DOCTORAL THESIS

"It's All About Survival"

Young Adults' Transitions within Psychiatric Care from the Perspective of Young Adults, Relatives, and Professionals

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Luleå 2014

Printed by Luleå University of Technology, Graphic Production 2014

ISSN 1402-1544
ISBN 978-91-7583-107-7 (print)
ISBN 978-91-7583-108-4 (pdf)

Luleå 2014

www.ltu.se

"Look on every exit as being an entrance somewhere else."

Tom Stoppard

To all young adults and relatives
who shared their experiences

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ABSTRACT

Aim: The overall aim of this thesis was to explore young adults' transitions within psychiatric care from the perspective of young adults, relatives, and professionals.

Method: The thesis includes four studies (I–IV) with a qualitative approach. Data for study I were collected through focus group discussions with professionals of child and adolescent psychiatry (CAP) and general psychiatry (GenP), and analyzed using deductive content analysis based on Meleis's theory of transition. Data for studies II–IV were collected from individual interviews with young adults and relatives with expectations and experiences of transfer from CAP to GenP (II), from young adults with experiences of care in both CAP and GenP (III), and from relatives with experiences of parenting young adults with mental illness (IV). The data from studies II–IV were analyzed using grounded theory (GT) as described by Corbin and Strauss.

Results: The synthesis of the four studies (I–IV) resulted in a grounded theory, "Support and intrinsic motivation as prerequisites for transition and recovery," describing young adults' transitions within psychiatric care. The result shows that young adults with mental illness undergo multiple simultaneous transitions during transfer from CAP to GenP, and that these include developmental, situational/organizational, and health/illness transitions. It was important for the young adult to achieve intrinsic motivation in order to take responsibility for healthcare matters, to continue care, and to strive for recovery. Intrinsic motivation to continue care was created by trustful, caring relationships with professionals who encountered the young adults as a person, with respect to maturity. Furthermore, the result shows the importance of inclusive attitudes towards relatives, with possibilities for them to participate in young adults' care as well as opportunities to receive professional support for themselves, which facilitated relatives' abilities to manage their own lives and, moreover, to continue to provide support to young adults with mental illness.

Conclusions: This thesis highlights knowledge about the multiple simultaneous transitions that young adults experience when they reach the age of 18 and have closure of their care at CAP and continue care at GenP. To facilitate these transitions and empower young adults to continue care when it is needed and to strive for recovery, professionals need to take into account the factors that facilitate or inhibit healthy outcomes. Transition planning in cooperation with CAP, GenP, the young adult, and his or her relatives is recommended in order to reduce uncertainty about the new situation. It is also important to take into account that young adults need continuity and support in order to create trustful relationships. To reduce the risk of "falling into the caring gap," individual assessments about young adults' needs, intrinsic motivation to receive care, and access to support from relatives should be implemented in the transition planning. If the young adults and their relatives fail to receive the support they need, the risk for their dropping out of care is increased.

Keywords: grounded theory, intrinsic motivation, psychiatric care, mental illness, qualitative content analysis, relatives, support, transition, young adults

ORIGINAL PAPERS

This thesis in based on the following papers, which will be referred to with the Roman numbers.

Paper I Lindgren, E., Söderberg, S., & Skär, L. (2013). The gap in transition between child and adolescent psychiatry and general adult psychiatry. *Journal of Child and Adolescent Psychiatric Nursing, 26(2), 103-109.*

Paper II 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 (8).*

Paper III Lindgren, E., Söderberg, S., & Skär, L. (2014). Swedish young adults' experiences of psychiatric care during transition to adulthood. *Issues in Mental Health Nursing. (Accepted for publication)*

Paper IV Lindgren, E., Söderberg, S., & Skär, L. (2014). Being a parent to a young adult with mental illness in transition to adulthood. *(In manuscript)*

PREFACE

I had been working in psychiatric care for almost 25 years before I started these doctoral studies. I took my exam as a psychiatric nurse in 1985 and started to work at a psychiatric ward in general psychiatry (GenP). After a number of years at GenP, I started to work at inpatient care in child and adolescent psychiatry (CAP). I have always been interested in professional development and how care can be improved. Therefore, I continued to educate myself, and during my master's degree studies, my view of nursing changed and I began to see patients and their families with new eyes. It was during this period that my interest in nursing research started, but it was another eight years before I had the opportunity to begin my doctoral studies. During these eight years, I led a project that aimed to facilitate cooperation between primary health care and child and adult rehabilitation; in addition, I worked as a head nurse in CAP. These years gave me additional insights into the broader context of psychiatry and municipality-based services. Furthermore, I became versed in how different views of patients, families, mental illness and disabilities have negative impacts on cooperation between services. It became obvious to me that, in the long run, lack of cooperation decreased young adults' potential for development and recovery.

When I started this research, the subject of transition was already chosen, but it was my experience in psychiatric care that influenced my decision in regard to the context of the transition process. Before this, I had experienced caring for young adults who were referred and transferred from CAP to GenP, but I had not yet heard the term transition in this setting. It was when I first read the literature on the subject that I realized its dimensions and the profundity of the phenomenon. My experiences as a psychiatric nurse were a benefit during the data collection. Even though the purpose of the interviews was not intended to be a therapeutic conversation, it became emotional for the participants as they disclosed their experiences. In these situations, I had a great advantage because of my experience, and I used it and my knowledge to address their concerns and support both the young adults and their relatives during the interviews. In accordance with grounded theory methodology, I also used my experiences during the analysis process, and I believe that has led to a deeper understanding of the topic. I am very thankful to the participants who shared their experiences with me, and I strongly hope that this research will lead to an improved transition process and a greater possibility for young adults and their relatives to receive high-quality transitional care.

INTRODUCTION

Children and adolescents up to 18 years old with mental illness and in need of psychiatric care have benefitted from child and adolescent psychiatry (CAP). Usually, the whole family is involved in care in CAP, and decisions about the patients' care are reached in agreement among relatives, the patient and professionals. If a young adult needs continuity in care when she or he reaches the age of 18 and comes of age, she or he needs to be transferred to general psychiatry (GenP). At GenP young adults are considered as adults with responsibility for themselves and for decisions about their care. Young adults have to make a decision about whether or not their relatives will be allowed to participate in their care, which means those relatives' possibilities to participate in the care change.

Transition from CAP to GenP is well described internationally (Bruce & Evans, 2008; Kaehne, 2011; Muñoz-Solomando, Townley, & Williams, 2010; Singh, Evans, Sireling, & Stuart, 2005; Swift et al., 2013), however, there is a lack of studies in the Swedish context. During the transition process, there is a risk for disruptions in the continuity of care, with the potential for poorer clinical outcomes (Singh, 2009). Rigid boundaries between the disciplines can, furthermore, be a disadvantage during transition (Bruce & Evans, 2008). Transition planning and collaboration between services is needed to decrease the risk of disruption in care (Hovish, Weaver, Islam, & Paul, 2012; Singh et al., 2010), and transition issues need to be a priority in both CAP and GenP to support young adults (Davis & Sondheimer, 2005). Transition from CAP to GenP is, therefore, not about a single transfer of a person from one discipline to another. Rather, it is about multiple changes that can have impacts on many areas of the young adult's life and changes the relatives' situations as well. Therefore, it is important to explore how young adults, relatives and professionals experience transition in order to be able to provide support to young adults and their relatives and thereby facilitate transition from CAP to GenP.

BACKGROUND

Mental illness among young adults

Mental illness among young adults in Sweden has increased during recent decades (Lager, Berlin, Heimerson, & Danielsson, 2012), and about half of all lifetime cases of mental illness start by the age of 14 (Kessler et al., 2005). Therefore, prevention and early treatment of ill health need to focus on children, adolescents and young adults. According to the Swedish National Institute of Public Health (Lager, Berlin, Heimerson, & Danielsson, 2012), depression is a common condition in Sweden; it has been estimated that 25 percent of all women and 15 percent of all men require treatment for depression at some point during their lives. In the 1980s, nervousness and anxiety were more prevalent in older age groups, but today the age disparities are minor. Anxiousness, nervousness, and angst are now most common among young women ages 16 to 24 (Danielsson et al., 2012). The percentage of young adults suffering from these symptoms increased from 9 to 30 percent for women and from 4 to 14 percent for men between the years 1988 and 2005 (Lager et al., 2012). Moreover, suicidal ideations are common among young adult as many as 20 percent of young women and 13 percent of young men ages 16 to 29 have reported having suicidal thoughts at some time in their lives. The percentage of young adults who have attempted suicide was 6 percent among women and 4 percent among men in the same age group. The rate of suicide has fallen among all age groups except for adolescents and young adults ages 15 to 24 (Danielsson et al., 2012).

According to Ciarrochi, Deane, Wilson, and Rickwood (2002), young adults with low emotional competence are less likely to seek social support when they experience mental illness than young adults with skills at managing and describing their emotions. To have such skills leads to better social support, and that, in turn, leads to greater intentions to seek help. One possible explanation may be that skills in identifying emotions might be a prerequisite for seeking help. However, a majority of young adults suffering from mental illness never seek psychiatric care (Merikangas et al., 2010), and most of them who receive care are treated as outpatients (Lager et al., 2012). The number of young adults admitted to inpatient psychiatric care has steadily risen; statistics from 2010 show that 0.5 percent of young women and 0.3 percent of young men were treated at either CAP or GenP (Lager et al., 2012). According to Engqvist and Rydelius (2007), approximately one-third of young adults treated in CAP are in need of care in GenP as adults, and Ramirez, Ekselius, and Ramklint (2009) showed that approximately one-fourth of patients ages 18 to 25 treated in GenP had previously received care in CAP.

Mental illness can be defined in different ways depending on whether symptoms, possible causes, or interventions are in focus. All perspectives are relevant, and it is not possible to ignore the condition's complexity. A holistic view of young adults is a prerequisite to be able to meet their needs for care (SOU, 1998:31). A term for mental illness that is frequently used in research focusing on young adults with mental illness is serious emotional disturbance (SED). SED is defined as encompassing conditions that affect the individual's roles of functioning in the family, at school or in community activities. There are different views in regard to whether the conditions of mental illness should be diagnosable or not to be defined as SED (Davis & Vander Stoep, 1997). In this thesis, mental illness is used as a term describing a condition that, for various reasons, interferes with everyday life. It includes experiences of mental suffering, even though the suffering is not consistent with a diagnosis of mental illness (Hedelin, 2006).

Despite the fact that mental illness is common among young adults, there is a lack of studies describing young adults' experiences of mental suffering from an insider perspective. Experiences of mental illness can be difficult for other persons in the surroundings to understand and even more difficult for the young adults themselves to manage. Mental illness described by persons with borderline personality disorder are interpreted (Perseius, Ekdahl, Åsberg, & Samuelsson, 2005) as living life on the edge, struggling for health and dignity, and balancing on a slack wire over a volcano. One way of dealing with such difficult emotions and experiences can be through self-harm (Solomon & Farrand, 1996), which is described as a way of coping with intense emotional distress and pain. According to (Åkerman, 2009), self-harm is a strategy for remaining calm and in control, and the physical pain endured is described as easier to handle than the mental suffering. Furthermore, self-harm can be a way of communicating, and paradoxically, it is a way to survive rather than an expression of a desire to die. Young adults who are dealing with such emotional distress and pain describe their needs to be accepted as human beings with assets, desires, longing and needs, and to be able to feel hopeful about their future and a recovery (Lindgren, Wilstrand, Gilje, & Olofsson, 2004). A failure to be validated may cause increased suffering and unwillingness to seek help and can further contribute to feelings of worthlessness as a person and being a burden. Halldorsdottir (2008) described the highest quality of the nurse–patient relationship as a life-giving one that is capable of empowering the person who is seeking help. The nurse–patient relationship consists of genuine caring for the patient as a person as well as a patient, having the necessary nursing skills and an ability to connect with the patient, and a combination of knowledge and experience.

Young adults in transition within psychiatric care

Healthcare in Sweden is organized in such a manner that children up to age 18 benefit from child and adolescent healthcare, and adults 18 and over benefit from adult healthcare. When young adults need to continue their care after they come of age, they are transferred to adult healthcare. Transfer and transition are closely related concepts, but there are differences between the two. Transition is about the process that addresses both therapeutic and developmental needs (Blum, 1993). Transfer between units of care has been well described, such as transfer from intensive care units to general wards (Forsberg, Lindgren, & Engström, 2011; Häggström, Asplund, & Kristiansen, 2009, 2012). Transition from child healthcare to adult healthcare units is also described (Blum, 1995, 2002; Doug et al., 2011; Fleming, Carter, & Gillibrand, 2002; Freed & Hudson, 2006), and these studies show that it is important to have a holistic view of transition. That means that each young adult's whole life situation needs to be taken into account, and his or her physical, psychological and social development must all be topics that are included during transition planning (Crowley, Wolfe, Lock, & McKee, 2011). To ensure that all young adults with special healthcare needs reach a successful transition, Rosen et al. (2003) recommend that a healthcare provider take responsibility for transition in a broader context of coordination and healthcare planning.

The transition process from CAP to GenP has also been well described (McGrandles & McMahon, 2012; Muñoz-Solomando et al., 2010; Murcott, 2014; Singh, Paul, Ford, Kramer, & Weaver, 2008; Singh et al., 2010), but there is a lack of studies in the Swedish context. The studies state that it is the age of majority that determines the transition from CAP to GenP, which means that young adults undergo several changes during that time. Transition to adulthood can be a critical period, especially for young adults with mental illness (McGrandles & McMahon, 2012; Singh et al., 2005), and because of their ill health, they may be less prepared to take care of themselves than their peers are (Davis, 2003). During transition from CAP to GenP, there is a risk for disruption in care, and therefore, there is a risk that young adults with ongoing needs might be disengaged from psychiatric care (Singh, 2009). The risk for disruption is particularly high for young adults with conditions such as neuropsychiatric or behavioral disorders that may not match the criteria for care at GenP. To support young adults and prepare them for such transitions, transition planning should be performed in cooperation with the young adult, relatives and professionals at both CAP and GenP (Paul et al., 2013). It should further include a period of handover of information and collaboration between the different services. To facilitate a successful transition for vulnerable young adults with a particularly high risk of dropping out of

care, the educational system and social welfare system should also be engaged in the transition in collaboration with the healthcare system (Osgood, Foster, & Courtney, 2010). Furthermore, family members and other relatives should, if possible, be considered as resources and collaborators with the professionals in supporting the young adults during transition (Jivanjee, Kruzich, & Gordon, 2009).

Transition to adulthood

In this thesis, the focus is transition from CAP to GenP, but simultaneously, young adults are undergoing the transition to adulthood. According to Arnett (2000), the late teens and early twenties are the years life in-between adolescence and adulthood that terms emerging adulthood. This period is characterized by changes and explorations of possible life directions. During emerging adulthood, the commitments and responsibilities of adults are often delayed, but role experimentation continues and may intensify. This period in the life span is culturally constructed and exists only in those cultures that allow young adults a prolonged period of independence, such as that of Sweden. It is also a critical period in their lives when young adults learn to be physically, psychologically, financially, and socially competent to face the responsibilities of adulthood (Xie, Sen, & Foster, 2014). To complete the transition to adulthood, young adults need to fulfill educational goals and become economically self-sufficient. Attaining these goals can be a complex process for all young adults, and for those with mental illness and vulnerability, it can be even more multifaceted. Bremberg (2013) showed that demands made on young adults to graduate from institutions of higher education, combined with the increased rate of unemployment among this group, could be one explanation for the increasing rates of mental illnesses such as depression. Emerging adulthood is a period of instability, and transition to adulthood is not a linear process from dependency to independency (Höjer & Sjöblom, 2011). During the years of emerging adulthood, it is common for young adults to leave home, return home, leave again, cohabit, and possibly move to a different area to attain higher education or training (Arnett, 2007). This prolonged period for young adults to reach independence may also leave many families overburdened, i.e. economically, as they support their young adults for an extended period (Settersten & Ray, 2010).

Relatives' participation in psychiatric care

When young adults are transferred from CAP to GenP, the conditions for decision-making change, and relatives' possibilities to participate in the care decrease (Jivanjee et al., 2009). As minors, society imposes legal boundaries on young adults, and relatives still influence their

decisions, but during the transition to adulthood, they will assume increased responsibility for themselves (Lenz, 2001). When young adults come of age, legal restrictions make it difficult and in some cases impossible for relatives to remain informed about young adults' health status and to participate in their care (Jivanjee et al., 2009). Therefore, young adults need to take responsibility for their choice of lifestyle and in healthcare matters after the age of majority (Lenz, 2001). This means, furthermore, that young adults need to grant their relatives permission to make it possible for them to participate in their care. According to Hovish et al. (2012), this change to less involvement from relatives can be seen as both welcomed and something that young adults want to retain although they have come of age.

Experiences of being a relative to a young adult with mental illness admitted to psychiatric care were described by Clarke and Winsor (2010) and Milliken and Northcott (2003). Relatives' ability to take responsibility for their young adults was blocked by laws and professionals when the young adults came of age, even though they were not able to take responsibility for themselves because of severe mental illness (Milliken & Northcott, 2003). Relatives first described a feeling of relief, which was followed by disbelief and shock when the young adults were admitted. They further described feeling alone and excluded, as the professionals seldom acknowledged their presence at the ward and did not allow their concerns to be heard (Clarke & Winsor, 2010). Living close to a person with mental illness was also like carrying a burden of guilt and shame, and was further described as a round-the-clock duty with constant worry (Ekdahl, Idvall, Samuelsson, & Perseius, 2011). They had limited opportunities to make plans and had to be prepared for the unpredictable (Ekdahl et al., 2011; Weimand, Hedelin, Hall-Lord, & Sällström, 2011). To be relieved of these burden, relatives wanted to be involved in care at an early stage and to be seen as resources (Nordby, Kjonsberg, & Hummelvoll, 2010). Moreover, to support the relatives in their everyday lives, they needed supportive family members and friends and opportunities to reach a balance between meeting the needs of the young adults and their own needs. They further needed support from professionals, with the goal of supporting the relatives to manage everyday life (Rusner, Carlsson, Brunt, & Nystrom, 2013).

Theoretical framework

Psychiatric nursing and mental health nursing

In this thesis, the term psychiatric care is used. It has not been a conscious choice of term, but it reflects the experiences of care that young adults have described. Most of them described care that focused more clearly on a diagnosis than on growing, development and finding ways of living. Peplau (1909–1999) is described as the mother of psychiatric nursing (Alligood, 2014); her theoretical and clinical work led to the development of the field of psychiatric nursing. She described the importance of the nurse–patient relationship and defined nursing as: *"a significant, therapeutic, interpersonal process. It functions cooperatively with other human processes that make health possible for individuals in communities... Nursing is an educative instrument, a maturing force, that aims to promote forward movement or personality in the direction of creative, constructive, productive, personal, and community living"* (Peplau, 1991, p. 16). Psychiatric nursing describes a human relationship between a person in need of healthcare and a nurse specially educated to recognize and respond to the person's needs.

Meleis states that "*to nurse is to build relationships"* (Meleis, 2007, p. 458), and it is through caring relationships that patients are encouraged to share their experiences and make them more understandable. The nurse–patient relationship is the essence of caring and therapeutic intervention. Nursing care is a health-oriented practice with a goal to support patients' available recourses, mobilize their strengths and empower them to take charge and manage the illness. Two additional recent views of psychiatric nursing describe further differences between psychiatric nursing and mental health nursing (Barker, 2009). When the purpose of nursing is to improve patients' mental health, nurses are practicing psychiatric nursing. It is described as problem-focused or situation-specific. On the other hand, when nurses help a person to explore ways of growing and developing, and to find ways of living with their difficulties, they are practicing mental health nursing. This aspect of nursing is more holistic and has as its focus providing the conditions necessary for a person's development, growth, and change. With that in mind, Peplau's view of psychiatric nursing is more suited to be called mental health nursing.

Theory of transition

The theory of transition was developed by Meleis (1975). The theory focuses on peoples' transitions and about interventions that facilitate healthy transitions. Symbolic interactionism played an important role in the research to conceptualize the symbolic worlds that shape interactions and responses (Im, 2014). According to the research (Chick & Meleis, 1986; Meleis, 2007; Schumacher & Meleis, 1994), transition is a central concept in nursing related to change and development. Transition theory describes different types of transitions that are not, however, mutually exclusive: developmental, situational, health/illness, and organizational transitions (Schumacher & Meleis, 1994). Developmental transition involves stages in the life span, such as the transitions from childhood to adulthood, to becoming a parent, or to retiring from work. Situational transitions can include changes related to discharge from a hospital or a transfer from one unit of care to another. Health/illness transitions include the recovery process or the diagnosis of a chronic illness. Developmental, situational, and health/illness transitions occur at the individual and family level. Organizational transitions occur on the organization level and can affect both professionals and their patients, and the transition process can be triggered by economic or political issues or by new policies and processes (Schumacher & Meleis, 1994).

Transition is a multidimensional issue, as it denotes changes in many areas in a person's life. Such changes usually require the individual to adapt to new situations and incorporate new behaviors and knowledge (Meleis, 2007), and they occur in a complex person–environment interaction that is embedded in the context and the situation. Therefore, the individual or the family cannot be separated from the environment, as it affects how the person will cope with the new situation (Chick & Meleis, 1986). Role supplementation is essential in the theory and includes both role clarification and role taking (Meleis, 2007). However, persons who undergo transitions may need support to understand their new roles and the new identities that they need to develop. A nursing intervention therefore, can be to clarify the new role and facilitate the person's ability to successfully assume it. Thus, the goal of healthy transitions is defined as *"mastery of behavior, sentiments, cues, and symbols associated with new roles and identities and non-problematic processes"* (Im, 2014, p. 379). Consequently, health is defined as mastery.

Awareness of the forthcoming transition and engagement in the changes it will involve are properties of a transition process (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). These properties interact with each other as awareness is considered to influence the level of engagement. Changes and differences are other properties and are associated with changes in

roles, identities, relationships, abilities and behaviors. All transitions are associated with changes, but not all changes are associated with transitions (Meleis et al., 2000). Challenging situations to deal with during a transition could include unsatisfied or unmet goals or expectations, feeling dissimilar or being realized as dissimilar. Time span is another property of transition; Chick and Meleis (1986) describe transitions as periods that occur in between fairly stable states. The time span extends from the first anticipation of a transition until the person has achieved stability in the new situation. The final aspect of transition is a critical point or event defined as a significant marker in the life span, such as birth, death, and diagnosis of an illness. Critical points and events usually lead to intensified awareness of changes.

Circumstances that facilitate or hinder transition processes towards a healthy outcome are referred to as conditions. These can be personal conditions such as meaning, attitudes, preparation and knowledge about the forthcoming changes (Im, 2014; Meleis et al., 2000). Stigma, community and societal conditions are also conditions that can facilitate or hinder transitions. Indicators for the process and the outcome for a healthy transition are described as feeling connected, interacting, being situated, and developing confidence and coping skills (Im, 2014; Meleis et al., 2000). Indicators for the outcome are described as mastery of the skills and behaviors that are needed in the new situation and environment, and, moreover, the reformulation of one's identity.

Methodological framework

Symbolic interactionism

This thesis was conducted within the naturalistic paradigm with a qualitative design (Patton, 2002). Qualitative methods are naturalistic by their purpose to understand naturally occurring phenomena in their naturally occurring contexts. The holistic approach in qualitative design means to understand the person in relation to others and to his or her environment as a whole, and it assumes that the whole is complex and more than the sum of its parts. Grounded theory was used as a methodological approach in studies II–IV, an approach that has its methodological framework in symbolic interactionism (Blumer, 1986). Symbolic interactionism is based on methodological and philosophical similarities as Chicago interactionism and the philosophy of pragmatism described by John Dewey and George Mead (Blumer, 1986). Actions and interactions are crucial in symbolic interactionism and focus on *"human beings act towards things on the basis of the meaning that the things have to them"* (Blumer, 1986, p. 2), and, furthermore, the meaning of things forms in the context of social interaction between members of

a group or society. The view of knowledge in symbolic interactionism is that it is created through acting and interacting with self-reflective human beings. Based on the pragmatic view of knowledge, Corbin and Strauss meant that the "truth" is changeable and knowledge is accumulative. They described the pragmatic view of knowledge by saying that *"knowledge leads to useful action, and action sets problems to be thought about, resolved and thus is converted into new knowledge"* (Corbin & Strauss, 2008, p. 5).

The implication of this methodological framework is that the world is complex and that there are no simple explanations. To understand experiences, they must be located and understood within their contexts (Corbin & Strauss, 2008). Therefore, it is important to describe the situations and contexts where the actions occur. Moreover, it means that there is no one "truth" to be explored but rather a constructed explanation of events and attempts to make sense out of experiences described in the data.

RATIONAL

The literature review shows that mental illness among young adults has increased during recent decades and, thereby, the number of young adults treated in psychiatric care. When young adults come of age and are still in need of care, they continue their care at GenP, which means that they undergo a transition process from CAP to GenP. Such a transition involves multidimensional changes that influence many areas in the lives of young adults. To reach a healthy transition, they have to adapt to new situations and incorporate new behaviors and knowledge. Simultaneously, the young adults undergo the transition to adulthood. When they come of age, they must take responsibility for their lifestyle choices and, furthermore, be able to make decisions about their psychiatric care. Their relatives cannot participate in their care unless the young adults give them permission to do so. Therefore, this can be a critical period in their lives, and even more so for young adults with mental illness, as they may be less prepared to take care of themselves. A successful transition is critical for empowering young adults and their relatives to manage the challenges related to a mental illness. Support through this phase of life is therefore essential, for both the young adults and their relatives. Thus, the focus for this thesis is to increase knowledge about the transition process from the perspectives of young adults, relatives, and professionals. This knowledge can be applied to transition planning based on individual needs and, thereby, help young adults to achieve a successful transition.

AIM

The overall aim of this thesis was to explore young adults' transitions within psychiatric care from the perspective of young adults, relatives, and professionals.

Study I

To describe professionals' experiences and views of the transition process from CAP to GenP

Study II

To explore expectations and experiences of transition from CAP to GenP as narrated by young adults and relatives

Study III

To explore young adults' experiences of psychiatric care during transition to adulthood

Study IV

To explore relatives' experiences of parenting a young adult with mental illness in the transition to adulthood

METHODS

To be able to explore young adults' transitions within psychiatric care, a qualitative design was applied to all four studies (I–IV) in this thesis. In study I, content analysis with a manifest, deductive approach was selected (Downe-Wamboldt, 1992; Elo & Kyngäs, 2008), and in studies II–IV, grounded theory (GT) designed by Corbin and Strauss (2008) was selected. An overview of all studies is shown in Table 1.

Table 1 Overview of the included studies' aims, designs/methods, participants, and data collection for each paper in the thesis.

Paper	Aim	Design/Method	Participants	Data collection
I	To describe professionals' experiences and views of the transition process from CAP to GenP	Qualitative content analysis with a deductive approach (Downe-Wamboldt, 1992; Elo & Kyngäs, 2008)	12 professionals at CAP, 11 professionals at GenP	6 focus groups with 3–4 participants per group, mixed according to profession, Dec 2010–May 2011
II	To explore expectations and experiences of transition from CAP to GenP as narrated by young adults and relatives	Qualitative study with a Grounded theory design (Corbin & Strauss 2008)	3 young adults (18 years old*), 6 relatives**	Individual interviews, Aug 2010–May 2012
III	To explore young adults' experiences of psychiatric care during transition to adulthood	Qualitative study with a grounded theory design (Corbin & Strauss 2008)	11 young adults, ages 18–26	Individual interviews, May–Dec 2013
IV	To explore relatives' experiences of parenting a young adult with mental illness in the transition to adulthood	Qualitative study with a grounded theory design (Corbin & Strauss 2008)	10 relatives	Individual interviews, Feb 2013–Apr 2014

* 2 of these young adults also participated in study III; ** 4 of these relatives also participated in study IV

Context

The four studies (I–IV) included in this thesis were conducted in the context of CAP and GenP in Sweden. CAP and GenP can either be together in the same organization, or they can be separate (SKL, 2010). In the northern part of Sweden where most of the interviews were conducted, the disciplines are organized separately. As the focus for this thesis is the transition within psychiatric care, it is important to describe the differences between CAP and GenP and the transfer between the units. CAP consists of inpatient and outpatient units, and children and young adults ages up to 18 years with mental illnesses can receive the benefits of CAP. Most of the young adults are treated at outpatient units, but in cases of more severe mental illness, they may need inpatient care. The care at CAP is family-oriented, which means that the relatives and siblings of the young adult with illness participate in his or her care. Decisions about care are made, as much as possible, in agreement with the young adult, his or her relatives, and the professionals. When young adults receive inpatient care, a relative usually stays at the ward with him or her.

Young adults 18 years and above who are in need of psychiatric care benefit from GenP, which also consists of inpatient and outpatients units. Inpatient care consists of general psychiatric units and forensic psychiatric units. The care at GenP is individual-oriented, which means that the young adult is considered and treated as an autonomous adult at GenP. To receive care at GenP after closure at CAP, young adults need to be referred either by CAP or by primary healthcare. A referral group at GenP assesses the referral and makes decisions about continuing care. If a young adult is transferred from inpatient care at CAP to inpatient care at GenP, the psychiatrists at CAP and GenP can make a joint decision about the transfer of care. The young adults who participated in studies II and III had experiences of inpatient and outpatient care at CAP and at GenP, and some had experiences of care at forensic psychiatry units. They even described experiences of care in municipality-based services such as treatment homes and foster families.

Participants and settings

Purposive sampling was used to select the participants for studies I–IV, which means that the participants selected were believed to have the most accurate knowledge about the purposes of the studies and would benefit most from and illuminate the questions under study (Patton, 2002). Consistent with GT methodology (Corbin & Strauss, 2008), theoretical sampling was applied in studies II–IV to gain a deeper understanding and facilitate the development of the conceptual framework that was the focus of this research. Theoretical sampling is a method of data collection based on concepts and/or themes derived from the data, i.e. data is collected from purposive participants and settings that will develop the concepts in terms of their properties and dimensions, uncover variations, and identify relationships between the concepts.

