



Pandemic Experiences of Family Caregivers of Individuals with Schizophrenia

Şizofreni Tanılı Bireylere Bakım Verenlerin Pandemi Deneyimleri

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ABSTRACT

Introduction: Caregivers of individuals with schizophrenia often experience worse quality of life, higher levels of care burden, and increased costs compared to caregivers of individuals with other chronic conditions like Alzheimer's disease, cancer, or stroke. The COVID-19 pandemic has further exacerbated the challenges faced by caregivers of people with schizophrenia, leading to increased care difficulties, burden, and impacts on mental health. The pandemic has highlighted the necessity of integrated collaborative care models to ensure continuous access to healthcare and prescribed treatments for individuals with schizophrenia.

Objectives: This study aims to explore family experiences in caring for schizophrenia patients during the Covid-19 pandemic using qualitative approach.

Methods: A qualitative thematic analysis method was used to evaluate data obtained with in-depth individual interview from caregivers for an individual diagnosed by schizophrenia. The data were collected between May and June 2023.

Results: The experiences of family caregivers were categorized under four themes, which were further divided into subcategories: "Challenging situations caused by the patient", "Challenging situations caused by institutional", "Facilitating situations", "Difficulties experienced by the caregiver".

Conclusion: It is thought that it will be important to develop additional intervention steps and facilitating policies for schizophrenia patients according to healthy population to protect the mental health of caregivers with heavy care burden in situations requiring restrictive measures such as pandemic.

Keywords: Caregiver, experiences, schizophrenia, pandemic

ÖZ

Giriş: Şizofreni tanılı bireylere bakım verenler, Alzheimer, kanser veya felç gibi diğer kronik hastalıkları olan bireylerin bakım verenlerine kıyasla sıklıkla daha kötü yaşam kalitesine, daha yüksek düzeyde bakım yüküne ve daha yüksek maliyetlere maruz kalır. COVID-19 salgını, şizofreni tanılı bireylere bakım verenlerin karşılaştığı zorlukları daha da kötüleştirerek bakım zorluklarının, bakım yükünün ve ruh sağlığı üzerindeki etkilerin artmasına yol açmıştır. Pandemi, şizofreni hastalarının sağlık hizmetlerine ve reçeteli tedavilere sürekli erişimini sağlamak için entegre işbirlikçi bakım modellerinin gerekliliğini göstermiştir.

Amaç: Bu çalışma, niteliksel bir yaklaşım kullanarak Covid-19 salgını sırasında şizofreni tanılı bireylerin bakımında görev alan aile üyelerinin deneyimlerini belirlemek amacıyla planlandı.

Yöntem: Şizofreni tanısı alan bir bireye bakım verenlerden derinlemesine bireysel görüşme ile elde edilen verilerin değerlendirilmesinde nitel tematik analiz yöntemi kullanıldı. Veriler Mayıs ve Haziran 2023 arasında toplandı.

Bulgular: Bakım veren aile üyelerinin deneyimleri dört tema altında toplanmış ve bu temalar ayrıca alt kategorilere ayrılmıştır: "Hastadan kaynaklanan zorlayıcı durumlar", "Kurumsal kaynaklı zorlayıcı durumlar", "Kolaylaştırıcı durumlar", "Bakım verenin yaşadığı zorluklar". Sonuç: Pandemi gibi kısıtlayıcı önlemler gerektiren durumlarda bakım yükü ağır olan bakım verenlerin ruh sağlığının korunması için şizofreni hastalarına yönelik sağlıklı popülasyona göre ek müdahale adımları ve kolaylaştırıcı politikaların geliştirilmesinin önemli olacağı düşünülmektedir.

Anahtar kelimeler: Bakım verici, deneyim, şizofreni, pandemi

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INTRODUCTION

The COVID-19 pandemic has caused some of the biggest medical, social, and political problems in recent decades when it first emerged in early 2020 around the world, and countries have focused on prevention, screening and finding treatment for this virus⁽¹⁾. Isolation strategies to prevent the spread of the virus have been able to cause psychological and social problems by closing schools and workplaces, decreasing autonomy, and causing economic and security concerns^(1,2). It has also caused loneliness by disrupting access to social support systems such as family and friends and may cause anxiety and depressive symptoms⁽³⁾. This situation has led to the emergence of stressors specific to the pandemic process.

