

Japanese Perception of Organ Donation and Implications for New Medical Technologies: Quantitative and Qualitative Social Media Analysis

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Table of Contents

Original Manuscript..... 5

Supplementary Files..... 33

Figures 34

Figure 1..... 35

Figure 2..... 36

Figure 3..... 37

Figure 4..... 38

Figure 5..... 39

Figure 6..... 40

Multimedia Appendixes 41

Multimedia Appendix 1..... 42

Multimedia Appendix 2..... 42

Multimedia Appendix 3..... 42

Multimedia Appendix 4..... 42

Japanese Perception of Organ Donation and Implications for New Medical Technologies: Quantitative and Qualitative Social Media Analysis

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Abstract

Background: The Rapid Autopsy Program (RAP) is a useful procedure to understand human biology and illnesses such as cancer. However, implementing RAP in Japan requires understanding good death and incorporating socio-cultural aspects. By revising perceptions of organ donation in social media, we can shed light on the issues of implementing new medical research procedures such as RAP.

Objective: We examined YouTube and Twitter to uncover actors and quality of organ donation communication, providing recommendations to implement new medical research procedures.

Methods: Using the term “????”(organ donation), we collected data from YouTube and Twitter, classifying it into five dimensions: time, individuality, place, activity, and relations. We employed a scale to assess the quality of organ donation information, and divided YouTube videos into three groups to understand their differences through statistical analysis. We also conducted a text-based analysis of narratives tied to donation.

Results: Most YouTube videos were uploaded in 2021 (189/638, 29.62%) and 2022 (165, 25.86%), while Tweets peaked between 2019 and 2022. Citizens (184/770, 23.89%), media (170, 22.07%) and unknown actors (121, 15.71%) uploaded most videos about organ donation, whereas most identified users in a sample of 100 average retweeted Tweets were citizens (70.32%), as well as in average liked Tweets (68.42%). Information quality in Hokkaido ($F(2.46, 147.74) = [5.28], p = .005$) and Kyushu and Okinawa ($F(2.46, 147.74) = [5.28], p = .005$) was high, whereas most mentioned countries in Twitter were Japan and China. Information videos versed on borrowed life and requests to register as donor, while No Information and Misinformation videos mostly contained organ trafficking accusations by American media. Tweets were mostly about donation intention statements and family consent. Most video hyperlinks pointed to YouTube and Twitter, whereas most Twitter hyperlinks pointed to news reports by Japanese media.

Conclusions: There is a high likelihood of implementing new medical research procedures such as RAP in Japan. Recommendations include the conceptualization of research data as borrowed data, horizontal and diversified management of donation programs, and paying attention to science misinformation trends and popular culture trends.

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Abstract

Background: The Rapid Autopsy Programme (RAP) is a useful procedure to understand human biology and illnesses such as cancer. However, implementing RAP in Japan requires understanding good death and incorporating socio-cultural aspects. By revising perceptions of organ donation in social media, we shed light on the issues of implementing new medical research procedures such as RAP.

Objective: We examined YouTube and Twitter to identify actors, quality of organ donation communication, and socio-cultural aspects associated with organ donation, providing recommendations to implement new medical research procedures.

Methods: Using the term '臓器提供' (organ donation), we collected data from YouTube and Twitter, classifying them into five dimensions: time, individuality, place, activity, and relations. We employed a scale to assess the quality of organ donation information, and divided YouTube videos into three groups to understand their differences through statistical analysis. We also conducted a text-based analysis of narratives tied to donation.

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Conclusions: There is potential to implement new medical research procedures such as RAP in Japan. Recommendations include the conceptualisation of research data as borrowed data,

horizontal and diversified management of donation programmes, and a focus on science-misinformation and popular culture trends.

Keywords

Japan; organ donation; social media; multidimensional analysis; Twitter; YouTube

Introduction

A New Medical Research Paradigm in Japan

Japan has a super-aging society where cancer was the first cause of death as of 2021 [1], and Japanese researchers must prioritise cancer prevention and treatments. However, recent advancements in gene sequencing have contributed to the appraisal of the Rapid Autopsy Programme (RAP) in North America [2]. RAP is a speedy removal of tissues within hours after death under prior permission of potential donors [3], and it is also an effective technique to research cancer. One of the main issues with implementing RAP in Japan is what is considered a 'good death', characterized by understanding diagnosis, treatment options and decision of the place to be treated or left to rest by the patient and relatives [4] and preparing for the outcomes of death.

