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Doctoral thesis

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“Mental illness is a family experience – shared together but suffered separately – and often changes families lives and relationships forever” (Marshall et al., 2010).

Sammendrag

Tittel

Familiefokus i tanke og handling! Familier som lever med psykisk lidelse. Perspektiver på hverdagen, familie sentrert omsorg og kvalitet i kommunalt psykisk helsearbeid.

Tema for avhandlingen

Tema for avhandlingen er oppfatninger om hverdagen i familier som lever med psykisk lidelse, støtte til familiene fra helsepersonell i kommunalt psykisk helsetjeneste, samt kvalitet i kommunalt psykisk helsearbeid, fra et familieperspektiv. Videre er det undersøkt familier og helsepersonells erfaringer fra deltagelse i Familie-støttende samtaler i kommunal psykisk helsetjeneste.

Metode:

Kvalitativ og kvantitativ metode ble benyttet. Kvalitative data ble samlet inn gjennom familieintervjuer av syv familier med unge voksen med psykiske lidelse (n=17) og individuelle intervjuer med helsepersonell (n= 13) i kommunal psykisk helsetjeneste. Kvantitative data ble innhentet fra 43 voksne pasienter med psykisk lidelse og 43 familiemedlemmer i kommunal psykisk helsetjeneste med følgende spørreskjema; Family Perceived Support Questionnaire (ICE-FPSQ), Quality in Psychiatric Care - Community Out-Patient (QPC-COP) og Community Out-Patient Next of Kin (QPC-COPNK).

Hva er de viktigste resultatene i avhandlingen?

Familiene balanserte mellom å slippe tak for å gjøre det mulig for den unge voksne med psykisk lidelse å bli uavhengig, samtidig være nær for å støtte ham/henne med å fullføre utdannelse, stå i jobb og ha et sosialt liv. De unge voksne prøvde å ikke være en byrde, men lengtet etter at familiemedlemmer skulle forstå dem og deres situasjon. Familiemedlemmene håndterte hverdagslivet så godt de kunne, men følte mangel på støtte, respekt, og bli invitert til å ta del i det psykiske helsearbeidet. Familiemedlemmene var betydelig mer negativ enn pasientene til kvalitet i kommunal psykisk helsetjeneste. Helsepersonell holdt tilbake informasjon selv om de unge voksne pasientene hadde samtykket til at familiemedlemmer skulle få innsyn. Familie støttende samtaler ble erfart av familiene som noe nytt, ubehagelig, samtidig nyttig og trygt og gav mulighet til å dele og reflektere over familiens oppfatninger om hverdagen, finne nye oppfatninger og muligheter i hverdagen. Familie støttende samtaler hjalp helsepersonell, som supplement til ordinære tiltak, å strukturere involvering av familiemedlemmer, men med behov for å justere samtalemodellen.

Navn kandidat: Lisbeth Kjelsrud Aass
Institutt: Helsevitenskap, Gjøvik
Veiledere: Øyfrid Larsen Moen, Hege Skundberg- Kletthagen og Agneta Schröder
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ABSTRACT

Think Family, Work Family! Families living with mental illness. Perspectives of everyday life, family-centered support, and quality of community mental healthcare.

Aims: The overall aim of this thesis was to illuminate perceptions of everyday life, family support from mental healthcare professionals, and quality of community mental healthcare from the perspectives of families living with mental illness. A further aim was to elucidate families' and mental healthcare professionals' experiences of Family Centered Support Conversations (FSCS) in community mental healthcare.

Methods: A descriptive design with qualitative and quantitative methods was used. Qualitative data were collected by means of family interviews with seven families living with a young adult suffering from mental illness (n= 17 participants) (**I, III**) and individual interviews with mental healthcare professionals (n= 13) (IV). The data were analyzed using phenomenography (**I, III, IV**). Quantitative data were collected from adult patients (n= 43) suffering from mental illness and family members (n=43) (**II**) in community mental healthcare using the Family Perceived Support Questionnaire (ICE-FPSQ), the Quality in Psychiatric Care − Community Out-Patient (QPC-COP) and Out-Patient Next of Kin (QPC-COPNK). The data were analyzed using non- parametric statistics (**II**).

Main findings: Families balanced between letting go and enabling the young adult to become independent while remaining close to help him/her complete education, work and have a social life (**I**)**.** The young adults tried not to be a burden, but still longed for family members to understand them (**I**). Family members intervened as best they could (**I**), but felt there was a lack of support and respect and no invitation to take part in the mental healthcare (**II**). Family members reported significantly lower quality of community mental healthcare than patients (**II**). Healthcare professionals held back information although young adult patients had consented to give family members insight (**I**). Athough the FCSC was experienced as new and uncomfortable, the families also regarded it as beneficial and safe **(III).** It facilitated an opportunity to share and reflect on the family`s beliefs, and enabled them to find new beliefs and opportunities in everyday life (**III**). The FCSC helped healthcare professionals to structure the involvement of family members as a complement to care as usual, although there was still a need to adjust the intervention (**IV**).

Conclusions: Young adults suffering from mental illness are reliant on support from family to manage everyday life. Mental healthcare professionals play an important role in facilitating a safe environment for sharing beliefs and bringing strengths and resources to the front seat in family-centered support conversations. When family are included as part of the mental healthcare team, this enhances their ability to be supportive.

SAMMENDRAG

Familiefokus i tanke og handling! Familier som lever med psykisk uhelse. Perspektiver på dagliglivet, familie sentrert omsorg og kvalitet i kommunalt psykisk helsearbeid.

Hensikt: De overordnede målene var å belyse fra et familieperspektiv oppfatninger om hverdagen i familier som lever med psykisk lidelse, familiestøtte fra helsepersonell og kvalitet i kommunalt psykisk helsearbeid. Videre belyse familier og helsepersonells erfaringer fra Familie sentrerte støttesamtaler (FCSC) i kommunal psykisk helsetjeneste.

Metode: Kvantitativ og kvalitativ design ble benyttet. Kvalitativ data ble samlet inn med familieintervjuer av syv familier med unge voksen med psykiske lidelse (n=17) (**I, III**) og individuelle intervjuer med helsepersonell (n= 13) i kommunal psykisk helsetjeneste **(IV).** Data ble analysert ved hjelp av fenomenografi (**I, III, IV**). Kvantitative data ble innhentet fra 43 voksne pasienter med psykisk lidelse og 43 familiemedlemmer (**II**) i kommunal psykisk helsetjeneste med følgende instrument; Family Perceived Support Questionnaire (ICE-FPSQ), Quality in Psychiatric Care - Community Out-Patient (QPC-COP) og Community Out-Patient Next of Kin (QPC-COPNK). Analysert med ikke-parametrisk statistikk (**II**).

Hovedfunn: Familiene balanserte mellom å slippe taket og gjøre det mulig for den unge voksne å bli uavhengig, men være nær for å hjelpe ham / henne med å fullføre utdannelse, jobbe og ha et sosialt liv (**I**). De unge voksne prøvde å ikke være en byrde, men lengtet etter at familiemedlemmer skulle forstå dem (**I**). Familiemedlemmene håndterte hverdagslivet så godt de kunne (**I**), men følte mangel på støtte, respekt, og bli invitert til å ta del i det psykiske helsearbeidet (**II**). Familiemedlemmene rapporterte betydelig lavere kvalitet i kommunalt psykisk helsearbeid enn pasientene **(II).** Helsepersonell holdt tilbake informasjon selv om de unge voksne pasienter hadde samtykket til at familiemedlemmer skulle få innsyn (**I**). FCSC ble erfart av familiene som noe nytt, ubehagelig, samtidig nyttig og trygt (III) og gav mulighet til å dele og reflektere over familiens oppfatninger, finne nye oppfatninger og muligheter i hverdagen (**III**). FCSC hjalp helsepersonell, som supplement til ordinære tiltak å strukturere involvering av familiemedlemmer, men med behov for å justere samtalemodellen (**IV**).

Konklusjon: Unge voksne med psykisk lidelse er avhengige av støtte og hjelp fra familien til å håndtere hverdagen. Helsepersonell i kommunal psykisk helsetjeneste har en viktig rolle med å tilrettelegge for familie- sentrerte støttesamtaler og som et trygt sted å møtes for å dele oppfatninger og løfte fram styrker og ressurser. Støtte og inkludering av familien som en del av helseteamet styrker evne til å være støttende når en lever med psykisk lidelse.

Table of contents

ORIGINAL PAPERS

This thesis is based on the following four papers (**I-IV**), which will be referred to by their Roman numerals:

I. Aass L.K., Skundberg-Kletthagen, H., Schröder A., Moen, Ø.L. (2020) It’s Not a Race, It’s a Marathon! Families Living with a Young Adult Suffering from Mental Illness, *Issues in Mental Health Nursing*, 42:1, 15-23. https://doi.org/10.1080/01612840.2020.1770384

II. Aass, L.K., Moen, Ø.L., Skundberg-Kletthagen, H., Lundqvist, L-O., Schröder, A. (2020). Family support and quality of community mental health care: Perspectives of families living with mental illness. *Journal of Clinical Nursing, June, 2021*. https://doi.org/10.1111/jocn.15948

III. Aass, L. K., Skundberg-Kletthagen, H., Schröder, A., & Moen, Ø. L. (2020). Young Adults and Their Families Living With Mental Illness: Evaluation of the Usefulness of Family-Centered Support Conversations in Community Mental Health care Settings. *Journal of Family Nursing*, *26*(4), 302-314. https://doi.org/10.1177/1074840720964397

IV. Moen, Ø. L, Aass, L. K., Schröder**,** A., Skundberg -Kletthagen, H. (2021). Young adults suffering from Mental Illness; Evaluation of the Family Centered Support Conversation Intervention from the perspective of Mental Health Care Professionals’. *Journal of Clinical Nursing, May 2021,* https://doi.org/10.1111/jocn.15795

Introduction

Globally, mental illness affects one in ten people at any one time, and accounts for a large proportion of the non-fatal disease burden owing to its frequency, chronicity and disabling effects. It is among the leading causes of overall disease burden (measured as disability-adjusted life years) (World Health Organisation, 2019). Depressive and anxiety disorders are globally ranked among the top causes in terms of years lived with disability and are estimated to affect over 200 million people (Vos et al., 2017; World Health Organisation, 2017b). The estimated prevalence of mental illness in Europe in 2015 was 110 million, equivalent to 12% of the entire population at any one time (World Health Organization, 2019). In Norway, over a 12-month period, around 16–22% of the adult population will experience a mental illness (Institute of Public Health, 2016).

Mental illness is affected by various factors, and must be seen as an interaction between biological, genetic, psychological, social and cultural phenomena. It can be described on the basis of the nature, degree and duration of the symptoms, which in return have major significance for the course of the illness. For the individuals concerned, the consequences include suffering caused by symptoms, lower quality of life, increased burden, the loss of independence, decline in work capacity and lower economic productivity (Doran & Kinchin, 2019), poorer social integration (Wang et al., 2018), and reduced life-expectancy (Thornicroft, 2013).

Living with mental illness may have important consequences, both for the individuals suffering from mental illness and for their families. Both the number of adult patients in psychiatric institutions and lengths of stay have been drastically reduced in the western world, including Norway (Directorate of Health, 2020). Most people with mental illness live outside institutions, and this is a significant family concern due to the substantial burden mental illness places on patients and their family (Skundberg Kletthagen, 2015). When living with mental illness, the family perform complex duties similar to those carried out by healthcare professionals (Collins & Swartz, 2011), and they play an important role in care across the entire illness trajectory (Kokorelias et al., 2019) even when family members do not live with the person suffering from mental illness (Johansson et al., 2010).

Young adults are prioritized in mental healthcare in Norway (Ministry of Health and Care Services, 2016). Mental illness may significantly impact on school dropout and unemployment and be characterized by a low level of independent living and lack of community support (Woodgate et al., 2017). In this thesis, special attention is given to the findings from the perspectives of families living with young adults aged 18– 25 years suffering from mental illness in community mental healthcare. Research gaps remain, as well as inadequate responses to mental illness in young adults (Mei et al., 2020). Moreover, the need for family-centered care in mental healthcare is an ongoing challenge, which is largely unmet (Foster et al., 2016). It is important that families living with mental illness are included in the process of developing the concept of quality of community mental healthcare (Schröder, 2006). Although we know that the provision of high-quality community mental healthcare is vital to both patients and families in reducing some of the burden (Brunt et al., 2019; Johansson et al., 2013; Lundqvist et al., 2012), there is a persistent gap due in part to the lack of descriptions and measures from the perspective of families (Kilbourne et al., 2018; Sveinbjarnardottir et al., 2012).

Through exploring everyday life, family-perceived support and quality of community mental healthcare, this thesis contributes to viewing families as a unit. Furthermore, experiences of Family Centered Support Conversations are examined from the perspectives of families and mental healthcare professionals as well in community mental healthcare settings. Everyday life is understood as the life that is lived, and includes all daily activities, tasks, and responsibilities that people have (Gullestad, 1989).

My interest in this area of research derives from my work in clinical practice as a psychiatric nurse and as a university assistant professor in the field of mental health in nursing education. My impression is that the focus of clinical practice and nursing education is on the individual suffering from mental illness, and the family is not seen as an essential part of the patient's everyday life and care unit. Consequently, the provision of family care is sparse. This is a major concern since families living with mental illness must shoulder great responsibility, especially young adults suffering from mental illness and their family. Given the fact that they are not prepared or qualified to support the individual with mental illness or nurture their own well-being, I wanted to contribute knowledge about their situation and the interventions aimed at supporting families as a unit.

Background

This chapter sets the scene, introduces the background and the theoretical and conceptual framework and rationale. It also presents the overall and specific aims of this thesis.

Young adults suffering from mental illness

The years between 18–25 can be described by a developmental concept referred to as emerging adulthood. This is a distinct period subjectively in terms of identity exploration. It is culturally constructed and exists in countries (such as Norway, where this thesis is formulated) that allow young adults an extended period of independence (Arnett, 2014). Illness and developmentally related transitions to adulthood (Arnett et al., 2014) involve the family as they experience the changes that occur (Meleis, 2010). Significantly, young adults suffering from mental illness need support from their family to manage everyday life (Andershed et al., 2017; Sommer et al., 2018), and while they strive to recover (Lindgren et al., 2015).

In Norway and globally, mental illness is a crucial health issue and the greatest public health challenge facing the young adult population (Gustavson et al., 2018; World Health Organisation, 2017a). About 10% of the young adult population have so much difficulty with anxiety, depression, psychosomatic disorders, behavioral or substance abuse problems that they need professional help (Ministry of Health and Care Services, 2016; Sletten & Bakken, 2016). Suicide is identified as the second leading cause of death among young people aged 15–29 worldwide (World Health Organization, 2014). Young adults suffering from mental illness experience unremitting fatigue, physical malaise, loss of motivation leading to poor academic performance, loss of self-esteem and lack of desire to socialize with friends and engage in family activities (McCann et al., 2012). Mental illness also impacts on independent living, establishing a family (Gustavson et al., 2018; Stengård & Appelqvist-Schmidlechner, 2010) and the life of family members (Woodgate et al., 2017).

Despite their manifest needs, young adults have the lowest rates of access to mental healthcare, largely because of poor awareness and help-seeking and a preference for self-reliance (Gulliver et al., 2010). Structural and cultural flaws are reported within the existing care systems as well as the failure to recognize the importance of investing in youth mental health (McGorry et al., 2014b). Within the target group (N = 4313) who receive community mental healthcare in Norway, 77% have some degree of functional impairment due to mental health illness, and fail to meet normal requirements for functioning in respect of friends, work, school, appointments, and public transport. However, they can take care of daily tasks and personal hygiene to a reasonable extent (Hustvedt et al., 2019). They value a youth-friendly approach that involves mental healthcare professionals fostering open and friendly engagement, responding promptly to problems with appointments and ensuring continuity of care (Woodgate et al., 2017).

To sum up, to the author`s knowledge, no study has been published from the perspectives of young adults suffering from mental illness and their family in community mental healthcare. Given the prevalence of mental illness in young adults, and the consequences of mental illness at the individual and family level, there is a need to arrive at an increased understanding of the meaning families assign to living with mental illness in everyday life and their experiences of family support in community mental healthcare. Descriptions of everyday life from their perspective is important information for both mental healthcare professionals and the municipality as healthcare provider when it comes to improvement of family care and development of interventions.

Families living with mental illness

Across cultures, family members often play important and even critical roles in the lives of the individual who suffers from mental illness (Hinton et al., 2019). Parents (Johansson et al., 2010, 2012; Weimand et al., 2011), spouses, grown-up children (Skundberg-Kletthagen et al., 2014), and siblings (Chen & Lukens, 2011) are frequently the care providers. The historical view that the family was to blame for the mental illness has fortunately been challenged. It is now believed that families can have a significant impact on the recovery of mentally ill family members. In line with the current diversity of family structures, the concept of family in this thesis is not limited to the family as a structure characterized by blood bands (Whall, 1986), but significant others are included as part of the family: a friend or a distant relative rather than parents or sibling, depending on the patient's perception of who is supportive. Moreover, the family is viewed as a system, implying that members of the family mutually affect each other as well as affecting the family system as a whole (Bateson, 1972). Notably, after the age of 18, the patient must formally consent to allow their family member access to information and to be involved in treatment and care in mental healthcare.

Family members' caring role for mentally ill people is diverse and situational (Directorate of Health, 2017). It may include different kinds of support: emotional, maintenance of social and living skills, financial, and monitoring signs for illness and relapse prevention (Flyckt et al., 2013). Being part of such a family is a precarious balance , and involves positive experiences (Ewertzon et al., 2010) with family members becoming more understanding and discovering inner strength. However, it also involves negative aspects such as continual worries about care and relapse (Skundberg-Kletthagen et al., 2014), feeling isolated (Ewertzon et al., 2012), deterioration in own physical health (Weimand et al., 2010), financial worries (Ahlström et al., 2009), concerns about adult life for the individual suffering from mental illness and dependency on family in the future (Moen, 2014).

There is a gap between the substantial burden put on families living with mental illness (Weimand et al., 2011) and the availability of resources and support for the families to manage and reduce it (World Health Organisation, 2019). Family members require collaboration, information, and support from the mental healthcare, but confidentiality concerns often prevent such needs from being met (McNeil, 2013; Weimand et al., 2011). Despite their contributions and unique knowledge of the people they care for, family are seldom recognized as members of the care team (Moen et al., 2020) and too often not offered appropriate support to help them in their role. Regardless of mental healthcare professionals' desire to involve the family as a unit in care, their daily clinical practice focuses on patient treatment and follow-up, often in accordance with the patient`s own wishes (Skundberg-Kletthagen et al., 2020).

To sum up: As far as the author is aware, no study has been found from the perspectives of families living with mental illness in community mental healthcare. Given their crucial role related to positive and negative aspects of living with mental illness, there is a need to acquire increased understanding of the family's experiences in managing everyday life. This also applies to the perceptions of mental healthcare professionals and community mental healthcare. Further knowledge is also needed about interventions related to supporting the family and the quality of care given. This knowledge would benefit both managers responsible for mental healthcare in the municipalities and mental healthcare professionals and provide a context for improving family care and developing new evidence-based interventions and delivery of those currently existing.

Community mental healthcare and family support

Adult mental healthcare in Norway is organized at three main levels: national level, health region level, and municipality level (community level). From the mid-1980s, community mental healthcare – care close to people's home (Thornicroft & Tansella, 2009) was the goal for psychiatry in Norway since the number of hospital beds available for patients with mental health problems was steadily declining (Directorate of Health, 2015). User-oriented local- and home-based care are emphasized, with a respectful partnership between patients, family and professionals, with a duty to increase family involvement and provide a greater degree of support to family-members (Borg et al., 2009; Directorate of Health, 2014; St.meld. 47, 2008). Youth mental healthcare models strive to create youth-friendly care that provide effective, appropriate, and meaningful care to young people and their families (McGorry et al., 2014a).

Family psychoeducation may improve patient outcomes such as patient recovery and functioning, relapse and rehospitalization rates (Brady et al., 2017; MacFarlane, 2011). Traditionally the primary goals of Family psychoeducation have been improved outcomes for the patient, so there is now an increasing focus on improving family members' well-being as well in recognition of the fact that the two are often interdependent (Lucksted et al., 2012). Support interventions with family and mental healthcare professionals help to educate or inform the family in relation to the experience of the illness, and enable families to handle the burden of illness and accompanying emotions (Ewertzon & Hanson, 2019; Shajani & Snell, 2019; Sveinbjarnardottir et al., 2013). By including family in care, family functioning may improve (Östlund & Persson, 2014). However, mental health professionals continue to view the patient and their alliance with him or her as their prime responsibility (Johansson et al., 2014; Weimand et al., 2013a). Including family members as a natural part of the care unit is found demanding, and distress arises from challenging and sometimes competing or contradictory demands (Weimand et al., 2013a).

To sum up: Although community mental healthcare have a duty to increase family support and involvement, the patient is still seen as the prime responsibility. For mental healthcare professionals, including the family as a natural part of the team in community mental healthcare requires healthcare managers and providers to make a conceptual shift, even a paradigm shift. It implies a need to take into account the interaction and reciprocity between suffering from mental illness and family functioning, and interaction between mental health professionals and the families in their care. Measuring family support from the perspectives of families helps us to get an idea of the influence and effectiveness of family support in two domains of family functioning – emotional and cognitive (Sveinbjarnardottir et al., 2012).

Family-centered care

As community mental healthcare emerged in the USA, Canada, Australia and Europe (Allen & Petr, 1998; Nicholson et al., 2015), the duty of providing care shifted back to the family, and the concept of family-centered care emerged. Family-centered care (FCC) is not a single intervention but rather a philosophical care approach where dignity, respect, information-sharing, participation, and collaboration are core values (Bell, 2011). The FCC approach implies that healthcare professionals invite and respect the patient's family members as partners in the caregiving (Johnson, 2000; MacNeil & Jaggers, 2013). Families and healthcare professionals engage in a relational process (Ho, 2020), to elicit the expertise of the family in their illness experience (Wright & Bell, 2009), and healthcare professionals' expertise in assessing the family and conceptualizing problems. Furthermore, they must agree on ways to promote family health, manage health concerns, and alleviate illness suffering (Shajani & Snell, 2019).

FCC may include fixed interventions geared to support and strengthen family resources when living with persons suffering from illness. Family-centered interventions are mostly implemented where the patient is a child or adolescent with physical chronic illness (Kokorelias et al., 2019) or mental illness (Gisladottir & Svavarsdottir, 2017; Svavarsdottir et al., 2018). Similar concepts are reported in adult inpatient psychiatric care (Svavarsdottir & Gisladottir, 2018; Sveinbjarnardottir & Svavarsdottir, 2019; Sveinbjarnardottir et al., 2013). The Family Centered Support Conversation (FCSC) model evaluated in this thesis (III, IV) is one such fixed intervention involved in FCC.

Notably, FCC interventions are not always required, and contradictions may exist. For example, family assessment may compromise the individuation of a family member and constrain trust in mental healthcare professionals. The family may state that they have no wish to pursue family meetings even though recommended (Shajani & Snell, 2019).

To sum up: Family-centered care has an important influence on mental healthcare philosophy and orientation (Dempsey & Keen, 2008; Foster et al., 2016). Even so, to our knowledge, working in line with the FCC approach has received little attention in community mental healthcare settings. To the author`s knowledge, no study has been found of FCC interventions from the perspectives of families living with mental illness and mental healthcare professionals in community mental healthcare. It must surely be important to acquire knowledge of both perspectives on the development of interventions and improvement of the quality of community mental healthcare.

Quality of care

The concept ‘Quality of care’ is complex and multidimensional. According to Donabedian (1988), the essence of quality is constituted by the balance of benefit and harm, related to the process of care in all its parts. The goal of high-quality care is to maximize patient welfare. In the context of the mental healthcare, the definition of quality has not yet been universally agreed upon. However, quality of care from the patient’s perspective is defined by Schröder et al. (2007b) as consisting of five dimensions: *Dignity is respected, Sense of Security with regard to care, Participation in the care, recovery and care environment*. These represent patients’ expectations of high-quality care.

Unfortunately, mental healthcare is often not delivered in accordance with evidence-based and commonly agreed professional standards, resulting in poor quality with far-reaching and considerable consequences for individuals, families and society (OECD, 2010). Notably, residents in housing support report quality as mainly high and connected to the staff’s capacity to meet them and provide care with kindness and respect (Rask et al., 2017). Others report that the quality of care facilities has several deficiencies and improvements are needed in staff training, environmental aspects, and participation (Brunt et al., 2019). Patients’ perception of the quality of care in mental healthcare is often used in determining the quality of the service (Schröder et al., 2010). Nevertheless, family judgments about service quality are seldom measured in mental healthcare (Schröder et al., 2007a), although addressing quality of care from the perspective of both the patients and family is recommended (Thornicroft et al., 2016). Quality measurement is a key driver in transforming the healthcare system, and routinely measuring quality using performance measures derived from evidence-based practice guidelines is an important step.

To sum up: No clear pattern in respect of how families perceive the quality of community mental healthcare has emerged, since previous studies have focused on patients (Schröder et al., 2006), and family members (Schröder et al., 2007a) individually. It is vital to acquire knowledge, and there is a need for healthcare managers in community mental healthcare to obtain valid information about the quality of care from a family perspective in order to identify family needs and make decisions on how to provide the best care, apply effective strategies to improve quality of care and reduce disparities. This is of crucial importance since the family with its stability and function not only influences quality of care in the home but also emotional and physical patient outcomes.

Theoretical and conceptual framework

This thesis is theoretically and conceptually guided by the Illness Beliefs Model (Wright & Bell, 2009), and the Calgary Family Framework (Shajani & Snell, 2019) including the Calgary Family Assessment and Calgary Family Intervention Model. The conceptual framework integrates theories of family systems, cybernetics, communication, reflection, and change. These theories are familiar and traditional in family-oriented ideology except for the strong conceptual influences of post-modernistic thoughts and the biology of cognition. Post-modern philosophy emphasizes multiple views, opportunities and lives (von Bertalanffy, 1972), and pluralism is a key notion in post-modern thinking. As a theory, it states that reality is composed of a plurality of existence, thus making the framework and models appealing to work with, in mental healthcare (Shajani & Snell, 2019; Wright & Bell, 2009).

Illness Beliefs Model

The Illness Beliefs Model's (Wright & Bell, 2009) approach to clinical practice brings to the foreground an emphasis on beliefs, attitudes, premises, values and assumptions held by individuals and families. When illness emerges, beliefs become affirmed, challenged and/or threatened. Patients, family members and healthcare professionals have beliefs that both facilitate and constrain their lives, relationships, behavior, and illness suffering. Healthcare professionals must recognize that there are as many ways of understanding and experiencing illness as there are families experiencing it (Wright & Bell, 2009), and acknowledge that living with illness (i.e. mental illness) can be perceived in different ways (Maturana & Varela, 1992). Thus, it is through interaction in communication and reflection about the mental illness and/or everyday life that individuals' beliefs, strengths, resources, and boundaries related to the present problems in everyday family life are identified (Benzein et al., 2008). Suffering may be alleviated by offering family-centered conversations in a context of changing beliefs including illness beliefs, constraining beliefs and facilitating beliefs (Wright & Bell, 2009).

Calgary Family Framework

In accordance with the Calgary Assessment Model, family assessment should consist of structural, developmental, and functional categories. Structural assessment examines who belongs to the family, connections among family members and the family context. The use of the genogram (family tree) – a clinical tool particularly helpful in outlining significant relationships (McGoldrick et al., 2008) – provides a way of engaging individuals in the family. Information about family structure and important personal relationships facilitates an opportunity to understand beliefs arising from family illness' experiences in everyday life. Developmental assessment identifies predictable and unpredictable events in everyday life. Predictable stages in a family life cycle are connected, for example, to the emotional process of transitions (Shajani & Snell, 2019). Developmental assessment is of importance with regard to families living with young adults suffering from mental illness in transitions to adulthood. Functional assessment identifies how individuals behave in relation to one another in routine everyday activities and expressive functioning (Shajani & Snell, 2019). The Calgary Intervention Model encourages health care professionals to intervene with a focus on family strengths and resilience in order to facilitate change by either promoting, improving or sustaining family functioning in any or all of the three domains – cognitions, emotions and behavior.

Rationale

This thesis adds new knowledge and strengthens evidence relevant to the perspectives of families living with adults suffering from mental illness and community mental healthcare professionals. As described and elaborated above, there seems to be a need for research regarding these young adults who are reliant on family support in everyday life. The focus on a family perspective contributes important knowledge about the impact of living with mental illness on everyday life, and how family member's cope. Although the value of engaging both patients and family in mental healthcare in a meaningful way is indisputable, acting on this can be challenging. The gap between the responsibilities put on the families and the availability of resources and support in community mental healthcare enabling them to manage everyday life and reduce the burden, highlights the importance of augmenting evidence of perceived support and quality of care from the perspectives of the families. Working in line with a family-centered care approach where the patient's family members are invited and respected as partners in the caregiving has received little attention in community mental healthcare settings. Given the lack of research, this thesis highlights the importance of strengthening the evidence on the usefulness of family-centered support conversations in community mental healthcare settings from the point of view of families and mental healthcare professionals.

Aims of this thesis

The overall aim of this thesis was to illuminate perceptions of everyday life, family support from mental healthcare professionals, and quality of community mental healthcare from the perspectives of families living with mental illness. A further aim was to elucidate families' and mental healthcare professionals' experiences of Family Centered Support Conversations in community mental healthcare.

The specific aims were as follows:

1. Explore families' perceptions of everyday life when living with a young adult suffering from mental illness (I).

2. Describe adult patients and family members' perceptions of family support from mental healthcare professionals, and quality of care in community mental healthcare. A further aim was to compare the perceptions of patients and family members (II).

3. Explore and evaluate how young adults living with mental illness and their families experienced the family intervention Family Centered Support Conversations (III).

4. Explore how mental healthcare professionals' experience and evaluate the use of Family-Centered Support Conversation Intervention (IV).

Methods

This chapter presents the philosophical foundation of this thesis, details of the overall design, methodological choices, the recruitment stage, data collection, pilot test, Family Centered Support Conversation (FCSC): pretest, education and skills-training seminar and procedure and overall analysis.

Study design

In the constructivist paradigm, reality exists within the participants' context, and many constructions are possible. When multiple interpretations of reality exists, there is no process by which the ultimate truth or falsity of the constructions can be determined (Kvale, 1992; Polit & Beck, 2012). Inquiry within constructivist approaches involves mostly qualitative data collection and analysis (Polit & Beck, 2012). However, the use of quantitative descriptive statistics for the purpose of description and comparison is also possible (Sandelowski, 2000; Sandelowski et al., 1989). Both qualitative and quantitative approaches were used in this thesis. The qualitative studies aimed to acquire deeper understanding of family everyday life when living with young adults suffering from mental illness, family, and healthcare professionals' experience of Family-Centered Support Conversation. The quantitative study aimed to acquire a broader insight into how families perceived support from mental healthcare professionals and the quality of community mental healthcare, by investigating families living with mental illness where there was a range of ages.

