



## Factors Influencing Attitude Toward Organ and Tissue Donation Among Patients in Primary Clinic, Sabah, Malaysia

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### ABSTRACT

**Introduction.** Worldwide, the gap between organ supply and demand has widened over the years. Malaysia has one of the lowest deceased organ donation rates. Success rate of organ or tissue procurement depends on not only the approach rate by health care providers but also the awareness among the public, whereby it can be a platform for family initiation of organ donation. The purpose of this study is to assess the knowledge of and determine the factors influencing attitude toward organ and tissue donation among patients in a primary clinic.

**Methods.** A cross-sectional analytical study was carried out. Self-administered questionnaires were given to 400 patients who registered at an outpatient clinic in April 2018. Convenience sampling was applied.

**Results.** Monthly income, education level, occupation, and knowledge level are significantly associated with attitude of the respondents toward organ and tissue donation. Occupation influenced attitude toward organ donation. Knowledge of organ donation and brain death both significantly affected attitude toward organ donation.

**Conclusion.** The greater the knowledge of organ donation and brain death, the more positive impression or attitude toward organ donation. Education level and income are the main predictors that influence attitude toward organ donation. Hence, it is important for public health units to promote and deliver public education on organ donation, change public misconceptions, and work parallel with hospitals to increase organ donation rates in Sabah.

**W**ORLDWIDE, the gap between organ supply and demand has widened over the years. Malaysia has one of the lowest deceased organ donation rates (0.7 donations per million population) compared with countries such as Spain, which had the highest with a donation rate of 36 per million population in 2014. Other Asian countries are not far off from Malaysia, such as Myanmar (0.02) and Thailand (1.26) [1]. The World Health Organization defines transplantation as the transfer of human cells, tissues, or organs from a donor to a recipient with the aim of restoring functions in the body [2]. In Sabah, the Sabah Regional

Transplant Procurement Management Unit has made effort for all government hospitals in Sabah to have a Tissue Organ Procurement team for identification and referral of eligible cases. Sabah is a Malaysian state with a high number of potential cadaveric or deceased donors for referral, but

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the consent for organ donation is still low. Transplantation is the only hope and definitive treatment for patients with organ failure. Donors can be either living or deceased. Unlike a deceased donor or cadaveric donor, a living donor can only donate part of the liver, 1 kidney, and bone marrow. A cadaveric donor can donate more organs and tissues without giving risk to the donor. Thus, a cadaveric donor is a preferable type of donor; however, cadaveric donation is very low in Malaysia. In 2015, Malaysia had its highest number of cadaveric donors, but Sabah only contributed 1 donor. The whole Malaysia had 35 cadaveric donors in 2017. Among them only 1 donor was from Sabah state. The demand and supply cannot meet up due to the lack of organs. Since 1998, the Malaysia Ministry of Health has initiated a number of activities to promote the development of organ donation and transplantation. Many countries have faced a similar problem of organ shortage for transplantation in patients with end-stage organ failure. Organ transplantation is the only hope for patients with end-stage organ failure to improve their quality of life. If a cadaveric organ donation program is not supported by the community, this may end up in organ trafficking. If the family of the deceased has a lack of knowledge of organ donation and the procurement process, this will lead to refusal in donating the organs and tissues. The deceased's family's consent is the last step in organ harvesting. Hence, it is important for public health units to promote and deliver public education on organ donation, change public misconceptions, and work together with hospitals to increase organ donation rates in Sabah. The purpose of this study is to determine the factors influencing attitude toward organ and tissue donation among patients, and to assess the knowledge of organ donation and brain death among patients.

## METHODS

A cross-sectional analytical study was conducted at primary health clinic Kota Kinabalu, from October 2017 to July 2018 with a total of 10 months' duration. It is located in Sabah state in Malaysia and is under the lead of 1 family medicine specialist with 15 medical officers. Monthly patients in outpatient clinic range from 4000 to 6000. The study population targeted is registered patients more than 18 years old who visited an outpatient clinic during the study period. Data collection was done during working hours until the preferable sample size was obtained. Nonprobability convenience sampling was used. Respondents who were selected followed the Queue Management Server (QMS) numbering system from number 1 to the end of the day. Those respondents who agreed to participate were given a self-administered questionnaire. The entire questionnaire was placed at the registration counter and distributed together with the QMS number before seeing the doctor. A sample size of 383 patients was taken by calculating the pilot study samples using the Sample Size Calculator for Prevalence Studies (SSCPS version 1.0.03). All the registered patients who agreed to participate and were above 18 years old were included in the study. Patients who were not registered or had no document or refused or were less than 18 years old were excluded from the study. Respondents could choose to withdraw at any time. The items in