Study I

For this study, participants with diverse views and perspectives on the topic were preferred; therefore, participants with different professions from different workplaces were selected. The units included were one inpatient and two outpatient units at CAP and one inpatient and two outpatient units at GenP. Three focus groups were conducted with professionals at CAP (n = 12) and three focus groups with professionals at GenP (n = 11). Each focus group was mixed according to professions, but the participants in each group shared a workplace; thus, they were familiar to each other. According to Morgan (1997), this can facilitate interaction when the topic for research is discussed. Each group had four participants, except for one group with three participants. The participants' professions were as follows: registered nurses (n = 6), assistant nurses (n = 6), a psychotherapist (n = 1), a psychiatrist (n = 1), heads of unit (n = 2), an occupational therapist (n = 1), a psychologist (n = 1), welfare officers (n = 3), and social educators (n = 2).

Study II

Study II was performed in two outpatient units of CAP. Young adults and relatives were recruited based on the inclusion criterion, which was the termination of their care at CAP and referral to GenP. Their therapists at CAP invited them to participate by giving each one a letter with information about the study. The young adults and the relatives agreed to participate in the study and gave their informed consent by signing a form and returning it by mail. The young adults and their relatives responded separately, and the interviews were conducted separately. A total of nine participated: three young adults (two young women and one young man) and six relatives (four mothers, one father, one key worker at a treatment home).

Study III

To recruit participants for study III, professionals at GenP were informed about the study and, in turn, invited patients to participate. Patients who met the inclusion criteria for the study received an information letter. The inclusion criteria were as follows: being 18 to 25 years old, having experiences of care at both CAP and GenP, and having been referred to GenP from CAP. One participant responded to the information letter, and two participants who participated in study II were recruited for study III. To facilitate additional recruiting, a decision was made to remove the inclusion criterion about referral from CAP to GenP and to submit an advertisement to local newspapers and invite participants of patient associations. That resulted in eight additional participants. Two young adults were allowed to participate, although they had reached the age of 26. A total of 11 participants were recruited, 7 young women and 4 young men ages 19 to 26 (m = 21). The young adults had experiences of psychiatric care in inpatient and outpatient units at CAP and GenP, forensic psychiatry, and primary health care, as well as at municipality-based services, such as care in foster families or treatment homes. They described their mental illnesses in terms of diagnosis, such as anorexia, anxiety, depression, self-harm, suicidal ideation, ADHD, Asperger syndrome, and drug addiction.

Study IV

To recruit participants for study IV, the managers of outpatient units at GenP were informed about the study and were asked to invite relatives of young adults receiving care to participate by giving them an information letter. The inclusion criteria were as follows: being a relative (parent/guardian) of a young adult 18 to 25 years old with experiences of care at both CAP and GenP, and having been referred to GenP from CAP. Since only one participant responded, the part of the criterion about referral was removed, and additional invitations to participate were handled by patients' associations, from which 5 participants were recruited. In addition, 5 relatives who participated in study II were invited to participate in study IV, and 4 of these agreed to another interview. Thus, a total of 10 relatives (2 fathers and 8 mothers) participated; one couple gave their interview together. Four relatives were married, 4 were single, and 1 was remarried. In all families except one, the young adult with mental illness had siblings. One family had its first contact with psychiatric care when their young adult was in early childhood; the others had their first contact when the young adults were 14 to 17 years old.

Data collection and analysis

Study I

For study I, data was collected through focus group discussions (FGDs), as described by Kitzinger and Barbour (1999) and Morgan (1997). Focus groups are suitable when the purpose of the study is to explore persons' experiences, opinions, wishes and concerns (Kitzinger & Barbour, 1999). Using FGDs, data was collected through group interactions based on the topic determined by the researchers in order to reach the aim of the study. I served as the moderator for all FGDs, which were attended by my main supervisor who provided summaries that concluded the discussions. The moderator's role was to introduce the topic for discussion and encourage all participants to share their views. To further facilitate interaction within the group, the moderator asked follow-up questions and encouraged the participants to continue the discussion and stay focused on to the topic. An unstandardized interview guide was used to provide the participants with opportunities to share their views and to allow free discussions (Morgan, 1997).

In qualitative nursing research, using a vignette is a valuable technique for studying peoples' attitudes, perceptions, and beliefs (Hughes & Huby, 2002). It can be used to invite the participants to respond to a particular situation and imagine how a character in the vignette reacts to the situation (Barter & Renold, 1999). Therefore, the moderator introduced each FGD by reading a vignette about an 18-year-old girl in the process of transferring from CAP to GenP. It described a commonly occurring situation related to a transition process. The vignette was as follows:

> *Think about an 18-year-old girl. Since the age of 15, she has had regular contact with CAP. During that time, she has been admitted to inpatient care twice, and her mother has stayed with her at the ward. The last time she was admitted to CAP, she was told that if she needed inpatient care again, she would be admitted to GenP. During the spring, she is told that her caring relations at CAP will be terminated, and she meets with her therapist for the last time just before mid-summer. At that time, they have a meeting together with the new therapist from GenP. Her first meeting with the new therapist at GenP is planned for the middle of August. However, during the summer, her mental illness worsens, and she requires inpatient care. She wishes to be admitted to CAP, but since she has turned 18, she is admitted to GenP. Her mother wants to stay with her at the ward, but there is no room for her to sleep over.*

The FGD started with the questions: How do you think this girl and her mother will react in this situation? Was it possible to do the transfer in another way? Open-ended follow-up questions were asked focusing on how the professionals prepare young adults and their relatives for this

transition, what information they are given, how transition affects relations, and what expectations the professionals have for the transition from CAP to GenP. Each FGD lasted between 50 and 70 min (m = 60 min), and each one was recorded and transcribed verbatim.

A deductive content analysis was applied to the transcript of each FGD, (Elo & Kyngäs, 2008) and Meleis's theory of transition (Meleis, 2007; Meleis et al., 2000) was used as a frame for categorization during the analysis. A deductive approach can be used when the structure of analysis is operationalized on the basis of previous knowledge (Elo & Kyngäs, 2008), and therefore it moves from the general to the more specific (Polit & Beck, 2008). There is no single meaning in the data, and the meaning to be discovered depends on the purpose of the study and what the researcher chooses to focus on (Downe-Wamboldt, 1992).

The initial step of the analysis was to read all interviews to gain an overall sense of the data. The next step was to create a categorization matrix based on the theory of transition; therefore, different types of transitions were applied to the data during the analysis. The interview text was divided into meaning units guided by the research question and the different types of transitions. As an unconstrained matrix was used, categories were created within its bounds (Elo & Kyngäs, 2008). The analysis continued with the coding and creating of categories within each type of transition, following the principles of inductive content analysis and based on similarities and differences in content (Downe-Wamboldt, 1992). Preliminary categories were then subsumed into final categories, according to the theory of transition.

Studies II–IV

Grounded theory designed by Corbin and Strauss (2008), was selected as a suitable method to reach the aims of studies II–IV. The purpose of GT methodology is to denote theoretical constructions derived from qualitative data. When conducting qualitative research with GT methodology, one concern is for how persons experience events and the meaning they give to those experiences. Another concern is to explain the experiences by locating them within a larger conditional frame or context in which they are embedded and to describe the process or the ongoing changing forms of action/interaction/emotions that are involved in the responses to the events. Finally, a third concern is to consider consequences because these will be the next sequence of action. This description of the methodology relies on the philosophical orientation of symbolic interactionism (Corbin & Strauss, 2008). In GT approach, the analysis goes from description through conceptual ordering to theorizing. Descriptions convey ideas of things and people, events and happenings, and are drawn from ordinary vocabulary (Strauss & Corbin,

1998). The description further becomes the basis for conceptual ordering and the more-abstract interpretation and theory development. Conceptual ordering means ordering data according to properties and dimensions in categories and using description to elucidate those categories (Corbin & Strauss, 2008).

Data for studies II–IV were collected through individual interviews with young adults and their relatives (II), young adults (III), and relatives (IV). The interviews were conducted at the university, the participant's home, a psychiatric unit, a workplace, or a patient association. Two interviews were conducted as telephone interviews (III, IV). An interview guide with open-ended questions was used for each study. The interviews started with questions such as the following: "Could you please tell me about why you first had contact with CAP?" (II); "Please tell me about your current contact with psychiatric services" (III); and "Please tell me about your first contact with psychiatric services and your experiences of parenthood in that situation" (IV). Follow-up questions were asked during the interviews, and questions were added to the interview guide in accordance with GT methodology. Such questions could be about the following topics: "young adults' expectations of their coming of age" (II); "how the professional could support the young adults in expressing their feelings" (III); and "the consequences of lack of professional support to the young adults" (IV). Each interview was recorded and transcribed verbatim. The interviews in study II lasted between 27 and 77 minutes (m = 53); in study III, between 25 and 133 minutes (m = 58); and in study IV, between 39 and 130 minutes (m = 73).

The analyses for studies II–IV started directly after the first interview was performed by reading through the interview texts to obtain a feeling for the overall meaning. The overall analysis was performed by open coding line-by-line and activity-by-activity, followed by axial coding and integration (Corbin & Strauss, 2008). Open coding pertains to defining concepts in order to discover categories and their properties and dimensions. By breaking the data apart and asking questions such as "what," "why," "when," and "with what consequence," the analyses were performed. Data were coded, and similar codes were grouped into categories. To stimulate thinking and to move each analysis forward, memos were also written during the analyses. By using constant comparison, codes were grouped together in categories by comparing similarities and differences. The computer program Open Code 4.01 was used during the whole coding process.

To gain a deeper understanding and to facilitate the development of the concepts and categories, theoretical sampling was applied (Corbin & Strauss, 2008). The purpose of theoretical sampling

is to collect data that will develop concepts in terms of their properties and dimensions. Therefore, each analysis and data collection was performed simultaneously, and literature was also read in parallel in order to stimulate a theoretical sensitivity. This approach opened up the sampling strategy and made it more flexible. Theoretical sampling and sensitivity resulted in questions being added to the interview guides, and subsequent interviews were based on concepts discovered in previous interviews. The analysis process also included an axial coding where actions were taken to relate categories to one another by specifying properties and dimensions of higher-level concepts. In reality, the different steps undertaken during the analysis were not linear. Instead, each analysis was conducted through the constant comparison of data, emerging codes, and categories several times in a back-and-forth process. Finally, each analysis resulted in a core category through the integration of all categories and concepts. In the core category, all categories are related and linked, and explain the theoretical formulation of the results. The core category thereby has the highest potential to link all categories together and the greatest explanatory relevance (Strauss & Corbin, 1998).

In study III and in the summary of all studies (I–IV) presented in this thesis, a grounded theory was formulated to explain young adults' transitions within psychiatric care. A theory, according to GT, is a theoretical framework that aims to explain and predict a phenomenon. By explaining the relationships between who, what, when, where, why, how, and with what consequences an event occurs, guides to action can be provided (Strauss & Corbin, 1998). The grounded theory was constructed through arranging and interpreting concepts by induction and deduction. By induction the concepts were derived from data, and by hypothesizing the relationships between the concepts the deduction were conducted.

Situational analysis

To gain a comprehensive understanding of the results of studies I–IV, situational analysis (SA) according to Clarke (2005) was conducted. Situational analysis (SA) refers to conventional GT analysis that is pushed further through supplemental analytic approaches by developing situational maps and analysis. In SA, the situation itself is the unit of analysis, and all the elements of the situation are visualized as in the action and as a part of the action. Such elements can be human and nonhuman, sociocultural and symbolic, organizational and institutional, and discursive constructions of actors. Two maps were constructed in this thesis, a social arena map (Figure 1, p. 31) and a positional map (Figure 3, p. 43). A social arena map is an analysis of the social/symbolic interaction and meaning-making of social groups and collective actors within the arena of transition. This one was constructed to understand and explain the complexity in the context of the young adults' transitions. Questions asked when producing the social arena map for this context were as follows: "What social worlds come together in the arena of transition?"; "Why do they come together?"; "What are their perspectives of transition?" The positional map was produced to articulate different positions taken in discourses that were in focus in the data (Figure 3, p. 43). The different positions chosen to visualize were articulations about the importance of access to support from relatives and the level of intrinsic motivation to continue care at GenP. The positions represent the heterogeneity of discourses, and positions not taken at all are also of interest.

ETHICAL CONSIDERATIONS

According to the Declaration of Helsinki (WMA, 2014), some groups and individuals are particularly vulnerable and may have an increased likelihood of being wronged or of incurring additional harm as a result of participating in research. Children are usually considered as lacking the legal right and the intellectual and emotional maturity to give informed consent to participate in research projects. In order to allow young adults to participate in studies, special demands for considerations and protections beyond those provided to adult participants were necessary, in view of their vulnerability (Field & Behrman, 2004). Ethical considerations in this thesis were made according to predictable risks and burdens caused by the interviews and the benefits of receiving the young adults' experiences of transition and psychiatric care (WMA, 2014). Moreover, the benefits of gathering the young adults' perspectives were assessed as outweighing the risk of participation. Without the participation of young adults, it is not possible to understand and explore their experiences and, consequently, not possible to identify or recommend interventions for their benefit. My personal experiences of psychiatric nursing at CAP were an advantage during the interviews. I tried to connect to the young adults and watched carefully for any signs of unwillingness to continue an interview. I ensured that my understanding of what they said in the interviews was correct and accurate by repeating and summarizing their words and ideas; in addition, several times I reformulated questions in order to clarify them for the interviewees' understanding. The young adults confirmed that they enjoyed taking part in the interviews.

Informed consent was obtained from all participants; all signed a form about informed consent and either returned it by mail or signed it before the interview began. They were informed about the procedure and the aim of the study and were guaranteed confidentiality. Furthermore, they were informed of their right to withdraw from the interview at anytime, without any disadvantages or repercussions (WMA, 2014). In cases (II) where interviews were conducted with a young adult and his or her relative individually, the young adults received special confirmation that their stories would not be shared with their parents and vice versa (Field & Behrman, 2004). One young adult and one relative withdrew from the interview after it had been scheduled.

The difficulties of recruiting additional participants led to an addendum to the ethical application in order to gain approval to advertise in local newspapers and to invite persons at patients' associations. As a result of the advertisement and personal contact with patients' associations,

additional participants were recruited for studies III and IV. Furthermore, several participants were recruited through so-called snowballing, where one participant asked a person he or she knew to fit the inclusion criteria if that person wanted to participate (Polit & Beck, 2008). In such cases, I strived to be particularly sensitive when I received informed consent so that these persons did not feel pressure to participate because a friend had asked them to.

RESULTS

The results in this thesis begin with a description of the complexity of the context in which the young adults' transition from CAP to GenP takes place (Figures 1, 2). The results are presented as a grounded theory, "Support and intrinsic motivation as prerequisites for transition and recovery."

The complexity of the context of transitions

The results in this thesis show that the young adults' transitions occur in a complex context (I–IV). The context is illustrated through a social arena map (Figure 1), which includes different organizations, units of care, and municipality-based services and how they interact with each other during young adults' transitions from CAP to GenP. One major difference between CAP and GenP was the family-oriented care at CAP vs. the individual-oriented care at GenP. These different perspectives affect the view of relatives' participation in care; furthermore, laws prevented relatives' involvement in the young adults' care, unless they were granted permission to participate by the young adults. In addition, the social arena map shows that medical records and the referral group had a role in the transition process. The referral group could accept or reject a referral, and professionals at CAP were concerned about whether or not the young adults would receive care at GenP. School, employment services, and municipality-based services were also important for the young adults' transitions, as these factors were part of their care and had impacts on their recovery.

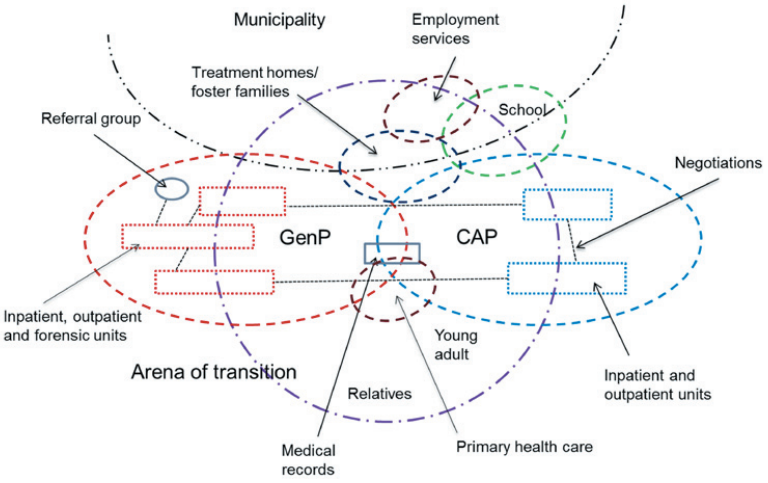

Figure 1 An illustration of the complexity in the context of young adults' transitions within psychiatric care in the form of a social arena map (cf. Clarke, 2005).

The complexity in young adults' transitions from CAP to GenP

The results further describe that the transition from CAP to GenP is a complex process for young adults and their relatives. Meleis's theory of transition (Meleis et al., 2000) is applied as a theoretical framework to the results of each study (I–IV) in order to understand this complexity. This means that the results are interpreted in relation to concepts of the theory and with references to the different types of transitions. The results show that young adults with mental illness undergo multiple simultaneous transitions during the transfer from CAP to GenP and that these include developmental, situational/organizational, and health/illness transitions. These transitions were not mutually exclusive, and the different transition processes interacted with each other in a complex way. Each transition starts with an ending, is followed by a period of instability, and ends with a new beginning (Bridges, 2004). These different transitions are illustrated in Figure 2 with their properties, conditions that facilitate or inhibit a healthy transition, and indicators for the process and the outcome.

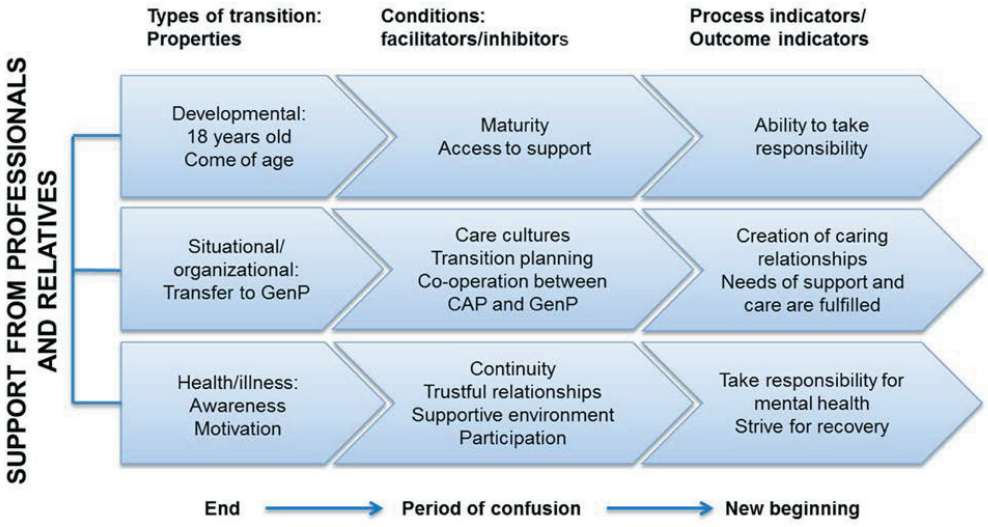

Figure 2 The results of studies I–IV describe that young adults undergo multiple simultaneous transitions during transition from CAP to GenP.

Support and intrinsic motivation as prerequisites for transition and recovery

The synthesis of the four studies (I–IV) resulted in a grounded theory, "Support and intrinsic motivation as prerequisites for transition and recovery," explaining young adults' transitions within psychiatric care. It was important that the young adult achieved intrinsic motivation to take responsibility for healthcare matters, to continue to receive care, and to strive for recovery. Intrinsic motivation to continue care was created by trustful, caring relationships with professionals who encountered the young adults as persons in their own right with respect for their maturity. Such caring relationships facilitated a willingness to disclose feelings and thoughts, which in turn resulted in hope for changes. A supportive care environment with opportunities to communicate with professionals and other patients further contributed to a sense of being a person instead of a patient. However, although they had come of age, the young adults were dependent on support from their relatives to manage transitions. Furthermore, their relatives were in need of support to manage their own lives and to be offered some relief from the inescapable duties of parenting a young adult with mental illness. With sufficient information about the forthcoming changes, transition planning in cooperation between CAP and GenP, and flexibility regarding the time of the transfer, the caring gap between CAP and GenP could be bridged. Transitions could further be facilitated by inclusive attitudes towards relatives, possibilities for both young adults and relatives to participate in care, and opportunities for relatives to receive support from professionals for their own sakes. When these conditions are achieved, the likelihood for young adults to master their new roles as adults and to strive for recovery increases. Furthermore, the risk of young adults dropping out of care will decrease. The following paragraphs describe the transition processes that young adults undergo (Figure 2). This represents a summary of the results of studies I–IV.

Being a young adult in transition to adulthood

Being a young adult in transition to adulthood was described as a struggle between the desire to fend for oneself and the frightening prospect of taking responsibility (II). It was experienced as complicated because the young adults not only wanted to manage by themselves but also to continue to receive help (III). When they come of age, they have to make their own decisions concerning their care and, in addition, must decide whether or not their relatives should be involved in their care (I). Professionals described that the transition to GenP provided the young adults with opportunities to be more mature and take responsibility, but they also experienced that it could be difficult for the young adults to make such decisions. Furthermore, professionals

described that young adults lacking support from their relatives were more vulnerable (I) and that having a trustful relationship with relatives was crucial, as the young adults may still be in need of support. Although they have come of age, their levels of maturity may not be synchronized with their chronological age. Therefore, the professionals at GenP described that it was important to adjust the amount of support and care to align with the young adults' maturity levels (I).

The relatives' possibilities of participating in their young adults' care depended on the relationship between the young adult and his or her relative (I–IV). Relatives described frustration at being close to the young adult and observing his or her needs for support without any possibility of participating in care because the young adult had refused to permit their involvement. Moreover, the young adults had to rely on support from relatives at some points, especially when gaps arose in the process of managing their transition to GenP (II). When young adults and relatives described their expectations about the transition to GenP, it was clear that they did not expect the same level of support from GenP as they had received at CAP, e.g., reminders of appointments (II). That put pressure on the young adults to take responsibility for themselves, but, according to the relatives, it was not certain that the young adults had the ability to do so because of immaturity or lack of insight concerning their needs (II). To achieve a healthy transition and master the role of an autonomous adult, the young adults need time to mature. To promote their transition to adulthood and support the young adults to master their new roles, the relatives and the young adults suggested a more flexible view of the transfer to GenP. They further described that the transition should be planned with regard to the individual's level of maturity and personal needs, and should take into account the possibility of receiving support from relatives (II–IV).

Transition from CAP to GenP

When the young adults required continuing psychiatric care after coming of age, they needed to be transferred to GenP (I–IV). After closure at CAP and before starting at GenP, there was a risk of falling into a gap between the care provided by the two services (II). The professionals described that the gap between CAP and GenP was related to different care cultures, as CAP was more family-oriented, and GenP was described as more individual-oriented (I). It became a challenge for the professionals to bridge the gap between the disciplines. Professionals at both CAP and GenP described that they felt insecure and uncertain about the performance of the transition and, further, that they felt insecurity in relation to each other. The professionals did not know each other and lacked knowledge about each other's workplaces, and that led to

assumptions instead of knowledge based on facts. The young adults and their relatives needed support to manage the transition (II), but as the professionals felt insecure, it became difficult for them to provide such support. This situation resulted in insufficient information about the transfer process being given to the young adults and their relatives during the transition process (II).

Because of the lack of information and support, the young adults and their relatives felt uncertain about the forthcoming care at GenP (II). To feel safe during the transition, both young adults and their relatives needed information about the timing of the transfer, and moreover, they wanted to have flexibility related to the timing of closure at CAP. Young adults and relatives alike realized that the different care cultures and views about diagnoses and care became hindrances to providing treatment that corresponded to the young adults' needs (III, IV). The results (I–II) showed that closure at CAP could be planned based on school semesters; that meant the young adult was left without any caring relationship during summer vacation. Young adults described that, while it might be convenient from the professionals' point of view, for them the gap in care resulted in increased suffering, and they felt neglected and left to their fate (II). Consequently, they had to handle many concerns by themselves during the transition process. Support from their relatives, therefore, became important in order to manage the transition and avoid the gap in care (II).

Transition planning in cooperation with CAP, GenP, and the family was seen as a condition that facilitated the young adults' transition (I–IV). Although the professionals tried to cooperate (I) and perform a well-planned transition, they did not always meet with success; there were plenty of examples where the plan was not followed through (III, IV). These situations put the young adults and their relatives in situations where they experienced both frustration and fear. Young adults described situations when they were transferred to inpatient care at GenP without being prepared for the changes involved, although they had been promised an opportunity to establish new caring relationships before the transfer. Moreover, in some cases, the relatives were not allowed to stay at the ward, and it was frightening for the young adults to be left alone in an unfamiliar care environment (III–IV).

The transfer to GenP also had impacts on the relatives. They felt powerless when the young adults' needs for care were not met, and consequently, the responsibility for the young adults' health and safety fell back on them (III–IV). The duties of parenthood became inescapable; relatives experienced feeling powerless against authorities, mental health services, and even the young adults, as no one was willing to take responsibility for the situation. Furthermore, relatives

had to fight for the young adults' rights and for them to receive care corresponding to their needs. They experienced the situation as walking a tightrope and having to balance between being seen as a troublesome relative and accepting being excluded from decision-making (IV). Some relatives described that, if they had followed the advice of professionals to stand back and accept their young adult's wishes in every situation, their young adult might not be alive. It was traumatic to realize that the care the young adults received could not protect them from suicide attempts, and these experiences led to a feeling of distrust of the mental health services (IV).

To be able to manage the heavy burdens of being a parent to a young adult suffering from mental illness, the relatives needed support for their own sakes (IV). The support they had received at CAP was cut after the transfer, and they missed it. They needed support themselves in order to continue providing support to their young adults and partly to reduce feelings of guilt, as it is easy to blame oneself for a young adult's mental illness (II), and furthermore, to cope with their own lives (IV). They described that they managed only because they had to; there were no other options. Although their burdens were often too heavy, they kept going because, in the end, it was all about survival—for the young adults and for themselves.

The results show that a mutual understanding of caring for young adults with mental illness was a condition for a successful transition (I–IV), and it seems important to remove the barriers that the different cultures might cause. The view of relatives' involvement was one difference between CAP and GenP; relatives wanted to be seen as a recourse in their young adults' care (IV), and young adults reported that their relatives were crucial to their health, well-being, and survival (III). However, the results showed that, with an inclusive attitude towards relatives, they could be involved in the young adults' care at GenP, which facilitated feelings of trust and security both for the young adults and their relatives (III–IV). When the professionals viewed relatives as persons important to the young adults' recovery, the relatives could be involved in their care, with respect for the young adults' autonomy preserved (IV). When the young adults had trustful relationships, the possibility for their relatives to relax and assume less responsibility also increased (IV).

Continue care and strive for recovery

The results of this thesis highlight the importance of young adults experiencing continuity of care, trustful relationships, a supportive environment, and participation in their care in order to feel hopeful and to be motivated to continue care at GenP (III). The majority of the young adults and relatives described having had experiences of continuity at CAP, and they felt uncertain

about their opportunities to have the same conditions after their transfer to GenP (II). The young adults requested continuity regarding regularly booked meetings, as well as having the possibility of meeting with the same professional regularly. They also requested a treatment plan, and all these conditions contributed to structure in their treatment and feelings of security and being taken seriously (III). When the young adults experienced discontinuity with psychiatrists, for example, they described it as pointless to see the doctor, since they had to tell their story all over again and thus would not make any progress in their treatment. Furthermore, because they had to pay for their consultations at GenP, they did not feel it was worth the money (III). In such situations, the young adults felt that the care they received failed to correspond to their needs; consequently, their motivation to continue care decreased (III). Lacking intrinsic motivation and any hope of support and care, their risk for dropping out increased.

It was important to be prepared prior to transfer (I–II) in order to reduce feelings of insecurity (II–IV). One factor in the transition planning was the possibility of establishing a new caring relationship during the transition process. Moreover, the young adults described how important it was for the professionals to have certain skills to communicate and facilitate the establishment of relationships (III). The young adults wanted the professionals to see them as unique persons, with respect for their age and maturity, without using power (III). They also described that relationships were created in a reciprocal process; when they felt that the professional understood their way of reasoning and what it is like to be a young adult, the professional became a "person" while still maintaining his or her professionalism. As a result, the young adults felt safe, which facilitated their willingness to open up and disclose their feelings and emotions (III).

The young adults described their initial meeting to establish a new caring relationship as crucial (III). It was also important to have adequate time to connect to the professional (I) and for the professional to be somewhat similar in personality to them in order to create a trustful relationship. Young adults who did not experience a feeling of trust wanted to change therapists, as it was difficult for them to express their feelings and thoughts. The young adults further described needing support from professionals to express their emotions and feelings (III). The professionals were seen as needing to have the skill to "read between the lines" and to maintain a subject by asking follow-up questions. Moreover, the young adults described the importance of professionals taking the opportunity to talk about sensitive subjects when the young adults opened up and started talking about them. By encountering the young adults in such a way, they were supported in putting their thoughts and feelings, which were difficult to express, into words.

The young adults further described that professionals need to understand that actions such as self-harming could be seen as ways to communicate when they had difficulties expressing themselves in words.