This thesis includes four scientific papers (I-IV) based on four studies performed in community mental healthcare in Norway. An overview of the studies in this thesis is presented in Table 1.

Table. 1. Overview of the four studies: design, participants, data collection and data analysis

Study	Design	No. of participants	Data collection	Analysis
I	Descriptive Explorative Qualitative	7 patients 10 family members	Qualitative Family interviews	Phenomenography
II	Descriptive Quantitative Cross-sectional	43 patients 43 family members	Questionnaire FPSQ QPC-COP/COPNK	Descriptive and comparative statistics
III	Descriptive Explorative Qualitative	7 patients 10 family members	Qualitative Family interviews	Phenomenography
IV	Descriptive Explorative Qualitative	13 mental healthcare professionals	Qualitative Individual interviews	Phenomenography

Qualitative studies (I, III, IV)

Phenomenography grasps the variety, similarities and differences of the phenomena: everyday life when living with mental illness (I), and how Family Centered Support Conversations (FCSC) are experienced and captured (III, IV). In this thesis, the author endeavors to capture qualitative data of the phenomena on a family level in studies I and III, and to identify multiple perspectives and mental healthcare professionals' perspectives of FCSC at individual level in study IV. Phenomenography takes a second-order perspective (Marton & Booth, 1997). Emphasis is on how everyday life and the FCSC appear to the participants – how they have come to experience it. Epistemologically, it is assumed that there are a limited number of qualitatively different conceptions of everyday life when living with mental illness and the FCSC that can be described. The conceptions are conceived in relation to both context and time, and may therefore vary not only among the participants, but also for the same person over time (Barnard et al., 1999). Everyday life when suffering from mental illness and the FCSC's significance depend on the patients, family members and mental healthcare professionals' cognitions.

Quantitative study (II)

In this thesis, a cross-sectional study with a descriptive design is used to collect quantitative data. This provides a picture of what might occur in the paired sample of patient and their family members at a particular time, with the aim of describing and comparing family-perceived support from mental healthcare professionals and the quality of community mental healthcare. There is no intention of looking for causal knowledge (Polit & Beck, 2012).

Study context

In Norway, the municipalities are responsible for the provision and co-ordination of free professional healthcare for people suffering from mental illness and their families in everyday life (Helse- og omsorgstjenesteloven, 2011) and play a key role in this (Brukerrettighetsloven, 1999). Health professionals in community mental healthcare for persons over 18 years old have different professions: primary physician (not included in this intervention), psychologist, registered nurse, public health nurse, social educator, social worker, nursing assistant, occupational therapist and physiotherapist. A number of these have supplementary education in mental illness. The responsibilities and tasks of these professionals with regard to the patient, are partly similar and partly different. Interdisciplinary cooperation is also a factor.
The municipalities included in this study varied in geographical extent and included urban city areas and rural agricultural or mountain areas, reflecting the variation in size of Norwegian municipalities (I-IV).

Family Centered Support Conversation (FCSC), education and skills-training program

The FCSC model and the educational and skills-training program was developed by the author at the Norwegian University of Technology and Sciences (NTNU), Department of Health Science, Gjøvik. A two-day seminar with healthcare professionals in community mental healthcare including psychiatric nurses, psychologists, social workers, and social educators with advanced training in mental health was carried out by the author, assisted by three colleagues with expertise in mental health, family nursing and advanced pedagogical and simulation skills. The seminar included an introduction to the theoretical framework, the use of the genogram and the family tree (Shajani & Snell, 2019; Wright & Bell, 2009), and intervening (circular) questions

(Benzein et al., 2012; Tomm & Liedén, 1989) followed by practical simulation-based training (Eggenberger & Regan, 2010).The simulation-based training included role-play with different scenarios with clinical vignettes from mental illness care related to families living with various mental health problems. This also included participation in a reflecting team observing behind a one-way mirror (Andersen, 1987, 1991). A debriefing-phase approach was used, promoting a reflexive learning process with the opportunity to develop metacognitive and non-technical skills through reexamination of the clinical encounters (Dreifuerst, 2009). After completing the seminar, the same mental healthcare professional took part in three conversations with participating families from their municipality. All worked in similar settings in community mental healthcare in Norway.

The pretest of the FCSC educational and skill-training program with 18 nurses taking a university course in advanced palliative care resulted in a decrease in theoretical input, increased time to practice skills in conducting family conversations and reflections/debrief afterwards.

Recruitment procedure

The informants in this thesis were recruited from community mental healthcare in municipalities in eastern and central Norway (I-IV).

Study I and III

Inclusion criteria for patient were: between 18−25 years of age, facing mental illness and strain, impaired function associated with distress, symptoms, and having diagnosable mental disorders. However, diagnosis was not required. Required living arrangements: alone or with family and/or friends and/or others and receiving treatment and /or care from community mental healthcare. Be able to speak and read Norwegian. *Exclusion criteria for patients* were: cognitive impairment; psychotic state, active alcohol or drug abuse, or living in a residential home for persons suffering from mental illness. *Inclusion criteria for family members* were: above 18 years of age and defined by the young adult to be in the family, and speak and read Norwegian. *Exclusion criteria for family members* were: cognitive impairment, psychosis, or active alcohol or drug abuse. Out of 26 municipalities requested to participate, five municipalities agreed to recruit participants**.** The managers supplied the email addresses of mental healthcare professionals in community mental healthcare who were then asked to participate by the author. Mental healthcare professionals in community healthcare asked young adults suffering from mental illness to participate, and one to two family members were recruited through the young adult asking them to participate in the study (Figure 1). When family members agreed, the patients submitted their names and telephone number to healthcare professionals. The participants differed in background characteristics such as sex, age and relationship to the patient. Characteristics of the participants are presented in Table 2.

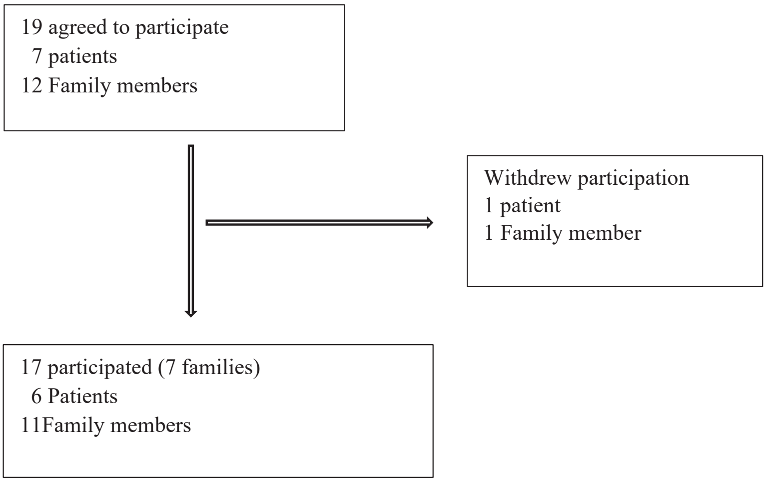

Figure 1. Overview of participants study I and II

Study II

Inclusion and exclusion criteria for patients and family members were the same as in studies I and III, except for the patient’s age – 18 years and upwards (no limit). Out of the 36 municipalities requested to participate, fifteen agreed to recruit participants. Recruitment took place over a period of 20 months from 2017 -2019. The managers supplied the email addresses of healthcare professionals in community mental healthcare who were asked to recruit participants by the first author. Oral and written information and questionnaires were handed out by the recruiting mental healthcare professionals to patients suffering from mental illness and any family members who wished to participate. Oral and written consent from each individual in this study was given. Out of the total of 86 participants, 33 patients and 33 family members had a family relation to one of the other participants – constituting 33 paired samples.

*Table 2. The background of the patients and family members (**I, II and III**).*

	Patients		**Family members**	
Study	**I** and **II**	**III**	**I and II**	**III**
Total	6	43	11	43
Age in years (median)	19−23	18-85 (36.6)	20−55	18-85(45.8)
Gender, n (%)				
Male	1 (16.6)	9 (20.9)	5(45.4)	16(37.2)
Female	5 (83.3)	34 (79.1)	6 (54.5)	27(62.8)
Family members relationship to the patient, n (%)				
Daughter				
Son				
Spouse/partner			1(9.0)	17(39.5)
Mother, Father/stepfather)			10(90.9)	25(58.1)
Other				1(2.3)
Living arrangements, n (%)				
Living alone	1(16.6)	15(34.9)		4 (9.3)
Living with others	5(83.3)	28(65.1)	11(100)	39 (90.7)
Educational level				
Basic education/Upper Secondary school,	5(83.3)	36(83.7)	7(63.6)	27(62.8)
Apprentice	1(16.6)			
College/University		7(16.3)	4(36.6)	15(34.9)
Missing				1(2.3)
Occupation				
Work /studying	1(16.6)	6(14.0)	7(63.6)	25(58.1)
Not working/retired	3(50.0)	26(60.5)	2(18.8)	8(18.6)
Other	2 (33.3)	11(25.6)	2(18.8)	10(23.3)

Study IV

Inclusion criteria for mental health professionals were: a minimum of a three-year bachelor's degree in health or social science, working in community mental healthcare with a minimum one year of work experience, and working with young adults from 18−25 years with mental health problems. A request for participants was sent to mental healthcare managers in nine municipalities. Recruitment took place during spring 2018. Nineteen mental healthcare professionals were recruited and participated in the FSCS educational and skills-training program. After the training program, they conducted FCSC in their work practice. Out of these (n=19), thirteen agreed to participate in an individual interview. The mental healthcare professionals were ten females and three men, aged from 36 to 61 years and qualified as occupational therapists, social workers, psychologist, social educators, and registered nurses. Twelve had further education in mental health and some also had training in family therapy and cognitive therapy. Work experience varied from one to twenty years in community mental healthcare.

Data collection

Qualitative data collection

Family interviews (I, III)

The data collection using family interviews took place from February 2018 to June 2018. In accordance with the wishes of the participants, the family interviews were conducted either at the family's home, at the mental health care service office, or the university. The interviews with each of the seven families (i.e., family members and young adults together) were conducted by the author of this thesis one or two months after the FCSC was completed. In the interviews, the young adults were first given the opportunity to talk about their experiences of the phenomena (Lepp & Ringsberg, 2002), and given time and space to answer questions. The author endeavored to use a language the young adults understood. When the young adult had no more to say or was reluctant to answer, family members were asked the same questions. Throughout the family research interview, the dialogue alternated between the family and the interviewer asking questions. The interviews lasted 50‒65 minutes and were audio-taped and transcribed verbatim by the author.

Family interview guide

An interview guide with two open-ended questions was used to invite the families to freely narrate their perceptions of everyday life (I) and their experience of the FCSC (III). The initial question asked of all participants was: '*How do you perceive family everyday life when suffering from or living with mental illness*?'(I). Furthermore, '*You have participated in three FCSCs. How did you experience the FCSC?'*(III). The focus was on how everyday life and the conversations were experienced and what was experienced. Some family members shared spontaneously while others needed time to loosen up. When silence occurred and/or to acquire a deeper sense of the experience/perceptions and variation in the conceptualization, probing questions like: '*Can you tell me more?', 'How?', 'Who?' and 'Can you give an example*?' *'Has it always been like this?* were used to encourage the family to describe more of their perceptions of everyday life (I) and experiences of the FCSC (III). The participants' response was the basis for further questions. This facilitated a dialogue alternating between the family and the interviewer asking questions, but occasionally the researcher had to get the interview back on track to focus on the phenomena.

Pilot test

Prior to the family interviews (I, III) the open-ended questions were pilot-tested (Kallio et al., 2016), by interviewing a family with young adult. The aim was to simulate an interview situation and gain information about the implementation of the family interviews (Åstedt-Kurki et al., 2001). Pilot-testing enabled the interviewer to decide if there were any flaws or limitations in the design (Chenail, 2011; Turner, 2010), and how much time was needed for each session (Cridland et al., 2015). The pilot test revealed the importance of the interviewer directing attention to the young adult first, giving them time and space to answer questions and letting the family members listen and wait.

Individual interviews (IV)

Two members of the research group carried out a qualitative data collection using individual interviews in the mental health professionals' workplace during spring 2018. The initial question was, *'Can you please describe your experiences of family-centered support conversations?*' To acquire a deeper sense of the perceptions and variation in the conceptualization, follow-up questions such as *'Could you explain….?', 'Is it always like this?*' and *'Could you please tell more…?'* were used. The interviews lasted from 43 to 61 minutes with a median time of 44 minutes.

Procedure for Family Centered Support Conversations

The Family Centered Support Conversation (FCSC) model in this thesis was operationalized in three conversations within a therapeutic relationship including young adults suffering from mental illness, those designated by the young adult as belonging to the family (1 or 2) and mental healthcare professionals (1 or 2). Mental healthcare professionals conducted FCSC with families living with a young adult suffering from mental illness as follows:

First Session. Each family member is invited to relate their narrative about their experiences and beliefs in relation to everyday life. Family structure, development, and function are explored and assessed in order to later reflect on these aspects of family functioning, and the strengths and resources that can have an impact on everyday family life.

Second Session. The focus of the second session is on cognitive, affective and behavioral domains of family functioning, and strengths and resources within and outside the family. The impact of problems/illness on the family is assessed. Problem-solving skills, coping strategies, and strengths are elicited, and change invited. Aspects of family functioning, strengths, and resources within and outside the family are reflected on.

Third Session. The focus of the third session is on families' experience of everyday life and support strategies for the future. Families are commended for individual and family strengths, competencies, and resources. While three conversations are recommended, the healthcare professional must evaluate if families need more than three conversations. If families need additional support conversations, they contact the mental healthcare professionals.

Quantitative data collection (II)

A quantitative data collection using a questionnaire took place from October 2017 to June 2019. Patients and their family members who met the inclusion criteria (see page 28) and were willing to participate, were invited to complete the questionnaires individually and return them by mail to the author. An ID code labelling A for patients and B for family members made it possible to send reminders, and to link patient and family member as a paired sample in the analysis.

The questionnaires

The questionnaire with 44 items consisted of two instruments about family support and quality of care. In addition, we collected background data on patient's and family members' age, gender, living arrangements, educational and occupational status, family members' relation to the patient and data about patients' and family members' current mental and physical state of health, whether they knew where to go if not satisfied with treatment/care and if they attended family support conversations.

To measure family-perceived support, the ICE Family Perceived Support Questionnaire (ICE-FPSQ) was used. The ICE-FPSQ is a self-administered questionnaire consisting of 14 items that covers patients' and family members' perceptions of family support. It measures two factors: *Cognitive support* (items 1-5) and *Emotional support* (items 6-14). All items are related to the statement: '*Community mental health professionals have*…..'. For instance, a Cognitive Support item is worded as follows: '[*Community mental health professionals have*] …….*offered us information and their professional opinion'* or an Emotional Support item: '*encouraged my family to become involved with the health care team and offered us support'*. Responses are made on a five-point Likert scale ranging from one (almost never) to five (all of the time). Family Perceived

Support Questionnaires, sum score ranged from 1 (low perceived support) to 5 (high perceived support). The score of the instrument ranged from 14 to 70 points, where a higher score represents better perceived support for families.

The original Icelandic FPSQ was translated into Norwegian and adapted to the Norwegian cultural context (FPSQ-N), using a forward and back translation process (Brislin, 1986). The translation process began with forward translation of the original ICE-FPSQ version into Norwegian by two bilingual native Icelandic nurses. A third bilingual layperson reviewed linguistic and cultural differences in the forward translation and another bilingual Icelandic nurse who was 'blinded' to the original Icelandic version then back translated from Norwegian to Icelandic (Brislin, 1970). Furthermore, for face validity test of the FPSQ-N, three persons filled in the questionnaire and commented on linguistical, and cultural concerns, and adapted the questionnaire by rewording some items to fit community mental healthcare context in Norway. The ICE- FPSQ is psychometrically tested with good results (Sveinbjarnardottir et al., 2012). The FPSQ-N has not yet been psychometrically tested but will be in a future study.

To measure quality of care, the questionnaire The Quality in Psychiatric Care − Community Out-Patient (QPC-COP) based on the original Swedish instrument Quality in Psychiatric Care–Out-Patient care (QPC-OP) (Schröder et al., 2011) was used. The QPC-COP is a self-administered questionnaire consisting of 30 items that cover patients' perceptions of quality of care in eight dimensions: *Encounter* (items 11,12,15,18, 20, 25), *Participation-Empowerment* (items 1, 5, 6), *Participation-Information* (items 13,14, 27, 29, 30), *Support* (items 19, 22, 23, 24), *Environment* (items 2, 4, 9), *Discharge* (items 8,17, 21), *Next of kin* (items 10, 28), and *Accessibility* (items 3,7,16, 26). Responses are made on a four-point Likert type scale, ranging from one (totally disagree) to four (totally agree). For all items, it was possible to answer, "not applicable". Quality of care ranged from 1 (lowest quality) to 4 (highest quality).

The original Swedish QPC-OP was translated and back-translated by professional translators into Norwegian and adapted to the community mental healthcare context. The QPC/COP-N (30 items) was tested for face validity with five patients in community mental healthcare filling in the questionnaire, responding in writing and orally. They were recruited from a community mental healthcare in a municipality not participating in this study. A checklist was used where each item was assessed as either ‘Clear and easy to understand’, ‘Acceptable’ or ‘Unclear and hard to understand’. Each item's importance for quality of care was rated on a five-point scale from 1 (Very important) to 5 (Of little importance) within each dimension. The questionnaire ratings resulted in changes in some wording for adjustment to a Norwegian community mental healthcare context. The Swedish version of QPC-OP has undergone psychometric testing with good results (Schröder et al., 2011)

The Quality in Psychiatric Care − Community Out-Patient Next of Kin (QPC-COPNK) is based on the QPC-COP and modified to cover family members’ perceptions of quality of care in the same eight dimensions as in the QPC-COP. Both the QPC-COP/COPNK instruments consist of the same number of items (n=30). The items are similar in content. Both instruments address the quality of care and treatment patients receive. The only difference is that in the QPC-COP, the wording is from the patient’s perspective as opposed to the family perspective in the QPC-COPNK. For example, an item in the Environment dimension is worded *‘I have confidence in the staff’* in the patient version, and *‘The patient has confidence in the staff’* in the next-of-kin version. The QPC-COP-N and QPC-COPNK-N have not yet been psychometrically tested but will be in a future study.

Data analysis

In this thesis, qualitative and quantitative methods of analysis will be employed separately to answer the research question.

Phenomenographic analysis (I, III and IV)

The data from the family (I, III) and individual interviews (IV) were analyzed as a ‘pool of meaning’ in line with the phenomenographic approach, by identifying qualitatively different ways to perceive a phenomenon (Marton & Booth, 1997) and move from an individual to a collective awareness. In this thesis, the phenomena were experiences of everyday life (I) and experiences of Family Centered Support Conversations (III, IV). The analyses were performed in accordance with the steps outlined by Dahlgren and Fallsberg (1991).

Data from studies I, III and IV were analyzed using Dahlgren and Fallsberg (1991) seven steps for analyzing data as follows: *1) Familiarization.* The transcripts were read through to become familiar with all details and acquire an overall impression in line with the aim of the studies**.** Studies I and III were analyzed separately. *2) Condensation.* Significant statements (I, III, IV) were identified and meaning units named in a brief and representative version**.** NVivo 11 version for Windows was used at an early stage of the data analysis in studies I and III with condensations imported and labelled as sources in NVivo (QRS International, 2018). 3) *Comparison*. Statements by young adults and family members that were analyzed in studies I and III and those of mental healthcare professionals in study IV were compared in discussions among the research team to find sources of variation or agreement. Seemingly similar statements were collated. 4) *Grouping.* Differences and agreements were compared within meaning units, and possible categories were tested by comparing them with the interviews. 5) A*rticulating*. A description of the essential meaning of each group was made. 6) L*abelling*. Description categories were labelled with suitable expressions decided in the research group. 7) C*ontrasting.* Categories were compared to ensure that each description category was mutually exclusive and at the same level. Two descriptive categories in studies I and III and three descriptive categories in study IV were identified. The last three steps were repeated several times within the research group. The outcome space (Marton & Booth, 1997) refers to the complex of descriptive categories reflecting the distinctions of perceptions of everyday life (I) and the experience of the FCSC (III, IV**).** The categories are equal and at the same level (horizontal) (Barnard & Gerber, 1999). The analysis was carried out with continuous negotiation and re-negotiation of the meaning of data extracts, with thorough discussion of the constant interplay between the various steps of the analysis. Analytic closure was reached when no new concepts emerged (Marton & Booth, 1997).

Statistical analysis (IV)

All statistical analysis was performed using IBM SPSS Version 25. The statistical tests (Altman, 1991; Greene & d'Oliveira, 2005) are shown in Table 3. The significance level was set to $p < 0.05$ (2-tail). Prior to analysis, three questionnaires with 30% or more missing items were discarded (SPSS, 2017). The demographic background variables: age, relation to the patient, educational and occupational status and background questions about current physical and mental health status were entered as dichotomized variables when comparing groups (MacCallum et al., 2002). For the remaining questionnaires, imputation was performed with case mean substitution (Fox-Wasylyshyn & El-Masri, 2005). In total, 66 participants were included when calculating the FPSQ and QPC-COP/COPNK total score due to being paired samples.

Table 3. Statistical methods in paper IV

Statistics	Application
Frequency, percentage, mean, standard deviation,	To describe the study sample and descriptive results.
Kruskal-Wallis test	To compare mental and physical health status, and occupational status (with Mann-Whitney U- test as a post hoc test).
Mann-Whitney U-test	To compare the differences between two groups – patients' and family members' mental and physical health status with regard to age-group, gender, roles and occupational status.
Spearman`s Rho	To explore the correlation between two groups – patients' and family members' current mental health status and age (years), and current mental health status by QPC-COP/COPNK – total and dimensions
Wilcoxon`s signed rank test	To compare the differences between two groups with a matched subject design due to the specific criteria being paired samples (patients and family members) on the FPSQ-N and QPC-COP/COPNK. This enabled analysis within families regarding family-perceived support and quality of care
Cronbach`s alpha	To test for the internal consistency of the instruments to assess reliability of the FPSQ-N and QPC-COP/COPNK.

Non-parametric tests (Table 3) were chosen due to data on ordinal level and small sample size (Polit & Beck, 2012).

Ethical and formal considerations

Ethical considerations and guidelines were applied in line with the Helsinki Declaration (World Medical Association, 2018) with regard to confidentiality, integrity and voluntariness of the participants. During the entire research process, the researcher followed research ethical principles such as autonomy, beneficence, nonmaleficence and justice. Studies I, II, and III were approved by the Norwegian Data Protection Official for Research (NSD) (ID: 2017/717). The Regional Committee for Medical & Health Research Ethics (REC), found Research Projects I, II and III, to be outside the remit of the Act on Medical and Health Research (2008), and the project could therefore be implemented without its approval. Study IV was approved by the Norwegian Social Service Data Services (ID:54962).

The principles of autonomy

Following ethical considerations and guidelines regarding *autonomy*, the participants were informed both orally and in writing about the purpose of the studies (I - IV), the voluntary nature of participation, their right to withdraw at any time during data collection without needing to provide any explanation, and confidentiality (World Medical Association, 2018). Informed written consent was obtained prior to the studies (I- IV). The patient gave written informed consent for the publication of patient information (I-III) (International Committee of Medical Journal Editors, 2018; World Medical Association, 2018).

The principles of beneficence and nonmaleficence

In this thesis, the research group considered the risk versus the benefits of the studies and assessed the benefits to exceed the disadvantages. The information letter described the benefits of sharing knowledge with other families and mental healthcare professionals (I, II, IV). It was emphasized that the participants would be safeguarded during family interviews (I, III), and respect would be demonstrated through eye contact, active listening, and attention to their words and emotions. Furthermore, there would be a balance between devoting attention to the family as a whole and recognising individual family members. If the interview had raised any questions or feelings, participants were assured that these would be addressed. The telephone phone number and e-mail address of the researcher were available to the participants if they had questions in retrospect. Nonetheless, no one contacted the researcher. There were no negative remarks regarding the questions in the questionnaire (II). The participants were informed that the material (I–IV) would be treated confidentially. Any information given by the participants was not made accessible to others than the research group. All information would be processed and used without a name or personal identification number, or any other information that is directly identifiable. Information given was linked to a code on a name list.

The principle of justice

Patients in several community mental healthcare services who fulfilled the inclusion criteria and had one or two family members who wanted to participate were invited to participate in the study. The families as a unit have a voice and freely express their opinions.

Main findings

This chapter gives an overview of the main findings in relation to everyday life, family support from mental healthcare professionals, and quality of community mental healthcare from the perspectives of families living with mental illness. Furthermore, experiences of Family Centered Support Conversations (FSCS) in community mental healthcare are presented from the perspectives of families and mental healthcare professionals. Focusing on a family perspective when living with mental illness contributes to understanding and viewing families as a unit by exploring firstly: everyday life in families with a young adult suffering from mental illness, family-perceived support from community mental healthcare professionals and quality of community mental healthcare; and secondly, families and mental healthcare professionals' perceptions of FCSC in community mental healthcare.

Everyday life in families living with mental illness (I), perceptions of family support from community mental healthcare professionals and quality of community mental healthcare (II).

Everyday life living with young adults suffering from mental illness **(I)** was experienced by the families as *'Finding a manageable balance'* and '*Using a variety of coping strategies',* which constituted two descriptive categories including four conceptions comprising the outcome space (Table 4).

Table 4. Families living with a young adult suffering from mental illness

Descriptive categories	Finding a manageable balance		Using a variety of coping strategies	
Conceptions	Desire to let go, still being close	Adjusting to limitations	Handling mental health symptoms in everyday life	A faceted partnership with mental healthcare professionals

The families (I) balanced between letting go and enabling the young adult to become independent while remaining close. This entailed providing emotional support, practical support regarding housing, giving them a feeling of safety and helping them to complete their education, be able to work and have a social life. At the same time, family members had to manage their own work and have a social life. The families experienced spending time on social activities and hobbies, focusing on something else and bonding in a different way, as a positive investment.

Even after reaching the legal age of responsibility at 18, the young adults (I) continued to rely on family members' support and help and lived together with or close to their family. Simultaneously, they had a strong need for autonomy and independence, and increasingly wanted to be able to handle symptoms and problems themselves and not be a burden, while longing for family members to understand them and the situation. When observing the young adult struggling with symptoms of mental illness, family members (I) took the initiative to talk to them about difficult emotions or thoughts but experienced the young adults as reluctant to talk. Nevertheless, the young adults (I) asked family members for support when they were unable to bear the symptoms of mental illness alone. Family involvement gave young adults a good feeling and family members became less concerned and calmed the situation.

Having a job, going to school and being occupied with social activities were important for the families (I). Everyday life for the young adults in this thesis included feeling depressed, anxious, lonely, and suicidal, although experiencing happiness as well. For young adults, work and vocational rehabilitation activities gave a sense of achievement, and interacting with and getting positive feedback from colleagues had a positive impact on self-esteem and mental illness symptoms (I). When comparing adult patients' (II) current mental status by age group and occupational status, no significant differences were identified. However, when comparing the current mental and physical health status and occupational status of family members (II) living with adults suffering from mental illness, significant differences appeared. Family members (II) who worked or studied reported significantly better mental health status (M=1.76, SD =.43, $p<.01$) and physical health status (M=1.76, SD = .43, $p<.01$). Family members (I) described how going to work gave them the opportunity to unwind. They regarded spending time on hobbies as meaningful – it gave a sense of liberty and enabled them to forget difficulties at home. Even so, family members (I) described how everyday life with the ups and downs of living with young adults suffering from mental illness was so difficult at times that sick leave from work was necessary.

Family members (I) intervened as best they could without seeking professional help in life-threatening situations such as young adults being suicidal. Meanwhile, family members asked to be involved in mental healthcare, and some experienced close and frequent relations, while others missed working as a team with mental healthcare professionals so that there was someone in the mental healthcare they could contact when they were concerned and needed advice.

In regard to family-perceived support (II) from mental healthcare professionals in community mental healthcare, significant differences were revealed on the total FPSQ-N. When comparing adult patients and family members as a paired sample (Table 5), family members (n=33) scored lowest on family support with a total mean sum score of 30.7, while patients (n=33) scored a total mean sum of 40.3. Significant differences between family members and patients within the paired sample were found in both the FPSQ-N Cognitive and Emotional support dimensions (II). Family members scored significantly lower on cognitive support (M= 11.8) than patients (M= 15.2), and the same applied to emotional support (M= 18.9) compared with patients (M= 25.1). Regarding mental healthcare professionals encouraging families to take respite from caregiving, both family members (M= 1.85) and patients (M=2.29) gave the lowest FPSQ-N score on item level (Table 5). Moreover, family members scored significantly lower than patients on single items concerning whether mental healthcare professionals offered family meetings. In parallel, the majority of patients (79.1%) and family members (76.7%) reported that they had not attended family conversations in study II.

Table 5 FPSQ-N. Patient and family members as paired samples (n=33)

	Patients n=33		Family members n=33			
	Mean	95% CI	Mean	95% CI	*P*<value[2]	Effect size
N-FPSQ TOTAL[1]	40.30	34.57–46.17	30.70	25.64–35.92	0.002	
Cognitive support	15.20	13.01–17.40	11.80	9.95–13.67	0.005	.34
Emotional support	25.1	21.41–28.84	18.9	15.49–22.44	0.003	.36

[1] Family Perceived Support Questionnaires, sum score ranged from 1 (low perceived support) to 5 (high perceived support). The score of the instrument ranged from 14 to 70 points, where a higher score represents better perceived support for families.

[2] *p*-value <.05 from Wilcoxon signed rank test.

Family members scored significantly lower quality of community mental healthcare on the total QPC-COP-N (M=3.06) than patients (M= 3.43) in a comparison between adult patients and family members as a paired sample (Table 6). Significant differences between family members and patients within the paired sample were found in six of the eight dimensions as showed in Table 6.

