvement, and thus the relatives felt more taken care of and included (Figure 3: "Establish contact"). Reaching this point of interplay was, among other aspects, due to improved engagement conversations with the patients leading to this contact being established (See section C). When engaging in more satisfying dialogues, mutual understanding and trust developed among the health personnel and the relatives. By giving the relatives a chance to contribute to patient care, the health personnel realised their value as information providers and informal helpers outside the services. Metaphorically speaking, during the implementation, a largely invisible group became more visible to the professionals. This became further evident in the patient study, which portrayed how some of the relatives served as the services' outstretched hand when the patient was not hospitalised. "Building bridges" between the relatives and the services in the form of mutual trust, collaboration and acknowledgement of each other's contributions to care, enabled the relatives to follow up on warning signals, strengthen medication adherence, and provide information to the clinicians at the CMHCs (Figure 3: strengthening relation A, positively influenced relation B). Thus, the relatives' role as informal carers was strengthened. Furthermore, while before the implementation support was introduced, professionals were focused on the alliance between themselves and the patient, yet after it was introduced, they also seemed to acknowledge the importance of the alliance between the informal carer and the patient.

In studies 1 and 2, the health personnel also emphasised the value of providing relatives with supervision and support, for the relatives' own sake. Spending time listening to relatives, relieving their emotional pressure, and acknowledging their situation promoted coping with the carer role. The significance of the relatives obtaining information and support was also expressed by several of the patients. These patients were thankful for the therapists who provided their family members with the opportunity for sharing their stories, for asking the difficult questions, and receiving needed information. Such support involved two key functions. First, the patients had experienced how important it was for their family members to be provided with knowledgeable and attentive health professionals. Meanwhile, it was also significant to them to know that someone was taking care of their relatives. This finding is important regarding the robust barrier "lack of consent". In the patient study, some expressed that reluctance to involve the family could be because patients feel they are overburdening their family, and thus refuse involvement to shield them from additional burdens. This finding, however, demonstrated how some patients learned the opposite: that saying yes to family involvement contributed to releasing the stress and burden on the relatives through the support from the professionals. This suggests that in initial conversations with patients about family involvement, emphasising how family involvement potentially may help their family and benefit themselves, rather than the opposite, is of the utmost importance.

The dual effect of improving relationship A can also be exemplified by the therapist that allowed a mother to have an open line to the services. Such measures may prevent the relatives from becoming emotionally overwhelmed and alone when faced by distress, which further may prevent expressed emotions among the relatives (Figure 3: support provided in relationship A, possibly prevented stress in relationship B).

A final, interesting finding concerning relationship A is how working with the families also constituted meaningful clinical encounters for the clinicians (Figure 3A: two arrows complementing each other). Experiencing the significance of these conversations made the participants feel that they could contribute meaningfully to how relatives coped, and thus increased motivation to continue their efforts to practice family involvement. In an implementation context, such motivational experiences are highly important, as clinicians serve as “gatekeepers to family involvement” in non-democratic processes (138). One example is that relatives’ rights to information and support when approaching the services was easily compromised when the professionals wrestled with confidentiality issues and lacked the necessary knowledge and experience to balance benefits and risks and diverging needs and interests among stakeholders. The clinicians gained a broader and more realistic understanding of what family involvement is about; enhancing core relations to the benefit of, and on the premises of, the patients, while supporting relatives in their roles as informal helpers and potentially vulnerable individuals with their own needs. They also learned that in most situations, it is possible to collaborate with and/or provide the family with supervision and support while respecting patient privacy and the alliance between the patient and the professionals (Figure 3: Triadic relationships as illustrated inside the triangle).

B) Building bridges between the patients and the relatives

Studies 1-3 also demonstrate how severe mental illness may create distance between the patients and their surroundings, in terms of the family members engaging in challenging interplay. Consequently, persons with severe mental illness may have more scarce social networks and support than other persons, although they might have special needs for social support to deal with the challenges associated with their illness. Breaching these devastating dynamics through systematic family interventions is of the utmost importance.

The main finding in study 3 is that family involvement increased mutual understanding, collaboration and support. This shows how bringing the relatives and the health personnel closer together (A) contributes to improvement of the relationships between the patients and their relatives (B). Receiving psychoeducation about psychosis in FPE sessions helped the relatives to better understand the patients’ symptoms and symptomatic behaviours that had previously provoked frustration, stress and perhaps meant that the patients experienced criticism from their relatives. This was of the utmost significance to the patients because when the relatives understood more about their situation, needs and sufferings, and at the same time they themselves were provided practical and emotional support from the professionals, their capability to provide good care was strengthened. Helping the helpers has been reported to be decisive in better problem-solving and better communication, and in improving patients’ quality of life. A crucial point here is how family involvement not only strengthened carer skills and capacity, but at the same time, stress was prevented. This is particularly relevant as relatives’ expressed emotions are predictors of relapse (139). The patients also reported that the therapist became an important facilitator of patient–relative communication (Figure 3: A-B-C working together). Several of the patients explicitly expressed that when being better understood by their surroundings, a closer and warmer relationship with, for instance, their parents arose.

The family involvement somehow also made the relatives more visible to the patients. These are interesting findings, as most literature focuses on the positive effects of FPE in providing the relatives with knowledge and understanding of the patients’ symptoms and situation, whereas the fact that FPE mutually increases the patients’ understanding and awareness of their relatives’ situation, and that this helps to improve their interaction, is less elucidated. This reciprocity that arose when the patients also became more aware of their relatives’ situation is assumed to be of high significance for the patients in terms of facilitating a more balanced relationship (Figure 3B: two arrows complementing each other). It is a basic human need both to receive care and to be able to give it to others. This is also true for persons with psychosis. Participating in FPE can enable patients not only to be at the receiving end of the relationship but also at the giving end.

C) Building bridges between patients and the health personnel

Findings in this thesis identify a kind of distance existing between patients and health personnel (C). Some patients had, for instance, experienced that the services had never included or made efforts to involve their family, although they had been severely ill for decades. They expressed this as a need that the services had failed to meet. Another example of distance in relationship C is the situation where the patient did not consent and, in the efforts not to breach the duty of confidentiality, the patients' underlying reasons for refusing involvement were not addressed.

With training and experience, health-care professionals balanced confidentiality issues better and altered information-sharing strategies so that they were tailored to each patient and their context. The national guidelines state that health-care personnel should see the patient's openness towards relatives and obtaining consent as a process because the desire to share information about illness and health care with relatives can change over time (9). Undertaking conversations with the patient about family involvement and taking a step-wise approach to consent improved the therapeutic dialogue and strengthened the patient in their process of giving consent. Findings from articles 1 and 2 suggest that lack of consent is a robust barrier to implementation. However, they also highlight the need to make more concrete what the exact refusal entails, what the reasons are, and whether the patient is aware of minimal information sharing needs, if any, and the pros and cons. In fact, we should perhaps not take a refusal for granted too fast, not because we disagree or want to convince the patient, but because we need a better understanding of the worries and values that underlie the refusal. This may also be an opportunity to give the patient adequate information about family involvement and information-sharing practices. During the IFIP study, we learned that turning to proper and sincere dialogue about family involvement is often a better way to promote patient autonomy than to simply accept the refusal right away.

Again, this highlights the need for conversations with all patients about family involvement and information sharing as a routine, as discussed in 8.2, as this can facilitate shared understandings of why the patients do not want to involve their relatives and how to adapt to both the patients' and the relatives' needs. Furthermore, if the patient remains reluctant towards triadic family involvement after adequate information has been provided, there are family support interventions that do not require any triadic activities or any type of information sharing (140).

8.4. Including all voices strengthens health care

Inspired by discourse ethics, the IFIP study has shown that allowing all stakeholders' perspectives to come forth is important. Relatives of persons with psychotic disorders are inevitably influenced by the illness, yet they are often not given the opportunity to participate as legitimate stakeholders. The services and society may gain a great deal by involving and providing support to relatives, and the IFIP study shows how we can achieve that. The possibility for all stakeholders to participate, and having conversations free of coercion or dominion are two key norms within discourse ethics (99). Some of the patients indicated during the interviews that the FPE sessions could help put these norms into practice. That is, the FPE model enabled all family members, including the patient, to "come as they are" and to facilitate the expression of needs, concerns, possible solutions to everyday problems, and what is important to them. Meeting together in a safe and containing space (physically and emotionally), helped the triadic partners to express themselves honestly and openly, solving everyday problems together, working towards shared goals, raising awareness of each other's life situation, relieving stress, and reducing loneliness.

There are situations where systematic family involvement may be contraindicated in health services for patients with psychotic disorders, for example with high risk of violence from the patient and/or the relatives or if there is a history of abuse. Furthermore, in the qualitative interviews with the patients, high risk of violence was an exclusion criterion. However, an important insight from the IFIP-project, and the interviews with the professionals included in this thesis, is that such contraindications may be more limited or less absolute than supposed, at least if more basic models of systematic family involvement is also a possibility. A minimum of family involvement may be appropriate also to help the patient or the family to set limits, or to protect the interests of the most vulnerable stakeholders.

In research on family involvement, the patients are the individuals who have been included most rarely in the discourse, if we consider the number of publications illuminating the patient perspective on family involvement, versus the health personnel's and relatives' perspective. This reduces the quality and objectivity of knowledge, as research participants speak from various perspectives, or so-called "fractured subjectivities" (126), and we need all these perspectives to create a comprehensive and intersubjective understanding of complex phenomena. The various patient narratives that came forth in the IFIP study brought to the table some of these "fractured subjectivities", and highlights why this triadic approach should also be employed in mental health research. Findings from the patient interviews were crucial to grasp the bigger picture of how family involvement is experienced and how it can be successfully tailored to individual patients. Participating in the research interviews was also described as meaningful and positive by many of the patients. They had the opportunity to share that previous life experiences had not been listened to or understood by those around them, including both health personnel and family. The research interview also became an opportunity to disclose important stories from their life-world to be shared with others, knowing that this could also be of help to others without compromising their privacy.

8.5. Strengths and limitations

A major strength of this thesis is that the qualitative data has been collected within a large cluster randomised study including many and varied CMHC units, which have succeeded in implementing systematic family involvement on a large scale. Qualitative studies are well suited to complement randomised controlled implementation trials (141) by providing in-depth explorations of the implementation process.

The mixed methods design, including qualitative and quantitative methods, process- and outcome evaluation studies, and data source triangulation in the form of the inclusion of patients, relatives, health personnel, and managers' perspectives on family involvement, is a main advantage of the IFIP study and this thesis. For instance, data from health personnel revealed that the engagement phase constituted a barrier to implementation. Data from the patient interviews supported the validity of these findings, by patients also describing this phase as particularly challenging. Together, these findings can be used in service development, to address the challenges that health personnel and patients face during the engagement phase and to tailor the systematic family involvement to the individual patient and family.

Several data collection points over time, combined with a responsive evaluation approach and close contact with the participating units and stakeholder groups, enabled ongoing input from various stakeholders. The opportunity to compare these inputs, and to see them together as a whole, was particularly valuable. Combined with formative evaluation, this approach made it possible to adapt both the implementation strategies and to some extent also the evaluation strategies to the target groups' needs and to the context in which the study was carried out, as the IFIP study progressed (142).

Furthermore, the varied and ample experience of the participants gave us rich data concerning the various stages of the patients' illness trajectories, from early onset to long-term illness. For instance, some of the health professionals interviewed had worked with patients with psychotic disorders for many years and some of the patients had been ill for many years. Adding to this, the demographic information about the groups of study participants' showed a high variation in all groups in terms of age, gender, and number of years working in mental health care or having a psychotic disorder. This may increase the transferability of findings to patients with psychotic disorders in various phases of the illness, and their families.

The close collaboration between several researchers in an interdisciplinary research group has been advantageous to this thesis. The way we have worked closely together throughout this project, on conducting both the research and the implementation support, has most likely strengthened the internal validity of the findings that is to which extent our interpretations of the data are valid. The core of the research group, consisting of six researchers, contributed to all parts of the project, e.g. developing the intervention, data generation, analysis, and the scientific dissemination. The combination of regular bimonthly project group meetings and special meetings to discuss the results included in this thesis, probably reduced the risk of biased or haphazard interpretations. This broad, interdisciplinary expertise has for instance been important when probing into the complexity of confidentiality in family involvement, which was investigated in study 2. Furthermore, close contact with the participating units, meetings with the advisory board, and being invited to give lectures at other CMHCs and mental health care services, have made it possible to get extensive feedback on preliminary analyses. So far, this kind of feed-back has indicated that the results are transferable also to other similar contexts, which may be an indication that the results may be valid or relevant also outside the participating units in the interventions arm in the IFIP-study (external validity).

Investigator triangulation, and the fact that I as a PhD candidate have undertaken a wider range of research and implementation activities than this thesis covers, have most likely contributed to strengthening the quality of the data collection and the analytical work of this thesis. Several of the researchers in the project group have extensive experience with working with and including vulnerable groups in research and to study complex interventions in real world clinical practice. This has probably contributed to all the participants being well cared for during the study, and the fruitful collaboration with the participating units. Most likely this further strengthens the quality of the data collected, e.g. through contributing to safety and honesty in the interview settings. For example, in the interviews with all the participant groups we tried not to make implicit or explicit normative evaluations in the way we formulated the questions in the interview guide and the interviews, and when we responded to the answers we got in the interviews.

However, there are certain limitations to this thesis' design and methodology. First, investigating causality or generalisation of findings are not possible with its qualitative design, but the data can be used to generate hypotheses for further investigations of causality. Furthermore, complementary qualitative data from clinicians and relatives, and also quantitative data would have strengthened the findings of this thesis. Such data will be analysed and published in forthcoming articles from the IFIP study. Preliminary findings from qualitative interviews with relatives and clinicians indicate that the main findings in article 3 are to a large degree corroborated by the other main stakeholder groups.

Moreover, the normative standing of the researchers in this study, that they are all trained as health professionals, and the close collaboration with the health services, constitute potential limitations (112). Evaluations of health interventions involves a risk of bias in the research process as the researchers are involved in delivering the intervention (143). The implementation interventions and strategies of the IFIP project aimed at increasing the implementation of the national guidelines on family involvement. This might have influenced both the data collection and analysis of data. The researchers collecting and analysing data had the main responsibility to support the local implementation teams, while also performing some of the staff training, which may have influenced the data collection and the interpretations. The FPE training was, however, conducted by other experts in the field (TIPS Sør-Øst). Furthermore, the key researchers represent various health professions, and have different types of additional education and training, as well as various professional and personal experiences. These variations and interdisciplinarity probably reduced the risk of bias and arbitrary methodological choices and interpretations.

Reflexivity and investigator-triangulation also served as means to alleviate these potential sources of bias, and increase trustworthiness of findings, since more than one researcher participated actively in the analyses of data. The reflexive process undertaken during this Ph.D.-period, and other measures to increase the validity of findings, are thoroughly described in Chapter 5.

Another limitation of the IFIP study is that the participants had to speak Norwegian, which exclude a part of the population that possibly could have contributed with significant data. Data is also limited to CMHCs in the South-East of Norway. Although the participating units differed greatly in terms of their patient population, service type, and level of family involvement (2), there may be regional differences that are not adequately represented in the data.

The findings in this thesis concern specific populations in a specific setting: health personnel and patients with psychotic disorders in CMCH units from the southeast of Norway. This population does probably not necessarily reflect the entire Norwegian population of health personnel and patients with psychotic disorders and their families. However, the fact that the IFIP study was performed in a real-world setting where the included units are serving approximately 25% of the Norwegian population (146), indicate that our findings concerning barriers and facilitators may be transferable to other similar contexts. For instance, after the implementation period, preliminary results were presented to all the control units, and the general feedback was that the main findings were recognisable and relevant also in their units and also in a wider context, for example not only for patients with psychotic disorders, but also other patients with severe mental illness. Thus, the findings of this thesis, in particular in combination with other results from the IFIP study, may be transferable to many similar settings and services attempting to improve the implementation of systematic family involvement, and possibly also relevant for policy development. Furthermore, the educational resources, tools, and measures developed as part of the trial may also be relevant to other similar settings in the mental health services, and possibly also to services in the Norwegian municipalities and hospital wards providing healthcare for the same patient group.

We know little about the transferability of the results to other countries but may assume they are more transferable or relevant to countries with similar cultural and socio-economic conditions, and where mental health care and other welfare services are mainly publicly funded. Discussions with international researchers and members of the advisory board indicate that findings may be transferable to some extent also outside Norway.

To make it easier for the reader to assess the transferability of the qualitative findings to their own setting, we have used quotes and “thick descriptions” as much as possible in the articles. Furthermore, the characteristics of the interventions, the participating units, and the implementation- and evaluation strategies in the IFIP study have been described thoroughly in the protocol article (1).

A special strength of study 3 is the collection of rich data from a stakeholder group that has rarely been included in qualitative research evaluating single-group FPE, or both FPE and BFIS. That is, patients with psychotic disorders have been included in qualitative research evaluating systematic family involvement less often than relatives and professionals. Other data from the IFIP study, such as the perspectives of clinicians or data on barriers and facilitators from relatives, and forthcoming publications, can help to further explore and compare the experiences and views on family involvement described by the patients in this study.

Close contact with the patients' therapists was established by the time of recruitment, which may have facilitated the inclusion of patients in the study. However, there is a risk of selection bias as the clinicians may have recruited the patients who were most positive towards the interventions, had the most well-functioning families, or the patients that were most well-functioning, assuming they were likely to participate meaningfully in the interviews. The retrospective design of this study may further lead to bias in recall, for example emphasizing mostly the positive experiences. To reduce these risks of bias we encouraged the units and the clinicians to also include participants with negative experiences with or critical views on family involvement. Furthermore, in all the interviews we asked explicitly about negative experiences with family involvement.

Caution should also be taken regarding the validity of findings in article 3, since we do not know for certain what kind of family involvement the participants had been exposed to or how much. The reason for this is that practicing other types of family involvement, before or during the trial, was not an exclusion criteria when we recruited the participating units. Furthermore, for the patients it was often difficult to know what kind of systematic family involvement he or she had participated in. This feature of the IFIP study`s design can be argued to be typical for pragmatic cluster randomised trials attempting to evaluate complex interventions in a large scale and real world setting. To reduce this risk, and to make sure that the participants had relevant exposure to systematic family involvement, an inclusion criteria was exposure either to BFIS and/or FPE. Thus, the experiences described are most likely related to BFIS and/or FPE. Furthermore, we assume that the patient data may be relevant also despite the possible risk of contamination, since the core components in many family involvement interventions are quite similar (3). Furthermore, the findings may also be relevant despite variations in “dose” or number of family involvement sessions, since evidence indicate that as little as 2-3 sessions may contribute to positive outcomes (43).

9. Implications

In general, the interventions, the implementation strategies, evaluation methods and findings from the IFIP study may be used as inspiration to operationalise, implement and evaluate guidelines on family involvement, in general in health care services, and in particular in CMHCs providing long-term health care for patients with psychotic disorders.

In this chapter I will now highlight some possible implications of this thesis – for future implementation of evidence-based and systematic family involvement in the health-care services, for clinical practice, and for policy, education and legislation. Finally, this chapter presents some implications for future research.

9.1. Implementation in CMHCs and similar settings

The findings in this thesis indicate that future implementation of evidence-based and systematic family involvement for patients with psychotic disorders and their families in CMCHs should employ a multi-level whole-ward approach where all staff obtain training in FPE and BFIS followed by practice, and where all patients are systematically offered family involvement. Strong leadership paving the way for implementation is a core feature of this whole-ward approach. For example, the leaders should foster shared knowledge and goals for the family involvement practices, prioritise such treatment and support, and facilitate standardisation. Leaders should also ensure that all clinicians get access to training, supervision, and practical experience as soon as possible after training. Furthermore, the leaders should strengthen health professionals` abilities to handle ethical challenges related to family involvement, such as confidentiality and information sharing, as this seemed particularly important to handle key barriers identified in study 1 and 2. Implementing local confidentiality guidelines, capacity building in clinical ethics, and clinical ethics support, are relevant measures.

Health-care professionals’ awareness and attitudes towards family involvement can be addressed through the facilitation of a family-friendly culture and flexible standardisation of the units’ family involvement practices. Discussing family involvement with all patients and relatives should be implemented as a default approach. For this purpose, the IFIP project provided a structured conversation guide as part of the intervention. This guide is currently under further development by the Division of Mental Health and Addiction, Vestre Viken Hospital Trust, and will most likely be available for general use in 2023-2024. This work has recently received social innovation funding from South-Eastern Norway Regional Health Authority.

The implementation tools and strategies can be further developed and disseminated through other innovation and research activities. For instance, a comprehensive tool-kit of varied measures and resources that have been developed in collaboration with the participating units as part of the implementation, will be further developed and utilised through a social innovation project funded by the University of Oslo (SPARK Social Innovation).

9.2. Clinical practice

Basic, systematic, and individually tailored family involvement, starting at onset of psychotic disorders should become a standard approach, followed by FPE or other more advanced and evidence-based family interventions. The use of flexible standardisation, as mentioned above, with structured but not rigid basic conversation about family involvement, may be useful in many different clinical settings and for many different patient groups with severe and chronic illness. Mental health professionals should probably inform and discuss systematic family involvement with all patients with psychotic disorders in the initial phases of the illness and try to establish contact with the patient’s relatives. More patients with psychotic disorders, probably all in the absence of clear contraindications, should be offered FPE as part of the mental health services’ standardised long-term treatment. However, BFIS and other more basic approaches may lower the threshold to establish contact with the relatives and initiate family involvement. A step-wise approach when asking for the patient's consent and when involving the next of kin, may be a fruitful strategy. Acknowledging that some of the barriers at the clinical level are ethical challenges, or caused by barriers at the organisational or policy level, rather than being someone's failure, may facilitate more open and constructive discussions. Furthermore, getting and sharing hands-on clinical experiences with systematic family involvement, in combination with training and supervision, seems to be a key both to inform the patient adequately and to motivate the clinicians to involve the family.

9.3. Education, policy and legislation

Adequate training of health personnel in family involvement is currently lacking in the Norwegian educational system and in the health services. If good family involvement practices are to take place, competence enhancement must start in the health educations to ensure nurses, psychologists, physicians and other mental health personnel can obtain proper training in family involvement, for example in evidence-based interventions, and in legislative and ethical aspects of confidentiality and information disclosure. Moreover, clinical exercises should be incorporated into such training programmes, as experiencing family involvement in real-life encounters was a strong facilitator in the IFIP study. Many of the findings can be included in education about family involvement, for instance how the initial phase of family involvement can best be undertaken to facilitate early triadic cooperation.

The main findings from this thesis and other relevant findings from the IFIP-study will be included in the new master's program in public health starting at the Institute of Health at Society in 2023. The findings are particularly relevant for one master's course (5 ECTS) focusing on user and family involvement and one master's course (5 ECTS) focusing on implementation and complex interventions. Furthermore, preliminary findings have already been incorporated into the institute's ethics teaching for medical students and at the master's programme in interdisciplinary health sciences.

Professional ethics is an important part of both health education and practice. There is probably a need to discuss whether the current professional ethics codes appropriately balance the interests of the professionals, patients, and the informal carers.

In decision-making processes concerning resource allocation and treatment recommendations, policy makers should give priority to family interventions such as FPE. This recommendation is supported in two recently published systematic reviews on relapse prevention in schizophrenia (43, 144).

The findings from this thesis indicates that the economic incentives in Norwegian health services (by and large publicly funded) do not favour family involvement, although it may be the most favourable interventions from a social and health economic perspective. Similarly, the digital health documentation systems and health legislation sometimes create unnecessary barriers to adequate family-based treatment for the patient and support for the informal carers. The tendency is however that the tasks and responsibilities for informal carers are increasing, thus, future health policy development probably need to address these imbalances.

Because family interventions are challenging to implement in clinical practice, and comprehensive implementation support is needed to make use of complex interventions (145), guidelines and other policy documents should take into account the required implementation resources pertaining to competence, financial support and time. Making use of evidence based complex interventions often require robust implementation support (136), but this does not seem to be the case today.

9.4. Research

Future qualitative research should explore further the active ingredients of family involvement, and their mechanisms of effect (88). There also is a need for more qualitative studies on the perspectives and experiences of various stakeholders. One example is to study in depth situations where patients are reluctant or do not consent to involve their families in treatment. Furthermore, we need further exploration of the relatives’ experiences with attending BFIS and FPE, and the significance to them, as well as the professionals’ perspectives. Scientific publications based upon this kind of data in the IFIP-study, using qualitative interviews, will be submitted soon.

Another is the exploration of barriers and facilitators from the perspective of patients and relatives to supplement the literature on health professionals’ views on such barriers and facilitators. Moreover, in-depth research on ethical dilemmas in family involvement is a less-explored area, and this thesis indicate that this may be key to successful implementation.

Furthermore, explorations of how family involvement is delivered, implemented, and experienced in other settings both nationally and internationally, and for other patient groups are needed. The results and experiences from the IFIP-study may be used as a starting point adapted, for example in in-patient units, and in the municipalities who provide treatment and care to persons with psychotic disorders, but also in studies focusing on other psychiatric conditions beyond the IFIP-context, such as severe substance abuse, bipolar disorders, severe depression, and severe eating disorders.

There is also a need for replicating the results from the IFIP-study, employing quantitative studies to compare various implementation strategies and mixed methods studies exploring the possible mechanisms of effects. Furthermore, investigations of the sustainability of the IFIP-intervention should be performed at the participating clinical sites after some time.

There is a general need to perform studies that explores how we can reduce the time it takes to integrate evidence-based and well-justified interventions such as FPE and BFIS and similar family interventions into education and the health services. Future research should also address how much and for how long external support is needed in health services to implement evidence based complex interventions, such as systematic family involvement, that are not yet integrated in the health education programmes.

Transparency in how intervention and implementation research is conducted, for example through thorough descriptions and process evaluation, are important to enable further development and research, and the use of important findings.

For the future, it is probably particularly important that the municipalities succeed in facilitating proper triadic collaboration. Furthermore, explorations of how continued treatment and care can be provided across service levels and how the specialist- and municipal health services in partnership can deliver FPE, for example by offering family psychoeducative sessions in collaboration between specialist and municipal health services, is encouraged.

Health services research should also investigate what is the most appropriate construction of health care services to succeed in integrating families in psychiatric treatment and to support the relatives in the informal carer role.

Furthermore, there is a need for investigations exploring whether minor changes in the health legislation can ensure that informal carers of competent patients receive a minimum of information needed to fulfil the role as informal carer, without unduly compromising patient privacy.

Finally, policy studies investigating how economic incentives can facilitate the use of family involvement interventions in the mental health services are needed.

10. Conclusions

An important aim in the IFIP-study was to implement the national guidelines on family involvement in the treatment of persons with psychotic disorders in Norwegian CMHCs. Nested in the IFIP study, this thesis provides a qualitative evaluation of the implementation process and the patients' experiences with the clinical intervention. While there is solid evidence that systematic family involvement is underutilized for this patient group, the key topics of the thesis - facilitators, ethical challenges related to the duty of confidentiality, and the patients' perspectives – all represent under-researched areas.

Focus group interviews with implementation teams and clinicians about their experiences with the implementation showed that several barriers exist both at the clinical and organisational level, and that the barriers can be mainly related to either the patient, the relative- or the provider. An overall lack of competence and experience with doing family involvement among the health personnel seemed to be a main barrier to implementation. The initial phase of family involvement generated key barriers, including ethical challenges, for example related to the process of obtaining patient consent, the duty of confidentiality, and information sharing.

Findings suggest that providing training in systematic family involvement and ethical and legal aspects to all staff, followed by clinical practice, reduced or dissolved several barriers to implementation. Capacity building for all staff was part the overall IFIP implementation strategy using a whole-ward and multi-level approach. It seems like this approach, including organisational- and leadership commitment, and flexible standardisation of family involvement, were key facilitators.

Furthermore, this thesis indicates that providing systematic family involvement in a CMHC context had great significance to the patients and their relatives. The systematic family involvement led to constructive change processes among health personnel, the patients, and their families. Simultaneously, crucial processes of change occurred at the organisational level, in terms of cultural and practice developments. A main feature of these change processes is that the stakeholders were brought closer together. Family involvement promoted shared understandings and awareness of each other's situation, which further facilitated trust, collaboration, support, and coping with the illness. In other words, negative circles - that could be both time consuming and gruelling - changed to positive circles. The adequately trained therapist seemed to constitute an important facilitator of these beneficial processes, and a continuous support to the relatives. Findings also provide insight into possible mediators of positive outcomes for the patients and the relatives.

Several of the patients in this study reported that they wished they had been offered family involvement at the onset of the illness. To support the afflicted families in a critical phase of their lives, and secure the abovementioned positive processes, CMHCs that provide treatment to persons with severe mental illness should implement systematic and individually tailored family involvement as a standard approach in the early phase of the disease trajectory. Using a step-wise process, starting with basic family involvement and support, and possibly continuing to more advanced family interventions, such as family psychoeducation, seem to a wise strategy.

Our findings indicate that mental health professionals who work with people with severe mental illness are often faced with unrealistic expectations to offer systematic family involvement without adequate training, support, and routines. It also seems like the implementation resources and competence required to implement complex interventions, such as systematic family involvement, are insufficient. This thesis provides in depth knowledge on how to better deal with these challenges, and solutions to improve the implementation of family involvement that seem to work in real-world clinical settings. Findings in this thesis may inform future policy, education, implementation, legislation, professional ethics and clinical practice when attempting to improve systematic family involvement and triadic collaboration when facing severe mental illness. Furthermore, the findings may also be further explored in future research in this field, for example in implementation and outcome research, and in similar research in other clinical settings or for other patient groups.

References

1. Hestmark L, Romoren M, Heiervang KS, Weimand B, Ruud T, Norvoll R, et al. Implementation of guidelines on family involvement for persons with psychotic disorders in community mental health centres (IFIP): protocol for a cluster randomised controlled trial. BMC Health Serv Res. 2020;20(1):934.
2. Hestmark L, Heiervang KS, Pedersen R, Hansson KM, Ruud T, Romøren M. Family involvement practices for persons with psychotic disorders in community mental health centres – a cross-sectional fidelity-based study. BMC Psychiatry. 2021;21(1):285.
3. Dirik A, Sandhu S, Giacco D, Barrett K, Bennison G, Collinson S, et al. Why involve families in acute mental healthcare? A collaborative conceptual review. BMJ Open. 2017;7(9):e017680.
4. Kuipers E, Yesufu-Udechuku A, Taylor C, Kendall T. Management of psychosis and schizophrenia in adults: summary of updated NICE guidance. BMJ : British Medical Journal. 2014;348:g1173.
5. Galletly C, Castle D, Dark F, Humberstone V, Jablensky A, Killackey E, et al. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the management of schizophrenia and related disorders. Australian & New Zealand Journal of Psychiatry. 2016;50(5):410-72.
6. Dixon LB, Dickerson F, Bellack AS, Bennett M, Dickinson D, Goldberg RW, et al. The 2009 schizophrenia PORT psychosocial treatment recommendations and summary statements. Schizophr Bull. 2010;36(1):48-70.
7. Nasjonal faglig retningslinje for utredning, behandling og oppfølging av personer med psykoselidelser. Oslo: Helsedirektoratet; 2013. Available from: https://www.helsedirektoratet.no/retningslinjer/psykoselidelser. Accessed January 2022
8. Psykoselidelser, inkludert mistanke om psykoseutvikling – barn, unge og voksne. Pakkeforløp 2018. Oslo: Helsedirektoratet; 2018. Available from: https://www.helsedirektoratet.no/pakkeforlop/psykoselidelser-inkludert-mistanke-om-psykoseutvikling-barn-unge-og-voksne. Accessed July 2022.
9. Veileder om pårørende i helse- og omsorgstjenesten. Strategi. Handlingsplan. Oslo: Helsedirektoratet; 2017. Available from: https://www.helsedirektoratet.no/veiledere/parorendeveileder. Accessed July 2022.
10. Vi – de pårørende. Regjeringens pårørendestrategi og handlingsplan. Oslo: Regjeringen; 2022. Available from: Vi – de pårørende (regjeringen.no). Accessed December 2022.
11. Oslostandard for pårørendesamarbeid. Oslo kommune, Helse og omsorg; 2020. Available from: https://www.oslo.kommune.no/helse-og-omsorg/oslostandard-for-parorendesamarbeid#gref. Accessed August 2022.
12. NICE. Psychosis and schizophrenia in adults (CG178). London: National Institute for Health and Clinical Excellence; 2014 Report No.: CG178. Available from: https://www.nice.org.uk/guidance/cg178. Accessed March 2022.
13. International Statistical Classification of Diseases and Related Health Problems - ICD-10. Schizophrenia, schizotypal and delusional disorders (F20-29): World Health organization; 2016. Available from: https://icd.who.int/browse10/2016/en#/F20-F29). Accessed May 2022.
14. Spaulding WD, Silverstein SM, Menditto AA. The Schizophrenia Spectrum. 2nd ed. Germany: Hogrefe Publishing GmbH; 2018.
15. Karambelas GJ, Filia K, Byrne LK, Allott KA, Jayasinghe A, Cotton SM. A systematic review comparing caregiver burden and psychological functioning in caregivers of individuals with schizophrenia spectrum disorders and bipolar disorders. BMC Psychiatry. 2022;22(1):422.
16. Bebbington P, Kuipers L. The predictive utility of expressed emotion in schizophrenia: an aggregate analysis. Psychological Medicine. 1994;24(3):707-18.
17. Shiraishi N, Reilly J. Positive and negative impacts of schizophrenia on family caregivers: a systematic review and qualitative meta-summary. Social Psychiatry and Psychiatric Epidemiology. 2019;54(3):277-90.
18. McFarlane WR. Family Interventions for Schizophrenia and the Psychoses: A Review. Family Process. 2016;55(3):460-82.

19. Johannessen JO, Joa I. Modern understanding of psychosis: from brain disease to stress disorder. And some other important aspects of psychosis…. Psychosis. 2021;13(4):289-301.

20. Mucci A, Kawohl W, Maria C, Wooller A. Treating Schizophrenia: Open Conversations and Stronger Relationships Through Psychoeducation and Shared Decision-Making. Frontiers in Psychiatry. 2020;11.

21. Zubin J, Spring B. Vulnerability: A new view of schizophrenia. Journal of Abnormal Psychology. 1977;86:103-26.

22. Mittal VA, Walker EF. Advances in the neurobiology of stress and psychosis. Schizophrenia Research. 2019;213:1-5.

23. Gray B, Robinson C, Seddon D, Roberts A. 'Confidentiality smokescreens' and carers for people with mental health problems: the perspectives of professionals. Health & Social Care in the Community. 2008;16(4):378-87.

24. Cree L, Brooks HL, Berzins K, Fraser C, Lovell K, Bee P. Carers' experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. BMC Psychiatry. 2015;15(1):208.

25. Saunders JC. Families Living with Severe Mental Illness: A Literature Review. Issues in Mental Health Nursing. 2003;24(2):175-98.

26. Lobban F, Postlethwaite A, Glentworth D, Pinfold V, Wainwright L, Dunn G, et al. A systematic review of randomised controlled trials of interventions reporting outcomes for relatives of people with psychosis. Clin Psychol Rev. 2013;33(3):372-82.

27. Flyckt L, Löthman A, Jörgensen L, Rylander A, Koernig T. Burden of informal care giving to patients with psychoses: a descriptive and methodological study. Int J Soc Psychiatry. 2013;59(2):137-46.

28. Onwumere J, Bebbington P, Kuipers E. Family interventions in early psychosis: specificity and effectiveness. Epidemiology and Psychiatric Sciences. 2011;20(2):113-9.

29. Spesialisthelsetjenesteloven. 1999. Lov om spesialisthelsetjenesten av 1999-07-02-61. Available from: https://lovdata.no/dokument/NL/lov/1999-07-02-61. Accessed June 2022.

30. Pasient- og brukerrettighetsloven. 1999. Lov om pasient- og brukerrettigheter. Available from: https://lovdata.no/lov/1999-07-02-63. Accessed September 2022.

31. Eassom E, Giacco D, Dirik A, Priebe S. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. BMJ Open. 2014;4(10):e006108.

32. Wainwright LD, Glentworth D, Haddock G, Bentley R, Lobban F. What do relatives experience when supporting someone in early psychosis? Psychol Psychother. 2015;88(1):105-19.

33. Wilson LS, Pillay D, Kelly BD, Casey P. Mental health professionals and information sharing: carer perspectives. Ir J Med Sci. 2015;184(4):781-90.

34. Doody O, Butler MP, Lyons R, Newman D. Families' experiences of involvement in care planning in mental health services: an integrative literature review. Journal of Psychiatric and Mental Health Nursing. 2017;24(6):412-30.

35. Cleary M, West S, Hunt GE, McLean L, Kornhaber R. A Qualitative Systematic Review of Caregivers' Experiences of Caring for Family Diagnosed with Schizophrenia. Issues in Mental Health Nursing. 2020;41(8):667-83.

36. Weimand BM, Hedelin B, Hall-Lord M-L, Sällström C. "Left Alone with Straining but Inescapable Responsibilities:" Relatives' Experiences with Mental Health Services. Issues in Mental Health Nursing. 2011;32(11):703-10.

37. Vermeulen B, Lauwers, H., Spruytte, N., Van Audenhove, C., Magro, C., Saunders, J. & Jones, , K. Experiences of family caregivers for persons with severe mental illness: an international exploration. Leuven: LUCAS KU Leuven/EUFAMI; 2015.

38. Rabstejnek C. Family Systems & Murray Bowen Theory. 2009.

39. Lakeman R. The Finnish open dialogue approach to crisis intervention in psychosis: A review. Psychotherapy in Australia. 2014;20(3):28-35.