The different contradictions impact medical research and end-of-life care. As it is difficult to discuss death, other cases of medical intervention must be analysed and compared with RAP to develop medical research procedures that respect human dignity and incorporate Japan's socio-cultural aspects. The process of organ donation has overlapping characteristics: surgical intervention in an anonymous donor's body, at least one anonymous recipient of the benefits, a donation coordinator, and involvement of medical actors and governmental institutions. This is why, in this study, we revise public perceptions of organ donation in Japan, with the aim of providing recommendations for the implementation of new medical research procedures strongly related to end-of-life-care such as RAP.

Organ Donation in Japan

In Japan, the first law regarding organ donation was the Law for Transplantation of Kidneys and Corneas in 1979, with the establishment of the Kitasato University Hospital Bone Bank and further legislation acknowledging brain death only in case of organ transplantation in 1997 [5]. Currently, the organisation in charge of overseeing organ donation is the Japan Organ Transplant Network (JOTN). It informed that 93.42% (71/76) of donation cases occurred after heart death and 6.57% (5) after brain death in 2000, whereas 88.31% (68/77) of donation cases occurred after brain death and 11.68% (9) after heart death in 2020 [6]. This resulted from the legal change in 2010 where donation under brain death was permitted only with the family's consent. Although the number of cases remained similar, that of organs handled per body was on average 6.8, which was considered high [7]. Furthermore, donation from living donors was among the highest in the world, with Japan being a leading country in terms of kidney donation and transplantation [8].

This may be partly due to the importance of kin in Japanese normativity. Ideally, societal systems should not be fully heteronomous (with rules implemented by experts and institutions) nor ontonomous (with rules implemented by traditional cultural practices), as they risk falling into

authoritarianism. Instead, incorporating as many actors as possible working together for the common good would be desirable. Fuse [9] calls this social dynamic *kyosei* (共栄, living together), which refers to acknowledging inequalities and subordination while respecting heterogeneity, and accepting conflict.

Age, religion, and trust in medical care were considered relevant factors affecting organ donation, whereas Confucianism was more relevant than brain death, and the opposite occurred when donating organs of relatives [10]. A study among medical staff and the public uncovered that according to both groups, families do not want to damage the body, or for the patient to suffer more, and autopsy provokes suspicion and might result in legal accusations of medical error [11]. Yasuoka [12] provided a thorough description of attitudes towards organ donation among medical professionals, donors, recipients, relatives, and coordinators, identifying contempt towards narratives from the JOTN and a challenging environment that often caused the coordinators to resign.

An Internet-based survey among medical actors and the public revealed that 25.4% of the public and 82.3 % of staff (in particular cardiothoracic surgeons) agreed with organ and tissue donation [13]. Further, a report on workshops for kidney transplant coordinators that included role playing revealed that donation related knowledge improved after 3 months [14]. An online survey among citizens noted that although living organ donation was favoured over donation after brain death, when the question framed the participant as being in a position to donate and receive organs, donation after brain death was more favoured than living donation [15]. Associations and the media were also found to be relevant promoters of donation [16, 17].

Akabayashi [18] argued that Confucianism through filial piety was a barrier for organ donation. A survey among medical staff uncovered that knowledge was not associated with becoming a registered organ donor but with willingness to become one [19]. A long-term survey among medical students highlighted an incomplete understanding of the organ transplantation law and that the main reason to become an organ donor was 'to help others' [20]. A literature review of nursing students' attitudes revealed that interest in organ donation translated in more donor cards [21]. The Kitasato Bone Bank stopped donations until protocols for COVID-19 screening were implemented [22], which indicates a potential impact on other organ and tissue donation. Further, a study conducted in a Baptist Hospital reported that religion seemed to provide relief for donor relatives [23].

Knowledge Gaps

Based on the reviewed studies, we estimate that the more medical training and experience with organ donation an actor has, the more positive their attitudes towards donation. The role of religion is unclear, as studies have lacked operationalisation or disclosure of exact religious arguments. Although some evidence has shown relief for donor relatives through Baptism, it is unclear whether similar effects are present in other religions in Japan. Further, only three studies [12, 16, 17] focused on specific narratives and on who adopts them. In summary, most studies have targeted the knowledge, attitudes, and capacitation of medical experts regarding organ donation, whereas few have addressed donors, recipients, patients, their families, and coordinators, and less is known about the media and the public. Therefore, it is necessary to examine attitudes towards organ donation by various contributors that may interact and influence each other.

