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The Concept of Illness among Ethnic Groups in Indonesia: A Meta-Ethnographic Study

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ABSTRACT

The illness was what the patient feels when he goes to the doctor, the disease was what he has on the way home. The illness was a patient context. The study was conducted to synthesize the concept of illness in ethnic communities in Indonesia. This research was carried out with a meta-ethnographic approach. A literature search was carried out for ethnographic studies in Indonesia which have been published with the help of Scopus, Google Scholar and Indonesia Publication Index, specifically for the last five years (2013-2018), with keywords: illness, disease, self-efficacy, traditional medicine, indigenous medicine, and health-seeking, we used in various combinations to identify relevant literature. The sample in this meta-ethnography study obtained 15 relevant research literature. The synthesis results reveal a metaphor that describes the concept of illness, that was "not being able to move as usual", and two metaphors for causing illness, are "due to supernatural or magical things", and "for violating taboos". This study concludes that the concept of illness in ethnic communities in Indonesia was different from the concept of disease in the modern medical world. The concept of illness from the perspective of ethnic communities was closely related to the pattern of health-seeking behavior.

Keywords: The concept of illness, tribes in Indonesia, meta-ethnographic study, medical anthropology

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BACKGROUND

Although the term is often used interchangeably, sickness, illness, and disease have different meanings that reflect different perspectives. The disease is an objective term that refers to abnormalities that can be diagnosed in organs, body systems, or physiology. The disease is a pathological condition, as defined by medical science. Illness is a subjective term that refers to an individual's experience of mental and physical sensations or circumstances and may not necessarily indicate disease. Illness can vary in different cultural contexts. Sickness includes both disease and illness[1–3]. An explanation of the concept of illness can be described as follows.

> "Illness... is a feeling, an experience of unhealth which is entirely personal, interior to the person of the patient. Often it accompanies the disease, but the disease may be undeclared, as in the early stages of cancer or tuberculosis or diabetes. Sometimes illness exists where no disease can be found. Traditional medical education has made the deafening silence of illness-in the-absence-of-disease unbearable to the clinician. The patient can offer the doctor nothing to satisfy his senses..."[4]

In simple terms, the difference between illness and disease is, "Illness is what the patient feels when he goes to the doctor, the disease is what he has on the way home"[5]. Illness is a symbol of pain felt by a patient. Illness is a patient context[6]. Illness as a social role is based on the premise that the behavior of patients, doctors, and nurses is related to social perception or the construction of disease[2]. Previous studies have informed that illness also has a different level for each individual. The individual is considered more resistant, feels less pain, because he is poor and far from health care facilities[7], including someone with a low caste in India [8,9]. This phenomenon is also captured in quantitative studies using big data, which informs that those who are poor always have low access to health facilities, even though they have social insurance[10,11].

The concept of illness in a community group does not just disappear or change, even though they have migrated to other regions. A study of diabetes in African descendants in the United States proves this. They assume that poverty affects unhealthy eating habits in African American societies, which causes diabetes among their ancestors, and this goes on for generations. These beliefs did not change, even when they had migrated to America[12]. The concept of illness that is different from the concept of disease in the medical world can cause its problems. A person can delay seeking treatment because they don't feel sick, even though he is suffering from a disease[13,14]. As a result, contact with health workers occurs after the person has severe disease. The consequences of delaying treatment are getting worse, and higher medical expenses[15,16]. Based on this background, this article was prepared to synthesize the concept of illness among some indigenous Indonesian ethnic groups. This literature review will provide insight into the concept of illness among the indigenous ethnic groups in Indonesia. Insights on the concept of illness are important for health workers up to the top-level policymaker. Insights on the concept of illness will complement the material of cultural competence that health workers must possess. The understanding of this concept is useful in dealing with patients with different backgrounds[17–19].

RESEARCH METHODS

This research was part of a health ethnographic study that was conducted using a meta-ethnographic approach. Meta-ethnography was chosen to synthesize the results of previous qualitative studies through systematic comparisons of the topic of the concept of illness. Meta-ethnography allows researchers to see phenomena in terms of interpretations and perspectives of other researchers and ultimately can get a more thorough interpretation[20].

