Original Article

Assessment of the perceived stress and burden of family caregivers of the head-and-neck cancer patients at a tertiary care cancer center: A cross-sectional study

ABSTRACT

Introduction: Cancer is a major life-threatening disease and has an impact on both patients and their family members. Caring for cancer patients may lead to several levels of stress which may affect their own health as well as their quality of life.

Aim: To assess the perceived stress and burden of family caregivers of head and neck cancer patients (HNC) attending cancer care centre at a tertiary care centre, Tamil Nadu.

OBJECTIVES: To assess the perceived stress and the burden among caregivers of patients with head and neck cancer using the Perceived Stress Scale (PSS) and Caregiver Strain Index (CSI) respectively.

Materials and Method: A Cross-sectional study was carried out for a period of three months among the caregivers of head and neck cancer patients at a cancer care centre, Madurai. A total of 200 caregivers were selected by Convenience sampling method. Data was collected using a pretested, self-structured, closed-ended questionnaire by face to face interview method.

Results: The study population consisted of Caregivers aged 21-60 years, mostly females (80%), spouses (54%), employed (57%) and uneducated (66%).Most of the caregivers were from lower socioeconomic status (66%) and those who are providing care for 1 to 6 months were more in number. In this study, 82% of caregivers reported high caregiver burden (CSI ≥7) and 67% of caregivers reported high stress (PSS ≥ 26 - 40).

Conclusion: Caregivers are experiencing significant burden, particularly with respect to their physical and psychological well-being, economic circumstances, social and personal relationships.

KEY WORDS: Caregiver burden, caregivers, head-and-neck cancer, perceived stress

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INTRODUCTION

The prevalence of cancer has increased dramatically over the years at a global level.[1] Demographic, epidemiological transitions and changes in lifestyles have to lead to the emergence of many types of cancers and other chronic oral diseases as a major dental public health problem in India. Among the cancers, head-and-neck cancer (HNC) would become a major life-threatening disease if not diagnosed at an early stage, and it has its impact on both patients and their family members who are providing care.[2]

Caregivers additionally play an important role within the care of patients with cancer.[2] A caregiver or carer is an unpaid or paid member of a person's social network who helps them with activities of daily living. Caring for a loved one with chronic illness may lead to strain even for the most resilient person. Caregiver stress may be due to exhaustion, anger, rage, or guilt ensuing from unmitigated caring for an inveterately sick patient. There are several symptoms that can indicate caregiver burden and stress includes the depression and anxiety, difficulty concentrating,

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irritability, exhaustion, easy annoyance, sleep disturbances, health problems, substance abuse, lack of interest in social or fun activities, withdrawal from responsibilities or obligations.

Chronic stress can lead to medical issues, including high blood pressure, diabetes, and a compromised immune system. This may reduce the care-giver's life expectancy. As a caregiver they provide support to their loved ones fear, depression and anxiety at the same time, they also experience the same emotions and all these emotions add up and lead to major stress. Thus, assessing the physical and psychological condition of the caregivers is most important to improve their quality of life and positive attitude which in turn will help the patients to cope up with their illness.

Hence, the aim of this study was to assess the perceived stress and burden of family caregivers of HNC patients attending tertiary care cancer centre at Madurai, Tamil Nadu, using Perceived Stress Scale (PSS)[3] and Caregiver Strain Index (CSI),[4] respectively, and to find the association between perceived stress and burden with demographic variables.

MATERIALS AND METHODS

A descriptive cross-sectional study was carried out for 3 months at the tertiary care cancer center, Madurai. A total of 200 family caregivers of HNC patients attending the oncology ward were included in the study. The sample size was recruited by using a convenience sampling technique. The ethical clearance to conduct the study was obtained from the institutional ethics committee and prior permission was obtained from the head of the cancer center before the study commenced. The data were collected after getting consent from the caregivers and the information sheet was provided to them.

The data were collected using a pretested, self-structured, closed-ended questionnaire which consists of four parts which consist of socio-demographics of the family caregivers, patient's clinical details, PSS and CSI, respectively, by face-to-face interview method.

