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**Caregiver or care receiver: Adolescents' experience of caregiving to a parent with severe mental illness: A qualitative study**

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## **Abstract**

Exploring the experiences of adolescent caregivers of mentally ill parents is important to understand their challenges and identify their care needs. Using a qualitative research design, 18 caregiving adolescents shared their experiences of living with and providing care to a parent with a severe mental illness. The analysis of the interviews resulted in the emergence of three main themes of 1) emotional exhaustion with associated subthemes of 'ongoing worries,' 'fear of loneliness,' 'feeling neglected and unloved,' 'feeling of shame and guilt', and 'fear of discrimination and stigma'; 2) being trapped in a difficult situation with subthemes of 'living a compromised life', 'alienating from peers' and 'caregiver rather than care receiver; 3) adapting to the situation with subthemes of developing new skills and growing accountability. The study findings suggest that adolescent caregivers of parents with severe mental illness experience significant challenges and psychological distress associated with their caregiving role. They need to be supported by health care providers to develop strategies to adjust to their situation and maintain their health and wellbeing.

## 1 | INTRODUCTION

The burden of mental health disorders is on the rise worldwide. It is estimated that the global burden of mental illness accounts for 32.4% of years lived with disability (YLDs) and 13.0% of disability-adjusted life-years (DALYs) (Vigo, Thornicroft & Atun, 2016). Between 12%-45% of mental health service consumers are parents. With the shift of the care and support from psychiatric hospitals to community mental health services, families including children increasingly assume the primary caregiver role to a patient with mental illness (Maybery & Reupert, 2018).

Adolescence is a critical period during which individuals need protection and support due to their physical, psychological and social vulnerabilities (Newman & Newman, 2020). While developmental and life experiences generally lead to strong adaptive skills, adverse exposures can have harmful effects on adolescents' life and health (Patton et al., 2016). Kamis (2021) suggest that parental mental health problem during adolescence is a significant predictor of poor mental health in adulthood. Although social supports could play a pivotal role in helping adolescents' transition to a new role and new responsibilities as a caregiver, adolescent caregivers often perceive themselves as a neglected member of the mental health care delivery system (Plöthner, Schmidt, De Jong, Zeidler & Damm, 2019). Research focusing on adolescents' experiences of caregiving to a parent with mental illness is scarce, and the available evidence suggest that caring for a parent with mental illness may have both negative aspects (such as experiencing stigma and social isolation) (Hinshaw, 2018) and positive aspects (such as developing accountability) (Källquist & Salzman-Erikson, 2019a). This study aimed to provide evidence to help mental health providers and researchers to design interventions to support young caregivers. The following section summarizes the literature on the experiences of adolescent caregivers.

## **| Compromised wellbeing**

It is estimated that one in five youth under 18 years of age live with a parent with mental illness (Reupert, J Maybery & Kowalenko, 2013). Children who live with a mentally ill parent or assume carer responsibility for their parents are more likely to encounter adverse life experiences, such as low family cohesion, chaotic home environment, poor communication and parent-child discordance (Wiegand-Grefe, Sell, Filter & Plass-Christl, 2019), which upsurge the risk of emotional and behavioral problems in children (Souza & Aparecida Crepaldi, 2019). Compared to children of healthy parents, those who live with a mentally ill parent experience greater material deprivation, childhood abuse, or neglect (Hinshaw, 2018), and suffer from poor quality of life (Backer, Murphy, Fox, Ulph & Calam, 2017). Overall, caregiving to a mentally ill family member is very challenging, leading to burnout and mental health issues, such as anxiety and depression in caregivers, particularly in children and younger adults caregivers (Zauszniewski & Bekhet, 2014). Adverse emotions, such as worries, fear, guilt, shame, and embarrassment (Källquist & Salzman-Erikson, 2019a; Reedtz, Lauritzen, Stover, Freili & Rognmo, 2019), as well as social isolation and exclusion are prevalent among these children (Yamamoto & Keogh, 2018). They are also at increased risk of behavioral and developmental disorders (Gladstone, Boydell, Seeman & McKeever, 2011), educational underachievement (Källquist & Salzman-Erikson, 2019a; Ng-Knight, Shelton, Frederickson, McManus & Rice, 2018) and physical and psychosocial health problems in their future life (Kallapiran & Jayanthini, 2021; Källquist & Salzman-Erikson, 2019a; Radicke et al., 2021a).