Individuals with schizophrenia and their families have been significantly impacted by the COVID-19 pandemic. Research suggests that individuals with schizophrenia may be at an increased risk of infection and poor outcomes due to COVID-19⁽⁴⁾. The stress related to the pandemic and the corresponding public health measures may worsen mental health in the general population, and this impact may be even higher in people living with schizophrenia^(4,5). Previous pandemics, such as the SARS pandemic in 2003, have also been associated with elevated rates of psychiatric disorders and psychological distress^(4,6). In addition to the short-term implications, there are concerns that the COVID-19 pandemic may result in an increased prevalence of psychosis in the coming decades⁽⁶⁾. Individuals with mental disorders are more susceptible to infections for various reasons. While the presence of severe mental illness itself is a risk factor for pneumonia, comorbid alcohol-substance use disorder and being homeless are also risk factors for both being infected with COVID-19 and a more severe COVID-19 infection^(6,7). In addition, discrimination against mental disorders may cause patients to be exposed to more barriers to accessing health services than other individuals in the community. Furthermore, the frequency of comorbid medical conditions, cognitive deficits, the lack of awareness of the COVID-19 pandemic and prevention methods, the inadequacy of their efforts on individual protection measures led to individuals with severe mental illness even more vulnerable to the pandemic^(4,7). Due to morbidity and mortality associated with COVID-19, psychiatric patients are also at risk for side effects related to the treatment of COVID-19 infection^(8,9). The

pandemic has also disrupted mental health service delivery for individuals with schizophrenia. Access to medical resources and community mental health services has been restricted, leading to increased loneliness and the risk of exacerbation⁽⁵⁾. The isolation and stress caused by the pandemic cause them to be more affected and at risk of relapse and exacerbation compared to the general population. The isolation and lockdown restrictions applied during the pandemic period made it difficult for patients to continue their regular hospital visits, prescribe maintenance treatments and administer depot antipsychotic treatments compared to their usual lives. In addition, COVID-19 infection itself may exacerbate symptoms in patients with schizophrenia, as coronaviruses may be associated with psychotic symptoms through immune mechanisms⁽⁸⁻¹⁰⁾. However, little is known about how people with schizophrenia spectrum disorders specifically experience the COVID-19 pandemic situation.

People with schizophrenia mostly live with their families. For this reason, family members also play an important role in the care of people with schizophrenia. Since the primary caregiver is at the center of the patient's daily life, as the caregiving responsibilities increase, the caregiving, care-receiving relationship may turn into a one-way, dependent, intensive and long-term obligation that puts the caregiver's life under stress^(11,12). The Covid-19 epidemic has given birth to stresses. In order to provide appropriate treatment for schizophrenia patients, families need to enhance their capacity to adjust to the Covid-19 pandemic. Amidst the Covid-19 outbreak, it is imperative to prioritize the health and security requirements of patients when providing care. Their requirements are mostly tied to their interpersonal connections, humanistic concerns, and familial relationships. Moreover, their growth requirements mostly manifest as a profound need for information. Existential demands take precedence during an epidemic, with the health and security requirements mutually affecting one another⁽⁸⁻¹⁰⁾.

The caregiver role is a difficult, demanding, and unpredictable experience. As a result of obstacles such as physical, emotional, and economic difficulties experienced by caregivers, and the lack of free time of the caregiver, they adversely affect the quality of life of the caregivers^(13,14). The restrictions applied during the pandemic and the interruption of outpatient services, the closure of community mental health

centers to prevent the spread of infection in this process, the patients' ignorance, or inability to using personal protective equipment (PPE), disruptions in the follow-up of drug therapy, stressors caused by the pandemic caused changes in the care roles of relatives of patients with schizophrenia. The experience of families in caring for schizophrenic patients has been differentiated in the Covid-19 pandemic, while adapting to health protocols related to Covid-19, taking care of patients has made care tasks difficult ^(8,11,13,15).

Numerous quantitative and qualitative insights into the general population's psychological response to this public health crisis have been uncovered through studies of the subject population as well as several subgroups ^(1,3), such as those who suffer from a variety of mental illnesses ^(5,6,16). When the literature was analyzed, not enough studies were found on this subject. Therefore, this study aimed to investigate family experiences in the care of individuals diagnosed with schizophrenia during the Covid-19 pandemic.