The PSS which was given by Cohen *et al*. (1988) which is the most widely used psychological instrument for measuring the perception of stress. It has been demonstrated to have satisfactory internal consistency and construct validity.[3,4] The questions in the PSS ask about feelings and thoughts during the last month. The caregivers stress level was classified according to the scores as low (0–13), moderate (14–26) and high (27–40), respectively.[3]

The CSI was given by Robinson is a screening instrument that can be used to identify the strain of carers, assess their ability to go on caring and to identify areas where support may be needed. It has a reliability coefficient of 0.86 and has good construct validity.[5] It consists of 13 questions are provided, with answers being Yes or No. The score is calculated by summing up all the "Yes" answers. A score of <7 indicates a low burden and score of 7 or greater indicates a high level of burden.[5]

Both the scales have been translated into the local language (Tamil) by the subjects experts as well as the linguistic expert. The PSS and CSI scales had demonstrated good internal (intra-observer) reliability with Cronbach's alpha ranging from 0.82–0.93 to 0.79–0.89, respectively.

The socioeconomic status (SES) was calculated by using the modified BG Prasad scale in 2017 by Consumer Price Index because it can be used in both urban and rural areas and is based on per capita monthly income.[6]

The inclusion criteria were caregivers aged more than 18 years, those who are providing unpaid care and the family member as the main caregiver will be confirmed by the patient.

Family members, visitors but not involved in caregiving, those who are not willing to participate in the study and Temporary caregivers those who are only accompanying the patients to the hospital on that particular day but they are not involved in caregiving were excluded or not regular caregivers were excluded from the study.

The data were analyzed using the Statistical Package for the Social Science software 20.0 version (SPSS Inc., Chicago, Illinois, USA). The Chi-square test was used to find the association between the variables and the burden and the stress scale. The level of statistical significance was kept at $P < 0.05$.

RESULTS

Of 200 caregivers majority (56%) of the caregivers are middle-aged (41–60 years) and the mean age was 45.19 ± 10.85. Among the caregivers' female gender (80%) and married (96%) are more in number. Most of the study participants are from a nuclear type of family (93%), spouse to the patient (54%), uneducated (66%) and those who are providing care for 1–6 months (62%) with lower SES (63%) are higher in number. Almost 94% of them are getting government health insurance [Table 1].

Regarding the patient's details, the mean patient age was 51.9 ± 15, most of them are males (73%) and patients with Stage III cancer (52%). Squamous cell carcinoma (SCC) is the most common type of cancer in this study (72%) with the majority undergoing chemotherapy and radiotherapy than other treatment modalities [Table 2].

On assessing the perceived stress and strain of the study participants more than half of them are experiencing a high level of stress (67%) and burden (82%) [Graphs 1 and 2].

Univariate analysis was performed with the CSI scores which indicates that the caregiver's gender ($P = 0.005$),

Table 1: Sociodemographic of family caregivers

Variables	Frequency (%)
Age (years)	
21-40	7 (37.5)
41-60	112 (56.0)
61-80	13 (6.5)
Mean±SD	45.19±10.846
Gender	
Male	40 (20)
Female	160 (80)
Marital status	
Married	192 (96.0)
Unmarried	0 (0)
Divorced	7 (3.5)
Widowed	1 (0.5)
Type of family	
Nuclear	186 (93.0)
Joint	14 (7.0)
Occupation	
Employed	113 (56.5)
Unemployed	10 (5.0)
Retired	0 (0.0)
Housewife	77 (38.5)
Relationship	
Father	5 (2.5)
Mother	28 (14.0)
Son	15 (7.5)
Daughter	15 (7.5)
Sister/brother	11 (5.5)
Spouse	108 (54.0)
Other relatives	18 (9.0)
Education	
Uneducated	131 (65.5)
Below graduation	58 (29.0)
Graduation	11 (5.5)
Duration of caregiving (months)	
<1	31 (15.5)
1-3	63 (31.5)
3-6	60 (30.0)
>6	46 (23.0)
Mean±SD	6.06±6.118
Health insurance	
Yes	188 (94.0)
No	12 (6.0)
SES	
Lower class	125 (62.5)
Lower middle	42 (21.0)
Middle	25 (12.5)
Upper middle	1 (0.5)
Upper	7 (3.5)