the questionnaire for the knowledge part were mainly modified from the study by Ozturk Emiral et al [3]. This was to ensure the items were appropriate and able to be answered by respondents. The Malay version of the questionnaire was pilot tested by the patients from the Emergency and Trauma Department 1 month before data collection. Thirty respondents were obtained by using patients grouped in the green zone at the Emergency and Trauma Department for reliability test. These 30 samples were not included in the study. Cronbach's alpha was used to determine the internal consistency of the scale on 12 knowledge and exposure questions in Part B and 11 questions on attitude toward organ and tissue donation in Part C of the questionnaires. A total of 23 items were tested for reliability. Cronbach's alpha for the overall scale was 0.870. There are a total of 36 questions in the questionnaires, which can be divided into the following 3 parts: Part A: Sociodemographic characteristics; Part B: Exposure and knowledge in organ donation and brain death; and Part C: Acceptance or attitudes toward organ donation. After the questionnaire was pilot tested and obtained acceptable reliability testing, the questionnaires were distributed to the study population. The questionnaire was validated before the main study was done. Descriptive analysis was done by using frequencies, and the  $\chi^2$  test was used to determine association between sociodemographic characteristics and attitude toward organ donation, and to study the association between knowledge levels of the respondents toward attitude for organ donation. Statistical analysis was performed using SPSS version 22 (IBM, Armonk, NY, United States) throughout the study.

## RESULTS

A total of 400 self-administered questionnaires were distributed, of which 383 (95.75%) were successfully completed. Most of the respondents had secondary educations, which consisted of 337 respondents (88%) compared with primary education of 46 (12%). A total of 313 (81.7%) were aged less than 40 years, and 70 (18.3%) of the total respondents were aged over 40 years. The mean age for the sample was  $32.69 \pm 9.239$ . Most of the respondents, 193 (50.4%), had monthly income of at least RM2000. A total of 151 (39.4%) of the respondents were government servants. Most were married 251 (65.5%). Respondents consisted of 155 (40.5%) men and 228 (59.5%) women.

### Knowledge of Organ Donation

A total of 339 (88.8%) respondents answered the first question correctly, which asked about the organ donation definition. For the second question, which is the age limit for organ donation, only 178 (46.5%) respondents answered correctly that there was no age limit for organ donation. Most of the respondents, 292 (76.2%), answered correctly for causes of organ transplant. Respondents correctly answered for organ transplant causes with the statement, "High blood pressure and diabetes are common causes for people to require a kidney transplant." A total of 307 (80.2%) respondents answered correctly what organs can be donated in Malaysia (kidneys, liver, heart, and lung), whereas 211 (55.1%) respondents answered correctly what tissues can be donated in Malaysia (bone, skin, heart valves,

**Table 1. Respondents Who Correctly Answered Knowledge Questions About Organ Donation (N = 383)**

Questions	Correct n (%)	Wrong n (%)
Definition of organ donation	339 (88.8)	44 (11.5)
Age limit for organ donation	178 (46.5)	205 (53.5)
Causes of organ transplant	292 (76.2)	91 (23.8)
Organs that can be donated in Malaysia	307 (80.2)	76 (19.8)
Tissues that can be donated in Malaysia	211 (55.1)	172 (44.9)

and cornea) (Table 1). Based on organ donation knowledge questions, responses were further categorized into good and poor knowledge of organ donation. One correct answer for 1 question was considered 1 mark, thus the maximum mark for this section was 5 marks and the lowest was 0 marks, with none of the questions answered correctly. We considered respondents with good knowledge of organ donation to be those who answered correctly for 4 questions and above (4 and 5 marks), whereas those poor knowledge answered correctly for 3 questions and below. A total of 213 (55.6%) had good knowledge of organ donation, whereas the other 170 (44.4%) respondents had poor knowledge of organ donation (Table 2).