40. Fadden G, Heelis R. The Meriden Family Programme: Lessons learned over 10 years. Journal of Mental Health. 2011;20(1):79-88.
41. Lucksted A, McFarlane W, Downing D, Dixon L. Recent Developments in Family Psychoeducation as an Evidence-Based Practice. J Marital Fam Ther. 2012;38(1):101-21.
42. Pharoah F, Mari J, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database Syst Rev. 2010(12):CD000088-CD.
43. Rodolico A, Bighelli I, Avanzato C, Concerto C, Cutrufelli P, Mineo L, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. Lancet Psychiatry. 2022;9(3):211-221. Erratum in: Lancet Psychiatry. 2022 Feb 23;: PMID: 35093198.
44. Pilling S, Bebbington P, Kuipers E, Garety P, Geddes J, Orbach G, et al. Psychological treatments in schizophrenia: I. Meta-analysis of family intervention and cognitive behaviour therapy. Psychological Medicine. 2002;32(5):763-82.
45. Sin J, Gillard S, Spain D, Cornelius V, Chen T, Henderson C. Effectiveness of psychoeducational interventions for family carers of people with psychosis: A systematic review and meta-analysis. Clinical Psychology Review. 2017;56:13-24.
46. Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, Young N, Woodhams P, Shiers D, et al. Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. Br J Psychiatry. 2018;206(4):268-74.
47. Ma CF, Chien WT, Bressington DT. Family intervention for caregivers of people with recent-onset psychosis: A systematic review and meta-analysis. Early Interv Psychiatry. 2018;12(4):535-60.
48. Bucci S, Berry K, Barrowclough C, Haddock G. Family Interventions in Psychosis: A Review of the Evidence and Barriers to Implementation. Australian Psychologist. 2016;51(1):62-8.
49. Ince P, Haddock G, Tai S. A systematic review of the implementation of recommended psychological interventions for schizophrenia: Rates, barriers, and improvement strategies. Psychology and Psychotherapy: Theory, Research and Practice. 2016;89(3):324-50.
50. Rummel-Kluge C, Pitschel-Walz G, Bäuml J, Kissling W. Psychoeducation in schizophrenia--results of a survey of all psychiatric institutions in Germany, Austria, and Switzerland. Schizophr Bull. 2006;32(4):765-75.
51. Dixon L, McFarlane WR, Lefley H, Lucksted A, Cohen M, Falloon I, et al. Evidence-based practices for services to families of people with psychiatric disabilities. Psychiatr Serv. 2001;52(7):903-10.
52. Susan D, Phillips MSW, Burns BJ, Edgar ER, Mueser KT, Linkins KW, Rosenheck RA et al. Moving Assertive Community Treatment Into Standard Practice. Psychiatric Services. 2001;52(6):771-9
53. McGuire AB, Kukla M, Green A, Gilbride D, Mueser KT, Salyers MP. Illness management and recovery: a review of the literature. Psychiatr Serv. 2014;65(2):171-9.
54. Shafaghat T, Imani Nasab MH, Bahrami MA, Kavosi Z, Roozrokh Arshadi Montazer M, Rahimi Zarchi MK, et al. A mapping of facilitators and barriers to evidence-based management in health systems: a scoping review study. Systematic Reviews. 2021;10(1):42.
55. Haddock G, Eisner E, Boone C, Davies G, Coogan C, Barrowclough C. An investigation of the implementation of NICE-recommended CBT interventions for people with schizophrenia. Journal of Mental Health. 2014;23(4):162-5.
56. Mairs H, Bradshaw T. Implementing family intervention following training: what can the matter be? J Psychiatr Ment Health Nurs. 2005;12(4):488-94.
57. Landeweer E, Molewijk B, Hem MH, Pedersen R. Worlds apart? A scoping review addressing different stakeholder perspectives on barriers to family involvement in the care for persons with severe mental illness. BMC Health Serv Res. 2017;17(1):349.
58. Grimshaw J, Eccles M, Tetroe J. Implementing clinical guidelines: Current evidence and future implications. Journal of Continuing Education in the Health Professions. 2004;24:S31-S7.
59. Grimshaw JM, Eccles MP, Lavis JN, Hill SJ, Squires JE. Knowledge translation of research findings. Implementation Science. 2012;7(1):50.

60. Harrington A. The art of medicine. The fall of the schizophrenogenic mother. The Lancet. 2012;379.
61. Petrakis M, Bloom H, Oxley J. Family Perceptions of Benefits and Barriers to First Episode Psychosis Carer Group Participation. Social Work in Mental Health. 2014;12(2):99-116.
62. Blomqvist M, Ziegert K. 'Family in the waiting room': A Swedish study of nurses' conceptions of family participation in acute psychiatric inpatient settings. International Journal of Mental Health Nursing. 2011;20(3):185-94.
63. O'Hanlon B, Hayes L, Perlesz A, Harvey C. Understanding the complex family experiences of Behavioural Family Therapy. Journal of Family Therapy. 2018;40(1):45-62.
64. Nilsen L, Norheim I, Frich JC, Friis S, Røssberg JI. Challenges for group leaders working with families dealing with early psychosis: a qualitative study. BMC Psychiatry. 2015;15(1):141.
65. Ingvarsdotter K, Persson K, Hjärthag F, Östman M. How Professionals View Multifamily Psychoeducation: A Qualitative Study. Psychiatr Q. 2016;87(3):479-91.
66. Lillemoen L, Pedersen R. Ethical challenges and how to develop ethics support in primary health care. Nursing Ethics. 2013;20(1):96-108.
67. Rapaport J, Bellringer S, Pinfold V, Huxley P. Carers and confidentiality in mental health care: considering the role of the carer's assessment: a study of service users', carers' and practitioners' views. Health & Social Care in the Community. 2006;14(4):357-65.
68. Pinfold V, Farmer P, Rapaport J, Bellringer S, Huxley P, Murray J, et al. Positive and inclusive. Effective ways for professionals to involve carers in information sharing Kingston-Upon-Thames: Rethink severe mental illness. 2004.
69. Marshall TB, Solomon P. Releasing Information to Families of Persons With Severe Mental Illness: A Survey of NAMI Members. Psychiatric Services. 2000;51(8):1006-11.
70. Marshall TB, Solomon P. Professionals' responsibilities in releasing information to families of adults with mental illness. Psychiatr Serv. 2003;54(12):1622-8.
71. Førde R, Norvoll R, Hem MH, Pedersen R. Next of kin's experiences of involvement during involuntary hospitalisation and coercion. BMC Medical Ethics. 2016;17(1):76.
72. Etiske regler for leger. Den norske legeforening; 2011. Available from: https://www.legeforeningen.no/om-oss/etikk/etiske-regler-koder-deklarasjoner-og-lignende/etiske-regler-for-leger/. Accessed September 2022.
73. Etiske prinsipper for nordiske psykologer. Norsk Psykologforening; 1998. Available from: https://www.psykologforeningen.no/medlem/etikk/etiske-prinsipper-for-nordiske-psykologer. Accessed September 2022.
74. Health Personnel Act. 1999. Lov om helsepersonell av 1999-07-02-64. Available from: https://lovdata.no/dokument/NL/lov/1999-07-0264?q=lov%20om%20helsepersonell. Accessed June 2022.
75. Psykisk helsevernloven. 2001. Lov om etablering og gjennomføring av psykisk helsevern. Available from: https://lovdata.no/dokument/NL/lov/1999-07-02-61. Accessed June 2022.
76. Nilsen L, Frich J, Friis S, Rossberg J. Patients' and Family Members' Experiences of a Psychoeducational Family Intervention after a First Episode Psychosis: A Qualitative Study. Issues in Mental Health Nursing. 2014;35:58-68.
77. Nilsen L, Frich JC, Friis S, Norheim I, Rossberg JI. Participants' perceived benefits of family intervention following a first episode of psychosis: a qualitative study. Early Interv Psychiatry. 2016;10(2):152-9.
78. Jensen E, Carr R, Degnan A, Berry K, Edge D. Exploring service user and family perspectives of a Culturally adapted Family Intervention (CaFI) for African-Caribbean people with psychosis: A qualitative study. Br J Clin Psychol. 2021;60(2):270-89.
79. Loh C, Liang W, Lee H, Koh A. Multi-Family Therapy for First Episode Psychosis: Experiences of Families in Singapore. Front Psychiatry. 2021;12:788827.
80. Allen J, Burbach F, Reibstein J. 'A different world' individuals' experience of an integrated family intervention for psychosis and its contribution to recovery. Psychol Psychother. 2013;86(2):212-28.

81. Giacco D, Dirik A, Kaselionyte J, Priebe S. How to make carer involvement in mental health inpatient units happen: a focus group study with patients, carers and clinicians. BMC Psychiatry. 2017;17(1):101.
82. Kaselionyte J, Conneely M, Giacco D. "It's a matter of building bridges…" - feasibility of a carer involvement intervention for inpatients with severe mental illness. BMC Psychiatry. 2019;19(1):268.
83. Grácio J, Gonçalves-Pereira M, Leff J. What do We Know about Family Interventions for Psychosis at the Process Level? A Systematic Review. Family Process. 2016;55(1):79-90.
84. Mottaghipour Y, Bickerton A. The Pyramid of Family Care: A framework for family involvement with adult mental health services. Australian e-Journal for the Advancement of Mental Health. 2014;4(3):210-7.
85. Maslow AH. A Theory of Human Motivation. Psychological Review 1943; 50, 370-396
86. Powell BJ, McMillen JC, Proctor EK, Carpenter CR, Griffey RT, Bunger AC, et al. A compilation of strategies for implementing clinical innovations in health and mental health. Med Care Res Rev. 2012;69(2):123-57.
87. Nilsen P. Making sense of implementation theories, models and frameworks. Implement Sci. 2015;10:53.
88. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ. 2008;337:a1655.
89. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for Implementation Research: Conceptual Distinctions, Measurement Challenges, and Research Agenda. Administration and Policy in Mental Health and Mental Health Services Research. 2011;38(2):65-76.
90. Campbell M, Fitzpatrick R, Haines A, Kinmonth AL, Sandercock P, Spiegelhalter D, et al. Framework for design and evaluation of complex interventions to improve health. Bmj. 2000;321(7262):694-6.
91. Craig P, Petticrew M. Developing and evaluating complex interventions: Reflections on the 2008 MRC guidance. International Journal of Nursing Studies. 2013;50(5):585-7.
92. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ. 2021;374:n2061.
93. Evaluation in health and wellbeing. A guide to evaluation of health and wellbeing projects and programmes: GOV.UK. Available from: Evaluation in health and wellbeing - GOV.UK (www.gov.uk). Accessed February 2022.
94. Oakley A, Strange V, Bonell C, Allen E, Stephenson J. Process evaluation in randomised controlled trials of complex interventions. Bmj. 2006;332(7538):413-6.
95. Proctor EK, Landsverk J, Aarons G, Chambers D, Glisson C, Mittman B. Implementation Research in Mental Health Services: an Emerging Science with Conceptual, Methodological, and Training challenges. Administration and Policy in Mental Health and Mental Health Services Research. 2009;36(1):24-34.
96. Dixon BE, Cusack CM. Chapter 15 - Measuring the Value of Health Information Exchange. In: Dixon BE, editor. Health Information Exchange: Academic Press; 2016. p. 231-48.
97. Førde R. Førde, R., Kjelland, M. & Stridbeck, U. (2016). Cand.mag., cand.med., cand.jur., cand.alt. Festskrift til Aslak Syse 70 år. Oslo: Gyldendal Akademisk. 2016.
98. Nordtvedt P. Omtanke. En innføring i sykepleiens etikk. 2. utgave, Oslo: Gyldendal Akademisk; 2016.
99. Pedersen R, Nordtvedt P. Etikk i psykiske helsetjenester. Oslo: Gyldendal Akademisk; 2017.
100. Beauchamp TL, Childress JF. Principles of biomedical ethics. 8th ed. New York: Oxford University Press; 2019. (1st ed. 1979).
101. Gómez-Vírseda C, de Maeseneer Y, Gastmans C. Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities. BMC Medical Ethics. 2020;21(1):50.
102. Gómez-Vírseda C, de Maeseneer Y, Gastmans C. Relational autonomy: what does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. BMC Medical Ethics. 2019;20(1):76.

103. Hippocratic Oath. Available from: https://www.britannica.com/topic/Hippocratic-oath. Accessed December 2022.
104. Jurgen Habermas. Stanford Encyclopedia of Philosophy. Available from: Jürgen Habermas (Stanford Encyclopedia of Philosophy). Accessed December 2022.
105. Hem MH, Molewijk B, Pedersen R. Systematisk etikkrefleksjon gjør en forskjell – Et ressurshefte for etikkrefleksjonsgrupper i psykisk helsevern. Oslo, Senter for medisinsk etikk, Universitetet i Oslo;2017
106. Abma TA. Responsive evaluation in health promotion: its value for ambiguous contexts. Health Promotion International. 2005;20(4):391-7.
107. Abma TA. The Practice and Politics of Responsive Evaluation. American Journal of Evaluation. 2006;27(1):31-43.
108. HVORDAN STARTE ET PSYKOEDUKATIVT FAMILIESAMARBEID MED ENFAMILIEGRUPPE. Del 1 2021. TIPS Sør-Øst, Regional kompetansetjeneste for tidlig intervensjon ved psykose. Available from: https://oslo-universitetssykehus.no/seksjon/Regionalt-kompetansesenter-for-tidlig-intervensjon-ved-psykoser/Documents/Metodebok%20NOVEMBER%202021_Del%201.pdf. Accessed September 2022.
109. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for Reporting Qualitative Research: A Synthesis of Recommendations. Academic Medicine. 2014;89(9):1245-51.
110. Lassiter LE. The Chicago Guide to collaborative ethnography. Chicago: Universiy of Chicago Press; 2005.
111. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. Administration and policy in mental health. 2015;42(5):533-44.
112. Nikolopoulou K. What Is Non-Probability Sampling? | Types & Examples 2022 Available from: https://www.scribbr.com/methodology/probability-sampling/. Accessed November 2022.
113. Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, et al. Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres – a nested qualitative study. BMC Health Services Research. 2022;22(1):1153.
114. Elo S, Kyngäs H. The qualitative content analysis process. Journal of Advanced Nursing. 2008;62(1):107-15.
115. Lindgren B-M, Lundman B, Graneheim UH. Abstraction and interpretation during the qualitative content analysis process. International Journal of Nursing Studies. 2020;108:103632.
116. Moen K, Middelthon AL. Qualitative methods. In P. Laake, H.B. Benestad & B. R. Olsen (Eds.) Research in Medical and Biological Sciences. Elsevier; 2015
117. Tjora A. Kvalitative forskningsmetoder i praksis. (2.utg.). Oslo: Gyldendal Akademisk; 2013.
118. Green J, Thorogood N. Qualitative Methods for Health Research. London: Sage; 2018.
119. Pedersen R. Empathy in medicine: a philosophical hermeneutic reflection [Doctoral thesis]. Oslo: University of Oslo; 2010.
120. Thoresen L. "I rather talk about football" A Study on Lifeworld in a Hospice Ward. In Perceiving the Other: Case Studies and Theories of Respectful Action. Vandenhoeck & Ruprecht; 2010.
121. Gadamer HG. Truth and Method. Bloomsbury Academic; 2013.
122. Noble H, Smith J. Issues of validity and reliability in qualitative research. Evidence Based Nursing. 2015;18(2):34-5.
123. Krieger S. Social Science and The Self. Personal Essays on an Art Form. Rutgers University Press; 1991.
124. Atkinson P, Atkinson P, Silverman D, Becker HS. Inside Interviewing. Thousand Oaks, California: SAGE Publications; 2003. Available from: https://methods.sagepub.com/book/inside-interviewing.
125. Kvale S, Brinkmann S. Det kvalitative forskningsintervju. (2. utg.) Oslo: Gyldendal Akademisk¸2009.

126. Warren C. A. B. Qualitative Interviewing. In J. F. Gubrium & J. A. Holstein (Eds.) Handbook of Interview Research, Context & Method London: Sage; 2001.

127. Holm S, Reino Olsen B. Ethics in Human and Animal Studies. In Research in Medical and Biological Sciences. Elsevier ldt.; 2015

128. World Medical Association. Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects. JAMA. 2013;310(20):2191-4.

129. Helseforskningsloven. 2009. Lov om medisinsk og helsefaglig forskning av 2008-06-20-44. Available from: Lov om medisinsk og helsefaglig forskning (helseforskningsloven) - Lovdata. Accessed June 2022.

130. Personopplysningsloven. 2018. Lov om behandling av personopplysninger av 2018-06-15-38. Available from: Lov om behandling av personopplysninger (personopplysningsloven) - Lovdata . Accessed June 2022.

131. Kvalitetssystem for medisinsk og helsefaglig forskning. Universitet i Oslo. Available from: https://www.uio.no/for-ansatte/arbeidsstotte/forskningsstotte/regelverk-og-forskningsetikk/kvalitetssystemhelse/#:~:text=Kvalitetssystemet%20best%C3%A5r%20av%20en%20overordnet%20kvalitetspolicy%2C%20en%20beskrivelse,dokumentere%20forskningen%20i%20henhold%20til%20lovverket.%201%20Kvalitetspolicy. Accessed November 2022

132. Hem M. Personer med psykisk lidelse. De nasjonale forskningsetiske komiteene; 2015. Available from: https://www.etikkom.no/FBIB/Temaer/Forskning-pa-bestemte-grupper/Personer-med-psykisk-lidelse Accessed November 2022

133. Beauchamp TL. Autonomy and Consent. In: Miller F, Wertheimer A, editors. The Ethics of Consent: Theory and Practice: Oxford University Press; 2009

134. Solbakk J H. Sårbare grupper. De nasjonale forskningsetiske komiteene; 2014. Available from: https://www.etikkom.no/FBIB/Temaer/Forskning-pa-bestemte-grupper/Sarbare-grupper/. (2014, 10. oktober). Accessed October 2022

135. Medical and health research. National Research Ethics Comittees. Available from: https://www.forskningsetikk.no/en/guidelines/medical-and-health-research/. Accessed October 2022

136. Sævareid TJL. Advance care planning in nursing homes – A mixed methods study of a complex intervention using a whole-ward approach [Doctoral thesis]. Oslo: University of Oslo; 2019.

137. McCann TV, Lubman DI, Clark E. Primary caregivers' satisfaction with clinicians' response to them as informal carers of young people with first-episode psychosis: a qualitative study. Journal of Clinical Nursing. 2012;21(1-2):224-31.

138. Bradley E, Green D. Involved, inputting or informing: "Shared" decision making in adult mental health care. Health Expectations. 2018;21(1):192-200.

139. Grácio J, Gonçalves-Pereira M, Leff J. Key Elements of a Family Intervention for Schizophrenia: A Qualitative Analysis of an RCT. Family Process. 2018;57(1):100-12.

140. Lobban F, Akers N, Appelbe D, et al. A web-based, peer-supported self-management intervention to reduce distress in relatives of people with psychosis or bipolar disorder: the REACT RCT. Southampton (UK): NIHR Journals Library; 2020 Jun. (Health Technology Assessment, No. 24.32.) Chapter 6, Relatives' experiences of using REACT. Available from: https://www.ncbi.nlm.nih.gov/books/NBK558722/. Accessed November 2022

141. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: Medical Research Council guidance. BMJ. 2015;350:h1258.

142. Stetler CB, Legro MW, Wallace CM, Bowman C, Guihan M, Hagedorn H, et al. The role of formative evaluation in implementation research and the QUERI experience. Journal of General Internal Medicine. 2006;21(2):S1.

143. Malterud K. Qualitative research: standards, challenges, and guidelines. The Lancet. 2001;358(9280):483-8.

144. Bighelli I, Rodolico A, García-Mieres H, Pitschel-Walz G, Hansen W-P, Schneider-Thoma J, et al. Psychosocial and psychological interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. The Lancet Psychiatry. 2021;8(11):969-80.

145. Saevareid TJL, Forde R, Thoresen L, Lillemoen L, Pedersen R. Significance of advance care planning in nursing homes: views from patients with cognitive impairment, their next of kin, health personnel, and managers. Clin Interv Aging. 2019;14:997-1005.

146. Hestmark L, Romøren M, Heiervang KS, et al. Implementation of Guidelines on Family Involvement for Persons with Psychotic Disorders (IFIP): A Cluster Randomised Controlled Trial. Adm Policy Ment Health. 2023;50:520-533.

Quote reference page II: 19.

Appendices and publications

Appendix 1	Informed consent form I, implementation teams
Appendix 2	Informed consent form II, implementation teams
Appendix 3	Informed consent form, clinicians
Appendix 4	Informed consent form, patients
Appendix 5	Interview guide focus group interviews I, implementation teams
Appendix 6	Interview guide focus group interviews II, implementation teams
Appendix 7	Interview guide focus group interviews, clinicians
Appendix 8	Interview guide, patients

Article 1 Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, Ruud T, Stølan Hymer I, Heiervang KS. *Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres – a nested qualitative study.* BMC Health Services Research. 2022; 22:1153. doi: 10.1186/s12913-022-08489-y

Article 2 Hansson KM, Romøren M, Weimand B, Heiervang KS, Hestmark L, Landeweer EGM, Pedersen R. *The duty of confidentiality during family involvement: ethical challenges and possible solutions in the treatment of persons with psychotic disorders.* BMC Psychiatry. 2022; 22:812. doi: 10.1186/s12888-022-04461-6

Article 3 Hansson KM, Romøren M, Hestmark L, Heiervang KS, Weimand B, Norheim I, Pedersen R. *"The most important thing is that those closest to you, understand you". A nested qualitative study of persons with psychotic disorders' experiences with family involvement*. Manuscript submitted for publication. 2022.

Appendix 1 - Informed consent form I, implementation teams

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET – VERSJON 03.05.2019

BEDRE PÅRØRENDESAMARBEID (BPS)

OM STUDIEN

Dette er et spørsmål til deg om å bidra inn i prosjektet «Bedre pårørendeSamarbeid (BPS)». Målet med dette prosjektet er å bedre samarbeidet mellom ansatte, pasient og pårørende og å bedre helsen til pasienten og deres pårørende. Vi ønsker å lære mer om pårørendesamarbeid sett fra ulike perspektiv; pasienter, pårørende og helsepersonell som jobber med psykosepasienter. Du er invitert til å delta i prosjektet fordi du representerer en av disse gruppene.

Det er 14 DPS (distriktpsykiatriske sentre)-enheter som deltar i prosjektet i tillegg til det behandlingsstedet der du er ansatt. Alle disse stedene vil få hjelp til å bedre samarbeidet med pårørende; først den ene halvparten (intervensjonsgruppen), så den andre halvparten (kontrollgruppen). Det skal bare fokuseres på tiltak som både er anbefalt og som er vist å være bra for pasienten og de pårørende. Eksempler på slike tiltak er å opprette en pårørendekoordinator og å gi de ansatte opplæring slik at pasienter og pårørende kan få informasjon, opplæring og oppfølging som er godt tilpasset deres behov.

Prosjektet er et samarbeid mellom Universitetet i Oslo, Akershus universitetssykehus HF, OsloMet, TIPS Sør-Øst og de deltakende behandlingsstedene. Dette er en multisenterstudie hvor Universitetet i Oslo er koordinerende institusjon med prosjektledelse og hvor Universitetet i Oslo, OsloMet, Akershus universitetssykehus HF, Vestre Viken HF, Sykehuset i Vestfold HF, Diakonhjemmet, Sykehuset i Telemark HF, Oslo Universitetssykehus HF, Helse Fonna HF og TIPS Sør-Øst er dataansvarlige/forskningsansvarlige institusjoner. Forventet prosjektslutt er 1. oktober 2027.

HVA INNEBÆRER DELTAGELSE I GRUPPEINTERVJUET?

Din deltagelse i prosjektet innebærer at du deltar i to gruppeintervjuer sammen med andre ressurspersoner i forbedringsteamet fra din enhet. De to intervjuene vil finne sted i starten av intervensjonsperioden (april-juni 2019) og underveis i intervensjonen (siste kvartal 2019-første kvartal 2020). To forskere vil gjennomføre intervjuet i forbindelse med enhetens veiledningsdag våren 2019 og høsten 2019. Hvert intervju vil ta ca. 1,5 time.

Temaer vi ønsker å spørre dere i forbedringsteamet om:

- Erfaringer med pårørendesamarbeidet og å delta BPS, inkludert implementeringsstøtten og arbeidet i forbedringsteamet.
- De viktigste hemmerne og fremmerne i pårørendesamarbeidet, inkludert etiske dilemmaer.

I intervjuet høsten 2019 vil vi også spørre dere om betydningen av pårørendesamarbeidet.

Appendix 1 - Informed consent form I, implementation teams

For å være sikker på at vi får med alt gruppen sier, ønsker vi å bruke lydopptaker. Forskerne vil ta ansvar for å utelate all informasjon som kan identifisere deg og andre personer i publisering og formidling fra prosjektet. Lydopptakene vil bli overført til en sikker server (TSD) og skrevet ut av forsker eller assistent uten identifiserbare kjennetegn.

Nedenfor ber vi deg fylle ut informasjon om alder og stilling, samt kontaktinformasjon. Dette vil bli oppbevart separat fra lydfiler og transkripsjoner.

MULIGE FORDELER OG ULEMPER

Det er ingen ulemper for deg utover det å bruke tid på å delta i intervjuet. Prosjektet skal bidra til bedre samarbeid mellom ansatte, pasient og pårørende ved alvorlig psykiske problemer, og gi mer kunnskap om hvordan en kan få til bedre behandling. Et viktig mål med studien er å bidra til helsetjenester som i enda større grad forstår og ivaretar også de pårørendes behov. Pasienter og pårørende på tjenestesteder som deltar i prosjektet vil få samme eller bedre hjelp enn de ellers ville fått.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du har også rett til å få informasjon om utfallet/resultatet av studien.

Du kan når som helst og uten å oppgi noen grunn trekke deg fra prosjektet. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder Reidar Pedersen: reidar.pedersen@medisin.uio.no, telefon: 22 84 46 63/41 57 59 87.

HVA SKJER MED INFORMASJONEN VI SAMLER?

Intervjuene skal kun brukes slik som beskrevet over. Samtykkeskjema, lydfiler og intervjuutskrifter vil alle oppbevares hver for seg. Alle data anonymiseres senest innen 5 år etter prosjektslutt.

Det er kun forskere tilknyttet prosjektet som har tilgang til dataene og de er underlagt taushetsplikt. Alle data vil lagres på en sikker server (TSD) ved Universitetet i Oslo i prosjektperioden. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Vi vil gjerne oppbevare kontaktinformasjonen din i inntil 5 år for å kunne ta kontakt med deg hvis det skulle bli behov for innhente supplerende informasjon senere.

Resultater fra studien vil munne ut i noen anbefalinger om fremtidig politikk- og lovutvikling samt systemutvikling av det psykiske helsefeltet for å styrke pårørendesamarbeid og implementering av pårørende-veilederen. Resultatene fra studien vil også presenteres i vitenskapelige forskningsartikler, populærvitenskapelige tidsskrift, eller i undervisning og foredrag. Du har også rett til å få informasjon om utfallet/resultatet av studien.

UTLEVERING AV OPPLYSNINGER TIL ANDRE

Det er ikke aktuelt å utlevere hverken direkte eller indirekte identifiserbare opplysninger til andre. Anonymiserte opplysninger og forskningsresultater vil bli brukt slik som angitt ellers i dette skrivet.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk (REK): Saksnr. 2018/128, dato: 29.05.2018.

Personvernombudets ved XX HF's tilrådning: XX Kontaktinfo: XX

Brudd på personvernregelverket kan klages inn til Datatilsynet; Postboks 458 Sentrum, 0105 Oslo.

Det rettslige grunnlaget for gjennomføringen av prosjektet er personvernforordningens artikkel 9 nr. 2 bokstav a, samt personopplysningslovens § 10.

Appendix 1 - Informed consent form I, implementation teams

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato	Deltakers signatur
	Deltakers navn med store bokstaver

Alder: ____

Stilling: ____

Kontaktinformasjon:

Telefonnummer: ____

E-postadresse: ____

Appendix 2 - Informed consent form II, implementation teams

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET – VERSJON 23.12.2019

BEDRE PÅRØRENDESAMARBEID (BPS)

OM STUDIEN

Dette er et spørsmål til deg om å bidra inn i prosjektet «Bedre pårørendeSamarbeid (BPS)». Målet med dette prosjektet er å bedre samarbeidet mellom ansatte, pasient og pårørende og å bedre helsen til pasienten og deres pårørende. Vi ønsker å lære mer om pårørendesamarbeid sett fra ulike perspektiv; pasienter, pårørende og helsepersonell som jobber med psykosepasienter. Du er invitert til å delta i prosjektet fordi du representerer en av disse gruppene.

Det er 14 DPS (distriktpsykiatriske sentre)-enheter som deltar i prosjektet i tillegg til det behandlingsstedet der du er ansatt. Alle disse stedene vil få hjelp til å bedre samarbeidet med pårørende; først den ene halvparten (intervensjonsgruppen), så den andre halvparten (kontrollgruppen). Det skal bare fokuseres på tiltak som både er anbefalt og som er vist å være bra for pasienten og de pårørende. Eksempler på slike tiltak er å opprette en pårørendekoordinator og å gi de ansatte opplæring slik at pasienter og pårørende kan få informasjon, opplæring og oppfølging som er godt tilpasset deres behov.

Prosjektet er et samarbeid mellom Universitetet i Oslo, Akershus universitetssykehus HF, OsloMet, TIPS Sør-Øst og de deltakende behandlingsstedene. Dette er en multisenterstudie hvor Universitetet i Oslo er koordinerende institusjon med prosjektledelse og hvor Universitetet i Oslo, OsloMet, Akershus universitetssykehus HF, Vestre Viken HF, Sykehuset i Vestfold HF, Diakonhjemmet, Sykehuset i Telemark HF, Oslo Universitetssykehus HF, Helse Fonna HF og TIPS Sør-Øst er dataansvarlige/forskningsansvarlige institusjoner. Forventet prosjektslutt er 1. oktober 2027.

HVA INNEBÆRER DELTAGELSE I GRUPPEINTERVJUET?

Din deltagelse innebærer at du deltar i et gruppeintervju sammen med andre ressurspersoner i forbedringsteamet fra din enhet. To forskere vil gjennomføre intervjuet i forbindelse med enhetens veiledningsdag januar 2020. Hvert intervju vil ta ca. 1,5 time.

Temaer vi ønsker å spørre dere i forbedringsteamet om:
Erfaringer med pårørendesamarbeidet og å delta BPS, inkludert implementeringsstøtten og arbeidet i forbedringsteamet.

- De viktigste hemmerne og fremmerne i pårørendesamarbeidet, inkludert etiske dilemmaer.
- Betydningen av pårørendesamarbeidet.

For å være sikker på at vi får med alt gruppen sier, ønsker vi å bruke lydopptaker. Forskerne vil ta ansvar for å utelate all informasjon som kan identifisere deg og andre personer i publisering og formidling fra prosjektet.

Lydopptakene vil bli overført til en sikker server (TSD) og skrevet ut av forsker eller assistent uten identifiserbare kjennetegn.

Nedenfor ber vi deg fylle ut informasjon om alder og stilling, samt kontaktinformasjon. Dette vil bli oppbevart separat fra lydfiler og transkripsjoner.

MULIGE FORDELER OG ULEMPER

Det er ingen ulemper for deg utover det å bruke tid på å delta i intervjuet. Prosjektet skal bidra til bedre samarbeid mellom ansatte, pasient og pårørende ved alvorlig psykiske problemer, og gi mer kunnskap om hvordan en kan få til bedre behandling. Et viktig mål med studien er å bidra til helsetjenester som i enda større grad forstår og ivaretar også de pårørendes behov. Pasienter og pårørende på tjenestesteder som deltar i prosjektet vil få samme eller bedre hjelp enn de ellers ville fått.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du har også rett til å få informasjon om utfallet/resultatet av studien.

Du kan når som helst og uten å oppgi noen grunn trekke deg fra prosjektet. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder Reidar Pedersen: reidar.pedersen@medisin.uio.no, telefon: 22 84 46 63/41 57 59 87.

HVA SKJER MED INFORMASJONEN VI SAMLER?

Intervjuene skal kun brukes slik som beskrevet over. Samtykkeskjema, lydfiler og intervjuutskrifter vil alle oppbevares hver for seg. Alle data anonymiseres senest innen 5 år etter prosjektslutt.

Det er kun forskere tilknyttet prosjektet som har tilgang til dataene og de er underlagt taushetsplikt. Alle data vil lagres på en sikker server (TSD) ved Universitetet i Oslo i prosjektperioden. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Vi vil gjerne oppbevare kontaktinformasjonen din i inntil 5 år for å kunne ta kontakt med deg hvis det skulle bli behov for innhente supplerende informasjon senere.

Resultater fra studien vil munne ut i noen anbefalinger om fremtidig politikk- og lovutvikling, samt systemutvikling av det psykiske helsefeltet for å styrke pårørendesamarbeid og implementering av Pårørende-veilederen. Resultatene fra studien vil også presenteres i vitenskapelige forskningsartikler, populærvitenskapelige tidsskrift eller i undervisning og foredrag. Du har også rett til å få informasjon om utfallet/resultatet av studien.

UTLEVERING AV OPPLYSNINGER TIL ANDRE

Det er ikke aktuelt å utlevere hverken direkte eller indirekte identifiserbare opplysninger til andre. Anonymiserte opplysninger og forskningsresultater vil bli brukt slik som angitt ellers i dette skrivet.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk (REK):
Saksnr. 2018/128, dato: 29.05.2018.

Personvernombudets ved XX HF’s tilrådning: XX Kontaktinfo: XX

Appendix 2 - Informed consent form II, implementation teams

Brudd på personvernregelverket kan klages inn til Datatilsynet; Postboks 458 Sentrum, 0105 Oslo.

Det rettslige grunnlaget for gjennomføringen av prosjektet er personvernforordningens artikkel 9 nr. 2 bokstav a, samt personopplysningslovens § 10.

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

--	________________________________
Sted og dato	Deltakers signatur
	--
	Deltakers navn med store bokstaver

Alder: ____

Stilling: ______________________________________

Kontaktinformasjon:

Telefonnummer: ____

E-postadresse: ____

Appendix 3 - Informed consent form, clinicians

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET - VERSJON 27.02.19

BEDRE PÅRØRENDESAMARBEID (BPS)

OM STUDIEN

Dette er et spørsmål til deg om å bidra inn i prosjektet «Bedre pårørendesamarbeid (BPS)». Målet med prosjektet er å bedre samarbeidet mellom ansatte, pasient og pårørende og å bedre helsen til pasienten og deres pårørende. Vi ønsker å lære mer om pårørendesamarbeid sett fra ulike perspektiv; pasienter, pårørende og helsepersonell som jobber med psykosepasienter. Du er invitert til å delta i prosjektet fordi du representerer en av disse gruppene.

Det er 15 distriktpsykiatriske sentre (DPS) som deltar i prosjektet i tillegg til det DPS-et der du er ansatt. Alle disse stedene vil få hjelp til å bedre samarbeidet med pårørende; først den ene halvparten (intervensjonsgruppen), så den andre halvparten (kontrollgruppen). Det skal bare fokuseres på tiltak som både er anbefalt og som er vist å være bra for pasienten og de pårørende. Eksempler på slike tiltak er å opprette en pårørendekoordinator og å gi de ansatte opplæring slik at pasienter og pårørende kan få informasjon, opplæring og oppfølging som er godt tilpasset deres behov.

Prosjektet er et samarbeid mellom Universitetet i Oslo, Akershus universitetssykehus HF, OsloMet, TIPS Sør-Øst og de deltakende behandlingsstedene. Dette er en multisenterstudie hvor Universitetet i Oslo er koordinerende institusjon med prosjektledelse og hvor Universitetet i Oslo, OsloMet , Akershus universitetssykehus HF, Vestre Viken HF, Sykehuset i Vestfold HF, Diakonhjemmet, Sykehuset i Telemark HF, Oslo Universitetssykehus HF, Helse Fonna HF og TIPS Sør-Øst er dataansvarlige/forskningsansvarlige institusjoner. Forventet prosjektslutt er 1. oktober 2027.

HVA INNEBÆRER DELTAGELSE I GRUPPEINTERVJUET?

Din deltagelse i prosjektet innebærer at du deltar i et gruppeintervju sammen med 4-8 ansatte ved din avdeling/enhet. Vi vil spørre deg og de andre deltagerne om deres synspunkter på- og erfaringer med hvordan pårørende til alvorlig psykisk syke personer involveres. To forskere vil gjennomføre intervjuet på et tidspunkt som passer deg og de andre deltagerne. Intervjuet vil ta ca. 1 time. Du vil få dekket eventuelle reiseutgifter og det vil serveres enkel bevertning i forbindelse med intervjuet.

Temaer vi ønsker at du/gruppen skal si noe om:

- Hvordan er arbeidet med pasienter og deres pårørende ved deres enhet i dag?
- Hva opplever dere er viktig for å bedre familiearbeid?
- Hvilke utfordringer har dere i møte med pårørende?
- Er pårørendearbeidet hos dere bedret av intervensjonen (prosjektet)?
- Har prosjektet ført til at pasienter eller pårørende har fått det bedre?
- Har dere tilbakemeldinger på hva som fungerer, eventuelt ikke fungerer hos dere?

For å være sikker på at vi får med alt gruppen sier, ønsker vi å bruke lydopptaker. Forskerne vil ta ansvar for å utelate all informasjon som kan identifisere deg og andre personer i publisering og formidling fra prosjektet. Lydopptakene vil umiddelbart bli overført til, og lagret på, en sikker server (TSD) og skrevet ut av forsker eller assistent uten direkte identifiserbare kjennetegn.

Nedenfor ber vi deg fylle ut informasjon om alder og stilling. Dette vil bli oppbevart separat fra lydfiler og transkripsjoner.

MULIGE FORDELER OG ULEMPER

Det er ingen ulemper for deg utover det å bruke tid på å delta i intervjuet. Prosjektet skal bidra til bedre samarbeid mellom ansatte, pasient og pårørende ved alvorlig psykiske problemer, og gi mer kunnskap om hvordan en kan få til bedre behandling. Et viktig mål med studien er å bidra til helsetjenester som i enda større grad forstår og ivaretar også de pårørendes behov.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Du har også rett til å få informasjon om utfallet/resultatet av studien.

Du kan når som helst og uten å oppgi noen grunn trekke deg fra prosjektet. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder Reidar Pedersen: reidar.pedersen@medisin.uio.no, telefon: 22 84 46 63.

HVA SKJER MED INFORMASJONEN VI SAMLER?

Intervjuene skal kun brukes slik som beskrevet over. Samtykkeskjema, lydfiler og intervjuutskrifter vil alle oppbevares hver for seg. Alle data anonymiseres senest innen 5 år etter prosjektslutt.

Det er kun forskere tilknyttet prosjektet som har tilgang til dataene og de er underlagt taushetsplikt. Alle data vil lagres på en sikker server (TSD) ved Universitetet i Oslo i prosjektperioden. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Vi vil gjerne oppbevare kontaktinformasjonen din i inntil 5 år for å kunne ta kontakt med deg hvis det skulle bli behov for innhente supplerende informasjon senere.

Resultater fra studien vil munne ut i noen anbefalinger om fremtidig politikk- og lovutvikling samt systemutvikling av det psykiske helsefeltet for å styrke pårørendesamarbeid og implementering av pårørende-veilederen. Resultatene fra studien vil også presenteres i vitenskapelige forskningsartikler, populærvitenskapelige tidsskrift, eller i undervisning og foredrag. Du har også rett til å få informasjon om utfallet/resultatet av studien.

UTLEVERING AV OPPLYSNINGER TIL ANDRE

Det er ikke aktuelt å utlevere hverken direkte eller indirekte identifiserbare opplysninger til andre. Anonymiserte opplysninger og forskningsresultater vil bli brukt slik som angitt ellers i dette skrivet.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk (REK):
Saksnr. 2018/128, dato: 29.05.2018.

Personvernombudets ved XX HF's tilrådning: XX Kontaktinfo: XX

Brudd på personvernregelverket kan klages inn til Datatilsynet; Postboks 458 Sentrum, 0105 Oslo.

Det rettslige grunnlaget for gjennomføringen av prosjektet er personvernforordningens artikkel 9 nr. 2 bokstav a, samt personopplysningslovens § 10.

Appendix 3 - Informed consent form, clinicians

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

--	____
Sted og dato	Deltakers signatur
	--
	Deltakers navn med store bokstaver

Alder: ____

Stilling: ____

Kontaktinformasjon:

Telefonnummer: ____

E-postadresse: ____

FORSLAG TIL DATOER OG KLOKKESLETT FOR INTERVJU

Kryss av for de tidspunktene du har mulighet til å stille til intervju. Dersom ingen av forslagene passer, vil vi kontakte deg senere for å avtale et annet tidspunkt som passer deg.

Appendix 4 - Informed consent form, patients

FORESPØRSEL OM DELTAKELSE I FORSKNINGSPROSJEKTET - VERSJON 25.02.20

BEDRE PÅRØRENDESAMARBEID (BPS)

OM STUDIEN

Dette er et spørsmål til deg om å delta i et intervju i prosjektet «Bedre pårørendesamarbeid (BPS)». Målet med prosjektet er å bedre samarbeidet mellom ansatte, bruker og pårørende og å bedre helsen til brukeren og deres pårørende. Prosjektet skal undersøke erfaringer med å involvere pårørende ved psykisk sykdom sett fra ulike perspektiv; brukere, pårørende og helsepersonell som jobber med personer med psykoselidelser. Du er invitert til å delta i prosjektet fordi du representerer en av disse gruppene.

