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Multifaceted support for caregivers of stroke patients to meet the dynamic needs of patients: A qualitative study

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Abstract:

BACKGROUND: Caregivers of stroke patients always have various concerns in the process of patient care, which requires the full attention and support of healthcare professionals. Understanding their needs is essential for careful care planning. The present study aimed to discover and explain the needs of caregivers for stroke patients.

MATERIALS AND METHODS: This qualitative content analysis was conducted with 24 purposefully selected participants who provide home care for stroke patients in Chaharmahal and Bakhtiari province, Iran, during 2019–2020. Data gathering was done through semi-structured interviews. Conventional content analysis was done, and trustworthiness was investigated through peer checking, member checking, and prolonged engagement based on Lincoln and Guba's criteria.

RESULTS: The main emerged themes showed caregivers' needs including physical empowerment (to overcome overwhelming care and physical exhaustion, and caregivers' deficit attention to self-care), emotional-social empowerment (to relieve caregivers' mental exhaustion, disrupted family relationships, and disrupted social relations), coping with stigma (to cope with stigma of guilt and fear of others' reactions and stigma of delegated care), and dynamics educational needs (big concern of hospital discharge and home care, constant effort to learn, and seeking help).

CONCLUSION: The basic, complex, and multidimensional needs of caregivers are unmet. Forgotten caregivers are afraid of hospital discharge and home care. Formal organizations for training and support, providing temporary cares, and planning for destigmatizing the delegated care of relatives are required.

Keywords:

Community, family caregiver, informal care, qualitative analysis, stroke survivors

Introduction

Stroke is a chronic debilitating disease[1] with an absolute number of incident strokes increased by 70.0 from 1990–2019,[2] which leads to long-term and severe disability and makes stroke the most expensive disease.[3] The cumulative burden of premorbid and new disabilities likely exceeds 10% in younger adults and 50% in older adults.[4]

Every year, 300,000 to 700,000 stroke survivors return home with nervous system disorders that have impaired their independent living.[5] Therefore, stroke survivors need formal and informal care at home. Informal paid or unpaid care is provided by nonprofessional caregivers that provide the most assistance for patient. Paid informal caregivers give the same care that could be provided by a family member.[6] Unpaid informal caregivers are family members, relatives, or a friend.[7] Therefore, patients' families play an important role in improving the patients' quality of life and treatment.[8]

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Despite the transition from the healthcare system to the home, which increases the role of family caregiver[9] as the most valuable and vulnerable source for patients, most research addresses disease rather than family caregivers.[10] The unmet increasing needs of families lead to dissatisfaction,[11] care burden,[11,12] problems related to patient care and treatment, and coping with responsibility.[13] However, tolerating chronic disease can increase the burden and pressure on family health and change family members' lives.[14] There is also evidence that caregivers are latent patients and need to protect themselves from physical and emotional harm.[15] Therefore, healthcare providers should support family caregivers and help them acquire the necessary knowledge and skills to provide high-quality care. The first step in supporting caregivers is to be aware of their needs.[16] Evaluating their skills will determine the type of training they need.[17] In fact, the patient and family should be considered a care unit.[18] Therefore, identifying the caregivers' concerns and needs should be considered by health planners when designing evidence-based supportive, educational, and empowerment programs.

Although the caregivers' needs have been explored, it is not clear whether there is coherence between what they manifested and what professionals observed as a need for the practice of care.[19]

In developing countries like Iran, given the scarcity or lack of a network of well-established formal services, family caregivers have the main responsibility for providing care to dependent patients. For example, Mirzaei *et al*.[20] (2020) findings show that it is necessary for mental health policymakers to consider measures that can reduce the care burden of home caregivers. Such understanding of family caregiver experiences can be achieved through qualitative research. Qualitative studies provide a better understanding of the social, cultural, political, and economic dimensions of health and illness. They show us how people in different parts of the world experience illness and how they interact with medical institutions, systems, and therapeutics.[21]

Chaharmahal and Bakhtiari province is located in the southwestern part of Iran and covers an area of 16,332 square kilometers. It has limited healthcare centers with distinct disparities in the distribution of healthcare.[22] Patients in Chaharmahal and Bakhtiari were discharged home without formal support, with limited access to rehabilitation centers, and their caregivers' experiences were not fully explored. Therefore, this study aimed to explore the needs of caregivers of stroke patients with in the Chaharmahal and Bakhtiari province.

