

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

Lisbeth Kjelsrud Aass, Hege Skundberg-Kletthagen, Agneta Schröder & Øyfrid Larsen Moen

To cite this article: Lisbeth Kjelsrud Aass, Hege Skundberg-Kletthagen, Agneta Schröder & Øyfrid Larsen Moen (2021) 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, DOI: [10.1080/01612840.2020.1770384](https://doi.org/10.1080/01612840.2020.1770384)

To link to this article: <https://doi.org/10.1080/01612840.2020.1770384>



© 2020 The Author(s). Published with license by Taylor & Francis Group, LLC



Published online: 30 Jun 2020.



Submit your article to this journal [↗](#)



Article views: 3474



View related articles [↗](#)



View Crossmark data [↗](#)



Citing articles: 4 View citing articles [↗](#)

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 

^aDepartment of Health Sciences, Faculty of Medicine and Health Sciences (MH), Norwegian University of Science and Technology (NTNU), Gjøvik, Norway; ^bFaculty 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

© 2020 The Author(s). Published with license by Taylor & Francis Group, LLC

This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

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-Klethagen 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 health-care. 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

Table 1. Participating young adults and family members.

	Patients	Family members
	19-23	20-55
Age		
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

informant's focus when describing the phenomenon under study and how is it described (Marton & Booth, 1997).

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 phenomenographic 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 (Uljen, 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 cherished 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.

