



Health-Related Quality of Life of Saudi Caregivers Responsible for Children with Anxiety Disorders

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ABSTRACT

Objectives: To assess the health-related quality of life (HRQOL) and identify the determinants of low HRQOL among Saudi caregivers of children with anxiety disorders. **Methods:** This study was conducted during October 2019 till January 2020, at four pediatric psychiatry clinics in Aseer Region. It included 220 Saudi caregivers of children with anxiety disorders. A self-administered questionnaire was used for data collection. It comprised the Physical Component Summary (PCS-12) and the Mental Component Summary (MCS-12) scores. **Results:** There were significantly low PCS-12 and MCS-12 scores among female and illiterate caregivers. PCS-12 and MCS-12 mean scores were significantly lower among caregivers of female children, those with several siblings and those with an illness duration >6 years. Predictors for a low PCS-12 score among caregivers included their educational level and a long duration of the child's illness, while those for a low MCS-12 score included the child's gender, their number of siblings, and the duration of their illness. **Conclusion:** The HRQOL of caregivers of children with anxiety disorders is compromised. Its determinants include mothers, illiterate people, caregivers of female children, caregivers of children with several siblings, and caregivers of children with a long duration of illness. Predictors for low PCS-12 scores among caregivers were their educational level and duration of child's illness, while predictors for low MCS-12 scores were female gender, large number of siblings, and long duration of anxiety disorders.

Keywords: Health-related quality of life, Physical component summary, Mental component summary, Anxiety disorders, Caregivers

INTRODUCTION

Mental illness is a serious medical condition that affects an individual's thoughts, feelings, mood, and behavior [1]. There is a wide range of conditions associated with mental illness, such as depression, anxiety, schizophrenia, bipolar disorder, obsessive-compulsive disorder, panic disorder, post-traumatic stress disorder, personality disorder, eating disorders, and addictive behaviors. These illnesses can affect people of all ages with different ethnicities, cultures, religions, and incomes [1,2].

Health care for children remains a significant area for consideration across the globe. Mental illness in children presents in many forms, which include social anxiety disorder, separation anxiety, specific phobias, selective autism, post-traumatic stress disorder, and obsessive-compulsive disorder. These illnesses are common in children, and each arises from particular contextual factors. The role of health care professionals is to observe children to identify any of the symptoms that characterize the above disorders. The trends are likely to vary based on the environment, and the analysis of these elements is essential in validating the factors that cause these disorders [3].

Anxiety is one of the most common psychological disorders among children and adolescents worldwide [4]. Several national studies indicated that the prevalence of anxiety among Saudi children is relatively high. In Al-Hassa, Saudi Arabia, it was reported that 14% of children suffer from anxiety [5], while Al-Qahtani and Harbi [6] reported that prevalence of morbid anxiety among secondary school girls in Al-Madinah, Saudi Arabia, was 25.5%. Moreover, two separate studies that explored anxiety among school children in the Aseer Region revealed high prevalence rates of anxiety among both boys (48.9%) and girls (66.2%) [7,8].

Quality of health care provided by caregivers of children with anxiety disorders varies based on the socioeconomic status of the parent(s) and the immediate environment. The quality of health care provided to children is affected by many factors, but the situation is complicated in young people who have medical conditions. Such scenarios demand extra attention and the creation of an environment that promotes the wellbeing of caregivers of children with anxiety. Moreover, caregivers must have the right state of mind to raise children effectively. This dictates a need for precaution because such children are likely to react to any new situation or change in the environment. Furthermore, consultation with competent practitioners increases the likelihood of parent(s) living a normal life despite raising kids with anxiety disorders [9].

Health-Related Quality of Life (HRQOL) of individuals with anxiety disorders is still in its early phase [10]. Research done to date portrays a consistent picture of anxiety disorders as conditions that markedly compromise HRQOL and psychosocial functioning across several functional domains [11].

Keighobadi, et al. [12] showed that the average score for quality of life (QOL) among caregivers of children with anxiety disorders was 4.49 (out of 10). Moreover, Akbari, et al. [13] reported that the QOL for caregivers was 17%, which is considered unfavorable.

Since the prevalence of anxiety disorders among children is high in Saudi Arabia, especially in the Aseer Region, [7,8] it is essential to explore whether children with anxiety disorders affect their caregivers' abilities and HRQOL.