Material and Methods

Study design and setting

Iranian family caregivers' experiences were explored using a qualitative content analysis approach. Caring is an intangible, ambiguous, and abstract concept. Qualitative studies assist in fully exploring lived experiences and capturing the complexities of the physical, psychological, and social aspects of caring. Content analysis can be used to describe a large amount of textual data to ascertain the trends and patterns of communication.[23]

Study participants and sampling

Volunteered literate family caregivers older than 20 years with caring experiences of at least three hours a week within the last six months in Chaharmahal and Bakhtiari province were eligible to participate. Chaharmahal and Bakhtiari province is located in the southwestern part of Iran and have 10 counties. All patients with stroke in Chaharmahal and Bakhtiari province are referred to the neurology department of the main university hospital, neurologist clinics, and Imam Ali clinic. So, the research fliers were distributed there during 2019–2020. Also, patients' phone numbers were extracted from records and contacted. The first three caregivers contacted were not interested in participating due to their patients' health status. People who agreed to participate in the study were interviewed briefly by the second author to assess their eligibility. Then, the time and place for the main interview were set based on participants' preferences.

Data collection tool and technique

Twenty people from different counties were recruited to achieve data saturation.[24] Interviews were continued with four more people for more probing, but there were no more findings. Sampling until data saturation was accomplished over an 18-month period. Recruiting subjects from various settings and using maximum-variation sampling helped the authors capture a vast range of perspectives and experiences. The goal was to access representative family members and informal caregivers.

Twenty-four family caregivers (10 male and 14 female) participated in the present study and had a history of providing patient care for eight months to nine years. The mean age of the patients was 62 years (with a range of 52–79 years). Eight patients had left hemiplegia, three had monoplegia, eight had quadriplegia, and five had right hemiplegia.

Face-to-face, semi-structured interviews were carried out. All interviews in Persian were conducted in a calm and private room at the patients' house and rarely at the hospital, and all were audio taped. Each interview lasted 45–80 min, based on caregivers' preferences.

The interviews were started by asking the following core question: "How would you spend a typical 24-hour day?" The explorative questions were asked based upon the participants' answers to enrich the information. For example, What is challenging for you during your caring role? Does caring for him/her impact your own life in any way? If yes, how? What kind of support do you receive (from family, friends, outside agencies, or people)? What are your thoughts and feelings about your caring role? Can you tell me what is happening when you encounter with patient-related problems? Some questions were asked for clarification, such as "please tell me" and "what do you mean." In order to collect the data precisely, a field note was also taken. For this purpose, the researcher documented more detailed information about events, conversations, and behaviors, their time, and any factors that caused this event or behavior, as well as the researcher's reflections on them.

Qualitative conventional content analysis was used.[25,26] Transcriptions were read several times to make sense of the whole transcription. The text was divided into meaning units that were condensed. The condensed meaning units were abstracted and labeled with codes. Codes were sorted into sub-categories and categories based on constant comparative analysis, to examine their similarities and differences. Finally, themes were formulated to express the latent content of the text.

Credibility was established through peer checking, member checking, and prolonged engagement based on Lincoln and Guba's evaluative criteria for trustworthiness. The second and forth authors (expert supervisors) conducted peer checking. Member checking was done by asking the respondents to verify the preliminary findings from the interviews. The maximum variation of the sampling enhanced the confirmability. The fifth and sixth authors independently analyzed the data in order to identify and categorize the initial codes, and then the codes and themes were compared. In areas where the two did not agree, definitions were clarified, and discussion continued until a consensus was reached.[25,27] Prolonged engagements in the field to collect data (18 months) attracted the participants' trust and helped gather in-depth data.

Ethical consideration

The study was approved by the ethics committee of Shahrekord University of Medical Sciences (No. IR.SKUMS.REC.1397.199). This study was conducted in accordance with the Declaration of Helsinki. Therefore, all volunteered, eligible participants who responded to research fliers and signed written informed consent, especially for audio recording were interviewed. They were assured that their participation was voluntary and anonymous, and they could refuse to participate at any time without any negative effects. All interviews were conducted in patients' houses and rarely at hospital based on their preferences. Participants information was written (not recorded) to maintain their privacy during the analysis.