Table 6.QPC-COP/COPNK-N. Patients and family members as paired samples (n=33)

	Patients n=33			**Family members n=33**			
	Mean	95% CI		Mean	95% CI	*p<value*[2]	Effect size
QPC-COP/COPNK TOTAL[1]	3.43	3.27–3.59		3.06	2.87–3.26	0.004*	
1. Encounter (6 items)	3.77	3.60–3.93		3.41	3.19–3.63	0.012*	.30
2. Participation—Empowerment (3 items)	3.48	3.24–3.72		3.41	2.79–3.31	0.012*	.30
3. Participation—Information (5 items)	3.48	3.29–3.67		2.99	2.74–3.24	0.001*	.41
4. Support (4 items)	3.51	3.30–3.73		3.24	3.04–3.44	0.06	
5. Environment (3 items)	3.34	3.11–3.58		3.32	3.08–3.57	0.80	
6. Discharge (3 items)	3.22	2.96–3.47		2.72	2.46–2.98	0.002*	.38
7. Next of Kin (2 items)	3.36	3.14–3.58		2.58	2.30–2.87	0.001*	.47
8. Accessibility (4 items)	3.29	3.07–3.51		2.79	2.59–2.99	0.001*	.45

[1] Quality of care, ranged from 1 (lowest quality) to 4 (highest quality)

[2] *p*-value <.05 from Wilcoxon signed rank test

The Encounter dimension (II), the interpersonal relationship between patient and mental healthcare professionals, was given the highest quality score by both family members and patient. Family members also scored the Participation–Empowerment dimension equally high (Table 6). However, 51.2% patients and 62.8% family members (II) reported that they did not know where to turn if they were dissatisfied with patient treatment and care. Patients gave the Disharge dimension the lowest quality score in relation to whether treatment and care helped, getting help to find an occupation and getting information on where to turn if in need of help after discharge. Family members gave the lowest quality score to the Next-of-Kin dimension in relation to family being respected and invited to take part in care (Table 6). After the young adults passed the age of 18, families (I) experienced difficulties in healthcare follow-up actions due to confidentiality, although the young adult had consented to full insight for their family.

Families living with mental illness (III) and mental healthcare professionals'(IV) experiences of Family Centered Support Conversations in community mental healthcare

The families living with young adults suffering from mental illness (III) experienced the Family Centred Support Conversations (FCSC) as '*Facilitating sharing reflections on everyday life*' and '*Possibility of change in everyday life*'. These constituted two descriptive categories including five conceptions comprising the outcome space (Table 7).

Table 7. Experiences of the usefulness of the FCSC: The perspectives of young adults and their families living with mental illness.

Descriptive categories	Facilitating sharing reflections on everyday life			Possibility of change in everyday life	
Conceptions	The unfamiliar conversations	A team with mutual understanding.	Experiencing a change in the patient approach	Awareness of strengths and resources	Support in everyday life on regular basis

The mental healthcare professionals (IV) experienced the FCSC as '*A new tool in the toolbox*', '*The family as a conversational partner*' and '*Implementing the intervention*', constituting three descriptive categories including seven conceptions comprising the outcome space (Table 8).

Table 8. Community mental health professionals' perceptions of conducting FCSC with young adults suffering from Mental Illness

Descriptive categories	A new tool in the toolbox	The family as a conversational partner	Implementing the intervention
Conceptions	A rewarding and challenging training program	Intervening with the diversity of families	Adjusting the intervention
	Obstacles to using the intervention	Strengths and resources in the mirror of suffering	Collegial support when practicing the conversations
		Sharing knowledge and experiences	

For most families (III), the FCSC was experienced as a new experience, both strange, unpleasant and uncomfortable, but also positive, beneficial and safe. It facilitated an opportunity to share and reflect on the family's beliefs on the past, present and future related to symptoms, problems, worries, and hopes. Young adults (III) found it easier to speak exclusively with mental healthcare professionals who were involved in their care. Even so, family involvement in FSCS was worthwhile and experienced as fairly reassuring and safe. Typically, the young adults often deny allegations or respond to family members' concerns dishonestly. They want to deal with illness concerns themselves, not be seen as different. Mental healthcare professionals put emphasis on encouraging the young adults to invite family members into the conversations (IV), in order to achieve a mutual understanding of their situation and to make it safe to talk about difficult topics without having the mental healthcare professionals in the driving seat.

Sharing thoughts was useful and informative (III) and dwelling on each other's experiences enabled the families to see the situation from other angles**.** According to mental healthcare professionals (IV), sharing of knowledge could have a link to psychoeducation, which is often described as being useful for the family although opinions differed.

Listening to the young adults'(III) descriptions of everyday life was painful and surprising for family members and constituted a moment of new realization. Prior to the FCSC, they did not know how seriously the patient was affected by mental illness, and what the patient needed in situations that trigger severe symptoms. The intervention made it possible for family members (III) to learn how they can approve, support, and help. This enables them to enlighten each other and mental healthcare professionals about what works when living with mental illness. Including the young adult's family members was considered of importance (IV), because mental healthcare professionals had a lot to learn from the families. For mental healthcare professionals (IV), having the family as a conversational partner together with the young adults was considered both somewhat new and rewarding but also challenging, demanding, and exhausting. Families were not unconditionally seen as a conversational partner (IV) when family members did not have insight or knowledge regarding the young adult's mental illness. Bringing the family into the conversations was considered as 'balancing on a knife-edge' – relations might worsen, and both making demands and giving praise are difficult aspects. In order to make their opinions on how to interact with their young adult heard, family members (III) described having to 'speak loudly' to the mental healthcare professionals in a sharp tone. For some mental healthcare professionals (IV), when families were seen as having high conflict levels or more than one family member suffered from mental illness, it was difficult to carry out the intervention and take care of everyone in the best way. Others (IV), however, said that the intervention would do no harm if it was adapted according to how they met each other – the young adult, the family and mental healthcare professionals. Before the FCSC educational and skills training program, the mental healthcare professionals (IV) had no routine regarding the presence of family members during the therapeutic conversations.

The Family Centered Support Conversations (FSCS) helped mental healthcare professionals (IV) to structure the involvement of family members, gain an overview of the family, map and elucidate their relations, their perceptions of family life and create milestones for the future. The FCSC was experienced as an arena for discussing difficult questions both by the families (III) and mental healthcare professionals (IV). Topics the families did not dare to raise at home, either because they were too hard for the young adults to broach or family members were afraid of stepping too close, were brought up naturally and talked about in the FCSC in the reassuring presence of the mental healthcare professional (III).

The families (III) described mental healthcare professionals as seeking approval from the young adults regarding the sharing of information. They held back information although the latter had given them oral and written consent allowing family members to access health information. For the mental healthcare professionals (IV), the relationship of trust with the young adult was considered the most valuable in the therapeutic relation, too valuable to ruin. When working with trust, mental healthcare professionals highlight the importance of ensuring that the young adult was comfortable with the family present in the conversations. To avoid disclosing sensitive matters, mental healthcare professionals (IV) let the young adult lead the conversation and were themselves active listeners in order to ensure confidentiality. The confidentiality requirement was considered a difficult obstacle to handle, even though they experienced that parents in particular knew the whole story (IV). According to family members (III), mental healthcare professionals need greater skills in working as a team with the family.

The wish to modify the intervention (IV) was also described, while merely focusing on strengths and resources seemed rather strange when the young adult and their family had many difficulties in their family life and most of their focus were on these. The balance between education, knowledge sharing, suffering and resources was highlighted. The use of elements from the FCSC and other known interventions was a way of adjusting the intervention to meet the families' needs (IV). Mapping family roles, interaction and functioning within the families (III) either by a family genogram ("family tree") or through spoken dialogue gave both the family and mental healthcare professionals insight and the opportunity to become acquainted with conscious or unspoken realities (III). 'The family-tree' was highlighted by the mental healthcare professionals (IV) as a fairly new illustrative method and raised awareness in terms of the family structure and their relations. This was also given as a reason not to use 'the family-tree' as it might depict the scarcity of relations both within the family and in other social contexts. Some family members (III) experienced this as a moment of realization because they had not previously considered the interconnections in that way.

Summary of findings

Everyday life in families with a young adult suffering from mental illness was a balance between being close in order to provide support and encouraging independence while providing a safety net. The young adults tried to deal with symptoms of mental illness by themselves and not be a burden, although longing for family members to understand them and the situation. The families found that healthcare professionals held back information although young adults had consented to family members gaining insight. Family members living with adult patients felt the lack of both emotional and cognitive support from mental healthcare professionals and were generally more negative than patients in regard to the quality of community mental healthcare. Patients as well as family members gave a high-quality score to the interpersonal relationship between patient and mental healthcare professionals. However, family members gave a low score to mental healthcare professionals in relation to being respected and invited to take part in care. FCSC allowed the families to find new meanings and opportunities in everyday life and promoted preparedness to deal with everyday life and support strategies for the future. Although mental healthcare professsionals stated that the conversations helped to structure the involvement of family members, they also described a need to adjust the intervention. Listening to and reflecting on each other`s beliefs about their daily life and family assessment were beneficial for the families. The families found that mental healthcare professionals played an important role and facilitated a safe environment for young adults and their families, allowing them to talk openly about the unspoken, and their experiences of living with and managing mental illness.

Discussion of the findings

The overall aim of this thesis was to illuminate perceptions of everyday life, family support from mental healthcare professionals, and quality of community mental healthcare from the perspectives of families living with mental illness. A further aim was to elucidate families' and mental healthcare professionals' experiences of Family Centered Support Conversations (FSCS) in community mental healthcare.

The findings show everyday life is about finding a manageable balance and using a variety of coping strategies. Family members were generally more negative than patients about the family support provided by mental healthcare professionals, and the quality of community mental healthcare. The families described the FCSC as enabling them to find new meanings and opportunities in everyday life, and mental healthcare professionals play an important role in facilitating a safe environment for them to talk openly. Mental healthcare professionals experienced the FCSC as a complement to care as usual, structuring the involvement of families, and the knowledge exchange could create a context of changing beliefs, strengths and resources. The discussion is carried out with a family perspective inspired by the Illness Beliefs Model (Wright & Bell, 2009) and Calgary Family Framework (Shajani & Snell, 2019). Significantly, the discussion brings into focus everyday life and the experience of FCSC in families living with young adults, since transition to adulthood can be a critical period and they may be less prepared to take care of themselves than peers.

Everyday life in families living with mental illness (I), perceptions of family support from community mental healthcare professionals and quality of community mental healthcare (II).

The findings in this thesis (I) show everyday life is a continuous process of balancing the demands of the illness and the demands of everyday life (I). This entails completing education, working and having a social life. In particular, transition to adulthood is a complicated path to navigate when suffering from mental illness (Lindgren et al., 2015; Xie et al., 2014) and trying to acquire physical, psychological, financial and social competence (McGrandles & McMahon, 2012).

The young adults (I) had a strong need for autonomy and independence, increasingly wanting not to be a burden and be able to handle problems themselves, and not be seen as different. Simultaneously, they long for family to understand them and their situation. Even so, family members (I) experienced young adults as reluctant to talk when they themselves took the initiative to talk about difficult emotions or thoughts. McCann et al. (2012) assert that young adults suffering from mental illness fear rejection by family and friends while Woodgate et al. (2017), describe their desperate struggle to maintain their existing relationships and roles. For young adults, apparently, disclosure or non-disclosure is an ongoing decision. Even so, Woodgate et al. (2017) describe how young adults found that they eventually had to stop concealing their illness in order to get help and support. This brings to the foreground that young adults suffering from mental illness (and family, as well) may have beliefs that constrain their relationships, behavior, illness suffering and family everyday life. In accordance with the Illness Belief Model (Wright & Bell, 2009), one useful way to challenge constraining beliefs and strengthen facilitating beliefs is to share beliefs and “to think about their thinking”. A process of self-reflection is fundamental to the co-evolution of new, more facilitating beliefs (Gisladottir & Svavarsdottir, 2017; Gisladottir et al., 2017). Notably, in this thesis the families participating in FCSC (III) experience that sharing beliefs and disclosure is beneficial. It is therefore of importance that mental healthcare professionals understand that these young adults need extra support from their family, even after the age of 18. Lindgren et al. (2015) described support from the family as crucial for the transition to adulthood and in striving to reach recovery.

Young adults do not become mature only because they have turned 18. Even after reaching the legal age of responsibility, young adults (I) relied on family members’ emotional support, practical support regarding housing and the feeling of safety when living together with them or close to them (I). Transition to adulthood is particularly complicated for those affected by a mental illness (Lindgren et al., 2015). Family members and mental healthcare also need to provide support based on individual needs instead of using age to assess maturity level (Murcott, 2014). Family members and parents in particular can add to the burden of mental illness if they do not appear to accept the young adult’s need for support, and continue to place unreasonable demands on them (Dundon, 2006). On the one hand, family involvement gave young adults a good feeling and family members became less concerned and calmed the situation (I). On the other hand, family members (I) felt unsure of the degree of involvement, how to be supportive and intervene without make things worse. This concurs with the theoretical framework of the Calgary Family Framework (Shajani & Snell, 2019) that views the family as a complex whole where family members' behaviors are best understood from a view of circular causality. Lindgren et al. (2015) demonstrate family members' critical role, responsibility and influence on everyday life and future life. Furthermore, Gustavson et al. (2018) emphasize that family members can strengthen young adults' resilience in relation to completing education, managing work and having a social life, by being understanding, tolerant, patient, aware of and accepting the young adult's mental illness.

Having a job, going to school, and being occupied with social activities were important for the families living with young adults. The young adults (I) described the impact of interacting with and getting positive feedback from colleagues on their self-esteem and mental illness symptoms. Disclosing to colleagues that they were struggling with mental illness, not having to pretend, made it easier to go to work. For people suffering from mental illness, interactions at work and in school are crucial for the development of a valued personal role and social identity (Sommer et al., 2018), and recovery (Borg & Kristiansen, 2008; Walsh & Tickle, 2013). Moreover, increased confidence and self-esteem may positively affect other aspects of their lives. Sommer et al. (2018) emphasize that regular conversations with colleagues affirm young adults' strength, create self-confidence, give hope, and motivate them to put effort into achieving their goals. Furthermore, according to Anvik and Gustavsen (2012), accepting challenges related to everyday life helps them to return to or stay in education or work. The Calgary Framework highlights the family as composed of many subsystems. (Shajani & Snell, 2019) This thesis contributes insight into school and work as important subsystems for young adults. Young adults' own descriptions of what they experience in the context of supportive interpersonal relationships in the family environment and school/workplace contribute knowledge about the importance of promoting education, work, and social life. Challenges and difficulties in completing education and remaining in the work force must be regarded as important elements of everyday life.

Family members (II) who worked reported significantly better mental health status – being at work gave them a chance to unwind. This is an important finding from a preventive and health-promoting perspective. Ha et al., (2008) state that taking a break from caregiving tasks and engaging in other activities increases psychological well-being and prevents acute stress. In contrast, unemployment limits family members' social lives and prevents them from assuming different roles (Kızılırmak & Küçük, 2016), thus increasing perceived burden level (Chen & Lukens, 2011). Notably, family members' and patients' lowest FPSQ-N score (II) was given to whether mental healthcare professionals encourage them to take respite from caregiving and stress the importance of emotional support. By emphasizing that respite is beneficial (Moen et al., 2014), mental healthcare professionals can give family members relief.

While being employed may provide benefits such as social inclusion and personal growth (Moen et al., 2014), this thesis identified barriers to work (I). These included both the difficulty of leaving the workplace because of the withdrawal of sick-leave days for sick children over 12 years and the disadvantage of working at some distance from the young adult's school or work. It was problematic to be accessible when unpredictable events occurred. Being involved in the ups and downs (I) was at times so difficult for family members that they said that sick leave from work was necessary. The Calgary Family Framework (Shajani & Snell, 2019) demonstrates how change and stability balance and coexist when living with illness (von Bertalanffy, 1967). During periods of illness remission and exacerbation, the balance constantly shifts between change and stability (Shajani & Snell, 2019). This complexity requires mental healthcare professionals to have a broad understanding of system and change theory.

Family members (I) intervened as best they could in life-threatening situations such as young adults being suicidal. Though unquestionably out of love, is this also because of an inescapable duty with a limited possibility of being relieved? Apparently, family members (II) felt a lack of cognitive support that embraced information, professional opinions, easy-to-read literature about the mental illness, and thoughts enabling them to learn from and reflect on. This gives reason to question whether family members have the competence and confidence needed to respond to the needs of the person suffering from mental illness? Reinhard et al. (2008) argue that family members are not trained and are frequently overwhelmed and unable to use their full set of skills to effectively manage roles they did not volunteer to undertake. In fact, the Calgary Family Assessment Model (Shajani & Snell, 2019) defines the cognitive domain of family functioning as a key concept. One of the most significant needs of families living with illness is to be offered cognitive support by healthcare professionals. Strengthening family members' competence and confidence improves their coping (Reinhard S.C et al., 2008; Shajani & Snell, 2019). Family-centered support interventions may result in more competent and confident family members as care providers and ensure safe and effective patient care.

Families living with mental illness (III) and mental healthcare professionals'(IV) experiences of Family Centered Support Conversations in community mental healthcare

For the families, the Family Centered Support Conversation (FCSC) was a new experience. As well as being strange, unpleasant, and uncomfortable, it was also positive, beneficial and safe (III). For the mental healthcare professionals, it was rewarding but also challenging, demanding, and exhausting (IV). Sharing beliefs and each other's experience in the FCSC was informative and enabled the families to see the situation from other angles (III). According to Wright and Bell (2009), it facilitates a richer understanding of family everyday life. Our findings importantly show that family members (II) felt the lack of cognitive and emotional support from mental healthcare professionals. This is of particular concern since, according to Andershed et al. (2017), lack of support renders family members unable to decide how to behave and what to do to be supportive. It also deviates widely from national (Ministry of Health and Care Services, 2021) and international (National Institute for Care and Health Exellence, 2020) recommendations that the healthcare services provide family members with personal, emotional and role support. Mental healthcare professionals may promote, improve and sustain effective family functioning by intervening in the cognitive domain with psychoeducation, skills-training, and counselling, and in the emotional domain with encouragement, family meetings, and recognition and commendation of strengths. This is reflected in the FCSC (III+IV) and is in keeping with the Calgary Family

Intervention Model (Shajani & Snell, 2019). It also agrees with the concept of Mental Health Literacy (Jorm, 2000), and other family models in mental health (Falkov et al., 2020) emphasize the importance of educating and supporting families.

However, the findings revealed that young adults (III) found it easier to speak exclusively with mental healthcare professionals. One may question whether this is a consequence of an individual-oriented approach in adult community mental healthcare? In view of the findings, a more plausible explanation is perhaps that mental healthcare professionals said they had no routine regarding the presence of family members during the therapeutic conversations (IV). A predominant focus on the patient (Johansson et al., 2014) means that mental healthcare professionals fail to understand the complex needs of the family. On the other hand, both the young adults and family members (III) felt the comfort of the mental healthcare professional's presence when revealing the unspoken or broaching difficult topics. This requires families and mental healthcare professionals to meet one another in dialogic relationships (Freire, 2018), as equal partners, aiming for mutual understanding, and to find new words to describe reality, thus enabling change.

In contrast, findings (III) unfortunately revealed that cooperation between family members and mental healthcare professionals was problematic in the sense that families experienced that their opinion on how to best interact with the patient was not valued, in line with Ewertzon et al. (2010). The Illness Beliefs Model and the Calgary Family Framework (Shajani & Snell, 2019; Wright & Bell, 2009) stress reciprocity and non-hierarchical relationship where each person's contribution is acknowledged and valued. Mental healthcare professionals in particular need to drift towards 'objectivity-in-parenthesis' (Maturana & Varela, 1992). From a stance of objectivity-in-parenthesis, other individuals are experienced as having legitimate views, albeit different from our own, followed by respect, non-judgemental curiosity and responsibility – a key to therapeutic change (Wright & Bell, 2009). Notably, the opposite from a stance of objectivity-without-parenthesis is illustrated in Dorell et al. (2016), where healthcare professionals typically asked questions but did not always wait for the answers, because they believed they already knew the answer or had the solution to a certain problem. Wright and Leahey (2019) recommend healthcare professionals to reflect on their contribution to the therapeutic relationship before meeting with the family and to invite the family’s reflections about the family-nurse relationship. This is beneficial not only to families living with mental illness but also to families affected by illness in general.

The mental healthcare professionals (IV) emphasized the balance between education, knowledge sharing, suffering and resources. The use of elements from the Family Centered Support Conversations (FCSC) and other known interventions was a way of adjusting the intervention to meet the families’ needs (IV). In line with the Calgary Family Framework (Shajani & Snell, 2019), interventions should be tailored to a family’s personal situation. According to mental healthcare professionals (IV), sharing of knowledge could have a link to psychoeducation, which is often described as being useful for the family. For family members (III), the FCSC made it possible to learn how they can approve, support and help, thereby enabling the family members to enlighten each other and mental healthcare professionals on what works when living with mental illness. As a result, Shajani and Snell (2019) describe how psychoeducation – offering information and opinions designed to influence change in the cognitive domain of family functioning – may facilitate change in the way a family perceive its illness problems so that members can discover new solutions. Our findings demonstrated that the FCSC improved the cognitive domain of family functioning to some extent, in that family members experienced increased understanding of how seriously the patient was affected by mental illness, and what the patient needed in situations that triggered severe symptoms (III).

It was evident that the mental healthcare professionals (IV) considered the inclusion of family members as of importance since they had a lot to learn from the families. Meanwhile, bringing the family into the conversations was like ‘balancing on a knife-edge’ where relations might worsen, and both might make demands (IV). Although young adults have given their consent (III), mental healthcare professionals hold back information. Indicates confidentiality is important in protecting the patient (Dreyer & Strom, 2019; Schröder et al., 2007a). However, in accordance with Weimand et al. (2013) mental healthcare professionals’ fear of acting illegally or misinterpreting the law of confidentiality are obstacles to family members receiving information and participating in care. This results in barriers to collaboration between families and professionals (Solomon et al., 2012). Moreover, families were not seen as a conversational partner (IV) if family members did not have insight or knowledge regarding the young adult's mental illness. A trusting, mental healthcare alliance between professionals and families is essential for patient care. In my opinion, if mental healthcare professionals are equipped with curiosity about the reciprocity of mental illness and family functioning, opportunities may also arise to witness the impact of mental illness on families and family relationships. In turn, both the positive and the negative impacts that family relationships can have on the course of mental illness may be uncovered.

Due to the crucial role that families play in the continuum of illness, Kokorelias et al. (2019) suggest that going beyond patient-centered care to a more encompassing-family-centered care seems logical, to address the needs of families. This thesis finds that young adults (I), even though they have reached the legal age of responsibility, are closely attached, need support, and require family inclusion in care. Granerud and Severinsson (2006) assert that family ties are often overlooked by healthcare professionals. This is consistent with the Calgary Family Assessment Model (Shajani & Snell, 2019). If mental healthcare professionals include family assessment in their 'toolbox', structural, developmental and functional areas that inhibit or promote everyday life may be discovered. Despite this, family members gave a low score in response to whether mental healthcare professionals offered family meetings. The majority of patients and family members reported that they had not attended family conversations (II). If the reason for this is that mental healthcare professionals lack education and training in working with families, then community mental healthcare managers and educators should place increased emphasis on education and skills training among those working and intervening with families.

There are different definitions in clinical practice of the concept of the family *as context* or *the family as a unit in care* (Foster et al., 2016). Wright and Leahey (2019) claim that by clearly distinguishing between generalists' and specialists' levels of expertise in healthcare with regard to clinical work with families, potential confusion of practice level is alleviated. Generalists who predominantly use the concept of the family *as a context* have a bachelor's degree, although those with further education begin to conceptualize the family as the *unit in care*. This however requires specialization on family-centered care enabling healthcare professionals to focus on both interaction and reciprocity at the same time. This may indicate a need for clinical practice to prioritize to train mental healthcare professionals to perform family-centered care?

Family members gave a significantly lower score to quality of community mental healthcare than patients (II). This may indicate that family members score quality of care from a different point of view, possibly as a result of different roles, or as a result of the unmet needs of family members (Shajani & Snell, 2019). Family members wanted to have someone in the mental healthcare services to contact when they were concerned and/or needed advice, and be a natural part of the healthcare team (I). Årestedt et al. (2015) describe families living with chronic illness as believing that their encounter with healthcare is an ongoing struggle. In this thesis, the findings show that both family members and patients give the highest quality score to the Encounter dimension (II) – interpersonal relationship between patient and mental healthcare professionals. This is reassuring when adding similar findings from patients' measurement of quality of care in housing support for people with mental illness (Brunt et al., 2019; Rask et al., 2017), and psychiatric outpatient care (Lundqvist et al., 2012). The latter finding, which underlines that mental healthcare professionals give emphatic and respectful care to the patient (II), may indicate that mental healthcare professionals fulfill families' quality expectations with regard to patients' dignity and sense of security, as defined by Schröder et al. (2007b). Interestingly, this contrasts with Kilbourne et al.(2018) who suggest that mental healthcare is often delivered with poor quality, with far-reaching and considerable consequences for individuals, families and society. The fact that most patients and family members (II) did not know where to turn if dissatisfied with the patient treatment and care, emphasizes the need for clinical practice to continue to improve their encounters and communication with the families. This is in line with Johansson et al. (2014), who report family members questioning the availability of mental healthcare.

Nonetheless, Donabedian (1988) argues that the essence of quality is related to the process of care in all its parts, and unquestionably the family unit is an essential part of the process of care. In other words, it could be claimed that mental healthcare and mental healthcare professionals do not fulfill the quality expectations until they invite and respect the patient's family members as partners in the caregiving (McNeil, 2013). This concurs with core values in family-centered care (Bell, 2011). Moreover, our findings demonstrated that family members gave the lowest quality score to the Next-of-Kin dimension concerning family being respected and invited to take part in care (II). Taking these elements into account can increase knowledge about causalities and experiences which often overlap welfare policy areas. This can also highlight how policies and support programs regulate everyday life.

Methodological considerations

Since the methods used in this thesis consist of a combination of qualitative (I, III and IV) and quantitative methods (II), several criteria are required to assess the quality of the studies. Qualitative and quantitative research are complementary because they lead to different kinds of knowledge that is useful for nursing and healthcare. While qualitative research is concerned with enhancing trustworthiness, validity and reliability are two important criteria in quantitative studies (Polit & Beck, 2012). The roles and responsibilities of authors matter and imply responsibility and accountability. Even though the role of the researcher differed in study I,II, III and IV, the authorship is based exclusively on the International Committee of Medical Journal Editors (2019) criteria for authorship.

Trustworthiness (I, III, IV)

A qualitative descriptive design with a phenomenographic approach was found suitable because the main purpose was to achieve an *authentic* understanding of the different experiences of families (I, III) and healthcare professionals (IV), thereby enabling a variation in perceptions of the phenomenon. Nevertheless, it is important as researchers to be aware of critical factors, for example if the perceptions and descriptive categories do not have enough depth or are over-close and influenced by the researcher's subjective role.

To ensure trustworthiness, Lincoln and Guba (1985) criteria of *credibility, dependability, confirmability, transferability and authenticity* were used. *Credibility* was strengthened by the size of the sample (seven families and 13 mental healthcare professionals). This was considered sufficient in terms of requirements for phenomenographic studies (Larsson & Holmström, 2007). The participants represented a varied group (Marton & Booth, 1997) in terms of different family relationships, gender, age, urban and rural. There was also considerable diversity as regards the healthcare professionals' background such as work experience, educational background and the variety of community mental health services represented. This gave rich descriptions and strengthened the authenticity (Sandelowski, 1986).

A pilot interview confirmed the relevance of the open- ended questions (I, III) to the aim of the studies, strengthening the *credibility. Dependability* was ensured (Lincoln & Guba, 1985; Polit & Beck, 2012) by carrying out all the interviews in a similar way. All the families were asked the same open-ended questions (I, III), and the same procedure was followed in the individual interviews with mental healthcare professionals (IV) *(dependability).* By posing follow-up questions, various experiences were elucidated (Marton & Booth, 1997), misunderstandings were avoided, and the participants were given the opportunity to contribute experiences not covered during the interview. This contributed to a respectful atmosphere. The family member's own choice of place for the interview probably made them feel safe and secure *(credibility).* Even so, the researcher's awareness of power balance in the interview was essential (Marton & Booth, 1997).

The families (I, III) were willing to share their experiences with each other, even if their stories included new thoughts that the family had never discussed, resulting in a deeper understanding. A limitation could be if destructive and problem areas become prominent, and family members were not able or willing to share their experiences with each other (Eggenberger & Nelms, 2007; Moen et al., 2014), or want to try to please one another or the interviewer by agreeing as far as possible with what the others are saying (Ahlström et al., 2009). On the other hand, family members are united by shared experiences and emotional bonds, which makes it easier for them to talk about private and sensitive issues.

The individual interviews with mental healthcare professionals (IV) were conducted by two other researchers (psychiatric nurse and public health nurse) than the one responsible for the training program, which strengthens the trustworthiness of the study. The family interviews (I, III) were conducted by the author, a psychiatric nurse, which can be considered both a strength and a weakness. The author`s long clinical experience from mental health nursing facilitated a trusting environment so that the families and mental healthcare professionals could open up, and rich data could be acquired. At the same time, this represented a risk in regard to the author`s preconceived beliefs about the phenomenon and their influence on the follow-up questions. *Credibility* was ensured through researcher awareness of own pre-understandings, discussion in the research group and an open-minded approach in the analysis. Ashworth and Lucas (1998) emphasize researchers to perform epoché – to set aside prior assumptions of the phenomena being studied. The research group included a public health nurse and psychiatric nurses, and their professional competence may well strengthen trustworthiness.

Awareness of the family interview (I, III) as a research method, not a therapeutic conversation, was maintained through a critical and reflective attitude (Fog, 2001). Efforts were also made to avoid ‘going native’ by keeping distance and not identifying with the participant (IV) (Sandelowski, 1986) *(dependability, authenticity, credibility*). The author`s advanced theoretical and skills-training competence in ‘Health fostering conversations’ (Linneuniversitet, 2021) strengthened her *credibility* as a developer and instructor in the FCSC educational and skills-training program.

Confirmability was enabled by an ‘audit trail’ (Guba, 1981) describing all steps in the analysis process. Seeing the family as a unit of analysis involved data collection from at least two family members (Åstedt-Kurki et al., 2001). Analysing family research interviews in this phenomenographic study was challenging in relation to the extent the experience of the conversations can be expected to be shared across the families. Furthermore, this was strengthened by the involvement of all researchers in the analysis process. One possible weakness may be the risk of the family interview reflecting the experiences of individuals rather than the family as a whole. However, data on both individual and family level still entails focusing on the family as a unit. The family members in the study are distinct individuals yet they share a common history, strengths, and belief systems, and have close contact with one another. The authors have exemplified the results with quotes from patients, family members and mental healthcare professionals to strengthen the *confirmability* (I, III, IV). In the analysis, the outcome space is portrayed as equal value (horizontal) based on the understanding of the relationships between the conceptions (Barnard et al., 1999), thus excluding a hierarchical relationship in terms of degree of complexity (Marton & Booth, 1997).

Although the families and mental healthcare professionals were recruited from several different municipalities in Norway, the applicability or *transferability* to other settings or groups should be taken into account. Moreover, this thesis may contribute to relevant knowledge for similar groups of families and healthcare professionals (Lincoln & Guba, 1985).

Validity and reliability (II)

The recruitment of the participants was done consecutively. To reduce the risk of bias (Altman, 1991), there were strict inclusion criteria for patients and family members. The study sample size is a pertinent limitation regarding generalization of the findings, and this should be done with caution. Despite two reminders, the response rate was very low, which may lead to a response bias (Polit & Beck, 2012). A number of individuals refused to participate when invited. The reason for not responding is not known, since details of refusers were not collected, but a low response rate is not uncommon in studies in mental health services (Siponen & Välimäki, 2003).

