

# The paradox of family care for patients with schizophrenia: A qualitative study

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## Abstract

**Context:** Schizophrenia is a severe mental disorder in which the individual's relationship with the reality is interrupted. Families can play an important role in the improvement of this disorder and help reduce its recurrence and ensure its better control and the patient's return to the society.

**Aims:** This study was conducted to explore the experiences of family caregivers of patients with schizophrenia.

**Setting and Design:** This study used the qualitative content analysis method proposed by Elo and Kyngäs. The study was carried out from 2019 to 2021 in the psychiatric wards of 5 Azar Hospital in Gorgan, Northern Iran.

**Materials and Methods:** A total of 16 family caregivers of patients with schizophrenia were examined. The participants were selected by purposive sampling. Sampling continued until data saturation was reached. Semistructured interviews were held to collect data. The data were analyzed with the support of MAXQDA 10 software.

**Statistical Analysis Used:** data were analyzed using conventional content analysis according to the technique described by Elo and Kyngäs. Their technique involves open coding, coding sheets, grouping, categorization, and abstraction.

**Results:** Two main themes were extracted from the data, including "family's committed and compassionate care for the patients' integrity" and "inadequacy of care," with a total of seven subcategories.

**Conclusion:** Providing care to a family member with schizophrenia is a task with several contradictory dimensions. Due to the chronic nature of the disorder, most family caregivers experience a kind of paradox in areas such as providing comprehensive care, protection, support, and inadequacy of care.

**Keywords:** Caregivers, Family, Qualitative research, Schizophrenia

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## INTRODUCTION

Schizophrenia is a complex syndrome with a heterogeneous combination of symptoms that interrupt the individual's relationship with the reality.<sup>[1]</sup> It is a severe disorder caused by genetic or environmental factors with both positive and negative symptoms and affects less than 1% of the human population.<sup>[2]</sup> In Iran, the prevalence of psychiatric disorders and schizophrenia has been reported as 31.03% and 17%, respectively.<sup>[3]</sup> Schizophrenia accounts for 50% of occupied psychiatric hospital beds.<sup>[4]</sup>

Schizophrenia can lead to severe impairment of the patients' social functioning, communication, and self-care.<sup>[5]</sup> Furthermore, it can impose a significant physical, social, psychological, and economic burden on the family.<sup>[6]</sup> Because the patient is a part of the family, this situation can lead to the disruption of the family system and transform the family to a hidden health-care system that is burdened by great care challenges.<sup>[7]</sup> It is believed that the family can greatly influence the outcome of this disorder. With continued treatment, family training, and rehabilitation, schizophrenia can become a controllable disease.<sup>[8]</sup> The family is the most important umbrella of support for schizophrenic people.<sup>[9]</sup> The range of recovery outcomes depends on the physical, emotional, and social support of the family as well as the experiences and reactions of the patients and their families with regard to the disease.<sup>[10]</sup> Social and clinical factors also affect the patient family's condition.<sup>[11]</sup>

The control of chronic diseases is highly dependent on the family's role in care and treatment activities.<sup>[12]</sup> Furthermore, therapeutic effects can be improved if these patients are cared for by their family members. Furthermore, due to the chronicity of the disease, it becomes the family's job to offer continued treatment and care.<sup>[13]</sup> Family caregiving improves the safety and quality of patient care, supports individual care needs, and facilitates the continuation of care.<sup>[14]</sup> Patients with families who play an active role in their care and treatment are different from patients who do not have family cooperation with regard to treatment adherence.<sup>[15]</sup> It has previously shown that the family members of schizophrenia patients experience a heavy burden of care and are prone to mental disorders and other problems.<sup>[16,17]</sup> Tamizi *et al.* conducted a study on the care burden and challenges of families with patients suffering from schizophrenia in Tehran, Iran. The results of that study indicated that the family caregivers of schizophrenic patients face multiple care burdens and problems related to this disorder and experience challenges in the health-care system.<sup>[18]</sup>

In addition, a study by Darban *et al.* on family caregivers' experiences and responses in providing care to schizophrenic patients in Zahedan, Southeast Iran, showed the positive consequences and success of the modality of caregiving, including strengthened family ties.<sup>[19]</sup> Studies have shown that reducing the burden of care, increasing the quality of care, and transferring the patients to the community require further attention to both patient-related and family-related factors.<sup>[16]</sup> These factors include the features of family care, the context in which care is provided, the patient's abilities, and the family members' skills and aptitudes.<sup>[12]</sup>

The contradictory results on the subject of family caregiving in schizophrenic patients indicate that the cultural context and the caregiving context can make a difference in the family caregiving experiences of schizophrenia patients. Given the lack of studies on family caregiving in schizophrenia patients within the cultural, social, and economic context of Northern Iran, the present study was carried out in Gorgan, the capital city of Golestan Province in the north of Iran, to explore the experiences of family caregivers caring for patients with schizophrenia.