When the young adults narrated experiences of inpatient care, the care environment was described as important for their recovery (II, III). They appreciated it when the ward was furnished to be homelike, as the environment then contributed to their feelings of being a person instead of a patient. On the other hand, a meager environment result in increased suffering and a feeling of offended dignity (III). The care environment was even compared to a warehouse, which resulted in increased illness. They described that it was difficult to recover in an environment that lacked stimuli and offered only limited opportunities to communicate with other patients and professionals. The young adults experienced poor environments as reflecting the professionals' views of humanity (III). Young adults also described events or turning points when they decided to strive for recovery (III). These could be intimations of death if they continued to live the same way, or a longing for an ordinary life of being independent and having a partner and a job like their peers. Anger, frustration, and deciding that they had had enough were also thoughts and feelings that contributed to a decision to strive for recovery. Support from their relatives was important for the young adults' recovery, as it gave them the strength to fight against their illness. Moreover, the young adults described that close relationships with their relatives instilled hope and a reason to live; therefore, supportive relatives were seen as crucial for their transition towards recovery (III).

The relatives described carrying an inescapable responsibility for their young adults (IV). When they experienced that the mental health services could not meet the young adults' needs for support, the responsibility fell back on them (II, IV), and it was impossible for them to let go; that had an impact on the relatives' life situations. Furthermore, it became crucial for the relatives to have the strength required to carry the family burden and continue providing support to the young adult. The relatives described receiving the strength they needed from supportive family and social relationships, and when the young adults achieved milestones such as graduating from high school or getting a job, they felt hopeful about change. The relatives described wanting greater support from professionals so that they could be relieved of their responsibilities, yet they wanted to be able to participate in their young adult's care (II, IV).

DISCUSSION

The overall aim of this thesis was to explore young adults' transitions within psychiatric care from the perspective of young adults, relatives, and professionals. The results showed that young adults undergo multiple simultaneous transitions within a complex context of psychiatric care. At the time of transfer from CAP to GenP, they become of age and are considered adults. Simultaneously, young adults are dealing with decisions concerning their care and treatment. That means that they must cope with changes related to their developmental stage as they reach the age of majority; and they need to adapt to changes related to GenP instead of the familiar CAP. Further, young adults must deal with decisions that will have consequences for their mental health and recovery. Therefore, the transition from CAP to GenP is not only about a transfer; it is about transitions with several changes that the young adults need to master (Meleis, 2007; Meleis et al., 2000).

The grounded theory based on the results of this thesis (I–IV) showed that intrinsic motivation and support were prerequisites for young adults to manage transitions and healthy outcomes. According to Ryan and Deci (2000), to be motivated means to be moved to do something, and with intrinsic motivation, the impetus for behavior and action comes from being inherently interested in growing and developing. When a person's essential needs for feeling competent, for autonomy, and for relatedness are supported, intrinsic motivation will be enhanced. The young adults in this thesis (II–III) needed to be encountered as unique persons with respect for their maturity and to have the possibility to participate in their transition planning and care. Furthermore, they needed to have opportunities to create trustful, caring relationships in a supportive, caring environment. In alignment with Meleis et al. (2000), these factors became facilitators for successful transitions and increased the development of intrinsic motivation (Ryan & Deci, 2000). When the young adults felt that they were encountered with respect for their maturity (III), and the encounter was adjusted to their ability, they could feel competence. When they were given the possibility of participating in decision-making (II–III), they could feel autonomy and self-determination; and when they experienced trustful, caring relationships (II–III), they could feel relatedness. According to transition theory (Im, 2014; Meleis et al., 2000), feeling connected, interacting, being situated, and developing confidence and coping skills are indicators of a healthy transition. However, lack of these experiences can indicate a movement towards vulnerability (Im, 2014). The young adults in this thesis (II–III) gave examples of when they felt left out and were encountered without respect, such as in situations where they lacked information about the transfer or when professionals did not listen to them or take their words

seriously. These situations caused distrust and increased the risk of young adults dropping out of care.

The starting point for the young adults' situational transition was the transfer from CAP to GenP (II), and this change interacted with their developmental transition. The transition to adulthood is part of a developmental process (Meleis et al., 2000), and the event that initiated a number of changes was when the young adults in this thesis came of age (I-IV). According to societal rules and regulations, they are considered adults when they come of age, with the expectation of being capable of caring for themselves (Lenz, 2001). Following young adults transfer to GenP, they needed to act as adults from one day to the next, without regard for their level of maturity, as they had to take responsibility for their own care. According to the theory of transition (Meleis et al., 2000), it may not be feasible and may even be counterproductive to put boundaries on a time span for transition. Thus, a young adult's level of maturity may inhibit a successful transition, with an increased risk for disruption in care and the greater likelihood of a poor outcome. Since the goal of a healthy transition is mastery of the new situation (Meleis, 2007), young adults need to be supported in taking on their roles as users of mental health services. Through transition planning and cooperation between CAP and GenP, the young adults can be supported to assume this new role; therefore, it is important for professionals to understand the differences between transfer and transition, and to contribute so that young adults are prepared for their transition (Paul et al., 2013). Flexibility related to the time schedule for transfer may be necessary in order to promote maturity and role-taking (McGrandles & McMahon, 2012), as well as continuity of care (Hultén & Wasserman, 1998). Ensuring professional support during transitions will be especially important for vulnerable young adults who may lack support from their relatives (Höjer & Sjöblom, 2010; Xie et al., 2014).

The results in study III demonstrate that being a young adult in between childhood and adulthood was a struggle between the desire to be independent and worries about being responsible; therefore, the future was experienced as both enjoyable and frightening. According to Höjer and Sjöblom (2011), the transition to adulthood is not a linear process but a trajectory back and forth between dependency and independency. Although they are assumed to be adults, they may need support related to economic issues, practical support and advice about accommodation, and emotional support in addition to the care they require at mental health services (Höjer & Sjöblom, 2010). Furthermore, young adults who experience themselves as independent may need their relatives to participate in their care, as emotional support in decision-making about difficult

health issues and treatment (Beresford & Stuttard, 2014). It is important that professionals ascertain young adults' desires with respect to their relatives' involvement in their care. As young adults are less likely to have replaced their relatives with a significant partner, they may be left alone to grapple with difficult decisions without their relatives participating in their care. On the other hand, professionals need to take into account that the young adults are undergoing a process of emancipation from their families and therefore want to make their own decisions (Beresford & Stuttard, 2014; McClure, 2000). The relatives in this thesis (II, IV) described situations when they had to stand back and let the young adults' decisions prevail, and that could result in feelings of powerlessness and frustration for the relatives. The young adults had the legal right to decide but lacked insight about the potential consequences of their decisions.

The results in study IV, show that the relatives felt powerless and that the duties of parenthood became inescapable, as no one seemed willing to take responsibility for the whole situation. Their burdens were often too heavy to carry; however, their only option for survival was to continue to provide support to the young adults. Rusner, Carlsson, Brunt, and Nystrom (2012) described similar situations when relatives were struggling for survival for both the young adults' sakes and their own. Relatives were struggling for the young adults' survival in a literal sense, such as bridging gaps in mental health care and trying to receive sufficient information and have the ability to be involved in decision-making (Lindgren, Åstrom, & Graneheim, 2010; Rusner et al., 2012). Struggling for one's own survival meant for the relatives that they were dealing with feelings of fear, sorrow, despair and worry about the future (Johansson, Anderzen-Carlsson, Åhlin, & Andershed, 2010; Rusner et al., 2012). In order to handle these feelings of powerlessness, the relatives needed to be involved in decision-making and to be able to participate in the young adults' care (Johansson et al., 2010; Johansson, Anderzen-Carlsson, Åhlin, & Andershed, 2012; Lindgren et al., 2010; Rusner et al., 2012; Weimand et al., 2011). The results in this thesis (III–IV) showed, furthermore, that relatives play an important role in young adults' transitions to adulthood and in their striving for recovery; therefore, they should be considered as resources in the mental healthcare of the young adults, as noted by Nordby et al. (2010).

Relatives described further that they struggled to maintain a balance between being seen as a troublesome relative and accepting being excluded from their young adults' care in GenP (IV). The different care culture and relatives' possibility to participate in the care was changed abruptly after the transfer to GenP. However, relatives knew that their involvement was essential for their

young adult's health and well-being, and in some cases, their engagement kept the young adult alive. Andershed and Ternestedt (2001) described that relatives can experience meaningful involvement through encounters with respect, openness, sincerity, and a confirming attitude, as well as contributing sufficient information about the person's health situation. As the family is a kind of system, and all members in the family interact with each other, the whole family is affected when one of its members suffers from mental illness (Bridges, 2004; Nordby et al., 2010). Therefore, mental illness needs to be grasped as a family affair, and the person's needs for care have to be understood, considered, and assessed in accordance with the whole family, the environment, and their situation (Wright & Bell, 2009). Moreover, decisions and actions that are undertaken as part of the care need to consider the welfare of both the patients and their families as their goal (McGavin, 2013). Sveinbjarnardottir, Svavarsdottir, and Saveman (2011) described that psychiatric nurses' attitudes about involving relatives in care can be altered in a more positive direction when they are educated in family nursing and the practice of therapeutic conversations with the patient and the relatives. These interventions strengthen the relationships between the nurse and the relatives, and, moreover, the relatives' experiences of emotional and cognitive support can be increased (Sveinbjarnardottir, Svavarsdottir, & Wright, 2013). According to Bell (2013), both families and nurses benefit from therapeutic conversations with families.

The grounded theory in this thesis described that intrinsic motivation was important for the young adults' transitions and recovery, and they were also dependent on support from relatives to manage in their everyday lives. To illustrate how young adults' intrinsic motivation and their access to support from relatives may have impacts on the outcomes of transition and recovery, a positional map (Figure 3) was constructed in accordance with SA (Clarke, 2005). Depending on their experiences of encounters with professionals, young adults' levels of motivation to continue care may differ (Wu, Chen, & Grossman, 2000). Young adults access to support may also differ depending on family and social situations or their relationships to their relatives (Osgood et al., 2010). The different positions taken in the map are related to levels of intrinsic motivation vs. levels of access to support from relatives. The diverse positions visualize the need for individual assessment in regard to these factors in transition planning, as each position requires different interventions depending on the young adult's interpersonal and social situation. When creating a positional map, the invisible positions or positions not taken are also of interest (Clarke, 2005). In this thesis, the position with a low level of motivation and a lack of support was not found;

however, this represents a group of young adults who may need extraordinary interventions, as their risk for dropping out of care can be assumed to be high.

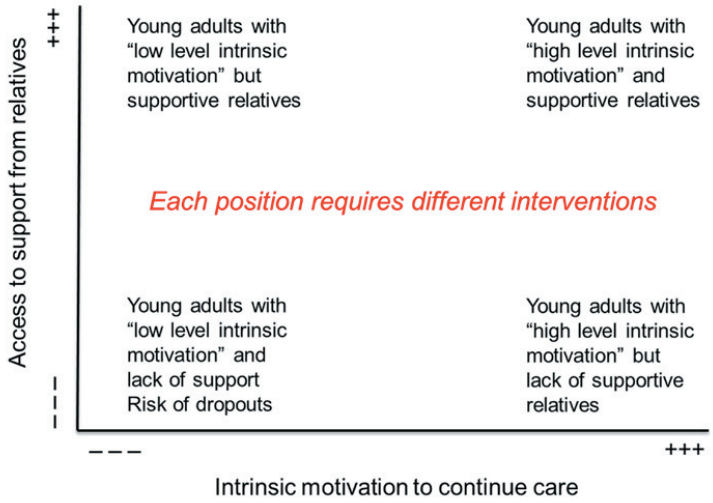

Figure 3 The positional map (Clarke, 2005) describe different positions taken with regard to level of intrinsic motivation to continuing care and level of access to support from relatives.

Although the young adults in this thesis (I–IV) require support to manage their transitions, their own responsibility for matters concerning their health matters was important for their health/illness transition, as the transition is about redefining their sense of self and taking control of disruptive life events (Kralik, Visentin, & Van Loon, 2006). According to Meleis et al. (2000), being aware of changes is a requirement for transition, and it can be increased by specific events and turning points. Such awareness can, in turn, foster engagement in transition and facilitate change. Recovery is described as "*a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness"* (Anthony, 1993, p. 15). The young adults (III) described that they came to turning points in their lives that encouraged them to fight against the mental illness. These could be an awareness of life or death or the longing for an "ordinary life" with a partner, work, and independent living. Although they had not reached this point in their process, they all knew what contributed to recovery, and they described that they needed support to strive for recovery. According to Topor et al. (2006), critical phases in a

person's recovery are directly related to interactions with other people. These could be family members, friends, or professionals that contributed to recovery. It is the quality of the caring relationships that determines whether the care is useful (Denhov & Topor, 2012), and it is the professionals' personal characteristics that facilitate recovery (Topor, Borg, Di Girolamo, & Davidson, 2011; Topor et al., 2006). The recovery process for the young adults is, therefore, more than a personal journey; it involves families, friends, and other social contributors, as the young adults need support to manage transitions and master their new roles as adults. Moreover, the mental health services may need their own recovery (Topor et al., 2011) in order to be able to meet the young adults' needs for care and to support them during their transitions to adulthood and recovery.

Methodological considerations

All the studies in this thesis (I–IV) have been conducted using a qualitative design, which is a process of discovering and interpreting data gathered from participants' experiences of events (Corbin & Strauss, 2008). Therefore, the insider perspective is the strength of the studies (I–IV) and in the grounded theory presented in this thesis. A further strength is the development of concepts with their properties and dimensions throughout all the studies in the thesis. Taking into account the different perspectives of the topic as described by the young adults, the relatives, and the professionals increased the density and the variation of the concepts. Through grounded theory, the young adults' transitions can be understood and explained, and therefore the findings are applicable to practice. Furthermore, the findings can be useful for the improvement of care for young adults with mental illness during their transitions to adulthood and GenP.

Study I

In study I, data was collected through FGDs and analyzed with content analysis using a manifest, deductive approach (Downe-Wamboldt, 1992; Elo & Kyngäs, 2008). In the FGDs, I took the role as moderator and introduced each FGD by reading a vignette describing a young girl's transition from CAP to GenP. The vignette was a fictive situation developed on the basis of my experiences as a psychiatric nurse working in CAP. During the FGDs, the professionals confirmed that the vignette represented a common situation, and, furthermore, it described experiences similar to those of the young adults (II–III) and relatives (II, IV), as noted during the interviews. This can be interpreted as the trustworthiness of the vignette's accuracy. Regarding the use of vignettes, Barter and Renold (1999) note that there is a risk for the researcher to make uncertain links between what the participants believe and how they act in reality. As the purpose of the vignette

was to introduce the topic for the study, encourage discussion, and facilitate reflections on young adults' transitions, and not to describe how professionals act in certain situations, the risk for such uncertain links was decreased.

The numbers of participants in the focus groups were few, but since the aim was to discuss shared experiences, this was an advantage (cf. Kitzinger & Barbour, 1999), as they felt safe expressing their views. Although the focus groups were homogeneous according to workplace, they differed in professions, which led to a broader range of experiences and perspectives of the topic (Morgan, 1997). Furthermore, they interacted and argued about others' opinions, and the group dynamic increased, which led to a deeper expression of views of transition (cf. Polit & Beck, 2008). Therefore, the risk for uncertain interpretations decreased (Barter & Renold, 1999). My role as moderator was to encourage each participant to express his or her opinion and to ask follow-up questions. Because of my pre-understanding, there was a risk that I believed I understood what they meant and might interpret their statements. To minimize that risk, I tried to keep that in mind during the FGDs, and I encouraged them to explain, even if I believed I understood. Since my main supervisor, whose experience of psychiatric care is limited, also attended the FGDs and asked follow-up questions, the trustworthiness was strengthened.

The analysis in study I was conducted using a deductive content analysis, as described by Elo and Kyngäs (2008). The deductive approach entailed that Meleis's theory of transition (Meleis et al., 2000) was applied to the transcribed interview text as a theoretical framework and, consequently, influenced the findings. According to Downe-Wamboldt (1992), *"there is no single meaning to be discovered in the data"* (p. 316), and depending on the research questions, multiple meanings can be discovered. The deductive reasoning and the development of specific predictions based on general principles in the theory led to a deeper understanding of the young adults' transitions (cf. Polit & Beck, 2008). However, there is a risk that deductive analysis influenced the findings in a limited way. The trustworthiness in this study was strengthened by a description of the recruitment process, the participants, and the analysis process. Furthermore, the trustworthiness was increased by using authentic citations in the results (Elo & Kyngäs, 2008). To minimize the risk that my pre-understanding of psychiatric care would have an impact on the interpretation, my supervisors and co-authors were involved in the whole analysis process. The results are consistent with those in other studies with a psychiatric context (McGrandles & McMahon, 2012; Muñoz-Solomando et al., 2010; Murcott, 2014; Singh, 2009; Singh et al., 2005) and in other

contexts (Blum, 2002; Doug et al., 2011; Fleming et al., 2002; Freed & Hudson, 2006), which further increased the trustworthiness and transferability to other situations and contexts.

Studies II–IV

In studies II–IV, data were collected through individual interviews, and GT was selected as a suitable method for data analysis as described by Corbin and Strauss (2008). By conducting interviews with young adults with mental illness and relatives, important insights into their experiences were obtained. The limitations in these studies were the sampling procedure and the difficulties of recruiting participants, resulting in the changes in the inclusion criteria and the recruitment process in studies III and IV. However, the young adults and the relatives who participated in the studies were willing to talk about their experiences and, as a result, the interviews included rich and detailed data. The mean duration of the interviews was 61 minutes. During the interviews and during the analysis, I had the advantage of my experiences in psychiatric nursing and in communicating with young adults with mental illness and relatives. According to Corbin and Strauss (2008), a researcher's professional experiences can enhance sensitivity about the topic, as the researcher is an integral part of both the research process and the results. During data collection, I used my knowledge and experiences in psychiatric nursing to support the young adults in expressing their experiences by asking follow-up questions and reformulating a question if they did not understand. Thus, by being a part of the research process and trying to capture the participants' viewpoints, the credibility of the findings was increased (Corbin & Strauss, 2008).

To minimize the risk of bias and to prevent my assumptions from influencing the interpretation, I wrote notes and memos during the data collection and followed the steps in the analysis. To maintain the focus on what the participants were saying and doing, and to develop concepts in terms of their properties and dimensions, constant comparison and theoretical sampling were used. My supervisors were involved during the entire process when the analysis and the findings were discussed. The results were consistent with other research (Lenz, 2001; Paul et al., 2013; Rusner et al., 2013; Xie et al., 2014), which strengthens their trustworthiness. To enhance the understanding of events, incidents, and actions, a description of the context in which they occur is needed (Corbin & Strauss, 2008). Therefore, a rich description of the context is presented in this thesis and facilitates a deeper understanding of the theoretical explanation presented in the grounded theory.

CONCLUSIONS AND IMPLICATIONS

This thesis explores young adults' transitions within psychiatric care. The transition from CAP to GenP is about multiple simultaneous transitions in a complex context, as young adults reach the age of majority and are considered to be adults at the time they are transferred to GenP. To facilitate these transitions and empower young adults to continue their care when needed and to strive for recovery, professionals need to consider the factors that facilitate or inhibit a healthy outcome. Transition planning in cooperation with CAP, GenP, the young adults, and their relatives is recommended in order to reduce uncertainty about the new situation. Furthermore, it is important to take into account that young adults need continuity and support to create trustful relationships. To reduce the risk of "falling into the caring gap," individual assessment of the young adult's needs, his or her intrinsic motivation to receive care, and the level of support from relatives should be considered in the transition planning process.

Extraordinary considerations should be taken in situations where a young adult with severe mental illness lacks intrinsic motivation and, additionally, lacks support from relatives. The positional map (Figure 3) can be used as a tool for professionals in transition planning to evaluate interventions that are needed during the closure of care at CAP and the planning for continuing care at GenP. The map may also point to directions for further research and interventions with the purpose of highlighting the invisible and giving a voice to the silent (Clarke, 2005). Furthermore, professionals need to change their perspectives in regard to relatives and offer them support in managing their own lives. Otherwise, there is an obvious risk of young adults dropping out of care, as they need support from their relatives. To ease transitions, extra effort should be taken to establish caring relationships at GenP prior to closure at CAP. It may also be important to investigate available supportive networks other than family members.

Future research

The results of this thesis can be applied in an intervention study to explore how transition planning from CAP to GenP can be improved and thereby facilitate young adults' transitions and their relatives' involvement during transition planning. In addition, it would be interesting to explore relatives' experiences and the outcomes of short, therapeutic conversations during their young adults' transitions.

SUMMARY IN SWEDISH–SVENSK SAMMANFATTNING

”Det handlar om att överleva”

Unga vuxnas transition inom psykiatrisk vård från unga vuxnas, närståendes och personalens perspektiv

Introduktion

Den psykiska ohälsan bland unga vuxna har ökat under de senaste årtiondena vilket också medför att fler unga vuxna behöver psykiatrisk vård. Statistik visar att oro och ångest är vanligast i åldersgruppen 16 till 24 år och ungefär 20 procent av unga kvinnor och 13 procent av unga män i har haft självmordstankar. Barn och ungdomspsykiatrin (BUP) ta emot barn och ungdomar upp till 18 år när de behöver vård på grund av sin psykiska ohälsa. Om personen behöver fortsatt vård efter 18 årsdagen och blivit myndig, remitteras hon eller han över till vuxenpsykiatrin (VP). Att bli myndig och vuxen kan för många unga vara en jobbig period och unga vuxna med psykisk ohälsa kan vara särskilt sårbara och sämre förberedda på ett vuxenliv än andra jämnåriga på grund av sin psykiska ohälsa. Att flyttas över till vuxenpsykiatrin innebär stora förändringar både för den unga vuxna och för de närstående. En stor förändring är att de betraktas som vuxna självständiga personer och därför måste fatta egna beslut om vård och behandling och ta ansvar för sin hälsa. På grund av sekretessregler måste de också fatta beslut om deras närstående ska få vara delaktiga i vården eller inte. Det är heller inte självklart att unga vuxna är mogna att ta ansvar bara för att de blivit myndiga.

Ett centralt begrepp i detta avhandlingsarbete är transition, vilket betyder förändring eller att genomgå en förändringsprocess. Meleis beskriver i sin transitionsteori fyra olika typer av transition. Det kan vara transition som är relaterat till utveckling, situation, organisation och hälsa/ohälsa. All transition handlar om förändring men all förändring behöver inte innebära transition. Enligt Bridges, författare till ”Transitions Making sense of life’s changes”, handlar transition om den inre process personen måste gå igenom för att införliva den nya situationen som förändringen medfört och finna sig i sin nya roll. Det kan till exempel handla om att bli vuxen, att bli förälder eller att bli pensionär. Det kan handla om att flyttas över från en vårdenhet till en annan exempelvis från BUP till VP. Det kan också handla om att lära sig hantera livet efter att ha fått en diagnos eller att återhämta sig efter en lång tids sjukdom. Transition är alltså ett begrepp som innebär betydligt mer än att flyttas över från BUP till VP. Det finns internationell forskning som beskriver transition från BUP till VP, men det finns inte mycket forskning från svenska förhållanden. Det vi vet är att det finns en risk att de unga vuxna ”faller mellan stolarna”

vid en överflyttning från BUP till VP och det sker i en instabil period i deras liv eftersom de samtidigt är på väg in i vuxenlivet. Det övergripande syftet med denna avhandling var därför att undersöka och förklara unga vuxnas upplevelser av transition inom psykiatrisk vård från unga vuxnas, närståendes och personalens perspektiv. Varje delstudies specifika syfte presenteras i Tabell 1.

Metod

För att kunna beskriva och förklara unga vuxnas transition har studierna genomförts med kvalitativ metod. I delstudie I användes kvalitativ innehållsanalys med en deduktiv ansats som metod och i delstudie II–IV användes grounded theory (GT) beskriven av Corbin och Strauss som metod. En översikt över alla delstudier med dess syfte, studiedesign, deltagare och metod för datainsamling presenteras i Tabell 1. Samtliga deltagare lämnade informerat samtycke om att delta i studierna.

Tabell 1 Översikt över delstudiernas syfte, design/metod, deltagare och datainsamling.

Studie	Syfte	Design/Metod	Deltagare	Datainsamling
I	Beskriva personalens erfarenheter och syn på transitionsprocessen från BUP till VP	Kvalitativ innehållsanalys med deduktiv ansats	12 personal från BUP 11 personal från VP	6 fokusgrupper Dec 2010–May 2011 3-4 deltagare/grupp
II	Beskriva och förklara unga vuxnas och närståendes förväntningar och upplevelser av transition från BUP och VP	Kvalitativ design Grounded theory	3 unga vuxna (18 år), 6 närstående	Individuella intervjuer, Aug 2010–Maj 2012
III	Beskriva och förklara unga vuxnas upplevelser av psykiatrisk vård under transition till vuxenliv	Kvalitativ design Grounded theory	11 unga vuxna 18–26 år	Individuella intervjuer, Maj–Dec 2013
IV	Beskriva och förklara närståendes upplevelser av föräldraskap till en unga vuxen med psykisk ohälsa under transition till vuxenliv	Kvalitativ design Grounded theory	10 närstående	Individuella intervjuer, Feb 2013–Apr 2014

Delstudie I

Deltagarna i delstudie I bestod av personal från BUP och VP och datainsamlingen genomfördes med fokusgruppers diskussioner (FGD). Varje FGD inleddes med att jag i rollen som moderator, läste en vinjett som beskriver en 18 årig flicka som haft kontakt med BUP under en längre tid och fått vård inom slutenvården ett flertal gånger. I samband med en akut inläggning strax efter sin

18-årsdag behövde hon slutenvård igen men flyttades över till VP i anslutning till inläggningen. Deltagarna i FGD fick sedan diskutera situationen utifrån följande frågeställningar: ”Hur tror ni att flickan och hennes mamma reagerade in denna situation?”, ”Kunde överflyttningen ha skett på något annat sätt?” Under FGD ställdes även öppna följdfrågor angående exempelvis förberedelser inför överflyttning, vilken information som ges och om hur relationer påverkas av överflyttningen. Intervjuerna skrevs sedan ut ordagrant och analyserades med deduktiv innehållsanalys. Den deduktiva ansatsen under analysen innebar att transitionsteorin användes som ett raster över de utskrivna intervjutexterna och första steget i analysen var att dela in texten under olika typer av transition. Därefter genomfördes induktiv innehållsanalys av data i respektive kategori. Analysen resulterade i en kategori som beskrev unga vuxnas utvecklingstransition och en kategori beskrev personalens erfarenheter av situations/organisationstransition.

Deltudie II–IV

Deltagarna i delstudie II–IV bestod av unga vuxna och närstående och datainsamlingen genomfördes med individuella intervjuer. Specifikt för GT är att datainsamling och analys sker parallellt, vilket innebar att analysen av den första intervjun påbörjades direkt efter den var genomförd och utskriven ordagrant. Den utskrivna intervjutexten analyseras rad för rad med öppen kodning för att upptäcka och beskriva begrepp utifrån dess egenskaper och dimensioner. Teoretiskt urval är en del i analysen som syftar till att samla data för att utveckla de funna begreppen och därför lästes litteratur parallellt med analysen för att ökar den teoretiska sensitiviteten och flexibiliteten i analysen. Det teoretiska urvalet innebar också att frågeguiden utvecklas och nya frågor tillfördes allt eftersom fler intervjuer var genomförda och analyserade. Analysen övergår sedan i axial kodning där begreppen relateras till varandra och mer abstrakta begrepp och kategorier formuleras genom så kallad ständig jämförelse. Avslutningsvis sker en integration av begrepp och kategorier till en kärnkategori som ger en teoretisk förklaring av resultatet. Genom att integrera resultaten i delstudierna (I–IV) i denna avhandling formulerades slutligen en grundad teori som förklarar unga vuxnas transition inom psykiatrisk vård.

Resultat

Resultatet i denna avhandling visade att unga vuxnas transitioner sker i en komplex kontext. Överflyttningen sker mellan BUP och VP, men aktörer som också påverkar processen är organisationer som primärvård, skola, arbetsförmedling, familjehem, behandlingshem. De olika vårdkulturerna inom BUP och VP påverkar också de unga vuxnas transition. Samtidigt som de flyttas över till VP genomgår de transition till vuxenliv och de genomgår en förändring som är relaterad till deras psykiska hälsa. Eftersom dessa förändringsprocesser sker samtidigt och de påverkar varandra, kompliceras situationen ytterligare. Syntesen av delstudierna resulterade i den grundade teorin ”Stöd och inre motivation är en förutsättning för transition och återhämtning”. Den förklarar att det är viktigt att unga vuxna har inre motivation för att kunna ta ansvar för beslut som rör deras psykiska hälsa och fortsätta ta emot vård inom VP när de behöver. Den inre motivationen till att fortsätta vården och sträva efter förändring av hälsa och återhämtning, skapas genom trygga relationer med personal som bemöter dem som unika personer och med hänsyn till deras mognadsnivå. Genom stöd att uttrycka sina tankar och känslor och en stödjande vårdmiljö kan de unga vuxna bygga upp hopp om att livet kan förändras. Det ger också hopp till att fortsätta kämpa för att nå hälsa och välbefinnande. Vid brist på stöd och möjlighet för unga vuxna att skapa tillitsfulla trygga relationer till vårdpersonal, ökar risken för att de avbryter vården trots att de är i behov av hjälp och stöd. Genom att de kan vara extra sårbara och mindre rustade för att vara självständiga, är deras behov av stöd från närstående och annat socialt nätverk särskilt viktigt.