Det er 14 distriktpsykiatriske sentre (DPS) som deltar i prosjektet i tillegg til det behandlingsstedet du tilhører. Alle disse stedene vil få hjelp til å bedre samarbeidet med pårørende; først en halvpart av stedene, så den andre halvparten. Det skal bare fokuseres på tiltak som både er anbefalt og som er vist å være bra for brukeren og de pårørende. Eksempler på slike tiltak er å opprette en pårørendekoordinator og å gi de ansatte opplæring slik at brukere og pårørende kan få informasjon, opplæring og oppfølging som er godt tilpasset deres behov.

Prosjektet er et samarbeid mellom Universitetet i Oslo, Akershus universitetssykehus HF, OsloMet, TIPS Sør-Øst og de deltakende DPS-enhetene. Dette er en multisenterstudie hvor Universitetet i Oslo er koordinerende institusjon med prosjektledelse og hvor Universitetet i Oslo, OsloMet, Akershus universitetssykehus HF, Vestre Viken HF, Sykehuset i Vestfold HF, Diakonhjemmet, Sykehuset i Telemark HF, Oslo Universitetssykehus HF, Helse Fonna HF og TIPS Sør-Øst er dataansvarlige/forskningsansvarlige institusjoner. Forventet prosjektslutt er 1. oktober 2027.

HVA INNEBÆRER DELTAGELSE I INTERVJUET?

Hvis du deltar i intervjuet vi vil spørre deg om dine synspunkter på- og erfaringer med hvordan dine pårørende skal involveres i behandlingen. En eller to forskere vil gjennomføre intervjuet på et tidspunkt som passer deg. Intervjuet tar ca. 1 time, og vi kan ta pauser hvis du trenger det. Du vil få litt mat og drikke og få dekket reiseutgifter i forbindelse med intervjuet.

Vi vil spørre om:

- Hva slags pårørendesamarbeid har du og dine pårørende deltatt i?
- Hva har pårørendesamarbeidet betydd for deg og dine pårørende, på godt og vondt?
- Hva mener du er viktig for å få til et godt pårørendesamarbeid?

For å være sikker på at vi får med alt du sier, ønsker vi å bruke lydopptaker. Navnet ditt vil ikke bli tatt opp på bånd. Lydopptakene vil umiddelbart bli overført til, og lagret på, en sikker server (TSD) og skrevet ut av forsker eller assistent uten direkte identifiserbare kjennetegn. Forskerne vil ta ansvar for å utelate all informasjon som kan identifisere deg og andre personer i publisering og formidling fra prosjektet.Nedenfor ber vi deg fylle ut informasjon om alder. Dette vil bli oppbevart separat fra lydfiler og transkripsjoner.

Appendix 4 - Informed consent form, patients

MULIGE FORDELER OG ULEMPER

Det er ingen ulemper for deg utover det å bruke tid på å delta i intervjuet. Prosjektet skal bidra til bedre samarbeid mellom ansatte, bruker og pårørende ved alvorlig psykiske problemer, og gi mer kunnskap om hvordan en kan få til bedre behandling.

FRIVILLIG DELTAKELSE OG MULIGHET FOR Å TREKKE SITT SAMTYKKE

Det er frivillig å delta i prosjektet. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har også rett til å få informasjon om utfallet/resultatet av studien.

Du kan når som helst og uten å oppgi noen grunn trekke deg fra prosjektet og det vil ikke få konsekvenser for behandlingen din. Dersom du senere ønsker å trekke deg eller har spørsmål til prosjektet, kan du kontakte prosjektleder Reidar Pedersen: reidar.pedersen@medisin.uio.no, telefon: 22 84 46 63

HVA SKJER MED INFORMASJONEN OM DEG?

Informasjonen som registreres om deg skal kun brukes slik som beskrevet over. Samtykkeskjema, lydfiler og intervjuutskrifter vil alle oppbevares hver for seg. Alle data anonymiseres senest innen 5 år etter prosjektslutt.

Det er kun forskere tilknyttet prosjektet som har tilgang til dataene og de er underlagt taushetsplikt. Alle data vil lagres på en sikker server (TSD) ved Universitetet i Oslo i prosjektperioden. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres.

Vi vil gjerne oppbevare kontaktinformasjonen din i inntil 5 år etter prosjektslutt for å kunne ta kontakt med deg hvis det skulle bli behov for innhente supplerende informasjon senere.

Resultater fra studien vil munne ut i noen anbefalinger om fremtidig politikk- og lovutvikling samt systemutvikling av det psykiske helsefeltet for å styrke pårørendesamarbeid og implementering av pårørende-veilederen. Resultatene fra studien vil også presenteres i vitenskapelige forskningsartikler, populærvitenskapelige tidsskrift, eller i undervisning og foredrag. Du har også rett til å få informasjon om utfallet/resultatet av studien.

UTLEVERING AV OPPLYSNINGER TIL ANDRE

Det er ikke aktuelt å utlevere hverken direkte eller indirekte identifiserbare opplysninger til andre. Anonymiserte opplysninger og forskningsresultater vil bli brukt slik som angitt ellers i dette skrivet.

GODKJENNING

Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk (REK):
Saksnr. 2018/128, dato: 29.05.2018.

Personvernombudets ved XX HF's tilrådning: XX Kontaktinfo: XX

Brudd på personvernregelverket kan klages inn til Datatilsynet; Postboks 458 Sentrum, 0105 Oslo.

Det rettslige grunnlaget for gjennomføringen av prosjektet er personvernforordningens artikkel 9 nr. 2 bokstav a, samt personopplysningslovens § 10.

Appendix 4 - Informed consent form, patients

SAMTYKKE TIL DELTAKELSE I PROSJEKTET

JEG ER VILLIG TIL Å DELTA I PROSJEKTET

Sted og dato	Deltakers signatur
	Deltakers navn med store bokstaver

Alder: ____

Kontaktinformasjon:

Telefonnummer:____

E-postadresse: ____

Appendix 5 - Interview guide focus group interviews I, implementation teams

Overview of topics to be covered during the interviews

1. Experiences with the IFIP project so far
- What are the most important changes in the units' family involvement practices up until now?
- Experiences with the work in the local implementation team. What have you achieved so far? What works well / does not work?

2. Barriers and facilitators related to family involvement
- Now that you have begun working more systematically with family involvement practices:
a) Which barriers have you experienced to be the most important? What could be the reasons why only 0-5 % of patients with psychotic disorders receive family psychoeducation (FPE), and that the remaining receive little or no family involvement at all?

- On a clinical level
- On an organisational level and national level
- Any ethical dilemmas / conflicts of interest? (If not already covered)
- Are the barriers to family psychoeducation, and to family involvement practices in general, the same?

b) Which facilitators/success factors have you experienced to be the most important? What can be done to deal with/overcome the barriers? Which factors are critical to successfully increase the proportion who receive FPE, and to provide a minimum of conversations and information about family involvement to the remaining patients and their relatives?

- On a clinical level
- On an organisational level and national level
- Are the facilitators for family psychoeducation, and for family involvement practices in general, the same?

- Hand out the document on barriers and facilitators - does this correspond to what they have reported, and their experiences? Feel free to share specific examples.
- What could be the most important contributions from the clinical staff, the management, the local implementation team, and the project group? Is there anything that the relatives and the patients can do themselves?

3. Feedback on the implementation support programme/IFIP intervention
- Family psychoeducation
- Basic family involvement and support, in particular the conversations with patients, with relatives and the joint conversations for those who do not receive FPE.
- Other measures?
- Any suggestions for changes to the implementation support program or IFIP intervention?

4. Any other experiences or views you would like to share with us?

Appendix 6 - Interview guide focus group interviews II, implementation team

Overview of topics to be covered during the interviews

Remember to ask for specific examples

Intro: Summarise the most important changes at the unit on all levels, check whether this information is correct, and then focus initially on the significance of the services that are increasingly offered to patients and relatives.

The significance of improved family involvement practices when in contact with patients and relatives (The clinical elements of the IFIP intervention: conversations, written information material, psychoeducative seminars for relatives, and family psychoeducation)

- For the patients.
- For the relatives.
- For yourself as health professionals, and the services.
- Is there anything else they should be offered?

Ethical dilemmas and conflicts of interest during family involvement, and other barriers and facilitators

- Which dilemmas/conflicts of interest have you experienced during family involvement, at the unit? (Patient vs. relatives. What roles do the clinicians' perceptions and interests play?)
- What challenges have you experienced concerning the exercise of the duty of confidentiality during family involvement?
- What challenges have you experienced with regard to receiving/documenting information from relatives?
- How were these situations handled? Could anything have been done otherwise?
- Hand out the ‘barrier and facilitator’ document and ask them to comment on any missing factors.
- Which measures could be useful at the administrative and policy level (health trust/national level)? (For instance legislation, financial incentives, documentation systems, more clearly stated policies on next of kin).

Experiences with the implementation effort (local implementation team, family coordinator, training, and guidance)

- The effort to implement the IFIP intervention. What works well or not so well at your unit? Possible changes? Any suggestions for other measures?
- Experiences with the implementation support program? Positive and negative experiences? Any suggestions for changes?
- Is everybody in the unit committed to the project? Understanding of responsibility: What role and responsibility towards next of kin do you consider yourself to have, as health professionals? (Are there variations related to professional background?). Any changes?
- What impact do the clinical pathways for mental health and substance abuse have on the way you practice family involvement today?
- If we have time: Standardisation versus professional autonomy – what is a good balance?

Appendix 7 - Interview guide focus group interviews, clinicians

Overview of topics to be covered during the interviews

Remember to ask for specific examples

Introduction: What are the most important changes that have taken place at your unit since the project began?

- How do you notice these changes in your daily work?
- Increased competence/assurance?
- Altered ways of thinking/attitudes?
- Altered ways of working?
- Changes in the services offered to the unit's patients and their relatives?

The significance of improved family involvement practices when in contact with patients and relatives (The clinical elements of the IFIP intervention: Conversations, family psychoeducation, crisis/coping plan, written information material, psychoeducative seminars for relatives). Positive and negative experiences. Ask a general open-ended question first, and then it is possible to ask specifically about each single element.

- For yourself as health professionals.
- For the health services.
- For patients and relatives.
- Specific examples.
- Any feedback from patients and relatives?
- Possibly mention the most important documented effects of family interventions and inquire whether they have experienced these effects.
- What has worked well at their unit, and why.
- What has not worked well at their unit, and why. Ask specifically about any suggestions for changes.
- Is there anything else that patients and relatives should be offered?

Challenges related to the duty of confidentiality and documentation

- Quite a few health professionals report that they face challenges related to the duty of confidentiality during family involvement. Have you experienced such challenges? Any changes?
- During the IFIP project, we have experienced that many clinicians are unsure of where and how they should receive/document information from relatives. Have you experienced such uncertainty? Any changes?
- (*If they report challenges*) How were these situations handled? Could anything have been done otherwise?

Appendix 7 - Interview guide focus group interviews, clinicians

The significance of competence development and improved structure of family involvement practices (procedures and routines, documentation, family coordinator, systematic assessments of FPE eligibility etc.) and tools/resources (e.g. the conversation guide). Positive and negative experiences. Ask a general open-ended question first, and then it is possible to ask specifically about each single measure.

- For yourself as health professionals.
- For the health services.
- Which measures/tools have worked well at their unit? Why?
- Which measures/tools have not worked well at their unit? Why? Ask specifically about any suggestions for changes.
- Are there any measures/tools that we have not prioritised, which could have been useful?

Shared understanding, leadership commitment, and the clinical pathways

- Does the local context affect these factors?
- Would you say that there is a shared understanding of why and how one practices family involvement at the unit? If so, how does this shared understanding manifest itself?
- What role would you say the leadership at the unit has played in the project/implementation work? How does this affect the implementation work?
- What impact do the clinical pathways for mental health and substance abuse have on the way you practice family involvement today?

Experiences with the coronavirus pandemic

- How would you say that the coronavirus pandemic has affected your daily work?
- Has the follow-up of patients and relatives changed? If that case how?
- Have there been challenges with the family involvement during the pandemic? Examples? If yes, how were these challenges dealt with?
- Are there any of the measures implemented as part of the IFIP trial that have worked particularly well during this crisis? Are there any of the measures that have worked poorly? Examples?
- Are there any other family involvement measures that could have been useful in relation to the crisis? Examples?

The IFIP-study:
Patient interview guide

Introduction

This interview is part of the IFIP project, where community mental health centres (CMCHs) receive support to improve the collaboration between the user, their family and health personnel at the CMCH. The purpose of the project is that close family or other significant persons can support the user, and also get information and support themselves (e.g. by participating in a family group together, that the hospitals have appropriate information sharing routines, or that the user and relatives are taken care of by a family coordinator). The project is a collaboration between the University of Oslo (Centre for Medical Ethics), Akershus University Hospital HF (R&D unit of the Division of Mental Health), OsloMet (Labor Research Institute and Faculty of Health Sciences), The Early Intervention in Psychosis Advisory Unit for South East Norway (TIPS Sør-Øst) and the participating units, and it will end in 2022.

We have established a program of measures for family involvement in the CMCHs and we will evaluate whether these measures can improve the health and quality of life of both the users and their families. Your experiences are important because we need knowledge of how we can optimilise this collaboration.

In this interview, we are particularly interested in your experiences with family involvement. By “family involvement" we mean collaboration with the people who are important to you in your everyday life, and especially those who are closest to you. We would like you to use examples in the interview.

The interview will last for approximately one hour, and will be audio recorded and written down afterwards. Everything you say will be kept confidential and anonymised. Details that can identify you or others, such as names and locations, are removed when the interview is written. It is voluntary to participate, and you can withdraw at any time without explanation. It is possible that we will contact you again on a later occasion for supplementary information.

The participant fills in the consent form and returns page 3 to the researcher if they have not done this beforehand together with the therapist.

Start audio recording.

Appendix 8 - Interview guide, patients

Overview of topics to be covered during the interviews

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? (*If necessary, exemplify: information, collaboration, support, seminar/course/group etc.)*
    - *If the participant does not mention family psychoeducation (FPE)/conversations:* Have you and your family participated in FPE and/or had one or more conversations about family involvement at the CMCH?
    - *If yes:* Who participated in these conversations, was the participant allowed to decide for himself who should participate, the number of participants, and performance?
    - *If no:* What is the reason(s) why your family has not been involved?
    - *(See Supporting questions Part 1 if necessary)*
    - Do you know if your relatives have had a conversation alone with your therapist or others at the CMCH? *If yes:* What do you think about that?

Experiences with- and significance of family involvement

- What has the family involvement meant to you?
    - How was it for you to participate in...? (*fill in what the participant has said about the involvement/collaboration). (See Supporting questions Part 2 if necessary)*
        - 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?
    - *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? *(See Supporting questions Part 3 if necessary).*
    - Was the form of collaboration important to your experience?
    - *If negative:* In what way do you feel that participation in FPE has been negative? *(See Supporting questions Part 4 if necessary)*

- What do you think the family involvement has meant to your family?
    - Do you perceive that your family/network has received support and help to understand what you are struggling with?
    - Have they been more helpful to you afterwards?

- For family involvement being helpful to you:
    - What do you want from your therapist?
    - What do you want from your closest relatives?

- Is there anything else you would like to share?

Supporting questions

Part 1 Reasons why the family has not been involved:

- Conflicts within the family
- Experiences of not being understood
- Worries and feelings of guilt in relation to that the family will be even more burdened if involved
- Negative thoughts about self-worth
- The illness is personal and private
- Shame and stigma
- The family gets too involved
- Care failure, other traumatic experiences (this should possibly not be thematised if the patient himself does not bring it up)

Part 2 After you and your family… (*fill in what the participant has said about the involvement/collaboration):*

Did you:

- Cope better socially?
- Feel that you had someone to turn to if you needed help?
- Get along well with your closest relatives?
- Experience increased or reduced mental health problems?
- Feel more or less satisfied with your life overall?
- Follow up on the treatment as agreed? (medication, appointments, other).

Have your relatives:

- Been more or less considerate towards you?
- Showed more or less understanding of your difficulties?
- Been more or less critical of you?
- Been more or less dissatisfied with what you do?
- Been hassling you more or less?
- Helped you in better ways?

With in the family:

- Is it easier to solve problems?
- Is it easier to communicate?

Did your therapists:

- Listen to what you consider is most important for your health situation?
- Take into account what is most important to you when choosing what to do next?

Part 3 FPE – What has been useful to you?

- Gaining knowledge and understanding about my own difficulties
- More openness/talk about psychological problems and symptoms
- Getting help to reduce stress
- Getting help to balance activities

- Getting support and help from the family
- Getting help to improve communication with in the family
- Getting help to solve everyday problems and challenges
- Getting help to prevent relapse and crisis

Part 4 FPE – Has family involvement been negative in any way?

- What happened that worsened your situation?
- How was this handled by the group leaders/therapists?
- Is there any particular topics you talked about that was difficult to you?
- How was it for you to participate in these meetings?
- What could have been done differently?

Errata list

Name of candidate: Kristiane M Hansson

Title of dissertation: Buildings bridges over troubled water. A qualitative evaluation of an implementation study on family involvement in the treatment of persons with psychotic disorders.

Abbreviations for type of correction:
Cor – correction
Add – added

Page	Original text	Type	Corrected text
VII	(Implementation of family involvement in psychotic disorders" ["Bedre Pårørendesamarbeid" (BPS)].	Cor	("Implementation of family involvement in psychotic disorders" ["Bedre Pårørendesamarbeid" (BPS)]).
IX	avhandlingen er bygget inn i en omfattende klynge-randomisert forsknings- og forbedringsprosjekt	Cor	avhandlingen er bygget inn i et omfattende klynge-randomisert forsknings- og forbedringsprosjekt
IX	Den klinisk intervensjonen	Cor	Den kliniske intervensjonen
IX	rutiner for hvordan inviterer pasienter	Cor	rutiner for hvordan invitere pasienter
X	synes å være forankring organisasjonen	Cor	synes å være forankring i organisasjonen
X	skape endret i bevissthet	Cor	skape en endret bevissthet
XII	Figure 2 Facilitators to the implementation of family involvement……….46	Cor	Figure 2 Facilitators to the implementation of family involvement…………31
XII	Figure 3 Overview of the findings of this thesis findings……….49	Cor	Figure 3 Overview of the findings of this thesis……….34
XII	Table 1 Methodological overview of the studies in this thesis……….33	Cor	Table 1 Methodological overview of the studies in this thesis……….19
XII	Table 2 Key characteristics of the participants in the focus group interviews………..35	Cor	Table 2 Key characteristics of the participants in the focus group interviews……….21
XIII		Add	HPA Health Personnel Act
8	nurses' association emphasise	Cor	nurses' association emphasises
9	(Hestmark, submitted 2022)	Cor	(146)
15	argues that that all voices	Cor	argues that all voices
15	Section 2.9	Cor	Section 2.8
17	(Hestmark, submitted 2022)	Cor	(146)
17	(Hestmark, submitted 2022)	Cor	(146)
19	is presented in Table 2.	Cor	is presented in Table 1
19	TABLE 2. METHODOLOGICAL OVERVIEW OF THE STUDIES IN THE THESIS	Cor	TABLE 1. METHODOLOGICAL OVERVIEW OF THE STUDIES IN THE THESIS
20	Table 3, adapted from	Cor	Table 2, adapted from
21	TABLE 3. KEY CHARACTERISTICS OF PARTICIPANTS IN THE FOCUS GROUP INTERVIEWS	Cor	TABLE 2. KEY CHARACTERISTICS OF PARTICIPANTS IN THE FOCUS GROUP INTERVIEWS
22	or challenge descriptions, analyses	Cor	or challenge descriptions and analyses
25	sampling of the patient interviews	Cor	sampling for the patient interviews
28	what Moen ad Middelthon	Cor	what Moen and Middelthon

31	Figure 2	Cor	Figure 2 inserted with higher resolution
34	Figure 3	Cor	Figure 3 inserted with higher resolution
34	(Hestmark, submitted 2022)	Cor	(146)
35	and knowledge of how stressors are found to provoke psychotic relapses (REF),	Cor	and knowledge of how stressors are found to provoke psychotic relapses (18-19),
37	(Hestmark, in preparation).	Cor	(Hestmark et al, accepted for publication 2023)
37	support in in the best interests	Cor	support in the best interests
40	(Figure 3, “Establish contact”).	Cor	(Figure 3: “Establish contact”).
41	what family involvement is about, enhancing core relations	Cor	what family involvement is about; enhancing core relations
41	(Figure 3; A-B-C working together)	Cor	(Figure 3: A-B-C working together)
41	focusses	Cor	focuses
42	as this this can facilitate	Cor	as this can facilitate
45	(Hestmark et al., submitted 2022)	Cor	(146)
47	implications of this thesis\` - for the	Cor	implications of this thesis - for the
47	this whole-ward, approach	Cor	this whole-ward approach
49	and for and for other patient groups	Cor	and for other patient groups
51	14. 14. Spaulding WD, Silverstein SM, Menditto AA. The Schizophrenia Spectrum. 2nd ed. Germany: Hogrefe Publishing GmbH; 2018.	Cor	14. Spaulding WD, Silverstein SM, Menditto AA. The Schizophrenia Spectrum. 2nd ed. Germany: Hogrefe Publishing GmbH; 2018.
52	20. Mucci. Frontiers. 2020.	Cor	20. Mucci A, Kawohl W, Maria C, Wooller A. Treating Schizophrenia: Open Conversations and Stronger Relationships Through Psychoeducation and Shared Decision-Making. Frontiers in Psychiatry. 2020;11.
53	42. Pharoah F, Mari J, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database Syst Rev. 2010(12):CD000088-CD. https://doiorg.ezproxy.uio.no/10.1002/14651858.CD000088.pub3.	Cor	42. Pharoah F, Mari J, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database Syst Rev. 2010(12):CD000088-CD.
53	43. Rodolico A, Bighelli I, Avanzato C, Concerto C, Cutrufelli P, Mineo L, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. The Lancet Psychiatry. 2022.	Cor	43. Rodolico A, Bighelli I, Avanzato C, Concerto C, Cutrufelli P, Mineo L, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. Lancet Psychiatry. 2022;9(3):211-221. Erratum in: Lancet Psychiatry. 2022 Feb 23;: PMID: 35093198
53	52. Susan D. Phillips, M.S.W. ,, Barbara J. Burns, Ph.D. ,, Elizabeth R. Edgar, M.S.S.W. ,, Kim T. Mueser, Ph.D. ,, Karen W. Linkins, Ph.D. ,, Robert A. Rosenheck, M.D. ,, et al. Moving Assertive Community Treatment Into Standard Practice. Psychiatric Services. 2001;52(6):771-9	Cor	52. Susan D, Phillips MSW, Burns BJ, Edgar ER, Mueser KT, Linkins KW, Rosenheck RA et al. Moving Assertive Community Treatment Into Standard Practice. Psychiatric Services. 2001;52(6):771-9
54	69. Tina Bogart Marshall, M.S.W. , and, Phyllis Solomon, Ph.D. Releasing Information to Families of	Cor	69. Marshall TB, Solomon P. Releasing Information to Families of Persons With Severe Mental Illness:

	Persons With Severe Mental Illness: A Survey of NAMI Members. Psychiatric Services. 2000;51(8):1006-11		A Survey of NAMI Members. Psychiatric Services. 2000;51(8):1006-11
58		Add	146. Hestmark L, Romøren M, Heiervang KS, et al. Implementation of Guidelines on Family Involvement for Persons with Psychotic Disorders (IFIP): A Cluster Randomised Controlled Trial. Adm Policy Ment Health. 2023;50:520-533.
58		Add	Quote reference page II: 19

Hansson *et al. BMC Health Services Research (2022) 22:1153*
https://doi.org/10.1186/s12913-022-08489-y

BMC Health Services Research

RESEARCH

Open Access

Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres – a nested qualitative study

Kristiane Myckland Hansson[1*], Maria Romøren[1], Reidar Pedersen[1], Bente Weimand[2,3,4], Lars Hestmark[1], Irene Norheim[5], Torleif Ruud[2,6], Inger Stølan Hymer[7] and Kristin Sverdvik Heiervang[1,2,3]

Abstract

Background: The uptake of family involvement in health care services for patients with psychotic disorders is poor, despite a clear evidence base, socio-economic and moral justifications, policy, and guideline recommendations. To respond to this knowledge-practice gap, we established the cluster randomised controlled trial: Implementation of guidelines on Family Involvement for persons with Psychotic disorders in community mental health centres (IFIP). Nested in the IFIP trial, this sub-study aims to explore what organisational and clinical barriers and facilitators local implementation teams and clinicians experience when implementing family involvement in mental health care for persons with psychotic disorders.

Methods: We performed 21 semi-structured focus groups, including 75 participants in total. Implementation team members were interviewed at the initial and middle phases of the intervention period, while clinicians who were not in the implementation team were interviewed in the late phase. A purposive sampling approach was used to recruit participants with various engagement in the implementation process. Data were analysed using manifest content analysis.

Results: Organisational barriers to involvement included: 1) Lack of shared knowledge, perceptions, and practice 2) Lack of routines 3) Lack of resources and logistics. Clinical barriers included: 4) Patient-related factors 5) Relative-related factors 6) Provider-related factors. Organisational facilitators for involvement included: 1) Whole-ward approach 2) Appointed and dedicated roles 3) Standardisation and routines. Clinical facilitators included: 4) External implementation support 5) Understanding, skills, and self-efficacy among mental health professionals 6) Awareness and attitudes among mental health professionals.

Conclusions: Implementing family involvement in health care services for persons with psychotic disorders is possible through a whole-ward and multi-level approach, ensured by organisational- and leadership commitment. Providing training in family psychoeducation to all staff, establishing routines to offer a basic level of family involvement to all patients, and ensuring that clinicians get experience with family involvement, reduce or dissolve core barriers.

---

*Correspondence: k.m.hansson@medisin.uio.no

[1] Centre for Medical Ethics, University of Oslo, Postbox 1130 Blindern, 0318 Oslo, Norway
Full list of author information is available at the end of the article

Having access to external implementation support appears decisive to initiate, promote and evaluate implementation. Our findings also point to future policy, practice and implementation developments to offer adequate treatment and support to all patients with severe mental illness and their families.

Trial registration: ClinicalTrials.gov Identifier NCT03869177. Registered 11.03.19.

Keywords: Family involvement, Family interventions, Family psychoeducation, Psychotic disorders, Implementation, Barriers, Facilitators, Mental health services research

Background

The uptake of family involvement in health care services for patients with psychotic disorders is poor [1–3] despite a robust evidence base of decreased rates of relapse and hospital admissions, and better adherence with medication among patients [4–7]. Moreover, family interventions are shown to reduce psychological distress and care burden, and to improve family functioning and quality of life among relatives [8–10]. This knowledge-practice gap paradox results in patients and relatives being deprived of highly recommended treatment and support [11–19]. Among the most important factors to improve the outcome of schizophrenia is the translation of psychosocial treatments from research to the field [20]. Family psychoeducation (FPE), designed to engage, inform, and educate family members so that they can assist the person with severe mental illness in managing the illness, but also to reduce family distress and burden [18], is one such treatment. The scientific evidence of improvement in patient outcomes has been consistent [4, 5, 7], and research studies, policies, and guidelines have been calling for an increased uptake of FPE for decades [2, 4, 21, 22]. In addition, moral and socio-economic arguments to involve and support relatives in the context of deinstitutionalisation and subsequent emergence of community care strengthens this appeal [8, 9, 23]. In this study, the terms “family” and “relative” cover anyone who provides substantial and unpaid support to a person with psychotic disorder. The term “family involvement” comprises both a basic level of family involvement and support and more comprehensive family interventions, such as FPE.

Why is the implementation of family interventions like FPE this scarce, despite being recognised as essential treatment during all stages of psychotic disorders [2, 24]? Multifaceted problems of integrating new evidence-based practices into usual care partly explain why several previous attempts to implement family interventions in routine care have failed [18]. The research literature suggests a lack of financial incentives and prioritisation, lack of managerial support, restricted access to training and supervision, lack of time, caseload size, and shortfall in staff resources as major system-level barriers [2, 25–28]. Factors that are particularly challenging when implementing family involvement include the lack of systems and structure for carrying out family involvement, and practical difficulties when attempting to realise family involvement [26, 28]. Furthermore, staff attitudes, organisational cultures and paradigms can hinder the uptake of family interventions, for example by leading to varying ownership, low confidence in that family involvement can be helpful, and that family involvement are considered secondary or optional [25, 26, 28]. Impediments at the clinical level include patients refusing to involve their relatives, patient confidentiality [26, 29], lack of therapist confidence and competence in conducting family involvement, and lack of families to work with [26]. Furthermore, different stakeholder groups often have contrasting perspectives regarding barriers, and lack of trust between stakeholders, in this case, patients, relatives and health care personnel, is considered a major challenge when collaborating with relatives [26].

To accelerate the implementation of family involvement in Norwegian mental health care, we established the IFIP study: Implementation of guidelines on Family Involvement for persons with Psychotic disorders in community mental health centres (CMHCs) [30]. The IFIP study is a cluster randomised controlled trial that aims to increase the uptake of recommendations on family involvement from the national guidelines in Norway [11, 12]. A key part of the implementation strategy was a so-called “whole-ward” or “whole-system” approach [28, 31]. The IFIP intervention consists of the following elements:

I Clinical interventions:

  1.1 A basic level of family involvement and support (BFIS).
  1.2 Family psychoeducation (FPE) in single-family-groups.

II Implementation interventions:

  2.1 Training and guidance of health care personnel.
  2.2 A family coordinator.
  2.3 Other implementation measures.

The IFIP study protocol [30] provides a detailed account of the IFIP intervention, including FPE and BFIS. BFIS includes offering patients at least one conversation where the major part is dedicated to discuss family involvement and FPE, offering relatives at least one conversation without the patient present, and inviting the patient and relative(s) for a conversation together. Structured conversation guidelines was developed to standardise the content of these conversations. BFIS also includes written information, crisis/coping plans and psychoeducative seminars for relatives. Further details of the planned intervention and implementation support can be found in our study protocol [30], and in a publication reporting fidelity outcomes (manuscript submitted).

Change in fidelity to the intervention (defined as the degree to which a program implementing an evidence-based practice adheres to specific model standards [32]), constitutes the IFIP trial's primary outcome [30]. Statistical analyses of fidelity outcomes (the quality of the clinical interventions, penetrance, and organisational implementation, measured with three different fidelity-measures) show significant differences between experimental and control conditions (manuscript submitted). This sub-study aims to explore what factors inhibit and promote the implementation of family involvement in CMHC units, both in general and more specifically within the context of a large-scale implementation study. To our knowledge, this paper is the first to explore what actually facilitates the implementation of family involvement for persons with psychotic disorders in CMHCs, as part of a successful and large-scale implementation study. Furthermore, the IFIP implementation strategy is probably also unique, since it combines both basic and comprehensive family interventions.

The following research question guided this study: "What organisational and clinical barriers and facilitators do local implementation teams and clinicians in CMHCs experience when implementing family involvement for persons with psychotic disorders?" We also explored local variations within and between the participating units. In this study, barriers are defined in the following way: "Factors are considered as barriers if they impede implementation of, or adherence to the guideline". We further define facilitators as follows: "Factors are considered as facilitators if their presence promotes the implementation of, or adherence to the guideline" [33].

Methods

This article conforms to the "Standards for Reporting Qualitative Research (SRQR): 21-items checklist" [34] (Additional file 1).

Study design and context

This study employed a qualitative approach, including both process and formative evaluation, nested within a cluster randomised implementation study [35]. Before the implementation period, we developed the IFIP intervention and drafted a summary of the most important barriers to and facilitators of implementing family involvement in mental health care. This work was based upon available guidelines, literature reviews, and extensive dialogue with the stakeholders. After inclusion and randomisation of the CMHC units, each clinical site in the experimental arm established a local implementation team (3–8 members) including dedicated clinicians and unit managers with a particular responsibility to oversee the implementation process. Throughout the implementation period, we explored how the IFIP intervention affected the stakeholders and the CMHC units through digital communication, face-to-face dialogue, ad-hoc meetings, planned teaching- and supervision activities, fidelity measurements, questionnaires, and qualitative interviews.

An important part of the IFIP intervention was the implementation support provided by the IFIP project group [3, 30]. One element of this support was a written summary of key barriers and facilitators. Inspired by a responsive evaluation approach [36] and as part of the formative evaluation [37], the summary of barriers and facilitators was shared with, used, and commented on several times by the stakeholders during the implementation period. During this process, the IFIP project group and the CMHCs (the implementation teams, clinicians, and leaders), regularly discussed and dealt with barriers to and promoters of family involvement. Thus, in this project the researchers and stakeholders (patients, families, mental health professionals, and health institutions) all contributed to the ongoing knowledge production. The close cooperation offered ample opportunities to explore barriers and facilitators. Preliminary findings from the qualitative interviews, together with field notes and informal feedback from the stakeholders, continuously assisted the implementation and research process, making it possible to adjust and improve the implementation support, including the summary of key barriers and facilitators.

The present study is based on data gathered through focus groups with the implementation teams in the beginning of the implementation period and after 10 months of implementation support, and with other clinical staff after 16 months of implementation support. However, the interviews, the interview guide, and the preunderstanding and interpretations of the researchers and the participants were inspired and influenced by the responsive and formative evaluation used before and during the implementation period, and the dynamic and co-produced summary of barriers and facilitators.

The focus groups—participants and data collection

Twenty one semi-structured focus groups with local implementation teams were performed during the spring of 2019 (M2-3 of the 18-month implementation period), and the winter of 2020 (M9-10), and with other clinicians/staff in the fall of 2020 (M15-16). A total of 75 clinicians and members of implementation teams (mainly clinicians and unit managers) participated, of which 27 participated twice (See Table 1).

As a natural consequence of the study design, we chose a purposive sampling strategy [38]. We wanted to explore the experiences of the implementation teams because they were particularly engaged in the implementation process. Clinicians with less commitment to the implementation work were interviewed to include less engaged and potentially more critical voices.

The data collection was performed at the CMHCs by five members of the IFIP project group (KMH, MR, RP, LH, and KSH). Each focus group was carried out by two researchers; one conducted the interview while the other assisted and took written notes. Before the start of each interview, we provided participants with information about the study and obtained written consent from all participants. Semi-structured interview guides (separate guides for each of the three interview sessions) containing a list of main topics and questions to be covered (Additional file 2), guided the interviews. We aimed at eliciting participants` thoughts, beliefs, and experiences with factors that would positively or negatively impact the implementation of family involvement. In both interview sessions with the implementation teams, the participants were initially encouraged to speak openly, before asked to comment more specifically on the summary of barriers and facilitators. In the interviews with other clinical staff, participants were encouraged to talk about a few, selected barriers that the process evaluation had revealed to be particularly demanding (for instance the duty of confidentiality). All interviews were audio recorded and lasted for 60–90 min. After each focus group, notes were summarised in a brief report to highlight important topics and to make data more accessible to the remaining research team. Audio-files, transcripts, and reports were immediately transferred to and stored in the University of Oslo's secure database (In Norwegian: "Tjenester for Sensitive Data"–TSD). Project members transcribed the interviews verbatim.

Analysis

Analysis of the interview transcripts was carried out by the first author (KMH), using manifest content analysis according to Elo and Kyngäs [39]. Content analysis can be divided into three main phases [39]: the preparation phase, the organising phase, and the reporting phase. The preparation phase involved preliminary analysis of notes and brief reports from the first session of interviews with the implementation teams. This work further informed the development of the barrier- and facilitator document, which served as an implementation tool during the implementation period (formative evaluation). In

Table 1 Key characteristics of the participants in the qualitative study

	STUDY SAMPLE					
	Members of implementation teams Initial phase of intervention (N = 38, 8 focus groups)		**Members of implementation teams Middle phase of intervention (N = 39, 8 focus groups)**		**Clinicians Late phase of intervention (N = 25, 5 focus groups)**	
CHARACTERISTIC	**N**	**%**	**N**	**%**	**N**	**%**
Sex						
Male	6	16	5	13	5	20
Female	32	84	34	87	20	80
Age in years						
20–35	6	16	5	13	7	28
36–50	11	29	16	41	11	44
51–70	21	55	18	46	7	28
Prof. background/role						
Section/unit manager	6	16	5	13		
Physician	4	11	3	8	4	16
Psychologist	5	13	5	13	16	64
Psychiatric nurse	14	37	15	38	1	4
Other	9	24	11	28	4	16

addition, the preparation phase included thorough reading of transcripts (the unit of analysis) and brief reports in their entirety to achieve immersion and obtain an overview of the whole data. Furthermore, members of the research group (KSH, RP, MR and KMH) discussed preliminary themes regarding special topics of interest. The organising phase consisted of coding and categorising the material, guided by the research question. Initially, open coding of the text was conducted by labelling meaning units with initial codes, which were grouped into higher code groups and further collapsed into higher order categories. Structuring the data was done through an inductive approach; that is the categories were derived from the data, moving from the specific to the general [39]. This paper focuses mainly on factors that potentially had a positive impact on the implementation process. However, since we understand barriers and facilitators as highly intertwined, we performed the analysis with regard to both. The final abstraction process resulted in categories being grouped into six barrier- and six facilitator themes, before the material was scanned over again to ensure that relevant contents were placed in the right categories. Codes, subcategories, categories, and themes were adjusted, restructured, and renamed throughout the analysis process, continuously asking: "Why and how is this code/subcategory/category/theme a facilitating or hindering factor to the implementation of family involvement?" The NVivo computer software package 12 was used to assist with storage, searching, and coding of qualitative data. In the results section below, as well as in Fig. 1 and Additional file 3 and 4, the main findings are presented partly as condensed text [40] and partly as illustrative quotes. Quotes are presented in condensed form and in some places we have reproduced conversations between the researcher and the participant (P). We aimed to uncover the meaning content of the participants' statements, rather than bringing out all the details.

Trustworthiness

To permit others to judge the quality of a study, one has an obligation to report sufficient details of data collection and analysis [41]. The reporting phase consisted of describing the step-by-step analysis (Fig. 1) and demonstrating defensible inferences from data to results [39] in coding schemes, including supporting excerpts (Additional file 3 and 4). Different types of triangulation [41] served as strategies to further reduce systematic bias and obtain trustworthiness. Members of the research team and an expert from The Early Intervention in Psychosis Advisory Unit for South East Norway (TIPS Sør-Øst) (KMH, KSH, MR, RP, BW and ISH) reviewed and discussed the way in which the data was labelled [42] and whether and how categories and themes were related to the research question (analyst triangulation). Data source triangulation was ensured by having mental health professionals with differing roles and perspectives participating in the focus groups, exploring what people said about the same phenomenon over time (comparing data at initial and late phase of the implementation). We also integrated ethnographic data on barriers and facilitators, derived through continuous feedback from stakeholders during the implementation period.

Results

We identified six themes with a total of 26 categories representing barriers to implement family involvement: 1) Lack of shared knowledge, perceptions, and practice 2) Lack of routines 3) Lack of resources and logistics 4) Patient-related factors 5) Relative-related factors 6) Provider-related factors. The first three themes represent barriers at the organisational level, while the latter three represent barriers at the clinical level (Fig. 1).