## MATERIALS AND METHODS

The present study is a part of a larger grounded theory study that deals with family caregiving within the context of all contributing factors. This qualitative study was conducted using content analysis on 16 family caregivers of patients with schizophrenia at Golestan University of Medical Sciences from February 2019 to September 2021. The eligible candidates were selected by purposive sampling with maximum diversity (in terms of disease stage, the caregiver's relationship to the patient, ethnicity, socioeconomic status, and education, the caregiver's and patient's gender, and the patient's marital status), which continued until data saturation was reached. In qualitative studies, data saturation is used to ensure sampling adequacy. Saturation occurs when no more new data emerge and nothing is added to the main categories anymore.<sup>[20]</sup>

The inclusion criteria were living with the schizophrenia patient, the caregiver's lack of known mental illnesses, willingness to participate in the study, and ability to express their experiences. Prior to the interviews, the purpose of the study was explained to the participants and they were assured of their anonymity and then gave written informed consent to participate in the interview. Semistructured interviews were used to collect the data. The interviews began with a general question, such as "Can you tell us about one regular day of your life with the patient? What do you do for your patient during the day?" and How do

you take care of them?” Probing questions, such as “Can you give further explanation?,” “Do you mean to say so and so?,” “Who?,” “How?,” “Where?,” and “When?” were used during the interviews to achieve more in-depth data. The interviews lasted from 45 min to 100 min. A total of 16 participants from 13 families of patients with schizophrenia were interviewed. In two of the families, more than one member was interviewed and more than one sessions were held with them. The time and place of the interviews were chosen based on participants’ convenience.

The interviews were often held at participants’ homes or the counseling room of the psychiatric ward of the hospitals. Prior to the interviews, the participants gave written consent for the interview and audio recording of the session. All the interviews were recorded and then typed up verbatim immediately after the session ended. Each interview transcript was then read several times. The obtained data were analyzed using conventional content analysis according to the technique described by Elo and Kyngäs.

Their technique involves open coding, coding sheets, grouping, categorization, and abstraction.<sup>[21]</sup> Open coding involves determining the meaning units and giving them names. Coding sheets constitute a stage in which all the open codes are placed in a coding sheet. Grouping involves the comparison of similarities and differences to classify the codes into groups and categories. The categories are then formed and abstracted by merging. In the abstraction stage, the comparison and merging of the categories lead to the emergence of the main category. In other words, in the abstraction stage, the subcategories with similar content are placed in a larger category to form the main category.

The steps taken to increase the trustworthiness<sup>[22]</sup> and credibility<sup>[23]</sup> of the data included concurrent data analysis, selection of key informants, prolonged engagement with the data, observation, and offering accurate and in-depth description of the data. To ensure transferability, attempts were made to provide a rich and comprehensive description of participants’ experiences and the data. Credibility was achieved by prolonged engagement with the data, continuous observation, and the application of a combination of methods. Peer review and member checking were performed to establish the data confirmability. Finally, direct quotes were taken from participants’ statements to ensure the data’s dependability.

The research protocol was approved by the university research ethics committee with the ethics code IR.GOUMS.REC.1398.317.

## RESULTS

In this study, six participants were male and ten were female. They all had different family roles and different economic and education levels. The participants ranged in education from primary school education to high school diploma and university education. The occupation of the family members included homemaker, medical staff, teacher, military worker, government employee, freelancer, and security guard [Table 1].

The analysis of the data led to the main category of “paradoxical care,” the two general categories “family’s committed and compassionate care for the patient’s integrity” and “inadequacy of care,” along with seven subcategories [Table 2].

