# Attitudes, acceptance, and registration in relation to organ donation in Hong Kong: a cross-sectional study

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### ABSTRACT

**Introduction:** The objective of this study was to investigate the discrepancy between individuals with positive attitudes towards organ donation and the actual number of registered organ donors in Hong Kong, and to investigate the best modalities for promoting more organ donor registrations.

**Methods:** This cross-sectional telephone survey was conducted in Hong Kong. Telephone numbers were selected randomly. Upon successful contact with a household, the eligible household member who had the most recent birthday was selected to participate in the telephone interview.

Results: A total of 1000 Hong Kong Chinese residents were interviewed successfully. The response rate was 53.8%. The majority of the respondents were female (68.3%) and were aged 51 to 60 years (24%) or ≥61 years (43.6%). Among the respondents, 31.3% were willing to donate their organs after death; 43.3% were indecisive, and 25.4% refused. Among those who were willing to donate organs after death, only 34.2% had registered with the Centralised Organ Donation Register (CODR). Among those who were willing to donate organs after death but had not yet registered on CODR, 52.2% said they were not determined enough to take action, 47.8% said they were too busy, 37.8% said they were too lazy, and 20.4% said they were always forgetful about

registering. In all, 32.8% of the interviewees were not aware of the ways to register as a prospective organ donor. Among non-messenger social media platforms, Facebook, YouTube, and Instagram were the most commonly used. Most participants believed that Facebook and YouTube were effective for engaging audiences.

**Conclusions:** More effort should be made to facilitate organ donor registration in face-to-face settings via promotional booths and in online settings via appropriate social media platforms.

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# New knowledge added by this study

- A large proportion of respondents had a positive attitude towards organ donation.
- The majority of respondents who were positive towards organ donation lacked the determination to register as
  organ donors.
- Among respondents who had registered as organ donors, most did so in person via a promotional booth.

## Implications for clinical practice or policy

- More effort should be made to proactively reach out to passive-positive donors.
- The importance of taking action to register as a prospective organ donor must be emphasised.
- The use of social media platforms may help engage passive-positive donors and provide immediate opportunities for online registration.

# Introduction

In 2017, Hong Kong had a low organ donation ratio of 6.0 deceased donors per million population, whereas the corresponding ratios were 46.9, 32.0, and 23.1

donors per million population in Spain, the United States, and the United Kingdom, respectively.<sup>1</sup> Among all types of solid organs, there is the greatest shortage of donated kidneys in our locality. In 2018,

there were 2318 patients on the waiting list for kidney transplantation.<sup>2</sup> However, there were only 60 kidney donations from deceased donors and 16 from living donors in the same year.<sup>2</sup> This marked mismatch has led to not only a long average waiting time for kidney transplantation of 51 months,<sup>3</sup> but also the accompanying costs of prolonged dialysis, increased risk of dialysis-related complications, and adverse effects on patients' quality of life.<sup>4-6</sup>

The majority of organ donations are from deceased donors. However, without knowing the wishes of deceased potential donors, it is often difficult to counsel their family members about organ donation. Therefore, it is important to engage the general public in prospective organ donor registration. Hong Kong has a population of approximately 7.39 million, but only 284185 individuals had registered as organ donors via the Centralised Organ Donation Register (CODR) through June 2018, corresponding to a registration rate of 3.8%.7 In contrast, 52.6% of the respondents of the Behavioural Risk Factor Survey conducted in Hong Kong reported that they were willing to donate their organs after death.8 These results suggest that most people who are willing to donate organs after death have not yet registered as prospective organ donors. These individuals represent a group of passive-positive organ donors who would potentially become prospective organ donors if successfully engaged.9

We conducted a local survey to investigate the underlying reasons for the discrepancy between the number of individuals willing to donate organs and the number of registered donors. We postulate that appropriate use of social media may play a role in motivating people to register as prospective organ donors. Hence, we also investigated the use of smartphones and social media platforms by Hong Kong citizens. The results will be useful for planning our future directions and strategies for promoting organ donation.