Results

Four themes emerged from the caregivers' experiences [Table 1].

Caregivers' physical empowerment

"Caregivers' physical empowerment needs" with two categories of "overwhelming care and physical exhaustion" and "caregiver's deficit attention to self-care" was the first emerged theme. Long-term care, especially where caregivers were one or two persons who had to care alone, led to physical problems for caregivers and an inability to perform both optimal care for patients and personal self-care. Most participants were alone without any help in providing care. 24-hours-7 care brings a burden for our participants. It's due to Iranian culture, especially in Chaharmahal and Bakhtiari province that nuclear family is important and highlighted.

In this regard, one of the participants described his experience of "overwhelming care and physical exhaustion" as follows:

> *My hand was harmed since I move him repeatedly... It is hard for me; I cannot handle it. My knees have been destroyed. Physicians said your knees need surgery, but If I have surgery, who will take care of him? (Caregiver No. 4)*

"Caregiver's deficit of attention to self-care" was another issue. This experience was related to a lack of time and the multiple tasks that participants must do for their patients. A participant said:

> *Day and night do not matter. These are not different for me. All our days are interconnected. Look at my face, my clothes are wrinkled, I am not in order, I just want a time*

Table 1: Extracted caregivers' needs

Component	Subcomponent
Caregivers' physical empowerment	Overwhelming care and physical exhaustion
	Caregiver's deficit of attention to self-care
Caregivers' emotional-social empowerment	Caregivers' mental exhaustion
	Disrupted family relationships
	Disrupted social relations
Coping with stigma	Stigma of guilt and fear of others' reaction
	Stigma of delegated care
Dynamics educational needs	Big concern about hospital discharge and home care
	Constant effort to learn
	Seeking help

> *to take a shower at home, but there is no time... (Caregiver No. 7).*

Another said:

> *Do you believe I forget myself? No, but it seems I forget for a long time. I don't remember when I ate or when I cooked my favorite food... (Caregiver No. 10).*

Caregivers' emotional-social empowerment

"Caregivers' emotional-social empowerment needs," with three categories including "Caregivers' mental exhaustion," "Disrupted family relationships," and "Disrupted social relations," was obtained from participants' experiences.

Being alone in the care or having an insufficient number of caregivers has caused the caregiver not only to have no time to take care of himself or herself physically and to be physically exhausted but also to cause limitations for him/her. Caregivers do not get a chance to relax, participate in social and family occasions, and even they have no time for their spouse and children. This causes the mental exhaustion of the caregiver and disrupts his/her relationship with their spouse and even their children. This disruption in relationships, in turn, leads to greater exhaustion.

"Caregivers' mental exhaustion" was obvious in the participants' statements. One participant said:

> *In general, I am not happy because I have not been feeling well for a long time. I've been going to the doctor for six months. I take medicine. I'm depressed and lonely. The doctor says you have to leave your father to someone else, but whom do I have? I don't have anyone. I am tired. (Caregiver No. 8).*

Another participant said:

> *I have been taking care of her for a year. My mood is affected a lot. I found myself very upset. My life has changed a lot. I have been devastated. Believe me; I'm more tired than she is. My night and day just pass. I don't understand days at all. I don't understand the passage of time. My life is gone. I'm very sorry for myself (Caregiver No. 10).*

"Disrupted family relationships" can be seen in many statements, such as:

> *We are dropping in a crisis suddenly. It is not clear how we should get out of it. The health system has done nothing for us at all. We are a lost ring; we are not at all (Caregiver No. 9).*

She continued:

> *With my husband, we got in trouble... Well, my husband was screaming. He was always saying why you are not at home. I had to make food in advance since I work, we were used to it. Now is different, I have to go to work and after that I have to care of my patient. So, I have no time for my husband. For example, Nowruz holidays, I was not at home even for a day. He accepted this situation first days well, but when it was too long, it was two months, conflicts started with my husband (Caregiver No. 9).*

"Disrupted social relations" was another subtheme. One participant stated:

> *We (my sister and me) have a problem with our children. My children cried when I want to leave home and my shift began. No play, no recreation, nothing. My sister's children, who are older than mine had the same restrictions, and sometimes their conditions were more difficult than mine were. Her children had more conflicts. They must go to university, and cook and do house chore without their mother. These last two months we couldn't go anywhere, they couldn't go anywhere (Caregiver No. 7).*

Another stated:

> *It is too hard. It's been a long time since I've been the only caregiver, I've been limited in many places, and I haven't been able to be with my family. I cannot go anywhere (Caregiver No. 6).*

Coping with stigma

"Coping with stigma" with two subthemes including "stigma of guilt and fear of others' reaction" and "stigma of delegated care" was the third theme. Most participants described that society believes that a relative's current illness is due to his/her sin. Based on their religious beliefs, the participants wanted to get closer to God by doing good deeds. They love their relatives, especially the sick person, and they don't want to be accused of committing a sin. Unfortunately, sometimes people believe that illness is a punishment for sin. They experience stigma. When this feeling exists, it causes the patient and caregiver to not feel empathy from society, and this adds to their suffering and fatigue. For example, a participant said:

> *Another point is the others' judgment and reaction. Many people say what you did to get sick... And the rest' reaction is that you must have done something wrong, you might did not care someone's right. This is the first reaction. Nobody say "they were good people. They helped the people and they were friendly, so why did they fall into this situation". People say that they must have sinned and in fact in this world, they are punished (Caregiver No. 14).*

Another said:

> *People looked down very badly. I wish there was no greeting. Their words are very heavy and overwhelming for the family and the patient. Many say he deserved his illness (Caregiver No. 9).*

The scope of this stigma is such that sometimes the patient internalizes this stigma. A participant said:

> *They themselves are upset about this and say, that maybe we annoyed someone. Maybe someone cursed us; say bad prayer (Caregiver No. 14).*

The second subtheme was "stigma of delegated care," The care burden is high, but the caregiver is unable to delegate this care even for a short time to alleviate his/her pain due to stigma. Both the community and the patient impose this stigma on the caregiver. It is related to the culture of the participants. In their culture, taking care of patients is pleasing to God. On the other hand, if the patients are family members, especially parents, the duty of care is the responsibility of the children, and refusing to do so is considered a great disrespect.

> *It is very difficult to care of this patient. Many people do not accept that a stranger comes to your house for helping you... My mother does not accept and says you want to leave me and go; she is angry and say don't come at all (Caregiver No. 11).*

The stigma of delegated care is seen at the heart of society. A participant said:

> *I see around me that they have (those who delegated care) are very annoyed and people's attitudes towards them change. They accuse me that did not care my patient well (Caregiver No. 9).*

Moreover, another said:

> *Wish the society didn't look at us so bad if we took her to a care center. Our lives are paralyzed. I'm tired. No one is helping us. We have a closed and small culture. I wish someone would help us. No one understands because no one is in our shoes. You have to have the same experience to understand and able to help (Caregiver No. 8).*

Sometimes the stigma is even seen among medical professionals. One participant described that:

> *I love my mom very much. When I told the doctor to introduce me a care center, he told me you care her yourself, what is the center? She is your mom. However, I can't. I wish they understood. If I delegated this care to a nurse, it does not mean I don't want to do, I'm so tired. I can't. I see she suffer (Caregiver No. 7).*

Dynamics educational needs

"Caregivers' dynamic educational needs" with three subthemes, including "big concern of hospital discharge and home care," "constant effort to learn," and "seeking help" was the fourth theme. Caregivers are afraid of patient discharge. This big concern is so huge that it seems like a monster for them. Although all the caregivers were trying to learn how to care, because of the new problems they faced daily, they tried to admit their patients to the hospital. They stated that the patient always finds new problems, and they and even others (including health care professionals) blame them. They need dynamic training periodically, and it cannot be guaranteed that they will easily overcome problems with one-session training. Participant No. 2 said:

> *The rest of the family is also concerned. They are afraid to come, and of course, everyone is worried about how to take care of her when she comes home.*

Another caregiver believed:

> *It's because we don't know what is right to do. We're doing something for him, and then he experiences a new problem. We just get a guilty conscience. We take him to the hospital. Then healthcare professions argue about why you did it. See, none of us had a bad intention. We didn't want to bother him and ourselves. So, the conflict is made in the house. Finally, the patient is annoyed because we do not know what to do (Caregiver No. 13).*