Missing responses (n=4) in the questionaires together with ‘Not applicable’ responses were treated as missing items, replaced by each participant’s mean score, i.e the case means substitution technique (Fox-Wasylyshyn & El-Masri, 2005). Participants with up to five ‘Not applicable’ responses were included in the analysis when calculating the FPSQ-N and QPCCOP/COPNK-N total score. To minimize risk of bias, missing and ‘Not applicable’ responses were explored and found to be dispersed over the entire scale. Replacing missing data has been debated since this underestimate’s variance (Polit & Beck, 2012), but case mean substitution has been found to be an acceptable method for imputation (Fox-Wasylyshyn & El-Masri, 2005; Polit & Beck, 2012). It was impossible to analyze the dropouts in this study because patient and family member registrations by the mental healthcare professionals were incomplete.

The ICE-FPSQ and QPC-COP/COPNK are designed to be completed individually, but even so the questions concern the family. Collecting data on both individual and family level is a strength since this entails also focusing on the family as a unit. Collecting data on a family level increases knowledge through identifying shared family experiences and family meaning that emerge as a result of an illness experience (Rayens & Svavarsdottir, 2003). Notably, a low response may be considered a limitation to achieving a broad insight.

The ICE-FPSQ instrument was chosen on the basis of the theoretical foundation of the Calgary Family Framework (Shajani & Snell, 2019), aimed to reflect family support measured where there is an illness in the family from the perspectives of both patients and family members (Sveinbjarnardottir et al., 2012). The conceptual framework is recommended in family nursing by the International Family Nursing Association (2017). The ICE-FPSQ was translated into Norwegian and modified to the context of families in community mental healthcare (II). The face validity and content validity (Polit & Beck, 2012) of the FPSQ-N were assessed by health professionals and found to be acceptable.

The QPC-COP instrument is based on the original QPC-OP questionnaire, and designed to measure the quality of care from the patient perspective. Additionally, the QPC-COPNK was modified to cover family members' perceptions of quality of community mental healthcare. Based on a specific definition of high-quality care and anchored in a patient and next-of-kin perspective, it enables comparison of quality of care from the perspectives of both patients and family members, and contributes to the improvement of psychiatric outpatient care and to the development of theory within this area.

The ICE- FPSQ (Sveinbjarnardottir et al., 2012) and the Swedish version of QPC-OP(Schröder et al., 2011) are psychometrically tested with good results. The FPSQ-N and QPC-COP-N and QPC-COPNK-N have not been psychometrically tested. However, with regard to reliability, the internal consistency measured with Cronbach`s alpha in this thesis of .952 for FPSQ-N and .921 for QPC-COP-N exhibited suitable values and were comparable with previous studies.

Non-parametric tests were considered appropriate due to the level of measurements (ordinal) in regard to statistical analysis even though sum scores from ordinal level may be considered continuous, given a normal distribution of the data (Altman, 1991; Greene & d'Oliveira, 2005). The significance level was set at $p < 0.05$ (two -tailed) and used for all tests in this thesis. Even if using a false discovery rate of 5%, which is not recommended, still more comparisons than at present will be statistically significant. Therefore, we believe that keeping the criterion for significant difference at $p<0.05$ will in fact result in fewer significant comparisons (McDonald, 2009).

Conclusions from this thesis

- Young adults suffering from mental illness try not to be a burden but are reliant on family support, care and help to complete education, manage work, and have a social life.
- The interpersonal relationship between patients and mental healthcare professionals is viewed as being of high-quality by patients and family members.
- Family members feel the lack of support from mental healthcare professionals and low quality of care with reference to not being respected or invited to take part in care by community mental healthcare professionals.
- Families living with a young adult suffering from mental illness benefit from listening to and reflecting on each other`s beliefs about everyday life and family functioning.
- Families want to be included in mental healthcare through family-centered support conversations that identify family strengths and resources, and focus on how to be supportive.
- Mental healthcare professionals play an important role in facilitating a safe environment for sharing, bringing strengths and resources to the front seat in family-centered conversations.

- Family Centered Support Conversations structure the involvement of families as a complement to care as usual.
- The Family Centered Support Conversation model needs some modification to meet the needs of the specific patient and their family in the community mental healthcare and may not suit all families.
- Mental healthcare professionals prioritized a trusting relationship and patient confidentiality when bringing family members to the therapeutic conversation. This could inhibit collaboration between families and professionals.

Implications for practice

Mental illness is a family affair, and the findings have implications for the following: mental healthcare managers and mental healthcare professionals when considering the development of care offered to families living with mental illness; the Norwegian Labor and Welfare Administration when considering family inclusion as a natural part of individual work placement and support; counsellors and educators when considering the inclusion of the family as a natural part of the team helping young adults suffering from mental illness to complete secondary education; university educators who should place increased emphasis on family-centered care in education and skills training among healthcare students. Moreover, this applies to all healthcare professionals who work and intervene with families living with illness.

- There should be more reflection and discussion among mental healthcare professionals regarding young adults suffering from mental illness and their need of support and help from family even after the legal age of responsibility. Such discussion should also focus on family and how to maintain a trusting relationship and patient confidentiality.
- Family members living with a person suffering from mental illness need emotional and cognitive support from mental healthcare professionals.

- Mental healthcare professionals should work on establishing a mindset whereby the family is regarded as a resource with important skills and life experience and should be included as a natural part of the mental healthcare team.
- Mental healthcare professionals need to pay greater attention to assessing complex family needs, offering family support conversations and focusing on beliefs and strengths, in addition to standard care.
- Mental healthcare professional require specific knowledge and skills to enter into conversations with families living with mental illness
- Improving the quality of family support to families living with mental illness by focusing on the family as the unit of care requires a conceptual shift, even a paradigm shift in community mental healthcare and by mental healthcare professionals.

Future research

- Exploration of contextual issues that might act as a facilitator or barrier to successful family-centered care implementation in community mental healthcare.
- Longitudinal studies that offer qualitative and quantitative evidence aiming for increased understanding of how the Family Centered Support Conversation approach may vary across parts of the life span and illnesses.
- Evaluation of family support and quality of care with a larger sample size and a comparison group.
- Due to the experience of the ongoing global pandemic situation caused by the onset of Covid -19, investigation of how long-term disruption of services impact on families living with young adult suffering from mental illness and family support in community mental healthcare.

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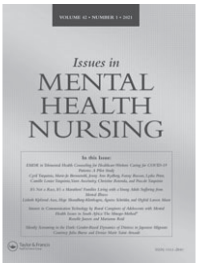
Appendix

App. 1: Study 1
App. 2: Study 2
App. 3: Study 3
App. 4: Study 4



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It's Not a Race, It's a Marathon! Families Living with a Young Adult Suffering from Mental Illness

Lisbeth Kjelsrud Aass, MCN, RNS, PhD student[a], Hege Skundberg-Kletthagen, MNS, RNS, PhD[a], Agneta Schröder, RNT, PhD[a,b], and Øyfrid Larsen Moen, MCC, RNT, PhD[a]

[a]Department of Health Sciences, Faculty of Medicine and Health Sciences (MH), Norwegian University of Science and Technology (NTNU), Gjøvik, Norway; [b]Faculty of Medicine and Health, University Health Care Research Center, Örebro University, Örebro, Sweden

ABSTRACT
The aim of this study is to explore families' perceptions of everyday life when living with a young adult suffering from mental illness. Findings include: 1) Families balance between letting go and enabling the young adult to become independent while remaining close to help him/her complete education, work and have a social life. 2) Young adults try to deal with symptoms of mental illness by themselves and not be a burden, although longing for family members to understand them and the situation. 3) Healthcare professionals still hold back information although young adults have consented to giving family members insight.

Introduction

In recent years, young adults with mental health problems have received increasing attention in research and clinical practice as a vulnerable group with special healthcare needs (Lindgren et al., 2015). Since mental healthcare services are mainly provided in outpatient and community health services, young adults are rarely hospitalized with the result that family members must play a key role in support, care and treatment (Andershed et al., 2017). This study focus on families living with mental illness where family is a self-identified group of two or more individuals who may or may not be related by blood or law, and who function in such a way that they consider themselves to be a family (Whall, 1986). Previous research has reported on the patient and family members individually (Lindgren et al., 2015), rather than as an entity. Since for various reasons mental illness interferes with the family's everyday life and family members are reciprocally affected (Lindgren et al., 2016), it is essential to describe the family's perceptions of everyday life. Everyday life is understood as the life that is lived, and includes all daily activities, tasks and responsibilities that people have (Gullestad, 1989).

Background

The prevalence of mental illness is greater among young adults aged 18–25 years than at any other stage of the lifespan. Anxiety and depression disorders are highly prevalent, and estimates indicate that they affect up to almost one fifth of the population in high-income countries worldwide (Gustavson et al., 2018). The World Health Organization (2014) has identified suicide as the second leading cause of death among young people aged 15–29 worldwide. What happens during these years has profound and long-lasting implications for young adults' physical, psychological and emotional well-being, future employment, career, economic security, the transition from living with, to living apart from parents and finding a life partner (Arnett et al., 2014). Unremitting fatigue, physical malaise and loss of motivation lead to poor academic performance, loss of self-esteem and lack of desire to socialize with friends and engage in family activities (McCann et al., 2012a). Fear of being stigmatized and shunned lead to increased social isolation as they are excluded from everyday activities (Woodgate et al., 2017). Young people suffering from mental illness tend to seek help from family and to use self-help interventions rather than accessing professional help (Reavley et al., 2011). Perceived stigma and embarrassment, problems recognizing symptoms and a preference for self-reliance are reported as barriers to seeking help (Gulliver et al., 2010). In Norway, mental healthcare services to young adults suffering from mental illness are provided free of charge in both specialist and primary (community) mental healthcare, as regulated by legislation (Ministry of Health & Care Services, 2011). Moreover, the Labour and Welfare Administration (NAV) may give financial support for renting an apartment but the young adult must find one him/herself.

CONTACT Lisbeth Kjelsrud Aass lisbeth.aass@ntnu.no Department of Health Sciences, Faculty of Medicine and Health Sciences (MH), Norwegian University of Science and Technology (NTNU), Gjøvik, Norway

The importance of family support has been demonstrated by young adults describing how family make a crucial contribution in supporting them with their illness, helping to strengthen their resilience through tolerance, understanding, assistance and encouragement (McCann et al., 2012b). Evidence show that the support provided by families can have a positive influence on recovery overall (Aldersey & Whitley, 2015; Pernice-Duca, 2010). Still, it is sometimes difficult for the family to find the right balance in the support they provide, because too much care could unintentionally have a contrary effect (McCann et al., 2012b). Nevertheless, according to Lindgren et al. (2015), lack of support could lead the young adult suffering from mental illness to experience decreased motivation to continue treatment and drop out. Family members living on the other person's terms report having poor health and being burdened (Skundberg-Kletthagen et al., 2014). Parents are often caring providers and describe everyday life as maintaining a strong façade while balancing on a thin line, always having the person struggling with mental illness on their minds (Johansson et al., 2010, 2012). However, family members experience being excluded from treatment and care due the patient needs for independence and different choice about the nature of family involvement (Johansson et al., 2014) or mental health care professionals being afraid of acting illegal or misunderstand the law of confidentiality (Weimand et al., 2013).

Mental illness is characterized as a family affair because family members are impacted and reciprocally influenced by the illness (Johansson et al., 2010, 2012) from the onset of symptoms, through diagnosis, treatment and mental healthcare. As far as we are aware, the perspectives on everyday life of families living with young adults suffering from mental illness are sparsely described in research (Ahlström et al., 2009). Given that young adults suffering from mental illness are reliant on support from family in everyday life, there is a need for research focusing on the family as a unit in mental health care.

The aim

The aim of this study is to explore families' perceptions of everyday life when living with a young adult suffering from mental illness.

Methods

Design

This study has a qualitative and explorative design. A phenomenographic approach was applied with the aim of investigating and describing the qualitatively different ways people perceive, understand, experience or think about the phenomenon—family everyday life living with mental illness (Marton, 1988). Phenomenography takes a second-order perspective, meaning that it is the different ways of conceiving the phenomenon that are of interest: what is in the informant's focus when describing the phenomenon under study and how is it described (Marton & Booth, 1997).

Table 1. Participating young adults and family members.

	Patients	Family members
Age	19 - 23	20-55
Gender		
Male	1	5
Female	5	6
Relationships		
Daughter	5	
Son	1	
Spouse		1
Mother		6
Father/stepfather		4
Educational level		
Lower secondary school,	2	
	3	7
Upper secondary school	1	
Apprentice		4
University		
Occupation		
Work	1	7
Job seeker	1	
Sick leave	1	1
Disability benefit		1
Work assessment allowance	1	
Other	2	2

Sample and settings

Healthcare professionals in community health services asked young adults suffering from mental illness to participate, and one to two family members were recruited through the young adult asking them to participate in the study. When family members agreed, the patients submitted their names and telephone number to healthcare professionals. *The inclusion criteria for young adults (patient) were*: between 18 and 25 years old, facing mental problems and strain, impaired function associated with mental distress, symptoms and diagnosable mental disorders. No diagnosis required. Either living alone or with family and/or friends and/or others, ability to speak and read Norwegian. Receiving care and/or treatment from mental community health services. *The exclusion criteria were*: cognitive impairment, psychotic state, active alcohol or drug abuse, or living in a residential home for persons suffering from mental illness. *Family members inclusion criteria were*: above 18 years of age and defined by the patient to be in the family and speak and read Norwegian. *The exclusion criteria were*: cognitive impairment, psychotic state, active alcohol or drug abuse.

A total of 17 people (seven families) participated in this study (Table 1). The family members' age ranged from 19 to 56 years old. Family members were related to the young adults—father, stepfather, mother or spouse. All those in the sample lived together with at least one other family member. Educational level ranged from secondary school to university, and their occupation status ranged from work, job seeker to sick leave, on disability benefit and work assessment allowance. The young adults were living with anxiety, affective disorder, personality disorder, attention deficit hyperactivity disorder and/or eating disorder.

Table 2. Outcome space.

Descriptive categories	Finding a manageable balance		Using a variety of coping strategies	
Conceptions	Desire to let go, still being close	Adjusting to limitations	Handling mental health symptoms in everyday life	A faceted partnership with mental health care professionals

Data collection

Qualitative data collection with family interviews (Eggenberger & Nelms, 2007) was conducted by the first author between February 2018 and June 2018 in order to explore the families' perceptions of everyday life. Family interviews were conducted with each of the seven families (i.e. family members and young adults together). Open-ended questions were used to invite the families to freely narrate their perceptions of everyday life. The initial question the first author asked all participants was: "How do you perceive family everyday life when suffering from or living with mental illness?" To acquire a deeper sense of the experience and variation in the conceptualization, probing questions like: "Can you tell me more?", "Has it always been like this?", "How?", "Who?" and "Can you give an example?" were used to encourage the family to describe more of their experiences. The participants' response was the basis for further questions. This facilitated a dialogue alternating between the family and the interviewer asking questions.

The family interviews were carried out either in the family's home, at the mental health care service office or the university, in accordance with the participant's wishes. The family research interviews lasted 50 – 65 min and were conducted, audio-taped and transcribed verbatim by the first author.

Ethical approval

The research is conducted in accordance with the common principles governing human clinical research, i.e. the principle of respect for autonomy, the principle of non-maleficence and the principle of beneficence (World Medical Association, 2018). The participants were informed both orally and in writing about the purpose of the study, the voluntary nature of participation, their right to withdraw at any time during data collection without needing to provide any explanation, and confidentiality. Informed written consent was obtained prior to the study. The Regional Committee for Medical & Health Research Ethics found the research project, ref. 2017/717, to be outside the remit of the Act on Medical and Health Research (2008), and the project therefore could be implemented without its approval. The Data Protection Official for Research at the Norwegian Centre for Research Data found that the processing of personal data in this study is in accordance with the Norwegian Data Act, ref: 54696, June 2017.

Data analysis

In line with the phenomenograhic approach, the interviews were seen as forming a "pool of meaning" in which variation in ways of experiencing the phenomena—family everyday life living with mental illness—were identified. The analysis was carried out by the authors with a continuous negotiation and re-negotiation of the meaning of extracts of data, both in the context of the family interviews and in the context of the collective pool of meaning (Marton & Booth, 1997). The data in the transcripts was audio-taped, transcribed and analysed in accordance with the steps indicated by Dahlgren and Fallsberg (1991) for analysing phenomenography studies. The transcripts were read through to become familiarized with all details and acquire an overall impression (*familiarization*). Significant statements were identified and meaning units named in a brief and representative version (*condensation*). Statements were compared in discussions among the research team to find sources of variation or agreement (*comparison*). Seemingly similar statements were collated. Differences and agreements were compared within meaning units, and possible categories were tested by comparing them with the interviews (*grouping*). A description of the essential meaning of each group was made (*articulating*). Description categories were labelled based on findings of suitable expressions (*labelling*). Categories were compared to ensure that each description category was mutually exclusive and at the same level (*contrasting*). The last three steps were repeated several times within the research group (Dahlgren & Fallsberg, 1991). The outcome space (Uljens, 1989) refers to the horizontal structure in which the descriptive categories reflect the distinctions of perceptions of everyday life.

Findings

Perceptions of everyday life as a young adult suffering from mental illness and family perceptions included two descriptive categories (Table 2); "finding a manageable balance" and "using a variety of coping strategies", including four concepts comprising the outcome space.

Finding a manageable balance

This descriptive category represents the degree of family dependency and closeness to each other in everyday life: emotional, physical, economical and practical support, communication and interactions and enabling education, work and social life. This descriptive category includes two concepts; "desire to let go, still being close" and "adjusting to limitations".

Desire to let go, still being close

The close emotional attachment and living close by were described by the families as for better or worse. In the case of privacy, the young adults experienced family members being caught up in details and interfering too much.

Meanwhile, family members described being past telling the young adult what he or she is not allowed to do and did not bother to argue anymore. Some described aggressive behaviour towards each other and arguing more if they spent too much time together. However, at times of less contact and not knowing what was going on, a young adult stated: "… when I was hospitalized, everyone had a hard time. Everyone just cracked up and we were all affected". Others tried not to be in the way and take up time, spending most of their time in their room.

Family members experienced that a lot of responsibility was delegated to them when the young adult was living at home. Uncertainty about the degree of involvement and how to be supportive in everyday life were frequently on family members' minds. Since they were involved in the ups and downs, everyday life had at times been so hard and difficult for family members that sick leave from work was necessary. At times when the young adults were too ill to attend work, for instance, family members did not know what to do or who to confer with and were concerned about whether the young adults would be able to keep their job. A family member said: "It's not easy knowing whether we should leave her in peace (when she has an anxiety attack). She really just has to decide herself what kind of contact she wants".

Both family members and young adults wanted young adult to live by themselves in the future. Being responsible for their own housing, economy and pets would strengthen the young adults' personal development process and self-confidence. They would have to cope with problems and decide by themselves when to ask family members or friends for help or seek help from community mental health care services. The family relationship would be more normal, better and positive. Other young adults desired to be independent, but still live close to their family for several years (for instance in a separate apartment in the family house) and were strongly dependent on the safety the family home provides and quick access to help and support in daily activities from family and mental healthcare professionals.

Adjusting to limitations

The families described having a job, going to school and being occupied with social activities as important. Work and vocational rehabilitation activities gave young adults a sense of achievement and gave family members a possibility to unwind. Notably, everyday life differed depending on whether the young adult went to work or not. A young adult described this as follows: "I'm happy at work. It's getting up in the morning that's difficult. Once I arrive at work, it's fine". Getting positive feedback from their manager, colleagues and family regarding work was valuable to the young adult and perceived as a safe arena where the young adults could challenge symptoms, for instance anxiety, through having to interact with colleagues. Disclosing to colleagues that they were struggling with mental illness, not having to pretend, made it easier to go to work.

Nagging the young adults to get up in the morning, making sure they get off to work was part of everyday life for family members. Others were told to let go and trust the healthcare team to guide the young adult in getting to work. To avoid being chained to home, the young adults sorely needed something to keep them occupied. In order to find an employer willing to employ a person who is not able to give 100%, the family was reliant on the Labour and Welfare Administration. Nevertheless, they continued to experience a back and forth situation, because new work placements/environment lead to the young adults falling ill after a week or two and unable to attend work.

Completing upper secondary education was a main goal for others who were motivated to continue education after dropping out the first time round due to lack of continuity in follow-up action from personal assistants. Having at least one family member working close to the young adult's school or work was described as advantageous, since it was easy to attend meetings about the young adult and be accessible when unpredictable events occurred. However, the withdrawal of sick-leave days for sick children over 12 years of age was a challenge for family members, and one said: "During a busy workday I get very upset because I can't go home since she's over 12 and I have no opportunity to take time off work to care for a sick child".

Spending time on hobbies and friends was described as essential for the young adult despite reporting physical and mental limitations in managing school and a job. However, young adults spent a large amount of their spare time at home either alone in their room or together with family members. Young adults revealed that they needed a considerable amount of time to prepare mentally in advance of social activities due to mental health symptoms. A young adult related: "If I'm thrown in at the deep end, it doesn't usually work well".

Family members described spending time on hobbies such as politics as meaningful, giving them a sense of liberty and enabling them to forget difficulties at home. When engaging in social activities together, family members described having a good connection with the young adult and experiencing no angry comments or annoyance. The use of humour to deal with difficult topics was emphasized.

Using a variety of coping strategies

A variety of strategies were described in handling symptoms. Moreover, the families stressed the importance of who they were connected to in the mental healthcare system and how interactions, care and support in everyday life from health care professionals were perceived. This descriptive category describes two concepts: *handling mental health symptoms in everyday life* and *a faceted partnership with mental health care professionals.*

Handling mental health symptoms in everyday life

The young adults described how the ability to feel happiness might nevertheless be accompanied by sadness and wanting to escape from everything due to being suicidal. One young adult experienced this in the following manner: "I have very many thoughts about not wanting to live any longer and …. Yes, it's just like there's nothing positive. If I'm feeling bad, then I'm feeling bad, then I'm at rock bottom".

Suffering from mental illness included feeling lonely, horrible and suicidal. At times of exacerbation of symptoms or hospitalization, young adults both included and excluded family members. When suicidal, depressed, paranoid or having panic attacks, the young adults included family members by asking them to be supportive and help, for instance by driving them to work, giving them time and space or calling the hospital. Being able to do things their way at their pace, they have more energy at work and for the family. However, they also excluded family members by running away, quarrelling, having outbursts of anger or withdrawing to their room without concealing how they feel.

While they lacked knowledge about how symptoms of mental illness affected the young adults in daily activities, family members admitted nagging a great deal to get the young adult to take part in social activities. When observing the young adult struggling with symptoms of mental illness, family members described taking the initiative to talk to the young adults about difficult emotions or thoughts. However, family members experienced them as reluctant to talk, replying that “Everything is ok, I’m just tired”. Others seldom sat down and talked because they were too busy. The young adults commented on this: “I kind of feel that we don’t talk so much any longer. We’ve kind of got into set routines …. Now things are at a standstill. It’s got to do with being cheered on. That you’re cheered on instead of being moved back”. When they dealt with difficult thoughts and emotions by opening up little by little and revealing their present mental health state, young adults experienced that family members’ concerns decreased and everyday situations became less dramatic.

Relations and interactions with other people, especially people they did not know, were difficult for young adults. This made, for instance, renting an apartment from strangers a challenge, or as a family member said: “He doesn’t dare to ring to the psychiatric outpatient services himself. I have to ring and ask when the appointment card has disappeared”. If family members were occupied with other activities or incapable due to illness, the young adult will be chained to the house. However, family members described being able to go away at weekends, leaving the young adult with responsibility for taking care of the house and pets, and considered that the young adult could help them out if someone was ill and needed assistance.

Lack of initiative in taking responsibility for their own health and wellbeing made young adults dependent on strict routines and rules in order to function optimally, not always cherish by the young adult, causing discussions and quarrels. Indeed, a step back may be necessary to rebuild physical and mental strength and everyday life skills, thus gradually becoming as independent as possible and taking responsibility. A family member said: “He will need follow-up for many years to come. We’ve understood this, and it’s something he (the patient) is insistent on”.

A faceted partnership with mental health care professionals

Regarding co-operation with health care professionals in community mental health services (CMHS), families believed healthcare professionals should cooperate closely and work in teams as early as the outbreak of symptoms in adolescence. A family member described: “Yes, the team we work with now is starting to fall into place. Things are beginning to go in the direction we ourselves really want …. It’s actually taken almost six months”. To facilitate working in the same direction, healthcare professionals need greater skills in working as a team with the family, to avoid causing more harm. This means regular contact with the CMHS ranging from a weekly to a monthly basis, either face to face or on the phone. However, when symptoms showed signs of exacerbation, the young adults were offered more frequent contact with mental healthcare professional in CMHS if they requested this.

After the young adults passed the age of 18, families experienced difficulties in health care follow-up actions due to confidentiality although the young adult have consented to full insight for their family. Family members described this as follows: “Even though he has given written authorization allowing Mum or Dad to have full insight into his medical records or authorizing me to speak on his behalf, they are restrictive. So-called data protection is an impediment in psychiatry”. Health care professionals holding back information to family members leads to young adults worrying that family members can no longer help and support them regarding work, health and economy. Others said it was part of the agreement with the young adult that family members could send text messages to healthcare professionals in CMHS, or telephone or email them when a quick response was needed, for example, when they wanted to give an indication of issues to discuss prior to the young adult meeting with mental health care professionals. Family members described their desire to have someone in the mental health care service they could contact and talk to when they were concerned and needed advice.

Discussion

The aim of this study is to explore the perceptions of everyday life of families living with young adults suffering from mental illness. The findings describe how young adults and family members interact in order to provide emotional, physical, economic and practical assistance to facilitate education, work and social life. Additionally, the findings show family perceptions of how symptoms of mental illness are coped with on a daily basis, and the faceted partnership with health care professionals.

Finding a manageable balance

Naturally the young adults have to adjust to more independent living, incorporate new knowledge and begin to regard themselves as adults (Lindgren et al., 2014). Thus, when suffering from mental illness, being adult for some is just a label, for example as in this study where young adults are seen to need someone to make sure they take care of personal hygiene and have a natural circadian rhythm.

The young adults in this study lived together or close to their family. This was necessary because they needed emotional and practical support from family members regarding housing, work, school and social activities, and the feeling of safety. Finding the right balance in the support provided by family is sometimes difficult, because too much care could unintentionally have a contrary effect (McCann et al., 2012b). In addition, independent living may contribute to family members' insecurity since it decreases their opportunity to keep an eye on the young adults (Lindgren et al., 2016).

Legally, young adults can refuse to permit family members' involvement. However, in line with Jivanjee and Kruzich (2011), young adults in this study continue to rely on family members' support after the age of legal responsibility of 18. Meanwhile, family members in this study notably strike a delicate balance between encouraging independence and providing a safety net. Simultaneously they experience uncertainty, conflicts and challenges in relationships, inclusion and exclusion in the illness trajectory, exacerbation of symptoms, hospitalization and the young adults' dependency on emotional and practical help (Jivanjee et al., 2009). Moreover, a changeable situation combined with love, compassion or sense of duty often makes it difficult to find a durable balance (Weimand et al., 2013).

Family members in this study adapt to and meet the daily demands of living with mental illness by being available round-the-clock and prepared for unpredictable situations, as described by Andershed et al. (2017) and Lindgren et al. (2016) for instance when young adults are suicidal at home and calling family members at work for help. Family members described themselves as burdened by not being able to take sick leave when they need to take care of a suicidal child who is not a minor by law. Consequently, living on other people's terms and having to adapt to this can affect everyday life to such an extent that family members themselves may need help and support (Skundberg-Kletthagen et al., 2014). Even so, the families in this study experience spending time on social activities and hobbies, focusing on something else and bonding in a different way, as a positive investment. This is in line with research that describes taking a break from caregiving tasks and engaging in other activities as increasing psychological well-being and preventing acute stress (Ha et al., 2008).

Young adults in this study face challenges in respect of educational achievement, unemployment, finding a suitable job, loss of employment (getting out of bed to work and managing a whole work day), social withdrawal and social isolation, in line with the findings of Armstrong et al. (2003). Significantly, being outside education and working life for a long period greatly increases the risk of permanent exclusion, and the prognosis is very poor in terms of becoming established in working life (Sommer, 2016). In this study, going to school, having a job and interacting with and getting positive feedback from colleagues are described as having an impact on self-esteem and mental illness symptoms, as also asserted by Reneflot and Evensen (2014). This emphasizes the importance of successful strategies for assisting young people with mental illness as they transition to post-secondary education, employment and independent lives (Woolsey & Katz-Leavy, 2008).

Using a variety of coping strategies

Everyday life for the young adults in this study included feeling depressed, anxious, lonely and suicidal, although they also experienced happiness. On the one hand, the young adults tried to hide because they felt they were a burden. On the other hand, they longed for family members to understand them and the situation. Moreover, they asked for support when they were unable to bear the symptoms of mental illness alone. To conceal their situation or withdraw may in the short term help to protect the young adults from stigma by reducing the possibility of differences being detected by others (McCann et al., 2012a). On the other hand, it may result in hindering contact with and obtaining support from others, lack of motivation, decreased energy, increasing social isolation and alienation, and contemplating or attempting self-harm or suicide.

The findings in this study show that mental illness puts considerable pressure on the relationship of young adults and family members (Lindgren et al., 2016). Consequently, poor communication and conflict in the immediate environment may undermine the young adults' ability to cope with their illness, increase the duration of the episode of illness and poorer outcomes for the young adults as they struggle to cope with their situation (McCann et al., 2012a). Notably, family involvement gave young adults in this study a good feeling, family members become less concerned and calmed the situation. Nevertheless, difficult questions arise for those caring for young adults regarding how to intervene in different situations without causing harm, similar to Andershed et al. (2017). What demands could they place on the young adult and what rights did they have in different situations to impose restrictions or not. Talking about current experiences of illness as well as individual family members' previous experiences of illness increases family members' understanding of each other and of the situation (Aass et al., 2020; Wright & Bell, 2009) and seems important for the well-being of families (Årestedt et al., 2014).

Clearly the young adults in this study have a strong need for autonomy and independence, and increasingly want to be able to handle problems themselves. However, they are still dependent on family support and help. In contrast to Reavley et al. (2011), the young adults in this study additionally tend to seek professional help. Nevertheless, the findings imply that family members intervene as best they can without seeking professional help in life-threatening situations such as young adults being suicidal. Family members take on responsibility because of love and compassion for the person suffering from mental illness (Weimand et al., 2013). But is this the result of lack of a reciprocal relationship between health care professionals and family, and being taken for granted as caregivers to the young adult (Andershed et al., 2017)? According to Weimand (2012), family members need support from professionals to find reliable solutions and knowledge enabling them to choose how they should act (be) and what they should do, in order to help and support their family member suffering from mental illness in managing everyday life (Andershed et al., 2017).