SD=Standard deviation, SES=Socioeconomic status

Table 2: Patient's details

Variables	Frequency (%)
Age group	
<20	10 (5.0)
21-40	22 (11.0)
41-60	125 (62.5)
61-80	38 (19.0)
>80	5 (2.5)
Mean±SD	51.90±15.206
Gender	
Male	146 (73.0)
Female	54 (27.0)
Stage of cancer	
Stage I	9 (4.5)
Stage II	41 (20.5)
Stage III	103 (51.5)
Stage IV	47 (23.5)
Diagnosis	
Non-Hodgkin lymphoma	7 (3.5)
SCC	144 (72.0)
Lymphoma	7 (3.5)
Adenocarcinoma	17 (8.5)
Glioblastoma	7 (3.5)
Adenoid cystic carcinoma	3 (1.5)
Anaplastic glicoma	2 (1.0)
Olfactory neuroblastoma	2 (1.0)
Synovial sarcoma	2 (1.0)
Anaplastic carcinoma	4 (2.0)
Keratocystic odontogenic tumour	4 (2.0)
Ependymoma	1 (0.5)
Treatment	
Only chemotherapy	44 (22.0)
Only radiotherapy	5 (2.5)
Only surgery	17 (8.5)
Radiotherapy and chemotherapy	50 (25.0)
Radiotherapy and surgery	7 (3.5)
Chemotherapy, radiotherapy and surgery	42 (21.0)
Not yet started	35 (17.5)

SD=Standard deviation, SCC=Squamous cell carcinoma

relationship with the patient ($P = 0.017$), diagnosis of patients ($P = 0.001$), duration of caregiving ($P \leq 0.001$), and stage of cancer ($P \leq 0.001$) showed statistical significance ($P < 0.05$). The level of burden is very high among Stage III cancer patients' caregivers and those who are providing care for more than 3 months [Table 3].

Similarly, the PSS score was analysed with the demographic variables, the results were being statistically significant with caregiver's age ($P = 0.021$), gender ($P = 0.001$), occupation ($P = 0.004$), relationship with the patient ($P = 0.004$), education ($P = 0.039$), duration of caregiving ($P = 0.001$), patient's age ($P \leq 0.001$), diagnosis of patients ($P \leq 0.001$), and stage of cancer ($P \leq 0.001$). As same as the earlier, the very high level of stress was observed in Stage III cancer patients' caregivers, and the level of stress increases simultaneously when the duration of caregiving increases by months [Table 4].

DISCUSSION

The current study shows that most of the caregivers are female, spouse, uneducated, employed. They are experiencing a high level of burden and stress while providing care to their loved one.

In the present study, the mean age of the caregivers is 45.2 ± 10.9. Other studies like Johansen *et al*.[1] the mean age was 56 years and in the study of Hiremath *et al*.,[2] the majority of the age group of 40–50 years, this reveals that most carers who involves in caregiving are the middle-aged.

In our study, more than half of the participants were female (80%), spouses (54%), married (96%) and from nuclear type family (93%), the reason for their high stress may be due to our societal norms are such that taking care of the diseased spouse is considered the duty of

Table 3: Comparison of caregiver's details and patient's details with Caregiver Strain Index