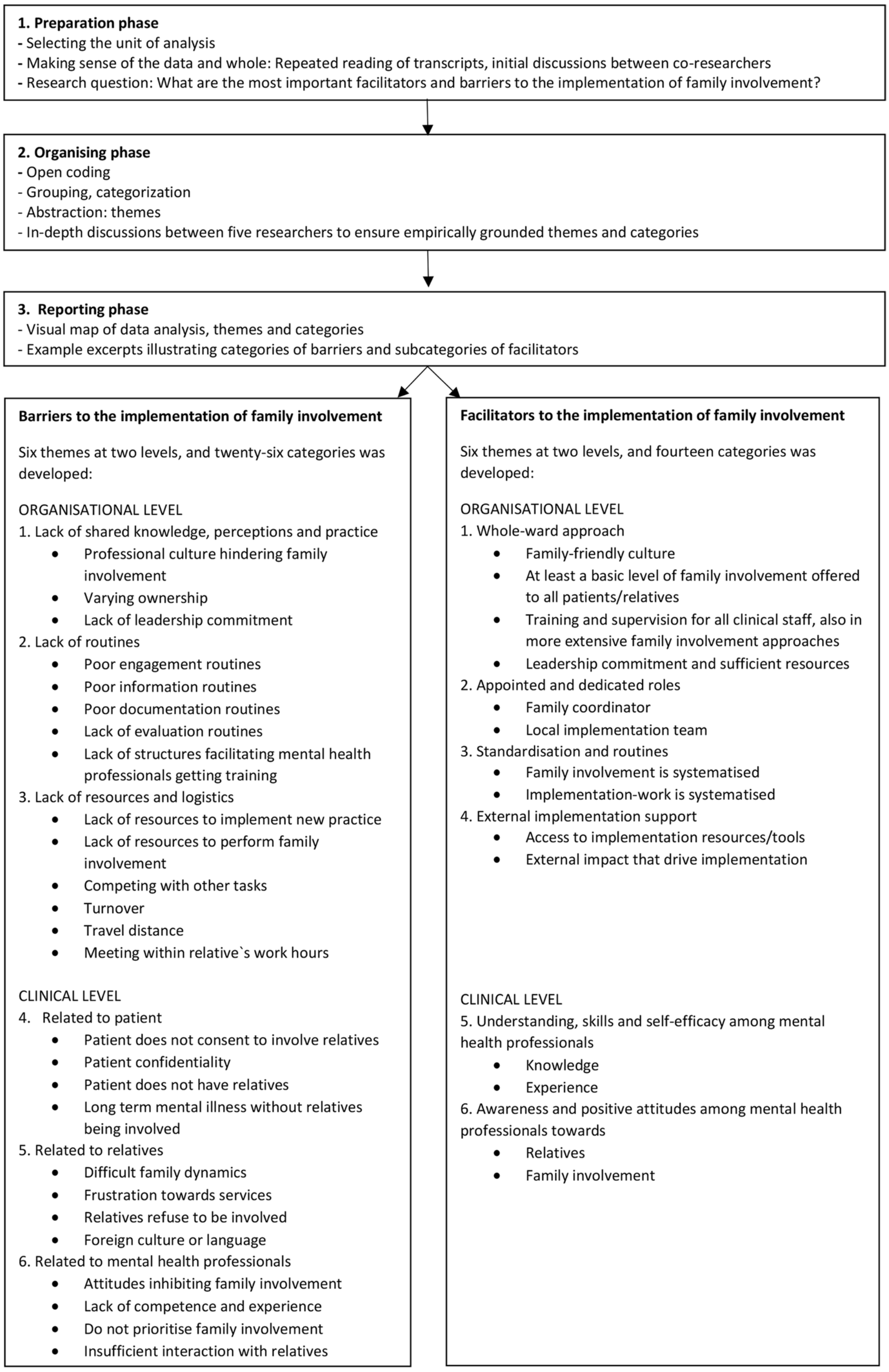
Furthermore, we identified six themes with a total of 14 categories representing facilitators for implementing family involvement: 1) Whole-ward approach 2) Appointed and dedicated roles 3) Standardisation and routines 4) External implementation support 5) Understanding, skills, and self-efficacy among mental health professionals 6) Awareness and positive attitudes among mental health professionals. The first four themes represent facilitators at the organisational level, while the latter two represent facilitators at the clinical level (Fig. 1).

In the beginning of the project, when experience with implementation of family involvement was sparse, the focus was mostly on the barriers and more general or common experiences with implementation of family involvement. During the implementation period the experience with- and focus on facilitators gradually increased, as well as the more specific experiences with systematic implementation through participating in the IFIP trial. In previous research, barriers to the implementation of family involvement have been rather extensively explored, while knowledge about facilitators remains sparse [2]. Thus, in the present article, we focus on the facilitators. An overview of both barriers and facilitators is presented in Fig. 1, while Additional file 3 (barriers) and 4 (facilitators) provide additional illustrative quotes pertaining to the various themes, categories, and subcategories.

Facilitators at the organisational level

Whole-ward approach

Prior to implementation, an important barrier was the lack of shared knowledge, perceptions, and practice. Family involvement practices appeared random, and



1. Preparation phase
- Selecting the unit of analysis
- Making sense of the data and whole: Repeated reading of transcripts, initial discussions between co-researchers
- Research question: What are the most important facilitators and barriers to the implementation of family involvement?

2. Organising phase
- Open coding
- Grouping, categorization
- Abstraction: themes
- In-depth discussions between five researchers to ensure empirically grounded themes and categories

3. Reporting phase
- Visual map of data analysis, themes and categories
- Example excerpts illustrating categories of barriers and subcategories of facilitators

Barriers to the implementation of family involvement

Six themes at two levels, and twenty-six categories was developed:

ORGANISATIONAL LEVEL
1. Lack of shared knowledge, perceptions and practice
    - Professional culture hindering family involvement
    - Varying ownership
    - Lack of leadership commitment
2. Lack of routines
    - Poor engagement routines
    - Poor information routines
    - Poor documentation routines
    - Lack of evaluation routines
    - Lack of structures facilitating mental health professionals getting training
3. Lack of resources and logistics
    - Lack of resources to implement new practice
    - Lack of resources to perform family involvement
    - Competing with other tasks
    - Turnover
    - Travel distance
    - Meeting within relative`s work hours

CLINICAL LEVEL
4. Related to patient
    - Patient does not consent to involve relatives
    - Patient confidentiality
    - Patient does not have relatives
    - Long term mental illness without relatives being involved
5. Related to relatives
    - Difficult family dynamics
    - Frustration towards services
    - Relatives refuse to be involved
    - Foreign culture or language
6. Related to mental health professionals
    - Attitudes inhibiting family involvement
    - Lack of competence and experience
    - Do not prioritise family involvement
    - Insufficient interaction with relatives

Facilitators to the implementation of family involvement

Six themes at two levels, and fourteen categories was developed:

ORGANISATIONAL LEVEL
1. Whole-ward approach
    - Family-friendly culture
    - At least a basic level of family involvement offered to all patients/relatives
    - Training and supervision for all clinical staff, also in more extensive family involvement approaches
    - Leadership commitment and sufficient resources
2. Appointed and dedicated roles
    - Family coordinator
    - Local implementation team
3. Standardisation and routines
    - Family involvement is systematised
    - Implementation-work is systematised
4. External implementation support
    - Access to implementation resources/tools
    - External impact that drive implementation

CLINICAL LEVEL
5. Understanding, skills and self-efficacy among mental health professionals
    - Knowledge
    - Experience
6. Awareness and positive attitudes among mental health professionals towards
    - Relatives
    - Family involvement

Fig. 1 Visual map of data analysis with themes and categories

seemed largely dependent on the individual professional's interest and competence [3], hence at risk of falling apart.

In the IFIP trial, the clinical and organisational levels were approached simultaneously. An explicit aim was that all patients and relatives should be offered at least a basic level of family involvement and support. To enable this, all clinical staff were offered training and supervision, and most participated in the training. This may be described as the key elements of a "whole-ward approach". The approach was experienced as consequential to develop a more family-friendly culture in most of the wards, as portrayed by this participant:

> *We take relatives into consideration in all settings, in all occasions, really. In the treatment team, reflective team, mini team. It`s hardly ever forgotten. There is something about our way of thinking that has changed. It is very evident with us. (FG12).*

Many of the participants emphasised the importance of developing common understanding and priorities among the staff through the whole-ward approach, and enabling the staff to engage with the relatives in new ways:

> *It is an asset that so many of us have this training, because then we kind of have the same way of thinking about it. For example, that relatives to a greater extent are allowed to share their own experiences, that we are not just focused on obtaining information, or on the patient. (FG13).*

Furthermore, the whole word approach was necessary for all clinicians and managers to acknowledge family involvement as a key ingredient in good care and treatment, and FPE as a recommended treatment option:

> *P: It was so important that all the professional groups were included in the FPE course (...) That helps it spread wider. For example, since I have received the training, I have a different view of the patients' treatment options.* (The researcher further asks whether the participant thinks that the other therapists are feeling the same way):
> *P: Yes, I think they feel the same. (FG12).*

Furthermore, the basic level of family involvement and more comprehensive approach (FPE) appeared to be mutually reinforcing. For instance, the threshold to invite the patient and relatives to more comprehensive family involvement seemed to be lowered by establishing a basic level of family involvement as default approach. This approach also seemed to further a process with stepwise consent, where consent for family involvement was discussed several times and obtained gradually in an ongoing process, starting out with the most basic type of family involvement. This was considered better than an "all or nothing" approach. At the other hand, being trained in the more advanced model of family involvement (FPE) was perceived as useful when practicing basic levels of family involvement. Particularly valuable was the experience that the staff could utilise selected model elements, also when providing basic family involvement:

> *For instance, in conversations with patients and relatives I have used the FPE information material. To kind of make it easier to present it. So this has contributed to... I was about to say... to the regular conversations with patients and relatives in a positive way. (FG11).*

A few participants mentioned that training all staff was time-consuming and was compounded by a high turnover of staff. Participants queried whether training would have been better with a small team of therapists working only with family involvement. However, in general the participants seemed to agree that the advantages of the whole-ward approach outweighed the disadvantages, particularly in a long-term perspective.

From a leader perspective, shared competence also contributed to strengthening the working environment and treatment practices because staff started to work in the same way:

> *Having a similar professional foundation affects the working environment (...) It ensures the quality of treatment because we think and work more synchronously. (FG9).*

Participants reported that the whole-ward approach led to all therapists initiating family involvement with all their patients from an early stage in the illness trajectory:

> *Especially with new patients, the initial focus on family involvement is much more present, and... yes, we try to really look into both the referral and the patient's chart, how things are. In addition, we have started to work on a checklist, to become even more conscious of that structure, so it is the same for all therapists, not coincidental, dependent on who is passionate about family involvement or not. It should be a somewhat standardised routine to invite relatives to conversations early in the trajectory, and provide appropriate information about why we think this is important. (FG2).*

Some participants reported that over time the whole-ward approach led to the emergence of positive attitudes among clinicians with regard to engaging families. This was in contrast to involving families as a token gesture obligation:

> *Initially, it was kind of not so important, and it was just like "is it done or not", but now it is on the checklists and markedly permeates the attitudes. A significant change has taken place, from family involvement representing an administrative measure towards being implemented in each individual persons practice. (FG12).*

Leadership commitment, through practical adjustments and motivational support, played a pivotal role in the realisation of various facilitators identified in this study. Barriers to implementation—such as competing tasks, lack of resources, and varying ownership—were surmounted by leaders who allocated sufficient resources, appointed dedicated positions (see below), and used the IFIP intervention in a standardised way. Leaders that held a long-term perspective and identified a clear change in team practice as family involvement was prioritised and valued, were vital to the implementation. Important examples include making a working plan that allowed all staff to participate in training and supervision, and to run FPE-groups, stating clearly that offering family involvement is mandatory and that FPE-sessions allowed for a reduction in other therapeutic sessions. Some leaders also mentioned another way to limit the resources spent by the CMHCs; to run FPE-groups in collaboration with municipal health- and care services. In Norway, the CMHCs are by and large part of the specialised health care services (together with the hospitals), so this was also mentioned as a way to improve coordinated care and collaboration between specialised health care and primary health care services before discharge or transfer.

Appointed and dedicated roles

To guide the local implementation effort and operate as a link between the unit and the IFIP project group, each unit in the intervention arm was recommended to appoint a local implementation team and a family coordinator. Overall, study participants experienced that having such dedicated positions was a key facilitator. Especially two main tasks conducted by the local teams and the family coordinator were reported to strengthen implementation: Organising the various interventions, for example by preparing, establishing, and disseminating routines for basic family involvement and FPE at the unit, and to keep staff motivated and committed when faced with stressful workdays and competing tasks, for example through involving all the staff in the development of locally adapted routines.

Not all the family coordinators were allocated time for the intended tasks, and there was some variation in which tasks the various family coordinators performed. However, most coordinators played a fundamental role during the start-up phase by promoting awareness of the implementation, "keeping the family involvement warm" and by contributing to the overall competence development in family involvement. The coordinators provided training and supervision to their colleagues, and several participants pointed out the low threshold for obtaining their help and guidance with challenging cases:

> *I find that our two coordinators are core resources in reminding us of relatives' rights, and how important they are. I think that we need them. My experience is that I can't cover all bases as a therapist, so it is nice to have them on the team. They remind me of something that is natural to them, but has not always been to me as a therapist, having been used to mainly focusing on the individual patient. (FG17).*

Concerning the implementation team, regular team meetings (often bimonthly or monthly) and working together as a team of enthusiastic personnel with the unit manager were factors reported to strengthen the implementation:

> *It requires very dedicated people (…) that kind of are passionate about working with relatives. This is crucial, and something that I notice in all quality development projects. If an implementation team does not have these very dedicated people, you are off to a poor start. (FG14).*

Nevertheless, some of the implementation teams did not function optimally, with a lack of leadership commitment being one of the explanations:

> *I do feel that as a leader I haven't done enough to schedule, invite, and prioritise the implementation team meetings. I have not taken that responsibility as I should have done. (FG11).*

Some participants mentioned that varying commitment among staff hampered the implementation process. There appeared confusion as to how to share responsibility and implement tasks effectively at the unit. Finally, a few participants mentioned that extensive commitment by the implementation team led to other clinicians withdrawing from engaging in family involvement, thinking that family involvement was not their responsibility.

Standardisation and routines

Participants` accounts highlighted the need for organising both the family involvement practices and the underlying implementation work systematically. At baseline of the IFIP-trial [3], most of the units' family involvement practices suffered from a lack of standardisation with poor engagement, information, documentation-, and evaluation routines. Systematising family involvement, for instance through written procedures and information leaflets, documentation templates, and systems for routinely developing crisis plans and inviting all relatives to relevant evening seminars/courses, reportedly promoted implementation.

Standardisation also reportedly promoted normalisation and anchoring of family involvement as an integrated practice among all staff. Particularly during the start-up phase, the establishment of routines, procedures, and checklists was considered very important to ensure that family involvement was actually performed:

> *When I worked in somatic health care, we were supposed to call the relatives within 24 h. I think it is natural that we do the same thing here, just call within a day or two to hear how they are doing and if they have any questions. To me, I assume, this is where the shoe pinches (...) If it's in the procedures, you just do it automatically, right. There is no need to wonder, that's just the way it is (...) Then we have established contact with the relatives and can catch things at an earlier stage (...) It would have been very helpful if we had a procedure assigning the responsibility to make a call to the relatives, to one of staff. (FG1).*

Some participants emphasised standardisation of patient conversations about family involvement as a means to better engage with the most severely and chronically ill patients. Many of these patients hadn't previously engaged family in their care, which led to a break down in close relationships, sometimes permanently:

> *It will be good to concentrate more on offering all patients a conversation about family involvement. Because I believe that ensures that we'll ask, even when the patient hasn't involved his family before. That the therapists do not just assume that the patients do not want it. (FG11).*

Some highlighted the importance of «flexible standardisation» and tailoring family involvement to the needs of each individual patient and family, such as this clinician describing how some relatives are more experienced in the role than others, thus having different needs:

> *...to establish contact, that applies to most of the patients, and is effective (...) while several other factors are more individual. It`s not always like "the more, the better". Because, you also have relatives who know a lot, and already have a lot of information. They may need something other than those who are relatives to a patient who has recently been diagnosed with a psychotic disorder. (FG17).*

Some participants described feelings of fatigue due to an overload of checklists and procedures. To meet such challenges, one of the units successfully introduced adjustments to fit the intervention to the local working culture and level of competence. They decided to establish a "procedure for family involvement" which all clinicians were encouraged to follow, but without having to tick off that the tasks were done, as in a checklist:

> *We are absolutely allergic to even more checklists where we have to tick off whether we have done it right. We cannot stand it. But (we want) a list of ideas for how to proceed and what is prudent to do (...) Not mandatory, but more as a support. Designed for adult, responsible therapists who know that they should—and want to do their job. (FG13).*

One advantage of such standardisation is that the procedure is available to all clinicians. Several months after the implementation, the manager at this particular unit reported that the procedure had been very useful when faced by staff turnover.

Another way to integrate family involvement was to secure that family involvement was always on the agenda in regular treatment meetings and included in all types of plans, e.g. work plans, treatment plans, capacity building plans, and discharge summaries. Furthermore, developing a clear plan on how to get started with FPE groups immediately after training seemed to be vital to get the most out of the FPE training and subsequent supervision, and also to increase the number of patients that were offered this kind of treatment. One way to achieve this was to have the family coordinator register patients and relatives who needed more comprehensive family involvement, and to match this list with available staff with FPE training. This could also be a way to prioritise FPE treatment fairly, if the units FPE capacity was not sufficient.

Some also mentioned the need to define required qualifications and a formal job description for the family coordinator:

> *Formalising the work... that the family coordinator holds an assigned position with competence requirements (...) is a way of making the family involvement visible. To me that would signalised that one took it seriously. (FG12).*

External implementation support

Access to implementation resources from the IFIP project such as fidelity monitoring, training in FPE, and ongoing external support and supervision was considered crucial. External support was reported to be particularly important in helping the units to get started, generate the imperative of family involvement, build enthusiasm, and promote the implementation:

> *The most important thing is that we got help to sit down and look at what we have..., those fidelity assessments sort of confirmed what we already knew... And the fact that we did not let go... Even in difficult times. Having an implementation team, trying to get started with the groups and systematising our practice, we had not achieved that if you were*

> *not there, on the field with us. Because it has driven us. So I'm very happy about that, because otherwise it would have faded out, I'm pretty sure. And the supervision is "gold". The training and supervision provided by TIPS Sør-Øst has been very important (...) Fantastic, yes. (FG13).*

Some participants expressed concerns regarding the sustainability of ensuing family involvement when the external support was no longer available:

> *I have had such negative experiences throughout the years (...) a lot is invested in various things, but when the follow-up disappears and management takes over... This is what I worry about the most. That shift. (FG12).*

Facilitators at the clinical level

Understanding, skills, and self-efficacy among mental health professionals

At baseline, participants reported that clinical staff were often unfamiliar with family involvement prior to training and experience. Several participants feared that involving relatives would jeopardise their therapeutical alliance with the patient. They lacked understanding of the significance of services involving and supporting the family, and they lacked sufficient knowledge and skills to conduct family involvement. Training in FPE reportedly promoted understanding of the significance of involving and supporting the family, and contributed to increased understanding, skills, and self-efficacy among participants:

> *The FPE education has made me more structured with regard to family... that is, I have received a method and confidence—and especially quantity training and practice (...) and I have received supervision along the way. Then you become more confident. (FG15).*

Clinical practice with regards to introducing family involvement to the patient and establishing contact with the family was noted to improve in response to training and experience. Several participants described how lack of knowledge and uncertainty previously meant they refrained from involving relatives, especially if the patient was reluctant:

> *One of the first patients where I was supposed to do it... you know, call the relatives... then the patient said: "No, you are not allowed to do that". So. Yes. That was it (laughing). (FG4).*

During implementation, when participants increased their knowledge and self-confidence on how to approach patients and relatives, core barriers such as lack of consent and the duty of confidentiality were dealt with in constructive ways. Conversations with patients about family involvement performed by skilled personnel provided them with information about how they could benefit from involving their closest relatives:

> *I think that they (colleagues) have improved in kind of introducing family involvement to the patient. For instance, taking that course taught me how to present it. If the patient says no right away, we do not resign, but continue to raise the issue. (FG3).*

With increased competence and experience, clinicians started to explore why the patient was reluctant, if this was the case. They also became more confident on how to tailor family involvement to the patient's needs, and to deal with the situation to benefit the patient and the relatives, thus increasing the odds that family involvement would actually take place.

Awareness, attitudes, and motivation among mental health professionals

Throughout the project, particularly in the beginning, many participants described how barriers related to mental health professionals (such as negative attitudes, lack of awareness and prioritisation of family involvement), barriers related to patients (such as lack of patient consent, confidentiality issues, and patients suffering from long-term illness without relatives being involved), difficult family dynamics and relatives` frustration towards services (see Fig. 1), hindered family involvement. This clinician emphasises the value of getting in touch with the relatives at early stage to prevent the patient's social network from dissolving:

> *It is important to establish early contact to prevent burnout and exhaustion. If relatives do not feel like been taken care of early enough in the process, the likelihood of them discontinuing contact with the patient increases (...) (thus some patients) live in group homes in which their closest next of kin is the personnel who work there. (FG14).*

Participants reflected on how the involvement in the training and practice led to an increased level of awareness and appreciation of the importance of family involvement as an important element of treatment:

> *I feel that family involvement is far more present now. It is discussed every Monday.., also the FPE groups, we discuss much more... I feel that the role clarification is much clearer, more staff are engaged and the coordinators have the main responsibility. We are more conscious about family involvement,*

> *all the time. Talk about, ask for, clarify... relatives. And that is very good. (FG18).*

Several participants noted that traditionally mental health services have neglected family involvement in the treatment of patients with psychotic disorders. Through the IFIP project, it became evident for many of the participants that this neglect, however widespread, is not very well justified:

> *So... I am a bit puzzled that we have been doing this for so many years without involving the relatives. It's a bit odd. (FG15).*

With experience participants came to appreciate the benefit of the patient – relatives – therapists alliance. This also led to a greater awareness of the strain and challenges experienced by relatives and the importance of recognising and responding to career burden:

> *Just asking relatives a simple question like: "What is your experience as next of kin?" right. Just to get a question like that.., it's something that all relatives feel that they have never been asked. And when you are that vulnerable and exhausted... a large proportion are on sick leave due to the great burden of being a next of kin, imagine how valuable it is when someone asks that simple question! You don`t have to be a professional FPE-supervisor to manage that. (FG2).*

Involving and supporting relatives at an early stage of the disease course also had an important function in preventing maladaptive interplay between patients, relatives, and health care personnel. Participants repeatedly identified the benefit of being trained in and practicing family involvement to help them understand their role and contribute to recovery:

> *P: We had this sick, sick girl. Then she moved to CITY (...) and the (therapists) there were much more committed to family involvement after they got that group (FPE) and saw the value in it (...) There were such ripple effects, I shudder when I say it (...) Basically (she was) very difficult to follow up or treat, but this group was the one thing that brought the family together. They thought that they (she) could not be released from HOSPITAL. But when they used problem solving techniques (core FPE-element to promote more adequate responses when symptomatic behaviors emerge) the moving process had gone well, so they were almost shocked.* (Further the researcher asks what would have previously happened—and the participant responds as follows):
> *P: The parents would have been frustrated, wouldn't understand and been angry at the treatment/clinic, at least that's what happened before. Coercion, perhaps (...) inside a closed psychiatric ward.* (The researcher then point out that these scenarios are quite different):
> *P: Yes (...) we need to think completely differently. Thinking of possibilities or... adapting to the individual, looking more broadly at the patients' needs and the family, alternative solutions and not simply "that's how we do it, medicine and then out and finished" (FG5).*

In response to positive clinical experiences, participants reportedly felt more motivated to continue providing family involvement:

> *A successful FPE course was raised several times. I believe that it kind of inspired the therapists to think that family involvement is important (...), at least after one such complete FPE course which was very successful. And that was one of the most ill patients. (FG19).*

We also found that clinicians` positive perceptions of- and experiences with the FPE-model strengthened the implementation of family involvement in general. For example did they convey that the model being evidence-based, containing useful clinical tools and that one could utilise selected model elements also when performing basic levels of family involvement (see whole-ward approach), had a motivational effect:

> *The overall FPE mindset, not just the FPE groups, is a useful tool when meeting the relatives (...) also "outside" the model. (FG13).*

Discussion

We have explored what barriers and facilitators mental health professionals in CMHCs experienced when successfully implementing family involvement in mental health care for persons with psychotic disorders. We found that organisational measures such as a whole-ward approach, leadership commitment, dedicated roles, standardisation/routines, and external implementation support facilitated the implementation and seemed to improve the handling of core barriers. At the clinical level, training and practice promoted improved understandings, skills, and self-efficacy, besides increased awareness and positive attitudes among staff that reinforced implementation. In the following, we will discuss the most critical facilitators across the organisational and clinical levels.

Whole-ward approach and leadership

The IFIP implementation strategy was a well-planned effort to make the units embrace family involvement comprehensively. Training all staff and implementing processes to provide all patients and relatives with at least a basic level of family involvement, gave rise to a more family-friendly culture and lowered the threshold to get started with family involvement and FPE. This approach seemed to promote the normalisation and integration of family involvement into daily clinical practice. In some units, a crucial change in "default mode" arose; while previously the act of involving relatives required a justification, the new practice required a justification when *not* involving the relatives. This is in line with previous studies reporting that a high level of trained staff facilitate implementation [27, 43].

However, factors affecting implementation are deeply intertwined and located at different levels [27]. For example, competent and motivated staff is not sufficient to succeed with implementation efforts, since quality improvement strategies focusing on individuals alone are seldom effective [44]. In this study for example, we found that the implementation of FPE was hampered when the clinicians were unable to practice FPE shortly after training. This is in line with previous studies reporting that although training was able to ensure good levels of competence within trainees, once they returned to their previous job roles, the implementation of new skills diminished or disappeared [45]. Therefore, organisational commitment and strong leadership that facilitate appropriate timing of training and practice is of the essence when implementing FPE.

Various studies demonstrate that a lack of protected time and heavy caseloads are core implementation barriers [46, 47], something the IFIP participants also reported. Nevertheless, our findings indicate that the whole-ward approach may have contributed to resolve resource-related barriers. Consistent with previous research we identified that implementation participants are not passive recipients of innovations [48] and their behavior is strongly affected by peer group influences and the culture of the organisation [44, 49]. It is possible that characteristics of individuals and the implementation climate have an even greater impact on implementation than increased resources. For instance, the top-down recognition that family involvement was obligatory allowed clinicians to prioritise allocating time to relatives [50]. Some clinicians also experienced time savings due to reduced ad hoc contact with relatives and improved treatment, for instance relatives contributing to medication adherence, more rapid discharge, and preventing relapse.

Systematically involving relatives at the onset of illness also promoted implementation by preventing negative interactions, often characterised by distrust, uncertainty, poor communication, and withdrawal among patients, relatives, and professionals [51–54]. Professionals neglecting relatives [55] can potentially harm the triadic relation in the form of barriers arising, while approaching relatives in attentive ways can lead to positive interactions (Fig. 1, clinical level).

Flexible standardisation

Standardisation, with some flexibility and room for local adjustments, promoted implementation. By implementing procedures, conversation guides, and treatment plans, the participating units provided directions for practice, prevented family involvement from being seen as “nobody’s responsibility” [56], and ensured that family involvement took place. Implementing a standardised family intervention (FPE) also benefitted the implementation of a basic level of family involvement (see below). Nevertheless, as stated by Selick et al. [22] family involvement is not a "one-size-fits-all" practice, hence it is imperative to offer diverse family services and to elicit user preferences [57]. While initiating family involvement with all patients as a standard procedure, one should also make adjustments to patients` and families` varying needs, and standardised interventions should allow for flexible usage.

Too strict requirements for practice might provoke resistance and frustration among professionals. The IFIP study aimed to sustain clinicians` professional autonomy by welcoming local variations in how to set up the implementation. When successful, this further promoted acceptance and positive attitudes towards the intervention among participants, instead of potentially harming implementation through the rise of resistance and frustration. Family involvement is most likely to succeed in units that manage to tailor family involvement to each treatment course and that manage to balance clinicians` need for professional autonomy with imposed implementation tasks.

Basic and comprehensive levels of family involvement are mutually reinforcing

Implementing a spectrum of family interventions, from basic to advanced, reinforced implementation. When initial contact with the relatives was established as a default approach, the threshold to invite the patient and relatives to more comprehensive family involvement (FPE) seemed lowered. This approach enabled a stepwise consent, which worked better than an “all or nothing” approach. The efficiency also of less comprehensive models is supported by a recent systematic review [7].

Training the staff in FPE facilitated the units` basic family involvement. Increased competence and recognition among staff, besides access to FPE model elements, increased accessibility [18] and laid the foundation for basic high-quality conversations with patients and relatives. FPE is a complex and resource-intensive intervention. However, also using selected elements of the model was experienced as useful to several of the participating units, while basic conversations about family involvement seemed to resolve initial FPE barriers.

Family involvement must be learned and experienced

One of the most important findings in this study is the fundamental need for adequate training and ongoing supervision of health professionals, so that they can offer family involvement [26]. Neither clinicians nor managers explicitly mentioned the lack of training and supervision as a barrier. It may be difficult to acknowledge a lack of competence if you have neither learned nor experienced what is missing. However, lack of training in family involvement practices constitutes a core implementation barrier [2]. In Norway, training in family involvement has generally been given little attention in the health education system and in the health services. An illustrative example is that none of the participating CMHCs had annual training in family involvement of their clinical personnel at baseline [3]. Strengthening the training in family involvement within basic and higher education for health professionals appears to be one of the most important areas of improvement for the future. Until then, it seems like the health services must provide this training, in anticipation of the health education programmes taking more responsibility. Hopefully, studies like the IFIP trial, indicating that it is in fact possible to increase the implementation of family involvement, may inspire necessary capacity building both within the health services and in health education.

Implementing family involvement in the context of severe mental illness is a complex intervention that confronts multiple barriers and complex ethical dilemmas [26]. In the initial phase, we experienced varying degrees of skepticism and resistance among participants, and the barriers were often considered unsurmountable. But in many cases, core barriers, such as the duty of confidentiality, decreased or dissolved when the clinicians started to practice family involvement after adequate training. Ensuring that clinicians gained experience with family involvement became—rather unexpectedly to the researchers—one of the most powerful facilitators throughout the implementation process. One possible explanation is that several of the identified barriers partly derive from insecurity with regard to relatives and family involvement practices that was alleviated when trained health professionals experienced family involvement in real-life settings. Furthermore, the whole-ward approach gave most staff new insights on the significance of family involvement, and made units less vulnerable to individual preferences and staff turnover.

Access to know-how and expertise

The external implementation support had a formalising, competence-enhancing and motivational effect. The units benefited from substantial research- and clinical expertise within the fields of family interventions, ethics, law, health services, and implementation. They were given access to various resources such as training and supervision in FPE provided by TIPS Sør-Øst, evidence-based training and support provided by researchers at the Centre for Medical Ethics (UiO), as well as access to relevant external networks. This most likely increased the legitimacy of the interventions, as highly educated clinicians often have more confidence in evidence-based training and interventions. In this project, the external monitoring and evaluation, combined with systematic feedback, also seemed critical to identify areas for improvement, and to tailor and adjust the implementation process. As successfully adopted interventions typically include personal and ongoing contact between the intervention developer and adopters [53], IFIP researches frequently reminded and assisted the units in their efforts, and engaged in mutual collaborations with participants that reinforced practice and research. Overall, it seems like the external support contributed to reduce complexity, increase acceptability and reduce unit costs associated with implementation.

Strengths and limitations

The current study finds its strength in how knowledge is developed, through continuous input and interpretation over time and in conjunction with stakeholders outside the research team. Process evaluation gave the opportunity to investigate different levels and stakeholders while the implementation proceeded. Formative evaluation made it possible to explore which measures actually worked well, thereafter adjusting accordingly. Responsive evaluation, which means that we turned into dialogue with the participants and all key stakeholders before and during implementation, strengthened the knowledge creation. Overall, this provided us with composite and robust data on multilevel facilitators from the perspectives of actors within mental health services. We might assume that this increases the likelihood that our implementation efforts are useful and sustainable in real-world settings [58]. The credibility of the findings is enhanced through the presentation of a rich amount of illustrating excerpts [41].

As a result of the nested study design, the facilitators described are probably to some extent molded by the planned intervention elements. The qualitative approach used in this study cannot demonstrate causality, generalisable findings, or outcomes for the patients and their relatives. We hope that other data from the IFIP study, such as fidelity outcomes and the perspectives of patients and relatives will help to further explore the impact of the facilitators described in this study.

Implications

Our findings can inform future efforts to implement family involvement in mental health services. Implementation strategies should employ a whole-ward approach fostering shared understanding, attitudes, and goals. Leaders must signalise prioritisation, appoint dedicated roles, facilitate standardisation, allocate sufficient resources, and ensure that all clinicians get access to training, supervision, and practice. A basic level of family involvement and support should be the standard approach at hospital admission, followed by further individually tailored family involvement, which preferably leads to FPE. The current study is limited to family involvement in CMHCs for patients with psychotic disorders, but the findings are most likely transferable to the implementation of family involvement practices for other services and other patient groups.

We encourage researchers to explore facilitators also from the perspectives of patients and relatives, to employ quantitative studies to test the causal mechanisms hypothesised in this study, and to investigate whether and how our findings can be extrapolated to the treatment of other psychiatric disorders such as bipolar disorder, severe depression, and substance abuse. Future research should also investigate how much external support health services need to implement recommended practices that are not yet integrated in health education programmes. The significance of regional and national policies on family involvement—for example as expressed in health law, financial systems and basic education—should be further explored.

In line with two recently published systematic reviews on relapse prevention in schizophrenia [4, 7], we recommend that policy makers and clinicians give priority to family interventions such as FPE in resource allocation and treatment planning. Health educational institutions should incorporate basic training in family involvement to counteract professionals´ negative attitudes towards family involvement, and lack of competence and self-confidence when facing relatives of patients with psychotic disorders. For the future, one could argue that the whole-ward approach should be extended to a "whole health care and education approach" where good family care starts in the health educations, and is further embedded in the whole health- and care services. To achieve these goals, guidelines should be complemented with sufficient implementation resources and support.

Conclusions

Implementing family involvement in mental health services for persons with psychotic disorders is possible through a whole-ward and multi-level approach, with organisational- and leadership commitment, and access to external implementation support. Our findings indicate that providing training in family psychoeducation to all staff, followed by clinicians getting experience with family involvement, may lower or dissolve core barriers. Together with routines to offer a basic level of family involvement to all patients as a default approach, these measures facilitate implementation and promote normalisation and integration of family involvement in treatment. As with other evidence-based treatment interventions for psychotic disorders, we must for the future expect entire units to hold a basic competence in family involvement. Training in family involvement should be incorporated in future health education programmes.

Abbreviations

FPE: Family psychoeducation; IFIP: Implementation of guidelines on family involvement for persons with psychotic disorders in community mental health centres; CMHC: Community mental health centre; BFIS: Basic family involvement and support; TSD: Tjenester for sensitive data; TIPS Sør-Øst: Early intervention in psychosis advisory unit for South East Norway.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-022-08489-y.

Additional file 1. Standards for Reporting Qualitative Research (SRQR): 21-item checklist.

Additional file 2. Interview Guides.

Additional file 3. Example excerpts illustrating barrier categories.

Additional file 4. Example excerpts illustrating facilitator subcategories.

Acknowledgements

The authors would like to thank The Early Intervention in Psychosis Advisory Unit for South East Norway (TIPS Sør-Øst) at Oslo University Hospital Trust and Østfold Hospital Trust, for providing teaching and guidance in family psychoeducation to the participating units and valuable input to the project in general. We would also like to thank Irene Norheim and her colleagues in the R&D unit of the Division of Mental Health and Addiction at Vestre Viken Hospital Trust, for valuable input and assistance. Furthermore, we would like to thank Kristin Weaver, Anders Tvedt and Lana Shukur for transcription support, and Kristin Weaver for her assistance with English language editing. Finally, we would like to thank all the participating units, collaboration partners, stakeholder groups, and the advisory board of the IFIP trial for their valuable input.

Authors' contributions

RP, KSH, BW and TR drafted the original research protocol, which this article is based on, and thus made significant contributions to the conception and design of the study. KMH, MR, LH, RP, and KSH provided the implementation support and performed the data collection. All authors contributed to the development of the written summary of key barriers and facilitators. KMH did the main analytical work with contributions from MR, RP, BW, KSH, and ISH. KMH wrote the first draft of this article, with major contributions from RP, KSH, MR, and LH, and also received substantial contributions from BW, IN, TR, and ISH. All the authors critically revised the article, gave their final approval before submission, and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding
The study is funded by The Research Council of Norway. This funding source had no role in the design of this study or during its execution, analyses, interpretation of the data, or decision to submit results.

Availability of data and materials
The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate
The study has been approved by the Norwegian regional committee for medical and health research ethics (REC) South East with registration number 2018/128. REC provides a general ethical approval to conduct the study as described in recruited clinical units. On the advice of local data protection officers at the trial sites, the PI on behalf of the University of Oslo has signed contracts on shared responsibility for data processing with each participating health care trust, allowing us to carry out the study at each trial site in accordance with the General Data Protection Regulation. We confirm that all methods were performed in accordance with the relevant guidelines and regulations. Verbal and written informed consent to participate in the study has been obtained from all participants.

Consent for publication
Not applicable.

Competing interests
The authors declare that they have no competing interests.

Author details
[1]Centre for Medical Ethics, University of Oslo, Postbox 1130 Blindern, 0318 Oslo, Norway. [2]Division of Mental Health Services, Akershus University Hospital, Sykehusveien 25, 1474 Nordbyhagen, Norway. [3]Center for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway, Drammen, Norway. [4]Faculty of Health Sciences, OsloMet Oslo Metropolitan University, Oslo, Norway. [5]Division of Mental Health and Addiction, Vestre Viken Hospital Trust, Drammen, Norway. [6]Institute of Clinical Medicine, University of Oslo, Oslo, Norway. [7]Early Intervention in Psychosis Advisory Unit for South East Norway, Division of Mental Health and Addiction, Oslo University Hospital, Oslo, Norway.