# Methods

A cross-sectional telephone survey of the general population of Hong Kong was conducted via the service provided by the Jockey Club School of Public Health and Primary Care, The Chinese University of Hong Kong. The survey was designed after consultation with doctors, nurses, living-related organ donors, organ recipients, and patient support groups. Demographic information including age, sex, marital status, education level, occupation, religion, smoking habits, drinking habits, exercise habits, and current health status was collected. Questions focusing on the respondents' views about organ donation and their actions taken with regard to organ donor registration were asked. Questions

# 香港市民對器官捐贈的態度、接受程度和登記 情況:橫斷面研究

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引言:本研究旨在檢視香港對器官捐贈持積極態度的人士與已登記器官捐贈實際人數之間的差異,並探討促進更多器官捐贈登記的最佳方式。

方法:在香港進行橫斷面電話訪談並隨機選擇電話號碼。與家庭成功 聯繫後選擇最近生日的合資格家庭成員參與電話訪談。

結果:成功與1000名中國籍香港居民進行訪談。回應率為53.8%。大部分受訪者為女性(68.3%),年齡介乎51至60歲(24%)或61歲及以上(43.6%)。當中31.3%表示願意死後捐贈器官、43.3%感到猶豫不決、25.4%則拒絕。願意捐贈器官的人當中,只有34.2%登記在中央器官捐贈登記名冊(CODR)內。願意死後捐贈器官但尚未登記的原因包括決心不足(52.2%)、太忙(47.8%)、太懶(37.8%)以及忘記(20.4%)。32.8%表示不清楚器官捐贈登記的方法。Facebook、YouTube和Instagram是受訪者最常用的非即時通訊社交媒體平台,大部份也認為Facebook和YouTube最吸引受眾注意。

**結論**:當局應透過不同渠道,例如宣傳攤位和社交媒體平台致力推廣 器官捐贈登記。

regarding potential misconceptions about organ donation were also asked. The respondents' habits of using smartphones and social media platforms were also evaluated. To minimise the sampling error, telephone numbers were first selected randomly from an updated telephone directory as seed numbers. Another set of three numbers was then generated by randomising the last two digits to recruit unlisted numbers. Duplicate numbers were then screened out, and the remaining numbers were mixed in random order to become the final sample.

Interviews were conducted by experienced interviewers between 10:00 and 22:00 on weekdays and other periods, including weekends and public holidays, should appointments with suitable subjects be arranged. The inclusion criteria for the study were Chinese Hong Kong residents aged  $\geq 18$  years. Upon successful contact with a target household, one qualified member of the household was selected among the family members using the last-birthday random selection method (ie, the respondent aged  $\geq 18$  years in the household who had his/her birthday most recently was selected) to participate in the telephone interview. We aimed for the survey to have 1000 respondents. All results were analysed and presented descriptively.

# **Results**

From 15 April 2019 to 8 May 2019, telephone numbers were sampled for the survey until 1000 valid responses from eligible individuals were received. Of 16373 telephone numbers called, 14514 were invalid for various reasons: 6556 were facsimile/invalid lines, 555 were non-residential lines, 1008 cut the line immediately, 6366 did not pick up the phone after three attempts, and 29 were non-Chinese persons. Among the remaining 1859 eligible individuals, 750 refused to participate in the survey, seven terminated the survey mid-way, and we failed to contact the remaining 102 after three attempted calls each. The overall response rate was 53.8% (1000/1859).

The majority of our respondents were female (68.3%) and within the age-group of 51 to 60 years (24%) or  $\geq$ 61 years (43.6%). In total, 73.6% of the respondents did not have any religious beliefs. The vast majority of them were non-smokers (95.2%) and non-drinkers (93.1%). In all, 65.6% of the respondents exercised regularly, with 65.7% and 10.3% considering themselves "healthy" and "very healthy," respectively (Table 1).

Table 2 shows the survey results on the respondents' views about organ donation and their actions taken with respect to organ donor registration. Unexpectedly, a relatively large proportion of interviewees (30.6%) had never heard of CODR, and 89.1% of the respondents had never visited the CODR website. Only 31.3% of the respondents were willing to donate their organs after death, and 43.3% were indecisive, while 25.4% refused. When interviewees were asked if they would support a family member's decision to become a prospective organ donor, 56.4% said they would be supportive, 7% would object, and 36.6% were uncertain. Looking further at the 313 respondents who were willing to become prospective organ donors, only 34.2% of them had registered on CODR, whereas 55.3% had expressed such wishes to their family members. Of those who had registered, 98.1% did so in the hope of rekindling others' lives, 93.9% believed that their organs would become useless after death, and 44.7% were influenced by successful organ donation stories publicised by the media.