This study aimed to assess the health-related quality of life and identify the determinants of low HRQOL among Saudi caregivers of children with anxiety disorders in the Aseer Region, Saudi Arabia.

METHODS

Following a cross-sectional study design, this study was conducted during the period from October 2019 till January 2020, at four pediatric child psychiatry clinics working under the umbrella of the Saudi Ministry of Health, which were in Abha and Khamis Mushait cities, in the Aseer Region, Kingdom of Saudi Arabia (KSA). These study settings included two governmental hospitals, Abha Psychiatry Hospital and the Maternity and Children's Hospital (Khamis Mushait), in addition to two private hospitals, Abha Global Private Hospital and the Happy Life Center in My Care Center.

The study population included Saudi caregivers of children (aged up to 18 years) who had suffered from anxiety disorders for at least one year and who had been registered at one of the four hospitals mentioned above. Exclusion criteria included non-Saudi children, those who were raised in the Orphan Care House, and those who were not registered at any of the four study hospitals.

The minimum sample size for the present study was calculated to be 217, according to Dahiru, et al. [14], with a z-value for the selected level of confidence of 1.96, an estimated prevalence throughout the population of 17% [13], and a maximum acceptable error of 5%.

A total of 220 caregivers of children with anxiety disorders were included in this study. They were selected following a consecutive sampling technique in each study hospital. The proportion of recruited participants from each hospital was proportionate to the number of registered children with anxiety disorders at the time data collection began.

A self-administered questionnaire (in simple Arabic Language) was designed by the researchers. For illiterate caregivers, direct interviews using the study questionnaire were conducted. The study questionnaire comprised two parts, as follows:

1. Questions covering socio-demographic variables (for both caregivers and their children) included: Age, current marital status, parents' education levels, parents' occupations, number of siblings, birth order of the patient within his/her siblings, monthly family income, duration of the illness, and caregiver's relation to the child
2. The Short Form Health Survey (SF-12) [15]: This is divided into twelve elements within eight domains. It was developed to reproduce the Physical and Mental Component Summary (PCS-12 and MCS-12) scores. It is a commonly used instrument to measure health-related quality-of-life (HRQOL) at various ages. The instrument is a shorter version of the SF-36, developed by Ware and Sherbourne [16]. The SF-12 is psychometrically valid and

reliable [17]. The SF-12 is often applied to assess the health status and health-related quality of life in a specific population and to identify predictors for their health status [18]

The scoring of responses was based on an algorithm for converting the responses to Physical and Mental Standardized Values that range from 0 to 100 [19,20].

Collected data were verified by hand, then coded and entered by the researcher into a personal computer. The statistical Package for Social Sciences (SPSS, version 23) was used for data entry and analysis. Descriptive statistics (e.g., frequency and percentage) and analytic statistics using tests of significance, i.e., t-test and F-test, were applied accordingly. Variables with $p < 0.10$ in bivariate analysis were included in a multiple linear regression model to determine significant predictors of low HRQOL among caregivers. $p < 0.05$ were considered to be statistically significant.

Prior to data collection, all official approvals for conducting this study were obtained. The Institutional Review Board (IRB) approval was obtained from the Directorate of Health Affairs in the Aseer Region (#3-9-2019). Written informed consent was obtained from each participant.

RESULTS

Table 1 Characteristics of study sample (n=220)

Characteristics	No.	Percentage (%)
Caregiver's Age		
<30 years	26	11.8%
30-40 years	137	62.3%
>40 years	57	25.9%
Caregiver's Gender		
Male	90	40.9%
Female	130	59.1%
Caregiver's Kinship to Child		
Father	87	39.5%
Mother	124	56.4%
Others ‡	9	4.1%
Caregiver's Marital Status		
Married	197	89.5%
Single	8	3.6%
Divorced/widow	15	6.8%
Caregiver's Educational Status		
Illiterate	14	6.4%
Primary	19	8.6%
Intermediate	18	8.2%
Secondary	53	24.1%
University	116	52.7%
Caregiver's Job		
Governmental	83	37.7%
Private	23	10.5%
Military	26	11.8%
Unemployed	80	36.4%
Retired	8	3.6%