Resultaten visade även att det var viktigt att vården har en öppen och inkluderande attityd emot närståendes. De bär ett tungt ansvar för sina unga vuxna, särskilt i situationer när de unga vuxnas behov av vård inte blir tillgodosedda. För att närstående ska orka fortsätta kämpa för sin unga vuxnas överlevnad, behöver de själva stöd för att klara av sin livssituation. Trots att bördan ibland blir för tung och de nästan inte klara hantera sin egen livssituation, kan de inte släppa taget eftersom det inte finns någon annan som tar ansvar. De fortsätter kämpa för att de har inget annat val. För att få en möjlighet att bli avlastade detta tunga ansvar önskar de närstående större möjlighet att vara delaktiga i vården, vilket också kan leda till ökad tillit och förtroende för den vård som erbjuds de unga vuxna.

Slutsats

För att ge stöd till unga vuxna som ska flyttas över till VP är det viktigt att personalen har kunskap om förändringsprocesser som unga vuxna genomgår och att överflyttning innebär mer än att byta avdelning. Överflyttningen behöver planeras och genomföras i samarbete med BUP, VP och familjen för att en bedömning ska kunna ske utifrån varje enskild ung vuxens behov. För att underlätta transitionerna bör kontakter med VP knytas innan vården på BUP avslutats. Om den unga vuxna får möjlighet att skapa trygga tillitsfulla relationer med personalen växer deras inre motivation till att ta emot vård. Det leder också till minskad risk för att de ska ”falla mellan stolarna” under denna förändringsprocess. Det är även viktigt att närstående ges möjlighet att vara delaktiga och erbjuds stöd för sin föräldraroll, trots att den unga vuxna blivit myndig, för att orka fortsätta ta det ansvar det innebär att vara förälder till en ung vuxen med psykisk ohälsa.

EPILOG

If one is truly to succeed in leading a person to a specific place,
one must first and foremost take care to find him where he is and begin there.
This is the secret in the entire art of helping.
Anyone who cannot do this is himself under a delusion if he thinks he is able to help someone else.
In order truly to help someone else,
I must understand more than he – but certainly first and foremost understand what he understands.
If I do not do that,
then my greater understanding does not help him at all.
If I nevertheless want to assert my greater understanding,
then it is because I am vain or proud,
then basically instead of benefiting him I really want to be admired by him.
But all true helping begins with a humbling.
The helper must first humble himself under the person he wants to help and thereby understand that to help is not to dominate but to serve,
that to help is not to be the most dominating but the most patient,
that to help is a willingness for the time being to put up with being in the wrong and not understanding what the other understands.
(Kierkegaard, 1998, p. 45).

ACKNOWLEDGEMENT

This thesis was carried out at the Division of Nursing, Department of Health Science, Luleå University of Technology. I would like to thank all those who helped and supported me in various ways as I worked to complete this thesis.

A special thanks:

To all of the young adults, the relatives, and the professionals who graciously and generously shared their experiences with me and, thereby, made this research possible. I am so grateful!

To my main supervisor, Associate Professor Lisa Skär. Thank you for encouragement and for believing in me. Thank you for supporting me throughout these years by sharing your knowledge. Thanks especially, for all your guidance and helpful discussions about the methodological questions.

To my assistant supervisor, Professor Siv Söderberg. Thank you for giving me the opportunity to conduct this research. Thank you for encouragement and for sharing your knowledge.

To my mentor, Associate Professor Gunilla Isakson. Thanks for listening when I expressed success and happiness as well as when I expressed frustration and doubt. Your support helped me to find the motivation to continue my own transition.

To all my colleagues and the doctoral students in the Department of Health Science and in the "research school." Thank you for sharing your experiences of being a doctoral student and for all your support. Thanks especially to Git-Marie Ejneborn-Looi and Sebastian Gabrielsson for sharing your knowledge and experiences in psychiatric nursing.

To my beloved husband, Lars-Erik. Thanks for all your support, supervision, and discussions during our daily dog walks. Thanks too for being my private computer support. But most of all, thank you for sharing your life with me and for reminding me about what is most important in life. I love you!

To my children, Markus, Simon, and Lina, and their loved ones. Thank you for bringing so much love and happiness and also so many dogs into my life. It's fantastic to have you around. Love you all!

To my mum, Kerstin. Thank you for all your love and prayers. I know you are proud of me, and that means so much. I have done some personal research and found that it is probably because of you that we in our family can never realize that we have been educated enough and can be finished with school ☺.

To my dogs, Douglas and Cezar, for telling me when it is time for a break and bringing me out for walks everyday. You make me live a healthier life.

I am grateful for the financial support of the Department of Health Science, Luleå University of Technology, and the National Associations of Social and Mental Health (RSMH).

REFERENCES

Alligood, M. R. (Ed.). (2014). *Nursing theorists and their work* (Vol. 8). Maryland Heights, Mo.: Mosby.

Andershed, B., & Ternestedt, B.-M. (2001). Development of a theoretical framework describing relatives' involvement in palliative care. *Journal of Advanced Nursing, 34*(4), 554-562. doi: 10.1046/j.1365-2648.2001.01785.x

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11-23. doi: http://dx.doi.org/10.1037/h0095655

Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469-480.

Arnett, J. J. (2007). Afterword: Aging out of care--toward realizing the possibilities of emerging adulthood. *New Dir Youth Dev*(113), 151-161.

Barker, P. (2009). *Psychiatric and mental health nursing: the craft of caring*. London: Hodder Arnold.

Barter, C., & Renold, E. (1999). The use of vignettes in qualitative research. *Social Research Update, 25*(25), 1-6.

Bell, J. M. (2013). Family Nursing Is More Than Family Centered Care. *Journal of Family Nursing, 19*(4), 411-417.

Beresford, B., & Stuttard, L. (2014). Young adults as users of adult healthcare: Experiences of young adults with complex or life-limiting conditions. *Clinical Medicine, Journal of the Royal College of Physicians of London, 14*(4), 404-408.

Blum, R. W. (1993). Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health, 14*(7), 570-576.

Blum, R. W. (1995). Transition to adult health care: Setting the stage. *Journal of Adolescent Health, 17*(1), 3-5. doi: Doi: 10.1016/1054-139x(95)00073-2

Blum, R. W. (2002). Improving transition for adolescents with special health care needs from pediatric to adult-centered health care: Introduction. *Pediatrics, 110*(6 II), 1301-1303.

Blumer, H. (1986). *Symbolic interactionism: perspective and method*. Berkeley: University of California Press.

Bremberg, S. (2013). Psykisk ohälsa bland unga i Europa under perioden 1980-2010–trender och förklaringar. *Socialmedicinsk tidskrift, 90*(5), 696-704.

Bridges, W. (2004). *Transitions: making sense of life's changes*. Cambridge, MA: Da Capo Press.

Bruce, H., & Evans, N. (2008). The transition into adult care. *Psychiatry, 7*(9), 399-402.

Chick, N., & Meleis, A. I. (1986). Transition: a nursing consern. In P. L. Chinn (Ed.), *Nursing research methodology, issues and implementation* (pp. 237-257). Rockville, Maryland: Aspen.

Ciarrochi, J., Deane, F. P., Wilson, C. J., & Rickwood, D. (2002). Adolescents who need help the most are the least likely to seek it: the relationship between low emotional competence and low intention to seek help. *British Journal of Guidance & Counselling, 30*(2), 173-188. doi: 10.1080/03069880220128047

Clarke, A. E. (2005). *Situational analysis: grounded theory after the postmodern turn*. Thousand Oaks, California: Sage Publications.

Clarke, D., & Winsor, J. (2010). Perceptions and needs of parents during a young adult's first psychiatric hospitalization: We're all on this little island and we're going to drown real soon. *Issues in Mental Health Nursing, 31*(4), 242-247.

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks: SAGE.

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child, 96*(6), 548-553. doi: 10.1136/adc.2010.202473

Danielsson, M., Heimerson, I., Lundberg, U., Perski, A., Stefansson, C. G., & Akerstedt, T. (2012). Psychosocial stress and health problems: Health in Sweden: The National Public Health Report 2012. Chapter 6. *Scand J Public Health, 40*(9 Suppl), 121-134. doi: 10.1177/1403494812459469

Davis, M. (2003). Addressing the needs of youth in transition to adulthood. *Administration and Policy in Mental Health, 30*(6), 495-509.

Davis, M., & Sondheimer, D. L. (2005). State child mental health efforts to support youth in transition to adulthood. *Journal of Behavioral Health Services and Research, 32*(1), 27-42.

Davis, M., & Vander Stoep, A. (1997). The transition to adulthood for youth who have serious emotional disturbance: Developmental transition and young adult outcomes. *Journal of Mental Health Administration, 24*(4), 400-427.

Denhov, A., & Topor, A. (2012). The components of helping relationships with professionals in psychiatry: Users' perspective. *International Journal of Social Psychiatry, 58*(4), 417-424.

Doug, M., Adi, Y., Williams, J., Paul, M., Kelly, D., Petchey, R., & Carter, Y. H. (2011). Transition to adult services for children and young people with palliative care needs: a systematic review. *Archives of Disease in Childhood, 96*, 78-84. doi: 10.1136/adc.2009.163931

Downe-Wamboldt, B. (1992). Content analysis: method, applications, and issues. *Health care for women international, 13*(3), 313-321.

Ekdahl, S., Idvall, E., Samuelsson, M., & Perseius, K. I. (2011). A Life Tiptoeing: Being a Significant Other to Persons With Borderline Personality Disorder. *Archives of Psychiatric Nursing, 25*(6), e69-e76.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107-115. doi: 10.1111/j.1365-2648.2007.04569.x

Engqvist, U., & Rydelius, P. A. (2007). Child and adolescent psychiatric patients and later criminality. *BMC Public Health, 7*.

Field, M. J., & Behrman, R. E. (Eds.). (2004). *Ethical conduct of clinical research involving children*. Washington: National Academics Press.

Fleming, E., Carter, B., & Gillibrand, W. (2002). The transition of adolescents with diabetes from the children's health care service into the adult health care service: A review of the literature. *Journal of Clinical Nursing, 11*(5), 560-567.

Forsberg, A., Lindgren, E., & Engström, Å. (2011). Being transferred from an intensive care unit to a ward: Searching for the known in the unknown. *International Journal of Nursing Practice, 17*(2), 110-116. doi: 10.1111/j.1440-172X.2011.01915.x

Freed, G. L., & Hudson, E. J. (2006). Transitioning children with chronic diseases to adult care: Current knowledge, practices, and directions. *The Journal of pediatrics, 148*(6), 824-827. doi: 10.1016/j.jpeds.2006.02.010

Halldorsdottir, S. (2008). The dynamics of the nurse-patient relationship: Introduction of a synthesized theory from the patient's perspective. *Scandinavian Journal of Caring Sciences, 22*(4), 643-652.

Hedelin, B. (2006). Att främja psykisk hälsa och förebygga psykisk ohälsa. In B. Arvidsson & I. Skärsäter (Eds.), *Psykiatrisk omvårdnad - att stödja hälsofrämjande processer*. Lund: Studentlitteratur.

Hovish, K., Weaver, T., Islam, Z., & Paul, M. (2012). Transition Experiences of Mental Health Service Users, Parents, and Professionals in the United Kingdom: A Qualitative Study. *Psychiatric rehabilitation journal, 35*(3), 251.

Hughes, R., & Huby, M. (2002). The application of vignettes in social and nursing research. *Journal of Advanced Nursing, 37*(4), 382-386. doi: 10.1046/j.1365-2648.2002.02100.x
Hultén, A., & Wasserman, D. (1998). Lack of continuity-a problem in the care of young suicides. *Acta psychiatrica Scandinavica, 97*(5), 326.
Häggström, M., Asplund, K., & Kristiansen, L. (2009). Struggle with a gap between intensive care units and general wards. *International Journal Of Qualitative Studies On Health And Well-being, 4*(3), 181-192. doi: 10.1080/17482620903072508
Häggström, M., Asplund, K., & Kristiansen, L. (2012). How can nurses facilitate patient's transitions from intensive care? A grounded theory of nursing. *Intensive and Critical Care Nursing, 28*(4), 224-233. doi: 10.1016/j.iccn.2012.01.002
Höjer, I., & Sjöblom, Y. (2010). Young people leaving care in Sweden. *Child and Family Social Work, 15*(1), 118-127.
Höjer, I., & Sjöblom, Y. (2011). Procedures when young people leave care — Views of 111 Swedish social services managers. *Young People's Transitions from Care to Adulthood, 33*(12), 2452-2460. doi: 10.1016/j.childyouth.2011.08.023
Im, E.-O. (2014). Transitions Theory. In M. R. Alligood (Ed.), *Nursing Theorist and their work* (Vol. 8, pp. 378-395). St. Louis, Missouri: Mosby.
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. doi: 10.1007/s10826-008-9247-5
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.
Johansson, A., Anderzen-Carlsson, A., Åhlin, A., & Andershed, B. (2012). Fathers' everyday experiences of having an adult child who suffers from long-term mental ellness. *Issues in Mental Health Nursing, 33*(2), 109-117.
Kaehne, A. (2011). Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems. *Advances in Mental Health and Intellectual Disabilities, 5*(1), 9-16. doi: http://dx.doi.org/10.5042/amhid.2011.0011
Kessler, R. C., Berglund, P., Demler, O., Jin, R. M., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of General Psychiatry, 62*(6), 593-602.
Kierkegaard, S. (1998). *The point of view* (Vol. 22): Princeton University Press.
Kitzinger, J., & Barbour, R. S. (1999). Introduction: the challanges and promise of focus groups. In R. S. Barbour & J. Kitzinger (Eds.), *Developing focus group research: politics, theory and practice* (pp. 1-20). London: SAGE.
Kralik, D., Visentin, K., & Van Loon, A. (2006). Transition: a literature review. *Journal of Advanced Nursing, 55*(3), 320-329. doi: 10.1111/j.1365-2648.2006.03899.x
Lager, A., Berlin, M., Heimerson, I., & Danielsson, M. (2012). Young people's health: Health in Sweden: The National Public Health Report 2012. Chapter 3. *Scandinavian Journal of Public Health, 40*(9 suppl), 42-71. doi: 10.1177/1403494812459459
Lenz, B. (2001). The transition from adolescence to young adulthood: a theoretical perspective. *Journal of school nursing, 17*(6), 300-306.
Lindgren, B. M., Wilstrand, C., Gilje, F., & Olofsson, B. (2004). Struggling for hopefulness: A qualitative study of Swedish women who self-harm. *Journal of Psychiatric and Mental Health Nursing, 11*(3), 284-291.
Lindgren, B. M., Åstrom, S., & Graneheim, U. H. (2010). Held to ransom: Parents of self-harming adults describe their lived experience of professional care and caregivers. *Int J Qual Stud Health Well-being, 5*(3). doi: 10.3402/qhw.v5i3.5482

McClure, M. (2000). Adolescence-the transition from childhood to adulthood. In P. Reder, M. McClure, & A. Jolley (Eds.), *Family Matters: Interfaces Between Child and Adult Mental Health* (pp. 71-82). Florence, KY, USA: Routledge.
McGavin, C. (2013). Colleen's Story: Reflections on the Concept of "Patient and Family Centered Care". *Journal of Family Nursing*, 1074840713496114.
McGrandles, A., & McMahon, K. (2012). Transition from child and adolescent to adult mental health services. *British Journal of Nursing, 21*(17), 1031-1039.
Meleis, A. I. (2007). *Theoretical nursing: development and progress*. Philadelphia: Lippincott Williams & Wilkins.
Meleis, A. I., Sawyer, L. M., Im, E., Messias, D. K. H., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *Advances in Nursing Science, 23*(1), 12-28.
Merikangas, K. R., He, J.-p., Burstein, M., Swanson, S. A., Avenevoli, S., Cui, L., . . . Swendsen, J. (2010). Lifetime prevalence of mental disorders in U.S. adolescents: Results from the National Comorbidity Survey Replication-Adolescent Supplement (NCS-A). *Journal of the American Academy of Child & Adolescent Psychiatry, 49*(10), 980-989. doi: http://dx.doi.org/10.1016/j.jaac.2010.05.017
Milliken, P. J., & Northcott, H. C. (2003). Redefining Parental Identity: Caregiving and Schizophrenia. *Qualitative Health Research, 13*(1), 100-113. doi: 10.1177/1049732302239413
Morgan, D. L. (1997). *Focus groups as qualitative research*. Thousand Oaks, California: Sage.
Muñoz-Solomando, A., Townley, M., & Williams, R. (2010). Improving transitions for young people who move from child and adolescent mental health services to mental health services for adults: Lessons from research and young people's and practitioners' experiences. *Current Opinion in Psychiatry, 23*(4), 311-317.
Murcott, W. J. (2014). Transitions between child and adult mental health services: service design, philosophy and meaning at uncertain times. *Journal of Psychiatric Mental Health Nursing*. doi: 10.1111/jpm.12150
Nordby, K., Kjonsberg, K., & Hummelvoll, J. K. (2010). Relatives of persons with recently discovered serious mental illness: in need of support to become resource persons in treatment and recovery. *J Psychiatr Ment Health Nurs, 17*(4), 304-311. doi: 10.1111/j.1365-2850.2009.01531.x
Osgood, D. W., Foster, E. M., & Courtney, M. E. (2010). Vulnerable populations and the transition to adulthood. *The Future of Children, 20*(1), 209-229.
Patton, M. Q. (2002). *Qualitative research & evaluation methods*. London: SAGE.
Paul, M., Ford, T., Kramer, T., Islam, Z., Harley, K., & Singh, S. P. (2013). Transfers and transitions between child and adult mental health services. *British Journal of Psychiatry, 202*(SUPPL. 54), s36-s40.
Peplau, H. E. (1991). *Interpersonal Relations in Nursing*. New York, NY, USA: Springer Publishing Company.
Perseius, K. I., Ekdahl, S., Åsberg, M., & Samuelsson, M. (2005). To tame a volcano: Patients with borderline personality disorder and their perceptions of suffering. *Archives of Psychiatric Nursing, 19*(4), 160-168.
Polit, D. F., & Beck, C. T. (2008). *Nursing research: generating and assessing evidence for nursing practice*. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.
Ramirez, A., Ekselius, L., & Ramklint, M. (2009). Mental disorders among young adults self-referred and referred by professionals to specialty mental health care. *Psychiatric Services, 60*(12), 1649-1655.
Rosen, D. S., Blum, R. W., Britto, M., Sawyer, S. M., Siegel, D. M., & Society for Adolescent, M. (2003). Transition to adult health care for adolescents and young adults with chronic

conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health, 33*(4), 309-311.
Rusner, M., Carlsson, G., Brunt, D., & Nystrom, M. (2013). Towards a more liveable life for close relatives of individuals diagnosed with bipolar disorder. *Int J Ment Health Nurs, 22*(2), 162-169. doi: 10.1111/j.1447-0349.2012.00852.x
Rusner, M., Carlsson, G., Brunt, D. A., & Nystrom, M. (2012). The paradox of being both needed and rejected: the existential meaning of being closely related to a person with bipolar disorder. *Issues Ment Health Nurs, 33*(4), 200-208. doi: 10.3109/01612840.2011.653037
Ryan, R. M., & Deci, E. L. (2000). Intrinsic and Extrinsic Motivations: Classic Definitions and New Directions. *Contemporary Educational Psychology, 25*(1), 54-67. doi: http://dx.doi.org/10.1006/ceps.1999.1020
Schumacher, K. L., & Meleis, A. I. (1994). Transitions: a central concept in nursing. *Journal of nursing scholarship, 26*(2), 119-127.
Settersten, J., R. A. , & Ray, B. (2010). What's Going on with Young People Today? The Long and Twisting Path to Adulthood. *The Future of Children, 20*(1), 19-41.
Singh, S. P. (2009). Transition of care from child to adult mental health services: The great divide. *Current Opinion in Psychiatry, 22*(4), 386-390.
Singh, S. P., Evans, N., Sireling, L., & Stuart, H. (2005). Mind the gap: the interface between child and adult mental health services. *Psychiatric Bulletin, 29*, 292.
Singh, S. P., Paul, M., Ford, T., Kramer, T., & Weaver, T. (2008). Transitions of care from child and adolescent mental health services to adult mental health services (TRACK study): a study of protocols in Greater London. *BMC Health Services Research, 8*(1), 135.
Singh, S. P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., . . . While, S. (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *British Journal of Psychiatry, 197*(4), 305-312.
SKL. (2010). Kartläggning av den psykiatriska heldygnsvården. Stockholm: Retrieved June 20, 2012, from http.//www.skl.se/vi_arbetar_med_socialomsorgochstod/psykiskhalsa/heldygnsvard/heldygnsvar_kartlaggning
Solomon, Y., & Farrand, J. (1996). “Why don't you do it properly?” Young women who self-injure. *Journal of Adolescence, 19*(2), 111-119.
SOU 1998:31 Det gäller livet - Stöd och vård till barn och ungdomar med psykiska problem (1998:31).
Strauss, A. L., & Corbin, J. M. (1998). *Basics of qualitative research: techniques and procedures for developing grounded theory* (2 ed.). Thosusand Oaks, California: Sage.
Sveinbjarnardottir, E. K., Svavarsdottir, E. K., & Saveman, B. I. (2011). Nurses attitudes towards the importance of families in psychiatric care following an educational and training intervention program. *Journal of Psychiatric and Mental Health Nursing, 18*(10), 895-903. doi: 10.1111/j.1365-2850.2011.01744.x
Sveinbjarnardottir, E. K., Svavarsdottir, E. K., & Wright, L. M. (2013). What are the benefits of a short therapeutic conversation intervention with acute psychiatric patients and their families? A controlled before and after study. *International journal of nursing studies, 50*(5), 593-602. doi: http://dx.doi.org/10.1016/j.ijnurstu.2012.10.009
Swift, K. D., Hall, C. L., Marimuttu, V., Redstone, L., Sayal, K., & Hollis, C. (2013). Transition to adult mental health services for young people with Attention Deficit/Hyperactivity Disorder (ADHD): A qualitative analysis of their experiences. *BMC Psychiatry, 13*(74).
Topor, A., Borg, M., Di Girolamo, S., & Davidson, L. (2011). Not just an individual journey: social aspects of recovery. *Int J Soc Psychiatry, 57*(1), 90-99. doi: 10.1177/0020764010345062

Topor, A., Borg, M., Mezzina, R., Sells, D., Marin, I., & Davidson, L. (2006). Others: the role of family, friends, and professionals in the recovery process. *Archives of Andrology, 9*(1), 17-37.

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.

WMA. (2014). *Declaration of Helsinki - Ethical Principles of Medical Research Involving Human Subjects*. Retrieved from http://www.wma.net/en/30publications/10policies/b3/.

Wright, L. M., & Bell, J. M. (2009). *Beliefs and Illness: A Model for Healing*. Canada: 4th Floor Press,.

Wu, C. Y., Chen, S. P., & Grossman, J. (2000). Facilitating intrinsic motivation in clients with mental illness. *Occupational Therapy in Mental Health, 16*(1), 1-14.

Xie, R., Sen, B., & Foster, E. M. (2014). Vulnerable Youth and Transitions to Adulthood. *New Directions for Adult and Continuing Education, 2014*(143), 29-38. doi: 10.1002/ace.20102

Åkerman, S. (2009). För att överleva. *Stockholm: Natur och Kultur*.

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Journal of Child and Adolescent Psychiatric Nursing

Journal of Child and Adolescent Psychiatric Nursing ISSN 1073-6077

The Gap in Transition Between Child and Adolescent Psychiatry and General Adult Psychiatry

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Search terms:
Child and adolescent psychiatry, focus group discussion, general adult psychiatry, mental illness, transition, young adults

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doi: 10.1111/jcap.12027

BACKGROUND: During transition from child and adolescent psychiatry (CAP) to general adult psychiatry (GenP) young adults with mental illness face multilevel transitions along with a risk for disruption in continuity of care. The aim of this study was to describe professionals' experiences and views of the transition process from CAP to GenP.
METHOD: Data were collected through six focus group discussions with professionals from both CAP and GenP and analyzed by content analysis.
RESULTS: The results showed a gap in transition between CAP and GenP when different perspectives and care cultures meet in a complex process.
CONCLUSIONS: Cooperation, transition planning, and a mutual understanding of care can support young adults in transition from CAP to GenP.

The Swedish Health Care system is organized in such a manner that when young adults reach the age of 18 they can no longer have benefit of child and adolescent health services but need transition to adult health services. Young adults undergoing child and adolescent psychiatry (CAP) therefore need continuing care referrals to general adult psychiatry (GenP). At this period of life, during transition from adolescence to adulthood, the young adults often become more vulnerable and transition may lead to changes in family structure and losses of social support and networks. They also have to adjust to more independent living (Lenz, 2001; Meleis, 2007). The legal status of young adults changes when they attain majority at the age of 18, and that entails certain rights and obligations (McClure, 2000). Parents are their legal guardians until their 18th birthday and at this time there are expectations from the society that the young adults should be mature and able to take responsibility for their actions. During childhood the family is responsible for health behaviors, but in early adulthood young adults have to take responsibility for matters of health, health care, and choices of lifestyle that affect health (Lenz, 2001).

According to Meleis and colleagues (Meleis, 2007; Schumacher & Meleis, 1994), transition is a central concept in the domain of nursing. In the middle-range theory of transition they described different types of transition such as developmental, health/illness, situational, and organizational. The different types of transition are, however, not mutually exclusive. Transition from childhood to adulthood is an example of developmental transition, and transition into chronic illness is an example of health/illness transition. Situational transition can be the discharge from a hospital or transfer from one unit of care to another, and organizational transition can be changes in the structure of environment or organization triggered by economic or political issues or new policies and processes (Schumacher & Meleis, 1994). Transition is a multidimensional process as it denotes changes in a person's life. The changes oblige the person to adapt to a new situation and incorporate new behavior and knowledge. Kralik, Visentin, and Van Loon (2006) described transition as the way people respond to changes over time and undergo transition when they need to adopt to new situations. How the person copes with the new situation is affected by the environment and the individual or the family cannot be separated from the environment (Meleis, 2007).

Transition from CAP to GenP is not about a single transfer from one unit to another, but about multilevel changes. For young adults with mental health problems transition can be a critical period (Singh, Evans, Sireling, & Stuart, 2005), and young adults with emotional and behavioral difficulties can be less prepared than their peers to take responsibility at the age of 18 (Davis, 2003). To be an "adult" becomes just a label. Legally, young adults can refuse relatives' involvement in care although relatives are usually the best resources during their time of transition.

Research (Bruce & Evans, 2008; Davis & Sondheimer, 2005; Hovish, Weaver, Islam, & Paul, 2012; Singh, 2009; Singh et al., 2010) has described the transition from CAP to GenP, emphasizing that during the transition process there is a risk for

disruption in continuity of care and poorer clinical outcome (Singh, 2009), and that rigid boundaries between the disciplines can be a disadvantage (Bruce & Evans, 2008). To decrease these risks, transition planning and collaboration between services are needed (Hovish et al., 2012; Singh et al., 2010). Davis and Sondheimer (2005) described that transition issues need to be a priority in both CAP and GenP to support young adults. In Sweden, CAP and GenP can either be organized together in the same organization or separated (SKL, 2010). In the northern part of Sweden, where this study took place, these two disciplines are organized separately with different heads of the organization and different economics. To be able to provide support to young adults and their relatives and facilitate a healthy transition from CAP to GenP, it is important to investigate how professionals, young adults, and relatives perceive the transition (Davis & Sondheimer, 2005). The aim of this study was therefore to describe professionals' experiences and views of the transition process from CAP to GenP.

Methods

A qualitative design (Polit & Beck, 2008, p. 69) was used to obtain an increased understanding of the transition process. In this study, professionals described their experiences and views of young adults' transition from CAP to GenP. Data were collected through focus group discussion (Morgan, 1997) and analyzed by content analysis (Downe-Wamboldt, 1992; Elo & Kyngäs, 2008).

Context, Participants, and Procedure

The study took place at government-funded CAP and GenP units located in the northern part of Sweden. The units included were one inpatient and two outpatient units at CAP and one inpatient and two outpatient units at GenP. A purposive sampling (cf. Polit & Beck, 2008, p. 355) was used to select participants. The head of each unit gave approval to the study and delivered an information letter to all staff. Those who wanted to participate in the study signed the letter and sent it back. The participants were guaranteed confidentiality and all were asked to give their informed consent. Three focus groups were conducted with professionals at CAP ($n = 12$) and three focus groups with professionals at GenP ($n = 11$). Each group had four participants except for one group with three participants, and the groups were mixed according to their profession: registered nurses ($n = 6$), assistant nurses ($n = 6$), psychotherapist ($n = 1$), psychiatrist ($n = 1$), heads of unit ($n = 2$), occupational therapist ($n = 1$), psychologist ($n = 1$), welfare officers ($n = 3$), and social educators ($n = 2$). The regional Ethical Review Board approved the study.

Data Collection

Data were collected from December 2010 to May 2011 through focus group discussions conducted by the first and the third author, in accordance with the guidelines by Morgan (1997). The first author took the role as moderator and introduced the topic for discussion, encouraged all participants to share their views, and facilitated the interaction in the group. The interview started with the moderator reading a vignette about an 18-year-old girl in transfer from CAP to GenP, describing a commonly occurring transition process. In qualitative research, a vignette can be used to let the participants respond to a particular situation or let them imagine how a character in the vignette reacts to the situation (Barter & Renold, 1999). The first question was: How do you think this girl and her relatives react in this situation? The following open-ended questions focused on how the professionals prepare young adults and relatives for transition, what information they get, how transition affects relations, and what expectations the professionals have on transition from CAP to GenP. Each interview lasted between 50 and 70 min, was recorded, and transcribed verbatim.