Disclosure statement

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

Funding

This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

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>

References

- Aass, L. K., Skundberg-Kletthagen, H., Schröder, A., & Moen, Ø. L. (2020). Young adults living with mental illness and their family in community mental healthcare settings: Experiences of a Family-Centered Support Conversations. Manuscript Submitted for Publication, *Journal of Family Nursing*.
- Ahlström, B. H., Skärsäter, I., & Danielson, E. (2009). Living with major depression: Experiences from families' perspectives. *Scandinavian Journal of Caring Sciences*, 23(2), 309–316. <https://doi.org/10.1111/j.1471-6712.2008.00624.x>
- Aldersey, H. M., & Whitley, R. (2015). Family influence in recovery from severe mental illness. *Community Mental Health Journal*, 51(4), 467–476. <https://doi.org/10.1007/s10597-014-9783-y>
- Andershed, B., Ewertzon, M., & Johansson, A. (2017). An isolated involvement in mental health care: Experiences of parents of young adults. *Journal of Clinical Nursing*, 26(7–8), 1053–1065. <https://doi.org/10.1111/jocn.13560>
- Årestedt, L., Persson, C., & Benzein, E. (2014). Living as a family in the midst of chronic illness. *Scandinavian Journal of Caring Sciences*, 28(1), 29–37. <https://doi.org/10.1111/scs.12023>
- Armstrong, K. H., Dedrick, R. F., & Greenbaum, P. E. (2003). Factors associated with community adjustment of young adults with serious emotional disturbance: A longitudinal analysis. *Journal of Emotional and Behavioral Disorders*, 11(2), 66–76. <https://doi.org/10.1177/106342660301100201>
- Arnett, J. J., Žukauskienė, R., & Sugimura, K. (2014). The new life stage of emerging adulthood at ages 18–29 years: Implications for mental health. *The Lancet Psychiatry*, 1(7), 569–576. [https://doi.org/10.1016/S2215-0366\(14\)00080-7](https://doi.org/10.1016/S2215-0366(14)00080-7)
- Åstedt-Kurki, P., Paavilainen, E., & Lehti, K. (2001). Methodological issues in interviewing families in family nursing research. *Journal of Advanced Nursing*, 35(2), 288–293. <https://doi.org/10.1046/j.1365-2648.2001.01845.x>
- Dahlgren, L. O., & Fallsberg, M. (1991). Phenomenography as a qualitative approach in social pharmacy research. *Journal of Social Administrative Pharmacy*, 8(4), 150–156.
- EGgenberger, S. K., & Nelms, T. P. (2007). Family interviews as a method for family research. *Journal of Advanced Nursing*, 58(3), 282–292. <https://doi.org/10.1111/j.1365-2648.2007.04238.x>
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology: A Journal of Theory, Research, and Development*, 29(2), 75–91.
- Gullestad, M. (1989). *Culture and everyday life* [Kultur og hverdagsliv]. University Press.
- Gulliver, A., Griffiths, K. M., & Christensen, H. (2010). Perceived barriers and facilitators to mental health help-seeking in young people: A systematic review. *BMC Psychiatry*, 10(1), 113. <https://doi.org/10.1186/1471-244X-10-113>
- Gustavson, K., Knudsen, A. K., Nesvåg, R., Knudsen, G. P., Vollset, S. E., & Reichborn-Kjennerud, T. (2018). Prevalence and stability of mental disorders among young adults: Findings from a longitudinal study. *BMC Psychiatry*, 18(1), 65. <https://doi.org/10.1186/s12888-018-1647-5>
- Ha, J. H., Hong, J., Seltzer, M. M., & Greenberg, J. S. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: Report of a national study. *Journal of Health and Social Behavior*, 49(3), 301–316. <https://doi.org/10.1177/002214650804900305>
- Jivanjee, P., & Kruzich, J. (2011). Supports for young people with mental health conditions and their families in the transition years. *Best Practices in Mental Health*, 7(1), 115–133.
- Jivanjee, P., Kruzich, J. M., & Gordon, L. J. (2009). The age of uncertainty: Parent perspectives on the transitions of young people with mental health difficulties to adulthood. *Journal of Child and Family Studies*, 18(4), 435–446. <https://doi.org/10.1007/s10826-008-9247-5>
- Johansson, A., Andershed, B., & Anderzen-Carlsson, A. (2014). Conceptions of mental health care—from the perspective of parents' of adult children suffering from mental illness. *Scandinavian journal of caring sciences*, 28(3), 496–504. <https://doi.org/10.1111/scs.12074>
- Johansson, A., Anderzen-Carlsson, A., Åhlin, A., & Andershed, B. (2010). Mothers' everyday experiences of having an adult child who suffers from long-term mental illness. *Issues in Mental Health Nursing*, 31(11), 692–699. <https://doi.org/10.3109/01612840.2010.515768>
- Johansson, A., Anderzen-Carlsson, A., Åhlin, A., & Andershed, B. (2012). Fathers' everyday experiences of having an adult child who suffers from long-term mental illness. *Issues in Mental Health Nursing*, 33(2), 109–117. <https://doi.org/10.3109/01612840.2011.627106>
- Lindgren, E., Söderberg, S., & Skär, L. (2014). Managing transition with support: Experiences of transition from child and adolescent psychiatry to general adult psychiatry narrated by young adults and relatives. *Psychiatry Journal*, 2014, 457160. <https://doi.org/10.1155/2014/457160>
- Lindgren, E., Söderberg, S., & Skär, L. (2015). Swedish young adults' experiences of psychiatric care during transition to adulthood. *Issues in Mental Health Nursing*, 36(3), 182–189. <https://doi.org/10.3109/01612840.2014.961624>
- Lindgren, E., Söderberg, S., & Skär, L. (2016). Being a parent to a young adult with mental illness in transition to adulthood. *Issues in Mental Health Nursing*, 37(2), 98–105. <https://doi.org/10.3109/01612840.2015.1092621>
- Marton, F. (1988). Phenomenography: A research approach to investigating different understandings of reality. *Qualitative Research in Education: Focus and Methods*, 21, 143–161.
- Marton, F., & Booth, S. (1997). *Learning and awareness*. Lawrence Erlbaum.
- McCann, T. V., Lubman, D. I., & Clark, E. (2012a). The experience of young people with depression: A qualitative study. *Journal of Psychiatric and Mental Health Nursing*, 19(4), 334–340. <https://doi.org/10.1111/j.1365-2850.2011.01783.x>
- McCann, T. V., Lubman, D. I., & Clark, E. (2012b). Views of young people with depression about family and significant other support: Interpretative phenomenological analysis study. *International Journal of Mental Health Nursing*, 21(5), 453–461. <https://doi.org/10.1111/j.1447-0349.2012.00812.x>
- Ministry of Health and Care Services (1999). *Act relating to patient's rights* [Patient's rights act]. Ministry of Health and Care Services.
- Ministry of Health and Care Services. (2011). *Act related to municipal health and care services*. Ministry of Health and Care Services.
- Moen, Ø. L., Hall Lord, M. L., & Hedelin, B. (2014). Living in a family with a child with attention deficit hyperactivity disorder: A phenomenographic study. *Journal of Clinical Nursing*, 23(21–22), 3166–3176. <https://doi.org/10.1111/jocn.12559>
- Pernice-Duca, F. (2010). Family network support and mental health recovery. *Journal of Marital and Family Therapy*, 36(1), 13–27. <https://doi.org/10.1111/j.1752-0606.2009.00182.x>
- Reavley, N. J., Yap, M. B. H., Wright, A., & Jorm, A. F. (2011). Actions taken by young people to deal with mental disorders: Findings from an Australian national survey of youth. *Early Intervention in Psychiatry*, 5(4), 335–342. <https://doi.org/10.1111/j.1751-7893.2011.00292.x>
- Reneflot, A., & Evensen, M. (2014). Unemployment and psychological distress among young adults in the Nordic countries: A review of the literature. *International Journal of Social Welfare*, 23(1), 3–15. <https://doi.org/10.1111/ijsw.12000>
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Sciences*, 8(3), 27–37. <https://doi.org/10.1097/00012272-198604000-00005>
- Skundberg-Kletthagen, H., Wangenstein, S., Hall-Lord, M. L., & Hedelin, B. (2014). Relatives of patients with depression:

- Experiences of everyday life. *Scandinavian Journal of Caring Sciences*, 28(3), 564–571. <https://doi.org/10.1111/scs.12082>
- Sommer, M. (2016). Mental health among youth in Norway: Who is responsible? *What is being done?* Nordens Valfärdcenter/Nordic Centre for Welfare and Social Issues.
- Uljens, M. (1989). *Fenomenografi: Forskning om uppfattningar (Phenomenography: Research on conceptions)*. Studentlitteratur.
- Weimand, B. M., Hall-Lord, M. L., Sällström, C., & Hedelin, B. (2013). Life-sharing experiences of relatives of persons with severe mental illness—A phenomenographic study. *Scandinavian Journal of Caring Sciences*, 27(1), 99–107. <https://doi.org/10.1111/j.1471-6712.2012.01007.x>
- Weimand, B. M., Hedelin, B., Hall-Lord, M. L., & Sällström, C. (2011). “Left alone with straining but inescapable responsibilities”: Relatives’ experiences with mental health services. *Issues in Mental Health Nursing*, 32(11), 703–710. <https://doi.org/10.3109/01612840.2011.598606>
- Weimand, B. M. (2012). *Experiences and nursing support of relatives of persons with severe mental illness* [Doctoral dissertation, Karlstad University Studies].
- Whall, A. L. (1986). The family as the unit of care in nursing: A historical review. *Public Health Nursing*, 3(4), 240–249. <https://doi.org/10.1111/j.1525-1446.1986.tb00495.x>
- Woodgate, R. L., Sigurdson, C., Demczuk, L., Tennent, P., Wallis, B., & Wener, P. (2017). The meanings young people assign to living with mental illness and their experiences in managing their health and lives: A systematic review of qualitative evidence. *JBISIRIR*, 15(2), 276–401. <https://doi.org/10.11124/JBISIRIR-2016003283>
- Woolsey, L., & Katz-Leavy, J. (2008). Transitioning youth with mental health needs to meaningful employment and independent living. *National collaborative on workforce and disability for youth*. Institute for Educational Leadership.
- World Health Organization. (2014). Preventing suicide: A global imperative. *Executive Summary*. https://www.who.int/mental_health/suicide-prevention/exe_summary_english.pdf?ua=1
- World Medical Association. (2018). *World Medical Association Declaration of Helsinki - Ethical principles for medical research involving human subjects*. World Medical Association.
- Wright, L. M., & Bell, J. M. (2009). *Beliefs and illness: A model for healing*. 4th Floor Press.