Of the 107 respondents who had registered to be prospective organ donors, 47.7% did so via organ donation promotional booths, 28% filled in the application forms and mailed them back to the Department of Health, and 24.3% registered online. Among the 206 respondents who were willing to donate organs after death but had not yet registered on CODR, 52.2% said they were not determined enough to take action, 47.8% said they were too busy, 37.8% admitted that they were too lazy to do so, 20.4% said they were always forgetful about

TABLE I. Respondents' demographic information

|                   | Responses |
|-------------------|-----------|
| Age (years)       |           |
| 18-30             | 12.2%     |
| 31-40             | 8.2%      |
| 41-50             | 11.8%     |
| 51-60             | 24.0%     |
| ≥61               | 43.6%     |
| Refused to answer | 0.2%      |
| Sex               |           |
| Male              | 31.7%     |
| Female            | 68.3%     |
| Marital status    |           |
| Single            | 17.4%     |
| Married           | 73.8%     |
| Divorced          | 0.6%      |
| Widow/widower     | 7.4%      |
| Refused to answer | 0.8%      |
| Education level   |           |
| Primary           | 34.2%     |
| Junior secondary  | 13.2%     |
| Senior secondary  | 29.4%     |
| Tertiary          | 21.7%     |
| Refused to answer | 1.5%      |
| Occupation        |           |
| Full time         | 26.4%     |
| Part time         | 3.3%      |
| Freelance         | 0.5%      |
| Homemaker         | 23.6%     |
| Student           | 5.5%      |
| Unemployed        | 0.7%      |
| Retired           | 39.0%     |
| Refused to answer | 1.0%      |

registering, and 32.8% said they were not aware of the ways to register as a prospective organ donor.

A total of 687 respondents were indecisive or refused to become organ donors. In all, 30.7% hoped to keep their bodies intact after death, 7.1% refused to register because of religious beliefs, 7.1% were worried that organ donation might increase their suffering, and 6.8% worried that by agreeing with organ donation, they would receive suboptimal or inadequate medical care. In total, 22% were not keen to donate organs owing to objections from family (Table 2).

TABLE 2. Survey respondents' views on organ donation and actions taken for organ donor registration

| Survey questions   | Responses |
|--|-----------|
| All respondents  |           |
| Have you heard of the Centralised Organ Donation Register (CODR)?  |           |
| Yes  | 69.4%     |
| No   | 30.6%     |
| Have you browsed the CODR website before?  |           |
| Yes  | 5.9%      |
| No   | 89.1%     |
| Forgot/not sure  | 5.0%      |
| Are you willing to donate your organs after passing away?  |           |
| Yes  | 31.3%     |
| No   | 25.4%     |
| Do not know/not sure   | 43.3%     |
| If your family member would like to donate their organs after passing away, will you support their decisions?        |           |
| Yes  | 56.4%     |
| No   | 7.0%      |
| Do not know/not sure   | 36.6%     |
| For those who were willing to donate their organs after passing away   |           |
| Have you registered at CODR yet?   |           |
| Yes  | 34.2%     |
| No   | 65.8%     |
| Have you told anyone that you would like to donate your organs after passing away?                                   |           |
| Yes  | 59.7%     |
| No   | 40.3%     |
| Have you told your family members that you would like to donate your organs after passing away?                      |           |
| Yes  | 55.3%     |
| No   | 44.7%     |
| Do you support organ donation because you want to rekindle other people's lives?                                     |           |
| Yes  | 98.1%     |
| No   | 1.9%      |
| Do you support organ donation because you think your organs will become useless after death?                         |           |
| Yes  | 93.9%     |
| No   | 6.1%      |
| Do you support organ donation because of your religious beliefs?   |           |
| Yes  | 9.3%      |
| No   | 90.7%     |
| Do you support organ donation because you have been touched by real-life organ donation cases reported in the media? |           |
| Yes  | 44.7%     |
| No   | 55.3%     |
| Do you support organ donation because of influence by your friends or family members?                                |           |
| Yes  | 16.6%     |
| No   | 83.4%     |
| Do you support organ donation because your friends or family members are organ recipients?                           |           |
| Yes  | 5.4%      |
| No   | 94.6%     |