Analysis

A deductive content analysis (Elo & Kyngäs, 2008) was applied to the transcript of the interviews. This method can be used when the structure of analysis is operationalized on the basis of previous knowledge. The deductive approach in this study was based on the middle-ranged theory of transition (Meleis, 2007; Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). All the transcribed interviews were first read to gain an overall sense of the data. The text was then divided in meaning units guided by the research question and the different types of transition in the middle-ranged theory, i.e., developmental and situational/organizational transition. The selected meaning units were then sorted according to content and a pattern of preliminary categories began to emerge. The next step in the analysis was to reread all transcribed interviews and the selected meaning units to gain an understanding of the content. The preliminary categories were then subsumed into final categories based on similarities and differences in content (cf. Downe-Wamboldt, 1992) according to the middle-ranged theory of transition. Thereafter, the authors discussed the categorization and the content until consensus about the categorization was reached.

Results

The results described different types of transition: developmental transition and situational/organizational transition. Each type is presented in categories (see Table 1).

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Table 1. Overview of Two Types of Transition and Categories

Developmental transition	Situational/organizational transition
Becoming an adult means own responsibility	Challenging when different perspectives and care cultures meet Cooperation as a condition for safe and secure transition

Becoming an Adult Means Own Responsibility

Healthcare professionals at CAP and GenP described that transition from childhood to adulthood can be seen as both uncertain and frightening for young adults with mental illness and that young adults can have conceptions about the transition to GenP. The professionals described that when young adults have been transferred to GenP they have to take responsibility for themselves; and their own motivation is important for receiving the care they are offered. Previously, relatives had initiated the care and lack of support from relatives makes young adults more vulnerable. Professionals at CAP described a possibility that young adults can "fall through the cracks" and to decrease that risk transfer was easily delayed and therapy continued at CAP.

> It's so obvious that children who have no representatives are vulnerable. We at the clinic become many times those who must ensure that life works . . . and hand over to something that feels like now it's you who must take responsibility. (CAP)

Professionals at GenP described the importance of a good relationship between the young adults and their relatives despite the fact that the young adults have attained majority. Lack of trust and confidence can lead to young adults not seeking support from their relatives. If the young adults give permission, the relatives can participate and professionals can provide support to enhance the relationship between the young adults and their relatives. The professionals had experience in which it could be hard for young adults to make the decision whether relatives should participate or not, when the relatives played an intermediary role at CAP.

> One can imagine that it's difficult when you're quite cherished at CAP and all relatives are involved and then you suddenly stand all alone and have choice if you want them to participate or not. That alone can be quite difficult. (GenP)

Professionals at GenP described cases when young adults refused to allow their relatives to participate in their care, e.g., when the relatives placed pressure on the young adults to receive care despite their lack of motivation. Professionals at GenP also described that relatives could have difficulties accepting that they could not participate in the same way as before and that the young adults' needs and desire determine the care at GenP. Professionals at both CAP and GenP described that transition to GenP may allow young adults to grow up and develop by providing them with the opportunity to take responsibility for themselves. But all young adults may not be capable of this due to differing levels of maturity among 18-year-old adolescents.

> The advantage with transition is a step in the right direction. Here we are very cherishing . . . they remain kids as long as they stay here. We don't give them any favors into adulthood. When they enter there [GenP] it is another step. (CAP)

Professionals at GenP described the significance of adjusting the encounter and care to the young adults' maturity level. They also described that confirming the diagnosis strengthened the awareness of their difficulties, and that contributed to increased maturity.

Challenging When Different Perspectives and Care Cultures Meet

Professionals at both CAP and GenP discussed the different perspectives and care cultures in CAP respective to GenP and that became a challenge to make an optimal transition. They referred to a network and family perspective in CAP and an individual perspective in GenP. Different views of diagnoses could also increase the disparity. Furthermore, they described they neither knew each other or each other's workplace. That led to opinions about each other instead of knowledge based on reality.

> It's quite a big difference between child and adult psychiatry in how you think, it can be a big gap between . . . what can I say, in CAP it's more family-oriented. (GenP)

Professionals at CAP stated that one challenge to overcome in making a satisfying transition is their lack of control over the process. They did not know how GenP handled confidentiality and the cutoff at 18 years. The lack of knowledge made them feel insecure to transfer young adults into GenP. They sent a referral but they felt uncertain what to do next and who to contact to get an answer. They also felt uncertain if the young adults would be received at GenP.

> It's hard to prepare the patient for a transfer when neither we nor the patient know if they will be received at GenP. (CAP)

Professionals at CAP felt that it was difficult to give information about GenP to young adults and their relatives and the inability to answer their questions gave the professionals a feeling of insecurity. This feeling also made it more difficult to realize a good ending with the young adults. Professionals at CAP described that they tried to convey a feeling of security

even though they themselves were uncertain and could not provide information about what would happen.

> You really try that your feeling of insecurity shall not be mirrored and you try to convey a positive image. But I have not much to say and no information to give and that sounds uncertain, when I can't tell what will happen. (CAP)

Professionals at both CAP and GenP described gaps according to the transfer and between different professions in the workplaces. The professionals believed one reason was that transfer usually was implemented in the end of term before vacation, even if the young adult had become 18 earlier. They also thought they had different regulations and laws to follow. Professionals at CAP described that young adults often had a long therapeutic relation at CAP and therefore transition also became a therapeutic issue. They described how they invested as much time as possible before transition, when a young adult became motivated to have further understanding in his/her difficulties. It was also urgent for professionals at CAP to give support to someone who turned 18 years and recently realized that their problems were caused by disabilities.

> It is hard to reject someone who hasn't been motivated and now is, yet it takes much of our resources. It is hard to say they have to wait to be transferred to GenP because it must work out well there. (CAP)

Professionals at GenP also described a challenge in the transition process if the young adults needed inpatient care before the new relationship at GenP had been established. They emphasized the importance of giving young adults information about what to do in an emergency before they finished their contacts at CAP. Their relatives also need information about confidentiality and their opportunities to participate in the care of their child.

> Yes, we have relatively strict [visiting hours] compared to child psychiatry and it can be seen as negative by the relatives, but if they get a good explanation so they understand it in another way it's not a problem. (GenP)

Professionals at CAP described the importance to hand over information about the young adults and receive information from GenP about their possibilities of continuing care. As a complement to the referral, the professionals at CAP wanted to give verbal information about the young adult. In some cases, GenP had been invited to a network meeting before a decision was made to refer the young adults. CAP initiated the meeting but it was not always GenP that accepted the invitation. If the young adults gave permission their relatives could participate. The professionals at CAP believed that the important information to hand over was background, current status, need of care, and also how the young adult is as a person. Professionals at CAP and GenP had different experiences about availability to medical records. From CAP's point of view professionals at GenP were not always taking part of the medical record from CAP. On the other hand, professionals at GenP had experienced that sometimes they had been denied access to medical records.

Despite the feeling of lack of control, the professionals at CAP had experienced that young adults and their relatives were participating in the transition. But if there was no other choice than inpatient care they considered that young adults were not participating in the same way as if they had alternatives. Many young adults who had been referred to GenP had complex needs and disabilities. On the other hand, professionals at GenP had experienced that young adults had been referred to them without any participation and motivation for continuing the care.

> Someone has not understood why they should come over here, they have felt their care completed. (GenP)

All professionals agreed there were shortcomings in the cooperation between CAP and GenP. They had tried to cooperate in some cases during transition, but failed. The main reasons it failed were lack of availability to psychiatrist and difficulties deciding who should be medically responsible.

Cooperation as a Condition for Safe and Secure Transition

Professionals at CAP described a need of being able to prepare for transition. They desired that transition be planned in cooperation with professionals at GenP and with young adults and their relatives participating. If so, the young adults' needs could be described and the possibilities of a continuing of the care could be discussed in a network meeting. Professionals at CAP wanted to make a decision when and how the transfer should be implemented. Their opinion was that cooperation in this way facilitated an ending at CAP and the young adults had possibilities to ask their questions about GenP.

> It's important that the patient is in the process about how we proceed and have the opportunity to meet someone from adult psychiatry who explains how everything works in ahead of time before transfer to reduce anxiety. The fantasies they have are often much worse. Although difficult, it's better to have a meeting so they get the opportunity to ask their questions. (CAP)

Professionals at GenP described the importance of a good relationship with the relatives and that cooperation was necessary for a successful transition. They also described how they try to encounter the young adults so they can feel secure and have confidence in the professionals in the new situation. Professionals at GenP described that a study visit at GenP

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could facilitate the young adults' transition through information about GenP, a phone number to call anytime, and the opportunity to put a face to the person they will meet in case of emergency.

> It sounds reasonable with a study visit so they can meet the persons they will face when they need to come . . . we can give some information and they'll get a number they can call anytime. What a safety and it takes only some minutes. (GenP)

Professionals at both CAP and GenP described that if they got to know each other and increased cooperation, the imaginations and assumptions about each other could be eliminated and the professionals would feel more secure during the transition. They suggested that joint planning and educational days could be one way to start. The professionals also discussed the possibilities to have an uninterrupted transition with cooperation during a period of time, especially in complicated cases. The professionals at both CAP and GenP discussed that it could be flexibility regarding age in transition from CAP to GenP and that it should be individual needs that regulated the transition and not the age.

The professionals at CAP agreed on flexibility between 18 and 20 years but professionals at GenP also thought it could be an advantage in some cases, e.g., young adults with anorexia nervosa, with an earlier transfer. Professionals at both CAP and GenP narrated further that it could be advantageous for young adults, and for professionals, to have a follow-up contact with the former therapist to decrease the risks of feeling abandoned. Together they could make an evaluation of the transition process and encourage the young adults to continue the care at GenP if needed.

> Maybe we can share some things, okay if they start to come to us but don't quit at once at CAP, a little more cooperation can you wish. (GenP)

Discussion

The aim of this study was to describe professionals' experiences and views of the transition process from CAP to GenP. The result showed a gap in transition between CAP and GenP that becomes both a challenge and an obstacle in the transition process. The gap arises when care ended up at CAP, before the young adults have been able to start at GenP. Kraus de Camargo (2011) described a similar situation in which the main challenge in the transition process was when young adults with mental illness lost eligibility to services due to their age before they could reapply as adults. This result showed that CAP and GenP had different care cultures and that CAP had family-oriented care while GenP had individual-oriented care. A gap could occur due to different perspectives, lack of knowledge, a mutual understanding, and cooperation. During the transition process, these two perspectives and care cultures meet but the professionals have limited skills to support young adults during the transition and prepare them for the new situation. The gap between CAP and GenP made it difficult to give support to the young adults and their relatives in a satisfactory way. The professionals at CAP felt insecure and experienced a lack of control over the situation. Research (Singh, 2009) shows that a poor transition may lead to a possibility that young adults in transition were falling through the care gap.

The result showed further that the professionals needed opportunities to get to know each other and generate a mutual understanding of caring for young adults. Ødegård and Bjørkly (2012) emphasized the importance of an open dialog between professionals and families and a shared awareness about expectations on different roles during transition planning and cooperation. Another study (Bruce & Evans, 2008) indicated that the gap between CAP and GenP could be reduced through greater understanding of each other's disciplines, liaison, and joint working.

An important aspect of young adults in transition from CAP to GenP was that they were undergoing developmental transition parallel to the experience of situational transition. Singh et al (2010) emphasized that professionals must pay attention to these multiple transitions in order to address the complex needs these young adults have. The result in this study showed that when the young adults came of age they were expected to take responsibility, despite some still being dependent on support from relatives. The results pointed out the liability for professionals and relatives to let the young adults grow up, although they did not feel satisfied with the situation. Shooter (2007) described that the relationship between professionals at CAP and young adults can become so strong that it will be difficult for professionals to trust the adult services and refer young adults. Professionals have to learn, like parents, to let them go. Gorter, Stewart, and Woodbury-Smith (2011) meant that transitional care is as much about professionals as about young adults. This can be interpreted as that it is important that professionals, as well as young adults and relatives, are prepared for transition.

To be able to adjust at GenP and master the new care culture, the young adults and their relatives needed to be motivated to continue the care and create new caring relations. According to Kirk (2008), transition should be managed in terms of person-centered planning and continuity involvement of young adults and relatives to create motivation and accept transition support. The result in this study showed that the transition affected the involvement of the relatives in the care. When the young adults had been transferred to GenP they had to make a decision about their relatives' involvement. However, before the professionals involve the relatives, the young adults must give permission, and if denied, the professionals had to respect the young adults'

requests. Sjöblom (2010) described that relatives' involvement in care could be seen both as an advantage and a strain, and that the decision must be an individual judgment depending on the patients' needs and desires. Sjöblom, Pejlert, and Asplund (2005) suggested that nurses in GenP might experience an ethical dilemma when the patients choose not to have any contact with their relatives. The nurses' loyalty was with the patients but they were also aware that the relatives need information and that they may have information that can improve the care.

To be able to support the young adults during the transition the professionals suggest an individual approach in the transition process. They had a desire for flexibility regarding age limit and a possibility to work parallel during a period of time. That would make it possible to provide support to those who needed it, even a while after the young adult's 18th birthday. Kirk (2008) suggested that there is a need for a holistic view of transition when young adults are continuing care in adult services after discharge from child and adolescent services. It is also necessary to pay attention to young adults' developmental needs when planning for transfer to GenP (Singh, 2009; Singh et al., 2005, 2010).

The results showed that the starting point for the transition process was based on achieving age 18 with little consideration of maturity. According to the middle-range theory of transition (Meleis, 2007; Meleis et al., 2000), it may be difficult or impossible and maybe even counterproductive to put boundaries in the time span of transition. However, the transition process can be characterized as a time span with a starting point through a period of confusion, distress, and instability to an ending point and a new beginning with stability (Meleis et al., 2000). In this study, only a portion of the process was described and it was obvious that it might be a concern when age was set up as a boundary and young adults were forced to go through the situational transition at the age of 18 despite maturity level. The young adults had to adjust at GenP during a particular time when the transfer was carried out and that could involve difficulties if the young adults did not have sufficient support and skills to manage in the transition.

The results in this study showed that transition from CAP to GenP is a complex process including developmental, situational, and organizational transition. To facilitate a healthy transition, the young adults need to incorporate new behavior and knowledge (Meleis, 2007) and the actions of the professionals need to be recognized as having an impact on the outcome of the transition process (cf. Meleis, 1975). The professionals can thus facilitate the transition by giving information, being a role model, and supporting the young adults in preparation for transition. To support the young adults, it is important that the professionals experience they have control over the transition process and feel secure. As Meleis said about role taking, "Roles are not dictated; they emerge through interaction and they are shaped by others' responses and interpretations" (Meleis, 2007, p. 217). The young adults in transition need to be aware of the changes that are occurring (cf. Chick & Meleis, 1986) when they become adults and are transferred to GenP. Their level of awareness has influence on their involvement in the transition process by seeking information, using role models, and preparing activities (cf. Meleis et al., 2000).

Methodological Considerations

A strength in this study was the qualitative design with data collection through focus groups conducted at both CAP and GenP. The number of participants in the focus groups could be seen as few; however, Kitzinger and Barbour (1999) describe that when the aim is to discuss a shared experience it can be an advantage to have small groups who already know each other. Data collection through focus group discussions was helpful in facilitating access to a sensitive research area (Farquhar & Das, 1999) and giving voice to professionals' experiences and views about each other's work, cultures, and organizations. Using a vignette gave the participants the possibility to discuss a commonly occurring transition situation (cf. Barter & Renold, 1999). Even though the professionals represent different perspectives, they had similar experiences and saw similar needs of enhancement.

Furthermore, it is possible that the organization is a contributor to the professionals' lack of mutual understanding and knowledge about each other described in the Results section. In the context where the present study took place, CAP and GenP are organized in different ways. However, the result in this study is consistent with the result in other studies, and that is something that increases the trustworthiness. This means that the results can be transferred to similar situations and contexts (Polit & Beck, 2008, p. 540).

Conclusion

To enable professionals to support young adults to reach a healthy transition and adjust to a new situation as adults and users of health care at GenP, the young adults need sufficient information and a possibility to prepare before the transfer. It is important that the professionals at both CAP and GenP focus on transition issues such as providing information, cooperating, and transition planning. A mutual understanding of caring for young adults and a possibility for the disciplines to work parallel during a period of time with an individual approach facilitate transition from CAP to GenP.

Acknowledgments

We are grateful for the shared experiences from the participants. This study is funded by the National Association of Social and Mental Health (RSMH) and Luleå University of Technology, Sweden.

References

Barter, C., & Renold, E. (1999). The use of vignettes in qualitative research. *Social Research Update*, *25*(25), 1–6.

Bruce, H., & Evans, N. (2008). The transition into adult care. *Psychiatry*, *7*(9), 399–402.

Chick, N., & Meleis, A. I. (1986). Transition: A nursing concern. In P. L. Chinn (Ed.), *Nursing research methodology, issues and implementation* (pp. 237–257). Rockville, MD: Aspen.

Davis, M. (2003). Addressing the needs of youth in transition to adulthood. *Administration and Policy in Mental Health*, *30*(6), 495–509.

Davis, M., & Sondheimer, D. L. (2005). State child mental health efforts to support youth in transition to adulthood. *Journal of Behavioral Health Services and Research*, *32*(1), 27–42.

Downe-Wamboldt, B. (1992). Content analysis: Method, applications, and issues. *Health Care for Women International*, *13*(3), 313–321.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107–115. doi:10.1111/j.1365-2648.2007.04569.x

Farquhar, C., & Das, R. (1999). Are focus groups suitable for "sensitive" topics? R. S. Barbour & J. Kitzinger (Eds.), *Developing focus group research: Politics, theory and practice* (pp. 47–63). London: SAGE.

Gorter, J. W., Stewart, D., & Woodbury-Smith, M. (2011). Youth in transition: Care, health and development. *Child: Care, Health and Development*, *37*(6), 757–763. doi:10.1111/j.1365-2214.2011.01336.x

Hovish, K., Weaver, T., Islam, Z., & Paul, M. (2012). Transition experiences of mental health service users, parents, and professionals in the United Kingdom: A qualitative study. *Psychiatric Rehabilitation Journal*, *35*(3), 251–257.

Kirk, S. (2008). Transitions in the lives of young people with complex healthcare needs. *Child: Care, Health & Development*, *34*(5), 567–575.

Kitzinger, J., & Barbour, R. S. (1999). Introduction: The challenges and promise of focus groups. In R. S. Barbour & J. Kitzinger (Eds.), *Developing focus group research: Politics, theory and practice* (pp. 1–20). London: Sage.

Kralik, D., Visentin, K., & Van Loon, A. (2006). Transition: A literature review. *Journal of Advanced Nursing*, *55*(3), 320–329. doi:10.1111/j.1365-2648.2006.03899.x

Kraus de Camargo, O. (2011). Systems of care: Transition from the bio-psycho-social perspective of the International Classification of Functioning, Disability and Health. *Child: Care, Health and Development*, *37*(6), 792–799. doi:10.1111/j.1365-2214.2011.01323.x

Lenz, B. (2001). The transition from adolescence to young adulthood: A theoretical perspective. *Journal of School Nursing*, *17*(6), 300–306.

McClure, M. (2000). Adolescence—the transition from childhood to adulthood. In P. Reder, M. McClure, & A. Jolley (Eds.), *Family matters: Interfaces between child and adult mental health* (pp. 71–82). Florence, KY: Routledge.

Meleis, A. I. (1975). Role insufficiency and role supplementation: A conceptual framework. *Nursing Research*, *24*(4), 264–271.

Meleis, A. I. (2007). *Theoretical nursing: Development and progress*. Philadelphia: Lippincott Williams & Wilkins.

Meleis, A. I., Sawyer, L. M., Im, E., Hilfinger Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science*, *23*(1), 12–28.

Morgan, D. L. (1997). *Focus groups as qualitative research*. Thousand Oaks, CA: Sage.

Ødegård, A., & Bjørkly, S. (2012). The family as partner in child mental health care: Problem perceptions and challenges to collaboration. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, *21*(2), 98–104.

Polit, D. F., & Beck, C. T. (2008). *Nursing research: Generating and assessing evidence for nursing practice*. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Schumacher, K. L., & Meleis, A. I. (1994). Transitions: A central concept in nursing. *Journal of Nursing Scholarship*, *26*(2), 119–127.

Shooter, M. (2007). An adult's guide to adolescence. *Paediatrics and Child Health*, *17*(11), 429–432. doi:10.1016/j.paed.2007.08.004

Singh, S. P. (2009). Transition of care from child to adult mental health services: The great divide. *Current Opinion in Psychiatry*, *22*(4), 386–390.

Singh, S. P., Evans, N., Sireling, L., & Stuart, H. (2005). Mind the gap: The interface between child and adult mental health services. *Psychiatric Bulletin*, *29*, 292–294.

Singh, S. P., Paul, M., Ford, T., Kramer, T., Weaver, T., McLaren, S., . . . While, S. (2010). Process, outcome and experience of transition from child to adult mental healthcare: Multiperspective study. *British Journal of Psychiatry*, *197*(4), 305–312.

Sjöblom, L.-M. (2010). *Family in the formal psychiatric care*. Doctorial thesis, Mid Sweden University, SE-831 25 Östersund, Sweden. (91).

Sjöblom, L.-M., Pejlert, A., & Asplund, K. (2005). Nurses' view of the family in psychiatric care. *Journal of Clinical Nursing*, *14*(5), 562–569.

SKL. (2010). *Survey of the psychiatric inpatient care (in Swedish)* Stockholm: Retrieved June 20, 2012, from http://www.skl.se/vi_arbetar_med/socialomsorgochstod/psykiskhalsa/heldygnsvard/heldygnsvard_kartlaggning

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Hindawi Publishing Corporation
Psychiatry Journal
Volume 2014, Article ID 457160, 8 pages
http://dx.doi.org/10.1155/2014/457160

Research Article

Managing Transition with Support: Experiences of Transition from Child and Adolescent Psychiatry to General Adult Psychiatry Narrated by Young Adults and Relatives

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Received 29 August 2013; Accepted 21 November 2013; Published 20 January 2014

Academic Editor: Claude Robert Cloninger

Young adults with mental illness who need continuing care when they turn 18 are referred from child and adolescent psychiatry to general adult psychiatry. During this process, young adults are undergoing multiple transitions as they come of age while they transfer to another unit in healthcare. The aim of this study was to explore expectations and experiences of transition from child and adolescent psychiatry to general adult psychiatry as narrated by young adults and relatives. Individual interviews were conducted with three young adults and six relatives and analysed according to grounded theory. The analysis resulted in a core category: managing transition with support, and three categories: being of age but not mature, walking out of security and into uncertainty, and feeling omitted and handling concerns. The young adults' and relatives' main concerns were that they might be left out and feel uncertainty about the new situation during the transition process. To facilitate the transition process, individual care planning is needed. It is essential that young adults and relatives are participating in the process to be prepared for the changes and achieve a successful transition. Knowledge about the simultaneous processes seems to be an important issue for facilitating transition.

1. Introduction

Young adults with mental illness who need continuing care when they turn 18 are referred from child and adolescent psychiatry (CAP) to general adult psychiatry (GenP). During this process, young adults are undergoing multiple transitions as they come of age while they transfer to another unit in healthcare [1]. During the transition from childhood to adulthood, they have to adjust to more independent living [2], incorporate new knowledge, and begin to regard themselves as adults [3]. This transition can be especially critical for young adults with mental illness [4, 5], since they can be less prepared than their peers to take responsibility for themselves [6]. Therefore, there is a need for a holistic view of transition wherein both developmental and situational aspects are taken into account [3, 7].

According to Paul et al. [8], there are differences between transfer and transition. Transfer implies the event of closure of care at CAP and reestablishment of care at GenP, while transition is the process requiring therapeutic intents. Criteria for optimal transition are stated as continuity of care, a period of parallel care or joint working, at least one transition planning meeting, and handover of information. Research showed that transfer is common but successful transition is rare [8] and there is a salient risk for disruption in continuity of care for young adults during transition from CAP to GenP [9].

Rigid boundaries between disciplines can be a disadvantage [10] and the transition process can be affected when different care cultures and different perspectives meet, that is, family-oriented care at CAP and individual-oriented care at GenP [11]. Differences in approach according to diagnosis may also create barriers in transition [4, 12, 13], as well as professionals' lack of knowledge about each others' workplaces, lack of a mutual understanding, and absence of cooperation [11]. During the transition, young adults need to make a decision whether their relatives should be involved in care, and a lack of support from relatives can make young adults

vulnerable. Transition can be facilitated through cooperation and transition planning [14, 15], good relationships with professionals, and support from relatives [15].

About half of all lifetime cases of mental illness start by the age of 14, and therefore prevention and early treatment need to focus more on young adults [16]. Engqvist and Rydelius [17] showed that around one-third of young adults at CAP need care from GenP in adulthood and Ramirez et al. [18] showed that around one-fourth of patients at GenP aged 18–25 had previously received care at CAP. However, there is to our knowledge a lack of studies about young adults with mental illness transitioning from CAP to GenP, especially research describing the young adults' experiences of transition. In Sweden, CAP and GenP can either be organized together in the same organization or separated [19]. In the northern part of Sweden, where this study was performed, these two disciplines are organized separately, with different heads of organizations and different economics. To be able to facilitate a transition in line with the needs of the young adults who are transferred from CAP to GenP, it is important to account for their experiences of the transition process. Thus the aim of this study was to explore expectations and experiences of transition from CAP to GenP as narrated by young adults and relatives.

2. Method

Grounded theory (GT) described by Corbin and Strauss [20] was selected as a suitable method for reaching the aim of this qualitative study. By using this version of GT, experience could be explained in context and processes and sequences of action could be described.

2.1. Settings and Participants. Consistent with grounded theory methodology, a theoretical sampling [20] was applied to gain a deeper understanding and facilitate the development of the conceptual framework that were the focus of this research. The study was performed in two outpatient units of CAP located in the northern part of Sweden. The participants were recruited when it was time for terminate care at CAP and referral to GenP. They were invited to participate by their therapist at CAP, who gave them a letter with information about the study, and obtained informed consent. The young adults' experience of transition was narrated by the young adults and relatives separately. The total number included nine participants, three young adults (two girls, one boy) and six relatives (four mothers, one father, one keyworker at a treatment home). The regional Ethical Review Board approved the study.

2.2. Data Collection and Analysis. Data was collected with individual interviews at the time when all young adults had ended their relations at CAP and some had their first meeting at GenP. The interviews took place in the participants' homes, at the university, or in a room at the CAP unit. The initial questions were the same for all interviews and were as follows: "could you please tell me about why you first had contact with CAP?" and "how long has the contact lasted?" Follow-up questions were asked during the interview concerning "how the participants had been prepared for transfer," "how they were informed," "closure of relations in CAP," the "beginning of new relations in GenP," and "expectations and experiences of the transition." The data collection was carried out in parallel with studies of literature and data analysis in order to stimulate a theoretical sensitivity, that is, make the sampling open and flexible to contribute ideas in accordance with the approach in grounded theory [20]. Concepts that were derived from data during the analysis and questions about those concepts affected the next interview in data collection. This resulted in an interview guide that had new questions added verbatim, for example, how relatives experienced giving support and what young adult expectations were of their coming of age. Each interview lasted between 30 and 80 minutes (md = 50) and was digitally recorded, transcribed, and analysed verbatim.

The analysis started directly after the first interview was performed by reading through the interview text to obtain a feeling for the participant's experiences of transition. The overall analysis process was performed by open coding line by line and activity by activity, followed by axial coding and integration [20]. Open coding was the initial step of the analysis that pertains to defining concepts in order to discover categories and their properties and dimensions. The first author performed the coding process through breaking the data apart and asking questions such as "what," "why," "when," and "with what consequences" and made notes that also sought activities in the data. By using constant comparison [20], different pieces of data were compared for similarities and differences. Data were coded and similar codes were then grouped into categories (Table 1). Codes like "feeling secure," "trustful relationship," and "feeling seen and confirmed" were grouped together into the subcategory "leaving secure relations behind." The Internet program Open Code 3.6 [21] was used during this coding process. It is a program for coding data in qualitative studies and was developed to follow the first steps in GT.

The analysis process also included an axial coding where the act was to relate categories to one another by specifying properties and dimensions of higher-level concepts. In reality, the different steps undertaken during the data analysis were not linear. Instead, analysis was conducted through the constant comparing of data, emerging codes, and categories [20]. Based on the analysis, six subcategories were grouped together into three categories. Finally a core category was defined by an integration of all categories and concepts. In the core category all categories are related and linked together.

3. Results

The results are presented in a core category, managing transition with support, and the three categories, are being of age but not mature, walking out on security and into uncertainty, and feeling omitted and handling concerns. The core category and categories are presented below with quotations from the interview texts.

Table 1: Overview of the analysis process.

Category	Subcategory	Interview text
Being of age but not mature	Still in need of support	I wanted company (relative) the first times we met because I didn't know the person, I didn't know what I should sit there and say (young adult)
		She is 19 but in many ways she's 13-14 years old and she is most probably not alone (relative)
	Being close yet letting go	It may be the hardest thing, you have been very close the whole life, but I have yet decided that I have to trust them. . .even if it feels like I'm not that important any more (relative)
		She should be involved as much as possible I think, but later on I can go there by myself. . .I want to decide if she should follow me to the meeting or not (young adult)
Walking out of security and into uncertainty	Achieving closure and starting again	I have vent to her for two three years and just started to work and so you have to start again with a new one and get to know and it will take some time. . .now I have start all over again from the beginning (young adult)
		It is important that the kids don't feel like they are thrown away. . .maybe you can meet two or three times depending on the situation (relatives)
	Leaving secure relations behind	I don't know, maybe because I met her so often and she helped me start talking. . .yeah we connected simply. . .some persons you like and some you don't and you must meet them to know if you will connect (young adult)
		I think we hit it off pretty well. . .she got to know me pretty well better than I knew myself (young adult)
Feeling omitted and handling concerns	Left to their fate	I don't like it, it sucks but I have no choice I just have to accept it (young adult)
		I must expect that they know what they do, that they have knowledge about different disabilities but I'm not sure (relative)
	Insecurity that needs to be relieved	The transfer shall take place in another way so it doesn't become an end and a gap (relative)
		Lack of knowledge about who when or anything, missing the security that disappeared, it has been really tough (relative)

3.1. Core Category: Managing Transition with Support. The transition from CAP to GenP is a time-consuming process without clear structure, except for the time when young adults reach the age of 18 and no longer have the benefit of child and adolescent health services. The core category describes how young adults and their relatives need support to manage the transition and avoid the caring gap and that their main concerns were that they might be left out and feel uncertainty about the new situation. The interpretation of the transition process from CAP to GenP showed that young adults may not be mature enough to take responsibility even though they come of age. The young adults needed support during the transition process when they had to leave secure relations behind, create closure, and start again. It was also essential for the relatives to get support so they could be close to the young adults while also letting go. During the transition process the young adults expressed that they felt left to their fate with the risk of falling into the caring gap, which in turn could lead to an insecurity that needed to be relieved (Figure 1).