### **1.2 | Caregiving rather than care receiving**

Over recent decades, the responsibility of caregiving to people with severe mental illness has shifted from institutions to families and family members are considered valuable resources for providing care and support to mentally ill persons (Tlhowe, Du Plessis, & Koen, 2017). As a result, children and adolescents live with mentally ill family members, participate in caregiving and or even assume a primary caregiver role (Hinshaw, 2018). Caregiving children may feel like victims, finding themselves trapped in various roles and responsibilities, such as carer role, job responsibilities, school work and household chores (Rahmani et al., 2018; Simpson-Adkins & Daiches, 2018). As a result, they are more likely to become over-achieving and overly responsible persons, or 'grown old before their time', referred to as 'parentification' (Rana & Das, 2021).

On the other hand, the parents themselves, who often cannot continue to support the family financially, look after themselves, or accomplish daily routines and responsibilities. They, therefore, over-rely on their children to provide care that sometimes needs to be immediate, flexible, or continuous, resulting in their feeling of passiveness and powerlessness (Dharampal & Ani, 2020). Naturally, parental acceptance and a pattern of flexible behavioral control are essential to adolescents' healthy social and cognitive development (Dandash, Cherbuin, Schwartz, Allen & Whittle, 2021). Yet, young caregivers of parents with a mental disorder may simultaneously be deprived of parental support and care (Ballal & Navaneetham, 2018).

### **1.3 | Young caregivers: invisible in mental health system**

The physical and psychosocial needs of children who are involved in caregiving to a mentally ill parent may be neglected by the family as well as health care providers, who often underestimate the extent to which these children's lives are affected and their ability to cope

with the situation (Brown, McKenna & Furness, 2018). Previous studies suggest that health professionals often do not consult caregiving children about their needs (Plöthner, Schmidt, De Jong, Zeidler & Damm, 2019). Also, these children rarely seek help from mental health care services, meaning that their needs remain neglected and they are left to cope on their own (Backer et al., 2017). Young caregivers may face many problems dealing with parental care issues while they, themselves, need parental support and a secure attachment (Dharampal & Ani, 2020). According to the Bowen's Family Systems Theory, parental mental illness could potentially contribute to child maltreatment (Bowen, 1993) due to factors, such as inadequate nurturing, bonding, and caring (Hernández-Alava & Popli, 2017). Further, parents' ability to provide a secure base for their children can hinder reciprocal behaviors required for normal attachment (Whittingham, Sanders, McKinlay & Boyd, 2019). Adverse childhood experiences can erode mental health or trigger parentification, a phenomenon that should be interpreted in a cultural context (Khafi et al., 2014). While a small degree of parentification can be beneficial to child development, it can be destructive if the tasks become too burdensome or the child feels obligated to take on the role of adult for maintaining a balance in the family system the family (Rana & Das, 2021).

Similar to many other countries, in the XXX mental health care system, the needs of family caregivers, including caregiving children, are overlooked (The references are blinded). To better understand the impact of living with and caring for a parent with mental illness, it is important to consider the context and circumstances where caregiving is taken place. As adolescence is a unique developmental period for physical, social, mental and cognitive growth, this research aimed to explore adolescents' experiences of caregiving to a parent with a severe mental illness.

## **2. | THE CURRENT STUDY**

The present study was conducted during June 2018 to February 2019 in Iran. Thus, caregiving was provided in the context of collectivist culture and Islam religion, where caring for an ill family member is highly valued and encouraged. The study sought to understand the young caregivers' experiences and challenges of providing caregiving to a parent with mental illness by answering the following research questions:

- 1- What are the experiences of adolescent caregivers of providing caregiving to a parent with mental illness?
- 2- What strategies do adolescent caregivers develop or adapt to cope with their situation?