#### Knowledge of Brain Death

Regarding knowledge of brain death, 296 (77.3%) respondents answered correctly on the brain death definition, which is "brain death is the irreversible and total cessation of all of the brain functions in the person, including the functions of the brainstem." Two hundred twenty-seven respondents (59.3%) agreed that brain-dead patients cannot recover or their condition is irreversible. However, for the statement "brain death is a death and not comatose," only 181 (47.3%) respondents agreed. A total of 197 (51.4%) answered correctly that brain-dead patients can donate organs and tissues, whereas 91 (23.8%) respondents correctly answered the question about the source of cadaveric tissue donation, which is natural death or cardiopulmonary death (Table 3). Based on brain death knowledge questions, responses were categorized into good and poor knowledge of brain death. Only 125 (32.6%) had good knowledge about brain death, whereas the other 258 (67.4%) had poor knowledge of brain death. Regarding the exposure toward organ donation program, about 329 (85.9%) participants had heard of organ and tissue donation; however, only

**Table 2. Number of Correct Answers on Knowledge of Organ Donation Questions**

Number of Correctly Answered Organ Donation Questions	n	%	
0	17	4.4	Mean = 3.47
1	14	3.7	Median = 4.00
2	52	13.6	Mode = 4
3	87	22.7	SD = 1.336
4	116	30.3	Variance = 1.784
5	97	25.3	
Total	383	100	

Abbreviation: SD, standard deviation.

**Table 3. Percentage of Respondents Who Correctly Answered Knowledge Questions About Brain Death (N = 383)**

Questions	Correct n (%)	Wrong n (%)
Definition of brain death	296 (77.3)	87 (22.7)
Brain dead cannot recover (irreversible)	227 (59.3)	156 (40.7)
Brain dead is a death, not coma	181 (47.3)	202 (52.7)
Brain dead donor can donate organ and tissue	197 (51.4)	186 (48.6)
Other death can only donate tissue	91 (23.8)	292 (76.2)

116 (30.3%) participants attended an organ donation program before. A total of 54 participants (14.1%) had never heard of organ donation and 267 participants (69.7%) had never attended any organ donation program before (Table 4).

#### Attitude of Respondents Regarding Organ Donation

Three hundred fifty-seven (93.2%) respondents agreed that organ donation can save lives. For the statement, "organ donation is for all regardless religion and races," 338 (88.3%) answered yes. A total of 284 (74.2%) respondents thought that organ donors should not be paid money. Surprisingly, 270 (70.5%) respondents agreed that their religion allowed the believer to donate. The majority of the respondents, 302 (78.9%), agreed that hospitals in Malaysia support organ donation. However, only 166 (43.3%) had a relative or friend register as pledger and 90 (23.5%) had their relatives or friends waiting for transplant. One hundred five respondents (27.4%) had a donor card. About 215 (56.1%) respondents had confidence with the hospital's cadaveric donation procurement procedure. One hundred fifty-three (39.9%) respondents thought that they should inform family members of their will on organ donation, but only 122 (31.9%) thought that it was easy for them to discuss. A total of 139 (36.3%) had an attitude mark fall into the group of 4-6 marks, 111 (29%) with 7-9 marks, 84 (21.9%) with 10-12 marks, and the remaining 12.8% had 0-3 marks (Table 5). Attitude was further divided into 2 categories, which were positive impression and negative impression of organ donation. A total of 195 (50.9%) respondents had a positive attitude toward organ donation, whereas another 188 (49.1%) respondents had a negative attitude toward organ donation (Table 6).

**Table 4. Number of Correctly Answered Questions on Knowledge of Brain Death**

Number of Correctly Answered Brain Death Questions	n	%	
0 correct answer	36	9.4	Mean = 2.61
1 correct answer	74	19.3	Median = 3.00
2 correct answer	68	17.8	Mode = 3
3 correct answer	80	20.9	SD = 1.533
4 correct answer	77	20.1	Variance = 2.349
5 correct answer	48	12.5	
Total	383	100	

Abbreviation: SD, standard deviation.