Monthly Household Income		
<5000 SR	39	17.7%
5000-10000 SR	83	37.7%
>10000 SR	98	44.5%
Age of Child		
<6 years	95	43.2%
6+ years	125	56.8%
Gender of Child		
Male	66	30%
Female	154	70%
No. of Child's Siblings		
0	12	5.5%
1-2	123	55.9%
3+	85	38.6%
Duration of Child's Anxiety Disorder		
<6 years	128	58.2%
≥ 6 years	92	41.8%

‡ Non-parent family members

Table 1 shows 62.3% of caregivers were 30-40 years old and 89.5% were married. Most caregivers had university or secondary levels of education (52.7% and 24.1%, respectively). Most employed caregivers had governmental jobs (37.7%), while 36.4% were unemployed. The monthly household income of 44.5% of caregivers was more than 10,000 SR. The age of more than half of the children with anxiety disorders (56.8%) was more than 6 years. Most children with anxiety disorders were females (70%). More than half of the children (55.9%) had 1-2 siblings. For 58.2% of children, the duration of their anxiety disorder was less than 6 years.

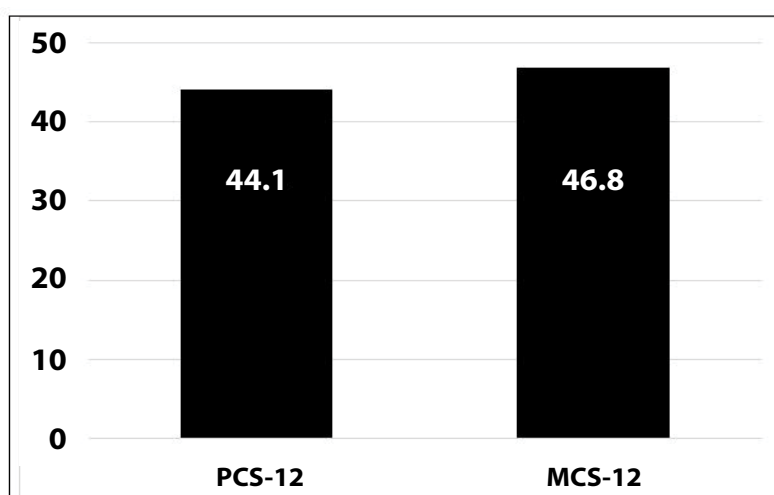


Figure 1 Caregivers' mean physical component score (PCS-12)

As shown in Figure 1, Caregivers' mean physical component score (PCS-12) was 44.1 ± 7.0 , while their mean mental component score was 46.8 ± 8.9 .

Table 2 Physical component scores according to caregivers' and children's characteristics

Characteristics	No.	Mean \pm SD	p-value
Caregivers' Age			
<30 years	26	43.7 \pm 6.2	0.94
30-40 years	137	44.2 \pm 7.1	
>40 years	57	43.9 \pm 7.4	
Caregivers' Gender			
Male	90	44.7 \pm 7.5	0.284
Female	130	43.7 \pm 6.7	
Caregivers' Kinship to Child			
Father	87	44.9 \pm 6.5	0.071
Mother	124	43.9 \pm 6.2	
Others ‡	9	48.7 \pm 7.5	
Caregivers' Marital Status			
Married	197	44.0 \pm 6.9	0.383
Single	8	47.4 \pm 10.2	
Divorced/widow	15	43.3 \pm 6.2	
Caregivers' Educational Status			
Illiterate	14	38.1 \pm 4.8	0.003§
Primary	19	41.9 \pm 4.9	
Intermediate	18	42.4 \pm 8.3	
Secondary	53	45.2 \pm 7.7	
University	116	44.9 \pm 6.6	
Caregivers' Job			
Governmental	83	44.6 \pm 6.2	0.659
Private	23	42.6 \pm 5.3	
Military	26	45.1 \pm 8.6	
Unemployed	80	43.7 \pm 7.4	
Retired	8	43.2 \pm 10.1	
Monthly Household Income			
<5000 SR	39	43.1 \pm 7.0	0.478
5000-10000 SR	83	43.8 \pm 7.0	
>10000 SR	98	44.7 \pm 7.1	
Child's Age			
<6 years	95	44.1 \pm 6.5	0.979
6+ years	125	44.1 \pm 7.4	
Gender of Child			
Male	66	44.6 \pm 5.7	0.477
Female	154	43.9 \pm 7.5	
No. of Child's Siblings			
0	12	51.1 \pm 6.0	<0.001§
1-2	123	44.9 \pm 7.0	
3+	85	41.9 \pm 6.4	