Family members asked to be involved in mental health care, and some experienced close and frequent connection while others missed working as a team with health care professionals. Nonetheless, family members should balance their desire to be involved in the young adult's care with the young adult's rights to confidential care (Ministry of Health & Care Services, 1999). However, family members in this study were confronted with the duty of confidentiality when they asked for information (Weimand et al., 2011), and health care professionals holding back information, although the young adults had consented to family members' insight. This inhibits partnership. Since young adults, family members and care professionals are mutually dependent, the ideal is to make use of each other's knowledge in a partnership to achieve common caring strategy (Aass et al., 2020; Andershed et al., 2017).

Methodological considerations

To ensure trustworthiness, Guba's four criteria (1981) were used in this study. The sample of seven families ensured variation in the different ways of experiencing the phenomenon (Marton & Booth, 1997) and there was a broad sample in terms of different family relationships, gender and age, which gave rich descriptions, strengthening credibility (Sandelowski, 1986). By asking the families the same open-ended questions, dependability was ensured, and the participants were given the opportunity to contribute experiences not covered during the research interview. All the research interviews were carried out by the first author. The authors have included quotes from both patients and family members to strengthen trustworthiness and authenticity. By establishing an "audit trail" (Guba, 1981) describing all steps in the analysis process, confirmability is enabled. In this phenomenographic study, analysing the family research interviews was challenging in relation to the extent to which the experience of everyday life can be expected to be shared across the families. However, this was strengthened by the involvement of all researchers in the analysis process. Transferability: we believe that this study contributes relevant knowledge to other families within similar contexts. On the one hand, there may be a risk of the interview reflecting the experiences of individuals rather than the family as a unit. On the other hand, focusing on the family as a unit entails data on both individual and family level. The family members in the study share a common history, strengths, and belief systems, and have close contact with one another, but they are still distinct individuals. The shared family experiences that emerge with an illness increase knowledge and the discovery of family meaning through collecting data on a family level (Eggenberger & Nelms, 2007). Family experiences of everyday life are assumed to be the sum of the subjective views of each individual family member (Åstedt-Kurki et al. 2001).

In the interview situation, the families shared willingly and spoke openly of their experiences with each other, even if their stories included new thoughts that the family had never discussed. Participating in family research interviews may be a beneficial learning experience for the family as they become more aware of each other's beliefs and opinions. One obvious limitation may be if family members are not able or willing to be open and share their experiences with each other (Eggenberger & Nelms, 2007; Moen et al. 2014). The interviews might include issues that were sensitive for the families. As a psychiatric nurse, the interviewer (first author) is used to talking to patients with mental illness and their families, and was aware of the power balance in the interview (Marton & Booth, 1997).

Conclusion

This study contributes to various concepts of families living with mental illness. From the participating families' perspectives, everyday life living with mental illness is about balancing between being close to support, care and help in everyday life, and enabling the young adult and family members to complete education, manage work and have a social life. Young adults try to deal with symptoms of mental illness by themselves and not to be a burden, although longing for family members to understand them and the situation. Families have a desire to be a natural part of the healthcare team. However, healthcare professionals held back information although young adults had consented to family members insight, thereby inhibiting partnership. To realize that mental illness is a family affair and thus focus on the family as the unit of care, requires a conceptual shift, even a paradigm shift.

This study reveals a need to acquire more knowledge of family support interventions of relevance to everyday life in this situation. Therefore, this type of knowledge is important for: 1) mental healthcare clinicians when considering the development of care offered to families living with mental illness, 2) the Labour and Welfare Administration when considering family inclusion as a natural part of individual work placement and support and 3) counsellors and educators when considering the inclusion of the family as a natural part of the team helping young adults suffering from mental illness to complete secondary education.

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ORCID

Lisbeth Kjelsrud Aass http://orcid.org/0000-0002-0723-1093
Hege Skundberg-Kletthagen http://orcid.org/0000-0002-1830-3136
Agneta Schröder http://orcid.org/0000-0002-2157-8579
Øyfrid Larsen Moen http://orcid.org/0000-0002-7970-6027

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ORIGINAL ARTICLE

Family support and quality of community mental health care: Perspectives from families living with mental illness

Lisbeth Kjelsrud Aass MCN, RNS, PhD student[1] | Øyfrid Larsen Moen MCC, RNT, PhD, Associate Professor[1] | Hege Skundberg-Kletthagen MNS, RNS, PhD, Associated professor[1] | Lars-Olov Lundqvist PhD, Professor, Research leader[2] | Agneta Schröder RNT, PhD, Professor[1,2]

[1]Department of Health Sciences, Faculty of Medicine and Health Sciences (MH), Norwegian University of Science and Technology (NTNU), Gjøvik, Norway

[2]Faculty of Medicine and Health, University Health Care Research Center, Örebro University, Örebro, Sweden

Correspondence
Lisbeth Kjelsrud Aass, Department of Health Sciences, Norwegian University of Science and Technology (NTNU), PO Box 191, N-2802 Gjøvik, Norway.
Email: lisbeth.aass@ntnu.no.

Abstract

Aim and objectives: Describe patients' and family members' perceptions of family support from nurses and other mental healthcare professionals, and quality of care in community mental healthcare service. Further, compare the perceptions of patients and family members.

Background: While patients value family involvement, family members feel unprepared and lack the necessary skills to be supportive. Since healthcare professionals predominantly focus on patients, they may fail to understand the complex needs of families. Family perceived support and quality of community mental health care may vary across patients and family members.

Design and methods: Cross-sectional study with patients suffering from mental illness and family members in community mental healthcare services in Norway. Altogether 86 participants, of whom 33 patients and 33 family members had a family relationship—paired samples. Participants filled in the translated version of the Iceland Family Perceived Support Questionnaire (FPSQ-N) and Quality in Psychiatric Care—Community Out-Patient (QPC-COP) and Community Out-Patient Next of Kin (QPC-COPNK). STROBE checklist was used.

Results: Family members scored family perceived support and quality of community mental health care lower than patients. Family members feel the loss of support. Patient and family members found the Patient—healthcare professionals' relationship to be of high quality, while family members gave low score to being respected and invited to take part in care by nurses and other mental healthcare professionals.

Conclusion: Family members' unmet need of support highlights the need for nurses and other community mental healthcare professionals to assess complex family needs and to intervene. Barriers to collaboration exist, and family members need to be respected and invited into community mental health care.

Relevance to clinical practice: Contributes knowledge of how to meet the family's needs and provides a basis for further care and treatment development in similar contexts nationally and internationally.

KEYWORDS
community mental health care, family support, mental healthcare professionals, mental illness, nurses, quality of care

1 | INTRODUCTION

Mental healthcare services aim to support healing, improve recovery and prevent illness (Norwegian Directorate and of Health, 2014). Increased involvement of patient and family has been assigned high priority in recent years and is endorsed in mental health policies and standards of practice nationally and internationally (Norwegian Directorate of Health, 2015; World Health Organization, 2013). Across cultures, families often play important and even critical roles as carers in the lives of persons suffering from mental illness (Hinton et al., 2019). They constitute an important resource and can be successful supporters to the person suffering from mental illness. However, family members feel unprepared or lack the necessary skills for support and care tasks related to mental illness (Skundberg-Kletthagen et al., 2014), and need help in sustaining their emotional resources in order to continue providing care (Sveinbjarnardottir et al., 2013). It is therefore important for healthcare professionals to understand family needs and functioning (Shajani, & Snell, 2019).

What does this paper contribute to the wider global clinical community?

- Community mental healthcare of highest quality consists of caring, empathic and respectful relationships between patients and healthcare professionals. However, in order to make family members feel respected and invited to take part in care, family– healthcare relationships should also be addressed.
- Family members play a key role as carers in the lives of persons suffering from mental illness, and need both emotional and cognitive support from mental healthcare professionals enabling them to be supportive.
- Family members must be involved as a natural part of the patient's mental healthcare team. In addition to standard care, mental healthcare professionals must facilitate an environment for families to share illness beliefs, as well as eliciting family strengths.

2 | BACKGROUND

Community mental healthcare services are responsible for delivering health services that patients and family find accessible and acceptable, uch as intensive case management, early crisis intervention or recovery rehabilitation services (Thornicroft et al., 2016).

In Norway, the vast majority of healthcare professionals working in community mental healthcare services are nurses, followed by social workers, social educators and occupational therapists. Several have supplementary education in mental illness, so that they have a preventive role and can offer treatment and follow-up for persons suffering from mental illness, and support their families (Karlsson and Kim, 2015).

Patients are entitled to care corresponding to their needs, which entails self-determination and participation in decisions related to their treatment and care (Thornicroft et al., 2016). Families need access to care which offers support, education and practical strategies for managing the sick family member and their own mental health concerns (Skundberg-Kletthagen et al., 2014). Patients have indicated that family involvement is valuable and felt satisfied with the mental healthcare services when family inclusion was encouraged (Aass et al., 2020b). Family is defined as a self-identified group of two or more individuals, who may or may not be related by blood or law and who function in such a way that they consider themselves to be a family (Whall, 1986). This includes spouses, children, parents, friends, neighbours or others named by the patient. Families have an important role to play in supporting people with illness and promoting increased coping in everyday life (Shajani & Snell, 2019). However, mental healthcare professionals may fail to understand the complex needs of the family, due to a predominant focus on the patient (Johansson et al., 2014).

When measuring family support provided by nurses and other healthcare professionals from the perspectives of patient and family members, it is helpful to get an idea of the influences and effectiveness of family support in two domains of family functioning—emotional and cognitive (Sveinbjarnardottir et al., 2012). Previous research has shown that families living with a family member suffering from mental illness experience emotional and practical difficulties (Aass et al., 2020b). While the provision of emotional support by nurses and other healthcare professionals enables families to handle the burden of illness and accompanying emotions, the provision of cognitive support helps to educate or inform the family in relation to the experience of the illness (Shajani & Snell, 2019). Short therapeutic interventions offering families the opportunity to reflect on their illness experience (Sveinbjarnardottir & Svavarsdottir, 2019) seem to be an important contributory factor in their perceived support, compared to normal family meetings not built on any particular conceptual framework (Sveinbjarnardottir et al., 2013). Improved relationships are reported by family members who are being included in care (Sveinbjarnardottir & Svavarsdottir, 2019).

Measuring the quality of community mental health care from the perspectives of patients and family members is important in ensuring that the services offer high quality, efficient treatment and care (Norwegian Directorate of Health, 2014), and fulfil the quality requirements (Shaw, 1997). The quality of mental health care has been described as a multidimensional concept and is described by patients (Schröder et al., 2006), healthcare professionals (Lundqvist and Schröder, 2015) and family members (Schröder et al., 2007) as something positive and normative.

It is essential to include patients and family when defining quality of care as they have unique information regarding community mental health care. Moreover, their view of what is important is an valuable aspect. To ensure the best possible quality of care for people suffering from mental illness, a process of recurring assessment and improvement is therefore important (Kilbourne et al., 2018). A growing proportion of mental health care is provided in the patient's home, and the quality of such care largely depends on the degree of family involvement. Consequently, measurement of what constitutes quality of care from the family perspective provides valuable information for nurses and other community healthcare professionals and healthcare authorities. Furthermore, a comparison of patient and family members' perceptions contributes an overall picture of quality of care in community mental healthcare services, helping to improve quality of care and the development of interventions.

To the best of our knowledge, patient and family members' perceptions of family support care from nurses and other community mental healthcare professionals as well as central aspects of quality of community mental healthcare services care are described in the literature to only a limited extent. Studies describing and comparing the following aspects from the perspective of families are urgently needed: cognitive and emotional support from nurses and other community mental healthcare professionals, and quality of care given to patients in community mental healthcare services. A shift is needed in research from an emphasis on nurses and other mental healthcare professionals and patient variables to family variables (Sveinbjarnardottir et al., 2012), enabling us to understand what patients and family find important and to identify domains where improvements can be made.

2.1 | Aim

The aim of this study was to describe patients and family members' perceptions of family support from nurses and other mental healthcare professionals, and quality of care in community mental healthcare services. A further aim was to compare the perceptions of patients and family members.

3 | METHODS

3.1 | Design and sample

A cross-sectional study was performed in community mental healthcare services in Norway. Information about the study and a request for participants were sent to mental healthcare managers in municipalities in Norway by mail. The managers supplied the email addresses of healthcare professionals in community mental healthcare who could recruit participants. An information letter and questionnaires were delivered to the recruiting mental healthcare professionals who handed these out to patients suffering from mental illness and any family members who wished to participate.

The sample in this study (Figure 1) included a total of 86 participants—43 patients and 43 family members from 15 municipalities. Out of the total of 86 participants, 33 patients and 33 family members had a family relation to one of the other participants—composing 33 paired samples. The sample size calculation shows that, given a power of 80% and a significance level of 5% (two sided), 34 pairs are needed for detecting a mean difference with an effect size of 0.5 (medium).

Patient inclusion criteria: ≥18 years old, facing problems and strain, impaired function associated with distress, symptoms and diagnosable mental disorders, diagnosis not acquired, living with someone or alone and receiving care and/or treatment from community mental healthcare services. Patient exclusion criteria: cognitive impairment, psychotic state, active alcohol or drug abuse, not able to speak and read Norwegian. The patients who consented to participate asked family members to give their name and telephone number to community mental healthcare professionals who contacted a family member and gave oral and written information. Family members inclusion criteria: >18 years old, defined by the patient to be family. Family members exclusion criteria: cognitive impairment, psychotic state, active alcohol or drug abuse, not able to speak and read Norwegian.

3.2 | Data collection

The data collection period took place from October 2017 to June 2019.

Patients and family members were informed by mental healthcare professionals about the study both orally and in writing and were advised that participation was voluntary and could be terminated at any time. Patients and family members who gave their written consent to participate were requested to complete the questionnaire individually and return it by mail to the first author. An ID code labelling A for patients and B for family members made it possible to send reminders, and to link patient and family member as a paired sample in the analysis.

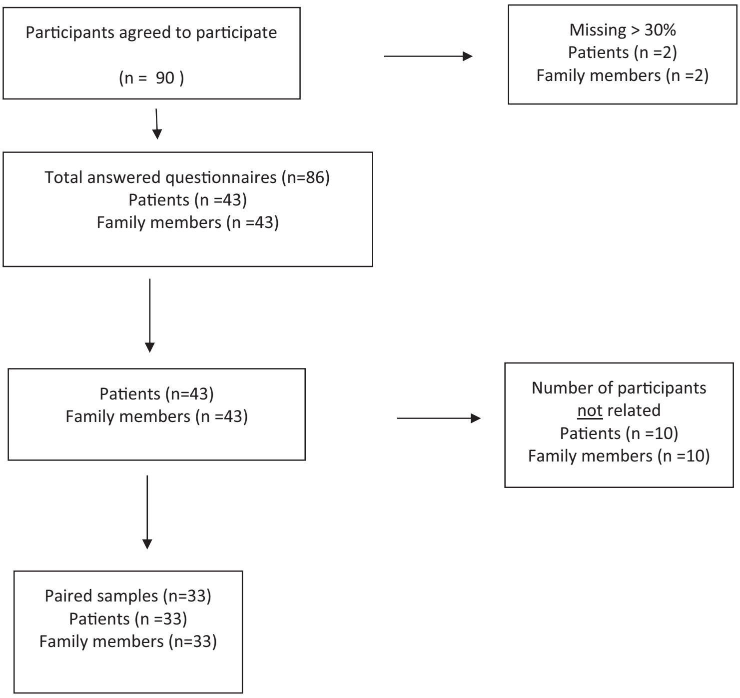

FIGURE 1 Flow chart of participants

3.3 | Measures

Demographic data were collected, for example age, gender, relation to the patient, living arrangements, educational and occupational status. In addition, data were collected about patients' and family members' current mental and physical state of health, whether they knew where to go if not satisfied with treatment/care and if they attended family support conversations.

The questionnaire consisted of instruments suited to measuring patient's and family members' perceptions of family support (ICE-FPSQ) (Sveinbjarnardottir et al., 2012) from community mental healthcare professionals, and quality of care from the perspective of patients (QPC-COP) and family members (QPC-COPNK).

3.3.1 | ICE-Family Perceived Support Questionnaire (ICE-FPSQ)

The ICE-FPCQ is a self-administered questionnaire consisting of 14 items that covers patients' and family members' perceptions of family support. It measures two factors: *Cognitive support* (five items) and *Emotional support* (nine items). All items are related to the statement: "Community mental health professionals have...." For instance, a Cognitive Support item is worded as follows: "[Community mental health professionals have] ...... offered us information and their professional opinion" or an Emotional Support item: "encouraged my family to become involved with the health care team and offered us support." Responses are made on a five-point Likert scale ranging from 1 (almost never), 2 (seldom), 3 (sometimes), 4 (usually) and 5 (all of the time) (Sveinbjarnardottir et al., 2012). The score of the instrument ranged from 14 to 70 points, where a higher score is considered to indicate a better perception of support. However, there is no exact cut-off score to distinguish between optimal and less than optimal perceived support from healthcare professionals. The original Icelandic FPSQ is translated and back-translated by professionals' translators into Norwegian and adapted to the Norwegian cultural context (FPSQ-N). The Icelandic version of the FPSQ is psychometrically tested with Cronbach's Alpha coefficient reported as 0.96 (Sveinbjarnardottir et al., 2012). Cronbach's Alpha coefficient in this study on the patient FPSQ-N was 0.95 and family member FPSQ 0.95. The Norwegian (FPSQ-N) version has not yet been psychometrically tested but will be tested in a future study.

3.3.2 | The Quality in Psychiatric Care—Community Out-Patient (QPC-COP)

The QPC-COP instrument is based on the original Swedish instrument Quality in Psychiatric Care–Out-Patient care (QPC-OP) (Schröder et al., 2011). The QPC-COP is a self-administered questionnaire consisting of 30 items that cover patients' perceptions of quality of care in eight dimensions: *Encounter* (six items), *Participation-Empowerment* (three items), *Participation-Information* (five items), *Discharge* (three items), *Support* (four items), *Environment* (three items), *Next of kin* (two items) and *Accessibility* (four items). Responses are made on a four-point Likert type scale, ranging as follows: 1 = Lowest quality (Totally disagree), 2 = Quite low quality (Partly disagree), 3 = Quite high quality (Partly agree) and 4 = Highest quality (Totally agree). For all items, it was possible to answer 'not applicable'.

3.3.3 | The Quality in Psychiatric Care—Community Out-Patient Next of Kin (QPC-COPNK)

QPC-COPNK is based on the QPC-COP and modified to cover family members' perceptions of quality of care in the same eight dimensions as in the QPC-COP.

Both the QPC-COP/COPNK instruments consist of the same number of items (*n* = 30). The items are similar in content. Both instruments address the quality of care and treatment patients receive. The only difference is that in the QPC-COP, the wording is from the patient's perspective as opposed to the family perspective in the QPC-COPNK. For example, an item in the Environment dimension is worded "I have confidence in the staff" in the patient version, and "The patient has confidence in the staff" in the next-of-kin version. The Original QPC-COP was translated and back-translated by professionals translators into Norwegian and adapted to the community mental healthcare context, and the translated QPC-COP modified to apply the QPC-COPNK. The Swedish version of QPC-OP has undergone psychometric testing. Cronbach's Alpha coefficient is reported as 0.70 on the QPC-OP (Schröder et al., 2011). The Cronbach's Alpha coefficient in this study on QPC-COP was 0.93 and on QPC-COPNK, 0.95. The QPC-COP and QPC-COPNK have not yet been psychometrically tested but will be tested in a future study.

3.4 | Statistical analysis

All statistical analysis was conducted using SPSS version 25. Frequencies, mean and standard deviation were used to describe the demographic characteristics of the 43 patients and 43 family members. Prior to analysis, questionnaires with 30% or more missing items were discarded (SPSS, 2017). For the remaining questionnaires, imputation was performed by replacing missing data and "not applicable" points with the mean of the remaining items in the dimension (Fox-Wasylyshyn & El-Masri, 2005).

The demographic background variables: age, relation to the patient, educational and occupational status and background questions about current physical and mental health status, were entered as dichotomised variables when comparing groups (MacCallum et al., 2002). The Kruskal–Wallis test was used to compare mental and physical health status and occupational status, with Mann–Whitney U test as a post hoc test (Altman, 1991). The Mann–Whitney U test was used to compare the differences between patients' (*n* = 43) and family members' (*n* = 43) mental and physical health status with regard to age-group, gender, roles and occupational status. To explore the correlation between patients' and family members' current mental health status and age (years), and current mental health status by QPC-COP/COPNK—total and dimensions, a non-parametric test with Spearman's rho was used.

A Wilcoxon's signed-rank test, with a matched subject design due to the specific criteria being paired sample (*n* = 33), was used to compare the differences between patients and family members on FPSQ-N and QPC-COP/COPNK. This enabled analysis within families regarding family perceived support and quality of care. The significance level was set to $p < .05$ (2-tail). Effect size was evaluated using Cohen (1988) criteria of .1 = small effect, .3 = medium effect and .5 = large effect.

The checklist STROBE Statement for cross-sectional studies has been used reporting this study (Von Elm et al., 2007; Appendix S1).

3.5 | Ethical considerations

Ethical considerations included confidentiality, integrity and the voluntary nature of participation (World Medical Association, 2018). The Regional Committee for Medical & Health Research Ethics (REC) found that the research project, ref. 2017/717, was outside the remit of the Act on Medical and Health Research (2008) and therefore could be implemented without REC's approval. The Data Protection Official at the Norwegian Centre for Research Data (NSD) found that the processing of personal data in this study is in accordance with the Norwegian Data Act, ref: 54696, June 2017.

4 | RESULTS

4.1 | Characteristics of patients suffering from mental illness and family members (*n* = 86)

There was a predominance of women among the 43 patients (Table 1). The majority of the patients were between the ages of 18–25, with a mean age of 36 years. With regard to patients' educational level, the majority had completed basic education or upper secondary school, and the majority were not engaged in work or studies. There was also a predominance of women among the 43 family members (Table 1). The majority of family members were between the ages of 40–59, with a mean age of 46 years. As regards their relationship to the patient, most of them were related by bloodlines such as mother, father, sibling, daughter or son. Notably, 41.5% were mothers. Among family members, almost half had a college/university degree and the majority worked or studied.

4.2 | Background questions (*n* = 86)

When comparing patients' current mental and physical health status by age group, gender and occupational status, we identified no significant differences.

TABLE 1 Characteristics of the study group (*n* = 86)

	Total	
	Patients **n = 43 (%)**	**Family members** **n = 43 (%)**
Gender, *n* (%)		
Male	9 (20.9)	16 (37.2)
Female	34 (79.1)	27 (62.8)
Missing		
Age, *n* (%) median, SD	36.6 (17.5)	45.8 (14.1)
18–25	18 (41.9)	5 (11.6)
26–39	9 (20.9)	9 (20.9)
40–59	6 (14.0)	22 (51.2)
60–85	9 (20.9)	7 (16.3)
Missing	1 (2.3)	
Relationship to the patient, *n* (%)		
Spouse/partner		17 (39.5)
Blood relationship		25 (58.1)
Other		1 (2.3)
Living arrangements, *n* (%)		
Living alone	15 (34.9)	4 (9.3)
Living with others	28 (65.1)	39 (90.7)
Education, *n* (%)		
Basic education/Upper secondary	36 (83.7)	27 (62.8)
Secondary		
School		
College/University	7 (16.3)	15 (34.9)
Missing		1 (2.3)
Occupation, *n* (%)		
Working/studying	6 (14.0)	25 (58.1)
Not working/Retired	26 (60.5)	8 (18.6)
Other	11 (25.6)	10 (23.3)
Current mental health status		
Very poor	3 (7.0)	
Poor	19 (44.2)	5 (11.6)
Neither good nor bad	9 (20.9)	13 (30.2)
Good	10 (23.3)	15 (34.9)
Very good	2 (4.7)	10 (23.3)
Current physical health status		
Very poor	2 (4.7)	
Poor	13 (30.2)	7 (16.3)
Neither good nor bad	13 (30.2)	8 (18.6)
Good	14 (32.6)	22 (51.2)
Very good	2 (4.7)	6 (14.0)

When comparing, family members' current mental and physical health status by age group, gender and role, using a Mann–Whitney U test, no significant differences were identified. Significant differences appeared exclusively between family members' current mental and physical health status and occupational status. Family members who worked or studied reported significantly better mental health status (M = 1.76, SD = .43, $p < .001$) and physical health status (M = 1.76, SD = .43, $p < .001$).

Regarding the question of whether they knew where to turn if they were dissatisfied with patient treatment and care, patients (51.2%), and family members (62.8%) gave a negative response. With reference to attending family conversations, the majority of patients (79.1%) and family members (76.7%) had not attended.

Patient age (years) and current mental health correlated significant ($r = .366$, $p < .01$), indicating that high age is associated with poorer mental health. In relation to patient mental health status, QPC-total and dimensions, correlations were found exclusively between patients' mental health and the Discharge dimension ($r = .319$, $p < .004$), including the items "My treatment has helped"(8), "I get help in finding an occupation" (17), "I know where to turn if I need help after discharge"(21).

4.3 | FPSQ-N—patients and family members as paired family samples (*n* = 33)

A comparison between patients and family members as a paired sample (Table 2) revealed significant differences on the total family perceived support questionnaire, that is the total FPSQ-N ($p < .00$). Patients ($n = 33$) scored highest on family support (FPSQ-N) with a total mean sum score of 40.3, while family members ($n = 33$) had a total mean sum score of 30.7.

Significant differences between patients and family members within the paired sample were found in both the Cognitive support dimension, ($p < .005$) where patients scored M = 15.5 and family members M = 11.8 and in the Emotional support dimension where patients scored M = 25.1 and family members M = 18.8 ($p < .003$), with a medium effect size in both the Cognitive and Emotional support dimension.

4.4 | Descriptive results on single items and dimensions

In both the Cognitive and Emotional support dimensions and in all the items as shown in Table 2, the patients gave a higher score than the family members.

In the Cognitive support dimension, family members gave significantly lower scores than patients in relation to the degree to which mental healthcare professionals focused on the following: "Offered us information and their professional opinion" and "Provided accessibility and easy-to-read literature about the mental health problem."

In the Emotional support dimension, family members' scores were significantly lower than patients scores in relation to the following items: [mental healthcare professionals] "Offered us family meetings" and "Looked for the family`s strenghts and opportunities to commend family members when their strengths have been revealed" (Table 2).

TABLE 2 FPSQ-N. Patient and family members as paired samples (*n* = 33)

	Patients *n* = 33		Family members *n* = 33			
	Mean	**95% CI**	**Mean**	**95% CI**	***p* < value***	**Effect size (Cohen`s d)**
N-FPSQ total[a]	40.30	34.57–46.17	30.70	25.64–35.92	**.002**	
Cognitive support	15.20	13.01–17.40	11.80	9.95–13.67	**.005**	.34
1. Offered us information and their professional opinion	2.94		2.24		**.012**	
2. Provided accessibility and easy-to-read literature about the mental health problem	3.36		2.42		**.001**	
3. Informed my family about the resources available in the community that have proven to be helpful for families in similar situations.	2.70		2.00		**.027**	
4. Provided ideas, information and thoughts in a manner which enabled us to learn from them and reflect on them.	3.03		2.39		0.068	
5. Emphasised the use of family rituals to promote family health	3.22		2.76		.153	
Emotional support	25.1	21.41–28.84	18.9	15.49–22.44	**.003**	.36
6. Offered us family meetings	2.88		1.91		**.002**	
7. Helped family members recognise that our emotional responses are valid and helped us to validate and/or normalise family members' responses	2.67		2.03		.053	
8. Encouraged my family to become involved with the healthcare team and offered us support	2.70		2.03		**.008**	
9. Encouraged family members to share their illness narrative- not only stories of illness and suffering, but stories of strengths and resilience	2.38		2.00		.221	
10. Elicited our family strengths	3.00		2.03		**.004**	
11. Helped family members understand how our emotional responses are related to the family member's illness	2.59		2.36		.425	
12. Encouraged my family to take respite from caregiving	2.29		1.85		0.154	
13. Were aware of the impact family members can have on one another, on well-being and on mental illness	3.33		2.42		**.007**	
14. Looked for the family's strengths and opportunities to commend family members when their strengths have been revealed	3.30		2.24		**.005**	

[a] Family Perceived Support Questionnaires, sum score ranged from 1 (low perceived support) to 5 (high perceived support). The score of the instrument ranged from 14 to 70 points, where a higher score represents better perceived support for families.

*p-value <.05 from Wilcoxon signed-rank test. Bold values are significant values.

As Table 2 shows, patients scored family support as highest on item: [Mental healthcare professionals] "Provided accessibility and easy-to-read literature about the mental health problem" (M = 3.36) in the Cognitive support dimension. In contrast, family members scored highest FPSQ-N on item: [Mental healthcare professionals] "Emphasized the use of family rituals to promote family health" (M = 2.76) in the Cognitive support dimension.

The lowest FPSQ-N was scored by both patients (M = 2.29) and family members (M = 1.85) on the same item: [Mental healthcare professionals] "Encouraged my family to take respite from caregiving" in the Emotional support dimension.

Items with the largest discrepancy between patients score (M = 3.30) and family members score (M = 2.24) were as follows: [Mental healthcare professionals] "Looked for the family's strengths and opportunities to commend family members when their strengths have been revealed," "Elicited our family strengths"—patients (M = 3.00) and family members (M = 2.03), "Offered us family meetings"—patients (M = 2.88) and family members (M = 1.91) all in the Emotional support dimension and "Provided accessibility and easy-to-read literature about the mental health problem"—patients (M = 3.36) and family members (M = 2.42) in the Cognitive support dimension.

4.5 | QPC-COP/COPNK—patients and family members as paired family samples (*n* = 33)

A comparison between patients and family members as a paired sample (Table 3) revealed significant differences in the total quality of community mental health care, that is the total QPC-COP/COPNK (*p* < .00). Patients scored higher on total QPC-COP (M = 3.43) than family members (M = 3.06). Significant differences between patients and family members within the paired sample were found in six of the eight dimensions with a medium effect size: Encounter (*p* < .012), Participation–Empowerment (*p* < .012), Participation–Information (*p* < .001), Discharge (*p* < .002), Next-of-Kin (*p* < .001) and Accessibility (*p* < .001). No difference was found in the Environment and Support dimension.

As shown in Table 3, both patients and family members scored the quality of the Encounter dimension as highest. Family members also scored the Participation–Empowerment dimension equally high. The lowest level of quality was found among patients in the Discharge dimension, while family members lowest level of quality was found in the Next-of-Kin dimension.

4.6 | Descriptive results on single items

At items level, the item gaining the highest score among patients was "Mental health care professionals respect my next of kin" (M = 3.86) in the Next of Kin dimension, while among family members the item scoring highest was "Mental health care professionals respect the patient" (M = 3.69) in the Encounter dimension.

The lowest score among patients was given for item "Easy for me to meet the doctor" (M = 2.59) in the Accessibility dimension, while family members scored "Easy for the patient to meet contact person" (M = 2.00) also in the Accessibility dimension, lowest.