Procedure

The criteria for this meta-ethnography were the publication of research that discusses the concept of illness according to the local community. The sample was limited to the results of research in Indonesia that uses the ethnographic research design in its implementation. A literature search was carried out for ethnographic studies in Indonesia which have been published with the help of Google Scholar and Indonesia Publication Index, specifically for the last five years (2013-2018). Keywords: illness, disease, self-efficacy, traditional medicine, indigenous medicine, and health-seeking, were used in various combinations to identify relevant literature. The references referred to in each article were also examined to identify other relevant publications to be included in this study.

Sample

From all publications about ethnographic health studies obtained from the search results, there are 15 relevant studies related to the concept of illness. All of these studies were conducted in 15 different districts in Indonesia. The distribution of meta-ethnographic sample areas could be seen in Figure 1. In ethnography design, each publication illustrates one ethnicity, so that 15 different ethnicities were obtained. The characteristics of each publication in this meta-ethnographic study could be seen in Table 1.

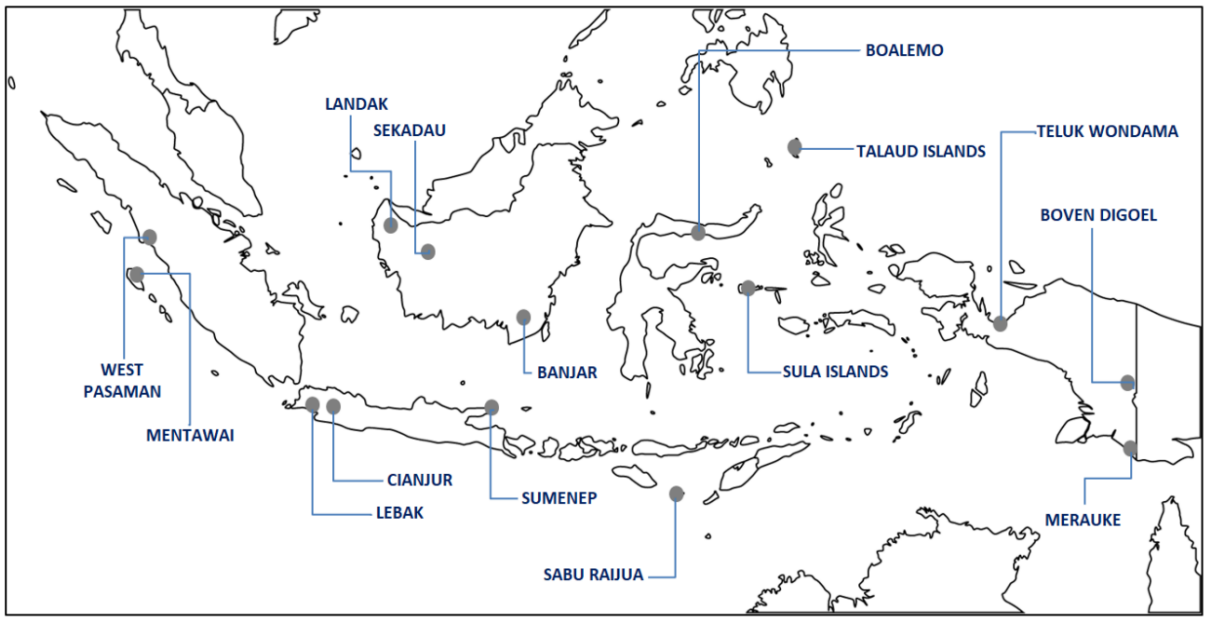

Figure 1. Sample distribution

Table 1. Characteristics of publications that are samples of meta-ethnography

No	Author/Year	Study Title	Ethnic	Location
1	Ningsi *et al.* (2014)	*Terengi* (tuberculosis) Track Record	Gorontalo	Boalemo, Gorontalo
2	Laksono *et al.* (2014)	Muyu women in exile	Muyu	Boven Digoel, Papua
3	Dinata *et al.* (2014)	Healthy house in Jubata, Radakng	Dayak Kanayatn	Landak, West Kalimantan
4	Ipa *et al.* (2014)	*Pikukuh* (customary law) bandage - labor in Baduy tribe	Baduy Dalam	Lebak, Banten
5	Agung *et al.* (2014)	*Turuk Sikerei* (shaman dance)	Mentawai	Mentawai, West Sumatera
6	Sadewo *et al.* (2014)	Yearn for a healthy life, Oroma	Mairasi	Teluk Wondama, West Papua
7	Supraptini *et al.* (2016)	Banjar Women in the arms of "*Kelalah*" disease	Banjar	Banjar, South Kalimantan
8	Pangalila *et al.* (2016)	*Maparaji* (shaman) in the circle of life. Women in Panyusuhan rural village	Sunda	Cianjur, West Java
9	Alfarabi *et al.* (2016)	Live in Malaria cradle	Kanume	Merauke, Papua
10	Saputra *et al.* (2016)	Mother and baby: in the grip of bird disease, *Palasik & Tatagua*	Minang-kabau	West Pasaman, West Sumatera
11	Nggeolima *et al.* (2016)	*Ro'Hili* leaf and methamphetamine sugar: Welcome newborn	Sabu	Sabu Raijua, East Nusa Tenggara
12	Effendi, Permana *et al.* (2016)	Shackles of '*Temau*' wooden and '*Untuyut*' roots: Mental health portraits in Sei Antu	Dayak Mualang	Sekadau, West Kalimantan

13	Imanhadi *et al*. (2016)	Childcare: on the earth of "*Adi Poday*" Sapudi Island	Madura	Sumenep, East Java
14	Sudrajat *et al*. (2016)	'*Mama Biang*': Shaman's paradise in the Poilaten	Talaud	Talaud Islands, North Sulawesi
15	Efendi, Siregar *et al*. (2016)	Elephantiasis in Sula ethnic culture	Sula	Sula Islands, North Moluccas

Data Analysis