Child's Duration of Anxiety Disorder			
<6 years	128	45.3 ± 7.0	0.002§
≥ 6 years	92	42.3 ± 7.0	
§ Statistically significant; ‡ Non-parent family members			

Table 2 shows significant differences in PCS-12 mean scores according to caregivers' educational status ($p=0.003$), with the lowest scores being among illiterate caregivers (38.1 ± 4.8). There were significant differences in caregivers' PCS-12 mean scores according to the number of children's siblings ($p<0.001$), with the lowest PCS-12 mean scores among caregivers of children with the highest number of siblings (41.9 ± 6.4). Moreover, there were significant differences in caregivers' PCS-12 mean scores according to the duration of children's disorder, with the lowest PCS-12 mean scores among caregivers of children with a disorder duration >6 years ($p=0.002$). However, caregivers' PCS-12 mean scores did not differ significantly according to their age groups, gender, kinship to the child, marital status, job, monthly household income, child's age, or child's gender.

Table 3 Mental component scores according to caregivers' and children's characteristics

Characteristics	No.	Mean ± SD	p-value
Caregivers' Age			
<30 years	26	46.4 ± 6.2	0.783
30-40 years	137	46.6 ± 9.6	
>40 years	57	47.5 ± 8.2	
Caregivers' Gender			
Male	90	49.1 ± 7.2	0.001§
Female	130	45.2 ± 9.6	
Caregivers' Kinship to Child			
Father	87	45.3 ± 7.2	0.011§
Mother	124	43.3 ± 6.6	
Others ‡	9	49.4 ± 8.6	
Caregivers' Marital Status			
Married	197	46.7 ± 9.0	0.435
Single	8	44.1 ± 9.0	
Divorced/widow	15	49.0 ± 6.9	
Caregivers' Educational Status			
Illiterate	14	40.6 ± 9.5	0.021§
Primary	19	48.5 ± 12.0	
Intermediate	18	48.6 ± 5.2	
Secondary	53	45.1 ± 8.1	
University	116	47.7 ± 8.7	
Caregivers' Job			
Governmental	83	46.1 ± 9.8	0.395
Private	23	49.1 ± 5.7	
Military	26	47.8 ± 9.8	
Unemployed	80	46.1 ± 8/2	
Retired	8	50.2 ± 9.8	

Monthly Household Income			
<5000 SR	39	45.6 ± 9.1	0.388
5000-10000 SR	83	46.3 ± 9.6	
>10000 SR	98	47.7 ± 8.1	
Child's Age			
<6 years	95	45.7 ± 8.5	0.117
6+ years	125	47.6 ± 9.1	
Gender of Child			
Male	66	47.8 ± 8.8	0.008§
Female	154	44.4 ± 8.7	
No. of Child's Siblings			
0	12	49.1 ± 9.7	0.042§
1-2	123	47.8 ± 8.9	
3+	85	44.9 ± 8.5	
Child's Duration of Anxiety Disorder			
<6 years	128	48.0 ± 8.0	0.019§
≥ 6 years	92	45.1 ± 9.8	

§ Statistically significant; ‡ Non-parent family members

Table 3 shows that female caregivers had significantly lower MCS-12 mean scores than male caregivers ($p=0.001$). Mothers had the lowest MCS-12 mean scores, with significant differences in MCS-12 according to the given caregiver's kinship to the child ($p=0.011$). There were significant differences in caregivers' MCS-12 mean scores according to their educational status ($p=0.021$), with the lowest scores among illiterate caregivers (40.6 ± 9.5). Caregivers of female children had significantly lower mean MCS-12 scores than caregivers of male children (44.4 ± 8.7 and 47.8 ± 8.8 , respectively, $p=0.008$). There were significant differences in caregivers' MCS-12 mean scores according to the number of children's siblings ($p=0.042$), with lower MCS-12 mean scores among caregivers of children with the highest number of siblings (44.9 ± 8.5). There were significant differences in caregivers' MCS-12 mean scores according to the duration of their child's disorder, with the lowest MCS-12 mean scores occurring among caregivers of children with disorder durations >6 years ($p=0.019$). However, caregivers' MCS-12 mean scores did not differ significantly according to age group, marital status, job, monthly household income, or their child's age.