Received: 10 February 2022 Accepted: 23 August 2022

References

1. Dixon L, McFarlane WR, Lefley H, Lucksted A, Cohen M, Falloon I, et al. Evidence-based practices for services to families of people with psychiatric disabilities. Psychiatr Serv. 2001;52(7):903–10. https://doi.org/10.1176/appi.ps.52.7.903.
2. Bucci S, Berry K, Barrowclough C, Haddock G. Family interventions in psychosis: a review of the evidence and barriers to implementation. Aust Psychol. 2016;51(1):62–8. https://doi.org/10.1111/ap.12172.
3. Hestmark L, Heiervang KS, Pedersen R, Hansson KM, Ruud T, Romøren M. Family involvement practices for persons with psychotic disorders in community mental health centres – a cross-sectional fidelity-based study. BMC Psychiatry. 2021;21(1):285. https://doi.org/10.1186/s12888-021-03300-4.
4. Bighelli I, Rodolico A, García-Mieres H, Pitschel-Walz G, Hansen W-P, Schneider-Thoma J, et al. Psychosocial and psychological interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. Lancet Psychiatry. 2021;8(11):969–80. https://doi.org/10.1016/S2215-0366(21)00243-1.
5. Pharoah F, Mari J, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database Syst Rev. 2010;12:CD000088. https://doi.org/10.1002/14651858.CD000088.pub2.
6. Pitschel-Walz G, Leucht S, Bäuml J, Kissling W, Engel RR. The effect of family interventions on relapse and rehospitalization in schizophrenia—A meta-analysis. Schizophr Bull. 2001;27(1):73–92. https://doi.org/10.1093/oxfordjournals.schbul.a006861.
7. Rodolico A, Bighelli I, Avanzato C, Concerto C, Cutrufelli P, Mineo L, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. Lancet Psychiatry. 2022. https://doi.org/10.1016/s2215-0366(21)00437-5.
8. Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, Young N, Woodhams P, Shiers D, et al. Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. Br J Psychiatry. 2015;206(4):268–74. https://doi.org/10.1192/bjp.bp.114.147561.
9. Lobban F, Postlethwaite A, Glentworth D, Pinfold V, Wainwright L, Dunn G, et al. A systematic review of randomised controlled trials of interventions reporting outcomes for relatives of people with psychosis. Clin Psychol Rev. 2013;33(3):372–82. https://doi.org/10.1016/j.cpr.2012.12.004.
10. Ma CF, Chien WT, Bressington DT. Family intervention for caregivers of people with recent-onset psychosis: A systematic review and meta-analysis. Early Interv Psychiatry. 2018;12(4):535–60. https://doi.org/10.1111/eip.12494.
11. Helsedirektoratet. Nasjonal faglig retningslinje for utredning, behandling og oppfølging av personer med psykoselidelser. Oslo: Helsedirektoratet; 2013. Available from: https://www.helsedirektoratet.no/retningslinjer/psykoselidelser. Accessed Feb 2022.
12. Helsedirektoratet. Veileder om pårørende i helse- og omsorgstjenesten. Oslo: Helsedirektoratet; 2017. Available from: https://www.helsedirektoratet.no/veiledere/parorendeveileder. Accessed Feb 2022.
13. Helsedirektoratet. Psykoselidelser, inkludert mistanke om psykoseutvikling – barn, unge og voksne. Pakkeforløp 2018. Oslo: Helsedirektoratet; 2018. Available from: https://www.helsedirektoratet.no/pakkeforlop/psykoselidelser-inkludert-mistanke-om-psykoseutvikling-barn-unge-og-voksne. Accessed Feb 2022.
14. Wallcraft J, Amering M, Freidin J, Davar B, Froggatt D, Jafri H, et al. Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. World Psychiatry. 2011;10(3):229–36. https://doi.org/10.1002/2Fj.2051-5545.
15. The National Institute for Health and Care Excellence (NICE). Psychosis and schizophrenia in adults (CG178). London: National Institute for Health and Clinical Excellence; 2014 Report No.: CG178. Available from: https://www.nice.org.uk/guidance/cg178. Accessed Feb 2022.
16. Galletly C, Castle D, Dark F, Humberstone V, Jablensky A, Killackey E, et al. Royal Australian and New Zealand college of psychiatrists clinical practice guidelines for the management of schizophrenia and related disorders. Aust N Z J Psychiatry. 2016;50(5):410–72. https://doi.org/10.1177/0004867416641195.
17. Westerlund A, Sundberg L, Nilsen P. Implementation of implementation science knowledge: The research-practice gap paradox. Worldviews Evid Based Nurs. 2019;16(5):332–4. https://doi.org/10.1111/wvn.12403.
18. Lucksted A, McFarlane W, Downing D, Dixon L. Recent developments in family psychoeducation as an evidence-based practice. J Marital Fam Ther. 2012;38(1):101–21. https://doi.org/10.1111/j.1752-0606.2011.00256.x.
19. The American Psychiatric Association Practice guideline for the treatment of patients with schizophrenia; Third edition. Washington DC: The American Psychiatric Association; 2021. https://doi.org/10.1176/appi.books.9780890424841.
20. Mueser KT, Deavers F, Penn DL, Cassisi JE. Psychosocial treatments for schizophrenia. Annu Rev Clin Psychol. 2013;9(1):465–97. https://doi.org/10.1146/annurev-clinpsy-050212-185620.
21. McFarlane WR. Family interventions for schizophrenia and the psychoses: A review. Fam Process. 2016;55(3):460–82. https://doi.org/10.1111/famp.12235.
22. Selick A, Durbin J, Vu N, O'Connor K, Volpe T, Lin E. Barriers and facilitators to implementing family support and education in early psychosis intervention programmes: A systematic review. Early Interv Psychiatry. 2017;11(5):365–74. https://doi.org/10.1111/eip.12400.
23. Szmukler G, Bloch S. Family involvement in the care of people with psychoses: An ethical argument. Br J Psychiatry. 1997;171(5):401–5. https://doi.org/10.1192/bjp.171.5.401.

24. Galletly C, Castle D, Dark F, Humberstone V, Jablensky A, Killackey E, et al. Royal Australian and new Zealand College of Psychiatrists clinical practice guidelines for the management of schizophrenia and related disorders. Aust N Z J Psychiatry. 2016;50(5):410–72. https://doi.org/10.1177/0004867416641195.
25. Mairs H, Bradshaw T. Implementing family intervention following training: what can the matter be? J Psychiatr Ment Health Nurs. 2005;12(4):488–94. https://doi.org/10.1111/j.1365-2850.2005.00871.x.
26. Landeweer E, Molewijk B, Hem MH, Pedersen R. Worlds apart? A scoping review addressing different stakeholder perspectives on barriers to family involvement in the care for persons with severe mental illness. BMC Health Serv Res. 2017;17(1):349. https://doi.org/10.1186/s12913-017-2213-4.
27. Haddock G, Eisner E, Boone C, Davies G, Coogan C, Barrowclough C. An investigation of the implementation of NICE-recommended CBT interventions for people with schizophrenia. J Ment Health. 2014;23(4):162–5. https://doi.org/10.3109/09638237.2013.869571.
28. Eassom E, Giacco D, Dirik A, Priebe S. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. BMJ Open. 2014;4(10):e006108. https://doi.org/10.1136/bmjopen-2014-006108.
29. Chen F. A fine line to walk: Case managers' perspectives on sharing information with families. Qual Health Res. 2008;18(11):1556–65. https://doi.org/10.1177/1049732308325539.
30. Hestmark L, Romoren M, Heiervang KS, Weimand B, Ruud T, Norvoll R, et al. Implementation of guidelines on family involvement for persons with psychotic disorders in community mental health centres (IFIP): protocol for a cluster randomised controlled trial. BMC Health Serv Res. 2020;20(1):934. https://doi.org/10.1186/s12913-020-05792-4.
31. Gilissen J, Pivodic L, Smets T, Gastmans C, Stichele RV, Deliens L, et al. Preconditions for successful advance care planning in nursing homes: A systematic review. Int J Nurs Stud. 2017;66:47–59. https://doi.org/10.1016/j.ijnurstu.2016.12.003.
32. Bond GR, Evans L, Salyers MP, Williams J, Kim HW. Measurement of fidelity in psychiatric rehabilitation. Ment Health Serv Res. 2000;2(2):75–87. https://doi.org/10.1023/a:1010153020697.
33. Feyissa GT, Woldie M, Munn Z, Lockwood C. Exploration of facilitators and barriers to the implementation of a guideline to reduce HIV-related stigma and discrimination in the Ethiopian healthcare settings: A descriptive qualitative study. PLoS ONE. 2019;14(5):e0216887. https://doi.org/10.1371/journal.pone.0216887.
34. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: A synthesis of recommendations. Acad Med. 2014;89(9):1245–51. https://doi.org/10.1097/acm.0000000000000388.
35. Stetler CB, Legro MW, Wallace CM, Bowman C, Guihan M, Hagedorn H, et al. The role of formative evaluation in implementation research and the QUERI experience. J Gen Intern Med. 2006;21(2):S1. https://doi.org/10.1111/j.1525-1497.2006.00355.
36. Abma TA. The practice and politics of responsive evaluation. Am J Eval. 2006;27(1):31–43. https://doi.org/10.1177/1098214005283189.
37. UK Government. Evaluation in health and wellbeing. A guide to evaluation of health and wellbeing projects and programmes. Available from: https://www.gov.uk/government/collections/evaluation-in-health-and-wellbeing. Accessed Feb 2022.
38. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Adm Policy Ment Health. 2015;42(5):533–44. https://doi.org/10.1007/s10488-013-0528.
39. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurse. 2008;62(1):107–15. https://doi.org/10.1111/j.1365-2648.2007.04569.x.
40. Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. African J Emerg Med. 2017;7(3):93–9. https://doi.org/10.1016/j.afjem.2017.08.001.
41. Patton MQ. Enhancing the quality and credibility of qualitative analysis. Health Serv Res. 1999;34(5 Pt 2):1189–208 (PMID:10591279 ncbi.nlm.nih.gov/pmc/articles/pmc1089059/).
42. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today. 2004;24(2):105–12. https://doi.org/10.1016/j.nedt.2003.10.001.
43. Dirik A, Sandhu S, Giacco D, Barrett K, Bennison G, Collinson S, et al. Why involve families in acute mental healthcare? A collaborative conceptual review. BMJ Open. 2017;7(9):e017680. https://doi.org/10.1136/bmjopen-2017-017680.
44. Ferlie EB, Shortell SM. Improving the quality of health care in the United Kingdom and the United States: A framework for change. Milbank Q. 2001;79(2):281–315. https://doi.org/10.1111/1468-0009.00206.
45. Ince P, Haddock G, Tai S. A systematic review of the implementation of recommended psychological interventions for schizophrenia: Rates, barriers, and improvement strategies. Psychol Psychother. 2016;89(3):324–50. https://doi.org/10.1111/papt.12084.
46. Prytys M, Garety PA, Jolley S, Onwumere J, Craig T. Implementing the NICE guideline for schizophrenia recommendations for psychological therapies: a qualitative analysis of the attitudes of CMHT staff. Clin Psychol Psychother. 2011;18(1):48–59. https://doi.org/10.1002/cpp.691.
47. Cohen AN, Glynn SM, Hamilton AB, Young AS. Implementation of a family intervention for individuals with schizophrenia. J Gen Intern Med. 2010;25(1):32–7. https://doi.org/10.1007/s11606-009-1136.
48. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. Milbank Q. 2004;82(4):581–629. https://doi.org/10.1111/j.0887-378x.2004.00325.x.
49. Rowlands P. The NICE schizophrenia guidelines: the challenge of implementation. Adv Psychiatr Treat. 2004;10(6):403–12. https://doi.org/10.1192/apt.10.6.403.
50. Chatzidamianos G, Lobban F, Jones S. A qualitative analysis of relatives', health professionals' and service users' views on the involvement in care of relatives in bipolar disorder. BMC Psychiatry. 2015;15:228. https://doi.org/10.1186/s12888-015-0611-x.
51. Gray B, Robinson CA, Seddon D, Roberts A. An emotive subject: insights from social, voluntary and healthcare professionals into the feelings of family carers for people with mental health problems. Health Soc Care Comm. 2009;17(2):125–32. https://doi.org/10.1111/j.1365-2524.2008.00803.x.
52. Slade M, Pinfold V, Rapaport J, Bellringer S, Banerjee S, Kuipers E, et al. Best practice when service users do not consent to sharing information with carers. National multimethod study. Br J Psychiatry. 2007;190:148–55. https://doi.org/10.1192/bjp.bp.106.024935.
53. Cohen AN, Glynn SM, Hamilton AB, Young AS. Implementation of a family intervention for individuals with schizophrenia. J Gen Intern Med. 2010;25(Suppl 1):32–7. https://doi.org/10.1007/s11606-009-1136-0.
54. Outram S, Harris G, Kelly B, Bylund CL, Cohen M, Landa Y, et al. 'We didn't have a clue': Family caregivers' experiences of the communication of a diagnosis of schizophrenia. Int J Soc Psychiatry. 2015;61(1):10–6. https://doi.org/10.1177/0020764014535751.
55. Kuipers E. Cognitive behavioural therapy and family intervention for psychosis evidence-based but unavailable? The next steps. Psychoanal Psychother. 2011;25(1):69–74. https://doi.org/10.1080/02668734.2011.542966.
56. Kuipers E, Yesufu-Udechuku A, Taylor C, Kendall T. Management of psychosis and schizophrenia in adults: summary of updated NICE guidance. BMJ. 2014;348: g1173. https://doi.org/10.1136/bmj.g1173.
57. Cohen AN, Drapalski AL, Glynn SM, Medoff D, Fang LJ, Dixon MB. Preferences for family involvement in care among consumers with serious mental illness. Psychiatr Serv. 2013;64(3):257–63. https://doi.org/10.1176/appi.ps.201200176.
58. Ramanadhan S, Davis MM, Armstrong R, Baquero B, Ko LK, Leng JC, et al. Participatory implementation science to increase the impact of evidence-based cancer prevention and control. Cancer Causes Control. 2018;29(3):363–9. https://doi.org/10.1007/s10552-018-1008-1.

Publisher's Note

Example excerpts illustrating barrier categories

Theme/Category	Example excerpt(s)
ORGANISATIONAL LEVEL	
1. Lack of shared knowledge, perceptions and practice	
Professional culture hindering family involvement	Traditionally, in the health care trusts, the focus is primarily on the individual, and ... it is noticeable (...) that there is more resistance in team meetings for example, if you are to raise an issue in relation to relatives, then it turns out a bit like ... "Ok, but do we have to spend time on this? I am used to concentrating on the individual patient, so this is such an unknown area to me, so ... I do not want to get into it". (...) Well,… various attitudes and ways of thinking kind of clash.
Varying ownership	To get people to want to do that planning and organising (to find time to practice family involvement), they have to be dedicated, and far from everyone is. Thus, many of the statements uttered in this room are characterised by the fact that these three are particularly motivated. If you had asked some of the other FACT-team members, you would have gotten completely different answers, right (...) That is how it is with all quality development projects, right, you have those who are the most dedicated that engage in these implementation teams, and then you have others who are moderately interested , and then there are some who are sort of completely unengaged.
Lack of leadership commitment	There is a lot of fear [among clinicians] due to the possibility of lawsuits, right. Especially psychologists (…), if you breach confidentiality, you can be sued, and, (.. .) lacking support from the management, (...) there are huge, tough sanctions if you breach confidentiality (...) They have their reasons for being worried about it (.. .) I have seen some examples of that.
2. Lack of routines	
Poor engagement routines	My experience is that family involvement is much more implemented in interdisciplinary substance abuse treatment, (...) and procedures are much more established (...) When I used to work at an outpatient clinic, inviting the relatives was always part of a set structure, preferably in the first conversation to ... receive information.
Poor information routines	We' ve talked about two things that could have improved it, but were rejected: that the notification letters that are sent to new patients should involve something about family (…) or relatives; “Feel free to bring your relatives” (…) right, “here we work systematically with”…,, because the letters that are sent out, they are so long… terrible letters with all the rights you have in the health care system and in Norway and all kinds of information. Thick letter ... They do not read it, you know. They do not read it. What matters is what the top four lines say, with the meeting time and with whom. That’s what they notice, and then they show up with that pile (of papers) (…) In meetings we have raised…, NAME, the psychologist in the team, raised this issue; “Should this not have been changed?” And we just got these “No, it's impossible”-answers, from the administration, who said that “This should be the same for the whole hospital and lalala, like that. (…) We also raised the issue of the hospital website (…) I haven`t looked at it lately, but our website has never been particularly good. Or informative or ... So for the future… I know some hospitals have managed to make a website that says “We work systematically with family involvement”, encouraging, really.. In a more modern style, more information on the internet and in the notification letters so that family involvement was presented as an obvious, integral part of our job. We have proposed this, but so far it’s somehow decided on a level we do not control.

Poor documentation routines	One example from yesterday, actually (…), I was supposed to code a phone call with a relative. But there was no applicable code on the phone, it was, every other… (..) municipality, eeh, yes, every field but relatives had their own code (…) So we gave feedback about that to the mercantile staff, who could bring it up higher in the system, that they also want to make it (telephone conversations with relatives) visible in the coding. It`s very strange that it does not say. Hence, we have to code (relative) phone calls as patient calls (…) and that's not legitimate. I do not think that's right (…) you can imagine, when geographical distances are as long as here, a phone call can be very important sometimes, right.
Lack of evaluation routines	I feel that it is not just the information to the relatives that is insufficient, it is structures in general. Right. Such as, we say that relatives are important, but we do not evaluate what relatives think, right... I feel that there is a lack of structure with regard to documentation, evaluation, organisation, on many levels.
Lack of structures facilitating mental health professionals getting training	Something that was a bit unfortunate is that we got that package (FPE course) and everyone was into it/excited about it, but then we came back (to the unit) and everything we had put on hold was there, sort of. And then there were days off and it was holidays It would have been so nice if we had the chance to actually get started, right away
3. Lack of resources and logistics	
Lack of resources to implement new practice	It requires more from us, in fact, than medication (…) providing medication, that's much easier, right (…) If you are going to learn a new method, such as psychoeducation, that requires.., for a new method to "settle", then you have to learn to work in a completely new way, you,.. it takes a lot more effort. And since there is such a strong focus on productivity... and quality development is not something that you get money for, right, it will always be downgraded in a system that has such clear financial incentives. In overall that makes quality development remarkably challenging in our hospital. It is very difficult to achieve any quality development within this framework, it involves leaders, dedicated individuals and it requires someone who is willing to give a little extra. Because there is no room for it within the existing framework.
Lack of resources to perform family involvement	I probably think that the overriding challenge in offering good family involvement is resources. That`s a bit of a boring thing to say [unclear] but just to illustrate: If you are going to run FPE-groups, which I think is very useful and which I think a lot of patients will be motivated to do, then you need two therapists who have the FPE-competence in each and every conversation. Now I have one (therapist) in my team, further we have two therapists that are quitting, thus there`s just one left that knows how to do FPE. So, for every (patient) I'm recruiting, she must have one hour available (…). FPE sort of adds an extra dimension to the patient treatment. But, I also think more resources are required to do it.
Competing with other tasks	The framework with regard to the reorganisation, and DIPS arena (patient record system) Well… there`s a lot.. less people in the teams, it creates a lot more pressure because we have patients on compulsory treatment, right.. paragraphs and heavy medication, and those are things that we just have to prioritise. And the work week is no more than 37 and a half hours to 40 hours, so you have some very hard prioritising, I would say. That`s the main barrier I think. Because I believe people want to.., or I can actually only speak for myself, but I want to and I see that .. I believe that the patients benefit from it. Both during the conversations, but also as part of a positive long run treatment effect. But (…) it`s the timing, simply said…
Turnover	I do not know if it would have been beneficial to have a small group, two or four, working only with that (FPE). Because people come and go all the time, requiring constant training of new (group leaders)… groups sort of dissolve.
Travel distance	So far, sufficient financial incentives with regard to family involvement are not implemented (…) And when you do not get that, it is difficult for managers to get motivated for it, because they get no gain. It may sound a bit cynical, but ..., but that`s how they

	have chosen to administer our hospital, then, so that I ... eeh ... I, I ... hope it does not take too long before the financial gains are set, so that you get paid for talking to relatives. Consider this FACT team, right.., we are talking long travel distances. It can be a matter of driving one hour to a patient, and if you are going to drive one hour to talk to a relative, which is in line with all the main guidelines, and then you must return, then you are up to three working hours, that is, half a work day. Eh ... And, and if you don`t get paid for that, you can bet on a salary in heaven. But, our hospital isn`t organised that way, investing in salaries in heaven… you invest in salaries here…, the system is very cynical, though, financially controlled.
Meeting within relative`s work hours	One of the barriers is also that we must do it within work hours because, uh, those who are not patients [relatives] may have a job ... that makes it difficult to get here. But ... we will make it. I believe that having a hectic everyday life is a barrier for many.
CLINICAL LEVEL	
4. Related to patient	
Patient does not consent to involve the relatives	I think the greatest challenges with regard to psychoeducation, is to get the relatives involved. To get a consent from the patient to provide their relatives with some insight. Because the patient spends a lot of time keeping facades, keeping people at a distance, and in being healthy in their eyes, the eyes of the relatives. Thus, to them, it is completely out of the question to involve the husband or wife so that they get to know. "If they knew..," well, they are telling me: "If you knew how much energy I use to stay healthy. And be normal…». But here, in the therapeutic room, they are allowed some reprieve [unclear], to be who they are. But, then again they straighten up and walk out from that room. It is completely out of the question for them to involve their relatives. It is a big challenge.
Patient confidentiality	We try to be some kind of catalyst and to do a bit of “cleaning up” in their environment, but it is difficult (…) we are forced into an “in-between”-position where we try to take care of the patient, meanwhile the relatives are crying for any kind of hope of improvement, stabilisation, explanations on what is going on. To some degree we can give them that, but even when it is written in the F5 chart (part of the electronic patient record) that the relatives are listed as relatives, if the patient says “you are not allowed to call my father”, suddenly they`ve changed it, right… And the patient’s rights are so strong, and we must respect that. So that is certainly challenging.
Patient does not have relatives	..and besides, some do not have relatives. They live alone and their parents live far away and ... Well, they [the patients] are maybe in their fifties, sixties themselves. With old parents.
Long term mental illness without relatives being involved	P: I believe that these patients which have received family involvement since they were young and were transferred to RE (rehabilitation team),.. it is completely different than those who have been in the system for twenty years. I’m sure they [those receiving family involvement since they were young] are used to having their parents involved in a completely different way. R: So you think it would be easier to continue a good collaboration if you had started earlier? P: I think so.
5. Related to relatives	
Difficult family dynamics	Then, there are some families where it is, you know.., there are many kinds of families. Obviously, we make adjustments to what the family looks like. Nor should all relatives be involved. Unfortunately. But I assume those are the exceptions.
Frustration towards services	... and when you are under enormous time pressure, like we are, the production demands are heavy, you constantly have to produce, then when you get those, those phone calls, with so much anger and frustration, that ... it does not increase the motivation to work with relatives. You have to break that cycle, right, that`s my concern.

Relatives refuse to be involved	P1: There will be a meeting on Wednesday in the outpatient clinic that I will attend along with the chief physician, in relation to a family which has been invited in, where they do not want to have contact with the patient (…) P2: Yes, but the relatives want contact with the services or with us? P1: No, do not want, no P2: Neither with us, nor the patient? P1: No. The relatives do not want to be involved, but the chief physician invited them anyway.
Foreign culture or language	Non-ethnic Norwegians, obviously that is also a challenge. It can be both cultural, you know, in understandings and such, and it can also be linguistic (…) but often there are both linguistic and cultural barriers. It can be sort of difficult to manage. I believe we have something to strive towards here
6. Related to mental health professionals	
Attitudes inhibiting family involvement	In the long run, family involvement is an appropriate measure. Well, it has somewhat surprised me that have we kept on for so many years without involving the relatives more than we did, it is a bit weird. It does not hold a high status in the world of therapists. It`s about to change, but so far it has not been. It`s not what the famous therapists are doing (…) especially psychologists, what psychologists intend to do, they want to do cognitive therapy or (…) assessments. Doing family work is basic work I assume that many have been thinking “others should do, not us”.
Lack of competence and experience	Many patients are considered not to have the capacity to consent (…) and the relatives often become part of the deficiency (…) or,.. yes, but true. And the relatives have immense needs (…) I think many of us find this so difficult to probe into that we avoid it, leading to limited contact with the relatives. And that is what we must try to change, right.
Do not prioritise family involvement	If we are going to think a bit broader. That this [family involvement] should somehow become an integral part of mental health care, I assume that, that it must be formalised and in one way or another, become as much a matter of course as very many of the other things we do (…) For example that to have offered proper - or good enough - treatment, family involvement is just as important as finances or counting, or routines. Because now, unfortunately, this [family involvement] is put on top of all the other things that we absolutely must do, therefore, unfortunately harder to prioritise. .
Insufficient interaction with relatives	I think we have an idea of…, I think that if we ask many of the relatives we are talking about, I am absolutely sure we feel that we give them more than they find that they get.

Example excerpts illustrating facilitator subcategories

Theme/Category	**Subcategory with example excerpt(s)**
ORGANISATIONAL LEVEL	
1. Whole-ward approach	
Family-friendly culture	**All staff involved** (NAME) somehow has a main responsibility, is the one having the main overview and does the most, but we are all involved and pull that load. **Change of attitudes from avoidance to accept** The project has also contributed to more openness. Daring to work with relatives. It is not that scary, it is not like... criminal. Like one used to think before. It joins the ranks of things that have changed quite a bit in a few years **Staff increasingly recognising family involvement as appropriate treatment** We experienced it most recently today with a patient. When we are stuck, which is not rare, however, you are stuck with "what do you do"? This is such a chronic issue. I recognise that family involvement and conversations with relatives, psychoeducation with relatives and perhaps this kind of structured FPE work, is actually a treatment method. **Shared understandings and focus** There are many benefits to so many of us having taken that course (FPE). You have that understanding and that focus with you, even though you may not actively work with groups.
At least a basic level of family involvement offered to all patients/relatives	**Establishing an alliance with the patient early in illness trajectory** I can imagine that maybe sometimes, at least for the patient, the fact that family involvement is systematised, makes it easier to say yes when it is embedded in the assessment package; "We have this and this and we also have conversations with relatives and together"… **Establishing contact and alliance with the relatives early in illness trajectory** I also find that I just have to make a phone call to establish that initial contact, showing openness and interest in how the relatives are experiencing the situation. This can have a positive effect in that I get an alliance also with the relatives, not just with the patient.
Training and supervision for all clinical staff, also in more extensive family involvement approaches	**Utilising FPE elements in the basic family involvement** If I do not have time to do the whole FPE from A to Z, I will at least try to use some elements that can be adjusted to the patient. (In that situation) I could not complete the whole FPE but at least I had two or three conversations with the relatives (...) And we had this other patient where we did not have time to talk to the relatives, but where we could use that problem-solving

	technique from FPE. Without the relatives, but ok. That also worked well (...) To use and adapt the different techniques that we learned, and adjust it to the patient. **Prevents varying practice** We have observed that it varies within the (FACT) team to what extent they [the clincians] feel confident in working with relatives (...) But (NAME) told me not long ago that he perceives that those who have been least confident in working with relatives now to a greater extent can refer to conversations with relatives. Thus, perhaps the differences are about to be somewhat evened out. **Facilitates integration of family involvement** I think like that with all the things ([implementation] we have done this semester. We have done a lot of family work before, and we have had several dedicated individuals, right, who have worked with it, but it has never been sufficiently implemented as part of “this is what we do”. We got started on that now. We planned that we (should) arrange for one day with these TIPS people ([experts performing the training]) to brush up ... because many of us previously have participated in multi-family courses. But, the fact that all of us now were offered a four-day course, of course that was absolutely, uh, essential to get as far as we have today, already. **Facilitates that staff practice family involvement** Those who took that education (FPE) were fully aware that this also obliged them to run groups (…) You cannot just get that education and not being active. This is a great improvement from before, now it was a matter of course that if they took that education they should be running groups as well. **Utilising FPE-elements enables clincians` practice** It was very important for us to realise that we can use elements of the model . Because then you can practice the elements. You can do that more frequently than ... (…) because we don’t manage to start, eh ... enough groups at any given time to gain enough training, so that ... using FPE-elements is good way of practicing. **Customised supervision** When I was running groups I found that the supervision was absolutely essential (…) especially as a novice. When you've done it a lot, it's easier, but as a novice it was totally... eh.. yes, very helpful to have the opportunity to return with your issues. Then, it was important that the supervision was so frequent that you (…) or to that extent available, so that you could “handle it here and now”. We did not have continuously access to supervision but having the opportunity to call them ahead of the next session when you needed it ... I find that very useful. Because when we simply weren`t getting anywhere, it would be silly to run five more sessions, before you get that supervision… **All staff are offered FPE-supervision** The management were very concerned that those who should be allowed to participate in the FPE-supervision that should only be those who were running these standarised FPE-courses. But then it turned out that just three people or something like that,

	three, four people would end up participating ... But, now I have been, eeh, very determined, and made them accept that those supervision sessions should be integrated into more mandatory ... working hours, which is mandatory meeting time. FPE should be accessible to everyone", with the purpose of implementing some kind of FPE-light, as I call it.
Leadership commitment and sufficient resources	**Positive management attitudes** Unit leader: It is about prioritising tasks, right. As an outpatient clinic, we have an overall budget and we have funding that we are required to deliver on (…) but it is a prioritisation to achieve a coherent and proper treatment process, right (…) Our health care system has become a place where we count what we can produce., like they do in, well, in real companies that produce things, right. And naturally, you ([the therapist]) can be left with a feeling…, what is in fact my contribution? So, when I have a conversation with an employee, for example, someone who mainly does IMR groups ([Illness Management Recovery]) (…), it's about contributing to the whole, right(…) helping people to understand what their role is, why it is important. Regardless of having a thousand codes, or you may have a hundred (…) running groups is more time consuming, right (…) it is about everyone carrying their essential role into the whole, so as many ([patients]) as possible are receiving the best possible treatment at our outpatient clinic. **Appointing dedicated positions** Family involvement should be formalised in a dedicated job position that is somehow visible. When someone quits, for example, others can apply for that position (…) I also believe that another way of making family involvement more visible is to make competence in family involvement a requirement in job advertisements. **Facilitates family involvement are regularly tematised** In addition, there is an increased awareness regarding setting aside time in meetings. That we have a structure for it, and this must necessarily be initiated by the management. Team meetings, morning meetings. Because ... eh, yes, my experience is that finding time is a challenge, everything is so important, so setting aside time for both the pediatric work and the adult relatives... **Resource allocation** We have experienced lots of those challenges here, they are well known. What set about the turnaround operation, was actually when family involvement was put into a system. And it was in a way equated with the other treatments. Resources were set aside for it. It was more acknowledged, simply put. . **Signalises prioritising** We also have an introductory course for all new employees. Mandatory, displaying to all new employees that family work is an expectation here. **Ensuring staff get started with FPE-groups after training** Many people have been admitted to that education here before, but some of them never get started (…) perhaps they are a little reluctant (…) Therefore it is important that… now they that have taken the course, the first thing is that they get started with groups while we will focus on the structure as we go.

	Long term perspective What sold me on it when we were introduced to it ([the project/family involvement]) was that it is supposed to be offered as an integral part of the treatment, right. That it should not come in addition to it (…) We are continuously imposed with tasks that come on top of what we already do. It is seldom followed by someone saying: "To compensate we will reduce some others tasks, right...” It is always on top of it. So, as I said, there are some minor costs with regard to the staff but in the long run I think it will lead to a considerable boost, right, that you get it as part of your everyday work. That is also because now everyone has a greater understanding of what family involvement is and how they can benefit from it, right. **Facilitating coordinated care across specialised- and primary health care** Another positive thing related to FPE was that the municipality was involved in it and have more knowledge. It improves the collaboration (…) We have experienced it in (NAME municipality) right, where they are very conscious about FPE., where patients start with family involvement in the specialised health care services, and if they are transferred to the municipality, this is done in collaboration with employees in the municipality who have the same competence. This is the way to go further, to spread the competence. Because high turnover is a challenge in the specialist health service because we have many who are taking further education. So that we indeed will be experiencing turnover here. The municipal health services, however, have a much more stable group of employees. And the expertise is great. So it would have been very nice to establish FPE as a method of coordinated care, quite simply.
2. Appointed and dedicated roles	
Family coordinator	**Main responsibility** The family coordinator in the psychosis team is responsible for follow up on the relatives. Because we have a family coordinator that has the main responsibility, it has been much more systematised, I think. Organised (…) that always… yes, remembers it and is nagging us about that stuff. So, that’s good (…) There's a lot that should be remembered and done for each patient, (…). When someone has that function, it is not... then it gets done. **Creates routines and structure** I really believe in establishing a family coordinator role. It is of course related to knowledge that X mentioned, and structure, but having someone who is responsible for driving the family work, it is something that I see generally in all professional development projects… Because before I had the impression that family involvement was much more random, depending on the individual therapist, (whether he / she) had a personal interest in relatives or not that was decisive whether the individual therapist followed up the relatives or not. While now it is much more systematised, right, now there are standards on how to have conversations, in what way and yes… **Provides training and guidance to colleagues** Sometimes the closest relative…, what shall I say .., does not act in the patient's best interest. And then it is perhaps extra important that we bring in X ([the coordinator]), to deal with it. Because we find that some relatives act inappropriately, or have an unfortunate impact on the patient (laughs a little) (…) and the patient suffers from it. And then it is extra important to work on

	it, and it is very good to kind of have X to lean on, who can approach the case from a slightly different point of view than us. So that it is not just discussions about treatment. **Initial dialogue with all patients** My experience is that very few patients prohibit us from providing the relatives with that kind of information. But, that's because every (patient) is assigned a conversation with me where they get information about the family involvement that we offer. All new patients. And I'm the one who approaches (the relatives) and sometimes it's the therapists who do it. Besides, I believe that the therapists speak a lot with the relatives now. That`s my impression.
Local implementation team	**Dedicated personnel and unit manager in team** R: Is there anything you want more of, or have not received that could be useful in this type of quality improvement project? P1: It would have been useful to have the leader present in the (implementation) team. P2: Exactly what I was going to say (several participants: yes, etc.) **Regular team meetings** It requires that you have time for preparation, you need time to somehow get mentally prepared, and.., and talk together afterwards and such, and there is not much time for that, you know. . So perhaps we have to get some help in a meeting to sort of, "ok, we have a patient who is in the target group, and then we should make a group, finding two therapists to be included in the group. This meeting on Fridays… that we can discuss family involvement, put aside some dedicated time together, I believe that... makes it easier to get started. If the four of us manage to raise this flag, then I think we can help each other to... get started. **Promotes awareness, knowledge and motivation among team members** R: Now that you`ve been working in this improvement team for a few months… Would you like to say a little about how it has been? Is it important to have someone who is especially dedicated to get this work going and, yes, how has it been to work that way, both for better or worse? P: It has been very interesting and ... uh, yes, I have learned a lot. And... gained a much greater awareness of the importance of it. I believe that we succeed in collaborating and that inspires me and I see, see the impact it has. **Practical work to facilitate family involvement measures** So far, we have planned two teaching seminars for relatives that have been sent out, but they don`t make themselves. . There's a lot of work with the marketing, you can't just send something out…, you have to send physical invitations by mail, call around to the leaders of the municipalities to motivate them, get access to meetings so that the leaders can further motivate their therapists to inform the relatives. Thus, there is a lot of practical and somewhat invisible work to be done. **Influencing the management** Leader of implementation team: The two family coordinators that we have are great, but if they are not taken care of with proper structures, if they are not given dedicated time…, it's about negotiations, about working hours, working systematically with

	management, anchoring and creating structures that make the family involvement stick. It is (...) important, because the coordinators last for a project period so that you might get good evaluations of this particular project, but they do not last over time. Therefore, I am much more concerned with structures, structures that will last. **Teamwork** R: What has it been like, working within an implementation team? P: It has been nice, but that, it`s a lot about the collegial dimension. That we work well together as colleagues. We plan groups together, we sit there with relatives, thus, good collaboration is important..
3. Standardisation and routines	
Family involvement is systematised	**Routines to support clinicians** We need the family involvement to be more structured … there are a lot of different things to keep in mind. Now we have clinical pathways, where we have to remember the coding. Further, all treatment plans must be revised every third month, then contact with the relatives... There are a thousand things like that.., and we do not have a good system. I really need someone to help me with… reviewing, checking and all these things. If I`m going to do it all that myself... It takes a lot of time and you barely get through the regular daily routines. “Have you done it? Have you offered it? Documented it in the patient-chart?” All that stuff. .. Yes it easily gets pushed aside by all kinds of hubbub and other crises. **Organising the engagement phase** P1: Maybe we should make a routine that once a week we contact [the relatives]) by phone? P2: This has to do with procedures.. Like who is going to do it…? Because the chief physician, she wants to control that part, so then it becomes a bit fuzzy- who is in fact contacting the relatives? If we managed to make a procedure that makes the primary contact responsible for doing it, then I believe it would get done. And perhaps a bit faster than today because when the chief physician wants the last word on who should call – whether we should call them at all, and at what time it should be done, it ends up being unclear. **Flexible standardisation** If the relatives know that the patient is here, confidentiality is not an issue. So we should have a system so that the relatives of patients who do not want them involved can get some guidance, too. Because they have the knowledge about these patients, about what they need. It`s not primarily us. So ensuring that they can get something without involving the therapist, I have found that to be incredibly effective. That`s how we do it (…) it is possible to solve it in other ways to prevent the relatives from just “floating at home alone” without getting advice, or any guidance. Be allowed to discuss with someone.
Implementation-work is systematised	**Ensure clinicians are allowed to practice** I can spend day in and day out at courses, but practicing is the still most important. Mass training to ensure sufficient practice of the method is a necessity. I mean, it is such a classic problem, there is actually such a large turnover of staff here that people do not get enough experience. Being responsible for this for a long time now, I see it very clearly; it is not the case that when you

	have taken a course, you've got it. So, you have to practice and practice and practice (…) and have enough time to actually have enough groups. So that it does not get old (…) the longer time that has passed, the higher the threshold. **Clear role distribution** The nurses/social educators has the main responsibility for ensuring the family involvement. Not necessarily doing it, but to follow up that it gets done and.. that they have been contacted and stuff .. That makes it much easier for me. The roles are clarified.. Eh ..because we work in a slightly special way. The patient does not have one person responsible for him/her, several staff members are involved. Thus, it's good to know who does what, so we don`t overlap, or forget it. **Replacing individual sessions with FPE-sessions** But it takes a lot of resources s when two therapists have to do it... In the long run (…) because now we do both; we have individual conversations and we have PEF, right. It is not like we define that «okay now we are going to do this as part of the treatment»… This IS treatment, so for some (patients) it is not necessary to have so many individual conversations during that period. At the same time. Because now, we do both. And I think that's very important to remember. Because the point is: it's the same group! I think this goes for all outpatient clinics; we are very good at individual therapy, and consider the groups as an add-on(…) But when running groups replaces individual treatment… Yes then you can reduce the number of individual sessions, because this is part of the treatment. **Setting aside dedicated time for family involvement** We are also looking at how we can set aside time in the appointment books specified for family work. (…) How to solve this is a topic at the unit.
4. External implementation support	
Access to implementation resources/tools	**Fidelity monitoring and evaluation tool** You have access to some tools, for example the fidelity measurements; "What are you actually doing?", right, the interviews, the focus you have brought with you. **Training in FPE and other competence developments** We are very grateful for the project because it helps us to focus and getting so many group leaders trained at once was a boost. **Ongoing support and supervision** I very much agree with you about that phone... Having it available quickly…It does not have to take that much time. But that someone is there and that you know them a little so that you're willing to make the call.. I think you have been very good at making our uncertainty feel legitimate, that we aren`t always able to do things right.
External impact that drive implementation	**Getting started** We got great help regarding the course, getting it started. It was a lot of work getting it off it`s feet, getting people to join. And really highlighting what we are going for, right?