METHODS

The authors followed to the Standards for Reporting Qualitative Research throughout this study ⁽¹⁷⁾.

Design

A phenomenological research pattern, which is a qualitative research approach, was used in this study. According to Braun and Clarke (2014), qualitative research makes it possible to describe participants' experiences and viewpoints in greater detail ⁽¹⁸⁾. This approach was chosen to reveal the experiences and problem of family members caring for patients diagnosed with Schizophrenia in Van, Türkiye and to understand their experiences, feelings, thoughts, and perspectives.

Research team and reflexivity

The researchers have been working as faculty members (PhD, Assistant Professor) on a health science faculty in the department of mental health and psychiatric nursing. In the past, they held positions as nurses at hospitals. Researchers are 35 and 38 years old. One researcher is female, and one is male, all of whom are trained in qualitative research. One has completed acceptance and commitment therapy training, and one has a psychodrama co-therapist license. The researchers were not previously acquainted the participants.

Setting and time

The data were collected between May and June 2023, in psychiatric outpatient services in Van, Türkiye.

Participants

The sample consisted of 11 family caregivers of individuals diagnosed with schizophrenia in Van, Türkiye. The most crucial factor in the phenomenological pattern of research group selection is that the chosen participants must have firsthand knowledge of the phenomenon being studied in all its manifestations ⁽¹⁹⁾. Thus, to be included in this study, family members were required to be over the age of 18 years, to have cared (who meet the physical needs of the patient, follow up their treatment and organize hospital appointments) for patients diagnosed with schizophrenia, living with the patient for at least 1 year during the pandemic, and being open to communication and cooperation. Exclusion criteria from the study were having a neurocognitive disorder, presence of mental retardation (intellectual disability), and having an acute mental disorder. The purposive sampling method was used for choosing the study sample. To determine the number of the sample, data saturation in qualitative research was considered, and 11 family members were determined to be sufficient to achieve data saturation ($N = 11$).

Participants' ages ranged from 29 to 60 ($M = 46.27$ and $SD = 11.70$). The sociodemographic characteristics of the sample presents in Table 1.

Data were collected with a Personal Information Form and a Semi-Structured Interview Form. The Personal Information Form was created by the researchers in line with the extant literature. It contains information about the age, gender, educational status, marital status, closeness to the patient, length of life with the patient, whether they have received psychoeducation.

The Semi-Structured Interview Form in line with the extant literature was also used, and it consisted of the following five open-ended questions ^(8,11,13).

1. What experiences did you have while caring for a patient diagnosed with schizophrenia during the pandemic?
2. What were the challenging situations for you experienced when caring for a patient diagnosed with schizophrenia during the pandemic?

Table 1. The Sociodemographic Characteristics of the Sample

| Characteristics | $\bar{X} \pm SS$ |
|--|---------------------------------|
| Age (Years) | 46.27±11.70 (Min:29, Max:60) |
| Duration of living with the patient (year) | 23.54±8.40 (Min: 4, Max: 30) |
| | N (%) |
| Gender | |
| Male | 5 (45.5) |
| Female | 6 (54.5) |
| Marital Status | |
| Married | 8 (72.7) |
| Single | 3 (27.3) |
| Employment Status | |
| Yes | 3 (27.3) |
| No | 8 (72.7) |
| Education status | |
| Primary School | 7 (63.6) |
| Secondary School | 1 (9.1) |
| High school | 3 (27.3) |
| Economic status | |
| Income covers expenses. | 4 (36.4) |
| Income does not cover expenses | 7 (63.6) |
| Chronic Physical Illness | |
| Yes | 3 (27.3) |
| No | 8 (72.7) |
| Do You Care for Anyone Else? | |
| Yes | 6 (54.5) |
| No | 5 (45.5) |
| Relation to the patient | |
| Spouse | 2 (18.2) |
| Parent or child | 6 (54.5) |
| Sibling or Close Relative | 3 (27.3) |
| Have you received psychoeducation about the disease before? | |
| Yes | 7 (63.6) |
| No | 4 (36.4) |

3. What were the facilitating situations for you experienced when caring for a patient diagnosed with schizophrenia during the pandemic?
4. How did you feel while caring for a patient diagnosed with schizophrenia during the pandemic?
5. How did you deal with challenging situations while caring for a patient diagnosed with schizophrenia during the pandemic?