Data were analyzed using a seven-phase meta-ethnographic approach[21]. After a sample of 15 ethnographic studies was chosen, the research team read repeatedly several times of literature. It was done until a detailed record of the metaphor or concept in the study was obtained regarding the emic concept of illness. Furthermore, the researchers compiled a matrix to list concepts of illness, causes of illness, limitation of illness, self-efficacy, and health-seeking behavior used in each literature (Table 3). This matrix helps researchers translate each concept into one ethnic group and see the interrelationship between concepts in each ethnic group. The result was an analogy that allows researchers to look more broadly at the phenomenon in terms of interpretations and perceptions of others. This was the first level of synthesis.

In the next step the researchers would do a systematic comparison of the concept of inter-ethnic illness to see the relationship with each other. This step was to see if there is a general type of translation or often found in some ethnic groups. At this step of the synthesis, a second synthesis level can be performed. Researchers interpret concepts between ethnic groups. The concept of an ethnicity was used to translate other ethnic concepts and vice versa. This step was done to find an understanding of a new concept. The final step of the analysis was to do synthesis in written form to bridge the concept of illness inter-ethnic, so it was easier for readers to understand.

Table 2. Methodological characteristics of publications that are samples of meta-ethnography

No	Author/Year	Dicipline	Data Collection Method	Data Analysis
1	Ningsi *et al*. (2014)	Nursing, public health, ethnography	Indepth interview, participatory observation	Thematic analysis
2	Laksono *et al*. (2014)	Midwifery, ethnography	Indepth interview, participatory observation, literature study	Thematic analysis
3	Dinata *et al*. (2014)	Public health, ethnography	Indepth interview, participatory observation	Thematic analysis
4	Ipa *et al*. (2014)	Midwifery, ethnography	Indepth interview, participatory observation	Thematic analysis
5	Agung *et al*. (2014)	Public health, ethnography	Indepth interview, participatory observation	Thematic analysis
6	Sadewo *et al*. (2014)	Public health, ethnography	Indepth interview, participatory observation	Thematic analysis
7	Supraptini *et al*. (2016)	Medicine, public health, ethnography	Indepth interview, participatory observation	Thematic analysis
8	Pangalila *et al*. (2016)	Midwifery, ethnography	Indepth interview, participatory observation	Thematic analysis
9	Alfarabi *et al*. (2016)	Nursing, ethnography	Indepth interview, participatory observation	Thematic analysis
10	Saputra *et al*. (2016)	Medicine, public health, ethnography	Indepth interview, participatory observation	Thematic analysis
11	Nggeolima *et al*. (2016)	Midwifery, ethnography	Indepth interview, participatory observation	Thematic analysis
12	Effendi, Permana *et al*. (2016)	Nursing, ethnography	Indepth interview, participatory observation	Thematic analysis
13	Imanhadi *et al*. (2016)	Public health, ethnography	Indepth interview, participatory observation	Thematic analysis
14	Sudrajat *et al*. (2016)	Medicine, public health, ethnography	Indepth interview, participatory observation	Thematic analysis
15	Efendi, Siregar *et al*. (2016)	Medicine, public health, ethnography	Indepth interview, participatory observation	Thematic analysis