Another said:

> *However, we try to be here, I mean at hospital as far as we can. What we can do at home. Nurses cared here. I don't know at all what to do if there is a problem at home (Caregiver No. 2).*

The "constant effort to learn" was the second subtheme of the dynamic educational needs. One caregiver believed:

> *We learned experimentally ourselves. My sister's son knew someone in the hospital. He took a video and a book from the internet [Google search engine] and brought us (Caregiver No. 6).*

Another said:

> *I learned injections... It's important to care well. It means it is important to have scientific literacy and of course experience. The first few days I was very unprofessional; Now, I can help in the crisis. Now I know how to work with any patient disability. However, I did not know ten years ago. Experience helped me, and of course, I asked many people and I studied, and I even watched educational movies. I took a training course. I read a nursing book. When my mother got sick, I had to learn everything (Caregiver No. 11).*

"Seeking help" was the last subtheme. One caregiver said:

> *Whenever we ask doctor, he does not answer at all, I expect him to help (Caregiver No. 3).*

Another said:

> *The doctor doesn't talk to us; he just writes his order and says something that we don't understand. I don't know, I wish someone would explain it to us (Caregiver No. 1).*

Another said:

> *I need help but they cannot help me. My daughter helps only in weekend when her children have no school or class (Caregiver No. 10).*

Another said:

> *Of course, everyone who has this type of patient has to learn a lot. It is very difficult to care. You know, Cooperation is very important, the cooperation of my husband and my husband's sister, et al. everything is important. It is so hard. Even a patient who is 50 kilograms cannot be moved easily (Caregiver No. 10).*

Discussion

This qualitative study explored caregivers' experiences of caring for stroke patients in the Iranian context. The emerged themes were four types of needs including caregivers' physical empowerment, caregivers' emotional-social empowerment, coping with stigma, and caregivers' dynamic educational needs.

The first theme shows the need for caregivers' physical empowerment. Huang *et al*.[28] (2023) concluded that caregivers of stroke patients who receive less social support and fewer resources feel more powerless, pressure, and negative emotions such as anxiety and depression. In the present study, it was found that physical empowerment of the caregivers of stroke patients in Iran is one of the pillars of improving their caregiving ability. Unfortunately, there are no organized homecare facilities in Iran, especially in poorly developed area such as Chaharmahal and Bakhtiari province. There is no rest time or any help for families who care of stroke or end-stage patients. Naturally, meeting several physical and nutritional needs, preventing complications along with promoting knowledge result in empowering the caregiver, relieving their burden, and improving caregiver status. Jaracz *et al*.[29] (2015) showed the amount of care burden decreased over time while caregivers' anxiety increased, but the finding showed that in prolonged homecare, heavy care burden requires caregivers' physical empowerment and proper recovery. This issue is more important for caregivers who care for patients alone. Therefore, it is necessary for healthcare planners to pay attention to one of the basic caregivers' needs, that is, their physical empowerment.

The second theme was caregivers' need for emotional-social empowerment. Sukhpal Kaur *et al*.[30] believed that the most important families' care needs are to have supportive tools, social support, and information about illness. Attending to the caregivers' individual needs can be an important factor in improving the level of community and family health for these patients. Ogunlana *et al*.[31] (2014) showed that a lower patient's care capacity led to a greater caregiver's care burden and a lower quality of life. In fact, providing appropriate care to caregivers of stroke patients depends on meeting their emotional and social needs, and this should be taken into account in the planning for their empowerment plans. Necessity of social and psychological support programs for improvement and reducing the burden of disease on caregivers in Iran was raised by Sheikhbardsiri *et al.* (2022).[32] Caregivers in the Vielvoye *et al*.[33] study find it difficult to combine care tasks with daily activities. The experiences of Iranian family caregivers of stroke patients indicated the important fact that emotional and social support is one of their most important care needs in order to provide care for their patients. Unfortunately, there is no actual family centered care as well as official institution for emotional and social support and assistance to caregivers in Iran. Obviously, paying attention to the patients' needs as well as meeting the patients' psychological needs requires competent and motivated caregivers who are empowered psychologically.