### **3 | Method**

#### **3.1 | Study design**

This qualitative study employed a content analysis approach to explore adolescents' experiences of providing caregiving for a mentally ill parent. Content analysis is a widely used qualitative research technique. In conventional content analysis, coding categories are derived directly from the text data (Hsieh & Shannon, 2005). With a directed approach, analysis starts with a theory or relevant research findings as guidance for initial codes (Erlingsson & Brysiewicz, 2017). The researchers used the SRQR checklist to adhere to the standards for reporting qualitative research.

#### **3.2 | Participants**

Participants were recruited from outpatient clinics of a tertiary referral psychiatric hospital in XXX. A purposive sampling method was applied to recruit 18 participants of 15-18 years of age who had a parent diagnosed with a severe mental illness, including schizophrenia, schizoaffective disorder, psychosis and bipolar affective disorder. Children of parents who



had significant physical comorbidities were excluded. All participants had assumed primary caregiving responsibility of their ill parent for at least one year preceding the study and were all the only family member responsible for their mentally ill parents' care. They were all high school students (grade 9= 2, grade 10=4, grade 11=8, and grade 12=4) and 43.6% were in average status, in terms of the socio-economic status of the family. About the family status of participants, 67.8% lived with both parents, and 32.2% lived with only one of their parents (28.1% with a separated parent and 4.1% with a divorced parent).

### **3.3 | Data collection**

Data were collected using semi-structured in-depth individual interviews. A rough interview guide was used to ensure that the key research questions were addressed by participants while also providing flexibility to explore any emerging topics. The key interview questions were: Can you tell me about your experience of caring for your mentally ill parent? What challenges do you encounter in caring for your parent? How do you deal with the difficulties that you face as a caregiver? How has your own life been affected by your parent's illness and your caregiving responsibilities?

All interviews were conducted in participants' first language by the last author (FR). Interviews lasted between 45-90 minutes; they were conducted at participants' choice of location. All interviews were completed either at the hospital or the participant's home between October 2018 and June 2019; audio-recorded and transcribed verbatim. Data collection and data analysis were conducted concurrently, with developing themes being further explored and examined through later interviews. Recruitment continued until data saturation was achieved.

Due to the dominant culture of collectivism in the research setting, it was difficult to gain the participants' trust to share their experiences of caring for a mentally ill parent. In some cases, adolescents refused to talk about it due to keeping family cohesion or fear of exposing family problems and seeking help. Therefore, the research team collected information after clearly explaining all the objectives of the study and how much participation in this research might be useful for them in terms of exploring their potential problems and challenges while caring.

### **3.4 | Data Analysis**

Data analysis was conducted using the content analysis method (Graneheim & Lundman, 2004). In the first step, two researchers (HE and FR) listened independently to the recorded interviews to gain familiarity with the content. In the second step, they read and re-read the transcriptions to achieve a holistic perspective of participants' experiences. In the third step, the last author (FR) assigned codes to the data. In the fourth step, based on the codes' properties and dimensions, categories were formed. In the last step, the categories were abstracted into themes and subthemes. The last two steps of the analysis were conducted by two researchers involved in the study. Dependability, credibility, confirmability and transferability were considered to ensure the study's rigor (Speziale, Streubert & Carpenter, 2011). Dependability was achieved through external checks by two researchers who were not involved in the data analysis but contributed to the study. The credibility of data was achieved by a long-term involvement of the researchers with the data. Also, three participants confirmed the compatibility of the results with their experiences. To address transferability, a clear description of the study context, participant selection, demographic data, data collection method and results was provided.

### **3.5 | Ethical considerations**

This study was approved by the ethical committee of XXX University of Medical Sciences (number XXX). Adolescents who met the study eligibility criteria were informed about the purpose and nature of the study and voluntary participation. Consent was obtained from both participants and their parents. The confidentiality of participants was maintained by using unique identifier numbers.

## **4 | Results**

Demographic characteristics of caregivers and their parents are presented in Table 1. The mean age of participants was  $16.9 \pm 1.3$  years. They had assumed primary caregiver responsibilities for their mentally ill parent for an average of  $2.2 \pm 0.8$  years. The most common type of parental illness was bipolar affective disorder (33.3%), with the mean duration of their illness being  $4.4 \pm 1.6$  years.