### Family’s committed and compassionate care for the patient’s integrity

This category consists of two subcategories, including “maintaining the individuality of the patient and acknowledging their separate existence” and “family’s supporting and protective role.”

#### *Maintaining the individuality of the patient and acknowledging their separate existence*

Despite the many difficulties in the way, families are willing to help their patient resume their previous roles, give insight to them, help them return to the community, and do their best to ensure the patient’s comfort.

#### *Giving insight to the patient*

Families provide insight and information to the patients about the disorder and the reason for their hospitalization. They also helped reduce the patient’s suspicions about their family members as a result of their hospitalization. “*I tell him, ‘you hit my mom, so we had to put you here, we brought you*

**Table 1: The key participants (family caregivers)**

Family	Participants	Caregivers	Patient’s gender - marital status	Ethnicity
F1	P1	Mother	Male - Single	Sistani
	P2	Sister		
	P3	Sister		
F2	P4	Mother	Female - Married	Fars
	P6	Son		
F3	P5	Mother	Man - Divorced	Fars
F4	P7	Sister	Male - Single	Turkmen
F5	P8	Mother	Male - Single	Fars
F6	P9	Wife	Male - Married	Fars
F7	P10	Brother	Female - Single	Fars
F8	P11	Husband	Female - Married	Fars
F9	P12	Wife	Male - Married	Fars
F10	P13	Son	Male - Married	Baloch
F11	P14	Sister	Female - Divorced	Baloch
F12	P15	Brother	Male - Single	Kurd
F13	P16	Father	Male - Single	Baloch

**Table 2: The main and subcategories: Family caregiving in patients with schizophrenia**

Subcategory	General category	Main category
1.1 Maintaining the individuality of the patient and acknowledging their separate existence	1. Family's committed and compassionate care for the patient's integrity	Paradoxical care
1.2 Family's supporting and protective role		
2.1 Misconduct with the patient (violence and aggression)	2. Inadequacy of care	
2.2 Depriving the patient of independence		
2.3 Negligence in care		
2.4 Escaping care responsibilities		
2.5 Hiding the patient from the community		

here [to the hospital] so you could get well. When all gets better, we will take you back home. I explain it to him like this" (P7).

#### Welfare and comfort of the patient

The family tries to meet the patient's physiological needs, such as the need for nutrition, clothing, hygiene, and physical health. They make sure that the patient is as comfortable as possible during the doctor visits despite incurring extensive costs, and see to it that the patient does not have to wait very long in the crowded environment of clinics. "I used to deposit 50,000 Rials a week into his debit card. I would go to see him every two weeks. I would bring everything to him, like clothes, towels, etc." (P8). Another participants said: "I brought my brother to live with me. I gave him a separate suite in my house with all the facilities. I take care of everything he needs for him" (P15).

#### Helping the patient resume previous roles and return to the community

The family helps the patient pursue an education and provides all the amenities needed for his employment. The members assist the patient in performing his role-related activities at home. Furthermore, during the recurrence of schizophrenic attacks, the family makes sure that the patient's activities and duties are duly performed. "When our mother is sick, we cook and do the house chores by ourselves, and whenever she's feeling better, she cooks and does the house chores and we just make sure she's okay; we take care of her" (P6).

#### Family's supporting and protective role

##### Family's protective role

There are two aspects to families' protective role toward schizophrenia patients: either the family feels like the patient belongs to them or they take care of the patient out of sheer compulsion.

##### Care to prevent injury to the patient

Family members tend to pay an utmost attention to their patient in efforts to prevent their committing of high-risk behaviors. This attention involves not leaving the patient alone at home, preventing drug overdose, preventing violence against the patient in the community, or continuous control of the patient. They also offer financial protection to the patient. "He wanted to go out, but I didn't let

him. He said you imprison me, and I said I wouldn't let him go take pills and that I've locked the door" (p1).

#### Family's self-protection from the patient's abnormal behaviors

The methods used by the family caregivers to protect their family included obedience of the patient's wishes, avoiding arguments, staying away from the patient, asking for help from the police or other relatives, and praising the patient to keep him calm. "We are so scared of him getting discharged from the hospital and coming back home. We try not to be left alone with him at home or we go to a room and lock the door" (P5). Another participant said: "His (the patient's) brother is so scared that he doesn't argue with him at all. He says he [the patient] will kill him if he does argue" (P8).