**Table 5. Attitude Score Toward Organ and Tissue Donation**

Attitude Marks	n	%
0-3 marks	49	12.8
4-6 marks	139	36.3
7-9 marks	111	29.0
10-12 marks	84	21.9
Total	383	100

#### Relationship Between Sociodemographic Variables and Attitude Toward Organ Donation

Four sociodemographic factors that are statistically significant to influence the attitude of respondents toward organ donation are ethnicity, education level, occupation, and monthly income. Ethnicity was one predictor of the attitude of the respondents ( $P = .001$ ;  $P < .05$  was considered as a significant level). However, in all the Bumiputra respondents, about 48% Bumiputra respondents (166 out of the 345 Bumiputras) had a positive impression toward organ donation. Education level is also a predictor of respondent's attitude toward organ donation ( $P = .008$ ). The lower the education level, the poorer the impression toward organ donation (odds ratio [OR] = 2.37, 95% confidence interval [CI] 1.23-4.55). Occupation and monthly income are also predictors of attitude toward organ donation ( $P < .001$ ) (Table 7). Monthly income less than RM2000 showed 3.97 times higher to have negative attitude toward organ donation (OR = 3.97, 95% CI 2.59-6.07). Poor knowledge of organ donation is 5.66 times higher to have a negative attitude toward organ donation (OR = 5.66, 95% CI 3.64-8.81). Poor knowledge of brain death is 5 times higher to have negative attitude toward organ donation (OR = 5.0, 95% CI 3.09-8.09) (Table 8). It revealed that respondents with good knowledge and a positive attitude toward organ donation was 147 (69%) respondents, whereas those with poor knowledge revealed a negative attitude included 122 (72%) respondents, which was statistically significant with  $P < .001$  (Table 9). From the analysis, at level of significance at 5%, the results presented in Table 10 show that there is a significant relationship between knowledge of brain death and attitude toward organ donation ( $P < .001$ ). It showed that 95 (76%) respondents with good knowledge of brain death had a positive impression of organ donation. One hundred fifty-eight (61%) respondents with poor knowledge had a negative impression of organ donation.

#### DISCUSSION

It was found that though respondents from this study had good knowledge of organ donation (56%), they lack

**Table 6. Positive and Negative Attitude Score Toward Organ and Tissue Donation**

Attitude Marks	n	%
7-12 marks (positive)	195	50.9
0-6 marks (negative)	188	49.1

**Table 7. Association of Sociodemographic and Attitude on Organ Donation**

Sociodemographic	Attitude			$\chi^2$	P Value
	Positive	Negative			
Sex					
Male (155)	78	77	0.036	.849	
Female (228)	117	111			
Age					
<40 years (313)	152	161	3.789	.052	
>40 years (70)	43	27			
Marital status					
Married (251)	133	118	1.254	.263	
Not married (132)	62	70			
Education level					
Secondary school (337)	180	157	7.009	.008	
Primary school (46)	15	31			
Occupation					
Government servant	84.1	15.9	40.875	<.001	
Private sector	52.8	47.2			
Student	65.6	34.4			
Unemployed	48.3	51.7			
Monthly income					
RM2000 and below	51.1	48.9	35.014	<.001	
RM2001 and above	79.8	20.2			

knowledge of brain death (33%). Organ donation promotion effort has widely introduced knowledge of organ donation but does not mention much about brain death. Besides that, people always try to avoid brain death discussion and many people cannot accept brain death as a true death. In view of this, the person delivering an organ donation program also will try not to mention brain death, and this leads to lack of knowledge of brain death. Lacking knowledge of brain death causes family members to not understand the pathophysiology of brain death and not accept it as death. When the family member cannot accept brain death, even though the anesthesiologist explained it to the family, they might not be able to accept brain death as a death. This ends up with a patient whose heart stops beating, and cadaveric organ procurement is already not possible as there is no blood flow to the vital organ. The most important source of organ donations is brain-dead people, but this type of donation has many limitations. There are 2 limitations for brain-dead organ donation, which are disagreement among the donor's relatives and the fact that organ donation from living donors has a more successful rate than brain-dead donors [4]. However, patients on the kidney transplant waiting list do not favor

**Table 8. Independent Risk Factors of Negative Attitude Toward Organ Donation**

Variables	OR	95% Confidence Interval	P Value
Education level	2.37	1.23-4.55	.008
Monthly income	3.97	2.59-6.07	<.001
Knowledge of organ donation	5.66	3.64-8.81	<.001
Knowledge of brain death	5.00	3.09-8.09	<.001

Abbreviation: OR, odds ratio.