The third theme was coping with stigma. One of the most common and challenging concerns among family members and caregivers in developed and developing countries is disease-related stigma. Stigma has been cited in numerous studies as the most important barrier to seeking treatment, continuing treatment, and rehabilitation processes. It is a global phenomenon and a source of stress for family caregivers.[34] Studies have shown that most stigmas are due to fear of society and misinterpretation of the disease.[35,36] One of the most important causes of stigma among caregivers in the present study was fear of others' reactions. Caregivers in Asian countries (unlike European countries) conceal their problems during patient care to protect their reputation, which eventually leads to the family withdrawing and losing social support.[34] Stigma could worsen negative consequences for caregivers' health and wellbeing.[37] The emotional consequences of the family experience of public stigma include feelings of disrespect, disregard, and discrimination in the community. Therefore, families usually avoid social relationships, expend energy to hide the family's secret, or move to a different location, which could eventually isolate the family and cause them to lose social support.[38] In Iran, which has a collectivist culture, family members are concerned about the disease-related negative effects on their reputation and others' reactions to their families. The more their self-assessment focuses on negative aspects (such as worthlessness and inadequacy), the more likely their family will experience emotional problems due to the patient's problems.[39] The findings of the present study showed that families not only fear social negative reactions about patients but also suffer from being alone for patient care. The last one is related to the stigma of delegated care. It is unusual for Iranians to delegate the care of their relatives to others. Findings show that it is also common among healthcare profession. So, caregivers are not understood and are left alone with the many physical and social needs that were mentioned earlier. Therefore, health planners need to identify stigma-inducing factors and coping mechanisms and help caregivers.

The fourth theme was caregivers' dynamics educational needs. In general, caring for stroke patients, due to the interwoven, multifaceted, and complex nature of care needs, requires a proper understanding of the fluctuating nature of these needs. Daveson *et al*.[40] (2014) found that coordination of collaborative and complex interventions is important for caring, and implementation of real-world appropriate interventions for patients and caregivers and their evaluations can help in the future. Kheirollahi *et al*.[41] (2014) showed that family centered empowerment in family caregivers of stroke patients can increase their awareness and self-efficacy and help them in efficient care and improvement of role-playing. Two important and influential components of caring, namely, increasing awareness and improving self-efficacy can lead to optimal care. Like our findings, it was shown that caregivers who are not well prepared present a safety risk for patients and caregivers and may increase preventable readmissions.[42] With regard to all aspects, discovering and explaining the caregivers' experiences for evidence-based planning is valuable because nursing and caretaking are not only thinking but also a suitable response to the patient's and family's experiences.

Limitations and recommendation

The participants were selected from Chaharmahal and Bakhtiari province. On the one hand, this province has more limited healthcare facilities than some other provinces. On the other hand, family members are more dependent on each other. Therefore, generalization of the findings should be done with caution. The wide transferability of the findings needs further exploration in other developing settings than Iran. The obtained data may lay the groundwork for more rigorous research in this area such as designing empowerment plans and supportive and educative programs.

Conclusion

This study showed that caregivers of stroke patients are often faced with multiple needs that are not limited to caregivers of stroke patients. These are initial needs that can be seen in any other chronic situation. So, at first, addressing caregivers' basic needs including caregivers' physical empowerment, caregivers' emotional-social empowerment, coping with stigma, and caregivers' dynamics educational needs is necessary. Then, the special needs of each different condition can be explored. But why only the basic needs have been obtained in this study. In fact, their needs are not only due to the complex nature of the disease and its multiple complications but also, and more importantly, rooted in Iranian culture and healthcare structure, especially in Chaharmahal and Bakhtiari. They provide both informal and formal care for their loved ones. While formal care is usually provided by professions in other countries. Often, they were alone and had any support from others and healthcare providers. This leaves them more exhausted and confused. This is a big point that needs very urgent attention from Iranian caregivers who live in Iran. Although the healthcare system in Iran has made advances in medical science, health planners should design formal organizations (except hospitals) to train and support family caregivers and provide temporary care for patients. This can give family caregivers a chance to recover.

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Ethics approval

The study was approved by the ethics in research committee of the Shahrekord University of Medical Sciences (No. IR.SKUMS.REC.1397.199) in Iran.

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Conflicts of interest

There are no conflicts of interest to declare.

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