RESULT AND DISCUSSION

Talking about illness means talking about the pain felt by someone. Illness is in the individual patient context, which is influenced by the cultural setting in which he is located[2]. The concept of illness behavior revealed that principal determinants affecting the inclination to seek medical care are social, cultural, and interpersonal factors[1,22]. Indonesia is a country with many ethnicities. There are more than 1,340 ethnic groups according to the 2010 Central Statistics Agency census. Locally, indigenous Indonesian religions and their local languages are very diverse. Based on the 15 analyzed literature shows three main metaphors are related to the concept of illness and its causes. The three metaphors are "unable to move as usual", "due to supernatural or magical things", and "because they violate taboos".

"Unable to move as usual"

In general, ethnic groups in Indonesia call someone suffering from illness if they are unable to move as usual[23–32], cannot get out of bed[23,26,32], and cannot carry out its

social role[32]. In extreme terms, people who are ill are depicted lying in bed and unable to do any activities. Those who are medically diagnosed with illness are still considered not sick, if they are still able to move, as usual, they can still make a living for the family. They don't even want to be considered sick if they can still work as usual.

> "People who suffer from Filariasis, even though their legs are slightly swollen, they are not said to be sick because they can still work in the garden and climb coconut trees." [33]

> "The concept of being sick according to the people of Prambanan Village is when they are no longer able to do a job. They don't want to be considered sick as long as they are still able to do work." [34]

> "If people can't go to the garden to grow vegetables, look for crabs or fish, it called sick... but if you can still work it's... healthy people" [35]

"Caused by supernatural/magical things" and "for violating taboos"

Some ethnic groups already have the concept of modern causes of sick. They believe that there are physical illnesses caused by bacteria, germs, or due to weather changes and diet[23,24,26,27,30,35,36]. Nevertheless, the concepts of belief in illness caused by occult or magical things are still very strong[23,26,36,28–35]. Some ethnic groups believe that illness caused by this occult is a shipment from another person because they are not happy or jealous[23,29–31,34], or because they are disturbed by a ghost or departed spirits of the ancestors[26,28,29,32,33,35,36]. Their belief in the existence of supernatural forces outside humans is also part of religious belief. The original Indonesian religions were dominated by the glorification of spiritual spirits, including ancestral spirits, which they worshiped.

> "Witchcraft. The Jorong Soriak community believes that there is an illness called *Sijundai* ..."[30]

> "People in Prambanan Village still believe that illness is witchcraft or a shipment from people who are not happy with them."[34]

> "Because of disturbances (gods or goddesses who inhabit in large trees, rivers, hills, large natural holes, etc.) which are believed to be sacred places (*ketpon*)."[32]

> "*Deme* disorder. *Deme* is the owner of nature and who gave birth to the ancestors of the Tomer village community."[29]

> "The cause of the sick person comes from the medical, disruption of spirits and the power of darkness and God's rebuke of the life events they have done."[35]

Sijundai is a type of magic that makes victims behave like crazy[37]. When someone is exposed to *Sijundai*, it will experience unnatural symptoms, so that they will lose consciousness. There are times when crying or otherwise laughing, without any reason[30].

Some symptoms of the disease that are often encountered as a result of violating the sacred place (*ketpon*), and interference of ancestors (*deme*), are skin bruising, the body is difficult to move, until unconscious. This phenomenon of the same symptoms is found in the Muyu tribe in Mindiptana and the Kanume tribe in Tomer[32,38]

Still related to the causes of illness from non-medical factors, some indigenous ethnic Indonesians believe that disease can also be caused by violations of certain restrictions or rules. Violating certain restrictions can result in falling ill, even bringing death[24,26,27,29,32,33,39].