**Table 9. Association Between Knowledge of Organ Donation and Attitude Toward Organ Donation**

Knowledge of Organ Donation	Attitude		$\chi^2$	P Value
	Positive	Negative		
Good	147 (69%)	66 (31%)	62.908	<.001
Poor	48 (28%)	122 (72%)		

receiving a related living organ, although their family member offered one of their organs [5]. Usually those patients who would accept a related, living donated kidney are young, single people with a high level of education. One strategy to solve the limitation of cadaveric organ donation is to improve the knowledge and attitude of the family or spouse of the brain-dead person toward organ donation [4]. Another article also supported the idea that attitude toward deceased organ donation can be influenced by family and religious factors [6]. The disagreement from family members or refusal for consent for the brain-dead person contributed to the lack of cadaveric organ donation. Due to this, the last step of organ harvesting cannot happen, especially in Malaysia, which practices an opt-in system. There are many studies that look into the knowledge of health care professionals, as this group of people is responsible for identifying potential cadaveric donors, contacting the procurement team coordinator, and approaching families of potential donors [7]. However, studies on patients and family members should be done to assess their knowledge of and attitude toward organ donation, whereby if they have knowledge of brain death before in tragedy condition, it will improve the outcome of family consent and fulfilling their family members' wishes. The current organ donation promotion program should emphasize cadaveric organ procurement more, which can procure only from a brain-dead patient. Cadaveric organ and tissue donation is always the preferable type of donation compared with living donation because there is no risk to the donor and it contributes more organs and tissues. Cadaveric organ donation usually does not involve commercial transaction compared with a living donor [8]. However, only related living donors are allowed in Malaysia. From this study population, more than half of the respondents knew about organ donation and comprised 56% of good knowledge of organ donation. However, more than half of the population thought that there was an age limit for organ donation, thus this factor can become one of the obstacles to organ donation whereby patients will assume that their age is a limit for them to donate and prevent them from further discussions with their

**Table 10. Association Between Knowledge of Brain Death and Attitude Toward Organ Donation**

Knowledge of Brain Death	Attitude		$\chi^2$	P Value
	Positive	Negative		
Good	95 (76%)	30 (24%)	46.726	<.001
Poor	100 (39%)	158 (61%)		

family member. Organ donation awareness programs should highlight this factor and brain death knowledge to improve the donation rate in Malaysia.

This study also found out that respondents had a lack of knowledge of brain death. For the question regarding the statement "brain death is a death and not in comatose," most answered wrongly because they did not think that brain death is death. The view of "brain death" in medicine and medical ethics is that patients who meet the criteria for "brain death" are biologically dead though they show apparent signs of being alive [9]. The reality is masked by the intervention of mechanical ventilation on bodies with a nonfunctioning brain [9]. Thus, the knowledge of patients in accepting the physiology of brain death should be emphasized, and good soft skill technique to deliver this message is important to increase the cadaveric organ donation rate. Physicians and health care workers fully understand and accept that a person is dead when his or her brain is dead. Widespread use of mechanical ventilators and advances in medicine have transformed the course of terminal neurologic disorder whereby vital functions of other organs can be maintained artificially for a longer period after brain function has ceased [10]. However, there is an urgency to diagnose brain death with the utmost accuracy because the increased awareness of early diagnosis of brain death can improve cadaveric organ donation and increase the success rate of organ harvesting [10]. Donors who died from other causes besides brain death can donate only tissues but not organs. People died of brain death can donate both tissues and organs. This is expected as organ donation programs seldom discuss what organs and tissues can be donated in the country and might contribute to the confusion of organ and tissue donation [11]. One of the factors influencing shortage of organ donation is nonrecognition of brainstem death [12].

It was found that 329 (86%) respondents in this study heard about organ donation; however, only 116 (30%) respondents had attended an organ donation program before. This suggests that more well-designed intervention is needed to increase the awareness of organ donation programs. It was found that 48.8% of respondents were thinking about donating an organ upon death; however, only 27.4% had a donor card. This reflected that the "Organ Donor Card" had not been selected as evidence of their act and support toward organ donations. This may be due to the religion aspect or cultural belief. Only 1 in 4 of those who were willing to donate were ready to pledge as an organ donor and register for a donor card [13]. Therefore, emphasis on having a donor card for those who pledged for organ and tissue donation upon death is a must. However, a study done in Germany showed varying results whereby 1 in 10 people who were willing to donate had a donor card [14].