Data collection process

The data were collected via an individual, in-depth interview technique. Pilot interviews with two people who were not the primary participants were conducted prior to the research interviews. These pilot interviews led to modified of the interviewing procedure and questions.

All the researchers (MCA and CHA) conducted in-depth interviews in a one-on-one, face to face setting. First the research purpose and method were explained to family members who met inclusion criteria and interview was arranged with family members who agreed to participate in the study. Interviews were held in the doctor's room with only the interviewer and the participant. At the start of each interview, verbal and written consent was obtained from participants. The duration of the interviews was 45-90 minutes. To record both verbal and nonverbal expressions written notes and a voice recorder were used. Interview transcripts were sent to the family members for approval, further comments and/or corrections.

Ethical issues

The study was approved by the Van Yuzuncu Yil University Non-Clinical Ethics Committee (2023/03-01). Institutional Permission was obtained from Van Yuzuncu Yil University Dursun Odabas Medical Center to carry out the study (362039).

All participants provided written informed consent prior to enrolment in the study. This research was conducted ethically in accordance with the World Medical Association Declaration of Helsinki. Audio records, transcripts, and interview notes were kept on a password-protected computer, and all data gathered will be deleted five years following the conclusion of the study and publication processes.

Data analysis

After transcribing the audio recordings, the consistency between the recordings and the transcripts was checked. For the analysis of the interview data, Braun, and Clarke's (2006) theme analysis standards were used. Stages of Thematic Analysis are given below ⁽¹⁸⁾:

1. The researcher's familiarity with the data: Transcribing the data (when necessary), reading the data repeatedly, notation of initial ideas.
2. Generating the initial codes: Coding the salient features of the data in a systematic way across the entire data set, collecting the data relevant to each code
3. Searching for themes: Gathering codes under potential themes, collecting all data under possible themes to which they relate
4. Review of themes: Checking the compatibility of the themes with the coded data content (Level 1) and the entire data set (Level 2), creating the thematic 'map' for the analysis.
5. Definition and naming of themes: Simplifying the features of each theme and continuing the analysis to define the whole story told in the analysis, clear identification, and naming of each theme.
6. Preparation of the report: Selecting concrete, striking, and convincing examples of direct quotations, analyzing the coded data contents for the last time, re-associating the analysis results with the research question and the literature, reporting the analysis in an academic language.

An experienced academician who was not one of the primary researchers reviewed the collected themes and codes, and the results showed that they overlapped.

RESULTS

Based on data analysis the revealed statements of the participants were divided into four themes as "Challenging Situations Caused by the Patient", "Challenging Situations Caused by Institutional", "Facilitating Situations" and "Difficulties Experienced by the Caregiver".

Challenging Situations Caused by the Patient theme emphasized the negative effects of restriction

practices on the patient and the difficulty of participating in hygiene practices. Challenging situations caused by Institutional the difficulties experienced at the institutional level such as the closure of CMHCs and isolation measures during the pandemic process. On the other hand, facilitating situation's theme emphasized the patient's use of his/her medication and the absence of symptoms, and the facilitator effect of family members on the care process during the pandemic. Difficulties experienced by the caregiver theme also highlighted the negative situations experienced by family members, such as negative emotions, being exposed to violence, and feeling depressed fatigue etc. Each main theme consisted of several subthemes that add nuance and depth to the analysis. Table 2 contains Quotes (translated from Turkish into English) illustrating and supporting the themes.

DISCUSSION

We examined that the COVID-19 pandemic affects the family caregivers of people with a schizophrenia spectrum disorder using a qualitative research method via face-to-face in-depth interviews. We determined that four main themes each involve different features of participants' experiences.

Main theme 1 identifies challenging situation related to patient situation during pandemic. Caregivers stated that they have some challenges to deal with hygiene problems, and emotions of patients. Interviewees' stated lack of hygiene, patient's crying, anger of patient, delusions at individual level. Patient with schizophrenia may be non-compliance with the pandemic hygiene protocols due to their impaired cognition and lack of self-care through negative symptoms ⁽⁷⁾. This situation caused families to be accompanying in self-care of their patients and increased their responsibilities in this regard for patients to comply with pandemic hygiene protocols.