# TABLE 2. (cont'd)

| Survey questions   | Responses |
|--|-----------|
| For those who were willing to donate their organs after passing away and who had registered at CODR                        |           |
| Do you carry an organ donation card to express your wish to donate your organs after death?                                |           |
| Yes  | 32.7%     |
| No   | 67.3%     |
| How did you register as an organ donor after death?  |           |
| Online registration  | 24.3%     |
| Filling in the application form and mailing it back to the Department of Health  | 28.0%     |
| Organ donation promotional booths  | 47.7%     |
| For those who were willing to donate their organs after passing away but had not registered at CODR                        |           |
| Is there a reason why you did not register at CODR?  |           |
| Yes  | 97.6%     |
| No   | 2.4%      |
| ls it because you are too busy?  |           |
| Yes  | 47.8%     |
| No   | 52.2%     |
| ls it because you are always forgetful about registering?  |           |
| Yes  | 20.4%     |
| No   | 79.6%     |
| Is it because you are not aware of the ways to register?   |           |
| Yes  | 32.8%     |
| No   | 67.2%     |
| Is it because you need to convince your family members about it first?   |           |
| Yes  | 16.4%     |
| No   | 83.6%     |
| Is it because you are not determined enough to proceed to registration?  |           |
| Yes  | 52.2%     |
| No   | 47.8%     |
| Is it because you are too lazy?  |           |
| Yes  | 37.8%     |
| No   | 62.2%     |
| For those who were not willing to donate their organs after passing away   |           |
| Do you not support organ donation because of personal reasons or beliefs?  |           |
| Yes  | 87.9%     |
| No   | 12.1%     |
| Do you not support organ donation because you want to keep your body intact after death?                                   | 12.170    |
| Yes  | 30.7%     |
| No   | 69.3%     |
| Do you not support organ donation because of religious beliefs?  | 03.070    |
| Yes  | 7.1%      |
| No   | 92.9%     |
| No Do you not support organ donation because you believe that organ donation will increase your suffering?                 | 32.370    |
| Yes  | 7.1%      |
| No   | 92.9%     |
| No  Do you not support organ donation because you are worried that you will receive suboptimal or inadequate medical care? | 32.370    |
| Yes  | 6.8%      |
| No   | 93.2%     |
| Do you not support organ donation because of objections from your family members?  | JU.Z /U   |
| Yes  | 22.0%     |
| No   | 78.0%     |

TABLE 3. Survey results on the potential misconceptions about organ donation

|  | True  | False | Not sure |
|--|-------|-------|----------|
| Which of the following statements regarding organ donation is true?    |       |       |          |
| There is an adequate amount of organs for transplantation in Hong Kong | 1.7%  | 84.1% | 14.2%    |
| It will hinder funeral arrangements                                    | 4.5%  | 76.0% | 19.5%    |
| It will induce unnecessary pain to the deceased person                 | 6.6%  | 84.8% | 8.6%     |
| The organ recipients will know the identity of the organ donor         | 7.6%  | 69.0% | 23.4%    |
| It will make the body of the deceased person incomplete                | 33.2% | 64.1% | 2.7%     |
| Only young people can donate organs after death                        | 34.0% | 62.7% | 3.3%     |
| Only perfectly healthy individuals can donate organs after death       | 60.6% | 36.2% | 3.2%     |

The questionnaire also studied potential misconceptions about organ donation (Table 3). Of the respondents, 6.6% believed that the process of organ harvesting would induce unnecessary pain to the deceased person, and 4.5% worried that organ harvesting would hinder funeral arrangements. A total of 60.6% thought that only perfectly healthy individuals could donate organs after death, 34% believed only young people could donate organs after death, and 7.6% believed that the organ recipients would always know the identity of the organ donor. Moreover, 1.7% were under the impression that there was an adequate supply of organs in Hong Kong.

Respondents were interviewed about their use of smartphones and social media platforms (Table 4). In all, 77% of the respondents often use their smartphones to access social media platforms. Among the various non-messenger types of social media platforms, Facebook, YouTube, and Instagram were the most commonly used. The majority of the respondents believed that Facebook and YouTube were effective at engaging the audience.