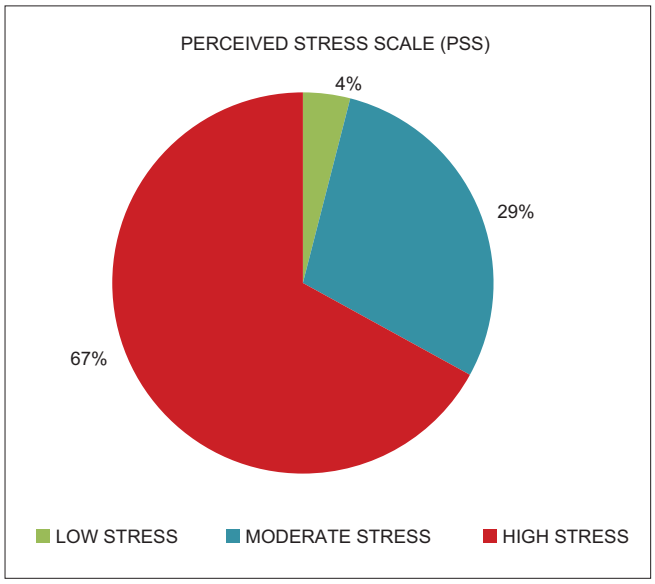
Variables	CSI level		*P*
	Low burden (*n*)	High burden (*n*)	
Caregiver's details			
Age			
21-40	12	63	0.151
41-60	20	92	
61-80	5	8	
Gender			
Male	14	26	0.005*
Female	23	137	
Marital status			
Married	36	156	0.050*
Unmarried	0	7	
Divorced	0	0	
Widowed	1	0	
Type of family			
Nuclear	35	151	0.502
Joint	2	12	
Occupation			
Employed	17	96	0.049
Unemployed	0	10	
Retired	0	0	
Housewife	20	57	
Relationship			
Father	0	5	0.017*
Mother	9	19	
Son	3	12	
Daughter	1	14	
Sister/brother	5	6	
Spouse	19	89	
Other relatives	0	18	
Education			
Uneducated	21	110	0.054
Below graduation	11	47	
Graduation	5	6	
Length of caregiving			
<1	3	28	0.000*
1-3	22	41	
3-6	11	49	
>6	1	45	
Health insurance			
Yes	37	151	0.079
No	0	12	
SES			
Lower class	27	98	0.495
Lower middle	4	38	
Middle	5	20	
Upper middle	0	1	
Upper	1	6	
Patient's details			
Age			
<20	1	9	0.201
21-40	5	17	
41-60	28	97	
61-80	3	35	
>80	0	5	
Gender			
Male	26	120	0.410
Female	11	43	
Stage of cancer			
Stage I	9	0	0.000*
Stage II	25	16	
Stage III	3	100	
Stage IV	0	47	
Diagnosis			

Contd...

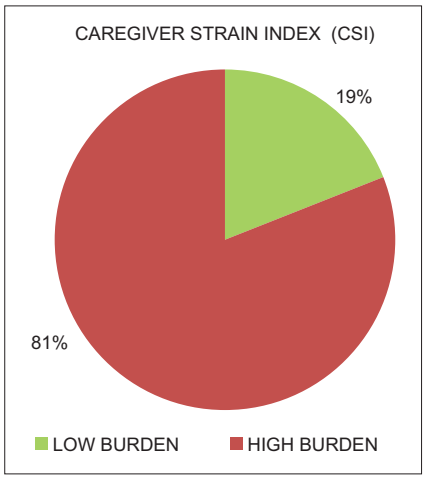
Table 3: Contd...

Variables	CSI level		*P*
	Low burden (*n*)	High burden (*n*)	
NonHodgkin lymphoma	3	4	0.001*
SCC	24	120	
Lymphoma	0	7	
Adenocarcinoma	6	11	
Glioblastoma	0	7	
Adenoid cystic carcinoma	0	3	
Anaplastic glioma	0	2	
Olfactory neuroblastoma	0	2	
Synovial sarcoma	0	2	
Anaplastic carcinoma	0	4	
Keratocystic odontogenic tumour	4	0	
Ependymoma	0	1	
Treatment			
Only chemotherapy	12	32	0.252
Only radiotherapy	1	4	
Only surgery	2	15	
Radiotherapy and chemotherapy	9	41	
Radiotherapy and surgery	0	7	
Chemotherapy, radiotherapy, and surgery	4	38	
Not yet started	9	26	

*Significant. *n*=Number of caregivers, CSI=Caregiver Strain Index, SES=Socioeconomic status, SCC=Squamous cell carcinoma



Graph 1: Distribution of the level of stress by Perceived Stress Scale (PSS)



Graph 2: Distribution of the level of burden by the Caregiver Strain Index (CSI)

the healthy partner. The burden and stress among these groups of caregivers are high which could be expected to assume more responsibility in terms of taking care of the diseased members in the family. Regarding the family type, Lukhmana *et al.*[7] in their study suggested that the reason for that would be when one of the family members in a nuclear family falls sick with a disease like cancer, the entire responsibility including domestic household chores, child-rearing, concomitant professional strains, managing finances coupled with the mammoth task of caregiving falls on the otherwise healthy caregiver. On the other hand, the structure of the joint family is such that roles are defined for each member of the family.