	Formalising effect We participated in that kind of project with the Norwegian Medical Association a few years ago, we did not get those results, we did not succeed in the follow-up and continuity. It`s the same with the X-project. So I believe that the support in this project has been absolutely crucial to (…) avoid practice relying on dedicated individuals and to help formalise the family involvement. **External implementers pushing implementation** The communication with THE RESEARCHER becomes an incentive, right? «How are you doing, can we talk», it gives a push to keep working. Because, we have done quality improvement work before, and it is, it is hard work. That`s my experience. And when we have done it before, it is hard to get the ward and colleagues on board, because everyone has so many important things in their own head. So, I find, that this is the most successful quality improvement work I have been part of, and we have had a few. In relation to relatives, we have tried things before regarding family work. **Creates awareness of own practice** To me, it helps just to sit here and reflect and discuss, to look at where we can improve. That helps me, at least. So it`s better if you set aside time, just to have you here asking these questions I find very helpful, because, well. It makes it so clear (...), so clear in a way.  **Facilitates administration and structure** It`s a while ago now, but you would hear «oh, another project». In a way, it felt, in the beginning maybe like a mandate. But I haven’t heard anything like that lately... and, for me, I feel like it has become more and more meaningful to have this focus. Now I almost feel like...we should have more...that we should only work with the families, at least for the youngest patients here. That...it is amazing to get such a...that you have given us administrative frameworks, and structures and things like that. **Facilitates management anchoring** The leadership commitment has definitely been improved. For example, that (NAME of leader) got such an "eye opener" (laughter); That`s what family involvement is about!
CLINICAL LEVEL	
5. Understanding, skills and self-efficacy among mental health professionals	
Knowledge	**FPE-courses strengthens implementation** One of the most important improvement measures is that we have completed the FPE courses. **Access to evidence-based knowledge** In both the groups I have been running, I have enjoyed doing it, and it’s been beneficial to have it there "okay, this is a package, for you to try... This is evidence based, we do this first followed by this"(…). I liked it very much, having this to offer them. So I think it's been great to get trained in that method.

	Improved handling of ethical dilemmas I have felt several times that.. Compared to before, I was hiding behind confidentiality, and could not tell ... Well, I felt that I had confidentiality hanging over me, so I did not give information, I wasn’t able to n say what I really wanted to say, because ehh .. always having that confidentiality-beast behind me. It's much easier now.
Experience	**Experiencing FPE as a useful method** What I do is very basic things…; I ask them if they (the patients) can tell me about their family. I ask the family members "How has it been for you?" I also provide very basic psychoeducation about stress and vulnerability and the filter, before we talk about it. Well, it's striking me how simple it is and how many people say "I recognise myself in this" and "we should have done this before" or.., especially that recognition part. And that it is something that is possible to get help to work on, right, a more optimistic view. As a therapist, I believe that is an important…feeling, that you have a valuable tool. **Experiences family involvement as meaningful work** We are getting feedback from the families that they find it useful. It does something to job satisfaction, quite simply. Satisfaction. When someone ([colleagues]) succeeds… I think: “this has been a good conversation, this is meaningful. **Increased self-efficacy** It`s about feeling comfortable and gaining experience in asking questions appropriately. Making the patient feel safe.
6. Awareness and positive attitudes among mental health professionals towards	
Relatives	**Sees relatives as a resource** Many of our patients are on medication. Stepping up or reducing medication… many patients want to do that with us, but without relatives knowing anything. But my experience is that it is crucial to bring in the relatives, so that they also know more about it. Based on experiences and family work that I have received feedback on, I assume I will have a different attitude now, if a patient says "No, my relatives cannot know about that". **Understands relatives have rights and needs** Now, when the patient does not want us to collaborate with the relatives, I have been even more confident in listening to the relatives about what they have.., about what they already know. And to talk to them. I have been much more confident in that now. **Wants to support relatives** There is still so much stigma, there is so much shame and there are so many families isolating themselves, right; "This is kind of my problem, and only my child is experiencing this." So you feel like such a small island in a way…, and "This is the problem we have to deal with on our own", right. Who to talk to? Perhaps they do not have many friends or acquaintances they can talk to about it, because they do not understand it because they do not have similar experiences. Therefore, I think it`s important that we (the professionals) are the ones…. Who know a little more about it… And we can give them hope too, hope for change.

Family involvement	**Increased awareness of the significance of early involvement** It is in a way higher up in the consciousness. I have experienced many times that it is wise, especially to get in touch with relatives in the beginning, because eventually you may very much want to get in contact with them, but then it may be too late in a way, then the patient no longer, or .. There is something about getting in touch (with the relatives) ahead of knowing the person (the patient) so it’s not due to us being a little worried about the children, or… Those experiences motivate me, makes me more conscious of it. **Increased awareness on long-term benefits** It costs there and then, but hopefully, in the long run, we will get it back in multiples, right. (…) Through many years of experience with patient treatment, we have seen families and relatives in all varieties, right. And it is clear that the more ([patients]) you can help to collaborate with their surroundings (…) the more people you help to live their lives out there .. We should approach the patients holistically, and the relatives and the family are an essential part of their lives. **Increased awareness on the national guidelines** P1: It reminds us of the national guidelines for treating psychotic disorders. That it is high up, among the most effective interventions, connecting with the relatives in one way or another. This is useful because that quickly gets forgotten We stick to individual therapy and medication, while forgetting the part of treatment that actually has the best evidence. P2: It feels ... sort of professional to say "This is in the guidelines". And it's a good feeling to be able to offer what we consider is the best treatment.

II

Hansson *et al. BMC Psychiatry* (2022) 22:812
https://doi.org/10.1186/s12888-022-04461-6

BMC Psychiatry

RESEARCH Open Access

The duty of confidentiality during family involvement: ethical challenges and possible solutions in the treatment of persons with psychotic disorders

Kristiane Myckland Hansson[1*], Maria Romøren[1], Bente Weimand[2,3], Kristin Sverdvik Heiervang[1,2,3], Lars Hestmark[1], Elleke G. M. Landeweer[4] and Reidar Pedersen[1]

Abstract

Background: Family involvement during severe mental illness is still poorly implemented, contrary to evidence-based recommendations. Confidentiality issues are among the most prominent barriers, with mental health professionals facing complex ethical, legal, and practical challenges. However, research focusing on this barrier is very sparse. Nested within a cluster-randomised trial to implement guidelines on family involvement for persons with psychotic disorders in community mental health centres, the aim of this sub-study was to explore ethical challenges related to the duty of confidentiality as experienced by mental health professionals, and to explore key measures that might contribute to improving the handling of such challenges.

Methods: In total 75 participants participated in 21 semi-structured focus groups, including implementation team members at the initial and late phase of the intervention period and clinicians who were not on the implementation teams, at late phase of implementation. We used purposive sampling and manifest content analysis to explore participants' experiences and change processes.

Results: Ethical challenges related to the duty of confidentiality included 1) Uncertainty in how to apply the legislation, 2) Patient autonomy versus a less strict interpretation of the duty of confidentiality, 3) Patient alliance and beneficence versus a less strict interpretation of the duty of confidentiality, 4) How to deal with uncertainty regarding what relatives know about the patients' illness, and 5) Relatives' interests versus the duty of confidentiality. Measures to facilitate better handling of the duty of confidentiality included 1) Training and practice in family involvement, and 2) Standardisation of family involvement practices.

Conclusion: When health professionals gained competence in and positive experiences with family involvement, this led to vital changes in how they interpreted and practiced the duty of confidentiality in their ethical reasoning and in clinical practice. Especially, the need to provide sufficient information to the patients about family involvement became evident during the study. To improve the handling of confidentiality issues, professionals should receive

---

*Correspondence: k.m.hansson@medisin.uio.no

[1] Centre for Medical Ethics, University of Oslo, Postboks 1130 Blindern, 0318 Oslo, Norway
Full list of author information is available at the end of the article

training in family involvement and confidentiality statutes followed by practice. Furthermore, family involvement should be standardised, and confidentiality guidelines should be implemented in the mental health services.

Trial registration: ClinicalTrials.gov Identifier NCT03869177. Registered 11.03.19.

Keywords: Confidentiality, Ethics, Ethical challenges, Family involvement, Severe mental illness, Facilitators, Health services research

Background

Patients with psychotic disorders and their relatives are often not offered the family involvement and support they are entitled to [1, 2], despite decades of substantial research evidence on patient [3–5] and relative [2, 6] outcomes, recommendations in government policies worldwide [7–10], and numerous attempts to increase the uptake of family interventions in routine care [4, 11, 12]. Meaningful engagement of family members in treatment and decision-making processes is hampered by clinical, organisational, cultural, and historical barriers [1, 12–14]. Among such impediments, the research literature identifies confidentiality issues as a prominent barrier, portrayed as a complex and controversial area of clinical practice [15–18].

The complexity of information sharing is partly due to a lack of trust between stakeholders – patients, relatives, and health care personnel [14], who may have different expectations, needs, and concerns [19, 20]. Patients express a number of concerns about involving their family in treatment, such as uncertainty regarding disclosure of sensitive information, fear of losing control, or notions that involvement will burden their family or will not be useful [21]. Relatives often contribute to the care process in various (implicit) ways [10], they want their contributions to be recognised [22, 23], and they express a need for information and support from professionals [24, 25]. Fulfilling these roles can become more challenging if relatives are kept "out of the loop" [18], affecting their commitment to caring and the relationship with the professionals/services [26, 27]. However, relatives experience devaluation, neglect, and lack of involvement [15, 22, 28], suffer from high unmet needs for information [16, 29, 30], and experience repeated refusals from the services who frequently invoke the duty of confidentiality as justification for this [15, 18, 26, 27, 31, 32]. Furthermore, studies show that mental health professionals frequently experience that patients refuse to involve their relatives [16], often are reluctant to share information with families [17, 18], struggle to balance patients' and relatives' interests regarding disclosure [33], and fear that breach of confidence could potentially result in legal or disciplinary action [15, 16]. Health care professionals also lack appropriate training in family involvement and confidentiality statutes, while confidentiality policies and guidelines are often ambiguous and under-implemented [34].

These different expectations, needs and concerns may create ethical challenges for care professionals. In this study an "ethical challenge" is defined as a situation where there is doubt or disagreement about what is right or good [35]. In this paper we draw on Beauchamp and Childress's four principles of biomedical ethics [36] because weighting the principles of respect for autonomy, beneficence, non-maleficence, and justice might be helpful when dealing with ethical challenges. The principle of respect for autonomy has in particular left its mark on current western confidentiality policies and practices [17]. Contemporary bioethics made a pivotal contribution in terms of strengthening the emphasis on patients' autonomy by formulating the concepts of "capacity to consent" and "informed consent" [37]. For a consent to be informed, the patient must be adequately informed by health personnel to hold substantial understanding and not be controlled by others, while intentionally authorising a professional to do something that is specifically mentioned in the consent agreement [36]. In the present context, respecting autonomy means that patients with the capacity to consent are to decide themselves which confidential information can be shared and with whom. The duty of confidentiality is also strongly emphasised in professional ethics codes, and is considered vital for the alliance with the patient and thus beneficial for the patient.

In most countries, the duty of confidentiality is included in health care legislation, stating that health care professionals shall prevent others from gaining access to patient information that they become aware of as professionals [38]. With few exceptions, health information may be disclosed to others only to the extent that the patient consents regardless of how sensitive the information is. In practice this means that relatives as a main rule are not entitled to get information about the patient if the patient has not consented. However, regardless of patient consent, professionals are often given the possibility to share general information, and to listen and provide support to relatives is usually not considered a breach of confidentiality [10]. In Norway, the health services also have an obligation to provide training and supervision for relatives, especially if the relatives have extensive tasks as informal careers [39].

This paper reports findings from a sub-study nested within the IFIP-trial: Implementation of guidelines on Family Involvement for persons with Psychotic disorders in community mental health centres (CMHCs) [40, 41]. When investigating which factors affected the implementation and how, the duty of confidentiality was identified as a key barrier [42]. Consequently, we performed a separate in-depth exploration of confidentiality issues with a particular focus on the changes that transpired within the participants and at the units while the implementation progressed.

Research focusing explicitly on ethical challenges related to confidentiality and family involvement is lacking, as are explorations of how barriers to information sharing are resolved ethically in practice [18]. In particular, situations where competent patients refuse to involve their family constitute an unresolved grey area. The aim of this paper is to contribute to a better handling of confidentiality by addressing these research gaps. Its scope is limited to challenges related to disclosure of information to relatives. The following research questions guided the data collection and analysis: 1) "What ethical challenges do mental health professionals experience related to the duty of confidentiality in family involvement during the treatment of persons with psychotic disorders?" and 2) "What measures are experienced as helpful to improve the handling of such challenges?".

Methods

This article conforms to the "Standards for Reporting Qualitative Research (SRQR): 21-items checklist" [43] (Additional file 1).

Study design and context

The cluster randomised IFIP trial employed a responsive evaluation design [44] including process and formative evaluations [45]. The knowledge was generated through exploration of various stakeholders' views and by continuously engaging in dialogue with the participants and key stakeholders before and during implementation.

Focus groups - participants and data collection

Each of the eight clinical sites in the experimental arm established a local implementation team of 3–8 persons who were responsible for the implementation at the unit. During the 18-month implementation period, we conducted 21 semi-structured focus groups with the implementation teams and clinicians (2019–2020). Implementation teams were interviewed twice at different stages of the implementation process. Figure 1 illustrates the data collection along with the IFIP implementation measures.

A purposive sampling strategy [46] followed naturally from the study design because we aimed at exploring experiences with confidentiality issues from participants engaged in the implementation work. When participating in the first round of focus groups (Fig. 1, initial phase), most implementation team members lacked competence and experience with family involvement. At the time of the second focus group (Fig. 1, middle phase), most had attended a four-day course in family psychoeducation (FPE), had received specific training in legal, ethical, and practical aspects of confidentiality, and were practicing family involvement. To expand on these accounts and learn from participants with less commitment to the implementation work, clinicians who were not part of the implementation teams were interviewed at a late phase of implementation (Fig. 1, clinicians). A total of 75 participants – including 67 clinicians and 8 unit managers

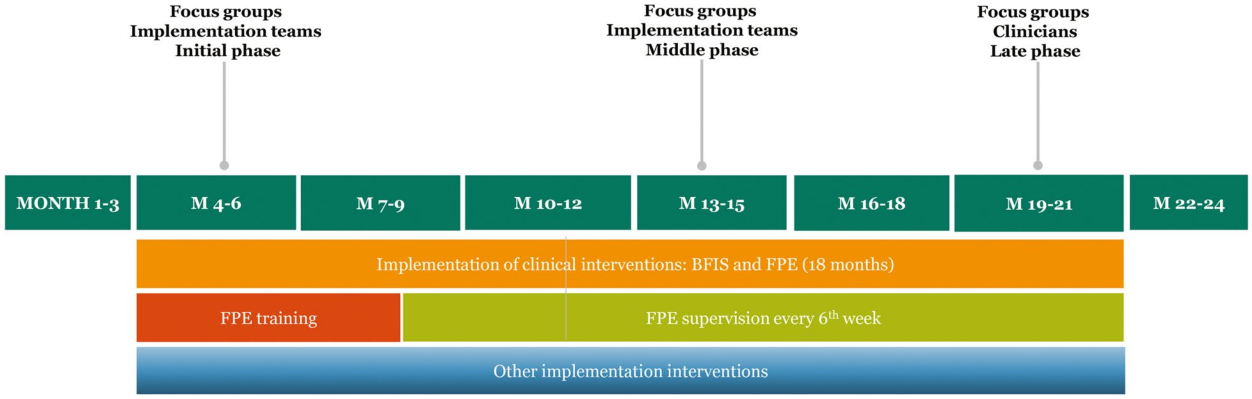


Fig. 1 IFIP timeline

BFIS: Basic family involvement and support FPE: Family psychoeducation

– were included in the study, and 27 implementation team members participated twice (Table 1).

We developed three semi-structured interview guides adapted to the three separate focus group sessions (Additional file 2). Five researchers from the IFIP project group (KMH, MR, RP, LH, and KSH) conducted the data collection at the CMHCs, working in pairs of two interviewers at each focus group. The focus groups lasted for 60–90 minutes and were audio recorded. All participants were informed about the study and gave written consent to participate. To become immersed with the data, and to adjust the interview guides according to new emerging themes, the interviewers wrote a brief report with important highlights immediately after each focus group. Scientific assistants and other project members transcribed the interviews verbatim. All data-material were stored in the University of Oslo's secure database (In Norwegian: "Tjenester for sensitive data"–TSD).

Analysis

The first author (KMH) performed the main analytical work. This sub-study is a follow-up on an overarching barrier-facilitator study [42], thus, the overall analysis of barriers and facilitators was extended by a separate in depth-analysis of ethical challenges, barriers, and possible solutions regarding confidentiality. The manifest content analysis [47] progressed through three main phases: 1) The preparation phase, which involved a thorough reading of the transcripts to become immersed in the data and obtain a sense of the whole, 2) The organising phase that involved the initial coding and categorising of the transcripts, and 3) The reporting phase in which a repeated abstraction process led to the identification of five themes describing ethical challenges and two themes describing measures to handle such challenges, in addition to making defensible links between the data and the results through the presentation of relevant quotes.

Data storage and the analytical work was performed with the NVivo computer software package 12. In the following we present the findings partly as condensed text [48] and partly as illustrative quotes. Our focus was to render the meaning content of the participants' accounts, thus the quotes are condensed.

Credibility and transferability

Various triangulation strategies increased the trustworthiness of the study's findings. To develop a comprehensive understanding of the phenomenon under investigation [49], health professionals with various professional background, experiences and roles in the implementation work were included in the study (data source triangulation). The study design further enabled an exploration of participants' perspectives and experiences with confidentiality issues over time, which provided us with knowledge on important change processes. Further credibility was established by seeking agreement among co-researchers [50] in which KMH, MR, and RP discussed the data labelling and the grouping of themes and subthemes in repeated sessions. Furthermore, members of the research group (KMH, MR, KSH, LH, BW, EL and RP) engaged in discussions about preliminary findings and contributed with drafts revisions during the writing process. Finally, the credibility of the findings is enhanced by presentation of the findings together with

Table 1 Participant characteristics

Study sample	**Implementation teams Months 2–3 of implementation (*N* = 38, 8 focus groups)**		**Implementation teams Months 9–10 of implementation (*N* = 39, 8 focus groups)**		**Clinicians Months 15–16 of implementation (*N* = 25, 5 focus groups)**	
	N	**%**	***N***	**%**	***N***	**%**
Sex						
Male	6	16	5	13	5	20
Female	32	84	34	87	20	80
Age						
20–35	6	16	5	13	7	28
36–50	11	29	16	41	11	44
51–70	21	55	18	46	7	28
Profession/ role						
Section/unit manager	6	16	5	13		
Physician	4	11	3	8	4	16
Psychologist	5	13	5	13	16	64
Psychiatric nurse	14	37	15	38	1	4
Other	9	24	11	28	4	16

rich and representative quotations that show the similarities within and differences between categories [50] and provide details and contextual information.

Results

The results are presented in two parts, Part 1: "Ethical challenges related to the duty of confidentiality" and Part 2: "Measures to facilitate better handling of the duty of confidentiality". Data on facilitating measures derived from participants who had experiences with family involvement as part of the IFIP trial, as well as from participants with extensive experience with family involvement prior to the trial.

Data from the initial phase of implementation (Fig. 1) demonstrate a wide range of understandings, practices, and challenges related to confidentiality. These variations often represented disagreement on how to handle various aspects of the duty of confidentiality. Rather than ethical challenges, some of these may be best described as unreflected attitudes or practices where the duty of confidentiality became an absolute barrier to family involvement. These variations and uncertainties were often due to a lack of knowledge, e.g. about the legal regulations, and lack of knowledge is not an ethical challenge. However, not all types of uncertainties were due to lack of knowledge, and there were disagreements on what to do when facing such uncertainties.

Part 1: Ethical challenges related to the duty of confidentiality

Uncertainty in how to apply the legislation

Fear of breaching the legal duty of confidentiality was described by many professionals as a major barrier to family involvement:

> *The duty of confidentiality is perhaps the greatest problem when working with relatives. It is what hinders us the most (…) People are very afraid of doing anything wrong (FG6).*

Accounts also demonstrated that the duty of confidentiality appeared difficult to understand and to transfer to clinical practice. Some participants interpreted the legislation very strictly, thus refraining from family involvement, while others saw possibilities to make their own clinical judgments:

> *On a national level, I imagine that the law itself can be a bit clearer (…) There are a lot of "gray areas" and a lot of ... yes, uncertainty. If you ask ten different health professionals, you get ten different answers to what is okay to say and what is not right (FG6).*

Some participants also admitted that they had been hiding behind the duty of confidentiality in order to "solve" demanding situations.

Patient autonomy versus a less strict interpretation of the duty of confidentiality

Ethical challenges occurred when participants tried to initiate family involvement but were faced with patients not consenting to involve/disclose information, when patients occasionally gave and withdrew consent, or when they suddenly changed who should be listed as their next of kin. Such situations were experienced as particularly challenging and caused doubt and uncertainty in terms of "What is the right thing to do?" Several were unsure whether and how they could engage and communicate with the relatives if the patient refused any contact, or if consent was not clarified, and they dealt with refusals quite differently:

> *(You) can't just call people, I think, if you haven't received consent (FG7).*

Another clinician chose to oppose the patient and legislation by contacting the relatives despite the refusal:

> *(…) the patient was adamant that the relatives should not be involved. And the relatives were extremely worried. With good reason (…) This is a typical situation, and sometimes we do say "In this case I choose to inform your relatives even if you deny it". But, the threshold is high (FG1).*

Even if the participants recognised the benefits of family involvement for the patients and the relatives, most respected the patient's refusal and decided not to challenge the lack of consent any further. According to some participants this could be due to strong patients' rights regarding confidentiality that they felt had to be fulfilled or fearing negative reactions leading to patient autonomy triumphing over other concerns:

> *When resistance arises, one withdraws very quickly. Avoids it. You somehow do not feel that you have anything to offer. You know, there are many paranoid patients and relatives...(FG6).*

Participants also shared their opinions on why patients refuse, for example, that they rejected family involvement to avoid burdening their family:

> *I am surprised (…) she (the patient) is quite ill, has been ill for many years, and then I suddenly was thinking… did we lose grip of him? I mean... she does have a boyfriend… "Does he know how you feel?" "No, she didn't want to burden him" (FG8).*

Other patients were sceptical and ambivalent to involving their family due to lack of control, and the fear that clinicians would disclose sensitive information:

> *Several patients are very skeptical that I should talk to their relatives because... they have an understanding of, or have thoughts that I'm going to disclose... how much hashish they have smoked (FG6).*

Patient alliance and beneficence versus a strict interpretation of the duty of confidentiality

Some participants noted that they accepted refusals because they worried that contacting the relatives or divulging any kind of information would damage patient trust, thus potentially threatening the therapeutical alliance that they considered crucial to enable appropriate treatment:

> *... I am concerned that the patient will reject home visits (having contact). That the therapeutical alliance can slip if one pushes too hard (FG14).*

Other participants expressed concerns that a disproportionate/excessive emphasis on the patient alliance could lead to professionals losing the alliance with relatives:

> *The first thing the relatives are saying is that they constantly are met by a "wall of confidentiality", thus they receive no information. And this creates a lot of despair, right, a feeling of not being seen. You somehow feel that the duty of confidentiality is just for the professionals so they can avoid doing a job (FG3).*

Some weighed the need to maintain the patient alliance against the possible benefits for patients of involving their family. By accepting the refusal, they were aware that they lost access to a potentially important treatment resource and to improve or sustain the patient's social network.

How to deal with uncertainty regarding what relatives know about the patient's illness

Managing information disclosure was experienced challenging when family involvement and family relations had not yet been discussed and clarified with the patient:

> *It can be a bit difficult sometimes when the relatives are calling; What kind of information have they received earlier? What can we say? I'm not sure whether we always document these phonecalls (FG2).*

Another typical situation where this ethical challenge emerged was when the participants wanted to get in contact with a relative for the first time, for example, to improve the medical investigation:

> *P1: But obviously, if you believe that the relatives know that the patient is here (at the hospital)...?*
>
> *P2: But how can I know if they have not made any contact? (FG7).*

At the initial treatment stage when contact was not yet established between the family and the services, uncertainty as to how one should operationalise the duty of confidentiality and the informed consent disrupted the onset of family involvement.

Relatives' interests versus the duty of confidentiality

Even if patient autonomy mostly triumphed other concerns, participants were repeatedly faced with stakeholders' (seemingly) diverging needs, for example, balancing patients' need for privacy against relatives' interests and their legal right to being informed and involved. Typical challenging situations arose when participants considered it important for relatives to receive support and information about the patient while the patient refused:

> *To receive consent that the relatives can gain some insight is one of the biggest challenges. The patient spends a lot of time "keeping people away" (...) being healthy in the eyes of the relatives. And the relatives are screaming for information (...) Through many years as relatives, there are many who certainly have not received information and who feel quite helpless (FG1).*

Part 2: Measures to facilitate better handling of the duty of confidentiality

Training and practice in family involvement

The most important measure to facilitate better handling of the duty of confidentiality seemed to be training in family involvement followed by practice. The new theoretical and experience-based competence, specific skills, and positive experiences with family involvement made the participants better equipped to deal with the ethical challenges.

Increased understanding of the significance of family involvement The participants stated that with increased competence and experience they became more aware of the significance of family involvement to improve treatment, help patients sustain core relationships, and support their families:

> *When relatives lack information and feel excluded from collaboration, I experience that many are very anxious and in some cases are calling us extensively. But if you take your time and talk and listen to them, and perhaps arrange for a joint conversation with patient and relatives, things calm down for them. And of course for the patient (FG16).*

Increased understanding of the significance, consequences, and alternative solutions further led to a change in how participants managed the engagement phase.

Improved strategies for approaching and informing the patients Learning how to exercise the duty of confidentiality and fulfil relatives' legal rights, while also feeling confident that their efforts to integrate family members in the treatment most likely would benefit the patient, made participants more self-confident when asking patients for permission to contact or disclose information to their relatives. Several participants informed their patients about their relatives' rights to information and support, and asked questions like: "How can we best tailor family involvement to your needs and concerns?" When participants approached the patients with thorough, attentive conversations about family involvement, trust and understanding increased among patients that openness towards their family could be helpful to all parties. Participants' accounts demonstrate how they successfully obtained consent by informing, assuring, and motivating the patient:

> *Many patients experience pressure from their relatives, a lot of expectations, demands and criticism. However, providing relatives with thorough information can actually alleviate that pressure. It is very important to take this approach because it can solve a number of such situations where the patient does not want (family involvement). Further I believe that for some of our patients it is important that they know that their relatives can talk to us and get some relief. It helps them, and in the end it helps the patient (FG11).*

To overcome distrust and scepticism, participants assured the patient that no sensitive information would be disclosed without their consent:

> *P1: Often it is useful to make an agreement with the patient about what information will be disclosed so that the patient knows – and has accepted – what is being said to the relatives.*
>
> *P2: We make clear that "We do not inform relatives about this and that, and they rarely want to know this and that" - it's more like "What will happen in the future, what kind of treatment the patient receives, what is the prognosis?" (FG4).*

When consent and mutual agreements were obtained, participants could provide the relatives with information about the state and treatment of their loved one. Several participants provided general information about the diagnosis, if known to the relatives, and they asked about what relatives already knew and thematised this further. Providing support and guidance to improve relatives' coping with their own situation and to optimise patient support was not only emphasised as crucial to the relatives, but also constituted meaningful clinical encounters for the participants. Their motivation to continue their efforts to balance the duty of confidentiality against other concerns increased when experiencing the significance of providing even limited information to the relatives.

Improved strategies for dealing with patient refusal Several participants experienced situations where patients refused to share information despite initiatives to increase trust. Those who knew how to differentiate the various types of information managed to meet the relatives' needs without breaching confidentiality:

> *It is important that both relatives and the patient are aware of this, that even if the patients don't want us to talk to the relatives, they actually have a right to receive information both about the treatment and psychosis in general. Understanding this was very "clarifying" to me, because this is what we have been struggling with all these years, and this has made us refrain from talking to relatives... (FG10).*

Suddenly, when encountering the relatives, the focus shifted from disclosing patient information to active listening and providing less sensitive, but at the same time tailored information:

> *... But in fact we should turn it around; we should "hear them out", we should investigate and the things they share, we can say something about this on a general basis (FG6).*

Some started to consider obtaining consent to be a stepwise process, which required patience, sincere recognition of patients' concerns, and explorations of possible reasons underlying the refusals:

> *I can ask the patient: "Why don't you want to talk about it?" (...) Is it shame, are they afraid that the parents will be worried, upset, (that they) will inflict on them something unpleasant - are there such thoughts? (FG12).*

An interesting finding was how some participants met the patients with completely different determination and stamina when suggesting family involvement than they had before the implementation:

> *Now, when the patient refuses family involvement, I have been even tougher to listen to relatives about known knowledge. And talk to them (FG5).*

Facilitating semi-open triadic dialogues When one managed to arrange conversations with the patient, relatives, and the therapist together, dealing with confidentiality was experienced as less challenging. The need for keeping things confidential decreased as a result of trust, openness, and shared understanding between stakeholders:

> *Confidentiality is generally a challenging topic (…), but when it comes to relatives and patients agreeing on a (family psychoeducation) group (…) there is usually no big problem with confidentiality because then they have received good information, then we have built up an alliance… and they have received knowledge. There is agreement on cooperation, but that does not mean that we can just pour out… everything somehow. The patient must always feel confident that their interests are the number one priority (FG19).*

Standardisation of family involvement practices

The focus group interviews demonstrated an explicit need for standardisation. In particular, the initial engagement phase seemed to constitute a recurring weakness in the units' family involvement practices. Procedures that support professionals in navigating confidentiality during this initial phase were welcomed by participants:

> *We have such a reception note that everyone must make at the first call / reception. The relatives are a separate point, same as for suicide risk, right (…) there you get something like "Who is your closest relative?", but in extension of that - how to talk about that collaboration? (FG7).*

Others considered standardisation to be a means to increase the legitimacy of family involvement:

> *It is easier for the patient to say yes to something that is known to be part of the standard package here (FG14).*

Furthermore, participants voiced a need for systematic training of professionals:

> *We simply need a lot of professional development in how to work with patients to motivate them to give consent (FG3).*

A key IFIP intervention measure was to offer early and standardised conversations about family involvement to all patients and relatives as a default approach [40]. The significance of such routines was appreciated by several participants:

> *(…) if one succeeds, then things are "put down" quite early (…) If you can get it done relatively early, then things can be shared, you can talk to each other without anything building up (FG5).*

Discussion

Within the frames of an implementation study, we explored what ethical challenges and facilitating measures mental health professionals in CMHCs experienced related to the duty of confidentiality regarding family involvement for persons with severe mental illness. Key ethical challenges identified were how to balance patient autonomy versus a less strict interpretation of the duty of confidentiality, how to balance patient alliance and beneficence versus a less strict interpretation of the duty of confidentiality, dealing with uncertainty when one does not know what the relatives know about the patient's illness, and how to balance the best interest of the relatives versus keeping patient information confidential. In addition, we found that participants' lack of knowledge on how to apply the legislation constituted an absolute barrier to family involvement in some cases. How participants dealt with a lack of consent or explicit patient refusals in the initial phase of family involvement appeared critical to the integration of the family in treatment and care.

Nevertheless, our findings clearly showed that there are ways to improve the handling of these ethical challenges. The key measures were training in family involvement followed by practice and standardisation. When participants gained competence in confidentiality statutes, in how to thematise confidentiality with patients and relatives, and how to perform recommended family involvement, most challenges were experienced as solvable.

Dealing better with ethical challenges by reframing the duty of confidentiality

We hypothesise that the improvements that took place in this study occurred through a reframing of the duty of confidentiality. This reframing can be understood as a change in interpretation and practice with regard to the legislation, a change in ethical reasoning, and a change in clinical practice.

A change in interpretation and practice with regard to the legislation

First, reframing the duty of confidentiality represents a "move away from simplistic rules about confidentiality" [29] towards practicing the legislation more flexibly (and legally correctly). In line with previous research [22], we found that confidentiality issues raised from a strong focus on and incorrect interpretation of legal matters. The overarching question of family involvement was often erroneously and too closely linked to the distinct question of disclosing information. Challenges arose because the professionals lacked the necessary understanding of a) how to differentiate between general information, which can be shared without consent, and personal information requiring consent because it involves new and specific information about the patient [15, 51], and b) how disclosing personal information about patients to third parties is seldom necessary to perform the recommended family involvement, nor is this what the relatives commonly demand [51]. While implementation progressed, participants increasingly managed to take various considerations and needs into account. Furthermore, information disclosure was to a greater extent experienced as a means to establish contact with family and to enable good treatment, rather than being a troublesome "obstacle".

A change in ethical reasoning

Second, reframing the duty of confidentiality denotes a changed weighting of autonomy against the other three basic ethical principles of beneficence (what would be beneficial to the patient (and/or their relatives?), nonmaleficence (does accepting the refusal outweigh the potential harm to the patient and/or their relatives?), and justice (can accepting this refusal be justified with regard to the relatives?). Before the implementation, the participants tended to accept patient refusals and prioritised patient interests/autonomy and the therapeutic alliance [18, 52]. During implementation, however, participants experienced that most of the diverging needs appeared reconcilable or that other concerns appeared to be equally important. With that, changed their ethical reasoning.

An interesting finding from this study is how some participants in their quest to protect patient autonomy unintentionally – and paradoxically – undermined autonomy by not providing a real basis for decision-making. When professionals do not ensure that refusal to involve the family is given on an informed basis, this may be described as "the duty of confidentiality paradox". To understand what the consent entails, patients are dependent on professionals to provide sufficient and tailored information about how the family can contribute to treatment and receive support, why this is important, possible side-effects and how to deal with them, that the information that needs to be shared is by and large general and not sensitive, and that collaboration and information disclosure can be tailored to both the patients' preferences and the relatives' needs. Only then patients are able to make an autonomous choice whether and how they want to involve their family.

Prior to implementation, several participants accepted refusals without having the necessary competence to a) provide the above-mentioned information, b) explore what the refusal entailed specifically and whether the patient was aware of its consequences, c) assess the advantages and disadvantages of involvement, and d) identify alternative solutions (e.g. to further thematise family involvement when the disease state is improving). Issues arose because the patients lacked the necessary understanding, which is required for autonomous actions [36]. Therefore, professionals should not accept a refusal too quickly because they need to understand the worries and values that underlie this refusal. During the IFIP trial, several participants shared experiences where patients refused involvement in order to spare their parents from burdens and worries, while the parents suffered greatly from being excluded from crucial life events of their child battling severe mental illness.

The "inflation" of the duty of confidentiality and "the duty of confidentiality paradox" constitute severe errors with severe consequences. Our data contain repeated descriptions of patient refusals leading to poor, interrupted, or absent family involvement and support. First, this leads to patients with varyingly impaired capacity being left alone and unenlightened when making critical decisions regarding treatment methods and support. Thus, the issue of (ambivalent and unsure) patients refusing to involve their closest relations is sustained. Second, a one-sided focus on patient alliance and autonomy comes at the expense of professionals losing the alliance with the relatives [15], which might further negatively impact the patient-relative alliance. Yet another problem is that patient refusals hinder family involvement before one has had the chance to experience the benefits of such collaborations. Several participants shared positive experiences from engaging with the families, for instance that they gained useful collateral information about the patient or realised how the family dynamics improved.

A change in clinical practice

Finally, reframing the duty of confidentiality requires new and more appropriate clinical practices, such as routinely initiating dialogues with patients at an early stage, tailoring disclosure to the individual's family [32, 33], asking patients how they want family members to be involved

[53], and implementing the use of "disclosure to consent" forms [16]. Further measures were to handle refusals more appropriately, for example, by further investigating the reasons for refusing, considering consent to be a stepwise process [27], and distinguishing between general and specific information [51]. Finally, consciousness was raised on relatives' own issues and on what one can offer the relatives when patients refuse [18]. Figure 2 summarises the changes that occurred during the IFIP implementation.

In line with previous studies, we found that the implementation of sound confidentiality practices presupposes the implementation of clear procedures for obtaining consent and for releasing information to families [29], in addition to familiarising clinical staff with family interventions, relevant legislation and mental health policies [15, 18, 20, 26]. A more overarching cultural shift in mental health care, including a change in attitudes towards working with families [15, 20, 32], is needed to facilitate the above-mentioned measures.

Unresolved legislative barrier

Although most ethical challenges can be diminished through competence measures, a residual legislative problem remains. As in many other countries, including England and Netherlands, Norwegian health legislation does not allow disclosure of even a minimum of information without consent (with a few exceptions) to relatives of competent adult patients. It is not an exception that the relative as "significant others" engage in a close relationship with the patient and provide essential daily care. One example of unlawful disclosure of minimum information is when a worried mother approaches the services inquiring about her sons' condition and receives a confirmation that he is ok and currently taken care of. The issue arises because the health legislation does not differentiate the degree of sensitivity of health information as long as it is can be linked to the patient. Thus, there is little room for discretion or for considerations of proportionality. This is contrary to, for example, the General Data Protection Regulation (GDPR) [54], where proportionality between privacy concerns and other interests, such as patient safety and the relatives' interests, is encouraged. Even if the information disclosed in the above-mentioned situations can be considered the least sensitive, the law applies the same as if the nurse were to share with the mother the entire patient record. This legislation with regard to relatives appears inappropriately limiting. We encourage minor legal changes to be made in order to allow mental health professionals, in certain situations

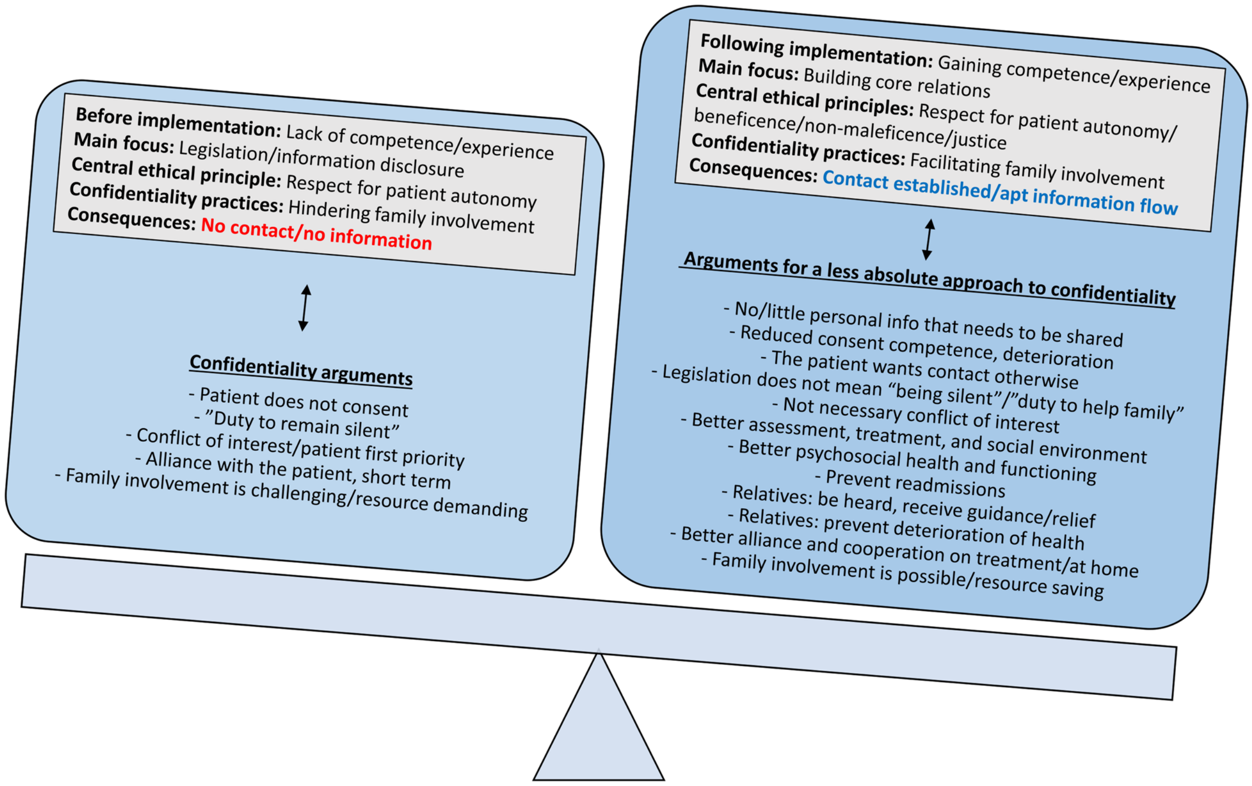


Fig. 2 Changes that improved the handling of the duty of confidentiality

where competent patients do not consent, to share a minimum of patient information with the relatives. The benefits of meeting the mothers' request, might be argued to outweigh the minimal damage inflicted on the patient.