#### Supporting

Family tends to support its suffering member in a variety of ways. This category included four subcategories under the following headings:

##### Responsibility in care

Despite the problems caused by the disease that lead to inefficient adaptation, family members still tend to care for their patient in various ways. They feel responsible about caring for the patient and handle their affairs for them. "My husband disagrees with me and says that I can't handle having him (the patient) at home with us. But I am a mother; if I do not feel responsible for this child, will others have a sense of responsibility toward him" (P8).

##### Monitoring adherence to the prescribed treatment and covert care

Family members follow up on their patient's doctor visits and treatment as well as their medication use and can help improve their adherence by strategies such as rewarding the patient when he adheres to the treatment regimen. When the patient refuses to take his medications, family members use covert care to continue the treatment process by secretly dissolving the medicine in the patient's food and drink. "He does not take his medicines at all. We secretly pour the meds in his food or tea. He likes orange juice and we buy it often. We

*secretly put his pills inside the juice for him to take. Sometimes I tell him that if you take your medicine, we will go to the park together and I will buy ice cream for you” (P7).*

#### **The facilitating role**

Families try to expand their patient’s communication network and improve his communication with other people. The primary caregiver is usually in charge of this matter and prevents the verbal and nonverbal violence of other members toward the patient and keeps the family atmosphere away from anxiety by acting as a mediator between the family members and the patient. *“My granddaughter comes and plays with my younger son. I ask her to go play with her other uncle too; I tell her to take her doll along and tell him “Look how beautiful my doll is!” She does this and then my ill son pats her head” (P8).*

#### **Emotional bond with the patient**

The existence of an emotional connection between the patient and the family is the family’s main motivation for care. Despite the exhaustion caused by the long-term battle with the disease, the family comes to terms with the behaviors of its ill member. *“I’m putting up with it all. I still love him. Would it work if people got divorced the instant their partner fell sick?” (P9).*

#### **Inadequacy of care**

The family members’ poor adaptation to their new conditions along with the suffering caused by the disease leads to an inadequacy of care that includes a range of incorrect care behaviors and causes the exacerbation of the disease or its recurrence.

#### **Misconduct with the patient (violence and aggression)**

One of the reactions of the family members was projecting behaviors caused by a lack of knowledge and having the wrong attitude toward the disease. The pressures of caring for the ill member that leave them frustrated and exhausted can also lead to misconduct, such as physical violence, arguing, obscenity, or behaviors such as cutting off communication, unkindness, and rejection. *“We get nervous. I sometimes hit him when I fail to control him” (P7).* Another participant stated: *“My son (who is sick) and I got into a fight. The fight was about me wanting to take him to the doctor but he said he wouldn’t come. He was grabbing every pill he could and taking them. I tried to take the pills away from him, but he wouldn’t give up. Next thing we were beating each other up. And then his mother came and tried to split us up” (P16).*

#### **Depriving the patient of independence**

Often, families make decisions on behalf of the patient to play their protective role, thus depriving the patient of

his authority and independence. Families tend to deprive schizophrenia patients of rights such as children’s custody and the right of inheritance and make financial decisions on their behalf and also take charge of the patient’s personal life, such as deciding about divorce for them. *“I took full custody of all my three children” (P9).*

#### **Negligence in care**

Medical noncompliance, multiplicity of roles, and family problems lead to negligence in care. Family members might neglect administering the patient’s medications on time or might deliberately prevent the patient from taking their medicines. Sometimes, when they notice the patient’s behavior is improving, they inadvertently neglect to continue the follow-up. *“She was all asleep, so I told my mom not to give her any more pills” (P6).*

#### **Escaping care responsibilities**

In the care process, the primary caregiver, who is often a woman (mother, sister, and spouse), is the only person responsible for caregiving while the other family members step down. *“Sometimes when the difficulty of taking care of our ill family member is too much, my husband takes a break and goes to his sister’s house and stays there for two or three nights. But I can never do such thing” (P8).* A participant said: *“He was hospitalized for a month. I didn’t visit him at all during that time, so did nobody else in the family. We didn’t have time to go visit him, because we also have to think of a way to make money for our living. A month later, they called from the hospital and said that he could be discharged. “Come and take care of his discharge procedure.” Still, I didn’t go, and the personnel discharged him from the hospital themselves and brought him to our house” (P13).*