The adolescents' experiences of caring for a mentally ill parent were illuminated in the overarching theme of 'being prematurely adult' consisting of three categories as follows: 1) emotional exhaustion, 2) living a compromised life and 3) adapting to the situation. Experiencing being prematurely adult encapsulates the range of challenges that young caregivers faced as they attempted to balance the caregiver role with everyday life as a young person who still requires support, help and encouragement. The following sections describe the main categories and associated subcategories.

### **4.1 | Emotional exhaustion**

Participants felt that they were emotionally drained due to their parent's illness and their role as the primary caregiver. Adolescents expressed experiencing a wide range of negative

emotions and feelings, such as worries, nervousness, insecurity, shame, embarrassment, guilt, discrimination and stigma. This category encompassed four subcategories: ongoing worries, fear of loneliness, feeling of shame and guilt and fear of stigma and discrimination.

#### **4.1.1 | Ongoing worries**

Participant adolescents expressed constant worries and nervousness because of living with a parent with a severe mental illness. They perceived their life as 'not normal' and 'unstable.' Some adolescents lacked adequate information about their parents' illness; they were not aware of the chronic nature of their parent's illness and how the disease may progress in the future. They were always concerned about their parent's health and had this ongoing worry that something catastrophic might happen anytime, making the situation out of control.

*"I do not know what may happen next, when my mum gets better. I'm scared and worried" (P.10)*

When they were not at home, they kept worrying about their parent and that something tragic might have happened to their parent while they were not at home. One participant described his experience as follow:

*"I go to school every day. When I come back home, I always expect something wrong has happened like my mom has not taken her medicine, and she is irate." (P.12)*

#### **4.1.2 | Fear of loneliness**

Participants were afraid of ending up being lonely and without any support in the future. It was highly stressful to realize that their relationship with their parent was deteriorating. A participant described this as 'a loss'. Some children had come to realize that their parent's illness was an ongoing problem and that life would never be normal for them again.

*"I always fear that this disease will result in losing my mum. Sometimes, I wish that I had the same relationship with my mother as before, but this is not possible." (P.12)*

They were uncertain of the ending and scared of what the future might bring. The thought of having had to take care of their ill parent forever distressed them and how that could impact their own life and goal achievements in the future. This impacted their ability to set life goals for themselves. One participant described her apprehension as below:

*"Where this life gonna end up. I do not know. Will I be able to leave my mum alone? I have no idea what this disease will bring about? Is it likely to be over eventually? Will I be able to pursue my study?" (P.4)*

#### **4.1.3 | The feeling of shame and guilt**

Some adolescents were blamed by others for their parent's mental condition. They were blamed for the onset or worsening of their parent's mental illness. The blames graduated to the feeling of guilt in participants, trusting that they were liable for their parent's current situation. Some adolescents tried to atone by assuming further responsibilities; yet, felt shame and guilt for not doing enough.

*"Some of our relatives believe that my mother's depression is my fault. They advise me to pay more attention to my mother and take care of her. They do not understand me. They do not know I'm suffering from my mother's illness. I have no fault. I have not done anything wrong about my mother's depression." (P.3)* *"I sometimes think it is my fault that my father (illness) is getting worse. I always feel guilty that I cannot do anything to end this situation and improve my father's illness. I try to do all the work at home and do everything I can, but my father's illness is not getting better." (P.4)*

Adolescents shared that they had to keep their concerns to themselves and felt guilty if they shared their problems with their parents making them disturbed.

*"I try to solve my problems by myself so as not to cause my father's illness to worsen.*

*I work as a casual in summer to save some money for my expenses. I always feel that I should not add to my home's problems. I feel guilty." (P.8)*

#### **4.1.4 | Fear of discrimination and stigma**

Adolescents felt shame and embarrassment associated with their parent's illness. They tried to hide their parent's mental illness by making excuses about their odd behaviors to avoid stigma, discrimination and misjudgments. They perceived their family as 'different' and believed neighbors, relatives and others did not see their family as 'normal.' Participants were particularly worried that their friends being aware of their parent's mental issues, leading to misjudgment, discrimination and stigma. One participant expressed:

*"I do not want people to know that my mum has a mental problem, they may misjudge us.... I would feel shame if my friends find out about my mum's illness." (P.5)*

*"The attitude of people to this illness (mental illness) is not right. Some people are afraid, some feel pity for us, and even some think that my father's behavior is deliberate. Because of these, I don't want anyone to know about his illness at all." (P.9)*

#### **4.2 | Being trapped in a difficult situation**

Adolescents reported that their lives are going through a different and difficult situation. They acknowledged that they experience many different problems than their peers. This category

encompassed three subcategorizes of 'living a compromised life', 'alienating from peers' and 'caregiver rather than care receiver'.