> "There are certain restrictions on the Muyu community against boys who are undergoing initiation are prohibited from eating certain local fruits such as *ketapang*, ethnic, *nibung*, and animals such as snakes etc. Including foods cooked by women."[32]

> "The sick that is considered severe by the Madobag villagers are sick due to abstinence, which violates the restrictions that exist in society. For example, when a *sikerei* (designation for a traditional healer) wants to do treatment he is not allowed to have sex with his or her partner when it is violated the *sikerei* will get sick that leads to the death."[26]

> "Disease can be caused by violations of abstinence. There is a belief that every tree or place inhabited by *Barajowa*. Violation of the prohibition on the place can result in disease. One example, the people who cut down a tree inhabited by *Barajowa* will get sick. Besides, the disease can come from owing in the form of snakes, frogs, cassowary birds, and millipedes. People who have no magic will get sick if they accidentally see these animals."[27]

Health-Seeking Behavior

The pattern of health-seeking behavior of ethnicity in Indonesia is closely related to beliefs in perceived illness, and beliefs in the causes of the illness. Based on these beliefs, there are two types of health-seeking behavior patterns based on their causes. If it is believed that illness is felt by medical causes (germs, bacteria, weather changes, etc.)[23,24,26,27,30,35,36], then at first they will try to do their treatment. If there is no improvement, they will go to a health worker (can be a nurse or doctor). If they feel have not recovered, then they will go to a health care facility (Figure 2). In the final stage, if the patient feels still sick, the patient will move to another hospital[27,36], while some other patients do a combination of treatment with a traditional healer[23,30].

Sick → Self-medication → Health worker → Health Center/Hospital

Figure 2. Health Seeking Behavior by medical causes

Meanwhile, if it is believed that the cause of the illness is supernatural or magical or because it violates restrictions[23,24,36,39,26–29,31–34], the treatment pattern is completely different. In the initial stages, they do their treatment. If they feel there is no improvement, they will go to a traditional healer (Figure 3). This step does not stop at only one traditional healer. When he felt there was no cure when he treated a traditional healer, he would look for another traditional healer who was considered more able to heal. And so on when there is no healing[24,27,31].

Sick → Self-medication → Shaman

Figure 3. Health Seeking Behavior by supernatural or magical or because it violates restrictions causes

Sometimes if the disease is felt to be quite severe, or they are not sure whether the illness is caused by medical factors or occult things, the different pattern of treatment is found. This pattern involves shaman and health workers simultaneously (Figure 4). This pattern can also be exchanged between modern or traditional healers when the patient feels he still hasn't healed. Also found a pattern of treatment in modern and traditional healer simultaneously when it starts to despair because it does not heal[24,27,31]. The choice for treatment simultaneously, between modern and traditional healers, often occurs when the patient feels the disease is getting worse or does not go away. This severity refers to the length of time the illness (months) or becomes unable to get out of bed[23,24,27,31,32].

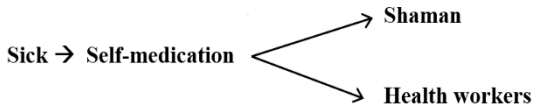

Figure 4. Health Seeking Behavior if the disease is felt to be quite severe, or not sure whether the illness is caused by medical factors or occult things

As a social role, the concept of illness can ultimately be different for each ethnic group. The individual construction of illness is influenced by the background. This condition depends on the cultural setting and health beliefs of the local community. Cultural conceptions of what disease are and how people respond to them are more influential than their beliefs about the biomedical concept of disease, which ultimately influences the patient's interactions with health providers[1,40,41]. An unusual condition for ordinary people[42,43], but also applies to health workers[44]. Different ethnic backgrounds can lead to perceived acceptance of different treatments, although access and quality of services provided are the same. This can create barriers to receiving needed health care[45]. The concept of illness owned by ethnic groups in Indonesia seems to ignore someone's sensitivity to the symptoms of the disease. They declare themselves sick when the physical condition is severe. This weakening sensitivity will cause delayed treatment for health facilities. So that ultimately health care costs will be more expensive because the disease suffered already in bad conditions when they get in contact with health facilities[15].