# **Discussion**

There has been a great demand for organ donations in Hong Kong, yet the number of organ transplantations conducted is very small. The organ donation rate in Hong Kong is much lower than that of many European countries, perhaps because of cultural, religious, governmental, legal, and regulatory differences, as well as differences in the level of intensive care unit support and organ donation criteria. 10-13 Hong Kong currently follows the opt-in approach to organ donation, as opposed to the opt-out approach, which is the standard in countries like Singapore and Spain. Although the opt-out approach may increase the availability of suitable organs for donation, there is a reasonable concern about differing views between members of the general public and the potential ethical issues

The questionnaire also studied potential TABLE 4. Survey results on the use of smartphones and social media platforms

| Survey questions   | Responses |
|--|-----------|
| How often do you use smartphones?                                |           |
| Do not use smartphone  | 32.5%     |
| <1 h per day   | 14.5%     |
| <4 h per day   | 31.7%     |
| <8 h per day   | 17.6%     |
| <12 h per day  | 2.2%      |
| ≥12 h per day  | 1.5%      |
| How often do you use smartphones for internet access every day?  |           |
| <1 h   | 32.4%     |
| <4 h   | 48.9%     |
| <8 h   | 16.4%     |
| <12 h  | 1.3%      |
| ≥12 h  | 0.9%      |
|  | Yes       |
| Do you often use smartphones to access social media platforms?   | 77.0%     |
| Do you often use the following social media platforms?           |           |
| Facebook   | 46.0%     |
| Instagram  | 17.2%     |
| YouTube  | 32.8%     |
| Twitter  | 1.1%      |
| WhatsApp   | 55.9%     |
| WeChat   | 14.7%     |
| LINE   | 2.8%      |
| Do you think the following social media platforms are effective? |           |
| Facebook   | 38.6%     |
| Instagram  | 8.6%      |
| YouTube  | 20.9%     |
| Twitter  | 0.4%      |
| WhatsApp   | 19.1%     |
| WeChat   | 4.2%      |
| LINE   | 0.4%      |

related to that approach. The degree of knowledge, awareness, and attitude towards organ donation is also important for an individual to take action to become a prospective organ donor.<sup>14</sup> More efforts should be made in these areas to improve the organ donation rate in Hong Kong.

In 2015, a Behavioural Risk Factor Survey with a total of 4253 respondents was conducted in Hong Kong.<sup>8</sup> Among the respondents, 52.6% reported that they were willing to donate their organs after death, 11.3% refused to donate their organs after death, and the rest remained undecided. However, until June 2018, the registration rate in Hong Kong was only 3.8%.<sup>7</sup> This represents a huge area of potential improvement if we are able to engage these potential organ donors successfully.

Our survey showed that only 34.2% of the respondents who were willing to donate their organs after death actually completed registration at CODR. A large proportion of respondents said they were too busy, too lazy, too forgetful, or simply not determined enough to take action to register at CODR. Of the respondents, 32.8% were not aware of the ways to register as a prospective organ donor. The majority of the respondents had not heard about CODR, and only 5.9% had browsed the CODR website. We need better ways to reach out to these passive-positive donors and to provide convenient methods for immediate registration after engaging them successfully. Our survey showed that the majority of the respondents use smartphones to access social media platforms every day and that Facebook, YouTube, and Instagram are the major social media platforms being used in Hong Kong. These social media platforms should be used for any organ donation promotion activities in the future.

Our survey showed that 47.7% of registered organ donors completed their registration via organ donation promotional booths. Face-to-face settings such as promotional booths allow the best engagement and interaction with the audience, and this definitely yields better results, especially for older adults who may not be familiar with the use of internet or social media platforms. Booths provide opportunities for educators to clarify people's misconceptions, resolve their queries, and provide live guidance regarding their registration. Our survey reflected the effectiveness of organ donation promotion booths established by the Hong Kong government in the past. It would be worth investing more resources to set up regular and frequent promotion booths in more diverse areas owing to their promising effects.