Lockdown procedures also have affected the patient negatively. Caregivers reported that their patients had negative emotions like anger and, they cried during the lockdown process. Similar results have been reported study conducted with patient with schizophrenia ^(10,20). Lockdown also negative affect on mood and mental health among general population ^(1,3). Loss of daily routine may be challenging for both patients and their family. We believe that different lockdown strategies should be applied for this vulnerable population, considering the risk-benefit ratio in future pandemics.

Table 2. Patient-Based Experiences of Family Members of Individuals Diagnosed with Schizophrenia During the Pandemic Process

| | | |
|--|--|--|
| | Lack of hygiene | ... I do the cleaning, she can't do it herself, sometimes I force her to do it. (K1) ... He doesn't pay attention to his hygiene, if you don't watch him, he doesn't wash his hands even when he comes out of the toilet, and we had problems in this process because he didn't pay attention to his hygiene (E3) |
| Challenging Situations Caused by the Patient | Inability cope with negative emotions of patients: Anger and Sadness | ... and then she keeps crying. He says what should I do, I am sick (E4) ... In this case, she cries. Cries when bored, lies down (K1) He says he is bored, he wants to go out, but we can't, so he gets angry (K2) ...he says he wants to smoke hookah. I can't allow. He gets angry at those times (K4) |
| | Delusions | He constantly says that he has caught the Coronavirus (K6) He was saying that we would infect him with Covid, and sometimes he would say "I have Covid" and lock himself in the room, but he had no symptoms. (E2) |
| Challenging Situations Caused by Institutional | problems related to isolation | He always wants to go out, he always wants to go out, he always wants to travel. There is a railing on the windows in my house so that he does not escape, I lock the door at night when I sleep, I am afraid that he will go out like that one night. (E5) We couldn't get it out for a while, he kept saying I'm going out. In this process, he always did, The problem we had was that he wore a mask for a week. (K5)I had a hard time keeping it at home... (E1) ... It never stayed at home, we could never keep it at home. I had to go out with him every time he went out so that he wouldn't do anything to anyone.(K3) |
| | closing the Community Mental Health Clinics (CMHC) | it bored him so much, he was coming here, he was lingering, it was relieving his boredom. (E2) ...Because he didn't come to CMHC, he always had a good attitude towards us, saying that he missed his friends and wanted to go. He suddenly shouted a few times...(K1) |
| Facilitating Situations | Medication effect-well-being | ... He was always asleep, he was fine, we did not have any problems because he used his drugs (K2) ...I swear, it's good because he used his drugs during this process, God knows what situation we would be in if he didn't use his drugs (E2) |
| Difficulties Experienced by the Caregiver | Negative emotions | ...Sometimes I used to go and stand by him, this process made me very tired...(E1) ... this situation makes me a little tired, but I can't say anything. After all, the patient is sick, what can I do? (K4) ... I'm crying, her mother is crying, and then she keeps crying. She says what should I do, I am sick. (E4) ...asks very depressing questions, speaks in a very loud tone.(E3) ...I'm always on your side, I'm always with you, that's why I get bored too...(E4) when that happens, he gets angry. When he gets angry, we are afraid that he will attack again. We are trying to manage. (K2) |
| | Inability to take time for yourself | ...We have to watch him all the time, and we can't spare time for ourselves. We were more comfortable when he continued CMHC. (E2) ...I can't spare time for my work, I have to deal with it all the time. I don't feel comfortable. (K4) |
| | Exposure to violence | For example, when a meal comes to him late, he gets angry and hits it... (E4) ...He constantly fights for nothing, fights, insults children all the time (K3) He suddenly shouted a few times, for example, I was starting the machine and he suddenly shouted. I'm so scared, what's going on? I said, never said. He threw a glass several times. It is affected in children... (K1) |

Several participants reported that delusion about infected by COVID occurred in patients. Fear of being infected in the pandemic also occurred in mentally stable people and this can sometimes be preceding of a psychotic crisis. Participants worried about that relapse.