#### **4.2.1 | Living a compromised life**

Parent's mental illness was perceived to have changed adolescents' normal life course, bringing consequences that adversely affected their lives, alienating them from peers. Living with a mentally ill parent and assuming caregiving responsibility meant that adolescents had to compromise their personal life and give up on their life goals. At times, participants went through internal conflicts with themselves, wondering if they would be able to eventually convince themselves to move away from home to pursue their own dream life, or should they stay with their parent forever.

*"I think I do not have the right to have a dream or plan for myself. Like, planning for study or having a dream job. I do not have these rights because I am living with a mentally ill dad." (P.2)*

#### **4.2.2 | Alienating from peers**

Participants perceived themselves as being different from their friends and peers because of living with and caring for a mentally ill parent. Participants stated that caring for a mentally ill parent imposed many restrictions on their life. They felt that the situation was a hindrance to their participation in social or leisure time activities. Adolescents had to exclude themselves from friends and limit their group activities due to their condition but experienced the frustration of being compromised. Failing to maintain a normal life similar to their peers upset the adolescents tremendously.

*"I cannot invite a friend to our house or participate in leisure activities. I must look after my mother. I cannot participate in their (friends) gatherings and parties. Well, I understand that I'm different from my friends. I cannot be like the rest. I cannot go out with my friends." (P11)*

*"Due to my father's illness, I couldn't attend the celebration of the school year. I usually can't attend such ceremonies." (P1)*

One participant described her experience as:

*"I understand this very well that I'm not like others to do whatever I want, or have a plan for myself. I'm the child of a father with mental illness... I should solve everything myself." (P8)*

These confines impacted on participants' social functioning and limited their capacity to enjoy life as an adolescent. They became isolated from friends and society, experiences that affected their sense of wellbeing and social belonging. A participant said:

*"I'm always excluded from parties and other activities that my peers usually take part. I'm left out of gatherings." (P.9)*

#### **4.2.3 | Caregiver rather care receiver**

Caring for a parent with a severe mental illness overwhelmed adolescents, leading to their burnout. Participants experienced a feeling of role reversal. They believed that they were still at the age that needed parental care and support, the need that was never met. Most participants stated that they had to leave their childhood behind and embark on caring responsibilities prematurely.



*"I don't have a mother's love or a supportive family. Sometimes, I wish I was like any of my friends. I know my mother needs me. She needs a person to take care of her, give her medicine, protect her from dangers, but who cares for me?" (P13)*

Their needs being neglected in the family. One participant said:

*"I'm always lonely. You know, my friends have parents who support them, but I am alone with all these responsibilities. I do not know whom to refer to when I have a problem. Sometimes I feel I'm not like my friends." (P.13)*

*Well, if something happens, there's a father or mother to help out for everyone else. But, I have to solve all my problems by myself while also taking care of my mum. Sometimes the situation gets out of control." (P.10)*

Some adolescents experienced feelings of profound loneliness, vulnerability and worthlessness. They perceived themselves as a 'lost child'. At home, they felt invisible. Adolescents needed to be continuously attentive about their parent's illness and carefully evaluating the situation that could quickly turn into a catastrophe. All of the participants were involved in providing instrumental and emotional support to their ill parent. They had to maintain the home environment calm and quiet for their parent, hold their problems to themselves and disguise in order to avoid distressing their ill parent. A participant said:

*"We must always be quiet, speak quietly, we must not talk about our problems with our mother. We have to live in silence. Sometimes you need to talk to your mom or dad, but it is not (the same in our home) ... I think if I share a problem, it'll distress or upset my parent" (P.6)*