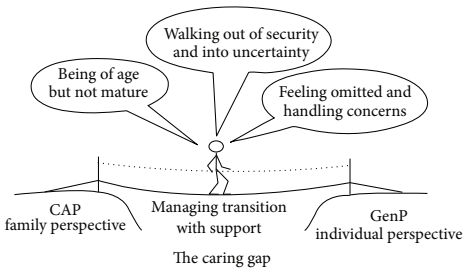

Figure 1: Managing transition with support. A description of how young adults and their relatives need support to manage the transition and avoid the caring gap.

3.2. Being of Age but Not Mature. This category is constructed from two subcategories: still in need of support and being close yet letting go.

3.2.1. Still in Need of Support. When young adults transfer to GenP, the requirements to manage themselves increase as they have to make their own decisions about continuity of care. At CAP, professionals were forthcoming with, for example, dates and reminders of appointments, but the young adults had no expectations that professionals at GenP will give support and reinforcement in the same ways they experienced at CAP. Both young adults and relatives realise that the different care cultures could be a hindrance for the young adults to accomplish treatment, especially in case of a lack of support from relatives.

I think they are more obliging at CAP, you get times for meetings and a phone number to call, but at GenP you have to contact them and get in touch and check that everything is working. . .that's the big difference. . .it's like written that you can fix it by yourself. (young adult)

Relatives described that it was not easy for young adults to grow up and it was not certain that the young adults became mature only because they turned 18 and come of age. It could be a struggle between desires to fend for themselves and the frightening prospect of taking responsibility. It was not obvious that young adults look forward to their 18, birthday because they know it entails obligations that may be difficult to meet. Relatives expressed that the young adults need awareness of the value of continuing care and the ability to be responsible for their treatment.

. . .need [of support], yes she is in great need but does not want it. . .but she has to mature and realize that. (relative)

Young adults and relatives suggested that the transition should be planned with regard to personal needs and maturity and according to possibilities of receiving support during the process. They also suggested that professionals should take into account to what extent the young adults were in need of care after transfer and provide the ability to terminate treatment at CAP if only a few appointments at GenP are needed.

3.2.2. Being Close Yet Letting Go. To undergo transition and become an adult was described as a step into adulthood and independence. Relatives noted that this transition might be easy for young adults who were prepared and mature and had support from relatives as a backup when needed. Relatives further described that it could be hard to know what kind of support the child may need, but they understood they cannot be involved in decisions as they were before. To what level relatives will be able to participate and give support depends on the relationship between the young adult and the relative. Relatives expressed frustration about being close but not having the possibility of participating in the planning of care.

I think it's horrible. . .not because I mistrust GenP but because I feel that I do not have control. . .she does not want us to be involved. (relative)

Some relatives said that their young adults were in need of support from them to manage daily life and that it was difficult to let them go. They also felt worried about their young adults' futures and how they would manage to find a job and a place in society. One relative described that she needed to be one step ahead to support the young adult, and it became important for the relative to receive sufficient information during the transition process. Relatives described further that participating during the transition could consist of support with structure, without involvement in treatment. They expressed that independence cannot be forced but must take place gradually.

I hope she leaves home in the long run. . .I want her to be at home yet for a while. . .say that she first got a job and then managed the medication by herself, and then in the long run. . .it must work out, you have to try. (relative)

3.3. Walking Out of Security and into Uncertainty. This category is constructed from two subcategories: achieving closure and starting again and leaving secure relations behind.

3.3.1. Achieving Closure and Starting Again. The young adults and the relatives described that they tried to negotiate terms of the transfer but were denied by the system. The decision to transfer the young adult to GenP was governed by rules that had to be followed. Participants appreciated when professionals broke the rules and let the young adult stay at CAP for some extra months.

I do not know, I did not want it at all, but I suppose it was the best way. . .they had no choice. . .that's laws and regulations that says so and then it is simply to obey. (young adult)

The experiences of how the transition process was carried out varied. Some young adults and relatives got a letter or a phone call with information about an appointment at GenP, and some experienced a well-planned process with an extensive involvement from the young adult, the relatives, and professionals from both CAP and GenP. The young adults and the relatives desired that the professionals from GenP come to CAP, where the family felt secure, and provide information about GenP to facilitate the process and give the young adult an opportunity to establish the new relationship before closure at CAP.

It's GenP that should come to CAP and tell what it's like. . .they forget that, they do the opposite. . .it's not CAP that should tell us about the other. . .because that's when you feel you're welcome, now you feel like you've been rejected. (relative)

To further facilitate the transition process, the young adults and relatives expressed that professionals at CAP should initiate the cooperation because they have knowledge about the family and the current needs to be met. The process should be planned according to individual needs despite age limit. Young adults and relatives expressed the importance of having enough time to establish new relationships and also gain sufficient information, providing both to the young adults and the relatives.

What information did you get about GenP? None, it feels like I'm walking into darkness. (relatives)

These factors were described as essential to reach a successful transition. Relatives also explained that if transition planning started before the young adults' 18th birthdays, the relatives' possibility to get involved in the process increased.

3.3.2. Leaving Secure Relations behind. Young adults described long-lasting relationships and continuity among professionals as one reason that they felt safe at CAP. They appreciated being able to meet the same professionals at each visit at CAP and sometimes the same professionals over several years of care. They had also met the same physician, which eliminated the need to repeat their story over and over again. Relatives expressed that professionals with competence and long experience contributed to a feeling of being secure at CAP. Both young adults and relatives expressed the desire to not have to terminate the caring relations, as the young adults wanted to avoid changing relationships and developing new ones.

> *We are secure with them and they always have knowledge about our problems. She thought it was good to know that they know. (relative)*

Being treated with respect and taken seriously and having the possibility to be involved in decisions contributed to a feeling of security, according to the young adults and relatives. Relatives described that they easily could blame themselves for their child's mental illness and pointed out how important support and encouragement from professionals was to manage that feeling of burden. Supportive relations led to a care environment at CAP that felt safe and secure.

> *It's more the people, and so the environment that makes it much different, it's a more cheerful environment, it feels like, what to say. . .it's a better environment to grow in. (young adult)*

Both young adults and relatives described that it takes time to create a trusting relationship, and they were concerned about how to manage that after the transfer to GenP. Preconditions for a successful relationship were continuity as well as feeling confident that the professionals had skills to give treatment based on needs. Overall, the young adults had more positive expectations and fewer worries than the relatives, which helped them to believe in the future and to believe that the transition should be successful. A young adult with good experiences talked about what she was expecting from the new therapist.

> *I will get along well with her, she'll understand me well and I shall thus be able to understand myself without me having to, like explain myself all the time. (young adult)*

The young adults and the relatives also described negative expectations and worries about the transition and were not convinced that care would function properly after the transfer to GenP. The future felt uncertain due to a lack of sufficient information about GenP.

3.4. Feeling Omitted and Handling Concerns. This category is constructed from two subcategories: left to their fate and insecurity that needs to be relieved.

3.4.1. Left to Their Fate. During the transition process young adults and relatives felt omitted due to disruption in the continuity of care. During the waiting time between ending at CAP and starting at GenP the young adults described that they had to be strong by themselves or rely on support from relatives. They could handle the situation because of previous knowledge about GenP and because of personal qualities.

> *You should probably not be that ill, you get to struggle a bit yourself too, but if you are too ill, it is hard to do that. (relative)*

Young adults said that the differences in the care cultures between CAP and GenP also gave a feeling of being omitted and feelings of uncertainty. A young adult described that at CAP, there was always continuity in care, and the experience from the first meetings at GenP revealed that the regularity in contact depends on the individual's current status.

> *When I went to CAP I met X regular, but now at GenP it's like, the worse you feel the more meetings you get, and the better you feel the less meetings you get, it's like more irregularly. (young adult)*

In cases when the transition process worked well, relatives and young adults felt that they had good luck. They were lucky receiving a medication that worked and they felt lucky getting a therapist who ensured a successful transition. From this point of view the outcome of the transition was a matter of chance instead of a well-planned process.

> *It has gone quickly and smoothly, it was probably what I needed, I have avoided a lot of hassle, I was lucky I guess. (young adult)*

Society's and even professionals' attitudes toward mental illness contributed to a feeling of being omitted. Relatives described that it is not possible to talk about mental illness in the same way as about a physical illness. Relatives gave the example that nobody tries to hide taking medication for a physical illness, but when it comes to mental illness, it is shameful. They also felt that mental healthcare at GenP was not prioritized.

3.4.2. Insecurity That Needs to Be Relieved. When relations at CAP were closed before summer vacation and new relations at GenP were not yet established, a caring gap arose, which led to insecurity and increased suffering. Both young adults and relatives described that the uncertainty about whom they would meet and when it would happen caused worries, anxiety, increased medication, and fears that ongoing medication would run out before they got an appointment. Relatives also worried that their young adults would decide not to continue care if professionals at GenP made the young adults responsible for making contact. During these circumstances of insecurity, relatives describe that they had great responsibility in supporting the young adults.

> *We had to go several times with her and increase the medicine, she has felt really ill. . .even if she's talking to me but it's not the same thing. . .I'm not a therapist. (relative)*

Young adults could understand that professionals needed vacation, but they said that it was not optimal for them to make the closure during summertime because it became a long, uncertain waiting time for them.

> *I would have been told more in time and then they should have fixed so I could meet someone during summer, a meeting with a doctor or anything. . .I think it sucks because I do not know how they think, if they think, yeah but now it's holiday, but it's not working so for all. (young adult)*

To bridge the caring gap, young adults and relatives asked for more cooperation between professionals at CAP and GenP and more flexibility on the appropriate time for transfer. They thought transition planning should be based on individual needs instead of professionals' working schedules so the young adults would not suffer because of a caring gap that could arise.

4. Discussion

The aim of this study was to explore expectations and experiences of transition from CAP to GenP. The results show that young adults were undergoing multiple simultaneous transitions. The transitions were complex for the participants because they had to adapt to new situations related to both developmental and situational changes [22–24]. According to Bridges [25], transitions are not only about the changes but also about the inner reorientation and self-redefinition a person goes through to incorporate the changes. Generally, the transition from childhood to adulthood is not a linear process since it includes a back and forth between independence and dependence and cannot be enforced pursuant a timetable [26]. For relatives it is also a balance between providing support and promoting independence [4] and it is important to support the relatives during the process of letting go [27]. According to McClure [28], adolescents in transition between childhood and adulthood have special needs that professionals have to understand and take into account. It is also important to take a family perspective as young adults are affected by their family and in turn also affect their family. Professionals have to consider that young adults undergo a process of emancipation from their family.

The young adults in this study had to adapt to a care culture with individual perspectives instead of a family perspective, although they were still in need of support to manage the transition from CAP to GenP. When young adults undergo multiple transitions, professionals must focus on both the situational transition to the new care unit and the developmental transition from childhood to adulthood [7, 29]. Meleis et al. [1] further stated that professionals need to consider the patterns of all significant transitions an individual or a family experiences, which include either a single transition or multiple transitions, and in the case of multiple transitions, either sequential or simultaneous. In this case, when young adults are transferred from CAP to GenP at the age of 18th they undergo multiple simultaneous transitions.

In this study, the young adults and the relatives described that they felt safe and secure at CAP because of close caring relations. Upon transfer to GenP, they had to leave these relations behind and establish new caring relationships at GenP. To promote young adults' willingness to disclose their mental health concerns and create relationships, they need a "space" in which a trusting relation might be built, and informal ways of keeping in touch can promote relations building [30]. In this study the young adults expressed that it takes time to establish trustful relationships and they expressed a need for continuity and confidence that professionals have skills to meet their current needs. It is, therefore, important to pay attention to young adult's narratives, in order to create trusting relationships in healthcare [31].

The results show further that young adults and relatives felt left out and had to rely on their own personal qualities. They described a lack of support and information about the future at GenP which increased the suffering and the risk of falling into the caring gap. Swift et al. [15] also describe that young adults were reliant on family support to take responsibility for their care and experience a feeling of being left out during the transition. According to Leavey et al. [30], young adults with mental illness most likely seek help from relatives and friends, and furthermore Ciarrochi et al. [32] found that young adults who are most in need of help and poor at managing their emotions least likely seek help when needed. This shows the importance of a well-planned transition process, through cooperation between CAP, GenP, and the families, to facilitate the young adults' ability to establish a caring relation and encourage continuity of care [33]. Otherwise, the risk is obvious that young adults will fall into the caring gap and not receive care when needed.

4.1. Methodological Considerations. The strength of this study is its insider perspective, that is, the young adults' and relatives' expectations and experiences. From this perspective, the result offers important insights into the sometimes unknown world of young adults with mental illness. The limitation of the study is primarily related to the sampling procedure. The sample was small and despite repeated attempts to draw additional participants, no more participants responded. However, according to Corbin and Strauss [20], the researcher is sampling concepts and not persons in theoretical sampling, and as the result was consistent with other studies in the same topic, the trustworthiness strengths. The categories and concepts contained in this study and the relationships between these categories are sufficiently abstracted to allow comparison to other clinical populations and other contexts, thereby enhancing the modifiability of the theoretical understanding. The results can be regarded as a synthesis of both research findings from this study and earlier research and knowledge in the field of transition. To reach a theory concerning transition from CAP to GenP, we need more empiric knowledge and theory embedded in nursing practice. Our results described in the core category can thereby be seen as a hypothesis that should be further explored to generate a theory of transition from CAP to GenP for young adults, contributing to theory development in nursing.

5. Conclusions

Based on these results, a person-centred transition planning is recommended to facilitate the transition from CAP to GenP. The framework for person-centred nursing comprises professionals' competence and interpersonal skills, the care environment, person-centred processes, and outcomes [34]. To decrease the risk of disruption in care and make the process person-centred, professionals should plan the transition through cooperation between CAP and GenP with the young adults and relatives participating. The professionals at both CAP and GenP also need to be aware of the simultaneous transitions young adults undergo and take into account their individual needs and maturity. Furthermore, it is important in person-centred nursing to pay attention to the care environment which includes system that facilitates effective relationship between professionals and a supportive organizational system [34]. In the context of CAP and GenP the gap between the different organizations and care cultures needs to be bridged. To achieve that, it could be an advantage to be more flexible in time for transfer. To facilitate young adults possibility to establish a caring relationship at GenP, parallel working during the transition process could be a benefit. With these interventions the young adults and the relatives will be prepared for the changes and they can manage the transition without a feeling of insecurity and uncertainty.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this paper.

Authors' Contribution

Eva Lindgren, Lisa Skär, and Siv Söderberg were responsible for conception and design of the study. Eva Lindgren and Lisa Skär participated in data collection of the three first interviews and the latter were performed by Eva Lindgren. Eva Lindgren performed the analysis and made the initial interpretations of data, which were presented and discussed with Siv Söderberg and Lisa Skär. Eva Lindgren drafted the paper while Siv Söderberg and Lisa Skär repeatedly revised it critically. All authors approved the final version to be published.

Acknowledgments

The authors are grateful for the shared experiences from the participants. This study is funded by the National Association of Social and Mental Health (RSMH) and Luleå University of Technology, Sweden.

References

[1] A. I. Meleis, L. M. Sawyer, E.-O. Im, D. K. H. Messias, and K. Schumacher, "Experiencing transitions: an emerging middle-range theory," *Advances in Nursing Science*, vol. 23, no. 1, pp. 12–28, 2000.

[2] B. Lenz, "The transition from adolescence to young adulthood: a theoretical perspective," *The Journal of School Nursing*, vol. 17, no. 6, pp. 300–306, 2001.

[3] A. I. Meleis, "Theoretical development of transition," in *Transitions Theory: Middle Range and Situation Specific Theories in Nursing Research and Practice*, A. I. Meleis, Ed., pp. 13–51, Springer, New York, NY, USA, 2010.

[4] A. McGrandles and K. McMahon, "Transition from child and adolescent to adult mental health services," *British Journal of Nursing*, vol. 21, no. 17, pp. 1031–1039, 2012.

[5] S. P. Singh, N. Evans, L. Sireling, and H. Stuart, "Mind the gap: the interface between child and adult mental health services," *Psychiatric Bulletin*, vol. 29, no. 8, pp. 292–294, 2005.

[6] M. Davis, "Addressing the needs of youth in transition to adulthood," *Administration and Policy in Mental Health*, vol. 30, no. 6, pp. 495–509, 2003.

[7] S. Kirk, "Transitions in the lives of young people with complex healthcare needs," *Child*, vol. 34, no. 5, pp. 567–575, 2008.

[8] M. Paul, T. Ford, T. Kramer, Z. Islam, K. Harley, and S. P. Singh, "Transfers and transitions between child and adult mental health services," *British Journal of Psychiatry*, vol. 202, supplement 54, pp. 36–40, 2013.

[9] S. P. Singh, "Transition of care from child to adult mental health services: the great divide," *Current Opinion in Psychiatry*, vol. 22, no. 4, pp. 386–390, 2009.

[10] H. Bruce and N. Evans, "The transition into adult care," *Psychiatry*, vol. 7, no. 9, pp. 399–402, 2008.

[11] E. Lindgren, S. Söderberg, and L. Skär, "The gap in transition between child and adolescent psychiatry and general adult psychiatry," *Journal of Child and Adolescent Psychiatric Nursing*, vol. 26, no. 2, pp. 103–109, 2013.

[12] A. Kaehne, "Transition from children and adolescent to adult mental health services for young people with intellectual disabilities: a scoping study of service organisation problems," *Advances in Mental Health and Intellectual Disabilities*, vol. 5, no. 1, pp. 9–16, 2011.

[13] A. Muñoz-Solomando, M. Townley, and R. Williams, "Improving transitions for young people who move from child and adolescent mental health services to mental health services for adults: lessons from research and young people's and practitioners' experiences," *Current Opinion in Psychiatry*, vol. 23, no. 4, pp. 311–317, 2010.

[14] K. Hovish, T. Weaver, Z. Islam, M. Paul, and S. P. Singh, "Transition experiences of mental health service users, parents, and professionals in the united kingdom: a qualitative study," *Psychiatric Rehabilitation Journal*, vol. 35, no. 3, pp. 251–257, 2012.

[15] K. D. Swift, C. L. Hall, V. Marimuttu, L. Redstone, K. Sayal, and C. Hollis, "Transition to adult mental health services for young people with Attention Deficit/Hyperactivity Disorder (ADHD): a qualitative analysis of their experiences," *BMC Psychiatry*, vol. 13, no. 74, 2013.

[16] R. C. Kessler, P. Berglund, O. Demler, R. Jin, K. R. Merikangas, and E. E. Walters, "Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication," *Archives of General Psychiatry*, vol. 62, no. 6, pp. 593–602, 2005.

[17] U. Engqvist and P.-A. Rydelius, "Child and adolescent psychiatric patients and later criminality," *BMC Public Health*, vol. 7, article 221, 2007.

[18] A. Ramirez, L. Ekselius, and M. Ramklint, "Mental disorders among young adults self-referred and referred by professionals to specialty mental health care," *Psychiatric Services*, vol. 60, no. 12, pp. 1649–1655, 2009.

[19] SKL, *Kartläggning Av Den Psykiatriska heldygnsvårDen (in Swedish), Survey of the Psychiatric Inpatient Care*, Stockholm, Sweden, 2010.

[20] J. M. Corbin and A. L. Strauss, *Basics of Qualitative Research: Techniques and Procedures For Developing Grounded Theory, SAGE*, Thousand Oaks, 2008.

[21] OpenCode 3. 4., *ICT Services and System Development and Division of Epidemiology and Global Health*, Umeå University, Umeå, Sweden, 2013.

[22] D. W. Osgood, E. M. Foster, and M. E. Courtney, "Vulnerable populations and the transition to adulthood," *Future of Children*, vol. 20, no. 1, pp. 209–229, 2010.

[23] D. Kralik, K. Visentin, and A. Van Loon, "Transition: a literature review," *Journal of Advanced Nursing*, vol. 55, no. 3, pp. 320–329, 2006.

[24] R. W. Blum, "Transition to adult health care: setting the stage," *Journal of Adolescent Health*, vol. 17, no. 1, pp. 3–5, 1995.

[25] W. Bridges, *Transitions: Making Sense of Life's changes*, Da Capo Press, Cambridge, Mass, USA, 2004.

[26] I. Höjer and Y. Sjöblom, "Procedures when young people leave care—views of 111 Swedish social services managers," *Children and Youth Services Review*, vol. 33, no. 12, pp. 2452–2460, 2011.

[27] P. Jivanjee, J. M. Kruzich, and L. J. Gordon, "The age of uncertainty: parent perspectives on the transitions of young people with mental health difficulties to adulthood," *Journal of Child and Family Studies*, vol. 18, no. 4, pp. 435–446, 2009.

[28] M. McClure, "Adolescence-the transition from childhood to adulthood," in *Family Matters: Interfaces Between Child and Adult Mental Health*, P. Reder, M. McClure, and A. Jolley, Eds., pp. 71–82, Routledge, Florence, Ky, USA, 2000.

[29] S. P. Singh, M. Paul, T. Ford et al., "Process, outcome and experience of transition from child to adult mental healthcare: multiperspective study," *British Journal of Psychiatry*, vol. 197, no. 4, pp. 305–312, 2010.

[30] G. Leavey, D. Rothi, and R. Paul, "Trust, autonomy and relationships: the help-seeking preferences of young people in secondary level schools in London (UK)," *Journal of Adolescence*, vol. 34, no. 4, pp. 685–693, 2011.

[31] B. Harper, J. M. Dickson, and R. Bramwell, "Experiences of young people in a 16-18 Mental Health Service," *Child and Adolescent Mental Health*, 2013.

[32] J. Ciarrochi, F. P. Deane, C. J. Wilson, and D. Rickwood, "Adolescents who need help the most are the least likely to seek it: the relationship between low emotional competence and low intention to seek help," *British Journal of Guidance and Counselling*, vol. 30, no. 2, pp. 173–188, 2002.

[33] S. P. Singh, M. Paul, T. Ford, T. Kramer, and T. Weaver, "Transitions of care from child and adolescent mental health services to adult mental health services (TRACK Study): a study of protocols in greater London," *BMC Health Services Research*, vol. 8, article 135, 2008.

[34] B. McCormack and T. V. McCance, "Development of a framework for person-centred nursing," *Journal of Advanced Nursing*, vol. 56, no. 5, pp. 472–479, 2006.

III

Swedish young adults' experiences of psychiatric care during transition to adulthood

Lindgren, E., Söderberg, S., & Skär, L. (2014). *Issues of Mental Health Nursing.*
Accepted for publication 2014-09-01

ABSTRACT

The number of young adults with mental illness and need of psychiatric care has increased during the last decades. The aim of the study was to explore young adults' experiences of psychiatric care during transition to adulthood. Individual interviews were conducted with 11 young adults and analysed according to Grounded theory. The analyses resulted in a grounded theory showed that support was a prerequisite for transition to adulthood and striving to reach recovery. By being encountered as a person and a supportive environment, young adults can be motivated to continue care and encouraged to express feelings.

Keywords: grounded theory, mental illness, psychiatric care, transition, young adults,

INTRODUCTION

During the last decades the number of young adults with mental illness has increased. Mental illness is described as a condition that, for various reasons, interferes with everyday life. It includes experiences of mental suffering even though the suffering is not consistent with a mental diagnosis (Hedelin, 2006). In Sweden, where the present study took place, the percentage of young adults aged 16-24 who suffer from anxiousness, nervousness, and anxiety, increased from 9 to 30 per cent for women and from 4 to 14 per cent for men between the years 1988 and 2005 (Lager, Berlin, Heimerson, & Danielsson, 2012). The number of young adults admitted to inpatient psychiatric care has also steadily risen, and statistics from 2010 show that 0.5 per cent of women and 0.3 per cent of men were treated at either Child and Adolescent Psychiatry (CAP) or General Psychiatry (GenP). However, most young adults suffering from mental illness were treated as outpatients. According to the Swedish National Institute of Public Health (Lager, Berlin, Heimerson, & Danielsson, 2012), 20 per cent of woman and 13 per cent of men aged 16 – 29 reported suicidal thoughts at any time in their lives, and six per cent of women and four per cent of men in the same age group have attempted suicide at some point.

Psychiatric care in Sweden is organized in such a manner that children up to age 18 benefit from child and adolescent health care and adults above 18 benefit from adult health care. Therefore, young adults need to take responsibility for their choice of lifestyle and in matters of healthcare when they come of age (Lenz, 2001). During transition from CAP to GenP there is a risk for disruption in continuity of care (Singh, 2009; Singh, Evans, Sireling, & Stuart, 2005); thus, it is important that professionals support the young adults and their relatives during transfer to avoid a gap in care (Lindgren, Söderberg, & Skär, 2014). By providing information and a plan for the transfer with cooperation between CAP and GenP, the transition can be facilitated and the young adults can be prepared for the changes. Further, it is important to take into account young adult needs and their maturity (Lindgren, Söderberg, & Skär, 2013). According to Peplau (1991) a patient may need support to express their needs, and identification of individual needs can take place in an interpersonal relationship with a professional. Thereby, young adults should be supported to establish trustful relationships when they initiate adult healthcare, to facilitate the possibility to express their feelings and needs.

Transition to adulthood can be a critical period, especially for young adults with mental illness (McGrandles, & McMahon, 2012; Singh et al., 2005), since they can be less prepared to take care of themselves than their peers (Davis, 2003). According to Arnett (2000), the late teens and early twenties is a period of life in-between adolescence and adulthood that he terms emerging adulthood. Emerging adulthood is characterized by change and exploration of possible life directions, while adult commitments and responsibilities are delayed but role experimentation continues and intensifies. This period of life is culturally constructed and exists only in cultures that allow young adults a prolonged period of independence (ibid.).

Transition is a central concept in nursing and the middle-range theory emphasizes different types of transitions; i.e., developmental, health/illness, and situational transitions (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). According to Bridges (2004), all transitions start with an ending before a new beginning, and, as transition denotes changes in roles (Meleis, 2010), young adults who undergo transition into adulthood need to change their definition of themselves in their social context and consider themselves as adults. As humans are biopsychosocial beings, psychosocial concerns cannot be separated from health and wellbeing; thus, it is important that professionals understand young adult behaviour in order to make appropriate interventions (Meleis, 2010). The aim of this study was therefore to explore young adults' experiences of psychiatric care during transition to adulthood.

MATERIALS AND METHOD

To reach the aim of this qualitative study a Grounded theory (GT) design was selected as a suitable method, described by Corbin and Strauss (2008).

Participants

To recruit participants for the study a purposive sampling was used. Professionals at GenP in the northern part of Sweden were informed about the study and invited patients to participate. Patients who fulfilled the inclusion criteria for the study received an information letter. The inclusion criteria were: aged 18-25, experiences of care at both CAP and GenP, and been referred to GenP from CAP. As only one participant responded to the information letter, a decision was made to remove the inclusion criteria about referral from CAP to GenP and to create an advertisement in local newspapers and at patient associations inviting participation. This resulted in eight more participants and two additional participants were recruited from an earlier study (Lindgren et al., 2014). According to the difficulties in the recruitment process, two of the young adults were allowed to participate even though they had reached the age of 26. In total, 11 participants were recruited and consisted of 7 young women and 4 young men, aged 19 to 26 years (m= 21). There was no requirement to declare diagnosis, but most described their mental illness in terms of diagnosis, such as anorexia, anxiety, depression, self-harm, suicidal, ADHD, Asperger syndrome, and drug addiction. The young adults described experiences of psychiatric care from inpatient and outpatient care at CAP and GenP, forensic psychiatry, primary health care, as well as municipality-based services, such as care in foster families or treatment homes.

Data collection and analysis

Data was collected through individual interviews from May to Dec 2013. The interviews took place in the young adults' home, at the university, in a room at a psychiatry unit, or at a patient association. In the beginning of the interview the young adults were asked to describe their current contact with psychiatric services and how and when the contact began. Follow-up questions were asked during the interview concerning "what makes a care relation trustful", "how do you prefer to be encountered to feel safe", and "can you give examples of a good and bad encounter". They were further asked to narrate their experiences of growing up and becoming an adult.

In order to stimulate a theoretical sensitivity, literature was read in parallel with data collection and analysis. According to the GT approach, theoretical sensitivity opens the sampling strategy and makes it flexible (Corbin, & Strauss, 2008). This approach resulted in questions being added to the interview guide based on concepts derived from data. One such question was how the professional could support the young adults in expressing their feelings. Directly after the first interview the analysis started by reading through the whole interview, followed by open coding line by line. To stimulate thinking and moving the analysis forward, memos were written. The initial step in the analysis pertains to defining concepts and discovering categories and their properties and dimensions. By using constant comparison, codes were grouped together in categories by comparing similarities and differences. The analysis continued with axial coding, where categories related to each other were grouped together. Based on the analysis, eleven subcategories were grouped together into five categories. Finally, a core category was defined by an integration of all categories and concepts. In the core category all categories are related together and explain a theoretical formulation of the result, and thereby have the greatest explanatory relevance and highest potential to linking all the categories together (Corbin, & Strauss, 2008). Each interview lasted between 25 and 133 minutes (m=58), and were transcribed and analysed verbatim. The Internet program Open Code 4.01 was used during the coding process.