Furthermore, problems related to isolation and closing of the CMHC were determined by institutional level. Similar findings were obtained in studies conducted with individuals diagnosed with

schizophrenia^(8,12,20). Non-compliance of the patient's lockdown procedures concerning stay at home is difficult for family members. In the pandemic, stay-at-home practices to prevent the transmission of the disease affected the social interactions of schizophrenia patients, families sometimes had to lock the patients so that they could stay at home, and this situation caused negative interaction between the patient and family members. Sanctions related to lockdown during the pandemic have been challenging for families. Closing the CMHC and having problem

due to lockdown also reported by family members. CMHC are not only treatment centers for people with schizophrenia but also centers that contribute positively to their cognitive and emotional state by improving social support and leisure time activities ^(6,9,11). Closure of these centers during pandemic, patients being away from their familiar surroundings have been a challenging factor for family members and has increased the burden of care ^(11,21).

It was a facilitating situation for family members that patients took their medication. Although hospital services are restricted in Turkey, it is thought that the reporting of medicines of individuals with chronic diseases through the online system, the coverage of medicines by the state and the fact that families do not have difficulty in obtaining medicines are effective on this situation. In some studies family members of patient with schizophrenia experienced financial difficulties needing extra expenses to purchase masks, transportation, and daily necessities ^(8,13,14). Contrary to this result, In Turkey government provided hygiene materials such as masks free of charge, and the fact that individuals with chronic diseases receive salaries and benefit from services such as transport free of charge did not cause more than the economic difficulties caused by the pandemic in families.

Finally, family members reported difficulties such as fatigue, crying, lack of time for themselves, boredom, fear of the patient having an attack, and exposure to patient violence. Spending more time with the patient during the pandemic, the patient's non-compliance with hygiene rules, and isolation problems increased the care burden of family members. Caring for patients while complying with Covid-19-related health protocols made care tasks more difficult. Similar results were reported in previous studies ^(5,9,20). It is known that caregivers of schizophrenia patients have high care burden. It is important for caregivers to spare time for themselves and to get away from the patient in terms of their psychological resilience ^(14,21). On the other hand, previous studies have reported that caregivers who spend more time with the patient are more exposed to patient violence ^(8,12). The caregiver's inability to spare time for himself/herself, having fears about having an attack, and being exposed to violence by the patient caused the caregiver to be negatively affected psychologically. It is thought that it will be important to develop additional intervention steps

and facilitating policies for schizophrenia patients according to healthy population to protect the mental health of caregivers with heavy care burden in situations requiring restrictive measures such as pandemic.

The results of this study have some limitations. As data collection took place after the pandemic, interviewees may not have reported the situations they perceived as more stressful when they were alive. The number of participants is also other limitations. Future research will conduct with large sample for providing more detailed family experiences when caring schizophrenia patients. However, the fact that the interviewees and researchers had not met before is a strength of the study.

CONCLUSION

The COVID-19 pandemic has had a significant impact on family caregivers of individuals with schizophrenia spectrum disorder. The current study has explored the effects of the pandemic on caregivers and have highlighted the challenges they faced. Overall, the COVID-19 pandemic has had a significant impact on family caregivers of individuals with schizophrenia spectrum disorder. Caregivers face increased challenges, including psychosocial adversities, illness-related factors, and the added burden of avoiding COVID-19 infection. It is crucial to provide support and resources to caregivers to help them navigate these difficult circumstances.

In conclusion, the increased vulnerability of individuals with schizophrenia to COVID-19 infection, coupled with the potential for adverse outcomes, has heightened concerns for their well-being. The pandemic has also disrupted routine care and support systems, leading to increased stress and burden for both individuals with schizophrenia and their caregivers. It is crucial for healthcare systems to recognize and address the unique challenges faced by this population, providing necessary support and resources to mitigate the impact of the pandemic on both individuals with schizophrenia and their caregivers.

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Author contribution

Study conception and design: MCA and CHA; data collection: MCA; analysis and interpretation of results: MCA and CHA; draft manuscript preparation: CHA. All authors reviewed the results and approved the final version of the manuscript.

Ethical approval

Van Yuzuncu Yil University Non-Invasive Clinical Research Ethic Committee (Protocol no. 2023/03-01/17.03.2023).

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The authors declare that there is no conflict of interest.

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