*"I have to be very careful every moment. I cannot comment freely on matters like my friends. I have to consider the circumstances of my family.... My father may need my care... I work at home. My father may be ill and I have to take care of him. I have to always consider the condition of my family." (P.8)*

In addition, some adolescents had to work casual jobs to alleviate some of the family's expenses:

*"I try to solve my problems by myself, so my father's illness doesn't get worse. I work as casual in the summer to save money for my expenses."(p.8)*

### **4.3 | Adapting to the situation**

Beyond all the negative experiences that participants described about living with a mentally ill parent and their caregiving role, assuming caregiving responsibility early in life created challenges that required adolescents to 'develop new skills' and 'grow accountability.' These subcategorizes are explained in the following section.

#### **4.3.1 | Developing new skills**

Assuming a new role and responsibility requires learning skills associated with the role. Participants stated that they gradually became better in their caregiving role. Through the caregiving journey, adolescents progressively learned to manage their personal lives while protecting and providing care to their mentally ill parent. Adolescents struggled with the challenges of being a primary caregiver to a mentally ill parent, such as experiencing emotional exhaustion, lack of support, social exclusion, and financial hardship. By navigating these challenges, adolescents learned to rely on themselves and acquire the essential information and skills, such as developing problem-solving skills, caring skills and empathy

and time management to be able to develop resilience and meet the care needs of the family.

One participant described his experience as following:

*"Well, things are much better now. I was really exhausted at the beginning, did not know anything. Gradually, I learned what to do. Of course, it was tough. After a while, I learned how to care for my mother and complete my school work as well. I learned how to manage my mum's medicines and ensure that she takes them. I did not know these things in the beginning." (P.3)*

Another participant said:

*I think I am able to solve many problems at the same time, much better than my peers. For example, when my mother is aggressive and the home environment is not calm at all, I can still concentrate and complete my homework. Or I can solve my personal problems, categorize and prioritize my tasks depending based on the amount of time I have. (P.8)*

#### **4.3.2 | Growing accountability**

Through caregiving to a parent with a mental illness, adolescents learned to hold responsibility and accountability to themselves and the family. They learned to take care of their personal need without the support and supervision of parents and hold accountable for the health and safety of their mentally ill parent. One participant expressed:

*"Well, you see, my situation is different from my peers. I must not forget what I am responsible for. I am responsible for my family's life. I'm responsible for my father. Sometimes you have to take care of your parent; sometimes, it's more like I'm the one*

*who is the parent, and he is the child. I feel like this is my responsibility and that I have to take care of him." (P.11)*

*"Before, I couldn't do all my work. But now, I feel stronger. I can do all my tasks by prioritizing them. I would feel overwhelmed before, but now I feel responsible for my duties and for the care of my father." (P.9)*

## **5 | Discussion**

This study aimed to explore adolescent caregivers' experiences of providing care to a parent with a severe mental illness. The consequences of caring for a parent with severe mental illness as perceived by adolescent caregivers were illuminated in the central theme "being a premature adult" comprising three categories: emotional exhaustion, living a compromised life and adapting to the situation. The results illustrated how caring for a mentally ill parent affected all domains of the children's' lives.

According to Patton et al., (2016) it is important to understand how these children's health and life are affected by their caregiving role, as early life adversities can affect children's development and health and wellbeing, impacting their future life outcomes (Patton et al., 2016). Caregiving to a family member with a chronic condition can be overwhelming, increasing the risk of burnout and leading to poor mental and physical health among caregivers (Gérain & Zech, 2019). Caregiving to a mentally ill parent can be even more challenging due to factors such as the breakdown of family relationships and perceived stigma and discrimination. These experiences can often diminish caregivers' wellbeing and quality of life (Ae-Ngibise, Doku, Asante & Owusu-Agyei, 2015). The adolescents in our study assumed the primary caregiving role to a parent with a severe mental illness. The setting of the study was the Middle East, where collectivism is emphasized, and respecting

elders and caring for a sick person, in particular, a parent is expected and encouraged culturally and religiously (Purnell & Fenkl, 2020).