ETHICAL CONSIDERATIONS

Ethical considerations were made according to predictable risks and burdens caused by the interview, but the benefits of receiving the young adults' points of view were assessed to outweigh the risk of participation (Declaration of Helsinki). Informed consent was obtained when the young adults sent a signed form to the first author, or prior to the interview. In the beginning of the interview all participants were given verbal information about the study and that they could discontinue the interview whenever they wanted without any disadvantage. The regional Ethical Review Board in Sweden approved the study.

RESULTS

The analyses resulted in a grounded theory that shows that support was a prerequisite for transition to adulthood and striving to reach recovery for young adults with mental illness (the core category). The core category was then related to five categories; Being motivated to continue care, Being encountered as a person, Being encouraged to express feelings, The importance of a supportive environment and Coming to a new beginning. The core category is described below and explains the result as a theoretically whole. The categories describe that certain factors determined the young adult's experience and their transition to adulthood and are illustrated with quotations.

Core category; Support as a prerequisite for transition to adulthood and striving to reach recovery

The core category shows that support was a prerequisite for transition to adulthood and a motivation to reach recovery for young adults with mental illness. The professionals in mental care need skills to support the young adults to increase their motivation to continue care; they also need to encounter young adults as unique persons and encourage them to express their needs and feelings. A supportive environment and support from significant others, such as relatives and school personnel, can further facilitate a young adult's transition to adulthood and motivate them to strive for recovery. Thus, the end of the transition became a new beginning. Alternatively, lack of such support could lead to dropouts and a decreased motivation to continue care.

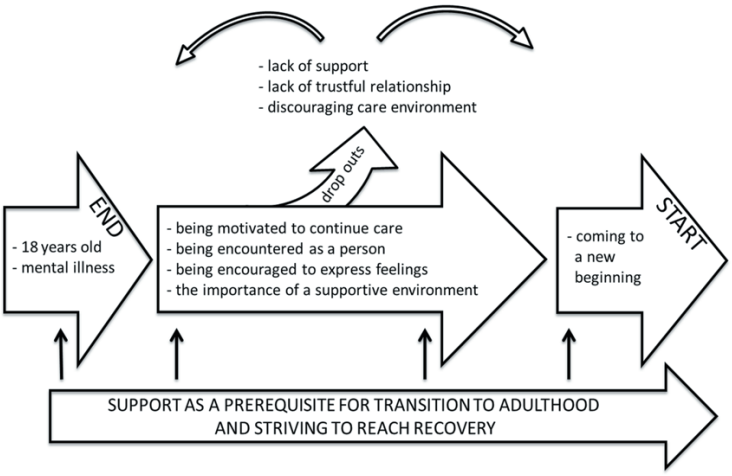

Figure 1 The grounded theory describe that support was a prerequisite for transition to adulthood and striving to reach recovery. The figure illustrated that certain factors determined the young adult's experiences of psychiatric care, and their transition to adulthood.

Being motivated to continue care

This category describes how important it was that a relationship was established so that young adults felt motivated to continue care. Furthermore, the category describes consequences of lack of support and trustful relationships in form of dropouts. It was important for the young adults that they match personally with the therapist; otherwise they could not feel trust in the relationship. Without a feeling of trust and confidence it was difficult to be motivated to open up and talk. They perceived that it depends more on luck and opportunity than on conscious decision if they met a professional with the 'right' skills. The connection was created early in the relationship; thus, the first meetings were crucial for becoming motivated. Young adults described how difficult it could be to establish first contact. One young adult described that the referral from primary health care to GenP was rejected, and lack of support gave a feeling of hopelessness and decreased motivation. At the end an emergency situation accelerated the referral process and resulted in an accepted referral and an opportunity to receive care.

> *"I came to the emergency room… and I said I don't know it feels so hopeless I don't know what to do because it feels like nobody wants to help me"*

In some cases the young adults were transferred to GenP at the age of 18. One young adult described how the transfer to GenP was well planned to facilitate the continuing care, before closure at CAP. But some weeks before her 18th birthday she needed inpatient care and because of overcrowding at CAP she was admitted to GenP. She felt neglected and unsafe when she suddenly came to the ward without knowing anyone and furthermore not allowed to have relatives near, as she required. To be able to create a trustful relationship and to feel safe, young adults described that they need continuity in care with regularly booked meetings and a treatment plan. This gave a structure to the treatment and contributed to a feeling of security and that they were taken seriously. Furthermore, the young adults appreciated when the therapist remembered what they talked about the last time they met and followed up on their conversation. One person described how this motivated her to continue care and probably kept her alive, because she made a promise to meet the therapist the next week.

> *"Many times it was like…you want to die but on Tuesday I'll see my therapist and talk for a while so I can manage. Sometimes I think it was vital or whatever to call it to go there, just to have a goal…and I can't disappoint this person, we have an agreement."*

The young adults further described how difficult it was when there was a discontinuity in care, such as with physicians, because they had to tell their stories all over again instead of perceiving a progress in treatment. Lack of continuity resulted in a lack of motivation and hope for the support. Because of this, one young adult ended contact with GenP, as it was found to be not worth money. Instead, the young adult handled many problems by himself and struggled to manage his everyday life.

> *"When I go there it's like I only give them a status update, that's all I have time for…I'm never going a step further."*

Young adults narrated the importance of being involved in decisions. Their experience was that they had to be strong to be able to participate in their care. Some young adults had experienced situations when they had no opportunity to influence decisions and they felt that the professionals did not take notice of their point of view. When professionals demonstrated power and determined the care, the young adults felt they were treated without respect or participation. Some young adults needed support from relatives to put demands on social and psychiatric services, when they felt that the received care did not correspond to their needs. They further described that they wanted to change their therapist when it was difficult to connect. The young adults, however, had diverse experiences of how their requests to change their therapist were met. Some could easily express their discomfort and

the request to change their therapist was fulfilled, while others felt they were ignored and forced to continue talking to a person they did not feel comfortable with or trusted.

The young adults further described how important it was that they felt that the received treatment corresponded to their needs to be motivated to continue care. Further, they experienced that the psychiatric care was not equitable. One young adult described how he asked for dialectical behaviour therapy as a treatment instead of drugs for his anxiety. As that treatment was not available in his hometown he found it impossible to travel the long distance to get the treatment. As a consequence of lack of support and neglectful encounter, he was not motivated to continue his care and instead struggled to handle the anxiety by himself using an app on his smartphone.

"I've learned to accept things…it's so sick, no one at psychiatry has taught me that, I've learned it through an app in my phone."

Being encountered as a person

This category describes the importance of encounters that support the young adults experiences of being a unique person. The young adults described that it was complicated to be young, though they want both to manage by themselves and still receive help. They described encouraging encounters when the professionals treated them without using power and saw them as a unique person instead of 'just another patient'. Thus, the therapist also became 'a person' while remaining professional. Therefore, they narrated the importance of the professionals having certain skills to communicate and relate and encounter them as a person. The young adults described that professionals needed to understand their reasoning so they could give support in the best way. One young adult remembered when she was a teenager and her therapist told that her that her mental illnesses would decrease when she became 20. That statement was no relief for her because she had no sense of time or an ability to plan for the future at the age of 15. Further, young adults described situations when they felt mistreated according to their level of maturity. One person remembered how she was treated like a small child when she was 16 and compared that with a pleasant experience at GenP, where she was treated with respect for her maturity. Even though she was an adult according to age, she did not feel like an adult but was pleased to be encouraged as a unique person.

"She talks to me neither as a child nor as an adult, but she talks to me in a way she notices that I want to be spoken to."

Some young adults had experienced forensic care and described the importance of being treated with respect even if you are in custody. Even with rules and boundaries the professionals needed to encounter them with respect and maintained integrity. Some described that the rules was necessary. Some also had experiences when the objective of care was to adjust to the professionals' requirements; they were punished if they did not manage to follow the rules. One person described that a consequence of this, was that the forensic care received was experienced as a total waste of time when the care not responded to their needs and they were not seen as a person.

"I just spent time there…it's like stepwise, you get more freedom the more you fit in…the years I spent there were totally wasted."

Being encouraged to express feelings

This category describes how important it is that young adults are supported to express themselves and what they feel. Young adults described that a trustful and caring relationship was important to be able to express emotions and feelings. The opportunity was something that depended on both the professional and the young adults as they created the relationship together in a reciprocal

process. One young adult described that when she felt safe and decided to accept and receive help, the therapist became motivated to give support. This helped the young adult feel that she was taken seriously and she continued to talk and became willing to disclose her feelings to the therapist.

"It's more about me and her, as I decided that if she will help me I'll receive her help."

The young adults described that it is difficult to talk about life events and that they need support from the professionals to be able to express emotions and feelings. They described that professionals need to understand young adults; even if the young adults say that everything is fine, this might mean something else. Thus, the professionals will be able to meet their needs. They also described that the professionals need to 'read between the lines' and hold on to a subject with follow-up questions and thereby support them to put words to their feelings and thoughts.

"It's not like I don't want to tell, I've no idea what I feel. I can't put words on it because I don't know what it is. You haven't learned so much about emotional life."

Furthermore, young adults described that it was difficult for them to express what they mean in words, and thus they try to communicate in other ways. One young adult explained that self-harm could be a way to communicate a need for someone to listen and understand their expression of feelings.

"You need someone to listen and that's maybe what you're trying to say by what you're doing, but you don't tell."

Young adults further described the importance of professionals supporting them to develop their narratives and to take the opportunity when they open up and begin to talk about traumatic experiences. One young adult described how she had mobilized bravery for a long time before she disclosed the trauma she had experienced. However, she experienced a lack of support when the therapist did not follow up on the narrative with further questions, she could thereby not express her feelings. Consequently, she did not talk about that occasion for several years. She thought that she might have had a faster recovery if she got the opportunity to verbalize her experiences earlier.

"They had a huge shot since I opened up and started talking…they should have kept asking but they didn't…if you don't talk about hurtful occasions it comes back to bite you in the ass."

The importance of a supportive environment

This category describes how the physical environment could be supportive and a contributor to relationships, but also leads to increased suffering. The young adults described the importance of a supportive environment to receive care. At both psychiatric units and at municipality based care a familiar environment with homelike furniture was described as supportive. They further described that an environment with the possibility to socialize with both patients and professionals facilitated the creation of relationships. Close relationships and support from the foster parents or staff at treatment homes were also important, as well as structure and rules at the foster home, so they could feel safe and secure. Such an environment contributed to a feeling of being a person instead of a patient and striving to reach recovery.

Furthermore, they described that inpatient care could support them when they need rest and help them establish daily routines. Inpatient care was also described as a place where they could feel safe and be helped to stop hurting themselves either with drugs or through self-harm.

"It was a calm and relaxed environment…I could calm down and I felt maybe I've come to a turning point…I thought it was nice because I could not hurt myself and then I could relax."

Young adults also described that the environment could contribute to increased suffering. As a consequence of a caring environment with lack of support and stimuli, and no chance to connect with either professionals or other patients, the young adults found no reason to seek help at inpatient care. They expressed that their illness increased in such an environment, and thought that the poor environment reflected the professionals' view of humans, which resulted in a feeling of offended dignity.

"It's like a warehouse: nothing happens there…I'm so bored when I'm there so I become more ill…how do they think anyone who's ill can come to better thoughts…it feels like I'm not so high in rank."

Coming to a new beginning

This category describes experiences of transition to adulthood and how turning points and important steps increase striving to reach recovery and leads to a new beginning. Young adults described that experiences of being in transition to adulthood were both frightening and enjoyable. Some described that they were afraid of being responsible for their own life while others thought it was a relief to grow up and be more independent. They described a trajectory from living in the present with little sense of time, to nowadays when they could reflect more analytically and critically and could consider the consequences of their conduct beforehand. Furthermore, they described that growing up and being more mature is something that comes successively in the process while you become more independent. The transition also includes awareness of who you will become as an adult and who you will become if you recover from mental illness.

"I was very scared, who will I be if I'm not ill, will I get as many hugs by mom and dad, will I get as much care and everything like that if I grow up and if I get healthy?"

Some of the young adults described that they came to a turning point and decided to strive for recovery and a new beginning. The turning point was either an insight of death if they continued to live in the same way, or a longing for an ordinary life with independent living, a partner, and a job. Also, anger and frustration about their situation could be a turning point and lead to the decision that it was enough. The young adults described that intrinsic motivation was crucial to change their way of living but they needed support to take steps towards recovery. Their relationships with relatives and the emotional support they received from them gave them the strength to fight against the mental illness and strive towards recovery. Close relationships with relatives gave young adults hope and a purpose in life even though it was difficult to share their feelings and emotions with relatives. Most of the young adults described that support from relatives was crucial for their transition towards adulthood and recovery.

"It has been my salvation, if I hadn't had them I would not be where I am today, they (parents) have really done everything to help me recover."

The young adults further described that taking part in social relations could give hope and encourage striving for recovery. A lack of support from relatives highlighted a need for guidance in daily life and emotional support from other adult persons, such as persons in a patient association. Some young adults described that social relations also could contribute to a loss of hope and motivation to strive for recovery, such as experiences of relapse when they returned to old friends. Thus, it became important to choose friends who were supportive. Furthermore, young adults narrated

about friendships that led to increased self-esteem and confidence. One young adult described the change in her relationships once she gained the courage to look at herself as a healthy person, which started the process towards recovery.

> *"Your relationships are much more fun when you are healthy and you can talk in a normal way. It's not like anyone needs to take care of me, I can take care of myself and my relationships. I can also give support if someone needs it from me."*

The young adults described how important it was for their recovery to continue school, get a job and have daily activities. Some had substantial support from school through a mentor or a teacher who made an extra effort and understood their situation. Such support could consist of phone calls during leisure time or an email to check that everything was right. It could further be assistance in making appointments at employment services to arrange a trainee program. It was also important that the teacher understood the young adult's situation so they did not put too much pressure on them or considered them lazy.

> *"They really cared; they talked and kept in touch after school…they could send an email on Sunday and ask how I felt…it wasn't just -hey I'm your teacher…they showed that they really cared."*

Some young adults said that the neuropsychiatric diagnosis they received made it possible to get support from school or social services. They also narrated the importance of communicating their diagnosis, to have the opportunity to come to a new beginning, by co-ordinate tasks and get a balance between requirements and capability.

DISCUSSION

The aim of this study was to explore young adults' experiences of psychiatric care during transition to adulthood. The results showed that it was complicated to become an adult because of the ambivalence in being in-between adulthood and childhood. According to Bridges (2004), life changes, such as transition to adulthood, starts with an end of the past and leads to a new beginning. According to Arnett (2001) the most important criteria for conception of being an adult is to accept responsibility for one's actions and being able to decide on one's own believes and values. The process can comprise a period of confusion and distress in-between fairly stable states (Chick, & Meleis, 1986). Therefore, it is important to take into account young adults' experiences of care at the period of transition to adulthood and transfer from CAP to GenP (Lindgren et al., 2014). The concept of transition is consistent with a holistic view of health and promotes thinking that a person undergoes simultaneous transitions (Meleis et al., 2000). According to Arnett (2001), only 46 percent of young adults felt they reached adulthood at the ages of 20-29, and 50 percent felt that they reached adulthood in some respects. As the pathway into adulthood is currently an extended process and young adults may need support from their families of origin even after age of 18, Settersten and Ray (2010) argue that there is a mismatch between young adults in transition to adulthood and the existing institutional supports. For already vulnerable young adults with less resources or a fragile family relationship, the cut-off from society support when they come of age may be especially appreciable. In the present study support was a prerequisite for a successful transition to adulthood. In contrast, lack of support could lead to dropouts from health care, making daily life become a struggle. Therefore, consistent with the result in this study, professionals need to provide support based on individual needs, instead of using age to assess for maturity level (Murcott, 2014).

The results in this study showed the importance of an ability to create a caring relationship and being encountered as a unique person to motivate to continue care and strive for recovery. According

to Ryan and Deci (2000), motivation concerns energy and directions for action; thus, it may have consequences for well-being. Social and environmental factors can facilitate or undermine intrinsic motivation. By supporting a person's autonomy, competence, and relatedness, self-motivation can increase. Professionals are important as helpers, supporters, enablers, and facilitators for a patient's motivation, sense of control, and sense of connectedness (Gibson, 1991). The care environment is an important factor to enable both social relations and relationships with professionals (Edvardsson, Sandman, & Rasmussen, 2005; Marcheschi, Brunt, Hansson, & Johansson, 2013). The young adults in this study narrated that a supporting care environment contributed to a feeling of being a person; however, a poor environment contributed to increased illness and a feeling of offended dignity. Therefore, professionals need to facilitate access to and utilizations of both personal and environmental recourses, such as self-esteem and social support (Jones, & Meleis, 1993), and empower the patients by viewing them as persons and treating them with respect and dignity (Craig, 2008). According to the result in this study, professionals need to put effort into creating a caring environment where connectedness with both other patients and professionals can be facilitated to increase intrinsic motivation for recovery and health.

This study further showed that an interpersonal relationship is essential and that through a supportive and trustful relationship the patient can be encouraged to express feelings and thereby improve their self-awareness, consistent with earlier research (Milton, 2008; Peplau, 1991). A person in transition needs awareness of the changes that are occurring, as the transition process is related to definition and redefinition of self and situation (Chick, & Meleis, 1986) Awareness can influence the level of engagement in the transition (Meleis et al., 2000). Through interpersonal relation the professionals can support the patients to identify and express their needs and goals (Peplau, 1991), which are crucial to be able to plan care and interventions based on patient needs. They then can further evaluate outcomes (Meleis, 1990). Therefore, it is important to put effort in a trustful relationship, which creates in a reciprocal process affected by both the patient and the professionals (Denhov, & Topor, 2011). Furthermore, both the patient and the professionals will be affected by the process (Eriksen, Arman, Davidson, Sundfor, & Karlsson, 2013).

In the present study, experiences of relationships were described as both supportive and unsupportive, with varying consequences. Relationships lacking in supportive communication fostered feelings of hopelessness and offended dignity, while supportive and caring relationships supported hope for change and recovery. For young adults in transition to adulthood while striving for recovery, a caring relationship may lead to steps and turning points that prevent changes in life situation. Experiences of recovery and health can only be understood in the context of everyday life, and social/environmental concerns must be considered along with personal matters (Meleis, 1990). In these results, support from relatives, friends, and significant others were seen as facilitators for a young adult's transition to adulthood and recovery. In the context of mental health nursing, recovery is defined as "a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness" (Anthony, 1993, p. 15). This could imply being able to work or go to school and living an ordinary life that includes friendship and finding a partner (Craig, 2008). According to results in the present study the concept of recovery is interpreted as correlated to the changes a person undergoes in a health/illness transitions process; thus, the different theories seem able to accommodate (Chick, & Meleis, 1986). Young adults described turning points, such as a conscious decision, that increased their motivation to strive for recovery and regain an ordinary life (Kartalova-O'Doherty, Stevenson, & Higgins, 2012). Their striving could include both the internal and external reasons they were fighting for and fighting against (Kartalova-O'Doherty, & Tedstone

Doherty, 2010). Recovery can further be explained in different stages (Slade, Amering, & Oades, 2008), and most of the young adults in the present study were in the beginning their recovery. Their hope for recovery had recently been found and these experiences of hope were important to sustain the dream for a future (Herrestad, Biong, McCormack, Borg, & Karlsson, 2014).

Methodological considerations

The strength of this study is its insider perspective, consisting of young adults' experiences. Because of impaired health status or mental disabilities the young adults had varied abilities in articulating their opinions, but through the first author's solid experience in psychiatric nursing they were supported to express their experiences. According to Corbin and Strauss (2008), a researcher's professional experiences can enhance sensitivity, which means being able to present the participants' view through immersion in the data. By using constant comparison and always working with concepts in terms of their properties and dimensions in the analysis, the researcher kept focus on what the participants were saying and doing. The limitations were the difficulties in recruiting participants and thereby the changes in the inclusion criteria and the recruitment process. In total, eleven young adults participated; each had different experiences and the results were consistent with earlier research in the same topic. Thus, the trustworthiness was strengthened (Corbin, & Strauss, 2008). Young adults with mental illness can be viewed as a vulnerable group and difficult to recruit, but their voices need to be heard; thus, participating in research is necessary despite vulnerability.

CONCLUSIONS

In conclusion, it seems to be more important *how* the professionals relate to young adults when they provide support than *what* the professionals do. This also includes creating a caring relationship, empowering them, and providing hope. It seems important to understand what it means to be a young adult and the ambiguity of being neither an adolescent nor an adult, to be able to connect with them and create a caring relationship. By being an active listener and asking questions, the young adults will be supported in expressing themselves; then it will be possible to support them in a way that corresponds to their needs. The young adults further need to feel that they are unique persons with competence and inherent value. With support from both professionals and significant others, the young adults can be empowered to reach recovery and adulthood and manage daily life. To increase understanding of the causes of dropouts, further research is needed that focuses on what kind of support the young adults need. It is also of interest to involve primary health care and municipality based services in further research.

Declaration of interest

The authors declare no conflict of interests.

ACKNOWLEDGEMENT

The authors are grateful for the shared experiences from the participants. This study was funded by Luleå University of Technology, Sweden.

REFERENCES

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal, 16*(4), 11-23. doi: http://dx.doi.org/10.1037/h0095655

Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. *American Psychologist, 55*(5), 469-480.

Arnett, J. J. (2001). Conceptions of the Transition to Adulthood: Perspectives from Adolescence Through Midlife. *Journal of Adult Development, 8*(2), 133-143.

Bridges, W. (2004). *Transitions: making sense of life's changes*. Cambridge, MA: Da Capo Press.

Chick, N., & Meleis, A. I. (1986). Transition: a nursing consern. In P. L. Chinn (Ed.), *Nursing research methodology, issues and implementation* (pp. 237-257). Rockville, Maryland: Aspen.

Corbin, J. M., & Strauss, A. L. (2008). Basics of qualitative research: techniques and procedures for developing grounded theory. Thousand Oaks: SAGE.

Craig, T. K. J. (2008). Recovery: Say what you mean and mean what you say. *Journal of Mental Health, 17*(2), 125-128.

Davis, M. (2003). Addressing the needs of youth in transition to adulthood. *Administration and Policy in Mental Health, 30*(6), 495-509.

Declaration of Helsinki - Ethical Principles of Medical Research Involving Human Subjects. Retrieved June 10, 2014, from http://www.wma.net/en/30publications/10policies/b3/

Denhov, A., & Topor, A. (2012). The components of helping relationships with professionals in psychiatry: Users' perspective. *International Journal of Social Psychiatry, 58*(4), 417-424.

Edvardsson, J. D., Sandman, P.-O., & Rasmussen, B. H. (2005). Sensing an atmosphere of ease: a tentative theory of supportive care settings. *Scandinavian Journal of Caring Sciences, 19*(4), 344-353. doi: 10.1111/j.1471-6712.2005.00356.x

Eriksen, K. Å., Arman, M., Davidson, L., Sundfor, B., & Karlsson, B. (2013). "We are all fellow human beings": Mental health workers' perspectives of being in relationships with clients in community-based mental health services. *Issues in Mental Health Nursing, 34*(12), 883-891.

Gibson, C. H. (1991). A concept analysis of empowerment. *Journal of Advanced Nursing, 16*(3), 354-361.

Hedelin, B. (2006). Att främja psykisk hälsa och förebygga psykisk ohälsa. In B. Arvidsson & I. Skärsäter (Ed.), *Psykiatrisk omvårdnad - att stödja hälsofrämjande processer*. [in swedish]. Lund: Studentlitteratur.

Herrestad, H., Biong, S., McCormack, B., Borg, M., & Karlsson, B. (2014). A pragmatist approach to the hope discourse in health care research. *Nursing Philosophy*. doi: 10.1111/nup.12053

Jones, P. S., & Meleis, A. I. (1993). Health is empowerment. *Advances in Nursing Science, 15*(3), 1-14.

Kartalova-O'Doherty, Y., Stevenson, C., & Higgins, A. (2012). Reconnecting with life: A grounded theory study of mental health recovery in Ireland. *Journal of Mental Health, 21*(2), 136-144.

Kartalova-O'Doherty, Y., & Tedstone Doherty, D. (2010). Recovering from recurrent mental health problems: Giving up and fighting to get better. *International Journal of Mental Health Nursing, 19*(1), 3-15.

Lager, A., Berlin, M., Heimerson, I., & Danielsson, M. (2012). Young peoples health: Health in Sweden: The National Public Health Report 2012. Chapter 3. *Scandinavian Journal of Public Health,* 40(9), 42-71. doi: 10.1177/1403494812459459

Lenz, B. (2001). The transition from adolescence to young adulthood: a theoretical perspective. *Journal of School Nursing, 17*(6), 300-306.

Lindgren, E., Söderberg, S., & Skär, L. (2013). The gap in transition between child and adolescent psychiatry and general adult psychiatry. *Journal of Child and Adolescent Psychiatric Nursing, 26*(2), 103-109.

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* (8). doi: 10.1155/2014/457160

Marcheschi, E., Brunt, D., Hansson, L., & Johansson, M. (2013). The influence of physical environmental qualities on the social climate of supported housing facilities for people with severe mental illness. *Issues in Mental Health Nursing, 34*(2), 117-123. doi: 10.3109/01612840.2012.731137

McGrandles, A., & McMahon, K. (2012). Transition from child and adolescent to adult mental health services. *British Journal of Nursing, 21*(17), 1031-1039.

Meleis, A. I. (1990). Being and becoming healthy: the core of nursing knowledge. *Nursing Science Quarterly, 3*(3), 107-114.

Meleis, A. I. (2010). Theoretical development of transition. In A. I. Meleis (Ed.), *Transitions theory: Middle range and situation specific theories in nursing research and practice* (pp. 13-51). New York: Springer Publishing Company.

Meleis, A. I., Sawyer, L. M., Im, E., Messias, D. K. H., & Schumacher, K. (2000). Experiencing transitions: an emerging middle-range theory. *Advances in Nursing Science, 23*(1), 12-28.

Milton, C. L. (2008). Boundaries: ethical implications for what it means to be therapeutic in the nurse-person relationship. *Nursing Science Quarterly, 21*(1), 18-21. doi: 10.1177/0894318407310755

Murcott, W. J. (2014). Transitions between child and adult mental health services: service design, philosophy and meaning at uncertain times. *Journal of Psychiatric and Mental Health Nursing*. doi: 10.1111/jpm.12150

OpenCode 4.0. (2013). University of Umeå, Sweden: ICT Services and System Development and Division of Epidemiology and Global Health. Retrieved from http://www.phmed.umu.se/english/divisions/epidemiology/research/open-code/?languageId=1

Peplau, H. E. (1991). *Interpersonal Relations in Nursing*. New York, NY, USA: Springer Publishing Company.

Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68-78.

Settersten, J., R. A. , & Ray, B. (2010). What's Going on with Young People Today? The Long and Twisting Path to Adulthood. *The Future of Children, 20*(1), 19-41.

Singh, S. P. (2009). Transition of care from child to adult mental health services: The great divide. *Current Opinion in Psychiatry, 22*(4), 386-390.

Singh, S. P., Evans, N., Sireling, L., & Stuart, H. (2005). Mind the gap: the interface between child and adult mental health services. *Psychiatric Bulletin, 29*, 292.

Slade, M., Amering, M., & Oades, L. (2008). Recovery: An international perspective. *Epidemiologia e Psichiatria Sociale, 17*(2), 128-137

IV

Being a parent to a young adult with mental illness in transition to adulthood

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(in manuscript)

ABSTRACT

Transition to adulthood can be a critical period for young adults with mental illness. That may put demands on relatives to continue providing support even though the young adults have reached the age of majority. The aim of this study was to explore relatives' experiences of parenthood to a young adult with mental illness in transition to adulthood. To reach the aim of the study, individual interviews were conducted and analysed according to Grounded Theory. The analysis resulted in a core category showing that parenthood was like walking a tightrope with being both a parent and a caregiver. Relatives experienced powerlessness and inescapable duty with limited possibility to be relieved. With a family nursing approach and a view of psychiatric care as a family affair, relatives can be supported in managing their own lives when young adults' needs are met, so that they could be relieved from their burden.

Keywords: grounded theory, transition, relatives, young adults, mental illness, psychiatric care

INTRODUCTION

Transition to adulthood can be a critical period for young adults and especially for young adults with mental illness (McGrandles, & McMahon, 2012; Singh, Evans, Sireling, & Stuart, 2005). Because of their ill health they can be less prepared to take care of themselves than their peers (Davis, 2003). A prolonged transition to adulthood may further put demands on relatives to continue providing support to the young adults, although they have already reached the age of majority (Davis, & Vander Stoep, 1997). Being a parent to a young adult with mental illness can also have an impact on family health due to the burden of being a caregiver (Doornbos, 2002).

Emerging adulthood is a period of life in between adolescence and adulthood (Arnett, 2000) and the onset and duration of transition usually occurs between the ages of 16–25 years (Davis, & Vander Stoep, 1997). This period in life represents several challenges for young adults with mental illness with high risks of dropping out of school, high unemployment rate, low level of independent living, and lack of community support (Armstrong, Dedrick, & Greenbaum, 2003; Stoep, et al., 2000). Mental illness among young adults in Sweden has increased during recent decades. The percentage of young adults aged 16–24 who suffer from anxiety, nervousness, and angst, increased from 9 to 30 percent for women and from 4 to 14 percent for men between the years 1988 and 2005 (Lager, Berlin, Heimerson, & Danielsson, 2012). In the 1980s mental illness was more prevalent in older age groups, but today the age disparities are minor. Suicidal thoughts are also common and as many as 20 percent of women and 13 percent of men aged 16–29 reported suicidal thoughts at some point, whereas six percent of women and four percent of men have attempted suicide.