Strengths and limitations

The main strengths of this study are the study design and the ongoing evaluation that enabled rich data on professionals' experiences with confidentiality issues over time. Most of the authors of this paper have been deeply involved in all aspects of the IFIP implementation/research from which this article emanates and possess a broad expertise relevant to probing into the complexity of confidentiality. This further strengthens the credibility of the findings. Limitations include the lack of patients and relatives' perspectives, thus it has not been possible to compare perspectives and experiences. Furthermore, this study was conducted within the frames of a distinct implementation effort, thus the training and implementation support provided may have influenced the results presented in this paper. In terms of generalisability, the scope of this study is limited to competent patients who suffer from psychotic disorders and who receive treatment in Norwegian CMHCs. Nevertheless, we might assume that the ethical challenges and facilitating measures identified in this study are relevant to other clinical settings.

Conclusions

Confidentiality issues are among the most prominent barriers to family involvement during severe mental illness, with mental health professionals facing complex ethical, legal, and practical challenges. Within the current implementation study, clinicians struggled with how to apply the legislation, how to balance patient autonomy, alliance, and beneficence with a less strict interpretation of the duty of confidentiality, and how to balance the best interest of the relatives with keeping patient information confidential. Training in family involvement, followed by practice, led to a vital change in how clinicians approached the patients when initiating family involvement, how they dealt with patient refusals, and how they valued and interacted with the families. To achieve such improved confidentiality practices standardisation of family involvement, implementation of confidentiality guidelines, and incorporating basic training in family involvement in the health educational institutions/services is required. An attitudinal, organisational, educational, and legal shift in terms of how clinicians relate to confidentiality and how they value informal care is essential to facilitate the integration of families as both collaborative partners and carers with their own sufferings and needs.

Highlights for clinical practice

- The duty of confidentiality is challenging and complex in family involvement for persons with severe mental illness, and is often interpreted too strictly as requiring "total silence".
- Relatives have the right to general, as well as known information, training, and support, even without the patient's consent.
- One can listen to and provide support to relatives without the patient's consent.
- Family involvement should be discussed with all patients as a default approach.
- Training and guidance in family involvement for professionals, followed by practice, improves confidentiality practices within mental health care.

Abbreviations

IFIP: Implementation of guidelines on Family Involvement for persons with Psychotic disorders in community mental health centre; CMHC: Community Mental Health Centre; FPE: Family Psychoeducation; TSD: Tjenester for Sensitive Data; GDPR: General Data Protection Regulation.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12888-022-04461-6.

Additional file 1. Standards for Reporting Qualitative Research (SRQR)*.

Additional file 2. Interview guides.

Acknowledgements

The authors would like to thank The Early Intervention in Psychosis Advisory Unit for South East Norway (TIPS Sør-Øst) at Oslo University Hospital Trust and Østfold Hospital Trust, for providing teaching and guidance in family psychoeducation to the participating units and valuable input to the project in general. We would also like to thank Irene Norheim and her colleagues in the R&D unit of the Division of Mental Health and Addiction at Vestre Viken Hospital Trust, for valuable input and assistance. Furthermore, we would like to thank Kristin Weaver, Anders Tvedt and Lana Shukur for transcription support, and Albert Christiaan Molewijk, Morten Magelssen, Carl Tollef Solberg and Trygve Johannes Lereim Sævareid at Centre for Medical Ethics, UiO, for their valuable feedback on this paper. Finally, we wish to express our gratitude to all the participating units, collaboration partners, stakeholder groups and advisory board of the IFIP trial for their valuable input.

Authors' contributions

RP, KSH, and BW drafted the original research protocol, which this article is based on, and thus made significant contributions to the conception and design of the study. KMH, MR, LH, RP, and KSH provided the implementation support and performed the data collection. KMH analysed and interpreted the data with contributions from MR and RP. KMH wrote the first draft of this article, with major contributions from RP, MR and LH, and further received substantial contributions from BW, KSH and EL. All the authors critically revised the article, gave their final approval before submission, and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Funding

The study is funded by The Research Council of Norway. This funding source had no role in the design of this study or during its execution, analyses, interpretation of the data, or decision to submit results.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The study has been approved by the Norwegian regional committee for medical and health research ethics (REC) South East with registration number 2018/128. REC provides a general ethical approval to conduct the study as described in recruited clinical units. On the advice of local data protection officers at the trial sites, the PI on behalf of the University of Oslo has signed contracts on shared responsibility for data processing with each participating health care trust, allowing us to carry out the study at each trial site in accordance with the General Data Protection Regulation. We confirm that all methods were performed in accordance with the relevant guidelines and regulations. Verbal and written informed consent to participate in the study has been obtained from all participants.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]Centre for Medical Ethics, University of Oslo, Postboks 1130 Blindern, 0318 Oslo, Norway. [2]Center for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway, Drammen, Norway. [3]Division of Mental Health Services, Akershus University Hospital, Sykehusveien 25, 1474 Nordbyhagen, Norway. [4]University Center of Medical Sciences, University of Groningen, Antonius Deusinglaan 1, 9713, AV, Groningen, The Netherlands.

Received: 16 July 2022 Accepted: 9 December 2022

References

1. Eassom E, Giacco D, Dirik A, Priebe S. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. BMJ Open. 2014;4(10):e006108. https://doi.org/10.1136/bmjopen-2014-006108.
2. Hsiao CY, Lu HL, Tsai Y. Factors associated with primary family caregivers' perceptions on quality of family centered care in mental health practice. J Nurs Scholarsh. 2019;51(6):660–88. https://doi.org/10.1111/jnu.12526.
3. Pharoah F, Mari J, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database Syst Rev. 2010;(12):CD000088. https://doi.org/10.1002/14651858.CD000088.pub3.
4. Bighelli I, Rodolico A, García-Mieres H, Pitschel-Walz G, Hansen WP, Schneider-Thoma J, et al. Psychosocial and psychological interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. Lancet Psychiatry. 2021;8(11):969–80. https://doi.org/10.1016/S2215-0366(21)00243-1.
5. Rodolico A, Bighelli I, Avanzato C, Concerto C, Cutrufelli P, Mineo L, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. Lancet Psychiatry. 2022;9(3):211–21. https://doi.org/10.1016/S2215-0366(21)00437-5.
6. Lobban F, Postlethwaite A, Glentworth D, Pinfold V, Wainwright L, Dunn G, et al. A systematic review of randomised controlled trials of interventions reporting outcomes for relatives of people with psychosis. Clin Psychol Rev. 2013;33(3):372–82. https://doi.org/10.1016/j.cpr.2012.12.004.
7. Wallcraft J, Amering M, Freidin J, Davar B, Froggatt D, Jafri H, et al. Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. World Psychiatry. 2011;10(3):229–36. https://doi.org/10.1002/j.2051-5545.2011.tb00062.x.
8. National Collaborating Centre for Mental Health. Psychosis and schizophrenia in adults: treatment and management. NICE clinical guideline 178: NICE; 2014. Accessed Sept 2021, Available from: http://www.nice.org.uk/guidance/cg178/.
9. Galletly C, Castle D, Dark F, Humberstone V, Jablensky A, Killackey E, et al. Royal Australian and new Zealand College of Psychiatrists clinical practice guidelines for the management of schizophrenia and related disorders. Aust N Z J Psychiatry. 2016;50(5):410–72. https://doi.org/10.1177/0004867416641195.
10. Helsedirektoratet. Veileder om pårørende i helse- og omsorgstjenesten. Oslo: Helsedirektoratet; 2017. Accessed Aug 2021, Available from: https://www.helsedirektoratet.no/veiledere/parorendeveileder
11. McFarlane WR. Family interventions for schizophrenia and the psychoses: a review. Fam Process. 2016;55(3):460–82. https://doi.org/10.1111/famp.12235.
12. Bucci S, Berry K, Barrowclough C, Haddock G. Family interventions in psychosis: a review of the evidence and barriers to implementation. Aust Psychol. 2016;51(1):62–8. https://doi.org/10.1111/ap.12172.
13. Szmukler G, Bloch S. Family involvement in the care of people with psychoses: an ethical argument. Br J Psychiatry. 1997;171(5):401–5. https://doi.org/10.1192/bjp.171.5.401.
14. Landeweer E, Molewijk B, Hem MH, Pedersen R. Worlds apart? A scoping review addressing different stakeholder perspectives on barriers to family involvement in the care for persons with severe mental illness. BMC Health Serv Res. 2017;17(1):349. https://doi.org/10.1186/s12913-017-2213-4.
15. Cree L, Brooks HL, Berzins K, Fraser C, Lovell K, Bee P. Carers' experiences of involvement in care planning: a qualitative exploration of the facilitators and barriers to engagement with mental health services. BMC Psychiatry. 2015;15(1):208. https://doi.org/10.1186/s12888-015-0590-y.
16. Wilson LS, Pillay D, Kelly BD, Casey P. Mental health professionals and information sharing: carer perspectives. Ir J Med Sci. 2015;184(4):781–90. https://doi.org/10.1007/s11845-014-1172-6.
17. Chen F. A fine line to walk: case managers' perspectives on sharing information with families. Qual Health Res. 2008;18(11):1556–65. https://doi.org/10.1177/1049732308325539.
18. Gray B, Robinson C, Seddon D, Roberts A. 'Confidentiality smokescreens' and carers for people with mental health problems: the perspectives of professionals. Health Soc Care Community. 2008;16(4):378–87. https://doi.org/10.1111/j.1365-2524.2007.00748.x.
19. Gold M, Philip J, McIver S, Komesaroff PA. Between a rock and a hard place: exploring the conflict between respecting the privacy of patients and informing their carers. Intern Med J. 2009;39(9):582–7. https://doi.org/10.1111/j.1445-5994.2009.02020.x.
20. Pinfold V, Farmer P, Rapaport J, Bellringer S, Huxley P, Murray J, et al. Positive and inclusive. Effective ways for professionals to involve carers in information sharing. Rethink severe mental illness: Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO); 2004.
21. Murray-Swank A, Glynn S, Cohen AN, Sherman M, Medoff DP, Fang LJ, et al. Family contact, experience of family relationships, and views about family involvement in treatment among VA consumers with serious mental illness. J Rehabil Res Dev. 2007;44(6):801–11. https://doi.org/10.1682/jrrd.2006.08.0092.
22. Førde R, Norvoll R, Hem MH, Pedersen R. Next of kin's experiences of involvement during involuntary hospitalisation and coercion. BMC Med Ethics. 2016;17(1):76. https://doi.org/10.1186/s12910-016-0159-4.
23. Giacco D, Dirik A, Kaselionyte J, Priebe S. How to make carer involvement in mental health inpatient units happen: a focus group study with patients, carers and clinicians. BMC Psychiatry. 2017;17(1):101. https://doi.org/10.1186/s12888-017-1259-5.
24. Weimand BM. Experiences and nursing support of relatives of persons with severe mental illness. Karlstad: Karlstad University; 2012. [PhD dissertation], Accessed Oct 2021, Available from: http://urn.kb.se/resolve?urn=urn%3Anbn%3Ase%3Akau%3Adiva-12821.
25. Skundberg Kletthagen H. Everyday life of relatives of persons suffering from severe depression: Experiences of health, burden, sense of coherence and encounters with psychiatric specialist health services. Karlstad: Karlstad University; 2015. [PhD dissertation], Accessed Oct 2021, Available from: http://urn.kb.se/resolve?urn=urn:nbn:se:kau:diva-35936.
26. McCann TV, Lubman DI, Clark E. Primary caregivers' satisfaction with clinicians' response to them as informal carers of young people with first-episode psychosis: a qualitative study. J Clin Nurse. 2012;21(1–2):224–31. https://doi.org/10.1111/j.1365-2702.2011.03836.x.
27. Marshall TB, Solomon P. Releasing information to families of persons with severe mental illness: a survey of NAMI members. Psychiatr Serv. 2000;51(8):1006–11. https://doi.org/10.1176/appi.ps.51.8.1006.

28. Care Quality Commission. 2015. Right here, right now: mental health crisis care review. People's experiences of help, care and support during a mental health crisis [Accessed Aug 2022, Available from: 20150630_righthere_mhcrisiscare_full.pdf (cqc.org.uk)].
29. Wainwright LD, Glentworth D, Haddock G, Bentley R, Lobban F. What do relatives experience when supporting someone in early psychosis? Psychol Psychother. 2015;88(1):105–19. https://doi.org/10.1111/papt.12024.
30. Outram S, Harris G, Kelly B, Bylund CL, Cohen M, Landa Y, et al. 'We didn't have a clue': family caregivers' experiences of the communication of a diagnosis of schizophrenia. Int J Soc Psychiatry. 2015;61(1):10–6. https://doi.org/10.1177/0020764014535751.
31. Brand U. European perspectives: a carer's view. Acta Psychiatr Scand. 2001;104(s410):96–101. https://doi.org/10.1034/j.1600-0447.2001.1040s2096.x.
32. Carers' subgroup of REFOCUS CPsychI. Who cares? Listening to the needs and experiences of carers of people with mental illness. 2013. [Accessed Sept 2021, Available from: https://www.irishpsychiatry.ie/wp-content/uploads/2019/10/REFOCUS201301.pdf].
33. Marshall T, Solomon P. Professionals' responsibilities in releasing information to families of adults with mental illness. Psychiatr Serv. 2003;54(12):1622–8. https://doi.org/10.1176/appi.ps.54.12.1622.
34. Marshall T, Solomon P. Confidentiality intervention: effects on provider-consumer-family collaboration. Res Soc Work Pract. 2004;14(1):3–13. https://doi.org/10.1177/1049731503257865.
35. Lillemoen L, Pedersen R. Ethical challenges and how to develop ethics support in primary health care. Nurs Ethics. 2013;20(1):96–108. https://doi.org/10.1177/0969733012452687.
36. Beauchamp TL, Childress JF. Principles of biomedical ethics. 8th ed. New York: Oxford University Press; 2019. (1st ed. 1979).
37. Gómez-Vírseda C, de Maeseneer Y, Gastmans C. Relational autonomy in end-of-life care ethics: a contextualized approach to real-life complexities. BMC Med Ethics. 2020;21(1):50. https://doi.org/10.1186/s12910-020-00495-1.
38. Health Personnel Act. 1999. Lov om helsepersonell av 1999-07-02-64. [Accessed June 2022, Available from: https://lovdata.no/dokument/NL/lov/1999-07-02-64?q=lov%20om%20helsepersonell].
39. Spesialisthelsetjenesteloven. 1999. Lov om spesialisthelsetjenesten av 1999-07-02-61. [Accessed June 2022, Available from: https://lovdata.no/dokument/NL/lov/1999-07-02-61].
40. Hestmark L, Romoren M, Heiervang KS, Weimand B, Ruud T, Norvoll R, et al. Implementation of guidelines on family involvement for persons with psychotic disorders in community mental health centres (IFIP): protocol for a cluster randomised controlled trial. BMC Health Serv Res. 2020;20(1):934. https://doi.org/10.1186/s12913-020-05792-4.
41. Hestmark L, Heiervang KS, Pedersen R, Hansson KM, Ruud T, Romøren M. Family involvement practices for persons with psychotic disorders in community mental health centres - a cross-sectional fidelity-based study. BMC Psychiatry. 2021;21(1):285. https://doi.org/10.1186/s12888-021-03300-4.
42. Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, et al. Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres – a nested qualitative study. BMC Health Serv Res. 2022;22:1153. https://doi.org/10.1186/s12913-022-08489-y.
43. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245–51. https://doi.org/10.1097/acm.0000000000000388.
44. Abma TA. The practice and politics of responsive evaluation. Abma TA. The practice and politics of responsive evaluation. Am J Eval. 2006;27(1):31–43.
45. Stetler CB, Legro MW, Wallace CM, Bowman C, Guihan M, Hagedorn H, et al. The role of formative evaluation in implementation research and the QUERI experience. J Gen Intern Med. 2006;21(2):S1. https://doi.org/10.1007/s11606-006-0267-9.
46. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. Admin Pol Ment Health. 2015;42(5):533–44. https://doi.org/10.1007/s10488-013-0528-y.
47. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurse. 2008;62(1):107–15. https://doi.org/10.1111/j.1365-2648.2007.04569.x.
48. Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. AfJEM. 2017;7(3):93–9. https://doi.org/10.1016/j.afjem.2017.08.001.
49. Patton MQ. Enhancing the quality and credibility of qualitative analysis. Health Serv Res. 1999;34(5 Pt 2):1189–208.
50. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today. 2004;24(2):105–12. https://doi.org/10.1016/j.nedt.2003.10.001.
51. Slade M, Pinfold V, Rapaport J, Bellringer S, Banerjee S, Kuipers E, et al. Best practice when service users do not consent to sharing information with carers: national multimethod study. Br J Psychiatry. 2007;190:148–55. https://doi.org/10.1192/bjp.bp.106.024935.
52. Moran GS, Oz G, Karnieli-Miller O. Psychiatrists' challenges in considering disclosure of schizophrenia diagnosis in Israel. Qual Health Res. 2014;24(10):1368–80. https://doi.org/10.1177/1049732314547085.
53. Maybery D, Jaffe IC, Cuff R, Duncan Z, Grant A, Kennelly M, et al. Mental health service engagement with family and carers: what practices are fundamental? BMC Health Serv Res. 2021;21(1):1073. https://doi.org/10.1186/s12913-021-07104-w.
54. European Union (EU). General data protection regulation (GDPR). 2018: [Accessed June 2022, Available from: https://ec.europa.eu/info/law/law-topic/data-protection/data-protection-eu_en].

Publisher's Note

“The most important thing is that those closest to you, understand you.” A nested qualitative study of persons with psychotic disorders` experiences with family involvement

Authors

Kristiane M. Hansson (corresponding author). Centre for Medical Ethics, University of Oslo, Postboks 1130 Blindern, 0318 Oslo, Norway. E-mail: k.m.hansson@medisin.uio.no.

Maria Romøren. Centre for Medical Ethics, University of Oslo, Postboks 1130 Blindern, 0318 Oslo, Norway. E-mail: Maria.Romoren@medisin.uio.no.

Lars Hestmark. Centre for Medical Ethics, University of Oslo, Postboks 1130 Blindern, 0318 Oslo, Norway. E-mail: Lars.Hestmark@medisin.uio.no.

Kristin Sverdvik Heiervang. Division of Mental Health Services, Akershus University Hospital. Sykehusveien 25, 1474 Nordbyhagen, Norway; Centre for Medical Ethics, University of Oslo, Postboks 1130 Blindern, 0318 Oslo, Norway; Center for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway, Drammen, Norway.
E-mail: Kristin.Sverdvik.Heiervang@ahus.no.

Bente Weimand. Center for Mental Health and Substance Abuse, Faculty of Health and Social Sciences, University of South-Eastern Norway, Drammen, Norway; Division of Mental Health Services, Akershus University Hospital. Sykehusveien 25, 1474 Nordbyhagen, Norway.
E-mail: Bente.Weimand@usn.no.

Irene Norheim. Division of Mental Health and Addiction, Vestre Viken Hospital Trust, Drammen, Norway. E-mail: Irene.Norheim@vestreviken.no.

Reidar Pedersen. Centre for Medical Ethics, University of Oslo, Postboks 1130 Blindern, 0318 Oslo, Norway. E-mail: Reidar.Pedersen@medisin.uio.no.

“The most important thing is that those closest to you, understand you” A nested qualitative study of persons with psychotic disorders` experiences with family involvement

Abstract

Background: Family interventions constitute effective treatment for persons with psychotic disorders. However, the active ingredients and beneficial processes of these interventions are insufficiently examined, and qualitative explorations of patients` experiences are lacking. This study was nested in a cluster randomised trial that implemented national guidelines on family involvement in Norwegian community mental health centres, including family psychoeducation and basic family involvement and support. The aim of this sub-study was to explore how patients with psychotic disorders experience systematic family involvement, and its significance.

Methods: We conducted semi-structured, individual interviews with thirteen persons with a psychotic disorder after systematic family involvement. The participants were recruited through purposive sampling. Qualitative content analysis guided the analysis.

Results: Participants reported overall positive experiences with systematic family involvement. It was significant that the relatives increasingly understood more about psychosis and their situation, while they themselves also gained more insight into the relatives` situation. The participants emphasised the need to enable both patients and relatives to safely share experiences in a containing space, led by professionals. Shared understanding and awareness of each other’s situation further improved communication, coping with the illness, reduced stress, and stimulated a more caring family environment. The therapist seemed crucial to facilitate these beneficial communication processes, and also to provide continuous support to the relatives. Reported challenges included that the participants felt vulnerable in the initial phase, a need for tailored approaches, and too late start-up.

Conclusion: Findings from this study suggest that persons with psychotic disorders may benefit greatly from participating in systematic family involvement. This study also gives new insight into possible mediators of positive outcomes both for the patients and the relatives. Systematic *family involvement* should probably be implemented a standard approach in the early phase of the disease, using a step-wise and tailored process.

Keywords: family interventions, family psychoeducation, schizophrenia, severe mental illness, patient experiences, qualitative research, implementation, process evaluation

Background

Family involvement interventions, together with pharmacological treatment and individual therapy are the key treatments recommended in clinical guidelines for the assessment, treatment, and follow-up of persons with psychotic disorders (1). Psychotic disorders (2) are severe mental disorders that may highly impact the life development of the affected individuals and their families (3). To experience psychosis has been described as “a state of confusion, where mental and emotional chaos has arisen, and where the most important characteristic is a reduced ability or inability to distinguish between oneself and the reality around oneself” (4). Although the symptoms, experiences, and severity of psychosis vary greatly among individuals (5), many patients may experience severe, enduring symptoms, debilitated psychosocial functioning, and reduced quality of life (6). Moreover, increased care burden for the relatives of individuals with psychotic disorders is reported frequently, such as relatives facing significant stressors, including not receiving timely information and support when it is needed (7-10). Furthermore, the psychotic disorders’ impact on the family dynamics is widely recognised in terms of dysfunctional communication patterns, high levels of expressed emotion (EE), and family disruptions (6, 7, 11). Psychotic disorders also have a vast socio-economic impact (4), imposing large costs on the health and welfare systems (12).

Family involvement interventions, such as family psychoeducation (FPE) (6) which is further described below, are effective and highly recommended types of treatment (1, 13-15). Research on such interventions has persistently demonstrated significant and robust outcomes for patients and relatives (6, 16-20), and the efficacy of family interventions in reducing relapse rates is particularly well documented (16, 19, 21, 22). A core function of FPE, and other similar interventions, is to alleviate the devastating processes that may arise within the family environment, due to psychosis. These processes are well described in the model of reciprocal causation (6), which has increasingly recognised the impact of stressors as mediating factors of exacerbations. In the context of psychosis, reducing patient and relative stressors is therefore of great importance.

However, there are severe obstacles and knowledge gaps hindering the use of systematic family involvement in mental health care (23, 24). As such, interventions can be considered complex interventions (25), and implementation is by nature associated with multilevel barriers (23, 26, 27). Furthermore, the mechanisms by which family interventions can stimulate positive outcomes are far from sufficiently investigated and understood (17, 19, 28, 29). When evaluating complex healthcare interventions, the Medical Research Council’s guidance (30) recommends that outcome evaluation should be complemented by process evaluation, for example to evaluate the quality and acceptability of implementation, and to explore possible causal mechanisms (31). Furthermore, attempts to scale up and optimise family involvement practices should be based on appropriate evidence. This includes knowledge that is informed by all stakeholders (28), as insights into first-hand experiences with systematic family involvement are crucial to deliver high quality family interventions in real-world clinical settings, and to get more knowledge about possible factors that may contribute to positive and negative outcomes. Thus, to evaluate complex interventions - like systematic family involvement - we need both qualitative and quantitative research (30).

However, only a few qualitative studies have explored FPE and similar interventions in depth from the perspective of patients with psychotic disorders (32-36). To learn more about the patients’ experiences with both basic family involvement (BFIS, further described below) and FPE, and to explore possible dynamics and mediating factors, we performed a qualitative study as part of a comprehensive evaluation of a randomised trial. To our knowledge, this is the first study based on interviews with this patient group about their experiences of receiving a combination of single-family FPE groups and BFIS. The study was guided by the following research question: How do patients with psychotic disorders experience systematic family involvement, and what significance does this family involvement have?

Methods

This article complies with the “Standards for Reporting Qualitative Research (SRQR) checklist” (37) (Additional file 1).

Setting, design and intervention

This article is based on a sub-study of the IFIP-study (24, 38), a large cluster randomised study on implementation of the Norwegian national guidelines on family involvement for persons with psychotic disorders that was conducted in Norwegian community mental health centres (CMHCs) from 2017-2022. Fifteen clinical units from twelve CMHCs in South-Eastern Norway participated in the study. Participating units differed greatly in terms of their patient population, service type, and level of family involvement at baseline (24). The IFIP-study was established to improve health services and the health of individuals with psychotic disorders and their relatives through implementing evidence-based national recommendations on family involvement. Based on the national guidelines (1, 39, 40), the project group developed the IFIP-interventions which is thoroughly described in the protocol article (38) and the fidelity outcomes article (Hestmark, submitted 2022).

The clinical interventions of the IFIP-study consist of Basic Family Involvement and Support (BFIS) and FPE in single-family groups. BFIS refers to three separate conversations about family involvement: one with the patient, one with the relative(s), and then joint conversation(s). This is in addition to written information about family involvement and support, seminars for relatives, and a crisis/coping plan. FPE is an evidence and manual-based model (6, 41, 42) that provides psychoeducation about the disorder, emotional support, means to improve stress coping, problem solving, communication skills, and crisis management (43). Ideally, an FPE course should be 4–9 months in duration and start with separate alliance sessions with patients and relative(s), followed by joint sessions. Among our study participants, nine out of thirteen had participated in alliance and joint sessions at the time of the interviews (Table 1). At the initial phase of implementation, all clinicians, leaders, and resource personnel were invited to attend a four day FPE training programme (44), followed by regular supervision throughout the intervention period.

In the IFIP-study, doing other types of family involvement before or during the trial, was not an exclusion criteria. Thus, some of the units also did other types of family involvement that FPE and BFIS, such as other types of systematic family interventions or more unsystematic forms of conversations, for example, when the next of kin called the services and demanded some information to be able to support the patient.

Inclusion and participants

We used a purposive sampling strategy (45) to ensure explorations of patients' experiences with systematic family involvement. Inclusion criteria included 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 included: not being competent to consent; not having any relatives, being a forensic patient, or having an increased risk of violence.

The recruitment process involved several contributors at the CMHCs. Initially, the unit leader, family coordinator, or research coordinator received information about the recruitment procedures. This information was further provided to the respective clinicians who were encouraged to assess eligible patients, provide them with proper information and obtain consent to participate in the study. The clinicians were asked to include patients with both short- and long-term illness, patients with both positive and negative experiences with systematic family involvement, and a wide distribution in age and gender. Table 1 presents some overall characteristics of the thirteen included patients. Further details about the participants are omitted for reasons of anonymity.

Table 1. Participant characteristics (n=13)

Age	The age ranged from 26-60 years, with some more participants below the age of 40.
Years since time of diagnosis	7 of the participants were diagnosed 0-5 years ago, 3 participants 10-20 years ago, and 3 participants over 20 years ago.
Next of kin participating in systematic family involvement	Parents, parents and their partners, husband, wife, sister, brother, aunt, children, professionals in mental health supported accommodation services.

Data collection

We conducted thirteen individual interviews with patients with psychotic disorders during spring 2020. The interviews lasted approximately one hour and were performed by MR and KMH, who both have extensive experience with conducting qualitative research on vulnerable groups. Physical attendance was not possible due to the Coronavirus pandemic, thus six participants were interviewed by phone, and seven by a digital conference platform (Zoom) (46). The interviews were guided by a semi-structured interview guide (Additional file 2). To ensure applicability, the guide was developed through input from several of the researchers in the IFIP group, and further piloted with a representative from the Norwegian user organisation Mental Health. Prior to each interview, the researcher in charge contacted the patient to schedule the interview and clarify whether the patient preferred to participate via telephone or Zoom.

Initially, the participants were asked to identify significant persons in their everyday life and describe how these had been involved in the treatment at the CMHC. We further explored their views of the benefits and significance of systematic family involvement to themselves and to their family, but also challenges and potential disadvantages. The participants were also encouraged to share their views on how their therapist and relatives could facilitate positive experiences with family involvement. When utterances particularly relevant to the research question occurred, we asked follow-up questions to stimulate further elaboration. The interviews were audio-recorded on external dictaphones, transcribed verbatim and immediately transferred to the University of Oslo's secure database (In Norwegian: "Tjenester for Sensitive Data"-TSD).

Analysis

Immediately after each interview, a brief report was written by the interviewer (researcher) to summarise immediate impressions and recurring themes. This initial process of analysis also stimulated researcher reflexivity concerning the interview performance, provided co-authors with initial data familiarisation, and formed the basis for discussions among KMH, RP, MR, BW, LH and KSH on preliminary findings. The first author applied qualitative content analysis (47, 48) to explore the interviews and NVivo computer software package 12 was used to structure the analysis. The transcripts (unit of analysis) were read through several times to obtain a sense of the whole (47). To identify various relationships and themes within data, a non-linear process of de-contextualisation and re-contextualisation further took place, which simultaneously involved abstraction and interpretation (48). The process of de-contextualising involved separating data from their context to uncover all participants' statements about the phenomenon in question. The material was descriptively coded by dividing it into separate meaning units and labelling each unit with a word or phrase (manifest content with low degree of interpretation and abstraction), for example "learning about psychosis". The process of selecting text excerpts and coding resulted in some comprehensive meaning units. This was deemed necessary to avoid unfortunate fragmentation of descriptions of individual's experiences with a complex phenomenon (47, 48). If a solitary code seemed to fit in more than one category/sub-theme, the code was placed into each (47). Re-contextualisation constituted the interpretation of data and refers to combining the various utterances into new patterns and relationships, allowing a deeper understanding of the phenomenon under investigation. Data were subjected to further grouping of codes into higher-level categories and themes (latent content, increasing degree of interpretation and abstraction). RP, MR, LH, and KMH reviewed the final analysis by discussing the content and levels of abstraction in the thematic map until agreement on the final categorisation was obtained. This collaborative process resulted in the final division of the material into two unifying "red threads" (49) – the overarching themes. Pseudonyms are used to obtain anonymity. Each patient participant got his or her own pseudonym in the analyses, to make it easy to assess whether quotations are from the same or different interviews.

Research ethics

The study has been approved by the Norwegian regional committee for medical and health research ethics (REC) South East with registration number 2018/128, and by the local data protection officers at the participating units and at the University of Oslo, to ensure that the study was carried out in accordance with relevant regulations and guidelines. All participants gave a written and informed consent, and confidentiality and privacy has been ensured.

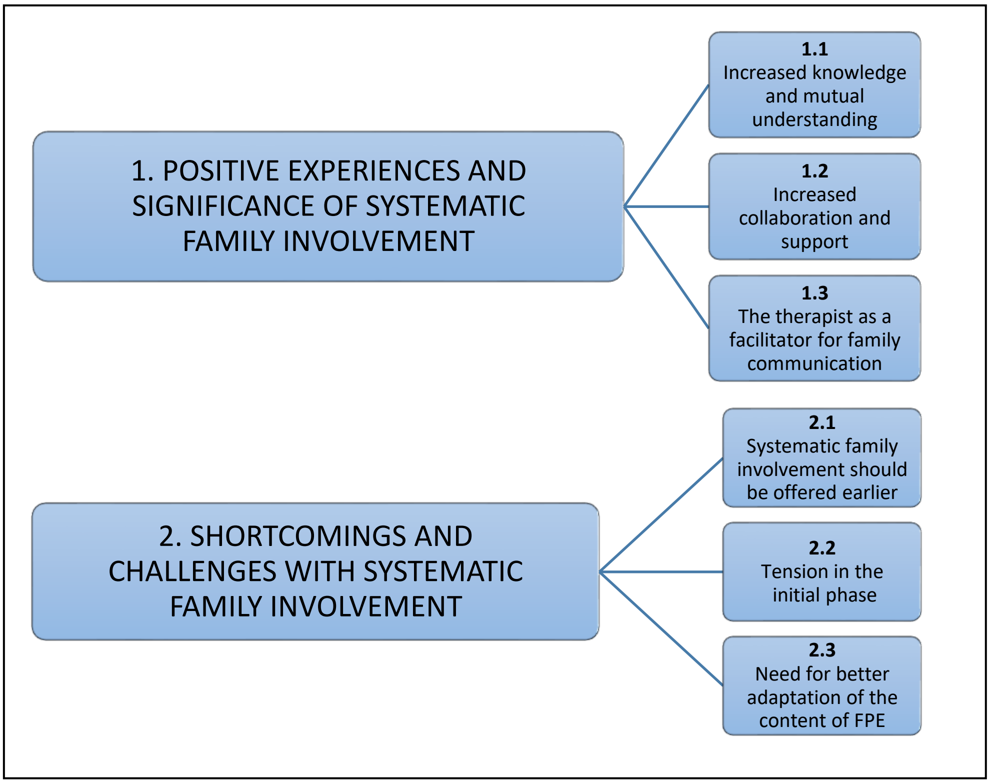
This study included vulnerable participants – that is patients with psychotic disorders. This was considered well-justified since this patient group has been relatively neglected in qualitative research on systematic family involvement.

However, particular ethical consciousness towards the study participants was thus required. For example, to make the interview situation less stressful, and to ensure that the participants fully understood which topics would be addressed during the interview, they were provided with the interview guide in advance. During the interviews, we strived to make the participants comfortable by being conscious of our appearance as researchers; meeting the participants with active listening, empathy, and sincere interest, and allowing for individual adaptations – such as providing short breaks where needed or the opportunity to turn off the screen during the interviews. At the end, we asked the participants how it had been to participate and whether they needed extra follow-up from their therapist in the aftermath. Several expressed that contributing to the research like this were experienced as meaningful.

Results

Analysis resulted in two main themes: 1) Positive experiences with and significance of systematic family involvement and 2) Shortcomings and challenges with systematic family involvement (Figure 1).

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



The participants described more general experiences and consequences of living with mental illness from before attending the study. Suffering from a psychotic disorder had negatively affected several of the participants throughout life in terms of experiencing hostility, conflicting understandings, loneliness, and difficulties in expressing their inner state or situation to those around them: “I didn't feel like anyone understood me, talked to me or listened to me...”, Susannah said. Cathrine detailed how unwanted patterns had arisen within her family: “If you have nothing to defend yourself with, having a hard time and in some way are being pushed into a corner and being faced with accusations... This is the kind of experience I have, but it does not mean that this is what they [the parents] want. The situation gets very tense, everyone is defending themselves, and the family dynamic becomes something that no one wants to deal with. Then we just stand there...".

Participants were also concerned about the burden the disease had caused their relatives, such as feelings of guilt, fear, and despair and, in some cases, deterioration of health: “My illness became such a strain on my partner that he also became ill”, said Susannah. Axel, for his part, expressed how his brother was paying the price for the lack of family involvement: “The biggest problem is probably that my brother didn't get involved … He is left with the biggest problem of us all really, because he has recieved the least information … thus from the beginning he thought that it was he who had been a bad brother”.

Most often the participants did not distinguish between BFIS and FPE, thus we mainly refer to the term “family involvement” as comprising both. When it was obvious that the participants were referring to FPE, this is specified.

1. Positive experiences and significance of systematic family involvement

Participants across the interviews reported overall positive experiences with the systematic family involvement they had been offered, despite there being large variability among them in terms of their experiences with such interventions, how long they had been ill, who their relatives were, as well as their age and gender.

1.1 Increased knowledge and mutual understanding

This theme refers to statements about how family involvement contributed to increase the patients and their relatives overall knowledge and understanding. Psychoeducation was perceived vital to gain a more thorough understanding of psychosis. Hannah noted that learning about psychosis had strengthened her cohabitant in the carer role: “I think my partner found it very useful. If I experience stress … how to avoid it, other causes of psychosis, prevent it a little”. Besides learning about psychosis, most participants reported a high value of getting insight into each other's situations and views. Caroline felt that participating in FPE had made her family less critical: “If there is something that is...overwhelming, or a little difficult, they are beginning to understand more that this is not what I do to be difficult but that I have a need to do the things I do.” John felt a renewed relation to his father: “The most important positive change that happened was that my father finally understood that there was something wrong then … that I haven't been well for a long time ... he got it like a punch in the face, as he said himself ... and he has changed for the better after that, I think.” The researcher asked him 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.”

The increased understanding was not only about the relatives understanding of the patient. The participants also reported an expansion in their awareness of their family members situation: “They have been very worried ... and it has put weight on them, I have not realised how tough it has been for them, right ... because I have been so preoccupied with myself, my problems. I haven't been able to see the problems they've had along the way. Which are not just my problems … but everything around. That they had a tough life that wasn't really about my story anymore, now it was about their story”, Axel said. Emily described how gaining knowledge and understanding made her regard her family more positively: “I think I have gained more trust in them, and perhaps have … gained more patience ... I still have moments where I don't trust almost anyone, but now I see more what their real purpose is - that they want to support me.”

Experiencing a relational shift was a recurring theme. Cathrine, who had been previously receiving critique from her surroundings, said: “They treat me differently … My brother said, for example [before]: “You can smile more, can't you? You almost never smile. You can be a little happier.” This was also the case for Emily and her aunt, who communicated better when mutual understanding increased: “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.”

In Axel and his mother’s case, understanding each other better was not about coming to a full agreement but rather finally being able to communicate, recognise, and accept that they carried different experiences and perceptions of how life with the illness had been. Axel said: “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 FPE."

1.2 Increased collaboration and support

This theme describes accounts concerning enhanced support and collaboration among the participants, relatives, and family system.

Perceived support

In the participants’ view, increased knowledge and understanding enabled their relatives to provide better support: “The best thing I have gotten out of it is more understanding in the family. They can help me adapt...help me get through tough days*...”* John said, while Anna expressed the importance of having her husband involved: “It has been very nice to have someone next to me who sees my problem and solves it - and grows together with me". Several accounts concerned how the patient felt they were met with greater interest and warmth from their relatives. Participating in FPE promoted emotional support: “They understand more in the family. You are not so alone with your problems” (Rita), “It means a lot. The support I get all the time and understanding and help when I need it" (Anna), while Emily experienced that her social function had improved: “I can be safer/more secure 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".

All in all, the interviews gave the impression that when the services were involved and supported their family, quality of life ameliorated. Emily, for instance, talked about how systematic family involvement had given her an increased sense of predictability and coherence in life: "I feel that I have gained a little more security in those relationships...it is more predictable...if there are many things I am thinking about, I know that I can bring this up at such a meeting. So I feel that my life has somehow become more complete, in some way, after we have had that collaboration."