Our study findings suggest that adolescents experienced far more harm than good from their caregiving role. They went through significant psychological turmoil, adverse emotions, and feelings associated with the caregiving role, including persistent worries, nervousness, insecurity, detachment from peers and the family, shame, embarrassment, guilt, discrimination, stigma and isolation. Similar findings have been reported in past researches. Children who assume carer responsibility for their mentally ill parent are at increased risk of compromised physical health, emotional wellbeing and longer-term prospects (Källquist & Salzmänn-Erikson, 2019a; Radicke et al., 2021a). They constantly worry about their parents' immediate and long-term health and this heightened arousal about their parent's health and the fear of inability to manage the situation negatively affect their wellbeing, healthy development and educational achievements (Ng-Knight et al., 2018).

The feelings of stigma and discrimination were common experiences among the adolescences, which they tried to avoid by hiding their parent's illness, making excuses for their parents' behaviors and isolating themselves from the community. Yamamoto and Keogh (2018) described how quickly children realize that mental health is taboo and should treat it as a 'family secret.' They are embarrassed by their parent's behavior (Ballal & Navaneetham, 2018), experience shame, and fear the associated stigma and discrimination (Reedtz et al., 2019). Perceived stigma by the family members of a mentally ill person is a common experience (Ebrahim, Al-Attar, Gabra, & Osman, 2020). Although developed countries are working towards social acceptance of mental disease to tackle the associated stigma and discrimination, it remains a significant barrier to accepting mental illness by patients and family members in developing countries that affects their help-seeking behaviors (Pocock,

2017). The burden of caregiving to a mentally ill family member coupled with perceived social stigma and discrimination could increase their risk of mental health problems, such as anxiety and depression (Zhang et al., 2018).

Although the family provides a safe, supportive, and nourishing environment for the adolescent to experience a smooth transition to adulthood as normal (Backes & Bonnie, 2019), adolescents in our study found their home environment as chaotic, stressful, unstable, and with broken relationships. They described their life as 'not normal' and being left alone with no parental support. Ballal and Navaneetham (2018) found that living with the complexity of a parent with a mental illness and being involved in caring responsibilities caused young adults to feel that they were neglected and abandoned as children. They were unable to communicate efficiently with their mentally ill parent or receive their support (Hinshaw, 2018). Furthermore, the magnitude of the problem was so great that some adolescents referred to it as "a loss." Radicke et al., (2021) argued that the lack of the ability of parents to protect and support them created a sense of loneliness and getting lost (Radicke et al., 2021b).

A sense of attachment, acceptance and trust is critical for healthy development throughout childhood and adolescence (Backer et al., 2017; Whittingham et al., 2019). According to Bowen's family systems theory, family members solicit each other's attention, approval and support and respond to each other's needs, expectations, and feelings. The connectedness and reactivity make the functioning of family members interdependent (Bowen, 1993). However, adolescents in our study did not receive adequate attention, approval, or support from the family and were underprivileged by a lack of family cohesiveness and connectedness.

Some adolescents experienced internal conflicts about their role as the primary caregiver for a mentally ill parent, and found themselves trapped in an ethically challenging situation that they could not get out of it. To alleviate the feelings of guilt and self-loathing, some adolescents took further responsibility in the family and held their personal needs and problems to themselves to not disturb their parents. According to Simpson-Adkins and Daiches (2018), they assume adults' roles before being emotionally or developmentally prepared (Simpson-Adkins & Daiches, 2018). Yet, they felt guilt when they failed to improve the situation. This finding is in line with the study of Källquist et al. (2019), reporting that children of a mentally ill parent felt guilty when they failed to manage their daily lives effectively. The blame from society and the resultant guilt in adolescents indicate the public's lack of knowledge of the nature and causes of mental diseases, which should be worked on.

Positive relationships with peers are critical to adolescents' healthy social and emotional development (Lam, McHale, & Crouter, 2014), however, adolescents in our study isolated themselves from peers and society. This occurred due to the caregiving responsibilities which left them with little time for social activities. Reduced social participation is a common experience among the family caregivers of mentally ill patients (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015). Children of parents with mental illness perceive themselves as alienated from others (Reedtz et al., 2019) and, therefore, keep their distance from peers, friends, and social activities to avoid rejection, affecting their sense of social belonging and social engagement and development of a healthy identity (Yamamoto & Keogh, 2018).