Young adults who need psychiatric care during transition to adulthood need to be transferred from Child and Adolescent Psychiatry (CAP) to General Psychiatry (GenP) when they reach the age of 18. To manage this transition and avoid the caring gap between CAP and GenP they need support from both relatives and professionals (Lindgren, Söderberg, & Skär, 2013, 2014). During young adults' transition to adulthood and transfer to GenP the circumstances for relatives change. The primary focus for professionals at GenP is to develop caring relationships with the young adult (Weimand, Sällström, Hall-Lord, & Hedelin, 2013) and therefore, the professionals have to deal with their loyalty to the young adults and the knowledge that relatives need participation and information about care (Sjöblom, Pejlert, & Asplund, 2005). Having the young adult admitted to inpatient care at GenP can be a time of crisis for the family (Clarke, & Winsor, 2010). Weimand, Hedelin, Hall-Lord, and Sällström (2011) further showed that relatives felt excluded from care and that their struggle to achieve involvement could end up with a feeling of powerlessness.

The family burden among relatives to young adults with mental illness is well known (Ekdahl, Idvall, Samuelsson, & Perseius, 2011; Wilhelmsson, Graneheim, Berge, Johansson, & Åström, 2010; Östman, Wallsten, & Kjellin, 2005) and research shows that relatives need support to manage daily life (Nordby, Kjonsberg, & Hummelvoll, 2010; Rusner, Carlsson, Brunt, & Nystrom, 2013). To be able to support the young adults in a way that corresponds to their needs, it is important that professionals have knowledge about the multiple simultaneous transitions they undergo during transfer from CAP to GenP (Lindgren, et al., 2014). It is a process requiring therapeutic intents, and moreover includes changes that have an impact on relatives' possibilities to be involved in care. Research showed that young adults need support from their relatives to manage transition and striving to reach recovery (Lindgren, Söderberg, & Skär, in press). This situation with persistent responsibility to provide support to a young adult with mental illness may have an impact on relatives' daily life and their possibility of letting go. The aim of this study was therefore to explore relatives' experiences of parenthood to a young adult with mental illness in transition to adulthood.

MATERIALS AND METHOD

Grounded Theory (GT) design described by Corbin and Strauss (2008) was selected as a suitable method to reach the aim of this qualitative study. Data was collected by individual interviews.

Participants

To recruit participants for the study a purposive sampling was used. The head of outpatient units at GenP in the northern part of Sweden was informed about the study and asked to invite relatives to participate. The inclusion criteria were: relative (parent/guardian) to a young adult aged 18–25 years old, with experiences of care at both CAP and GenP, and referred to GenP from CAP. As only one participant responded, the criteria about referral were removed and further invitations to participate in the study were handled by patient associations. Five participants were recruited through patient associations through so-called snowballing (Polit, & Beck, 2008, p. 355), when one relative asked another person to participate. Five relatives who participated in an earlier study (Lindgren, et al., 2014) were also asked to participate. Four of them responded positively to give another interview. In total, 10 relatives participated (2 fathers and 8 mothers). One couple gave the interview together. Four relatives were married, four relatives were single and one relative was re-married. In all families except for one, the young adult with mental illness had siblings. One family had their first contact with psychiatric care in the young adult's early childhood; the others had their first contact when the young adults were between 14–17 years old.

Data collection and analysis

Data was collected through individual interviews (Kvale, & Brinkmann, 2009) with eight relatives and one interview with a couple. The interviews took place at the relatives' homes, at the participants' workplace, at the university, and at a patient association. In the beginning of the interview the relatives were asked to narrate about when they had their first contact with psychiatric care and their experience of parenthood in that situation. The interview continued with questions about the young adults' current need of care and support, their experience of parenthood in that situation, their possibility to participate, how to manage daily life, and how to get the strength they need to manage.

In accordance to GT approach, literature was read in parallel with data collection and analysis in order to stimulate theoretical sensitivity (Corbin, & Strauss, 2008). This approach resulted in an opened and flexible sampling strategy, thus questions were added to the interview guide based on concepts derived from data. Such questions were about relatives' possibility to be relieved from responsibility, the value of a diagnosis, and the consequences of a lack of professional support to the young adults.

The analysis started directly after the first interview by reading through the whole interview text, followed by open coding line by line. The initial step in the analysis pertains to defining concepts and discovering categories and their properties and dimensions. By using constant comparison, similarities and differences were compared and codes were grouped together into categories. The analysis continued with axial coding, where categories related to each other were grouped together. Finally, a core category was defined by an integration of all categories and concepts (Corbin, & Strauss, 2008). Each interview lasted between 39 and 130 minutes (m = 73), and was transcribed verbatim. The Internet program Open Code 4.01 was used during the code process.

Ethical considerations

In the beginning of the interview all participants were given verbal information about the study and told that they could discontinue the interview whenever they wanted without any disadvantage. Informed consent was obtained when the relatives received information and signed a form. Ethical considerations were made according to predictable risks and burdens caused by the interview, but the benefits of receiving the relatives' points of view were assessed to outweigh the risk of participation (WMA, 2014). The regional Ethical Review Board in Sweden approved the study.

RESULTS

The analysis resulted in a core category: feeling powerless when walking a tightrope but holding onto hope. The core category was then related to three categories: being a powerless round-the-clock parent; being part of a frustrating and frightening world; and hoping for changes and a possibility of letting go.

Core category: Feeling powerless when walking a tightrope but holding onto hope

The core category shows that experiences of parenthood to a young adult with mental illness in transition to adulthood were like walking a tightrope with a feeling of powerlessness. The tightrope act was like being both a parent and a caregiver or letting the young adults take own responsibility. It was also like a tightrope act fighting for the young adults' right to receive appropriate care, or accept being excluded from the young adults' care. The relatives felt powerlessness towards society, mental health services, and even to the young adults themselves. They felt powerless as they saw the young adults' needs, but had no possibility to be involved in decisions, or became excluded because of secrecy. To being able to continue to provide support to the young adults and moreover, manage their own lives, the relatives wanted supportive relationships with professionals and involving attitudes where they were seen as resources. When mental health services met the young adults' needs, the relatives could be relieved from responsibility. Furthermore, they were relieved and gained the strengths they needed, by a supportive network in their family, in social relations and among colleagues. Hope for changes and recovery was the lifeline they held on to, in order to survive and keep the young adults alive.

Being a powerless round-the-clock parent

This category describes that relatives to young adults with mental illness experienced parenthood as an inescapable duty with limited possibility to be relieved from responsibility. Most of the relatives described that they felt powerless against authorities, mental health services, and even against the young adults, since they had come of age. Because of secrecy the relatives' possibility to have impact on care decisions were decreased. They felt powerless, because no one seems to be willing to take responsibility for the young adults' whole life situation. Lack of resources, discontinuity, and that the care did not meet the young adults' needs, were described as the main reasons for their feelings of powerlessness. That became especially obvious when the young adult had comorbidity, i.e., mental illness and drug addiction. In these situations the responsibility to take care of the young adult fell back on the relatives. They further described that in some situations it was easier to take the responsibility and be the young adults' caregiver, then fighting for care corresponding to the young adults' needs. The fight for the young adults' sake and right to receive care took more energy from the relatives than providing the care themselves.

"You get tired of trying to scream. You get tired of make phone calls to get help. At the end it's easier to do it yourself. It takes less time and engagement."

The relatives described that they carried an extensive duty though the young adults were grown up. They needed someone to take care of them such as making sure that the young adult took care of personal hygiene and had a natural circadian rhythm. It could further require protecting them from self-harm or looking after them so they were eating and not vomiting after the meal. Furthermore, relatives said that it was a tightrope act to let the young adult take responsibility for their own lives. The relative could give advice and support, but they felt powerless as they could not take for granted that the young adults followed their advice and listen to them. They also described that they wanted the young adults to be independent and have their own housing, whilst that also contributed to insecurity as the relatives' chances to keep an eye on them decreased.

"It's not always a benefit that he has his own housing. It's a huge insecurity letting him be there because you never know what's happening behind those doors. With that in mind it's easier for me to have him on my sofa."

For those relatives the parenthood became a matter of survival for the young adults and even for themselves. They thought that their young adults probably would not be alive, if they not had been that much engaged in their health and well-being. Although the relatives felt powerless and experienced a heavy burden, they managed simply because they had to and had no other options. The relatives also described that they felt powerless when they had to fight for the young adults' possibility to finish school, get a job or any kind of financial assistance. Furthermore, when required, they had to fight for support and assistance to make it possible for the young adult to move on to their own apartment. One relative described that because of the lack of professional support she had to search for all of the information about available social and financial services by herself. However, because of her employment she had some advantages of knowing how to do things and where to seek help, and she was thankful for that.

"I've got to be active and I believe I've some advantage of working in social service. I know a little what the municipality can offer, but I've search information on Internet and pondered and talked to people."

Some of the relatives had their own experiences of mental illness and psychiatric care, and that could be both a drawback and an advantage, and enhance the sense of powerlessness. The drawback was that it took so much energy to fight for the young adults' rights, depending on the young adults' mental health status and need of care, that they hardly manage their own daily life. They described the experience as a tightrope between fighting for the young adults' rights and being viewed as troublesome or judged because of their own mental illness. The advantage could be that they understood how it felt to be admitted to inpatient care and thereby could support the young adult by confirming their feelings. The relatives also described that they had the great advantage of knowledge about the health organization, their rights and who to contact, when they supported their young adults and struggled that they should receive the care they needed.

"I get a good encounter because I'm so well-read so they can't make tricks with me, but I hear about others who have it really hard."

Relatives further described that taking responsibility for young adults with mental illness affects their own life in different ways. Some relatives described that they had to be available round-the-clock, and prepared for unpredictable situations. That was something that had an impact on their social

relationships, as it became difficult to make plans. Some even told that they consciously limited their social relations to be able to handle the family situation. Those who were married said that it was a miracle and strength that the relationship was stable, and some single relatives told that they had no time or capacity to invest time and emotions in a relationship with a potential partner. They further talked about how siblings had to stand back to benefit the young adults' needs and that it sometimes was difficult to provide equal attention to all children in the family. Though the young adults' mental health put high pressure on the family the relatives described it as also having positive impact on relationships in the family. The family bonds got stronger and they learned to be open and talk to each other about all kinds of subjects.

Be part of a frustrating and frightening world

This category describes how relatives experienced changes related to psychiatric care when their child had ended care at CAP and continued at GenP. They described that it felt like they stepped into a frustrating and frightening world. In some cases the transfer was well planned but some had frustrating and frightening experiences of the transfer to GenP. Some young adults had a transition plan including establishment of relationships at GenP before transfer, but the plan was not carried out, and the young adult became admitted to GenP without previous contacts at GenP. The new arising situation was terrifying for both the young adults and the relatives, and they felt disappointed that the promises that were made were broken. One relative told about a situation when she tried to convince the professionals that the plan they had was valid, but their protests had no impact on the final decision.

> *"We have a plan…it's not completed yet, we should make connections first...but 'NO, you have to go to the adult side'. It was horrible, X was totally in shock…and when visiting time was over I had to leave her."*

Relatives further described changes that occurred related to the ability to participate in care. At CAP they were involved in all decisions and it was almost compulsory for them to stay at the ward with the young adult. After transfer to GenP they felt excluded, as they could not participate as they had before. They also felt that the support the whole family received from professionals at CAP was cut off and they felt left on their own. Secrecy towards the relatives was further a new experience at GenP and the relatives described both good and bad experiences. Some had good experiences of making an agreement between the young adult, the relative, and the professional and thereby the relatives could participate in the young adults' care. One relative who was participating by proxy, found that convenient but she wished that she got information about that possibility much earlier. Relatives also described extreme frustration and powerlessness when they became excluded from their young adult's care. They told about situations when the young adult was missing or they had no information about their health condition, and no one in health care could answer their questions because of secrecy.

> *"I respect it [secrecy] but it's very, very difficult to handle…when he suddenly is missing and no one can tell me where he is…it's a huge work trying to get past that obstacle."*

The relatives also felt powerless and frustrated, because they had no possibility either to give support to the young adult, or participate in their care by sharing their knowledge about the young adult with the professionals. That feeling became even stronger when they realized that the communication between CAP and GenP was deficient, as there was little interest to read the medical records from CAP. Some relatives even thought that the psychiatric care caused more harm than cure. They described that the young adults suffered from a lack of resources though they had to wait years

for examination or required treatment. Furthermore, one relative described that her son was in need of support from municipality-based services to get daily activities and an apartment. It was crucial that the interventions were synchronized to be efficient, as it was wasted resources to support him with an apartment without daily routines and work simultaneously. The relatives also felt guilty for admitting the young adult to inpatient care when they had no other choice. They narrated situations when inpatient care, i.e., mental health services or municipality-based care, caused increased drug addiction or could not prevent suicide attempts, which led to notifications made to the National Board.

> *"The social services raised the alarm and took him from there. He came out as a really full-blooded drug addict."*

The relatives narrated that the psychiatric care needs to be adjusted to young adults' needs. They said that the young adults in many ways have delayed maturity because of the mental illness and that they need to be encountered according to maturity. The relatives expressed a need for smaller units designed for young adults, as they felt worried and frightened about all of the different patients the young adults would meet at the inpatient care. They also wanted professionals at GenP to have an inclusive attitude towards relatives, and that they were seen as resources. Relatives had experiences that the diagnosis was more important than the young adults' needs, and when they tried to express something about the young adults, the professionals were not willing to listen. The relatives had the feeling that professionals did not want their opinions.

> *"Not counteract, but more a feeling that they are not interested…I had an action but I realized that it didn't fall into the good ground. They had already made up their minds about his problems…I could tell a lot but they listened only with half an ear."*

Although the relatives felt powerless and frustrated, they narrated about the importance of encountering the young adults with respect to their autonomy. Relatives with good experience of being part of the young adults' care told said the professional first checked with the young adult about their relation, and then talked to them about the importance of relatives for their recovery. The young adult and the therapist then made a decision when the relative should be participating and what they were going to talk about, before they invited the relative to participate.

Hoping for changes and a possibility to letting go

This category describes how relatives, although they felt powerless and carried inescapable responsibility for the young adults, were holding onto hope for changes, for the young adults' recovery, and for their own situation. They described episodes when they felt that the young adults reached a milestone and that gave hope for stability in the future. They described situations such as when the young adults managed to graduate from high school, connected in a partner relation, or got a job. It could further be when the young adult moved from his or her origin family to an apartment of their own. All these circumstances were described as important for the young adult to reach recovery, but by extension even for the relatives to experience hope for changes. They further narrated about encounters with 'the right person' who finally took responsibility and showed they were willing to "walk an extra mile" to meet the young adults' needs. That led to a feeling of hope and a possibility to be relieved from responsibility. They further described how they became relieved and could rest from taking responsibility by a supportive caring environment, which included security, treatment based on the young adults' needs, and relationships with professionals based on trustful communication and participation.

"It's relieving to being able to leave the responsibility to someone else…then I can rest…let it go in my mind for a while…not having it both physical and thought all the time."

and

"To be honest, I'm thankful for every day someone other than me, take responsibility for him…that I can wake up in the morning and know that someone else check that he is alive."

Relatives described further that they needed support from professionals for their own sake, to facilitate their ability to handle the situation. They described a need to find out their role as a relative to the young adults, as it was difficult to be both a parent and a caregiver with responsibility for the young adults' health. One relative who received support described that it was crucial for her to find herself again and manage her own life, after she had been relieved from responsibility. The support she received also facilitated her ability to letting the young adult go. The relatives further described that a supportive network was important for holding on to hope and be supported in letting go. It could be support from family members, grandparents, friends and colleagues, or other relatives with similar experiences. The importance was to have relationships with others, where they could relax and be honest about their situation and not have to keep up a façade. They also described that they got the strength to keep going and manage life by reading books, walking outdoors, sleeping, traveling, doing workouts, or by indulging themselves doing nothing at all. One relative narrated that she, one day when she had time, will give herself a present by letting herself take therapy sessions.

"I've actually thought to indulge myself going to therapy…to deal with this anxiety…I actually can't control whether he is alive or not."

DISCUSSION

The aim of this study was to explore relatives' experiences of parenthood to a young adult with mental illness in transition to adulthood. Being a parent to a young adult with mental illness meant a heavy burden and round-the-clock responsibility with limited opportunities to be relieved. According to Johansson, Anderzen-Carlsson, Åhlin, and Andershed (2010) parents to young adults with mental illness described the parenthood to be permanently on-call. The parenthood was compared with an emotional burden associated with distress and disruption for the whole family. It was like an ongoing challenge to balance between the young adults' needs and those of other members of the family (Johansson, Anderzen-Carlsson, Åhlin, & Andershed, 2012). According to Bridges (2004) all parts in the family system interact with each other; one member in the family is part of a larger whole and what happens to one family member affects the whole family. Mental illness is therefore a family issue as relatives are affected by the the person with mental illness and in turn the relatives are most likely to affect the person with mental illness (Hoffman, Fruzzetti, & Buteau, 2007).

Relatives in this study described significant changes related to transition from CAP to GenP. It was frustrating and frightening when planning for transition was not followed and when they experienced that the young adults did not received appropriate care. Furthermore, they felt powerless when they could not be involved in decisions, as they were used to at CAP. Consistent with this, Weimand et al. (2011) and Wilhelmsson (2011) showed that distrust of mental health services and insufficient support to the person with mental illness put the relative in an inescapable situation and it was difficult to balance between being a parent and a caregiver (Lindgren, Åstrom, & Graneheim, 2010). Ekdahl et al. (2011) showed further that relatives struggled with a feeling of guilt and questioned if they could have done something to stop or prevent the ill health. Because of lacking

supportive encounters from professionals, the relatives felt that they were useless as a parent. Relatives in this study struggled with guilt when they had no other choice than admitting the young adult to inpatient care, even though they felt that the care caused more harm than cure.

Relatives further described that they felt frustration and powerlessness when they were excluded from care. It was difficult to handle the secrecy, and when they needed information about their young adults' health and well-being, no one was able to answer their questions. Nicholls and Pernice (2009) described that relatives perceived rights to information from professionals but it could cause stress when they were left out, as the patient has rights of confidentiallty. Relatives also felt a growing distrust towards professionals as they were not informed about the family member's health situation, which resulted in frustration, fear, powerlessness and despair. Professionals might therefore experience an ethical dilemma when patients choose not to share information about their health with relatives (Sjöblom, et al., 2005). Nurses' loyalty with the patients and relatives' need of information could therefore both be a disadvantage or a strenght but the decision must be based on an individual judgement of the patients' desires (Sjöblom, 2010). However, some relatives in this study described experience of commitments between the young adults, the professionals, and the relative, which created opportunity for the relative to be involved. When the young adult had established trustful caring relations, the relatives could also rely on care and be relieved from responsibility. According to Sveinbjarnardottir, Svavarsdottir and Wright (2013) relatives can perceive significantly higher emotional support from professionals with decreased feelings of powerlessness if they are invited to a short, therapeutic conversation (Wright, & Leahey, 1999). This conversation would be a means to share information based on expectations of hospitalization, suffering, and the most pressing concerns within the family.

The relatives in this study balanced between leaving the responsibility of care to the young adults and the professionals or being seen as a troublesome parent. It was a traumatic experience for relatives when the young adults were admitted to inpatient care and they felt excluded from information. According to Clarke and Winsor (2010) professionals could relieve the burden by acknowledging the family and showing that they understand their situation. Relatives in this study further described that they wanted the professionals to have an inclusive attitude towards them and encounter them as resources for their young adults. Nordby et al. (2010) showed that professionals should concider relatives as experts on their young adult and let them be heard and supported in sharing their knowledge and experiences with the professionals. Relatives play an important role in the young adults' recovery and transition to adulthood (Lindgren, et al., in press) but being in between demanding needs is a balancing act, especially if the relative is a parent. Relatives who do not manage their own lives are at risk of not being able to support the person with ill health (Rusner, et al., 2013). This seems transferable to our findings, when relatives experienced parenthood like walking a tightrope with a feeling of powerlessness, as their engagement became a matter of life or death for both the young adults and the relatives themselves.

Relatives in this study hold onto hope for changes and recovery for their young adults. Hope for change was lit when the relatives could rely on the care the young adult received, or when the young adult reached a milestone in life. Important tasks for professionals are to provide sufficient information, involve the relatives in decisions and instill hope (Clarke, & Winsor, 2010). With a family nursing approach professionals views of families can be changed (Bell, 2013; Wright, & Bell, 2009) and the relatives can be viewed as less burdensome in psychiatric care (Sveinbjarnardottir, Svavarsdottir, & Saveman, 2011). Furthermore, by considering mental illness as a family affair and changing the view of relatives, the relatives can be relieved from the family burden.

Methodological considerations

The strength of this study is its insider perspective, consisting of relatives' experiences of parenthood to a young adult with mental illness. Through the first author's experiences of psychiatric nursing, support was lent in expressing those experiences, though it sometimes became hard to narrate about all memories. According to Corbin and Strauss (2008), a researcher's professional experiences can enhance sensitivity, which means being able to present the participants' view through immersion in the data. The researcher kept the focus on what the participants were saying and doing by using constant comparison and always working with concepts in terms of their properties and dimensions in the analysis. The limitations of this study were the difficulties in recruiting participants and thereby the changes in the inclusion criteria and the recruitment process. Some participants were recruited through so-called snowballing, when one participant asked another person to participate (Polit, & Beck, 2008, p. 355). In such cases the first author was extra sensitive when receiving informed consent from new participants, so they did not feel pressure because a friend asked them to participate. In total, 10 relatives participated; each had different experiences and the results were consistent with earlier research on the same topic. Thus, the trustworthiness was strengthened (Corbin, & Strauss, 2008).

CONCLUSIONS

Based on these results, it seems important to support relatives to reach balance between taking responsibility and letting go, during young adults' transition from CAP to GenP and from childhood to adulthood. By supporting relatives and considering them as resources, their feeling of powerlessness can be reduced. With a family nursing approach and a view of psychiatric care as a family affair, relatives can be supported in managing their own lives. When young adults' needs are met, relatives could be relieved from their burden of responsibility. When their young adults created trustful caring relationships the relatives could rely on the care and feel hope for changes and recovery for their young adults' futures. It seems further important to provide individual support to relatives and give them strength to manage daily life.

Declaration of interest

The authors declare no conflict of interests

ACKNOWLEDGEMENT

The authors are grateful for the shared experiences from the participants. This study was funded by Luleå University of Technology, Sweden.

REFERENCES

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+91.

Arnett, J. J. (2000). Emerging adulthood. A theory of development from the late teens through the twenties. American Psychologist, 55(5), 469-480.

Bell, J. M. (2013). Family Nursing Is More Than Family Centered Care. Journal of Family Nursing, 19(4), 411-417.

Bridges, W. (2004). Transitions: making sense of life's changes. Cambridge, MA: Da Capo Press.

Clarke, D., & Winsor, J. (2010). Perceptions and needs of parents during a young adult's first psychiatric hospitalization: We're all on this little island and we're going to drown real soon. Issues in Mental Health Nursing, 31(4), 242-247.

Corbin, J. M., & Strauss, A. L. (2008). Basics of qualitative research: techniques and procedures for developing grounded theory. Thousand Oaks: SAGE.

Davis, M. (2003). Addressing the needs of youth in transition to adulthood. Administration and Policy in Mental Health, 30(6), 495-509.

Davis, M., & Vander Stoep, A. (1997). The transition to adulthood for youth who have serious emotional disturbance: Developmental transition and young adult outcomes. Journal of Mental Health Administration, 24(4), 400-427.

Doornbos, M. M. (2002). Predicting family health in families of young adults with severe mental illness. Journal of Family Nursing, 8(3), 241-263.

Ekdahl, S., Idvall, E., Samuelsson, M., & Perseius, K. I. (2011). A Life Tiptoeing: Being a Significant Other to Persons With Borderline Personality Disorder. Archives of Psychiatric Nursing, 25(6), e69-e76.

Hoffman, P. D., Fruzzetti, A. E., & Buteau, E. (2007). Understanding and engaging families: An education, skills and support program for relatives impacted by borderline personality disorder. Journal of Mental Health, 16(1), 69-82. doi: doi:10.1080/09638230601182052

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.

Johansson, A., Anderzen-Carlsson, A., Åhlin, A., & Andershed, B. (2012). Fathers' everyday experiences of having an adult child who suffers from long-term mental ellness. Issues in Mental Health Nursing, 33(2), 109-117.

Kvale, S., & Brinkmann, S. (2009). InterViews : learning the craft of qualitative research interviewing. Los Angeles: Sage Publications.

Lager, A., Berlin, M., Heimerson, I., & Danielsson, M. (2012). Young people's health: Health in Sweden: The National Public Health Report 2012. Chapter 3. Scandinavian Journal of Public Health, 40(9 suppl), 42-71. doi: 10.1177/1403494812459459

Lindgren, B. M., Åstrom, S., & Graneheim, U. H. (2010). Held to ransom: Parents of self-harming adults describe their lived experience of professional care and caregivers. Int J Qual Stud Health Well-being, 5(3). doi: 10.3402/qhw.v5i3.5482

Lindgren, E., Söderberg, S., & Skär, L. (2013). The gap in transition between child and adolescent psychiatry and general adult psychiatry. Journal of Child and Adolescent Psychiatric Nursing, 26(2), 103-109.

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, 8. doi: 10.1155/2014/457160

Lindgren, E., Söderberg, S., & Skär, L. (in press). Swedish young adults' experiences of psychiatric care during transition to adulthood.

McGrandles, A., & McMahon, K. (2012). Transition from child and adolescent to adult mental health services. British Journal of Nursing, 21(17), 1031-1039.

Nicholls, E., & Pernice, R. (2009). Perceptions of the relationship between mental health professionals and family caregivers: has there been any change? Issues Ment Health Nurs, 30(8), 474-481. doi: 10.1080/01612840802601408

Nordby, K., Kjonsberg, K., & Hummelvoll, J. K. (2010). Relatives of persons with recently discovered serious mental illness: in need of support to become resource persons in treatment and recovery. J Psychiatr Ment Health Nurs, 17(4), 304-311. doi: 10.1111/j.1365-2850.2009.01531.x

OpenCode 4.0. (2013). University of Umeå, Sweden: ICT Services and System Development and Division of Epidemiology and Global Health. Retrieved from http://www.phmed.umu.se/english/divisions/epidemiology/research/open-code/?languageId=1

Polit, D. F., & Beck, C. T. (2008). Nursing research: generating and assessing evidence for nursing practice. Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Rusner, M., Carlsson, G., Brunt, D., & Nystrom, M. (2013). Towards a more liveable life for close relatives of individuals diagnosed with bipolar disorder. Int J Ment Health Nurs, 22(2), 162-169. doi: 10.1111/j.1447-0349.2012.00852.x

Singh, S. P., Evans, N., Sireling, L., & Stuart, H. (2005). Mind the gap: the interface between child and adult mental health services. Psychiatric Bulletin, 29, 292.

Sjöblom, L. M. (2010). Family in the formal psychiatric care. (Doctorial thesis), Mid Sweden University, SE-831 25 Östersund, Sweden.

Sjöblom, L. M., Pejlert, A., & Asplund, K. (2005). Nurses' view of the family in psychiatric care. Journal of Clinical Nursing, 14(5), 562-569.

Stoep, A. V., Beresford, S. A. A., Weiss, N. S., McKnight, B., Cauce, A. M., & Cohen, P. (2000). Community-based Study of the Transition to Adulthood for Adolescents with Psychiatric Disorder. American Journal of Epidemiology, 152(4), 352-362. doi: 10.1093/aje/152.4.352

Sveinbjarnardottir, E. K., Svavarsdottir, E. K., & Saveman, B. I. (2011). Nurses attitudes towards the importance of families in psychiatric care following an educational and training intervention program. Journal of Psychiatric and Mental Health Nursing, 18(10), 895-903. doi: 10.1111/j.1365-2850.2011.01744.x

Sveinbjarnardottir, E. K., Svavarsdottir, E. K., & Wright, L. M. (2013). What are the benefits of a short therapeutic conversation intervention with acute psychiatric patients and their families? A controlled before and after study. International journal of nursing studies, 50(5), 593-602. doi: http://dx.doi.org/10.1016/j.ijnurstu.2012.10.009

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.

Weimand, B. M., Sällström, C., Hall-Lord, M. L., & Hedelin, B. (2013). Nurses' dilemmas concerning support of relatives in mental health care. Nursing Ethics, 20(3), 285-299.

Wilhelmsson, A. B. (2011). Relatives' Experiences of Care and Caregivers in a Psychiatric Caring Context. Procedia - Social and Behavioral Sciences, 30(0), 2296-2304. doi: http://dx.doi.org/10.1016/j.sbspro.2011.10.448

Wilhelmsson, A. B., Graneheim, U. H., Berge, B. M., Johansson, S., & Åström, S. (2010). Everyday life experiences among relatives of persons with mental disabilities. Procedia - Social and Behavioral Sciences, 2(2), 4896-4900. doi: http://dx.doi.org/10.1016/j.sbspro.2010.03.791

WMA. (2014). Declaration of Helsinki - Ethical Principles of Medical Research Involving Human Subjects. Retrieved from http://www.wma.net/en/30publications/10policies/b3/.

Wright, L. M., & Bell, J. M. (2009). Beliefs and Illness: A Model for Healing. Canada: 4th Floor Press,.

Wright, L. M., & Leahey, M. (1999). Maximizing Time, Minimizing Suffering: The 15-Minute (or less) Family Interview. Journal of Family Nursing, 5(3), 259-274. doi: 10.1177/107484079900500302

Östman, M., Wallsten, T., & Kjellin, L. (2005). Family burden and relatives' participation in psychiatric care: Are the patient's diagnosis and the relation to the patient of importance? International Journal of Social Psychiatry, 51(4), 291-301.

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