A series of studies suggest that caregiver burden can be increased by the length of time as being a caregiver.[8,9] Cui *et al.*, said that a cancer diagnosis is often unpredictable for both the patient and his family caregiver. When the patient confronts physiological, psychological, and economic issues, his family caregiver experiences increased responsibilities and a variety of problems.[10] Thus, this situation can be distressful and needs adaptation. On the other hand, the progression of the illness and the process of treatments require readaptation and flexibility about the roles and responsibilities within the family.[11]

The epidemiological studies suggested that among the types of HNC, SCC accounts for about 90% and its is the sixth leading cancer by incidence worldwide.[12] In the present study, SCC is the most common type of HNC of about 72%. Regardless of

Table 4: Comparison of caregiver's details and patient's details with the Perceived Stress Scale

Variables	PSS level			*P*
	Low stress (*n*)	Moderate stress (*n*)	High stress (*n*)	
Caregiver's details				
Age				
21-40	2	26	47	0.021*
41-60	6	24	82	
61-80	0	8	5	
Gender				
Male	0	21	19	0.001*
Female	8	37	115	
Marital status				
Married	8	54	130	0.498
Unmarried	0	3	4	
Divorced	0	0	0	
Widowed	0	1	0	
Type of family				
Nuclear	8	52	126	0.403
Joint	0	6	8	
Occupation				
Employed	0	30	83	0.004*
Unemployed	0	3	7	
Retired	0	0	0	
Housewife	8	25	44	
Relationship				
Father	0	0	5	0.004*
Mother	5	13	10	
Son	0	3	12	
Daughter	0	5	10	
Sister/brother	0	5	6	
Spouse	3	28	77	
Other relatives	0	4	14	
Education				
Uneducated	8	31	92	0.039*
Below graduation	0	21	37	
Graduation	0	6	5	
Length of care giving (months)				
<1	0	8	23	0.001*
1-3	3	27	33	
3-6	5	19	36	
>6	0	4	42	
Health insurance				
Yes	8	54	126	0.743
No	0	4	8	
SES				
Lower class	5	34	86	0.108
Lower middle	3	9	30	
Middle	0	14	11	
Upper middle	0	0	1	
Upper	0	1	6	
Patient's details				
Age				
<20	0	7	3	0.000*
21-40	5	3	14	
41-60	3	41	81	
61-80	0	7	31	
>80	0	0	5	
Gender				
Male	6	40	100	0.713
Female	2	18	34	
Stage of cancer				
Stage I	5	4	0	0.000*
Stage II	3	33	5	
Stage III	0	21	82	
Stage IV	0	0	47	
Diagnosis				

Contd...

Table 4: Contd...

Variables	PSS level			*P*
	Low stress (*n*)	Moderate stress (*n*)	High stress (*n*)	
Non-Hodgkin lymphoma	3	3	1	0.000*
SCC	5	32	107	
Lymphoma	0	7	0	
Adenocarcinoma	0	7	10	
Glioblastoma	0	0	7	
Adenoid cystic carcinoma	0	3	0	
Anaplastic glicoma	0	2	0	
Olfactory neuroblastoma	0	0	2	
Synovial sarcoma	0	0	2	
Anaplastic carcinoma	0	0	4	
Keratocystic odontogenic tumour	0	4	0	
Ependymoma	0	0	1	
Treatment				
Only chemotherapy	3	12	29	0.134
Only radiotherapy	0	2	3	
Only surgery	2	0	15	
Radiotherapy and chemotherapy	0	14	36	
Radiotherapy and surgery	0	3	4	
Chemotherapy, radiotherapy and surgery	3	13	26	
Not yet started	0	14	21	

*Significant. *n*=Number of caregivers, PSS=Perceived Stress Scale, SES=Socioeconomic status, SCC=Squamous cell carcinoma

the different types of HNC more than half of the caregivers are experiencing a high level of burden once their loved one was diagnosed with cancer and the results are statistically significant.

The patients with Stage III cancer are more (103/200) than other stages of cancer. The caregivers those who are providing care for these patients are experiencing a higher level of stress and burden this could be because of the caregivers' task of providing care is more because of the patient's terminal stage of disease than the starting stage. Then the burden and the stress level is decreased in the Stage IV cancer patients this may probably due to the increased sample size of Stage III cancer patients or may be the carers were overwhelmed that their loved one is in the fatal stage of the disease or at the end of their lifetime. This study was the first to compare the stage of cancer with the stress and burden level.