Table 4 A multiple linear regression model of physical and mental component scores for the prediction of low health related quality of life among caregivers of children with anxiety disorders

Independent variables	B Coefficient	Standard Error	p-value	R ²	F-value
Physical Component Summary (PCS-12) score					
Kinship to child	-0.803	0.696	0.25	0.228	5.434*
Educational level of caregiver	1.221	0.388	0.002§		
No. of Siblings	0.137	0.278	0.623		
Duration of illness	-0.475	0.188	0.012§		
Constant	41.876	2.525	<0.001§		
Mental Component Summary (MCS-12) score					

Gender of caregiver	-1.863	1.695	0.273	0.281	5.836**
Educational level of caregiver	0.793	0.49	0.107		
Kinship to child	-1.695	1.267	0.182		
Gender of child	-3.46	1.247	0.006§		
No. of Siblings	0.872	0.343	0.012§		
Duration of illness	-0.517	0.234	0.028§		
Constant	53.503	3.469	<0.001§		
§ Statistically significant; *p=0.001; **p<0.001					

Table 4 shows that significant predictors for low physically-related HRQOL (PCS-12) among caregivers of children with anxiety disorders included caregivers' educational level and the duration of their child's illness. On the other hand, significant predictors for low mentally-related HRQOL (MCS-12) among caregivers of children with anxiety disorders included the gender of the child, the number of siblings they had, and the duration of their illness.

DISCUSSION

Our study showed that caregivers of children with anxiety disorders were mainly mothers. Most caregivers were high school or university educated. Most children with anxiety disorders were females.

Schneider, et al. [21] stated that worldwide, women are the main caregivers for their children. In Iran, Noghani, et al. [22] found that almost three-quarters of caregivers of patients suffering from mental disorders were females. Marcon, et al. [23] explained that caregivers are mostly females since the home care of patients is usually delegated to women, especially to mothers. Moreover, the female gender was identified as a risk factor for anxiety disorders among children, with such disorders almost twice as common among girls as boys [24-26].

Our study revealed that caregivers of children with anxiety disorders had a mean PCS-12 score of 44.1 ± 7.0 , while their MCS-12 mean score was 46.8 ± 8.9 . These scores are lower than those describing the HRQOL of general populations in Saudi Arabia and several other countries. In Dammam, Saudi Arabia, Al-Shehri, et al. [27] reported that PCS-12 and MCS-12 scores among their control subjects were 47.5 ± 9.5 and 51.5 ± 9.4 , respectively. Researchers in Tunisia, Younsi, and Chakroun [28] found that the PCS and MCS scores across those general populations were 50.11 ± 8.53 and 47.96 ± 9.82 , respectively. Kontodimopoulos, et al. [29] reported that the PCS-12 and MCS-12 scores among the general population in Greece were 49.42 ± 10.56 and 48.91 ± 9.20 , respectively. In Brazil, Campolina, et al. [30] found that the general population in Brazil had a mean PCS-12 score of 49.3 ± 8.7 and a mean MCS-12 score of 52.7 ± 9.7 .

Therefore, the mean PCS-12 and MCS-12 scores of caregivers in our study indicate that the HRQOL of caregivers of children with anxiety disorders has become compromised.

Leng, et al. [31] explained the poor HRQOL among caregivers of children with anxiety disorders by observing that caregivers in societies with cohesive families usually spend much of their time caring for the mentally ill family members. Therefore, they lack time for entertainment or social activity. It has been suggested that social support and sharing stress with others can improve caregivers' QOL by reducing the experienced burden and perceived stress. Moreover, the provision of health education campaigns about anxiety disorders to caregivers would stand to improve caregivers' QOL.