Items ranked higher by patients than by family members were "Easy for me to meet the contact person" (Accessibility) and "I get help in finding an occupation" (Discharge). Items ranked lower by family members than patients were as follows: "Mental healthcare professionals invited the patient`s next-of- kin to take part" (Next of Kin), and "Mental healthcare professionals respect the patient's next of kin" (Next of Kin).

5 | DISCUSSION

The aim of this study was to describe patients and family members' perceptions of family support from nurses and other mental healthcare professionals, and quality of care in community mental healthcare service. A further aim was to compare the perceptions of patients and family members. Significant differences within the paired samples were identified, as family members scored lower on Family Perceived Support as well on the Quality of Care compared to patients.

5.1 | Perceived family support within the paired family samples

There were differences in perceived family support as measured by the total FPSQ-N score in this present study with the patients scoring this at 40.3, while family members scored it at 30.7. Family members in this study reported the loss of emotional and cognitive support. The findings contribute knowledge to clinical practice and may encourage mental healthcare professionals to improve their collaborative relationship with families, since the relationship between mental healthcare professionals and family members indirectly affects the patient's well-being (Johansson et al., 2014).

In this study, family members assign higher scores to nurses and other mental healthcare professionals' emphasis on the use of family rituals and routines to promote family health, as measured by the FPSQ-N on the Cognitive support dimension. Indeed, this is a cognitive support approach of major importance, since the relationships between rituals, routines and family functioning have indicated positive health outcomes (Moen et al., 2014). According to Fiese (2007), this is crucial since family routines could be at risk when illness occurs.

Furthermore, family members scored significantly lower than patients with regard to the following: being offered information, professional opinions, provided with easy-to-read literature enabling the families to learn and reflect, and being informed of resources available, as measured by the FPSQ-N on the Cognitive support dimension. Consequently, family members may feel unsure about how to respond to the patient's symptoms (Weimand et al., 2011), which adversely affecting their coping (Skundberg-Kletthagen et al., 2014). The Norwegian Directorate and of Health (2017) recommends that mental healthcare services provide family members with skills to cope with their supporting role and identify strengths and resources that enable them to be supportive. Shajani and Snell (2019) claim that encouraging families to listen to each other's concerns and feelings helps them to cope with emotions connected to living with an illness.

When comparing Emotional support as measured on the FPSQ-N, family members in this study reported lower scores than patients about being encouraged by nurses and other mental healthcare professionals to share beliefs of the illness situation and being offered support and family meetings. This is unfortunate, since beliefs function as a protective factor against family members disconnecting from each other (Wright & Bell, 2009). Factors such as sharing and reflecting on experiences facilitate new meanings and possibilities in everyday life (Aass et al., 2020b). Both patients and

TABLE 3 QPC-COP/COPNK. Patients and family members as paired samples (*n* = 33)

	Family members *n* = 33		Patients *n* = 33			
	Mean	**95% CI**	**Mean**	**95% CI**	***p* < value[*]**	**Effect size (Cohen`s d)**
QPC-COP/COPNK total[a]	3.43	3.27–3.59	3.06	2.87–3.26	**.004**	
1. Encounter (6 items)	3.77	3.60–3.93	3.41	3.19–3.63	**.012**	.30
11. Mental healthcare professionals show empathy	3.76		3.23			
12. care if I/the patient gets angry	3.68		3.30			
15. respect me/the patient	3.82		3.69			
18. show understanding for me/the patient	3.76		3.55			
20. have time to listen to me/the patient	3.79		3.28			
25. care about my/the patient care	3.82		3.44			
2. Participation—Empowerment (3 items)	3.48	3.24–3.72	3.41	2.79–3.31	**.012**	.30
1. I / the patient has influence over patient care	3.45		2.97			
5. My /the patient's views of the right care are respected	3.42		2.97			
6. I/ the patient take(s) part in decision-making about the patient's care	3.58		3.21			
3. Participation—Information (5 items)	3.48	3.29–3.67	2.99	2.74–3.24	**.001**	.41
13. Benefits drawn from earlier experience of my/the patient treatment are respected and heard	3.55	.	2.91			
14. I/ the patient recognises signs of deterioration	3.52		3.10			
27. I/the patient is given information in a way that can be understood	3.50		2.97			
29. I/ the patient is given knowledge about mental illness and opportunity to participate in the patient care	3.53		3.16			
30. I/the patient is given information about treatment alternatives	3.32		2.85			
4. Support (4 items)	3.51	3.30–3.73	3.24	3.04–3.44	.057	
19. Mental healthcare professionals stop me/ the patient from hurting others	3.64		3.05			
22. stop me/the patient from hurting myself	3.41		2.97			
23. Nothing shameful about having mental troubles	3.52		3.50			
24. Shame and guilt must not get in the way	3.52		3.45			
5. Environment (3 items)	3.34	3.11–3.58	3.32	3.08–3.57	.808	
2. I /the patient has confidence in the staff	3.42		2.94			
4. I/the patient can feel safe at home	3.33		3.62			
9. I/the patient feels safe in own living environment and neighbourhood	3,28		3.43			
6. Discharge (3 items)	3.22	2.96–3.47	2.72	2.46–2.98	**.002**	.38
8. My/the patient treatment has helped	3.27	.	2.85			
17. I/the patient gets help in finding an occupation	3.42		2.73			
21. I/ the patient knows where to turn	2.97		2.59			
7. Next of Kin (2 items)	3.36	3.14–3.58	2.58	2.30–2.87	**.001**	.47

(Continues)

TABLE 3 (Continued)

	Family members *n* = 33		Patients *n* = 33			
	Mean	95% CI	Mean	95% CI	*p* < value*	Effect size (Cohen`s d)
10. Mental healthcare professionals invited my/the patient's next of kin to take part	2.88		2.01			
28. respect my/the patient's next of kin	3.86		3.16			
8. Accessibility (4 items)	3.29	3.07–3.51	2.79	2.59–2.99	**.001**	.45
3. Easy for me/the patient to meet contact person	3.52		2.00			
7. Easy for me/the patient to get an appointment	3.50		3.44			
16. Easy for me/the patient to reach the mental health service by phone	3.56		3.19			
26. Easy for me/the patient to meet the doctor	2.59		2.55			

[a]Quality of care ranged from 1 (lowest quality) to 4 (highest quality).

**p*-value <.05 from Wilcoxon signed-rank test. Bold values are significant values.

family members in this study give a low score in relation to mental healthcare professionals encouraging them to take respite from caregiving as measured on the FPSQ-N, Emotional support dimension. Since families are impacted and reciprocally influenced by living with illness (Shajani, & Snell, 2019), arguably nurses and other mental healthcare professionals could give family members relief from their bad conscience by emphasising that respite is beneficial (Moen et al., 2014).

Notably, a comparison in this study of family members' health status and occupational status indicates that being occupied with work or studies has a good impact on mental and physical health. This concurs with the Norwegian Directorate of Health's (2015) emphasis on the importance of family members having a profession in terms of meeting social (and economic) needs.

5.2 | Quality of care within the paired family samples.

The difference within the paired samples on the QPC-COP/COPNK may indicate that family members score quality of care from a different point of view, possible as a result of different roles, but perhaps as a result of the unmet needs of family members (Shajani & Snell, 2019). This is in line with Johansson et al., (2014) who report family members questioning the availability and quality of mental health care.

The highest quality of care scores given by both patients and family members are found in the Encounter dimension and are similar to findings from patients' measurement of quality of care in housing support for people with mental illness (Brunt et al., 2019; Rask et al., 2017), and psychiatric outpatient care (Lundqvist et al., 2012). The concordance in this present study between patient and family members in assigning high quality on the Encounter dimension may indicate that relationships between patients and healthcare professionals relationships are not only perceived as routines and procedures, but also as caring relationships with empathy and understanding (Karlsson & Kim, 2015). This is reassuring, since Donabedian (1980) asserts that the highest quality of care minimises risk and maximises the benefit for the patients.

Moreover, both patients and family members in this study scored mental healthcare professionals' support to the patient in relation to not feeling guilt and shame for being mentally ill as high quality as measured on the QPC-COP/COPNK. This is uplifting since the shame of suffering from mental illness is strongly related to self-stigma (Rüsch et al., 2011), which is identified as a barrier to help-seeking, thus affecting the patients and their family as well. Nevertheless, the finding that the majority of patients and family members in this present study did not know where to turn if dissatisfied with the patient treatment and care emphasises the need for clinical practice to continue to improve their encounters and communication with the families.

The lowest quality score by patients was measured on the QPC-COP- Discharge dimension and is consistent with an earlier study by Schröder et al., (2011).

By contrast, the lowest quality score by family members in this present study was in the Next-of-Kin dimension, in relation to the invitation to take part in care, and respect from mental healthcare professionals. This might indicate that family members believe mental healthcare professionals are responsible for inviting them to take part in care? However, research has shown (Skundberg-Kletthagen et al., 2015) that mental healthcare professionals' line of approach shows the opposite tendency—they assign responsibility to family members to get in touch when necessary. On the other hand, the failure to invite family members to take part in care may be derived from patients' reluctance to include the family due to the need for independence and different choices about the nature of family involvement (Johansson et al., 2014). Nevertheless, family members have the legal right to be involved and respected (Ministry of Health and Care Services, 1999; Norwegian Directorate and of Health, 2017). However, family members are not required to know everything about the patient, but in line with findings in Aass et al. (2020a), struggling must be talked about to be able to be supportive.

Family members in this study score lower quality on the Participation-Information dimension as measured by the QPC-COP/COPNK, than patients. In comparison with the Participation-Information dimension, the Cognitive support dimension as measured by the FPSQ-N also measures accessibility and provision of information, available resources and patients' treatment alternatives, and reports lower family members' scores.

Notably, among other studies using the QPC instruments across different mental healthcare settings, for example supported housing (Brunt et al., 2019) and out-patient care (Schröder et al., 2011), patients commonly score participation concerning information and involvement in care as low. Nevertheless, family members in this study scored even lower than patients, suggesting that family members perceive patient autonomy and the patient`s involvement in decision-making over own care, as low quality. This perhaps reflects the hierarchical structure prevalent in community mental health care (Brunt et al., 2019) rather than shared decision-making. With this in mind, how can we then understand the highest quality score given by family members to the Participation-Empowerment dimension as measured on the QPC-COPNK in this study? It appears somehow self-contradictory, since the high score indicates that family members perceive the patient as having influence over their own care, being respected for their views of the right care and taking part in decision-making about their care.

5.3 | Methodological considerations

There are some limitations to this study, so generalisation of the findings should be made with caution. A pertinent limitation regards the study sample size. Despite two reminders, the response rate was very low, which may lead to a response bias (Polit & Beck, 2012). This is, however, minimised by imputation, that is replacing missing data points with the overall mean of that item. A number of individuals refused to participate when invited. The reason for not responding is not known, since details of refusers were not collected, but a low response rate is not uncommon in studies in mental health services (Pinfold et al., 2019).

It was impossible to analyse the dropouts in this study because patient and family member registrations by the services were incomplete. It is a strength that data were collected on both individual and family level, since this entails focusing on the family as a unit as well. Although the questionnaires used in this study are designed to be completed individually, the questions concern the family. The original ICE-FPSQ is grounded and developed to reflect family support measures where there is an illness in the family from the perspectives of both patients and family members (Sveinbjarnardottir et al., 2012). The QPC-COP instrument is based on the original QPC-OP questionnaire, designed to measure the quality of care from the patient perspective. Additionally, the QPC-COPNK was modified to cover family members' perceptions of quality of care. This enabled comparison of quality of care from the perspectives of both patients and family members. Due to performing many single item comparisons, a Benjamini-Hochberg Procedure (Benjamini & Hochberg, 1995) was used to control the false discovery rate, giving a FDR of 5%.

Collecting data on a family level increases knowledge through identifying shared family experiences and family meaning that emerge as a result of an illness experience (Aass et al., 2020b).

6 | CONCLUSION

Patients in this study were generally more positive than family members about the family support provided by nurses and other mental healthcare professionals, and the quality of community mental health care. Our results indicate that family members feel the lack of emotional and cognitive support from mental healthcare professionals. The results call for mental healthcare professionals to pay greater attention to assessing complex family needs and offering family conversations, focusing on beliefs and strengths, in addition to standard care. Community mental healthcare leaders and educators should place increased emphasis on education and skills training among nurses and other mental healthcare professionals working in the services to work and intervene with families. Importantly, both patient and family members give a high quality score to Encounter—the interpersonal relationship between patient and mental healthcare professionals accommodating, empathic, respectful and caring mental healthcare professionals. However, family members gave a low score to nurses and other mental healthcare professionals with regard to being respected and invited to take part in care. This indicates barriers to collaboration between families and professionals. This type of knowledge is important for mental healthcare clinicians in the development and provision of care. The inclusion of the family as a natural part of the team greatly assists persons suffering from mental illness and family members living with illness in everyday life. Being occupied with work or studies has a positive impact on family members' mental and physical health, and mental healthcare professionals should be aware of the importance of respite from caregiving.

7 | RELEVANCE TO CLINICAL PRACTICE

In order to improve family support provided by nurses and other community mental healthcare professionals, and the quality of community mental health care, it is recommended that mental healthcare professionals invite family members to take part in care and offer family support conversations, focusing on emotional and cognitive needs, in addition to standard care. Our study shows that nurses and other community mental healthcare professionals play an important role in facilitating an environment for families to feel respected and be included in the care. Furthermore, the results of this study show that mental healthcare professionals need to increase their efforts to help the patients find an occupation and to encourage families to take respite from caregiving. Further research could include evaluating family support and quality of care with a larger sample size and a comparison group. Moreover, an evaluation of family support conversations could explore how families as a unit experience inclusion in care.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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CONFLICT OF INTERESTS

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

AUTHOR CONTRIBUTIONS

Conceptualisation of the study, methodology design, data investigation, data analysis, writing the original draft, writing, review and edit the manuscript and project manager: LKA; Conceptualisation of the study, methodology design, data investigation, writing the original draft, writing, review and edit manuscript: ØLM and HS-K; Conceptualisation of the study, methodology design, data investigation, writing the original draft, data analysis, writing, review and edit manuscript: AS; Designed methodology, investigated the data, data analysis, reviewed and edited the manuscript: L-OL.

ORCID

Lisbeth Kjelsrud Aass https://orcid.org/0000-0002-0723-1093
Øyfrid Larsen Moen https://orcid.org/0000-0002-7970-6027
Hege Skundberg-Kletthagen https://orcid.org/0000-0002-1830-3136
Lars-Olov Lundqvist https://orcid.org/0000-0002-6703-7575
Agneta Schröder https://orcid.org/0000-0002-2157-8579

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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Young Adults and Their Families Living With Mental Illness: Evaluation of the Usefulness of Family-Centered Support Conversations in Community Mental Health care Settings

Lisbeth Kjelsrud Aass, RNS[1], Hege Skundberg-Kletthagen, RNS, PhD[1], Agneta Schrøder, RNT, PhD[1,2], and Øyfrid Larsen Moen, RNT, PhD[1]

Abstract

The aim of this study was to evaluate the usefulness of Family-Centered Support Conversations (FCSC) offered in community mental health care in Norway to young adults and their families experiencing mental illness. The FCSC is a family nursing intervention based on the Calgary Family Assessment and Intervention Models and the Illness Beliefs Model and is focused on how family members can be supportive to each other, how to identify strengths and resources of the family, and how to share and reflect on the experiences of everyday life together while living with mental illness. Interviews were conducted with young adults and their family members in Norway who had received the FCSC intervention and were analyzed using phenomenography. Two descriptive categories were identified: "Facilitating the sharing of reflections about everyday life" and "Possibility of change in everyday life." The family nursing conversations about family structure and function in the context of mental illness allowed families to find new meanings and possibilities in everyday life. Health care professionals can play an important role in facilitating a safe environment for young adults and their families to talk openly about the experience of living with and managing mental illness.

Keywords
young adults, mental illness, family nursing, family intervention, community mental health care

Being diagnosed with mental illness often has a negative impact on many aspects of a young adult's life including decreased self-esteem, optimism, confidence, as well as difficulties concentrating and carrying out daily taken for granted tasks (McCann et al., 2012). In addition, young adults experiencing mental illness face the developmental challenges of emerging adulthood that include making the transition from living with, to living apart from parents; obtaining education or vocational training; making their way into the workforce; and finding a life partner (Arnett et al., 2014). Being a family member who is caring for a young adult with mental illness can be a highly positive experience through the provision of empathy, love, and support; it may also entail burden and difficulties (Ewertzon, 2015).

Families Living With Mental Illness

Young adults living with mental illness need support from their family as they strive to find healing and recovery; family members unquestionably play a key role in supporting the young adult's pathway to recovery (Aass et al., 2020; Lindgren et al., 2015). Parents of young adults describe involvement in informal and professional mental health care as an isolated involvement with lack of being informed, seen, or acknowledged by health professionals (Andershed et al., 2017). Parents and adult children suffering from long-term mental illness describe dependency and influencing each other's lives. Nevertheless, parents experience being excluded from care, simultaneously being taken for granted and expected to contribute to the care (Johansson et al., 2014). Relatives of inpatients with depression report that

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[1] Norwegian University of Science and Technology, Gjøvik, Norway
[2] Faculty of Medicine and Health, University Health Care Research Center, Örebro University, Sweden

Corresponding Author:
Lisbeth Kjelsrud Aass, Doctoral Student, Department of Health Sciences in Gjøvik, Norwegian University of Science and Technology, P.O. Box 191, 2802 Gjøvik, Norway.
Email: lisbeth.aass@ntnu.no

health problems, burdens, and worries in everyday life are challenging (Skundberg-Kletthagen et al., 2014). Their lives are often very intertwined with the life of their severely mentally ill family member (Weimand et al., 2010). The well-being of siblings of an individual with a severe mental disorder like psychosis has also been shown to be negatively affected as they experience challenges in relation to be a sibling (Ewertzon et al., 2012).

Mental Health Care of Families Living With Mental Illness

The range of services for young adults with mental illness in Norway is split among administrative levels. The municipalities have a legal obligation and responsibility for young adults with mental health and mental illness. The regular general practitioner (GP) service in the primary health service plays a key role as a "gate-keeper" of other services and welfare. Community mental health services are staffed by health care professionals such as nurses, social workers, social educators, and occupational therapists. A number of them have supplementary education in mental illness so that they have a preventive role and can offer treatment and follow-up to young adults with mental illness. The importance of involving and acknowledging family as a resource in treatment and care is emphasized (Aass et al., 2020; Schröder et al., 2007; Weimand, 2012) as well as the implementation of strengths-based approaches (Gottlieb, 2013). Studies have found that approximately 18%–34% of young people with high levels of depression or anxiety symptoms seek professional help. Research about this population reports perceived stigma and embarrassment, problems recognizing symptoms, and a preference for self-reliance as barriers for help-seeking (Gulliver et al., 2010). However, insufficient attention has been paid to the care that young adults receive once they are in the health care system (Stroud et al., 2015). Interventions which focus on interactions and the family as a resource for offering unique skills, strengths, resources, and unmet needs are needed. These kinds of interventions may facilitate the experience of mental health treatment and care (Goudreau et al., 2006; Tedeschi & Kilmer, 2005) and increase knowledge and the coping abilities of families (Chesla, 2010). As community-services often rely on the commitment of families and their coping capacity, families should be assessed regularly to ensure that they benefit from the necessary support, education, and provision of resources (World Health Organization, 2013).

Intervention Studies: Families Living With Mental Illness

The families in this study participated in three Family-Centered Support Conversations (FCSC). The FCSC is theoretical grounded in Wright and Leahey's Calgary Family Assessment Model (CFAM) and Calgary Family Intervention Model (CFIM) which are strengths-oriented family nursing assessment and intervention models for families living with illness (Shajani & Snell, 2019; Wright & Leahey, 2013). The Illness Beliefs Model (IBM; Wright & Bell, 2009) also guided the FCSC and is based on the principle that it is not necessarily the illness itself, but rather the beliefs about the illness that are potentially the greatest source of individual and family suffering. Emphasis must be placed on recognizing that families, as well as health care professionals, have beliefs that both facilitate and constrain their lives, relationships, behavior, suffering, and healing (Wright & Bell, 2009).

Previous family nursing intervention studies have been conducted with individual and group psycho-educational training, tasks, and therapeutic conversations combined with family interviews involving family members of adolescents and young adults with eating disorders and attention-deficit hyperactivity disorder (ADHD) in a hospital unit. Findings revealed improvement and differences in caregivers' emotional and cognitive support, illness beliefs, emotional functioning, caregiving demands and caregivers, and patient behavioral difficulties (Gísladóttir et al., 2017) and better quality of life and social functioning for caregivers (Gísladóttir & Svavarsdóttir, 2017). Intervention studies with patients and family members in acute psychiatric hospital units, who received family nursing conversations focused on family strengths, reported that family members perceived significant higher emotional and cognitive support after the intervention (Sveinbjarnardóttir et al., 2013). In addition, benefits were observed in families of young people living with severe mental illness regarding revisiting and building new connections among family members, and strengthening and supporting the family network (Sveinbjarnardóttir & Svavarsdóttir, 2019). These family nursing intervention studies were guided by the CFAM and CFIM and/or the IBM as the theoretical framework to inform the interventions offered (Gísladóttir et al., 2017; Gísladóttir & Svavarsdóttir, 2017; Svavarsdóttir et al., 2019; Sveinbjarnardóttir et al., 2013; Sveinbjarnardóttir & Svavarsdóttir, 2019). Nevertheless, to our knowledge, strengths-oriented family support conversation studies with young adults and their family as the unit of care in community mental health services have only been reported to a limited extent. Moreover, interventions need to be explicitly tested in young adults because they can be influenced by many factors including the challenges of emerging adulthood, maneuvering developmental transitions, and adjusting to adult mental health care (Lindgren et al., 2015). Therefore, knowledge from this study can provide direction about how to meet young adults and the family's needs and will also help to expand information about family focused care for this population of families nationally and internationally.

Aim of the Study

The aim of this study is to explore and evaluate how young adults living with mental illness and their families experienced a family intervention called FCSC.

Method

This intervention study used an explorative qualitative design with a phenomenographic approach (Marton, 1988). Phenomenography was chosen to incorporate variety and differences in how the phenomenon was experienced, conceived, and captured at the family level. In this study, we endeavored to capture data at the family level to identify multiple perspectives and focus on the family as a unit. Phenomenographytakesasecond-orderperspective, meaning that it offers different ways of conceiving the phenomenon that are of interest and how it is described (Marton & Booth, 1997). In this study, the phenomena was the family members' experiences of receiving the FCSC intervention.

Recruitment of Participants

The focus of this study was on families living with mental illness of a young adult family member where family was a self-identified group of two or more individuals who were or were not related by legal or blood relationships and who functioned in such a way that they considered themselves to be a family (Whall, 1986). Health care professionals recruited patients who were young adults living with mental illness in urban and rural communities and asked them both verbally and in writing to participate, both in the family conversation and in a follow-up family research interview. Family members (one or two) were recruited through the young adult patient who asked his or her family members to participate in the study. Family members then gave the patient permission to submit their name and telephone number to health care professionals. Both the patient and the family members gave oral and written consent (International Committee of Medical Journal Editors, 2018).

Patient inclusion and exclusion criteria. Inclusion criteria for patients: aged 18–25 years, facing mental illness and strain, impaired function associated with distress, symptoms, and diagnosable mental disorders; living alone or with family and/or friends and/or others; could speak and read Norwegian; and had contact with community health services related to mental illness. Exclusion criteria for patients included cognitive impairment; psychotic state; active alcohol or drug abuse; or living in a residential home for persons suffering from mental illness.

Family member inclusion and exclusion criteria. Family members over 18 years old who were defined by the young adult to be part of the family, and who were able to speak and read Norwegian. This study excluded family members who showed evidence of cognitive impairment, psychosis, or active alcohol or drug abuse.

Description of the Intervention: FCSC

FCSC included the young adult who was suffering from illness, those designated as belonging to his or her family, and a mental health care professional. Operationalized within a non-hierarchical therapeutic relationship, three conversations with each family were conducted by the same mental health care professionals that include a psychiatric nurse, social worker, and social educator with advanced training in mental health. The goals of the FCSC were to (a) shift the focus from a deficit- or dysfunction-based family assessment to a strengths- and resource-based family conversation including those persons who were important in the patient's life and (b) recognize that family members serve a variety of roles including advocate, care provider, trusted companion, and surrogate decision maker (Levine & Zuckerman, 1999; Wright & Leahey, 2013). The mental health care professionals involved in this study had completed a 2-day educational program on family assessment and intervention as well as skills training with different clinical vignettes from mental illness care (Benzeinetal.,2012; Sveinbjarnardóttir et al., 2011; Wright & Bell, 2009; Wright & Leahey, 2013).

Procedure for FCSC

First session. Each family member was invited to relate their narrative about their experiences and beliefs in relation to everyday life. Family structure, development, and function were explored and assessed to later reflect on these aspects of family functioning, and the strengths and resources that can have an impact on everyday family life (Benzein et al., 2015; Gísladóttir & Svavarsdóttir, 2011; Wright & Leahey, 2013).

Second session. The focus of the second session was on cognitive, affective, and behavioral domains of family functioning and strengths and resources within and outside the family. The impact of problems/illness on the family was assessed. Problem-solving skills, coping strategies, and strengths were elicited, and change invited. Aspects of family functioning, strengths, and resources within and outside the family were reflected on.

Third session. The focus of the third session was on families' experience of everyday life and support strategies for the future. Families were commended for their and individual strengths, competencies, and resources. While three conversations are recommended, the health care professional must evaluate if families need more than three conversations (Benzein et al., 2008, 2012). If families needed additional support conversations, they were free to contact the mental health care professionals.

Data Collection

Family research interviews with open-ended questions were conducted with each of the seven families who received the FCSC intervention. Data were collected 1 to 2 months after the FCSC was completed. The families were allowed to narrate freely about their experience of the FCSC. The initial research interview question asked was: "You have participated in three FCSC. How did you experience the FCSC?"

The focus was on how the conversations were experienced and what was experienced. To gain a deeper sense of the experiences, follow-up questions were asked such as: how? who? can you tell more? what do you mean? is it always so? to elicit a richer and more detailed description, and further questions were adjusted to the participants' response. In each family research interview, consideration was given to the developmental level of the patient (Donalek, 2009) who was asked first to talk about his or her experiences in a relaxed and accepting atmosphere, giving the patient time and space to answer questions, and focusing the conversation in the direction of the phenomenon (Lepp & Ringsberg, 2002). When the patient had no more to say or was reluctant to answer, the family members were asked the same questions. Throughout the family research interview, the dialogue alternated between the family and the interviewer asking questions. The family research interviews were conducted by the first author and took place either at the family's home, at the mental health care service office, or the university according to the wishes of the participants. Notably, one patient and a partner who participated in the FCSC did not participate in the family research interview due to private concerns. The interviews lasted 50–65 min and were audio-taped and transcribed verbatim by the first author.

Ethical Considerations

Ethical considerations and guidelines with respect to confidentiality, integrity, and the voluntary participation of the participants were followed throughout the study (International Committee of Medical Journal Editors, 2018; World Medical Association, 2001). Both the patient and family members received written and oral information and gave their written consent. They were informed that the material would be treated confidentially. The patient gave written informed consent for the publication of patient information (International Committee of Medical Journal Editors, 2018). The Regional Committee for Medical & Health Research Ethics (REC) found the Research Project, Ref: 2017/717, to be outside the remit of the Norwegian Act on Medical and Health Research) and the project could therefore be implemented without its approval. Approval was given by the Data Protection Official for Research (NSD), June 2017, Ref: 54696.

Data Analysis

The data were analyzed as a "pool of meanings" (Marton & Booth, 1997) inspired by Dahlgren and Fallsbergs' (1991) steps for analyzing phenomenography studies: (a) Familiarization—the researcher read through the transcripts to become familiar with all the details and establish an overall impression of the data; (b) Condensation—the most significant statements made by the families concerning the phenomenon were condensed to give a short but representative version of the entire dialog; (c) Comparison—significant conceptions were compared to find sources of variation and agreements in how the phenomenon were experienced; (d) Grouping—concepts appearing to be similar were grouped together; (e) Articulating—a preliminary attempt was made to describe the essence of the similarity within each group of concepts; (f) Labeling—descriptive categories were labeled based on findings of suitable linguistic expressions; and (g) Contrasting—description categories were compared to ensure that each category was mutually exclusive and at the same level. The last three steps were repeated several times. The outcome space refers to a horizontal structure in which the descriptive categories reflect the distinctions of the FCSC.

Table 1. Participating Young Adults and Family Members.

Characteristics	Patients	Family members
Age (years)	19–23	20–55
Gender		
Male	1	5
Female	5	6
Relationships		
Daughter	5	
Son	1	
Spouse		1
Mother		6
Father/stepfather		4
Educational level		
Secondary school	2	
High school	3	7
Apprentice	1	
University		4
Occupation		
Work	1	7
Job seeker	1	
Sick leave	1	1
Disability benefit		1
Work assessment allowance	1	
Other	2	2

Findings

Research Participants

A sample of 19 family members from seven families participated in the FCSC with mental health care professionals in four different municipalities in Norway in the period from December 2017–May 2018. Out of the 19 family members, 17 consented to participate in family research interviews. The sample represented variation with respect to age, gender, education, and occupation (see Table 1). Mental illness among the young adults ranged from depression and anxiety distress or disorders, personality disorders, ADHD, and eating disorders.

Table 2. Experiences of the Usefulness of the Family-Centered Support Conversations: The Perspectives of Young Adults and Their Families Living With Mental Illness.

Descriptive categories	"Facilitating sharing reflections on everyday life"			"Possibility of change in everyday life"	
Concepts	The unfamiliar conversations	A team with mutual understanding	Experiencing a change in the patient approach	Awareness of strengths and resources	Support in everyday life on regular basis

Families' Experience of the FCSC

The findings describe the families' experiences of FCSC under two descriptive categories, "Facilitating sharing reflections on everyday life" and "Possibility of change in everyday life." The descriptive categories embody five concepts that comprise the outcome space (Marton & Booth, 1997) (Table 2).

Facilitating sharing reflections on everyday life. The FCSC facilitated an opportunity to share and reflect on the family's beliefs on the past, present, and future of everyday family life related to symptoms, problems, challenges, worries, and hopes. This descriptive category includes three concepts: the unfamiliar conversations, a team with mutual understanding, and experiencing a change in the patient approach. The category describes the FCSC in regard to potential benefit for individuals and family, state of consciousness, and degree of confidence after reflecting on everyday family life together with a mental health care professional.

The unfamiliar conversations. How the families experienced the FCSC varied, and for most, it was a new experience, perceived as strange, unpleasant, and uncomfortable but also positive, beneficial, and safe. The patients, who were used to having conversations with mental health care professionals alone, described the FCSC as strange and unpleasant. One patient said, "It's a bit strange because I don't usually talk about these things with my mother." Some of the patient's symptoms, strain, and difficult thoughts had never been shared with the family prior to the FCSC because it was too hard to talk about. However, when struggling to explain, reveal, and talk with the family about difficult topics such as how mental illness, decreased confidence, and self-esteem affected them in everyday life, the patients were reassured by the presence of the mental health care professional. A patient said, "It's been almost taboo. I've hardly ever wanted to talk about it. So, it was good that she (health care professional) was in charge, then we talked about it." Other families stated that after each session they talked about how good they felt about the conversations.