It was found that education level, occupation, and monthly income had statistically significant associations with attitude of the respondents toward organ donation in this study. Education level has been shown to be an important predictor for knowledge of and attitude toward organ

donation. Another article emphasized that formal training about organ donation has positively influenced the attitude and registration of organ donation [15]. McGlade et al had done a quantitative measurement of assessing participants by using pre-test and post-test methods, and they found that the short program on organ donation could improve their knowledge and subsequently affect the positive attitude towards organ donation [15]. Nevertheless, higher income and greater education levels are associated with more positive attitudes toward organ donation [16]. This finding was further supported by an article by Riyanti et al, which found that those with no formal education and those with monthly income less than RM1000 were less likely to pledge as organ donors [17].

However, our study revealed that age, sex, marital status, and religion have no significant association with the attitude of the respondents toward organ donation. This is in contrast with findings by Huern et al, whereby there is a positive correlation among age, sex, ethnicity, and religion and knowledge of organ donation [18]. Even though, in this study, the relationship between religion and attitude are not statistically significant, clinically the religion issue may be associated with attitude toward deceased organ donation. The religion issue is important in religious permissibility of organ donation, especially cadaveric donation [19]. People who believe organ donation is against their religion will directly and indirectly affect deceased organ and tissue donation [19]. The direct effect is that the person will not donate his or her organ upon death, whereas the indirect impact is that they will not facilitate others' donation. These implications will affect deceased donation rates. Thus, the religious permissibility of organ donation needs to be emphasized, which is key to improving deceased donations in Malaysia.

From this study, there is a significant association between knowledge of organ donation and brain death. Both organ donation and brain death knowledge are important to influence positive attitude towards organ donation. However, there is low correlation between knowledge and attitude regarding organ donation among undergraduate medical students [18]. Another study discussed that education and knowledge plays an important role in influencing attitude toward organ donation [15]. It should be understood that though the individual decision about whether to donate organs is vital, the final decision rests with relatives. Thus, the most common reason for low organ donation rates is the failure to obtain consent from the deceased's relatives and sometimes the family member not being aware of the deceased's wishes when he or she was alive. The greater the knowledge of organ donation and brain death, the more positive impression of organ donation.

#### LIMITATIONS

One of the limitations of this study is that the sample population of this study was from 1 health clinic, and

therefore sociodemographic distribution such as ethnic distribution might not represent the whole state. Second, the questionnaires were distributed to those patients in the study period and there may be selection bias in this study. The sample population was only from 1 health clinic and was not a true reflection of the general Sabahan population. Due to time constraints, this study was unable to expand to other health clinics in Sabah.

#### CONCLUSION

Higher education level and income more than RM2000 are significantly associated with a positive attitude toward organ donation. The greater the knowledge of organ donation and brain death, the more positive impression of or attitude toward organ donation. This study has effectively identified 5 main factors influencing the attitude toward organ donation among patients, which are education level, occupation, monthly income, ethnicity, and knowledge regarding organ donation and brain death. The knowledge regarding brain death is the easiest and most effective factor to modify. A multilevel approach, consisting of governmental and nongovernmental organizations, must be undertaken to ensure effectiveness of this strategy.

#### RECOMMENDATIONS

The deceased's family's consent is a vital and final step in organ harvesting. Community awareness of the importance of organ donation pledge cards needs to be increased as a form of evidence of the patient's desire to donate organs. Hence, it is important for public health units to promote and deliver public education on organ donation, change public misconceptions, and work parallel with hospitals to increase organ donation rates in Sabah. A concerted effort from the government needs to increase the promotion of organ donation in the primary health care facilities. All public hospitals have procurement units and are well versed in organ donation, but primary health care facilities lack the manpower and resources to promote such awareness. Road shows focusing on awareness and education regarding organ donation should be taken to the general public.

With adequate and sufficient education and awareness, patients' relatives initiate the donation process without being approached by the health care team. The ministry of health should work together with religious institutions to promote organ donation among the general public. Organ donation should be included in all forms of end-of-life care or palliative care counseling.

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