#### **Hiding the patient from the community**

In order to prevent stigma and feeling ashamed of the patient’s behaviors, the family caregivers of schizophrenia patients often avoid presence in public and hide their patient from other people. By doing so, families further isolate the patient and act as a barrier against the return of the patient to the community. *“My children do not like for their father (who is the ill member) to travel along with us, because they fear getting embarrassed for his behaviors. I don’t want him to join me at parties, so I only go to my family home. Because when he does something, it’s a disgrace for us” (P9).* Another participant stated: *“I don’t want anyone to see my sister (who is the ill member) in this situation. We haven’t told any of the relatives because they make fun of her or say the girl is crazy” (P10).*

## **DISCUSSION**

The results of this study showed that family caregiving for a patient with schizophrenia has different and

contradictory dimensions. These families suffer from a kind of contradiction and paradox. Their experience of caring for a schizophrenic patient has been a care paradox. Due to religious and cultural factors and the family's sense of the patient belonging to them, the family members tried to care for to the patient's integrity in a committed and compassionate way by maintaining the patient's individuality and acknowledging their separate existence and supporting and protecting the patient. Nonetheless, because of the challenges they faced, they sometimes felt an inadequacy of care on their part, such as misconduct with the patient (violence and aggression), depriving the patient of independence, negligence in care, escaping care responsibilities, and hiding the patient from the community. This paradoxical nature of family caregiving can be caused by a variety of factors. According to Leal *et al.*, living with chronic diseases is complex and multidimensional and could entail some paradoxical feelings. This paradox lies in the dual and complex experience of both positive and negative emotional states throughout the family member's illness. These paradoxical experiences can affect the provision of support to the patient.<sup>[24]</sup> This results confirmed that families experienced a contradiction in their behaviors and feelings and a care paradox as a result of living with the patient and providing care to them.

Findings of the present study indicate that family members feel responsible for providing care to their patient, offering financial, emotional and family support, and not leaving the patient alone. This finding is congruent with the results reported by Yu *et al.*, who found that families provide financial support, companionship, and emotional support to the patients despite their many needs.<sup>[6]</sup> Sharif Ghaziani *et al.* also confirmed that families monitor the patients' medication and treatment adherence and provide adequate support to them.<sup>[25]</sup> Blomgren Mannerheim *et al.* found that despite the stressful situation experienced and the many challenges, family members provide responsible care to their patient with schizophrenia.<sup>[26]</sup>

The present study showed that despite the positive role of the family and the support it provided, their inefficient adaptation with the disease and suffering, economic pressures, and lack of external support can lead to an inadequacy of care. Most often, only the primary caregiver was responsible for patient care and the other members abdicated their care responsibilities. Problems related to the patient's treatment and the multiplicity of roles of the caregiver led to negligence in care. The lack of knowledge and attitude and misconceptions about health caused behaviors such as ridiculing, blame, and

destruction of the patient's personality. This finding is consistent with the results, suggesting that factors such as the lack of knowledge<sup>[27]</sup> and lack of emotional and financial resources create contradictions and conflicts in the family care process of patients with schizophrenia.<sup>[28]</sup> Vaghee and Salarhaji also reported that families sometimes show inappropriate behaviors such as depriving the patient of playing a role in family decisions and blaming and ridiculing him.<sup>[29]</sup>

Azman *et al.* demonstrated the negative effects of family care, such as financial burden and social, mental and physical health problems, and emphasized the need for support resources for the families of schizophrenia patients.<sup>[30]</sup> Furthermore, due to the stigma of this disease, the family members tend to hide the patient from the society. In line with the above results, Torabi *et al.* reported that the burden caused by caring for a mentally-ill person can reduce the quality of care and lead to poor care, abandonment, or violent behaviors toward the patients.<sup>[31]</sup> Families have limited information, resources, and support,<sup>[32]</sup> and due to the stigma of the disease, may try to hide the patient's condition.<sup>[33]</sup> According to Sharif Ghaziani *et al.*, this tendency can lead to the social isolation of the patient.<sup>[25]</sup> Studies have confirmed that families tend to hide their schizophrenia patient's disease from others<sup>[34]</sup> and limit their social relations due to the disease stigma.<sup>[35]</sup> The present study showed that families had limited their relationships with others due to shame and their relatives had broken up their relations out of fear and worry. Nonetheless, Fitryasari *et al.* showed that families of patients with schizophrenia achieve resilience by living with the patient. This outcome is achieved as they face more stressful situations and move toward acceptance and give positive meaning to their experiences and develop positive behaviors. Through their sense of commitment, strong intrafamily communication, and the exchange of support among the family members, these families move toward solving any problems that emerge as a result of the illness and end up showing good behaviors toward the patient.<sup>[36]</sup> This disparity in the findings of different studies can be due to the differences in the study setting, level of access to support, and other factors. Shamsaei *et al.* also confirmed in their study that family care is affected by various factors, such as socioeconomic factors, the cultural background, and the health policies and services.<sup>[37]</sup>