The topics of discussion varied within the three conversations and experienced by some as being defined by others or occurring randomly. They talked about how the situation was at the moment, how things had been and what thoughts they had about the future. Sharing thoughts was described as useful and informative, and dwelling on each other's experience enabled them to see the situation from other angles. One father said, "We realized that we maybe hadn't understood how bad it really is for A . . . We found out how difficult it is for her through the conversations with the health care professional." Listening to the patient's description of everyday life was experienced as painful and surprising, and as a moment of new realization. Prior to the FCSC, they did not know how seriously the patients were affected by mental illness, and what the patient needed in situations that trigger severe symptoms. A father said,

> It was much worse than we thought. A bit surprising but good to hear. If the family is going to the store, for example, and she is coming along, she has to be prepared. It can take half an hour till she's ready to leave. We didn't understand why she didn't come in, and we nagged a lot sometimes. We weren't aware that she had to have this time for preparation . . .

However, for some family members, the FCSC did not lead to new understanding but was a repetition of what they had been through because they had discussed the topics in the conversations beforehand and dealt with them thoroughly. Others described having to "speak loudly" in a sharp tone to make their opinions on how to interact with their patient heard. The justification for this was that they live with them and know what works and does not work concerning symptoms and behavior in everyday life related to the patient's mental illness.

Topics that family members earlier did not dare to bring up or mention to the patient because they were afraid of stepping too close were naturally brought up and talked about in the FCSC. One mother talked about how she experienced that the patient excluded her from information. She did not know anything about the mental health status or the care process, which led to self-interpretation and conclusions based on assumptions and worrying.

The patients were familiar with most of what the family members shared in the conversations, such as concerns regarding the patient being suicidal, having severe anxiety and being depressed, as well as concerns about education, getting to work, and even keeping a job.

A team with mutual understanding. Meetings concerning the patient's mental health issues with the general practitioner physician, therapist, and social security officer at the Labor and Welfare Service were familiar. However, the families described attending few conversations with focus on family strengths, resources, and support with mental health professionals prior to the FCSC. They described being able to speak honestly and sincerely about emotions and thoughts regarding situations in the past concerning family everyday life for the first time. One mother shared how she felt when the patient had been seriously ill and hospitalized and excluded the family from being informed. The families sorely desired collaboration with the health care professionals, with the aim of working in the same direction. Still they experienced the opposite. A mother said,

> We as a family and the help we give A works to a certain extent if the team around us work in the same way. However, when the team don`t work with us but against us, they actually do a lot more damage.

Family members emphasized that they sense when symptoms worsen, but the patients often deny or answer their concerns dishonestly. They do not have to share everything but struggling must be talked about to be able to be supportive. According to one mother, ". . . I ask and then 'Yes, yes, I`m alright,' but maybe it's not alright. I can see it, but each time I ask, she replies, 'I'm tired'." A patient said, "I don't like people knowing too much about me. I want to deal with things myself, not be seen as different." Getting a third person's view was helpful in relation to how the patient's mental illness affects the management of daily activities such as getting to work. A patient replied, "Yes, I also found it a bit reassuring because NN (mental health care professional) could explain to my mother and boyfriend how things were. I'm not always good at explaining and saying things." The intervention made it possible for family members to learn how they can approve, support, and help, thereby enabling the family members to enlighten each other and mental health care professionals on what works when living with mental illness. One mother experienced becoming aware of how to communicate so that misunderstandings do not occur, and the importance of giving positive feedback and praise. One stepfather said, "He has apparently not appreciated boundaries in relation to us . . . but in one of this meetings he admitted he actually appreciated some boundaries."

The patients described being absent minded or distracted and perceiving no more than one third of what was going on in conversations and not always being able to explain and express needs. Therefore, it was important to have family members present to help grasp what was said. Others stated that they did not pay attention when family members spoke to health care professionals. Notably, not having all the family present in conversations was seen as a drawback. A mother said, "No, if it's going to be of any use, I think the four of us have to talk together. That is, if we as a family are to benefit from it".

Experiencing a change in the patient approach. The families described mental health care professionals asking several questions concerning how the families were coping at home. In addition to being concerned about the patient, mental health care professionals were sincerely concerned about family members' time for each other and for taking care of their own relationships. The mental health care professionals described bringing forth strengths and resources within the family through mapping and reflecting on actions and activities they perform in everyday life. One mother said, "He wondered about what you do when things are going well, kind of . . .? What did you do then? What happened that day? And what is good about those days? Both NN (patient) and we were asked that question."

Mental health care professionals were described as seeking approval from the patients regarding the sharing of information although the latter had given them oral and written consent to access family members' insights into health information. A father said,

> The so-called data protection in psychiatry is a drawback. If NN (patient) had told that I am not supposed to know things, that would be ok for me. That's something else, but NN (patient) wants to be open and wants us parents to help him, but still mental health care professionals hold back.

Family members said that they urged the mental health care professional to listen to them. Thus, the FCSC had some significance in that health care professionals gained greater understanding through listening to the family describing how they were functioning at home.

The families perceived that mental health care professional focused on statements the family disagreed on and asked for clarification before they moved on. The mental health care professionals commenced the dialogs with a couple of questions and did not interrupt if the conversation flowed freely, so the families experienced the topics as a bit random. Others experienced setting goals from the first, second, and third conversation, so that it was not random in that there was an overall emphasis on positive activities, that is, a focus on things they did well. A mother reported, "We kind of agreed on setting some goals from one meeting to the next. That we should try out whatever made things better." The health care professionals gave information on health care support and actions aiming to unburden the family as well as suggestions as to how families could solve problems in everyday life, which was perceived as positive. A mother said, "I do know we talked about remedial actions for A. What NN (health care professional) could help us with as regards applying for respite care in order to give us some relief."

Possibility of Change in Everyday Life

This descriptive category includes two concepts: awareness of strengths and resources and support in everyday life on regular basis. Mapping the family as a whole facilitated the development of new meanings and possibilities and unwrapped strengths, competence, and skills. In addition, it promoted preparedness to deal with everyday life and put in place support strategies for the future.

Awareness of strengths and resources. Mapping the family roles, interaction and functioning within the families was experienced as valuable. In practical terms, this meant assessing who is in the family and how those individuals' function within the family. Some families developed a diagram of the two-generation family genogram (family tree), while others did the family mapping through spoken dialogue. The family mapping revealed how the patients position themselves and other family members. A patient said, "I put myself as far out as possible because I don't want to be in the way," and the father replied, ". . . NN drew me as the core" . . . then he put himself as far out as possible on the tip of a branch . . ."

The family mapping was experienced as a moment of realization because the family members had not previously considered the connections between themselves in that way. Mapping was experienced as giving both the family and mental health care professional's insight and the opportunity to become acquainted with or conscious of unspoken realities.

Regardless of whether it entailed drawing the family tree or just talking about who is in the family and how they function, family mapping was described as beneficial due to the family becoming more aware of what they meant to each other and did together, because when things went wrong, the feeling of remorse often cast a shadow over everything. A mother said, "It's pretty useful to go over it and see that we actually do positive things too, which is good." Awareness of interactions within the family and own reactions when things went wrong or there was a conflict was the subject of discussion, and importantly, this had rarely been discussed before. One mother described becoming aware of whether they paid each other respect or took each other into account.

Families described doing the best they could based on their assumptions. They learned to emphasize the importance of giving the patients approval for things they achieved rather than focus on problems when they did not cope. Others knew already that the whole family functioned as a team with strengths and resources.

Support in everyday life on regular basis. The patients found it easier to speak exclusively with mental health care professionals who were involved in their care. They reported that mental health care professionals viewed things differently than family members who saw them daily. Yet family involvement in care was worth having. A patient stated, "Think there should be more conversations. As mentioned, in everyday life the effect fades away after a while. No, I feel as if there's not much talk of it anymore. Things return to the usual, old routines." Further contact with mental health care professionals was also desirable for family members, who missed having someone to talk to when they came up short in supporting their ill family member. Family members described being in need of guidance on issues concerning themselves being at work, worrying about the patient who was home alone—potentially suicidal and not getting to work. Others felt it was up to the patient to decide together with the mental health care professional when family should take part in future conversations, despite the fact that the mental health care professional had told family members to get in touch when they wanted another meeting.

Family members expressed a need for the patient to live close to the family because it provided a feeling of being safe and supported. However, mental health care professionals emphasized the importance of the patient being as independent as possible to tackle everyday life in the future with extra support and help from the health care services in daily activities. Both the mental health care professionals and the family felt that progress had been made during the FCSC. The families described patients as being in a better state of mental health and function level now than 2–3 years ago. A mother stated, "I feel you have come quite a long way, that you are in better health now. In any case, we have a completely different starting point now." Nevertheless, the families stressed the value of mental health care professionals asking if they could contribute with help and support, even though the families did not necessarily need this.

Discussion

The aim of this study was to explore how young adult patients living with mental illness and their families experienced the FCSC. Findings highlighted the families' desire to be included in mental health care through FCSC that focused on how to be supportive and acknowledged family strengths and resources. Sharing beliefs about everyday life and assessing and reflecting on family function and structure facilitated new meanings and possibilities in everyday life. Mental health care professionals play an important role in facilitating a safe environment for sharing in a non-hierarchical and co-creating relationship.

Facilitating Shared Reflections on Everyday Life

The findings of this study highlighted that on the one hand that patients wanted to include their family in the FCSC to achieve increased understanding, while still dealing with things on their own; on the other hand, they feared to be looked upon differently, resulting in their concealment of certain aspects of mental illness in daily living. Significantly, it was challenging for the patients to talk to family about difficult and taboo topics such as how mental illness affected them—at school, at work, and in social life—and their decreased confidence and self-esteem. However, with mental health care professionals by their side, the patients in this study felt more confident about including family members and disclosing their problems. Moen et al. (2014) similarly describe family members valuing a neutral third person leading the discussion and ensuring that they kept to the subject. This indicates that mental health care professionals build trustful relationships with the patient and family members, framing family support conversations as a safe arena. Sveinbjarnardóttir and Svavarsdóttir (2019) assert that mental health care professionals who have the knowledge, training, and capacity to build a partnership with the family as the unit of care can improve patient services.

According to Woodgate et al. (2017), disclosure or nondisclosure is often grounded in the fear of being stigmatized, treated differently, and/or fear of being rejected by their family. Even though it was hard, disclosure enabled understanding and acceptance from the family and facilitated a dialogue about how to best help and support the patient. The findings of Schröder et al. (2006) indicate that de-dramatizing mental illness reduces or avoids stigmatization of the person with mental illness. On the one hand, disclosure made family members realize shortcomings in their own understanding due to exclusion or concealment. This was also painful because they became aware of how much the patient was struggling to manage everyday life. On the other hand, family members had the opportunity to get answers to issues they did not know about or to questions they had not dared to ask earlier. Stengård and Appelqvist-Schmidlechner (2010) and Woodgate et al. (2017) similarly describe how patients living with mental illness often seem to underestimate the need for help from others and try to deal with their problems on their own, experiencing difficulty communicating their thoughts at times. They expressed the need for additional pathways to share how they feel.

In Norway, the age of majority is 18 years and, from that point on, an individual can decide whether family members are to be given information regarding one's health issues (Ministry of Health and Care Services, 1999). Family members in this study emphasized that the patient does not have to tell them everything, but it is important to share symptoms, status of illness and suffering, as it enables them to give help and support. Similarly, Andershed et al. (2017) found parents' need to know about symptoms, the illness, the illness trajectory, and treatment and how to read and understand signs of suffering.

How health care professionals relate and listen has implications for families and matters to them (Wright & Leahey, 2013). Families in this study experienced that mental health care professionals were concerned about how the families were doing at home, whether family members had time for each other and took care of their relationships as well as the patient's health well-being. This is in contrast to Weimand and colleagues (2011) who found family members reported not being seen, listened to, or understood in mental health and psychiatric in- and outpatient care. Interpersonal relationships and good communication between health care professionals, patient, and family members are key factors in quality of care from the perspective of family members (Schröder et al., 2007). According to Freire (2018), families and health care professionals who encounter each other in dialogic relationships are equally partners, aiming for mutual understanding and finding new words to describe reality, thus enabling change. A dialogical approach is related to and dependent on humility, faith in humans, trust, hope, and critical thinking. According to the CFAM (Wright & Leahey, 2013), the relationship between the mental health care professionals and families is characterized as non-hierarchical and a co-creating of reality. Nevertheless, this study supported the earlier findings of Ewertzon et al. (2010) that cooperation between staff and family members was problematic in the sense that families experienced that their opinion on how to best interact with the patient was not valued. To build a family–nurse relationship, Wright and Leahey (2013) recommend it is useful for health care professionals to reflect on his or her contribution to the therapeutic relationship before meeting with the family and, at the end of the meeting, to invite the family's reflections about the family–nurse relationship.

A growing body of literature emphasizes the importance of exploring beliefs that shape individual and family narratives of everyday life when living with illness and coping strategies within families (Bell & Wright, 2011; Wright & Bell, 2009). Personal narratives and reflections are significant and joined closely together and are intended to facilitate the appearance of new beliefs and the discovery of alternatives or new meanings that can have an impact (Benzein et al., 2015). Findings showed that beliefs appeared in the family's narratives, evolving through their history together as a family and revealed when others could confirm and give further examples. Similar to Wright and Bell (2009), we found that understanding beliefs develops in interaction with others over time; however, beliefs are not static and evolve like nurses and families do. In addition, the revealing of new beliefs made acceptance for mutual realities possible and increased understanding for each other's perspectives on everyday life. This was significant, not only for the families but also for the mental health care professionals. Benzein et al. (2008) suggests that health care professionals' task is to listen to what the families really says and not what the health care professionals think the families says or means. In this way, health care professionals can take a participatory position in the conversation rather than an influencing one. Families in this study reported that their own beliefs were respected and viewed as equally legitimate by mental health care professionals. However, some experienced that mental health care professionals were more concerned about protecting the patient's legal rights regarding confidentiality. According to Weimand and colleagues (2013), the trusting alliance between nurse and patient is governed by confidentiality and respect for the patients' autonomy (Dreyer & Strom, 2019). Mental health care professionals were perceived to be continuously seeking approval from the patients regarding sharing information, despite the latter having given consent. This indicates that mental health care professionals are afraid of acting illegally (Weimand et al., 2013), or misunderstand the law of confidentiality, resulting in barriers for collaboration between families and professionals (Aass et al., 2020; Solomon et al., 2012). Notably, the FCSC were significant in the sense that mental health care professionals showed increased understanding of family everyday life after listening to the family's narratives. Confidentiality protects the patient but can also be viewed as an obstacle preventing relatives receiving information and participating in care (Schröder et al., 2007). Even though confidentiality makes it difficult for mental health care professionals to talk to family members, there is some scope within statutory regulations that enables a kind of transparency and does not prohibit health care professionals from listening to the family (Weimand et al., 2011).

Possibilities of Change in Everyday Life

Findings revealed that assessing family roles, interaction, and function either through visualization of a family genogram or through a spoken dialogue facilitated the process of self-reflection and opened up for a new understanding and awareness of what family members meant to each other. According to Wright and Bell (2009), the process of self-reflection is essential to the co-evolution of new, more facilitating beliefs, meanings, and opportunities. In this study, the use of a structural assessment tool like a genogram seemed to have significance for visualizing and facilitating reflections of family positions and hierarchy, who participates in everyday life, and how communication, emotions, and interactions influenced family behaviors. Wright and Leahey (2013) state that the purpose of the genogram is to describe and understand family members' relationships with each other; however, the visual impact of the genogram on families seems to concretize these family connections in a new and meaningful way. The families in this study described family deficits, strengths, and resources and became more aware of not only how they interact and activities they do together but also what they meant to each other. When health care professionals focused on strengths, the families reported that it was good to hear that they were doing something right. Gottlieb (2013) describes a focus on strengths as helping families to see themselves in a new light. When health care professionals adopt a salutogenic approach, opportunities and resources rather than deficits are emphasized (Benzein & Saveman, 2008; Langeland, 2014). Nevertheless, mental health care programs for youths often tend to focus on what is going wrong in families rather than what is going right and fail to see and appreciate the family's strengths and competencies. In addition, families are perceived as lacking ability to solve problems or cope without the help of the professional (Gottlieb, 2013). According to Stengård and Appelqvist-Schmidlechner (2010), this can have the potential of stigmatizing, undermining motivation, or discouraging young people from becoming involved in support programs.

The families agreed on the importance of proceeding with support-conversations with mental health care professionals as an arena for continuity of sharing and guidance. However, they did not agree on who should decide when and how often the conversations should occur. The patient and the mental health care professionals wanted family members to initiate meetings, while family members believed it was up to the patient, together with the mental health care professionals, to decide. Community services often rely on family commitment, support-capacity, and competencies (World Health Organization, 2013). Consequently, a family–mental health care professional relationship should include and be characterized by family and mental health care professionals each bringing expertise, strengths, and resources to the relationship and the valuing of reciprocal and non-hierarchical relationships where each person's contribution is acknowledged and valued (Aass et al., 2020; LeGrow & Rossen, 2005).

Although the FCSC was intended to influence support in family everyday life, the specific outcome can never be predicted in advance. Families carry out their functions through their subsystems (Wright & Leahey, 2013), and findings in this study revealed that the inclusion of many family members was needed if the FCSC was to make an impact on everyday life. According to Wright and Leahey (2013), to be effective, there must be a fit between the intervention offered and the structure of the family. When fit is absent, there is a possibility of no effect. The families decided who participated in the FCSC and this varied across different persons at various times. Handling this with flexibility and adjusting to the family's situation is recommended (Benzein et al., 2012). This underscores the importance of health care professionals assessing family functioning and structure and asking who is in the family and whether others should be invited (Wright & Leahey, 2013). Mental health care professionals should ensure a specific focus on family structure because it is insufficient to focus on a family everyday life situation with problem solving when the specific family structure is unknown (Wright & Leahey, 2013; Svavarsdottir & Gisladottir, 2019).

In this study, the four criteria offered by Guba (1981) were used to ensure trustworthiness. *Credibility* was strengthened by the sample of seven families ensuring variation in different ways of experiencing the phenomenon (Marton & Booth, 1997) and by the broad sample in terms of different family relationships, gender, and age, which gave rich descriptions (Sandelowski, 1986). *Dependability* was ensured by asking the families the same open-ended questions and gave the participants the opportunity to contribute experiences if they had not been covered during research interview. The first author carried out all the research interviews. To strengthen trustworthiness and authenticity, the authors have reported the findings with quotes from both patients and family members.

Confirmability was enabled by establishing an "audit trail" (Guba, 1981) describing all steps in the analysis process. Analyzingfamilyresearchinterviewsinthis phenomenographic study was challenging because the experience of the therapeutic conversations was shared across multiple families. However, the involvement of all researchers in the analysis process was a strength. *Transferability*: We believe this study contributes relevant knowledge that may apply to other families within similar contexts. One possible weakness may be the risk of the interview reflecting the experiences of individuals rather than the family as a whole. However, data on both individual and family level were generated by focusing on the family as a unit. The family members in the study are distinct individuals yet they share a common history, strengths, and belief systems and have close contact with one another. Collecting data on a family level increases knowledge and the discovering of the shared family experiences and family meaning that emerge with an illness experience (Chesla, 1995; Eggenberger & Nelms, 2007). The assumption is that family experiences of the FCSC are the sum of the subjective views of each individual family member (Åstedt-Kurki et al., 2001). The families spoke openly in the interview situation and were willing to share their experiences with each other, even if their stories included new thoughts that the family had never discussed. Participating in family research interviews can be a beneficial learning experience for the family as they become more aware of each other's beliefs and opinions. One limitation, however, could be if family members are not able or willing to be open and share their experiences with each other (Eggenberger & Nelms, 2007; Moen et al., 2014).

The research interviews included issues that were sensitive for the families. As a psychiatric nurse, the interviewer (first author) was skilled in talking to patients with mental illness and their families and was aware of the power balance in the interview (Marton & Booth, 1997).

Family conversations like the FCSC, which is theory-driven (Wright & Bell, 2009; Wright & Leahey, 2013), have a major strength in that they are based on research and previously tested, although to our knowledge not with young adults living with mental illness and their family. The FCSC in this study were examined in real-world community mental health settings and contribute to knowledge about family nursing intervention with this unique population of families.

Conclusion

This study extends knowledge about the usefulness of FCSC for families and their young adult child living with mental illness. From the participating families' perspective, there is a desire to be included in mental health care through FCSC focusing on how to be supportive and identify family strengths and resources. One way to meet this need is to offer FCSC as a central complement to usual mental health care practice. The family participants benefit from listening to and reflecting on each other`s beliefs about their daily life and their family functioning. Mental health care professionals play an important role in facilitating a safe environment for sharing.

To acknowledge that mental illness is a family affair and thus focus on the family as the unit of care requires a conceptual shift, even a paradigm shift, by health care providers. Clinicians require specific knowledge and skills to enter into these important conversations with families living with mental illness. Resources such as the International Family Nursing Association (IFNA) Position Statements on Generalist Practice (IFNA, 2015) and Advanced Practice (IFNA, 2017) with families may be useful to guide the development of knowledge and skills necessary for family-centered practice. Further exploration is needed about the family beliefs about mental illness and how the family perceives support and the quality of care offered to them. Finally, this study should be followed by further research evaluating FCSC intervention with a larger sample size of families, with the inclusion of a comparison group, and conducting more mixed methods studies about the benefits of bringing the family together for family-centered conversations in the context of mental illness.

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ORCID iD

Lisbeth Kjelsrud Aass https://orcid.org/0000-0002-0723-1093.

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Author Biographies

Lisbeth Kjelsrud Aass, RNS, is a doctoral student at the Norwegian University of Science and Technology NTNU, Faculty of Medicine and Health Sciences, Department of Health Sciences in Gjøvik, Norway. She is particularly interested in young adults and families living with mental illness and developing interventions that focus on the family as the unit of care. Recent publications include: "It's Not a Race, It's a Marathon! Families Living With a Young Adult Suffering From Mental Illness" in *Issues in Mental Health Nursing* (2020, with H. Skundberg-Kletthagen, A. Schröder, & Ø. L. Moen.

Hege Skundberg-Kletthagen, RNS, PhD, is an associate professor at the Norwegian University of Science and Technology NTNU in Gjøvik, Norway. Her research interests include mental health, mental health nursing, and family-centered care. Recent publications include: "It's Not a Race, It's a Marathon! Families Living With a Young Adult Suffering From Mental Illness" in *Issues in Mental Health Nursing* (2020, with L. K. Aass, A. Schröder, & Ø. L. Moen), "Mental Health Work in School Health Services and School Nurses' Involvement and Attitudes, in a Norwegian Context" in *Journal of Clinical Nursing* (2017, with Ø. L. Moen), and "Relatives of Inpatients Suffering From Severe Depression: Their Burden and Encounters With the Psychiatric Health Services." *Issues in Mental Health Nursing* (2016, with M. L. Hall-Lord,. Hedelin, & S. Wangensteen).

Agneta Schrøder, RNT, PhD, is a professor at the Norwegian University of Science and Technology NTNU, in Gjøvik, Norway and an associate professor, University Health Care Research Center, Faculty of Medicine and Health at Örebro University, Sweden. Her research focuses on mental health, quality of care, and instrument development. Recent publications include: "Residents' Perceptions of Quality in Supported Housing for People With Psychiatric Disabilities" in *Issues in Mental Health Nursing* (2019, with D. Brunt, L.-O. Lundqvist, & M. Rask), "Patients' View of the Quality of the Danish Forensic Psychiatric Inpatient Care" in *Journal of Forensic Psychiatry & Psychology* (2016, with K. Lorentzen,. Riiskjaer, & L.-O. Lundqvist), and "Next of Kin's Conceptions of the Quality of Care in the Psychiatric Setting: A Phenomenographic Study" in *International Journal of Mental Health Nursing* (2007, with B. Wilde Larsson & G. Ahlström).

Øyfrid Larsen Moen, RNT, PhD, is an associate professor in nursing at Norwegian University of Science and Technology, Faculty of Medicine and Health Sciences (MH), Department of Health Sciences in Gjøvik, Norway. Her central research focus is on families, particularly mental health of children and adolescents and the influence on families living with mental illness. She also studies health professionals working with children, adolescents, and families who have mental health concerns. Recent publications include: "Adolescents' Mental Health, Help Seeking and Service Use and Parents' Perception of Family Functioning" in *Nordic Journal of Nursing Research* (2019, with M.-L. Hall-Lord), **"**Public Health Nurses' Experience, Involvement and Attitude Concerning Mental Health Issues in a School Setting" in *Nordic Journal of Nursing Research* (2018, with H. Skundberg-Kletthagen), and "Mental Health Work in School Health Services and School Nurses' Involvement and Attitudes, in a Norwegian Context" in *Journal of Clinical Nursing* (2017, H. Skundberg-Kletthagen).

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ORIGINAL ARTICLE

Young adults suffering from mental illness: Evaluation of the family-centred support conversation intervention from the perspective of mental healthcare professionals

Øyfrid Larsen Moen PhD, Associate Professor[1] |
Lisbeth Kjelsrud Aass PhD Student, Assistant Professor[1] |
Agneta Schröder PhD, Professor, Associate Professor[1,2] |
Hege Skundberg-Kletthagen PhD, Associate Professor[1]

[1]Faculty of Medicine and Health Sciences, Institute of Health sciences, Norwegian University of Science and Technology (NTNU), Gjøvik, Norway

[2]Faculty of Medicine and Health, University Health Care Research Center, Örebro University, Örebro, Sweden

Correspondence
Øyfrid Larsen Moen, Norwegian University of Science and Technology (NTNU), P.O Box 191, N-2802 Gjøvik, Norway.
Email: oeyfrid.moen@ntnu.no

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Abstract

Aims and objectives: To explore how mental healthcare professionals' experience and evaluate the use of Family-Centred Support Conversation Intervention.

Background: Mental health professionals working in the community mental health service provide treatment, care and support to young adults suffering from mental illness. Young adults suffering from mental illness are dependent on other family members and live close to the family. The Family-Centred Support Conversation promotes healing and alleviates the suffering of the family.

Design and methods: A qualitative explorative design was used. Individual interviews with health professionals (n = 13) were conducted in Norway and analysed using a phenomenographic approach. The COREQ checklist was used.

Results: Three descriptive categories emerged: A new tool in the toolbox, the family as a conversational partner and Implementing the intervention, with seven conceptions. The mental health professionals had no previous routine for family support. The conversations helped them to structure the involvement of family members. Having the family as a conversational partner together with the patients was considered both somewhat new and rewarding but also challenging. The mental health professionals described a need to adjust the intervention.

Conclusions: The Family-Centred Support Conversation was described as a complement to care, as usual, structuring the involvement of families. The knowledge exchange between the families and the mental health professionals may create a context of changing beliefs, strengths and resources.

Relevance to clinical practice: Clinical practice is challenged to work on establishing a mindset; whereby, the family is regarded as a resource with important skills and life experience. The family should be offered individualised support and follow-up, and FCSC may be a relevant intervention.

KEYWORDS
family nursing, family-centred care, mental health, psychiatric nursing, qualitative study

Impact Statement

What does this paper contribute to the wider global clinical community?

- Family-Centred Support Conversations are suitable for structuring the involvement of family members in the therapeutic conversations.
- Confidentiality regarding the patients can be solved letting the patient determine the content of the conversations.
- The mental health professional facilitates the conversation and creates a climate for sharing.

1 | INTRODUCTION

Mental healthcare professionals working in the community mental health service provide treatment, care and support to young adults suffering from mental illness. Living with mental illness impacts on many aspects of a young adult's life: for example, decreased self-esteem, optimism and confidence, difficulties concentrating and carrying out daily, taken-for-granted tasks (MCCann et al., 2012). These young adults often live together with their family or need support from family members in their everyday life. In addition, young adults with mental illness are dependent on other family members and need to live close to the family because it gives them the feeling of being safe and supported (Aass et al., 2020). For the young adult, support from significant others may open up for a sense of a space to live in and be nourished (Sommer & Saevi, 2018). Traditionally, mental healthcare professionals in the community mental health service meet the young adults suffering from mental illness in individual or group consultations without the family being present or there being a family assessment focus (Reed et al., 2018; Skundberg-Kletthagen et al., 2020). A literature review shows that although various forms of support interventions can be of importance for the family members, they are only put to limited use (Ewertzon & Hanson, 2019). It was, therefore, interesting to evaluate the change in the practice of mental healthcare professionals using Family-Centred Support Conversations (FCSC).

2 | BACKGROUND

The Family-Centred Support Conversation (FCSC) used in this study is grounded in the conceptual frameworks of the Illness Beliefs Model (IBM), the Calgary Family Assessment (CFAM) and Intervention Models (Wright & Leahey, 2012; Wright et al., 2009). In the Illness Beliefs Model (Wright et al., 2009), the family members' beliefs about health and illness may be determining factors for how the family respond to symptoms of illness. Illness beliefs are understandings about aetiology and the role of family members and the influence of family members' behaviour (Clausson & Berg, 2008). The IBM is based on the conviction that healthcare professionals can encourage family members to share their illness story and facilitate beliefs about the experienced illness. Furthermore, mental healthcare professionals may choose interventions that alter beliefs in order to alleviate suffering and the illness. They also encourage the family to work in a collaborative manner. The Calgary Family Assessment (CFAM) and Intervention Models (CFIM) (Wright & Leahey, 2012) are nursing models founded on systems theory, communication theory and change theory (Shajan & Snell, 2019). According to these, the attitudes of mental healthcare professionals influence their family care practices (Sveinbjarnardottir et al., 2011). Positive attitudes towards families may strengthen their caregiving role vis-à-vis families (Sveinbjarnardottir & Svavarsdottir, 2019) and improve the quality of care.

In this study, the family is seen as a group of persons who consider themselves as belonging to each other and having close ties. Thus, the family consists of persons who need not be related by bloodlines or law but function in such a way that they consider themselves to be a family (Whall, 1986). In addition, the family is viewed as a system, which allows mental healthcare professionals to work with the family as a whole and facilitate a therapeutic change leading to healing and decreased suffering in the family. Focus is on the interaction, interplay and relations in and between family members' beliefs rather than on the family members individually (Benzein et al., 2008; Shajan & Snell, 2019). A change or illness in one family member affects all family members one way or another. Family members influence each other, and the family dynamics may create a balance between change and stability (Wright & Leahey, 2012). The mental healthcare professionals recognise that mental illness is a family affair (Skundberg-Kletthagen et al., 2020).