If not managed properly, health belief can be an inhibiting factor for the community in diagnosing and preventing disease early, and also in seeking for the treatment[46]. This is related to their sensitivity to signs of disease, as a result of their belief in the causes of illness in the cultural context[46]. Their belief in the causes of illness determines the health-seeking behavior that is carried out[47,48]. Those who believe that illness is caused by occult things will try to find a suitable cure, who can overcome the cause of the illness. The choice is a traditional healer or shaman[49] because it is considered more successful than medical care[50].

From a different perspective, a previous study found a different phenomenon. Those who have (religious) beliefs, hold on to these beliefs, are found to have a better cure rate than those who do not[51,52]. Believing in something has a better suggestive effect than not[53].

An understanding of an illness that is influenced by the belief by health workers can make the treatment pattern effective. Health workers must understand those situations, so that appropriate care can be formulated and delivered to such patients. For example, by entering spiritual factors into patient care or treatment. This has been proven to provide positive results for patient recovery[54]. Religion as a spiritual factor plays an important role in seeing and handling diseases. The patient's spiritual belief is a powerful source of overcoming disease[55].

Evidence of the success of the treatment patterns based on a good understanding of people's beliefs is to allow pregnant women to choose how they will give birth according to their beliefs. This can have a positive effect, both during the antenatal care process during pregnancy, and in the final phase when giving birth in a health care facility. At the time of delivery, the mother was not afraid and more acceptable medical interventions[56–58].

Understanding of illness as an effort to support social and understanding cultural issues will have an impact on people's access to health facilities, health-seeking behavior, and participation in health promotion initiatives. Interventions with cultural approaches and social support are important strategies in promoting self-management in patients[59]. This intervention proved to have the potential to empower and encourage individuals to take control and manage their chronic diseases better[60,61].

Someone who holds tightly to his belief about the concept of illness (emic) often overestimates almost all information about medical information, including about vaccines [62,63]. A study in Indonesia and the US found that those who have a different concept of illness from an ethical concept are less likely to trust medical providers run by the government[64,65]. On the other hand, the government is informed that it tends not to adopt or make health beliefs developing in the community concern in its health policy[65].

In Indonesia, the government issued a special policy that recognizes traditional medicine as part of the health care system. The decree of the Minister of Health number 1076 in 2003 was issued to regulate the administration of traditional medicine. Besides, also released Minister of Health Regulation of the Republic of Indonesia number 61 of 2016 concerning traditional empirical health services. The two policies were released not only to embrace traditional medicine but also to develop traditional medicine with an empirical approach. Other policies were also released to regulate traditional medicine as a complement to modern medicine[66–68]. This policy is regulated in the Minister of Health Regulation number 37 of 2017 regulating traditional health services integration. In acupuncture medicine, the Ministry of Health also regulates licensing issues between traditional acupuncturists and medical personnel who practice acupuncture[69–71].

The Indonesian government through the Ministry of Health also released the Minister of Health Regulation of the Republic of Indonesia number 003/Menkes/Per/I/2010. This policy specifically regulates herbal medicine in health service-based research. This policy specifically accommodates efforts to develop native Indonesian medicinal plants. This policy encourages the use of herbal medicine at formal health

service facilities[72,73]. Similar government policies are also found in several other countries, including Kenya, Nepal, Thailand, and Pakistan[74–78].

Understanding the concept of disease and its causes emically will make health workers more easily understand the behavior of patients. The understanding of health workers will be useful to gain empathy and trust from patients so that any therapy given can be trusted by patients. This makes an important contribution to understanding the problem of underutilization of medical services despite the government's extensive efforts to improve accessibility[22,64]. Although health workers still have to be able to distinguish between the concept of emic disease in which they live with the community and the ethical concept of disease that is accepted during education[44,79].

Limitation of The Study

This literature study is limited to 15 ethnicities studied. There are still many other ethnic groups in Indonesia that are likely to have similar or even different concepts of illness. However, the strength of this research was the first in synthesizing the concept of illness among the tribes in Indonesia.

CONCLUSIONS

This study describes a profound emic perspective on the concept of illness and its causes according to ethnic communities in Indonesia. The concept of illness found is different from the concept of disease in the modern medical world. The concept of illness from the perspective of ethnic communities was found to be closely related to the health-seeking behavior pattern revealed.

DECLARATION OF CONFLICTING INTERESTS

The authors declare that they have no conflict of interest.

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