In the current study, some patients received single therapies such as surgery, radiotherapy and chemotherapy and some of them received combined therapy also. Even though the results are not statistically significant with the treatment modalities, most of the caregivers are experiencing moderate-to-severe stress and burden. Lukhmana *et al.*,[7] suggested that this might be because while caring for patients receiving both in-patient and day-care, caregivers may have had to spend a lot of time in accompanying patients to the hospital. This may have led to a disruption in their daily routine. Some of the caregivers even had to miss work to accommodate time for their patients, which might have led to a disruption in their daily routine. A large number of hospital visits may also have entailed more financial burden in terms of transportation and meals besides direct treatment expenses. Similar findings have been reported in another study as well. Greimel *et al.*,[13] in his study stated that an in-patient, he/she is taken care of by the formal caregivers such as doctors, nurses, and other paramedic staff, and family caregivers have comparatively lesser role to play. They may not even be required to be physically present with the patient at all times.

It seems that receiving both cancer diagnosis and the process of treatment can be stressful for family members and maybe a reason for greater caregiver burden.

In our study, the participants felt high level of burden (81.5%) and stress (67%) which is higher than the other studies done by Hiremath *et al.*,[2] McPeake *et al.*,[14] Hsu *et al.*[15] The reason for this high stress and burden could be because of the sociodemographics of the caregivers, such as the majority of the caregivers are female, spouse, employed, and uneducated, but in Hiremath *et al.*[2] study most of them were males, educated below graduation and homemakers. Another reason for that could be due to the mean age of caregivers which is younger (45 years) than the other studies such as McPeake *et al.*,[14] Hsu *et al.*[15] and Rani and Banu.[16] In general, older caregivers would have better mental health, well experienced and have less psychological distress when compared with the younger ones.

In another study which was done by Precious *et al.*, shows that nearly half of the caregivers were family members (46%), and the patients itself felt that 68% it was not too hard for their carers to take care of them and 32% felt that it was very hard.[17]

The study was done by Chen *et al.*, results indicated that patients with oral cancer perceived higher levels of care needs in every domain[18] when compared with patients with prostate cancer,[19] large bowel cancer,[20] and melanoma.[21] The top three ranked supportive care needs were health system and information, psychological, and patient care and support needs.

Limitations and recommendations

There are a few shortcomings to this study. Some of them are we used convenience sampling to select research participants and it is a single-center study. Hence, the findings may not be generalizable. Since it is a cross-sectional design the relationship between burden on family caregivers and various factors cited as predictors, could not be delineated in the study. The presence of chronic illness, general and oral health status of the caregivers was not assessed, these also have an impact on their stress and burden and also the caregivers' quality of life, their coping strategies to overcome their stress and burden was not assessed.

We would like to recommend a longitudinal study with large sample size, development of standardized guidelines that address the caregiver assessment, education, and resources; will help in improvement for providing care, provision of referrals to established support organizations for caregivers (e.g., cancer support community, cancer care); collaboration among caregiving, professional, and cancer-related organizations to advocate policy and practice changes for family caregivers would provide better enhancement in nonprofessional care by caregivers, a qualitative research regarding the interaction between patients and carers could be done by interviews to better understand how this dynamic relationship alters with time and counseling centers be set up in all cancer hospitals and appropriate interventions and support groups be formed so as to help the caregivers cope and deal with the wretched multifaceted "burden."

CONCLUSION

The current study concludes that the caregivers of HNC patients are experiencing a high level of stress and burden while providing care to their loved one with an advanced stage of disease and those who are providing care for a prolonged period of time. This stress level of the caregivers may increases which depend on factors like the caregiver's physical and psychological well-being, economic circumstances of the family, stage of cancer of the patient, duration of caregiving, social and personal relationship with the patient. The findings from this study have important implications for clinical practice as they can help social workers and other health care professionals to better understand the complexity of caregivers challenging situation and needs of support in the early phases of the illness trajectory Recognizing the caregivers as the most important supporter, and the impact of cancer on the lives of the family as a whole is essential in providing optimal support by psycho-educational skills training like coping, communication and problem-solving skills and therapeutic counseling to the caregivers to help them to support them to meet their needs.

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Conflicts of interest

There are no conflicts of interest.

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