Family conversations were found to benefit families in hospital psychiatry settings in both the short- and long-term perspective (Svavarsdottir & Gisladottir, 2019). FCSC has been used by school nurses in their meetings with adolescent girls with health complaints and their parents (Clausson & Berg, 2008). Patients and family members have described and evaluated FCSC in the community mental health services (Aass et al., 2020). To our knowledge, there is a lack of studies describing mental healthcare professionals' perceptions of conducting the intervention in community mental health service. It is, therefore, important to explore and evaluate mental healthcare professionals' perceptions of involving families in care and treatment.

There is a gap in research and a need to try out interventions that support the family as a unit in community mental healthcare settings. The study will contribute to the body of knowledge in how to strengthen the evidence for such interventions in order to improve quality of care. Family-centred support intervention can contribute a more family-supportive and purposeful focus and approach to mental health care through viewing the family as a system in mutual interaction (Sveinbjarnardottir & Svavarsdottir, 2019).

2.1 | Aim

To explore how mental healthcare professionals' experience and evaluate the use of Family-Centred Support Conversation Intervention.

3 | METHODS

3.1 | Design

A qualitative explorative design with a phenomenographic approach was used to investigate the qualitative variations in how people experience, conceptualise, perceive and understand the phenomena and the world around them (Marton & Booth, 1997). Phenomenography assumes that the only world we can communicate about is the world as experienced. Individuals experience the world differently, but these different conceptions can be described, communicated and understood by others (Sjostrom & Dahlgren, 2002). Phenomenography makes a distinction between description of the phenomenon and the phenomenon as experienced. The second-order perspective (How) is the focus of interest and refers to the informants' experiences and recollections of the phenomenon, in contrast to the first-order perspective (What), which is the description of the phenomenon (Marton & Booth, 1997). The phenomenon in the current study was mental healthcare professionals' conduct of family-centred support conversations with families living with a young adult suffering from mental illness.

3.2 | Setting

In Norway, the mental health service is divided into the specialist health service and the community health service. The mental healthcare professionals in community mental health services included in this study represent a range of professions with a variety of competence. Several of them have supplementary education in mental health, even though they have similar responsibility and roles. The patients focussed in this study ranged from 18 to 25 years of age and received follow-up and treatment from the community mental health service; furthermore, their families are included. Prior to the intervention, the patients usually met the mental healthcare professionals once a week or once every two weeks in individual therapeutic conversations in the former's office or in the patient's home.

Prior to conducting the Family-Centred Support Conversations (FCSC), the mental healthcare professionals attended a two-day training programme at the University NTNU, held by LKA. The training programme was both theoretical, covering the theoretical framework of the intervention, and practical, using simulation-based training with cases and role-play (Benzein et al., 2008). The simulation-based training included different scenarios with role-play related to families with various mental illnesses, using family-centred support conversations.

3.2.1 | The Family-centred support conversations

The Family-Centred Support Conversation (FCSC) shifts the focus of healthcare professionals from deficit- or dysfunction-based assessments to strengths and resource-based family intervention. The Calgary Models emphasise collaborative relationships and focus on reinforcing, improving and sustaining an active family life on three levels: intellectual, emotional and behavioural (Wright & Leahey, 2012). Similar interventions with FCSC have been used in acute psychiatric inpatient settings (Sveinbjarnardottir & Svavarsdottir, 2019).

Key elements are family assessment, family beliefs on everyday life, reflection, commending and drawing on family strengths and resources. The intervention is operationalised within a therapeutic relationship and consists of three conversations between the family, including the young adult suffering from mental illness and their family member(s) together, and a mental health professional. The conversation model recommends the presence of one to two healthcare professionals (Benzein et al., 2008). In some of the conversations, two mental healthcare professionals were present. Both the young adult and their family member(s) participate in the three conversations. The conversations last for 45–60 minutes over a period of from six to ten weeks. The FCSC is given in addition to the planned follow-up and treatment of the young adult suffering from mental illness. The mental health professionals conducted the conversations in similar contexts and adhered rigorously to the following descriptions of the three conversations.

3.2.2 | Description of the three conversations

The first conversation

The goal is to establish a relationship and engagement and make an assessment through developing, promoting and establishing an atmosphere of comfort, mutual trust and cooperation between the family and healthcare professionals (Sveinbjarnardottir & Svavarsdottir, 2019; Wright & Leahey, 2012). The purpose is to clarify expectations and roles. Healthcare professionals explore and assess family functioning, structure and development using an assessment tool such as the family tree or genogram (Shajan & Snell, 2019). Furthermore, emphasis is placed on exploring the family's beliefs on everyday life by giving each family member the opportunity to tell their narrative about the family's situation. Reflection on the narratives and the nature of problems, suffering and coping strategies is stressed.

The second conversation

The focus is on the cognitive, affective and behavioural domains—strengths and resources within and outside the family that can be utilised to increase support in everyday life (Shajan & Snell, 2019; Sveinbjarnardottir & Svavarsdottir, 2019). Healthcare professionals use interventive questions to assess the impact of problems/illness on the family, to elicit problem-solving skills, to coping strategies and strengths and to invite change. Reflection on aspects of family functioning, strengths and resources within and outside the family that may have an impact on everyday family life and coping is of prime importance.

The third conversation

The focus is on families' experience of everyday life and support strategies in the future (Shajan & Snell, 2019). The healthcare professional should routinely commend family and individual strengths, competencies and resources. This serves as a closure of the conversations.

3.3 | Participants

The managers of mental healthcare professionals in nine Norwegian municipalities were asked to recruit mental healthcare professionals. Inclusion criteria were a minimum of a three-year Bachelor's degree in health or social science, working in community mental health service with a minimum one year of work experience, and working with young adults from 18 to 25 years suffering from mental illness. Nineteen mental healthcare professionals were recruited by their manager and participated in the training programme FCSC. After the training programme, they conducted FCSC in their work practice. Out of these (n = 19), thirteen agreed to participate in an individual interview, giving a convenience sample. They received written and oral information and gave their written informed consent.

The participants were three males and ten females aged from 36 to 61 years. They were qualified as occupational therapists, social workers, psychologist, social educators and registered nurses. They were all engaged in the same treatment and follow-up of young adults suffering from mental illness. Twelve had further education in mental health and some also had training in family therapy and cognitive therapy. Work experience varied from one to twenty years of experience in community mental health services. The participants had conducted FCSC with one or two young adults and their families prior to the interview. They worked in both urban and rural municipalities that varied in geographical extent and number of residents.

3.4 | Data collection

Data were collected using individual interviews in the mental healthcare professionals' workplace during spring 2018. The initial question was, "Can you please describe your experiences of family-centred support conversations?" Follow-up questions such as "Could you explain....?" "Is it always like this?" and "Could you please tell more...?" were used to obtain variations in conceptions. The interviews lasted from 43 to 61 minutes with a median time of 44 minutes.

3.5 | Ethical considerations

Ethical considerations and guidelines were applied with regard to the confidentiality, integrity and voluntariness of the participants (World Medical Association, 2008). The study was approved by Norwegian Centre for Research Data (NSD), Ref: 54962.

3.6 | Data analysis

The interviews were audio-taped and transcribed verbatim and analysed as a pool of meanings (Marton & Booth, 1997). The analysis was conducted using the seven steps described by Dahlgren and Fallsberg (1991). *1) Familiarisation*: All the interviews were carefully read by the first and last author in order to obtain an overview and gain an overall impression. *2) Condensation*: Statements used by the participants were selected to describe a short but representative version of the entire dialogue concerning the phenomenon. *3) Comparison*: The condensations were compared with find sources of similarities and differences. *4) Grouping*: Condensations that appeared similar were put together, classified, discussed and compared in order to choose the appropriate group and develop mutually exclusive conception groups. *5) Articulating*: A preliminary attempt was made to describe the essence of the similarities within each group of conceptions. Some of the preliminary groups were revised. *6) Labelling*: The various conceptions and descriptive categories were denoted by constructing a suitable linguistic expression. *7) Contrasting*: The descriptive categories obtained were subsequently compared regarding similarities and differences, making them mutually exclusive.

There was a constant interplay between the various steps of the analysis, and the researchers discussed this thoroughly. The findings were presented in an outcome space with a horizontal structure (Barnard & Gerber, 1999). The checklist Consolidated Criteria for Reporting Qualitative Research (COREQ) was used (Tong et al., 2007) (Table S1).

4 | FINDINGS

The findings are presented in an outcome space with three descriptive categories: 'A new tool in the tool box', 'The family as a conversational partner' and 'Implementing the intervention' with seven conceptions (see Table 1).

4.1 | A new tool in the toolbox

The Family-Centred Support Conversation (FCSC), was considered to be a new tool in the toolbox in the mental healthcare professionals' therapeutic conversations with young adults suffering from mental illness and their families. Before the training-programme, the mental healthcare professionals had no routine regarding the presence of family members during the therapeutic conversations. The FCSC was described as helping them to structure the involvement of family members, gain an overview of the family, map and elucidate their relations, their perceptions of family life and create milestones for the future. The mental healthcare professionals asserted that the FCSC gave family members an opportunity to explain and describe how they experienced everyday life and the situation when living with a family member suffering from mental illness. The mental healthcare professionals' role was described as that of someone outside the family who could facilitate openness, trust and cooperation and provide a method of mobilising the family's own resources.

4.1.1 | A rewarding and challenging training programme

The mental healthcare professionals described the training programme as a useful and essential part of being able to offer the family support conversations. The use of case training with role-play was perceived as not only important but also stressful and unpleasant. On the other hand, the training programme gave them power and confidence to practice the conversations with real families. As one participant said: "*And reflecting on each role-play situation that was presented… I think that was very useful.*" Acquiring techniques to facilitate safe and trust-building family support conversations was described as a skill they needed in order to facilitate the conversations in the best way. When conducting the conversations with families, the mental healthcare professionals asked for supervision, as it was a new tool and a new way of thinking.

'The family-tree' was highlighted as a fairly new illustrative method and raised awareness in terms of the family structure and their relations. This was also given as a reason not to use 'the family-tree' as it might depict the scarcity of relations both within the family and in other social contexts.

4.1.2 | Obstacles to using the intervention

The mental healthcare professionals reported the difficulty of implementing the FCSC with young adult patients, given that young adults want to seek independence from their parents. In order to respect the young adults' wishes, the mental healthcare professionals sometimes did not ask the patients whether they wanted family present in the conversations. The intervention was regarded as easier to apply in families with older patients or adolescents than in families with young adults as patients.

The intervention was also described as demanding and exhausting when there was more than one person in the conversation—this was described as new and challenging. *It's important to observe how this develops in the family, how can they support each other, the advantages and the disadvantages, As far as I'm concerned, I need to practise encouraging them to speak about how they experience the situation, how they perceive one another in the situation.*"

Mothers and fathers have described to the mental healthcare professionals the feeling of guilt, shame and fear of criticism as one reason why they refuse to participate in the FCSC. One health professional said: "*Mum takes quite a lot of the blame for her daughter's problems and has also been criticized by the health service, but now she would like to have even more conversations. She felt that finally she was being taken seriously and felt stronger as a family member after these conversations.*"

Even though the patients wanted the mental healthcare professionals to be open despite the confidentiality requirement, the mental healthcare professionals were described as holding back information, especially when others than the closest family were present. The mental healthcare professionals stated that family was what the patient needed for support in everyday life. In order to avoid disclosing sensitive matters, mental healthcare professionals described how they let the patient lead the conversation and they themselves were active listeners in order to ensure confidentiality. The confidentiality requirement was considered a difficult obstacle to handle, even though they experienced that the parents, in particular, knew the whole story. The importance of preparing the family and the conversations was highlighted when working with trust and ensuring that the patient was comfortable

TABLE 1 The health professionals' perceptions of conducting family-centred support conversations

Descriptive categories	A new tool in the toolbox	The family as a conversational partner	Implementing the intervention
Conceptions	A rewarding and challenging training programme	Intervening with the diversity of families	Adjusting the intervention
	Obstacles to using the intervention	Strengths and resources in the mirror of suffering	Collegial support when practicing the conversations
		Sharing knowledge and experiences	

having the family present in the conversations. The relationship of trust with the patients was considered the most valuable in the therapeutic relation, too valuable to ruin. One described the importance of getting to know the family before the intervention started: "*.....but we're working here with people with different kinds of mental problems and I believe it's extremely important for those who have a mental disorder to be understood. So, if you come in and are not completely certain how mum and dad understand the situation, maybe it will be a bit hard*."

4.2 | The family as a conversational partner

Having the family as a conversational partner together with the patients was considered both somewhat new and rewarding but also challenging. The mental healthcare professionals considered the family as those having the responsibility most of the time, while the time they spent with the health professional was limited. Being conscious of the family as a resource was the subject of reflection, as some families were a resource for the young adult, while other families, due to many difficulties, were not able to be supportive.

Mental healthcare professionals described earlier experiences of meeting family members as a support in the regular therapeutic conversations when patients did not have the courage to go alone or wanted their parents' support. In contrast, others described having family members present as fairly new experience.

4.2.1 | Intervening with the diversity of families

Bringing the family into the conversations was considered as 'balancing on a knife-edge'—relations might worsen, and both making demands and giving praise are challenging. In families where family members did not have insight or knowledge regarding the young adults' mental illness, the mental healthcare professionals did not see the family as a conversational partner. But even so, the FCSC may be used to clarify the family members' perceptions. For example, one health professional said: "*I can use it in families I had maybe 'given up', but now I can try again*."

Some families were also seen as having high conflict levels or had more than one family member suffering from mental illness, making it difficult to carry out the intervention and take care of everyone in the best way. In contrast, the opposite was described: "*I don't think it will do any harm, so I'll give the intervention a chance. I'll adapt according to how we meet each other – the young person, the family and the parents*."

At times, the mental healthcare professionals perceived they could be a catalyst in bringing up conflict areas or topics the family otherwise did not talk about. In the FCSC, the main goal was to give support to the entire family and not only treat the patient. As one health professional claimed: "*And I believe in any case that I've become a lot braver when it comes to inviting them to take along family members as well*."

Including the parents in the collaboration was considered important, since the parents were the ones who often had to carry the burden.

If the young adult was not so talkative, the parents could dominate the conversation, creating an imbalance. Getting used to balancing the conversation and gaining experience of this represented a new challenge for the mental healthcare professionals. One health professional described this as follows: "*Yes, as soon as I asked the patient, mum took over and answered on her behalf, it was the same for both of them. When I asked questions, I just looked straight at the patient in the hope that mum would understand that she shouldn't interrupt at that point*."

4.2.2 | Strengths and resources in the mirror of suffering

Focussing on strengths and resources was new, both for the mental healthcare professionals and for the families. It was described as easily causing a negative spiral, and sometimes the parents had difficulties in describing their daughter or son in a positive way, or the family was not open and listening. The mental healthcare professionals described families who had lived with severe problems, often over a long period of time, even before seeking help. In some cases, the mental healthcare professionals felt that families often wanted help to solve their problems and find quick solutions due to their exhaustion. In such cases, the mental healthcare professionals said that families found it provoking to focus on strengths and resources. Allowing family members to talk freely about what was on their mind eased the problems and made them more aware of their resources. This was described as follows: "*Hearing yet again about resources. What they can contribute and how they feel problems can be solved… I have kind of become more aware of this*." One health professional described her own role in the conversations: "*Yes, I'm just a contributor. I'm like a crutch you can lean on and support yourself with. But the individual has to do the job on their own and so on. Having too much focus on the illness … we actually confirm that things are challenging, and that it's difficult. And we also confirm …. the opposite of normalization*."

They described the conversations as not having the goal of solving or treating the families' problems or challenges but being a place to talk about difficult matters and focus on the resources in the family. The intervention was described as a paradigm shift, but it was important to bridge problems and resources. As one of the participants stated: "*It's almost a paradigm shift. In the past we have focused on what has been difficult, but now we're turning our focus to what is positive*."

4.2.3 | Sharing knowledge and experiences

The families shared their knowledge and experiences of family and individual life, which was experienced as a fairly new experience for the mental healthcare professionals. When there were topics the family did not dare to raise at home, the FCSC became an arena for discussing difficult questions. The mental healthcare professionals stated that they had a lot to learn from the families, and it was considered important to meet and include the young adult's family members. The balance between revealing difficulties on the one hand and taking care of the patient and not causing new conflicts on the other hand was challenging. The patients suffer from their mental illness and taking care of the patients was regarded as the mental healthcare professionals' main responsibility.

In the conversations, emphasis was put on encouraging the patients to invite family members in, in order to achieve a mutual understanding of their situation and to make it safe to talk about difficult topics without having the mental healthcare professionals in the driving seat. One health professional said: "*It's important for mum to be understood as well, and also the boyfriend or girlfriend. And it's hard for the patient to hear.*"

The FCSC was experienced as giving the family a space for sharing. The mental healthcare professionals highlighted the importance of giving the parents praise for sharing, for example experiences from their own youth, as these experiences may contribute to normalising some of the young adults' feelings. Patients had reflected on their relations with their mother and the patients' own habits in their meeting, and others described this realisation as redemptive in the patients' recovery. The sharing of knowledge could also have a link to psychoeducation, which is often described as being useful for the family although opinions differed: "*In answer to the question of whether they wanted instruction about the diagnosis, the mother got furious again, saying 'If anyone knows anything about this, it's me far more than you in any case'.*" The FCSC was described as a way of mirroring the families, reflecting their relations and feelings and opening up for new insights.

4.3 | Implementing the intervention

This descriptive category describes the mental healthcare professionals' descriptions of their thoughts regarding adjustment of the intervention and the need of collegial support. They had different backgrounds and different further education and courses. Their thoughts regarding what was new in comparison with other interventions varied. The importance of implementing the intervention in the entire service rather than its being adopted by only a few mental healthcare professionals was highlighted.

4.3.1 | Adjusting the intervention

The mental healthcare professionals were familiar with network-meetings, family therapy, motivational interviews, early detection and treatment of psychoses (TIPS), psychoeducation and other more informal interventions, and they saw similarities and differences between these interventions and family support conversations. One participant said: "*So you can kind of zigzag on the basis of what comes up.In my mind,during the training I was sort of thinking:'What other categories can I assign this to? Oh,of course,there's a bit of the cognitive approach,and there's a bit of acceptance and commitment therapy.'*".

The literature, based on Antonovsky's theory of salutogenesis (Antonovsky, 1987), was familiar to some of the mental healthcare professionals and made sense in their work with patients suffering from mental illness. Some elements from the FCSC such as the family tree and the focus on resources are already well-known interventions, as well as the use of psychoeducation. One health professional described this as follows: "*When the patient has expressed a wish to know more,I have explained a bit about the clinical picture.And in that connection,I've sometimes talked about fluctuations,that despite the depression you have qualities you can reinforce. Put focus on the strengths the patient has and continues to have to ensure the family also sees that they can still have good qualities even though they are depressed and full of anxiety in this crisis.*"

The wish to modify the intervention was also described, while merely focussing on strengths and resources seemed rather strange when the patients and their family had many difficulties in their family life and most of their focus was on these. The families and the young adult needed training in using tools to manage the illness. The balance between education, knowledge sharing, suffering and resources was highlighted. The use of elements from the FCSC and other known interventions was a way of adjusting the intervention to meet the families' needs. The responsibility for the contact and conversation lay with the mental healthcare professionals. This responsibility was highlighted when they described how they made contact with the patients and their families, established a relationship, talked about what the family had in mind and acted as guides in the conversations. This could benefit the involved partners. The experience of using the family-centred support conversations was described as follows: "*Including the family in the conversation resulted in more structure.The first conversation was devoted to mapping the situation here and now. What opportunities are there? And then the next time evaluating and discussing the way ahead.*"

4.3.2 | Collegial support when practicing the conversations

When all colleagues used the FCSC intervention, this meant broader implementation. Frustration arose when only a few of the staff had participated in the training programme and practiced FCSC, while others gave little support or encouragement. Those who had undertaken the FCSC together with a colleague described it as useful, and one person stated: "*I don't get upset even though I need guidance and I wonder what I could have done better.I think it's good to take along a colleague,but that's not possible most of the time.*" When two colleagues are involved in conducting the conversations, it is possible to safeguard both the patient and the other family members. The mental healthcare professionals wanted the use of the FCSC to be established in the specialist team and highlighted the conversations as an intervention they could develop together in order to structure the involvement of families in treatment and care.

5 | DISCUSSION

The main findings in this study illustrate in various ways how mental healthcare professionals experienced the use of the new tool—Family-Centred Support Conversations—in the therapeutic consultations with the family as a conversational partner. Although using the FCSC was a fairly new experience, some elements were also recognisable from other interventions. The systematisation of family involvement given in the structure of the FCSC was highly valued.

5.1 | A new tool in the toolbox

The mental healthcare professionals described a kind of loyalty conflict between the patient and the family members, while the trusting relationship between the patient and the mental healthcare professionals was a core value in the therapeutic relation. Confidentiality vis-à-vis the patients was experienced as an obstacle for the mental healthcare professionals. Patients and their family members also state that the mental healthcare professionals' loyalty always lies with the patient (Aass et al., 2020). In the current study, the mental healthcare professionals described how they played a more passive and listening role in the FCSC and let the patient determine the content of the conversation in order to avoid problems related to confidentiality.

An Islandic study found that after being trained and in the FCSC, nurses perceived the family as less burdensome (Sveinbjarnardottir et al., 2011). The mental healthcare professionals in the current study described the FCSC as fairly new and a paradigm shift in their practice. They also described the positive results of including the families in conversations with their patients after trying out the intervention. Parents of young adults with mental illness have described negative contact with healthcare professionals as related to lack of continuity and being dependent on who they met in the healthcare system (Andershed et al., 2017). The healthcare professionals in the current study described FCSC as systemising the inclusion of family members in therapeutic conversations. Mental healthcare professionals have reported that they did not perceive the family as a burden, but they did not invite the family as a conversational partner in the community mental health service (Moen et al., 2020). This highlights the need for family-centred interventions such as the FCSC.

The mental healthcare professionals described themselves as a catalyst in the FCSC. Reed et al., (2018) describe the professionals as translators when they support patients in community mental health services. They help the patients to understand their own experiences of interaction with others, and in different situations, help others to understand users in order to promote a mutual understanding. Families have described the value of sharing experiences and thoughts with healthcare professionals present (Aass et al., 2020). Sharing of everyday family life stories might offer valuable information in the therapeutic conversations and help the family to new understandings. Furthermore, when mental healthcare professionals learn how the family copes with their suffering, and this will help them to arrive at a mutual understanding of the patient's condition when making clinical decisions on patient treatment and care. Ewertzon et al., (2010) describe how relatives experienced alienation when not participating in a dialogue with the health professionals, while Skundberg-Kletthagen et al., (2014) describe relatives experiencing strengthened ability to support the person suffering from depression when their knowledge about the symptoms of depression is enhanced. The mental healthcare professionals in the current study described gaining increased insight into the families' sufferings and resources when conducting FCSC.

5.2 | The family as a conversational partner

The family-centred support conversation includes the emotional support of alleviating painful emotional experiences, enhancing well-being, and validation and normalisation of expressed emotions. The family is encouraged to tell the story of the illness and to listen to each other's concerns and feelings. This may highlight the strengths and resources of all family members (Sveinbjarnardottir & Svavarsdottir, 2019).

The mental healthcare professionals in this study said that they would not recommend FCSC for families that had more than one family member suffering from mental illness or had troublesome family relations. Interestingly, registered nurses always have to be aware of complex family situations where family nursing or the involvement of families is questionable or even not recommended, for example code of ethics (International Council of Nurses, 2012). However, mental healthcare professionals may also find that through the conversations, knowledge is gained of family life, the different perceptions of problems and different ways of solving these problems (Benzein et al., 2012). The FCSC might challenge constraining beliefs and make it possible to speak of the unspeakable (Aass et al., 2020). A study by Skundberg-Kletthagen et al., (2020) described meeting families experiencing many difficulties and a high level of conflict as a balancing act. Ensuring that all the family members are addressed in a caring way places demands on the mental healthcare professionals.

The conception strengths and resources in the mirror of suffering describe elements of the FCSC in the conversations with the families with the young adults suffering from mental illness. This may reflect the findings of Biringer et al. (2017), which describe patients in the community mental health service as wishing for their own recovery in relation to family life and wanting to be able to work and experience enjoyable activities just as much as symptom relief. They stress that the patient's recovery cannot be viewed separately from the person's surroundings and life. The inclusion of family-centred support may be one move in that direction with a focus on strengths and resources (Shajan & Snell, 2019). On the other hand, recognising the family's suffering and working with the family as a whole and navigating towards realistic goals are of importance. Focussing on how people are able to connect and attach with each other—family members and mental healthcare professionals—can facilitate a therapeutic change (Sveinbjarnardottir & Svavarsdottir, 2019).

In the current study, some of the mental healthcare professionals stated that the intervention was part of a paradigm shift in their practice and that the FCSC may create a context of changing beliefs where both the family and the health professional undergo change. Families with young adults suffering from mental illness have also described FCSC as creating a context of change (Aass et al., 2020). The mental healthcare professionals in the current study experienced a knowledge exchange between the family and themselves. The non-hierarchical, mutual relationship between family and mental healthcare professionals is the goal in FCSC (Shajan & Snell, 2019). To be involved in helping families change requires that healthcare professionals possess certain essential competencies and skills (Shajan & Snell, 2019). The mental healthcare professionals who participated in the current study had specialised competence and professional knowledge. The families have knowledge of family life and the suffering of family members. This is also described by Blomqvist and Ziegert (2011) who assert that mental healthcare professionals felt that the family could increase their understanding of the patient, which would enhance their understanding of how to manage family life. Both the mental healthcare professionals and the families bring strengths and resources to the conversations in the current study. Skundberg-Kletthagen et al., (2020) found that mental healthcare professionals facilitate meetings with the family and bring up difficult matters and sufferings. Conducting FCSC may demand specialised competence in the healthcare professionals and may entail a need for more competence than a bachelor's degree, which means that supplementary education is required.

5.3 | Implementing the intervention

Family care was described as unstructured, and the mental healthcare professionals use of FCSC helped them to include family members in therapeutic conversations. There is evidence that the professionals' attitudes towards involving the family in an intervention are affected by their competencies regarding working with families (Landeweer et al., 2017). In the present study, support from colleagues was found to be important, and this may lead to mental healthcare professionals feeling more comfortable when facilitating the therapeutic conversations. Additionally, the mental healthcare professionals described a need to adjust the intervention, as the FCSC is not suitable for all families. The frames and structure formed by the intervention were described as a benefit, but on the other hand, some families needed additional help, such as cognitive therapy or psychoeducation.

There is a need to evaluate family interventions such as the FCSC (Ewertzon & Hanson, 2019) in order to improve family support and involvement and to improve quality of care. There are many support interventions for families as summarised by Ewertzon and Hanson (2019). These give improved family functioning and support but do not necessarily result in a decreased burden. The intervention may help family members to manage the situation and thus help them in supporting the person(s) suffering from mental illness. A relationship is established between the family members' experience of the professional's approach or attitude and their feeling of alienation (Ewertzon et al., 2010). This confirms the importance of improving the quality of the mental health services delivered to the patient and the family. Implementing FCSC could be one such solution.

5.4 | Methodological considerations

The diversity in the participants background, such as work experience, educational background and the variety of community mental health services, strengthened the credibility of the study (Sandelowski, 1986) and yielded different ways of experiencing conducting Family-Centred Support Conversations. As the participants are mental healthcare professionals representing the community mental health services in Norway, they gave a variety of perceptions. The goal in phenomenography is not to compare the diversity in the participants' background but to describe the variety of description of the phenomenon (Marton & Booth, 1997). The participants received oral and written information, and thirteen out of the nineteen participating in the training programme, agreed to participate. They represented both women and men, they varied in age and job experience and gave rich and varied descriptions of conducting FCSC. The interviews were conducted individually, allowing the participant to talk freely about the phenomenon of interest. The credibility of the findings was also assessed using open-ended questions enabling the healthcare professionals to freely describe their experiences. Quotations were used to strengthen the confirmability (Sandelowski, 1986). The interviews were conducted by two other researchers than the one responsible for the training programme, which strengthen the trustworthiness of the study. Throughout the entire analysis process, the authors reflected critically on the contents of the conceptions and the descriptive categories in terms of gaining trustworthiness. The research group had different professional competences in their role as registered nurses, public health nurse and psychiatric nurses, which may strengthen trustworthiness. The data were analysed in line with to Dahlgren and Fallsberg (1991) to help maintain auditability (Sandelowski, 1986). The analysis process continued until nothing new emerged (Marton & Booth, 1997).

A limitation of the study is that some managers in the municipalities declined to participate in the intervention due to a lack of resources or because of too many other ongoing projects. On the other hand, most of the mental healthcare professionals who had conducted the training programme participated in the interview. Another limitation is the lack of information as to why the remaining six persons did not volunteer to take part in the study.

6 | CONCLUSIONS

The Family-Centred Support Conversation was described as a complement to care as usual. Conducting the FCSC was considered as a new way of structuring the involvement of family members in the therapeutic conversations with the young adult patients. Confidentiality regarding the patients was in focus when bringing family members to the therapeutic conversation. The trusting relationship between the patient and the mental health professional was the priority. The mental healthcare professionals found that they gained insight into the families' sufferings and how each family member experienced everyday life. By conducting FCSC, the mental healthcare professionals perceived that the families increased their knowledge of the young adults' mental illness and how to manage everyday life. The intervention may not suit all families and may need some modification to meet the needs of the specific patient and their family in the community mental health services.

7 | RELEVANCE TO CLINICAL PRACTICE

The Family-Centred Support Conversation may help registered nurses and other health professionals to structure the involvement of family members in the follow-up of patients suffering from mental illness. The involvement of various family members may help family members to manage the situation and thus help them in supporting their young adult suffering from mental illness on a daily basis. With this backdrop, clinical practice is challenged to work on establishing a mindset whereby the family is regarded as a resource with important skills and life experience. The family should be offered individualised support and follow-up, and the FCSC may be a relevant intervention. The knowledge exchange between the families and the mental healthcare professionals may create a context of changing beliefs. The mental health professional facilitates the conversation and creates a climate for sharing, bringing strengths and resources to the front seat in the therapeutic conversations.

8 | RECOMMENDATIONS TO FURTHER RESEARCH

We believe that further research should focus on initiating and performing intervention studies addressing the benefits or effects of the FCSC, in addition to exploring contextual issues that might act as facilitator or barrier to successful implementation.

In the future, longitudinal studies should also be carried out in order to offer qualitative and quantitative evidence aiming for an increased understanding of how the FCSC approach may vary across a part of the life span.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

AUTHOR CONTRIBUTION

Study design: ØLM, AS, LKA and HS-K; data collection: ØLM and HS-K; data analysis and manuscript preparation: ØLM, AS, LKA and HS-K. All the authors have seen this last version and agreed upon it.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Øyfrid Larsen Moen https://orcid.org/0000-0002-7970-6027
Lisbeth Kjelsrud Aass https://orcid.org/0000-0002-0723-1093
Agneta Schröder https://orcid.org/0000-0002-2157-8579
Hege Skundberg-Kletthagen https://orcid.org/0000-0002-1830-3136

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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