What was most striking was the reluctance of the participants to disclose their parents' mental illness and seek help from a relative or friend due to the fear of discrimination or stigma. It is, therefore, important that mental health professionals consider this issue and raise

it even if adolescent caregivers did not speak up about their concerns and challenges (Plöthner, Schmidt, De Jong, Zeidler & Damm, 2019).

On the other hand, assuming the primary caregiving role for a mentally ill parent provided the adolescents with opportunities to develop new skills and grow accountability. It was reported that adolescents' caregivers who were confronted with multiple physical, emotional and social challenges gradually learned to manage their personal life while also providing care to their parent (Källquist & Salzman-Erikson, 2019a; Radicke et al., 2021a). Difficulties of the care process could help the adolescents learn how to rely on themselves and obtain essential information and skills, such as problem-solving skills, caring, prioritization, and time management (Mechling, 2016). Through caregiving, the adolescents also developed responsibility and accountability to both themselves and their families. They learned to take care of their own needs without parental support while also holding themselves accountable for the health and safety of their ill parent (Masten & Barnes, 2018).

### **5-1 | Limitation**

The generalization of this study is limited by the self-selected, homogenous sample from one city in. XXX. Therefore, it is suggested to conduct further studies to gain a better understanding of adolescents' challenges while caring for a parent with mental illness with a larger sample of caregivers from diverse socio-demographic backgrounds. It is also suggested that future research could be conducted in the field of young caregivers' experiences using the focus group method. According to the purpose of the future studies, mentally ill parents' experiences could also be included in them.

### **5-2 | Conclusion**



The results of this study suggest that adolescent caregivers of parents with severe mental illness experience significant psychological distress and adverse emotions and feelings associated with the caregiving role, including ongoing worries, feelings of loneliness, social isolation, detachment from peers and the family, shame, embarrassment, guilt, stigma and discrimination. Although caring for parents with mental illness may provide an opportunity for adolescents to grow empathy and develop resilience and coping skills, a lack of supportive resources can damage young caregivers' normal development. They need to be supported to adjust to their situation and maintain their health and wellbeing. Support services, such as access to respite care, self-help groups, online support programs and psychosocial education and counseling, can help mitigate the impact of the caregiving burden on adolescents. Unfortunately, these services are minimal, particularly in low and middle-income countries.

### **5-3 | Implications and recommendations for clinical practice**

Despite the limitations discussed above, our findings make an important contribution to the literature and have significant implications for clinical practice. The findings revealed that adolescents experienced considerable negative impact associated with their role as the primary caregiver of a parent with mental illness. Mental health care providers should be aware of the impact of mental illness of a member of the family on the entire family, including the stresses and challenges associated with the family caregiving role, particularly children caregivers. They should shift their focus from solely the patient to include the broader family unit and support young children and adolescents in transitioning to their new role as a primary caregiver. Mental health care providers can discuss with adolescents the common stresses and challenges associated with the primary caregiving role, and inform them of the risk of caregiving burden. They should encourage adolescent caregivers to

practice self-care and teach them effective strategies to build resilience and reduce anxiety, stress and the risk of caregiving burden.

To our knowledge, this is the first study that explored adolescent caregivers' experiences of caring for a mentally ill parent, thus, there is need for further studies to confirm the findings of this study and compare the results with experiences of adolescent caregivers in resource-rich countries or in countries with individualistic cultures. These studies should also examine the mediating effects of social support—especially formal support from mental health professionals on adolescent caregivers' experiences, perceived stressors, and coping strategies. Although adolescents experienced mainly negative impact from caregiving to a parent with mental illness, some positive outcomes were also observed. Future research should, therefore, explore not only challenges but also opportunities associated with caregiving to mental ill parent. Health professionals, teachers, school nurses, and school counsellors can identify these children with special needs, support them, and refer them to appropriate support services. Building a supportive environment can be of major importance, as young caregivers may not know how to seek help to care for their mentally ill parent or locate relevant information.

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