Mendlowicz and Stein [11] noted that research findings describe a consistent picture of caregivers of patients with anxiety disorders as a situation that markedly compromises caregivers' HRQOL and psychosocial functioning in several functional domains. Nevertheless, many research findings indicate that caregivers of patients with any mental illness are at a high risk of poor HRQOL. Pérez and Marqués [32] added that caregivers of those with mental disorders usually endure high levels of burden and become negatively affected both physically and psychologically. Basheer, et al. [33] and Kumar, et al. [34] in India, Imran [35] in Pakistan, Leng, et al. [31] in China, Ndikuno, et al. [36] in Uganda, and Stengler, et al. [37] in Germany each noted that all domains of quality of life among caregivers of patients with different psychiatric disorders become severely impaired.

Wong, et al. [38] noted that due to the chronic nature of mental illnesses, caregivers of mentally ill patients usually experience considerable stress and frequently suffer frustration, loneliness and boredom, which significantly impair their mental and physical health. Kumar, et al. [34] add that the poor QOL among caregivers is attributed to their perceived high levels of burden, in terms of more attention, sparing much of their time and energy in caring for patients with psychiatric disorders.

According to caregivers' characteristics, our study revealed that HRQOL was significantly poorer among females, non-parents, and illiterate caregivers, but did not differ significantly according to caregivers' jobs, or monthly household incomes. On the other hand, regarding children's characteristics, the MCS-12 was significantly lower among the caregivers of female children, while significantly lower PCS-12 and MCS-12 scores were observed among caregivers of children with more siblings and caregivers of children with a long duration of disorder. Moreover, predictors for low physically-related HRQOL among caregivers included their educational level and the duration of their child's illness, while significant predictors for low mentally-related HRQOL included the female gender, a big number of siblings, and long-lasting anxiety disorders.

These findings are in accordance with those reported by Marcon, et al. [23], who noted that caregivers' gender is significantly associated with their QOL, with men consistently having higher QOL in all domains compared with women. Awadalla, et al. [39] found that females, parents and less educated caregivers of patients with psychiatric disorders had poor HRQOL. Kumar, et al. [34] also reported that the QOL of caregivers differed significantly according to their gender and level of education. They added that patient characteristics associated with poor caregiver QOL included the female gender and the long duration of mental illness.

In our study, the significantly lower HRQOL among non-parents may reflect a lower threshold and account for the lack of significant differences according to caregivers' economic characteristics, (e.g., job, or monthly household income), which can be explained by the fact that almost half of caregivers earned more than 10,000 SR monthly income (equivalent to >2,700 US) and the healthcare at governmental healthcare facilities is entirely free of charge. At the same time, health insurance covers most health services at private hospitals.

Caregivers' prolonged stress and continuous burden associated with caring for children with long-lasting anxiety disorders, and those with many siblings may explain the associated caregivers' poor QOL. Zendjidian, et al. [40] argued that since women usually undertake the role of caregivers, their QOL often becomes more negatively affected due to the heavy load of caring for patients. Moreover, the association between higher education and better QOL among caregivers of patients with psychiatric disorders was explained by the fact that more educated caregivers enjoy better understanding, acceptance, and awareness of their patients' mental disorders.

There are several limitations to our study that ought to be considered. The study followed a cross-sectional design, which is primarily suitable for hypothesis generation for future research. Participants included only caregivers of children with anxiety disorders and did not include a control group. Moreover, caregivers were selected following a consecutive, i.e., convenient, non-random sampling technique. Also, the findings of this study may be affected by participants' data, which were collected through a self-administered and self-reported questionnaire.

CONCLUSION

The HRQOL of caregivers of children with anxiety disorders is compromised. Generally, HRQOL is poor among caregivers who are females, mothers, and those who are illiterate. HRQOL is also poor among caregivers of female children, children with more siblings, and those with long lasting anxiety disorders. Predictors of low physically-related HRQOL among caregivers include their educational level and the duration of child's illness, while predictors for low mentally-related HRQOL include the female gender, a large number of siblings, and long duration of the anxiety disorder.

Healthcare policymakers should develop appropriately-structured, home-based programs for monitoring any physical or psychological problems among the caregivers of children with anxiety disorders. Such policy ought to be implemented by healthcare personnel to improve the HRQOL of the general population. Family and social support are a necessary means to improving caregivers' HRQOL by reducing perceived stress. Moreover, providing psychological

counseling and educational programming is essential for the patients' families. Further, nationwide, prospective research is needed to assess HRQOL among caregivers of adults and children with different mental disorders.

DECLARATIONS

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Conflicts of Interest

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

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