Two systematic reviews and meta-analyses have been conducted to identify effective community-based interventions to increase organ donor registration.<sup>15,16</sup> Among all studies reviewed, four randomised controlled trials demonstrated the

effectiveness of an intervention based on an increase in verified organ donor registrations.<sup>17-20</sup> The first study investigated the role of group discussions about organ donation in a church setting together with a 32-minute video featuring organ donation, organ transplantation, and the personnel involved during the whole process.<sup>17</sup> The second study investigated the effects of a 5-minute video using an iPod Classic or iPod Touch with noise-cancelling headphones.<sup>18</sup> The video was designed to address a number of concerns related to organ donation. The participants were then interviewed and given written information about organ donation. The third study investigated the role of a brief motivational intervention by hair stylists that encouraged organ donation.19 Hair stylists received training on communication skills, motivational interviewing, and discussion of ways to integrate organ donation into their client interaction. Each client was given a package containing organ donor registration cards. The fourth study investigated the use of the IIFF model (Immediate opportunity to register, Information, Focused engagement, and Favourable activation) to increase the rate of organ donor registration in the setting of Secretary of State branch offices.<sup>20</sup> Participants were gathered at the Town Hall, where organ donation was discussed, and there were registration cards at the end of the session.

The four successful studies have common features. 17-20 First, all four studies successfully engaged the public with motivational interactions. 17-20 Intervention participants were 1.23- to 7.02-times more likely than comparison participants to report positive registration status. 17-20 Passive-positive organ donors already have beliefs and attitudes that favour organ donation; what they need is additional motivational interactions to convert their belief into action. Second, three studies adopted a faceto-face approach in their interventions, which yielded positive results. 17,19,20 This is consistent with our findings, in that we have also seen the positive effects of face-to-face promotion (ie, booths) in Hong Kong. Third, two studies used video media to provide information about organ donation and organ transplantation.<sup>17,18</sup> Mass media alone are unlikely to produce any substantial effects, but the combination of media with motivational interaction can have synergistic effects in engaging the general public. Media intervention must also be innovative enough to attract the general public for better engagement. Fourth, three studies provided immediate opportunities for organ donor registration.<sup>18-20</sup> The opportunity for organ donor registration must be immediately present following successful engagement of an individual, and it must be rapid and convenient enough for the individual to complete the process. All four studies demonstrated the effectiveness of their promotion strategies.

Although it might not be suitable to duplicate and References apply those interventions directly in Hong Kong due to discrepancies in promotion setting and target audience, by learning from these successful examples, we can identify the essential components 2. of a successful organ donation promotion project.

Our study has several limitations. First, we only randomly selected 1000 Chinese Hong Kong residents to complete the survey, and this cannot represent the views of all Hong Kong citizens. Second, as this was a telephone survey, the majority of our respondents are aged ≥51 years. The results may not be a good reflection of the younger generation. Third, although our survey enables us to understand more about the situation of passive-positive donors in Hong Kong and the appropriate channels for engaging these potential organ donors, the exact ways to achieve audience engagement cannot be ascertained based only on the results of our survey. We intend to conduct future studies to investigate the effectiveness of social media platforms for interventions such as short videos, online challenge campaigns, online question-and-answer forums, online polling, live interviews, and live talks.

# **Conclusions**

There are many passive-positive organ donors in Hong Kong. Many of those surveyed were not aware of the ways to register as prospective organ donors. The majority also lacked the determination to register as organ donors. Engaging these individuals and providing immediate opportunities for registration is necessary. Promotional booths are most effective at providing this face-to-face, and social media platforms can provide this on an online setting.

# **Author contributions**

Concept or design: JYC Teoh, NY Far, SKK Yuen, BSY Lau. Acquisition of data: JYC Teoh, NY Far, SKK Yuen, BSY Lau. Analysis of data: JYC Teoh, NY Far, SKK Yuen, BSY Lau. Drafting of the manuscript: JYC Teoh, NY Far. Critical revision of the manuscript for important intellectual content: CH Yee, SSM Hou, TSC Teoh, CF Ng.

# **Conflicts of interest**

As editors of the journal, JYC Teoh and CF Ng were not involved in the peer review process. Other authors have disclosed no conflicts of interest.

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# **Ethics** approval

The study has been approved by Survey and Behavioural Research Ethics Committee (Ref SBRE-18-241). Survey respondents provided verbal consent to participate in the telephone interview.

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