Improved problem solving in everyday life

Several participants noted that the problem-solving sessions stimulated the family collaboration. The families increasingly dealt with their problems – individually and within the family - through a more solution-oriented approach, and began solving problems together and working towards shared goals – which mitigated their everyday life: Magnus said that “the problem solving was good since, yes, we have to organise the everyday life together ... so then it was certainly useful to plan on two fronts", while Susannah appreciated attending the problem solving sessions regularly: “Problem solving every 14 days was really great ... Because then we could work on a new problem solution in everyday life, then we could talk about problems, things we wanted to fix, then we made a little plan, and then we were testing it until the next session.” Susannah was also relieved that the FPE-sessions were problem-focused rather than person-focused: 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”. Anna expressed how communication improved through being together: "It has been very nice to sit together and talk about everyday life ... they can hear about my difficulties and about my anxiety - try to find help for me ... The communication between me, my husband and the therapist becomes good when we resolve our thoughts together.”

Help to prevent a relapse
The knowledge and skills gained through FPE were linked explicitly to relapse prevention: “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", Rita noted. Magnus explained the value of having a crisis plan when his condition deteriorated: “It's quite difficult for me to take action when I get sick, it's somehow much better when someone else notices it ... the one who takes action then is primarily my mother ... then she calls the CMHC and gets an admission."

The relatives are taken care of
Participants also shared how they considered their relatives to benefit from family involvement for their own sake. Emily valued how the services were supporting her family: “It is very nice that the relatives can get involved (in the treatment), and at the same time they can be "protected" in a way, by the health care services.” Alliance sessions were described as highly valuable for enabling the relatives to speaking openly about issues that they were reluctant to disclose in the presence of the patient. Susannah said of her husband: “[he is] able to ask questions that he finds uncomfortable asking me. And finally he can get some decent answers.” Christian, for his part, reflected on how his mother had benefitted from the conversations with his therapist: “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."

Some of the participants also appreciated that their therapist had provided their relatives with an open line to the services. Firstly, the patients recognised how such continuous support reduced their family members’ stress and feelings of carrying the burden alone. Secondly, they also considered it to have a positive impact on themselves and the family dynamics. A recent episode in Rita’s life was used to exemplify how such an open line of communication could potentially prevent a deterioration of the family climate: “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

This theme concerns the role of the therapist during systematic family involvement, who seemed to play an important function in facilitating the enhanced knowledge, understanding, collaboration, and support outlined in the former themes.

Facilitator of patient-relative communication
The participants reported that, in their opinion, the therapist was critical in supporting them in their communication with the relatives. Christian, for example, expressed how he expected that having the therapist by his side would help him to express himself to his mother in a forthcoming session: “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”. Caroline, for her part, was relieved that the therapist had conveyed information about her on her behalf: “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.” To Monica, relying on professional authority when communicating with her mother and children had been imperative: “I feel a great relief that they are family therapists because then I don't have to try to get them to understand. It’s coming from someone who knows their subject."

Creator of a safe and containing space
FPE components like psychoeducation, emotional support, and communication rules facilitated by a supporting therapist laid the groundwork for an increased openness regarding mental health within the family. While previous issues with stigma, shame, and difficulties with talking about mental illness were repeatedly addressed by participants, FPE sessions were described as a means of providing dedicated time and a confined space for dealing with sensitive topics which was not possible in their everyday life alone with their relatives. Being able to talk more openly about sensitive issues and each individual’s struggles seemed to dampen the emotional pressure in some of the families: "There has been less despair about the whole thing", said Martin.

2. Shortcomings and challenges related to systematic family involvement

2.1 Systematic family involvement should be offered earlier

The interviews unveiled how some participants during times of severe relapse felt an unmet need for help to involve and interact with their family. They pointed at systematic family involvement as a measure they should have received earlier in life - for their own and/or their relatives sake. For example, Monica said that “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..." Susannah noted that her husband had benefitted greatly from the alliance sessions, but “he wished it could come a little earlier.” While Susannah was offered one-to-one conversations at initial hospitalisation, her husband had to wait for six months before receiving any information from the unit. The problem was that he needed these conversations the most at the beginning, information about the prognosis and what would happen next, as soon as his wife had become seriously ill.

Two participants shared their views and advice to future patients not to exclude the family when they get ill. Christian for example was very concerned with his own troubled story, and wished for others to avoid the mistakes that he and the health and social services had formerly made: “Try to reach out to your family before it goes to hell. If I had managed that, I would have been sober by now. I didn't make it, that's why I'm saying it … Just try …they love you.”

2.2 Tension in the initial phase

A few participants felt particularly vulnerable and uncertain when being asked for consent to involve their family and before attending the joint sessions: “It's not that I don't want to, but I've been afraid. Until now.”, Christian explained, while Martin pointed out that patients can be reluctant to consent because of a felt need to protect their relatives: "I don't want to be a burden". Caroline found the waiting time before the joint sessions very challenging: “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.”

However, both Christian and Caroline learned that their fears were unfounded when they finally started with FPE. Caroline added that being reassured during the alliance sessions that her views on information disclosure were taken into account was helpful: “One thing I really liked was that I got to decide what the therapist was going to say to my parents". When asked what action they needed from the therapist to make the initial phase more comfortable, Caroline responded: “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 ...”, while Christian was content with the therapist’s patient approach: “He has done it completely right, because he has taken it carefully. He understands "that the things I struggle with are quite bad, so he has moved slowly forward, talked a little about what he and my mother have talked about - and maybe in the future we will have a joint meeting."

2.3 Need for better adaptation of the content of FPE

Some statements revealed that the FPE content was not sufficiently adapted to the individual family and their specific situation. John felt that far too much time was spent on problem solving: “It's been interesting, but it has also been very … much of the same every time [laughs]. In the end it was just like ... ‘now we'll have to come up with something’”. Rita experienced conflicts, but emphasised that she did not think the therapist could have done anything differently: ”Twice I didn't accept my dad’s suggestions. The second time he was offended and wanted to quit the group ... but I spoke to the therapist on the phone afterwards, and was reassured that it wasn't me, there is something wrong with.”

Susannah had some suggestions for improvements. Firstly, she wished there had been more focus on her husband in the joint sessions: “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". Secondly, she felt that separate conversations with the therapist alone where she could express herself in private had come at the expense of the joint sessions.

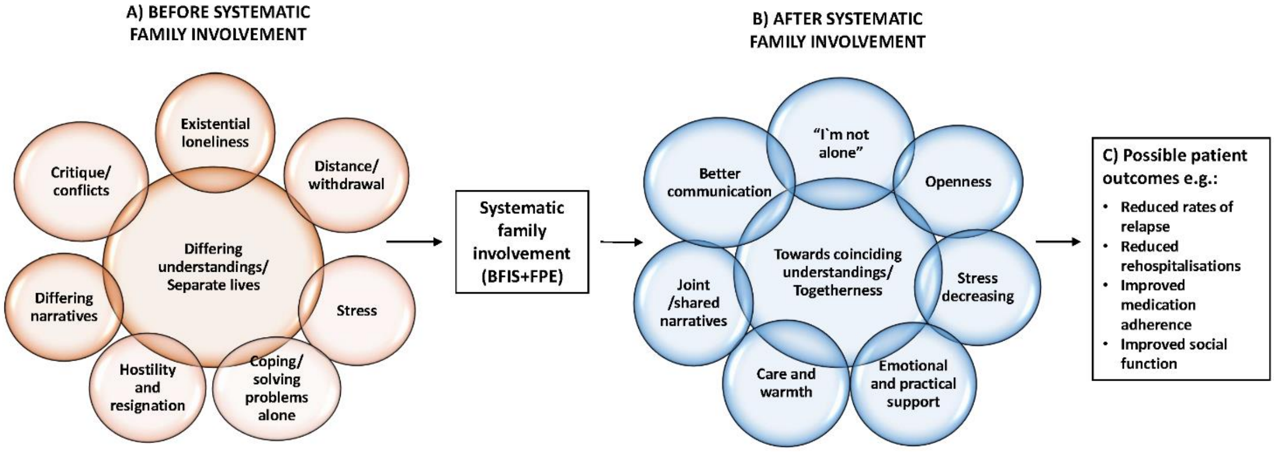
Discussion

Through patients’ accounts, we found that enhanced knowledge and understanding became key mediators of collaboration and support. It was imperative to the patients that their closest ones had knowledge about their illness and understood their situation, strains, and needs. While a lack of understanding seemed to promote stress, conflicting communication, and worsening of disease, the new understanding and awareness of each other's situation improved communication, reduced stress, stimulated a more supporting family environment, and improved the overall coping with the illness. The therapist functioned as a facilitator of patient-relative communication, creator of a safe, containing space, and as a source of continuous support to the relatives. It also seemed that the therapist was crucial during the initial phase of FPE, to reduce tension and stress and patiently pave the way for the patient into systematic family involvement. Shortcomings related to systematic family involvement were that the participants felt vulnerable and uncertain in the initial phase, a need for better adaptation of the content of FPE, and that systematic family involvement should be offered earlier.

How systematic family involvement improved the family dynamics

Being severely mentally ill had had a devastating impact on the patients' life and relationships. Several patients wished that they had received help with how to interact with their family at an earlier time to avoid the suffering they had undergone (Figure 2, Part A). The patients' narratives demonstrated that participating in family involvement contributed to a positive change within the family system (Figure 2, Part B). In the following section, we discuss the potential mechanisms of impact that led to such a relational turnaround:

Figure 2. Systematic family involvement: key processes and possible patient outcomes



Access to knowledge and guidance to understand psychosis

Psychotic disorders are complex biopsychosocial illnesses (50), thus understanding how they develop and potentially influence the afflicted individuals and their surroundings is challenging without help from professionals. The psychoeducational component of FPE provided the patients with access to knowledge about the illness, the diathesis-stress model, treatment options, and prognosis. This was experienced as helpful for understanding themselves, coping with life with severe illness, and creating hope for the future, which in line with Nilsen et al (33).

Furthermore, psychoeducation worked as a supportive means to convey complex medical information to the relatives. We cannot expect relatives to deal with the devastating consequences of psychosis and provide good care without adequate knowledge and coping skills. However, the patients in this study voiced how they struggled with expressing their challenges and needs, and how poor communication on several occasions had deprived their social life. To reduce loneliness, be understood and supported, the patients needed help to communicate effectively with their peers, which was accomplished through FPE. Before attending FPE, conflicts and critique had arisen in several of the families due to divergent perceptions and understandings. When knowledge about psychosis increased, the relatives seemed to adjust their expectations, both of the patient and of the treatment. This demonstrates the significance of providing psychoeducation to relatives at an early phase of the illness trajectory. Only when relatives' expectations of their seriously ill family member are realistic it is possible to work coherently towards common goals.

Experiences of being acknowledged and understood

Another core significance of FPE was that the patients were enabled to express themselves in a safe and contained room (50), for some it was the first time since they got ill. Such communication facilitated healing experiences of being met, acknowledged, and understood, both by the therapist and significant persons in their everyday life. This is in line with previous studies identifying "common therapeutic factors" as mediators of the positive outcomes of systematic family involvement identified in the literature (51).

An important point is that, in contrast to individual therapy, the FPE model also provided their relatives access to therapeutic experiences, which was highly valued across the interviews. Research has shown that relatives may have an intense need to share their narratives about caring for an individual with severe mental illness (51). Our findings highlight that it is significant also for the patients that their relatives are given the opportunity to speak out and be acknowledged by the therapist. During alliance sessions their family members could disclose the fear, doubt and grief that often accompanies the caring role – again, for some it was the first such opportunity since the patient's diagnosis. These healing dynamics can be understood as "acknowledging communication", a milieu-therapeutic approach commonly used in mental health care. "Mutuality" is a core concept of acknowledging communication and refers to this inter-subjective sharing of feelings and beliefs, performed in a respectful way (52). The "open line" to the services which some relatives had been offered, also contributed to coping with the illness. Especially in times of illness deterioration, having the therapist as a "lifeline" was imperative to manage providing care while also caring for themselves in demanding situations. These findings support the studies showing that relatives' expressed emotions are identified as robust predictors of relapse (29) (Figure 2, Part C).

Taking part in the narratives of their significant others

Attending the FPE joint sessions allowed the patients to be exposed to their relatives narratives. Joint sessions characterised by a supportive climate (for instance, communication rules were said by one participant to create a calm atmosphere) increased the participants understanding of the others' point of view, experiences, and needs. This led to a crucial change in the relatives` attitude towards the patient: from previously perceiving the patient as "challenging" or with behavioural faults, the family members increasingly attributed challenging behaviour to the illness. Together with psychoeducation, this promoted relatives` reframing, which is a mediating factor of reduced expressed emotions (51). Similar findings has been reported in a qualitative study exploring patients' and relatives' perceived benefits after participating in multi-family or single-family FPE-groups following a first episode of psychosis (33).

Strikingly, we also saw this change in attribution among some of the patients. Their beliefs about their relatives' behaviour had similarly influenced how they related to and interpreted their actions. Listening to the family members concerns enabled them to explore new perspectives of themselves and others, and listen to the family members worries. This finding, showing how systematic family involvement may contribute to balance family relationships, is less elucidated in the scientific literature, which focuses mostly on how family involvement can provide relatives with insight into the patients' symptoms and situation.

Furthermore, this is relevant factor to assess the pros and cons of single- versus multi-family FPE-groups. Although the sample is small, these finding may indicate that single-family groups may be more suitable to facilitate this reciprocal understanding than multi-family groups, since the single-family approach is more suitable to explore and improve the mutual understanding between the individual patient and his/her family.

The therapist played a key role in facilitating the abovementioned experiences of gaining knowledge of psychosis, being acknowledged, and learning from each other's narratives. FPE was portrayed by the participants as a safe, contained space (35) in which the families could disclose, discuss, and navigate sensitive topics. The therapist was central to creating these spaces, in strengthening patient-relative communication, providing emotional support, and building trust and alliance within the triad.

Systematic family involvement should start early, focus on the initial phase, and be tailored

Three key findings in this study concerns aspects of timing. First, systematic family involvement should start at the onset of the illness, or as early as possible, to support the afflicted family in a critical phase of their lives. Several of the patients expressed that systematic family involvement had been initiated too late, with negative consequences for them and their family (Figure 2, Part A). This is particularly important in the prodromal phase, in order to prevent young patients in the early stages of their illness from relational disruptions and to facilitate the strengthening of emotional bonds. At this stage, the family is most likely to still be involved, with a potential for building supportive relationships, contrary to what is found to be the case among patients with a long history with severe mental illness (6).

Secondly, particular attention should be given to the initial conversations about systematic family involvement before FPE, and the time span before and during alliance sessions when consent to involve the family has been successfully obtained. The participants seemed especially vulnerable at these moments, expressing how they were burdened by uncertainty, fear, lack of information, and that they dreaded the participation. Similar findings has been reported in a qualitative study exploring patients' and relatives' experiences after participating in multi-family or single-family FPE-groups following a first episode of psychosis (33). This is not surprising, taking into account that both the patient and the family may be in state of chaos or crisis in the initial phase of a psychotic disorder. Furthermore, these findings integrate well with previous implementation research, where patient reluctance and lack of consent are identified as core barriers to systematic family involvement for persons with severe mental illness (26). However, they found that their worries and fears were often unfounded; that is when first attending the joint sessions they mostly found it positive. This alludes to yet more important functions of the therapist: providing the patients with thorough information, listening actively to their worries, and demonstrating a sincere intention to involve them as equal partners in decisions regarding information disclosure. Due to the vulnerable situation and the complexity of the intervention, it may be wise to start the most basic type of systematic family involvement (such as BFIS) and to guide the patient through a process with step-wise consent where the more advanced interventions, such as FPE, may be introduced at a later stage. This seems to be in line with the needs and interests expressed by the patients in this study. That is, a step-wise approach, may both lower the threshold and increase the likelihood that the patient consent to and benefits also from more advanced family involvement interventions, despite ambivalence in the beginning. Such an approach, is also in line with another IFIP sub study exploring the mental health professionals' views on barriers and facilitators to family involvement (26)

Finally, it seems to be a need to adapt or tailor the systematic family involvement to the individual patient and family needs. Such adaptation may be easier using a step-wise approach and a single-family group approach if FPE is introduced at after more basic family involvement and support.

Strengths and limitations

Demonstrating causality or to generalise the findings is not possible in qualitative research. However, the findings can provide knowledge of possible mediating factors, and generate hypotheses that can be tested in future studies. Furthermore, the findings may be relevant or transferable to other similar contexts.

A challenge in the IFIP-study is that we do not know for certain what kind of family involvement the participants have been exposed to or how much. This is often the case when evaluating complex interventions in a large scale and real world setting, and when using a design inspired by pragmatic trials, as in the IFIP-study. They may have participated in both BFIS and FPE or only one of them. They may also have been exposed to other types of family involvement. However, the experiences described are most likely related to BFIS and/or FPE, and that entails (for the patients) at least two systematic conversations focusing on family involvement. Furthermore, although many different systematic family interventions exists, it seems like the core components are similar and that as little as two family involvement sessions can give positive effects (21, 53). Thus, the experiences and findings may be relevant also if the interventions or the experiences have been "contaminated" or influenced by other family interventions, and also with few or many family involvement sessions.

A strength of this study is the context and design of how it was performed - in a real world clinical setting, as part of a large cluster randomised study which has succeeded in improving the implementation of systematic family involvement (Hestmark, submitted 2022). Close collaborations with many researchers in an interdisciplinary research group guided the research, and the authors of this article are well experienced in accommodating vulnerable groups in research and clinical practice. Most likely, this contributed to strengthen the overall quality of findings, and to facilitate trust and openness among the participants and interviewers leading to rich and valid data.

However, the normative position of the researchers can possibly influence data collection and analysis. Nested in a study which aimed at implementing specific interventions, there is a risk of observer bias if the researcher's expectations or opinions may impact what they perceive or record in a study (54). To increase trustworthiness of findings, this required that the researchers performed ongoing "reflexive objectivity" (55) that is reflecting on how we contributed to the production of knowledge.

An important strength of this study is that it leans on rich first-hand data from a patient group whose voices are seldom heard, and who can find it challenging to participate in research. A further strength concerns the variation in participants in terms of age, gender and length of illness trajectories which gave us rich and varied data. We assume that the design of the recruitment phase most likely contributed to the richness of data as close contact with the patients' therapists was established by the time of recruitment. Most likely, this facilitated a “tailored” inclusion of patients who were considered well suited to participate meaningfully in the interviews. On the other hand, this implies a risk of sample bias in terms of poorly functioning patients or families not being included, or that the clinicians, whether consciously or not, encouraged the patients that were most satisfied with the intervention. It is also likely that the participants who consented to participate in general had a positive view of family involvement, and that they had mainly positive experiences with the IFIP-intervention. Another potential limitation concerns bias in recall due to the retrospective design of this study.

Furthermore, it would have been a strength if complementary qualitative data from clinicians and relatives, and quantitative data from the study had been analysed, but for practical reasons these data will be published later. Preliminary findings from these two sub-studies, however, indicate strong coherence in findings.

Clinical implications and future research

These findings, although not able to generalise, indicate that systematic family involvement should be routinely offered to patients with psychotic disorders as soon as possible after the onset of illness. However, it is important that the clinicians are responsive to the individual patient and relatives' situation and adapt the intervention accordingly, and consider to use a step-wise approach. The pitfalls that may arise during the initial phase of family involvement should be given special attention. Therapists should probably be given relevant training and supervision to be able to facilitate the positive processes described in this study.

To inform the design and application of systematic family involvement interventions in clinical practice for various groups and settings, more qualitative research exploring the active ingredients of systematic family involvement, and how they are exerting their effect, is needed (56). Studies voicing the patient perspective are particularly encouraged. The scope of this study is limited to patients that have participated in systematic family involvement. To optimise future practice and implementation, research should also explore the perceptions of patients who do not consent to systematic family involvement. Research should also investigate how systematic family involvement is delivered and experienced in other settings, such as in in-patient units and the municipalities.

Conclusion

The patients in this study reported overall positive experiences with systematic family involvement during psychotic illness and reported immediate and long-term 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 and its ripple effects on the family system and everyday life. 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. The findings indicate that it is important to start with systematic family involvement early after the onset of a psychotic disorder, to pay special attention to the initial phase of family involvement, use a step-wise approach, and ensure that FPE content are adapted to each patient and family`s needs. These findings agree with, and lend additional weight to, the existing evidence and guidelines which suggest that basic levels of systematic 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 pragmatic efforts to implement systematic family involvement in CMHCs.

Abbreviations

BFIS – Basic Family Involvement and Support
FPE – Family psychoeducation
CMHCs – Community mental health centres

Declarations

Ethics approval and consent to participate

study has been approved by the Norwegian regional committee for medical and health research ethics (REC) South East with registration number 2018/128. REC provides a general ethical approval to conduct the study as described in recruited clinical units. On the advice of local data protection officers at the trial sites, the PI on behalf of the University of Oslo has signed contracts on shared responsibility for data processing with each participating health care trust, allowing us to carry out the study at each trial site in accordance with the General Data Protection Regulation. We confirm that all methods were performed in accordance with the relevant guidelines and regulations. Verbal and written informed consent to participate in the study has been obtained from all participants.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

The study is funded by The Research Council of Norway. This funding source had no role in the design of this study or during its execution, analyses, interpretation of the data, or decision to submit results.

Authors’ contributions

RP, KSH, and BW drafted the original research protocol, which this article is based on, and thus made significant contributions to the conception and design of the study. KMH, MR, LH, RP, and KSH provided the implementation support. KMH and MR performed the data collection. KMH, RP, MR, BW, LH and KSH contributed in discussions on preliminary findings. KMH analysed and interpreted the data with major contributions from MR and RP, as well as contributions from LH. KMH wrote the first draft of this article, with major contributions from RP and MR, and further received substantial contributions from LH, IN, BW and KSH. All the authors critically revised the article, gave their final approval before submission, and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Acknowledgements

The authors wish to express our gratitude to the persons who shared with us their experiences with participating in this study`s family involvement intervention. These are valuable contributions, which can inform future improvements to family involvement practices in mental health care. Thanks also to the unit leaders, family coordinators, and clinicians and at the clinical intervention sites for facilitating the recruitment and follow-up before and during the data collection. We also would like to thank The Early Intervention in Psychosis Advisory Unit for South East Norway (TIPS Sør-Øst) at Oslo University Hospital Trust and Østfold Hospital Trust, for providing teaching and guidance in family psychoeducation to the participating units and valuable input to the project in general. Thank also to the R&D unit of the Division of Mental Health and Addiction at Vestre Viken Hospital Trust, for valuable input and assistance. Finally, we would like to thank all the participating units, collaboration partners, stakeholder groups and advisory board of the IFIP trial for their valuable input.

References

1. Nasjonal faglig retningslinje for utredning, behandling og oppfølging av personer med psykoselidelser. Oslo: Helsedirektoratet; 2013. Available from: https://www.helsedirektoratet.no/retningslinjer/psykoselidelser. Accessed February 2022.
2. International Statistical Classification of Diseases and Related Health Problems - ICD-10. Schizophrenia, schizotypal and delusional disorders (F20-29): World Health organization; 2016 [Available from: https://icd.who.int/browse10/2016/en#/F20-F29).
3. Patel V, Chisholm D, Parikh R, Charlson FJ, Degenhardt L, Dua T, et al. Addressing the burden of mental, neurological, and substance use disorders: key messages from Disease Control Priorities, 3rd edition. The Lancet. 2016;387(10028):1672-85.
4. Johannessen JO, Joa I. Modern understanding of psychosis: from brain disease to stress disorder. And some other important aspects of psychosis…. Psychosis. 2021;13(4):289-301.
5. Spaulding WD, Silverstein SM, Menditto AA. The Schizophrenia Spectrum: Hogrefe Publishing GmbH; 2018.
6. McFarlane WR. Family Interventions for Schizophrenia and the Psychoses: A Review. Family Process. 2016;55(3):460-82.

7. Shiraishi N, Reilly J. Positive and negative impacts of schizophrenia on family caregivers: a systematic review and qualitative meta-summary. Social Psychiatry and Psychiatric Epidemiology. 2019;54(3):277-90.

8. Cleary M, West S, Hunt GE, McLean L, Kornhaber R. A Qualitative Systematic Review of Caregivers' Experiences of Caring for Family Diagnosed with Schizophrenia. Issues in Mental Health Nursing. 2020;41(8):667-83.

9. Weimand BM, Hedelin B, Hall-Lord M-L, Sällström C. "Left Alone with Straining but Inescapable Responsibilities:" Relatives' Experiences with Mental Health Services. Issues in Mental Health Nursing. 2011;32(11):703-10.

10. Karambelas GJ, Filia K, Byrne LK, Allott KA, Jayasinghe A, Cotton SM. A systematic review comparing caregiver burden and psychological functioning in caregivers of individuals with schizophrenia spectrum disorders and bipolar disorders. BMC Psychiatry. 2022;22(1):422.

11. Bebbington P, Kuipers L. The predictive utility of expressed emotion in schizophrenia: an aggregate analysis. Psychological Medicine. 1994;24(3):707-18.

12. Patel V, Chisholm D, Parikh R, Charlson FJ, Degenhardt L, Dua T, et al. Addressing the burden of mental, neurological, and substance use disorders: key messages from Disease Control Priorities, 3rd edition. The Lancet. 2016;387(10028):1672-85.

13. Morillo H, Lowry S, Henderson C. Exploring the effectiveness of family-based interventions for psychosis in low- and middle-income countries: a systematic review. Social Psychiatry and Psychiatric Epidemiology. 2022;57(9):1749-69.

14. NICE. Psychosis and schizophrenia in adults (CG178). London: National Institute for Health and Clinical Excellence; 2014 Report No.: CG178. Available from: https://www.nice.org.uk/guidance/cg178. Accessed March 2022.

15. Galletly C, Castle D, Dark F, Humberstone V, Jablensky A, Killackey E, et al. Royal Australian and New Zealand College of Psychiatrists clinical practice guidelines for the management of schizophrenia and related disorders. Australian & New Zealand Journal of Psychiatry. 2016;50(5):410-72.

16. Pharoah F, Mari J, Rathbone J, Wong W. Family intervention for schizophrenia. Cochrane Database Syst Rev. 2010(12):CD000088-CD. https://doi-org.ezproxy.uio.no/10.1002/14651858.CD000088.pub3.

17. Claxton M, Onwumere J, Fornells-Ambrojo M. Do Family Interventions Improve Outcomes in Early Psychosis? A Systematic Review and Meta-Analysis. Frontiers in Psychology. 2017;8.

18. Yesufu-Udechuku A, Harrison B, Mayo-Wilson E, Young N, Woodhams P, Shiers D, et al. Interventions to improve the experience of caring for people with severe mental illness: systematic review and meta-analysis. Br J Psychiatry. 2018;206(4):268-74.

19. Bighelli I, Rodolico A, García-Mieres H, Pitschel-Walz G, Hansen W-P, Schneider-Thoma J, et al. Psychosocial and psychological interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. The Lancet Psychiatry. 2021;8(11):969-80.

20. Hasan AA-H, Jaber AA. The effect of a family intervention on primary caregivers psychological outcomes: Findings from the integrative literature review. Perspectives in Psychiatric Care. 2019;55(2):277-90.

21. Rodolico A, Bighelli I, Avanzato C, Concerto C, Cutrufelli P, Mineo L, et al. Family interventions for relapse prevention in schizophrenia: a systematic review and network meta-analysis. The Lancet Psychiatry. 2022.

22. Pitschel-Walz G, Leucht S, Bäuml J, Kissling W, Engel RR. The Effect of Family Interventions on Relapse and Rehospitalization in Schizophrenia—A Meta-analysis. Schizophrenia Bulletin. 2001;27(1):73-92.

23. Bucci S, Berry K, Barrowclough C, Haddock G. Family Interventions in Psychosis: A Review of the Evidence and Barriers to Implementation. Australian Psychologist. 2016;51(1):62-8.

24. Hestmark L, Heiervang KS, Pedersen R, Hansson KM, Ruud T, Romøren M. Family involvement practices for persons with psychotic disorders in community mental health centres – a cross-sectional fidelity-based study. BMC Psychiatry. 2021;21(1):285.

25. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ. 2021;374:n2061.

26. Hansson KM, Romøren M, Pedersen R, Weimand B, Hestmark L, Norheim I, et al. Barriers and facilitators when implementing family involvement for persons with psychotic disorders in community mental health centres – a nested qualitative study. BMC Health Services Research. 2022;22(1):1153.

27. Eassom E, Giacco D, Dirik A, Priebe S. Implementing family involvement in the treatment of patients with psychosis: a systematic review of facilitating and hindering factors. BMJ Open. 2014;4(10):e006108.

28. O'Hanlon B, Hayes L, Perlesz A, Harvey C. Understanding the complex family experiences of Behavioural Family Therapy. Journal of Family Therapy. 2018;40(1):45-62.

29. Grácio J, Gonçalves-Pereira M, Leff J. Key Elements of a Family Intervention for Schizophrenia: A Qualitative Analysis of an RCT. Family Process. 2018;57(1):100-12.

30. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: Medical Research Council guidance. BMJ. 2015;350:h1258.

31. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for Implementation Research: Conceptual Distinctions, Measurement Challenges, and Research Agenda. Administration and Policy in Mental Health and Mental Health Services Research. 2011;38(2):65-76.

32. Nilsen L, Frich JC, Friis S, Norheim I, Rossberg JI. Participants' perceived benefits of family intervention following a first episode of psychosis: a qualitative study. Early Interv Psychiatry. 2016;10(2):152-9.

33. Nilsen L, Frich J, Friis S, Rossberg J. Patients’ and Family Members’ Experiences of a Psychoeducational Family Intervention after a First Episode Psychosis: A Qualitative Study. Issues in Mental Health Nursing. 2014;35:58-68.

34. Jensen E, Carr R, Degnan A, Berry K, Edge D. Exploring service user and family perspectives of a Culturally adapted Family Intervention (CaFI) for African-Caribbean people with psychosis: A qualitative study. Br J Clin Psychol. 2021;60(2):270-89.

35. Allen J, Burbach F, Reibstein J. 'A different world' individuals' experience of an integrated family intervention for psychosis and its contribution to recovery. Psychol Psychother. 2013;86(2):212-28.

36. Loh C, Liang W, Lee H, Koh A. Multi-Family Therapy for First Episode Psychosis: Experiences of Families in Singapore. Front Psychiatry. 2021;12:788827.

37. O’Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for Reporting Qualitative Research: A Synthesis of Recommendations. Academic Medicine. 2014;89(9):1245-51.

38. Hestmark L, Romoren M, Heiervang KS, Weimand B, Ruud T, Norvoll R, et al. Implementation of guidelines on family involvement for persons with psychotic disorders in community mental health

centres (IFIP): protocol for a cluster randomised controlled trial. BMC Health Serv Res. 2020;20(1):934.

39. Veileder om pårørende i helse- og omsorgstjenesten. Oslo: Helsedirektoratet; 2017. [Available from: https://www.helsedirektoratet.no/veiledere/parorendeveileder]. Accessed July 2022.

40. Psykoselidelser, inkludert mistanke om psykoseutvikling – barn, unge og voksne. Pakkeforløp 2018. Oslo: Helsedirektoratet; 2018. Available from: https://www.helsedirektoratet.no/pakkeforlop/psykoselidelser-inkludert-mistanke-om-psykoseutvikling-barn-unge-og-voksne. Accessed July 2022.

41. McFarlane WR, Dixon L, Lukens E, Lucksted A. Family psychoeducation and schizophrenia: a review of the literature. J Marital Fam Ther. 2003;29(2):223-45.

42. Anderson CM, Reiss DJ, Hogarty GE, editors. *Schizophrenia and the Family: A Practitioner's Guide to Psychoeducation and Management*. 1986. The Guilford Press; 1st edition.

43. Dixon LB, Dickerson F, Bellack AS, Bennett M, Dickinson D, Goldberg RW, et al. The 2009 schizophrenia PORT psychosocial treatment recommendations and summary statements. Schizophr Bull. 2010;36(1):48-70.

44. KURS I METODEN PSYKOEDUKATIVT FAMILIESAMARBEID (PEF). Familiesamarbeid. Oslo: TIPS Sør-Øst - Regional kompetansetjeneste for tidlig intervensjon ved psykose. Available from: https://oslo-universitetssykehus.no/avdelinger/klinikk-psykisk-helse-og-avhengighet/forsknings-og-innovasjonsavdelingen-i-pha/regionalt-kompetansesenter-for-tidlig-intervensjon-ved-psykoser/familiesamarbeid Accessed November 2022.

45. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. Administration and policy in mental health. 2015;42(5):533-44.

46. Zoom. Available from: https://zoom.us/. Accessed November 2022.

47. Graneheim UH, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. Nurse Educ Today. 2004;24(2):105-12.

48. Lindgren B-M, Lundman B, Graneheim UH. Abstraction and interpretation during the qualitative content analysis process. International Journal of Nursing Studies. 2020;108:103632.

49. Graneheim UH, Lindgren B-M, Lundman B. Methodological challenges in qualitative content analysis: A discussion paper. Nurse Education Today. 2017;56:29-34.

50. Allen J, Burbach F, Reibstein J. 'A different world' individuals' experience of an integrated family intervention for psychosis and its contribution to recovery. Psychology & Psychotherapy: Theory, Research & Practice. 2013;86(2):212-28.

51. Grácio J, Gonçalves-Pereira M, Leff J. What do We Know about Family Interventions for Psychosis at the Process Level? A Systematic Review. Family Process. 2016;55(1):79-90.

52. Vatne S, Hoem E. Acknowledging communication: a milieu-therapeutic approach in mental health care. J Adv Nurs. 2008;61(6):690-8.

53. Dirik A, Sandhu S, Giacco D, Barrett K, Bennison G, Collinson S, et al. Why involve families in acute mental healthcare? A collaborative conceptual review. BMJ Open. 2017;7(9):e017680.

54. Nikolopoulou K. What Is Non-Probability Sampling? | Types & Examples 2022 Available from: https://www.scribbr.com/methodology/probability-sampling/. Accessed November 2022.

55. Kvale S, Brinkmann S. (2009). *Det kvalitative forskningsintervju.* (2. utg.) Oslo: Gyldendal Akademisk.

56. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluatinG complex interventions: the new Medical Research Council guidance. BMJ. 2008;337:a1655.

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

Page/line no(s).

Title and abstract

Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	p. 2

Introduction

Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	p. 3
Purpose or research question - Purpose of the study and specific objectives or questions	p. 3

Methods

Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	p. 4-5
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	N/A (p. 17)
Context - Setting/site and salient contextual factors; rationale**	p. 4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	p. 4
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	p. 6
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	p. 4-5
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	p. 5
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	p. 4-5
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	p. 5

Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	p. 5-6
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	p. 5-6

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	p. 7-11
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	p. 7-11

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	p. 12-16
Limitations - Trustworthiness and limitations of findings	p. 15-16

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	p. 17
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	p. 17

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

The IFIP-study:
Patient interview guide

Introduction

This interview is part of the IFIP project, where community mental health centres (CMCHs) receive support to improve the collaboration between the user, their family and health personnel at the CMCH. The purpose of the project is that close family or other significant persons can support the user, and also get information and support themselves (e.g. by participating in a family group together, that the hospitals have appropriate information sharing routines, or that the user and relatives are taken care of by a family coordinator). The project is a collaboration between the University of Oslo (Centre for Medical Ethics), Akershus University Hospital HF (R&D unit of the Division of Mental Health), OsloMet (Labor Research Institute and Faculty of Health Sciences), The Early Intervention in Psychosis Advisory Unit for South East Norway (TIPS Sør-Øst) and the participating units, and it will end in 2022.

We have established a program of measures for family involvement in the CMCHs and we will evaluate whether these measures can improve the health and quality of life of both the users and their families. Your experiences are important because we need knowledge of how we can optimilise this collaboration.

In this interview, we are particularly interested in your experiences with family involvement. By “family involvement" we mean collaboration with the people who are important to you in your everyday life, and especially those who are closest to you. We would like you to use examples in the interview.

The interview will last for approximately one hour, and will be audio recorded and written down afterwards. Everything you say will be kept confidential and anonymised. Details that can identify you or others, such as names and locations, are removed when the interview is written. It is voluntary to participate, and you can withdraw at any time without explanation. It is possible that we will contact you again on a later occasion for supplementary information.

The participant fills in the consent form and returns page 3 to the researcher if they have not done this beforehand together with the therapist.

Start audio recording.

Overview of topics to be covered during the interviews

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? (*If necessary, exemplify: information, collaboration, support, seminar/course/group etc.)*
    - *If the participant does not mention family psychoeducation (FPE)/conversations:* Have you and your family participated in FPE and/or had one or more conversations about family involvement at the CMCH?
    - *If yes:* Who participated in these conversations, was the participant allowed to decide for himself who should participate, the number of participants, and performance?
    - *If no:* What is the reason(s) why your family has not been involved?
    - *(See Supporting questions Part 1 if necessary)*
    - Do you know if your relatives have had a conversation alone with your therapist or others at the CMCH? *If yes:* What do you think about that?

Experiences with- and significance of family involvement

- What has the family involvement meant to you?
    - How was it for you to participate in...? (*fill in what the participant has said about the involvement/collaboration). (See Supporting questions Part 2 if necessary)*
        - 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?
    - *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? *(See Supporting questions Part 3 if necessary).*
    - Was the form of collaboration important to your experience?
    - *If negative:* In what way do you feel that participation in FPE has been negative? *(See Supporting questions Part 4 if necessary)*

- What do you think the family involvement has meant to your family?
    - Do you perceive that your family/network has received support and help to understand what you are struggling with?
    - Have they been more helpful to you afterwards?

- For family involvement being helpful to you:
    - What do you want from your therapist?
    - What do you want from your closest relatives?

- Is there anything else you would like to share?

Supporting questions

Part 1 Reasons why the family has not been involved:

- Conflicts within the family
- Experiences of not being understood
- Worries and feelings of guilt in relation to that the family will be even more burdened if involved
- Negative thoughts about self-worth
- The illness is personal and private
- Shame and stigma
- The family gets too involved
- Care failure, other traumatic experiences (this should possibly not be thematised if the patient himself does not bring it up)

Part 2 After you and your family… (*fill in what the participant has said about the involvement/collaboration):*

Did you:

- Cope better socially?
- Feel that you had someone to turn to if you needed help?
- Get along well with your closest relatives?
- Experience increased or reduced mental health problems?
- Feel more or less satisfied with your life overall?
- Follow up on the treatment as agreed? (medication, appointments, other).

Have your relatives:

- Been more or less considerate towards you?
- Showed more or less understanding of your difficulties?
- Been more or less critical of you?
- Been more or less dissatisfied with what you do?
- Been hassling you more or less?
- Helped you in better ways?

With in the family:

- Is it easier to solve problems?
- Is it easier to communicate?

Did your therapists:

- Listen to what you consider is most important for your health situation?
- Take into account what is most important to you when choosing what to do next?

Part 3 FPE – What has been useful to you?

- Gaining knowledge and understanding about my own difficulties
- More openness/talk about psychological problems and symptoms
- Getting help to reduce stress
- Getting help to balance activities

- Getting support and help from the family
- Getting help to improve communication with in the family
- Getting help to solve everyday problems and challenges
- Getting help to prevent relapse and crisis

Part 4 FPE – Has family involvement been negative in any way?

- What happened that worsened your situation?
- How was this handled by the group leaders/therapists?
- Is there any particular topics you talked about that was difficult to you?
- How was it for you to participate in these meetings?
- What could have been done differently?