Malakouti *et al.* found that despite the heavy care burden and costs, families endured any stress imposed on them by the disease as well as the resultant social stigma, made sacrifices, and provided optimal care to their patient to the point of being excessively supportive and did not

reject the patient.<sup>[38]</sup> In the present study, however, the family members' misconduct toward the patient due to the problems and challenges faced by the disease as well as the care burnout resulting from multiple relapses led to a rejection of the patient, their transfer to care centers or the hospital for long term, and distancing measures. These disparities in findings may be attributed to the different contexts of care delivery and the varying social and economic status of the study participants. Today, with the changes in lifestyle and increased care responsibilities and economic problems, it seems that caregivers suffer greater care exhaustion. Haresabadi *et al.* believed that in the Iranian culture and beliefs, people are not willing to entrust their patient to care institutions,<sup>[39]</sup> while the present findings did not confirm this assumption. The surveyed families were in fact willing to hand over their patient to care centers because they were desperate despite feelings of belonging and guilt.

The results of the present study were also incongruent with those reported by Hernandez-Yáñez *et al.*, who showed good family support and better outcomes.<sup>[40]</sup> This disparity could be due to the differences in the studies' context and access to facilities. Considering the impact of environmental factors on disease management and family care, it should be noted that the families had access to specialized treatment facilities for schizophrenia and a different socioeconomic status in Hernandez-Yáñez *et al.*'s study, which could have caused the better outcomes. Doval *et al.* stated that some variables affect the experience of care, such as having higher education, living in urban areas, higher family income, more extensive knowledge, and having access to support, which promote positive experiences.<sup>[41]</sup> According to Fereidooni *et al.*, families who possessed greater knowledge about the disease expressed less negative emotions and accepted the disease better.<sup>[42]</sup> The results reported by Haresabadi *et al.* also showed that greater knowledge about mental illness and how to deal with it meant better acceptance of and willingness to take care of the patient.<sup>[39]</sup> Sharif Ghaziani believed that people with higher levels of education, better employment positions, access to facilities, and financial support have more extensive communication networks and higher adaptability,<sup>[25]</sup> which was not consistent with the results of the present study. The results of the present study showed that care burden can even impact a person's knowledge and neutralize it in some cases, which is why some family members showed inadequate care or rejection despite their higher education and financial abilities. They even used their financial means to keep the patient away from the family. Ahmadi showed that access to community resources could also affect family

care, as families offered a range of care to their patient based on their access to resources and support.<sup>[8]</sup> This study has some limitations. Difficulty of accessing the patients' families due to their own struggles as well as the conditions imposed by the COVID-19 pandemic was a limitation of this study.

## CONCLUSION

Families with schizophrenic patients experience different dimensions with regard to caregiving. On the one hand, they try to protect their patient, preserve their individuality and existence, and support them. On the other hand, due to their inadequate training, poor attitudes, lack of financial support, inadequate organizational and social support systems, and burnout, they fail to provide good care to their patient and experience an inadequacy of care, and these negative effects impact both the patient and the family. Providing resources of support and further training and assessing the families' needs are steps that can help these families provide better care to their schizophrenic members.

## Conflicts of interest

There are no conflicts of interest.

## Authors' contribution

Z. E. M contributed to conception, designing, data acquisition, data analysis, manuscript preparation and manuscript editing. G.R.M contributed to conception, designing, data acquisition, data analysis, manuscript preparation and manuscript editing. K.Y contributed to conception, designing, data analysis and manuscript editing. M.M contributed to conception, designing, data acquisition, data analysis and manuscript editing.

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