As Japanese people are particularly active in social media, opportunities to encounter information about organ donation may abound, whereas people interested in the topic may consult, discuss, and share such information more openly than in a one-on-one interview format. This is a common method adopted in reviewed studies, which could be supplemented with network analysis methods applied to the contemporary usage of social media.

Objectives of the Present Study

We formulated the following objectives:

1. Identify contributors of the organ donation discourse in Japanese social media.
2. Evaluate the quality of their organ donation discourse.
3. Identify socio cultural aspects associated with organ donation and provide recommendations for the implementation of new medical research procedures.

Methods: Quantitative and Qualitative Social Media Analysis

Data Collection

In Japan, YouTube and Twitter (some now call it 'X') are among the top 5 most visited social networking sites [24, 25]; thus we considered these social media platforms for data collection in two formats: video and tweets. We employed the term '臓器提供' (organ donation) as a search query.

We extracted video data using YouTube Data Tools [26] in two modules that employ the YouTube Application Programming Interface (API). The Video List module retrieves a list of videos and related information (publication date, title, description, duration, views, and comments). We verified the video titles and watched the videos to identify those related to organ and tissue donation post-mortem, which left 638 videos from 2166. We used identifiers (the last part of the video hyperlink) obtained through the Video List module to extract comments with the Video Comments module. Regarding Twitter, we requested tweets from the company Tweet Binder [27], who provided us with 133434 tweets. As the software for conducting further analysis can manage up to 100000 Tweets, we extracted a sample of that size as described in the following section.

Classification of Data

We analysed social media data by considering multiple actors and other factors in line with *kyosei*, as illustrated in Figure 1 (based on [28, 29]). We considered YouTube videos (left of Figure 1) and tweets (right of Figure 1) as the studied entities. We obtained the factors written in non-italics from the data, and one of the authors verified the factors in italics.

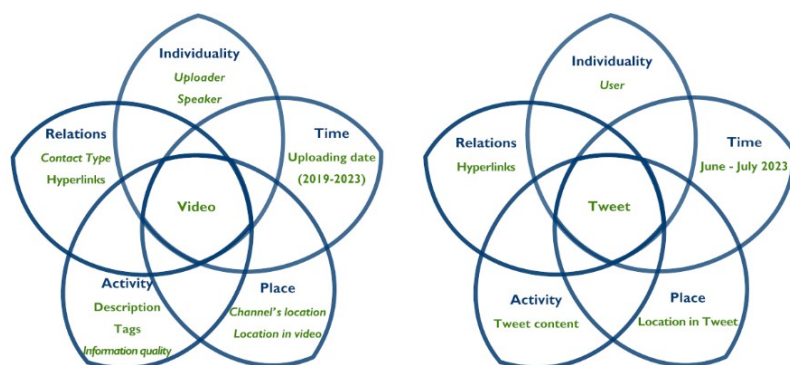


Figure 1. Data model of social media entities.

The entities' five dimensions were operationalised as follows:

1. Time: the YouTube videos; upload date was between January 2019 and May 2023, whereas the tweets' date was between September 2018 and July 2023.
2. Individuality: We consulted the 'About' page of the YouTube channel to identify uploaders, whereas speakers were identified as those who appeared, talked, or whose words were conveyed in the video. For Twitter, we used a randomizer [30] to extract a sample of 100 users with average retweets and likes. We also examined the authors of the top 10 liked and/or retweeted tweets and classified them based on Multimedia Appendix 1.
3. Place: we identified the location on the channel's 'About' page and in the YouTube video. For Twitter, we examined the location in the tweet's content. We identified countries and regions, and employed a place classification scheme (Multimedia Appendix 2).
4. Activity: for the YouTube videos, we employed description and an Information Quality score (Textbox 1) based on [31, 32]. The Information Quality score consisted of eight items formulated as questions regarding the video content, with a maximum possible score of 7. The last item indicated misinformation and disinformation, which if present, received a score of -1. We considered misinformation and disinformation as unreliable, false, deceptive and/or heavily politically charged medical information [33]. A researcher specialised in social media and public health verified the items while watching the videos, and a second researcher specialised in bioethics and public health verified the same items in 122 (19.12%) videos. Their agreement per item was 0.91, 0.81, 0.85, 0.91, 0.83, 0.92, 0.97 and 0.76. Although the last item had a moderately low agreement, we adopted the first researcher's coding. For Twitter, the top frequent words in the tweets were considered.
5. Relations: for the YouTube videos, we examined hyperlinks and contact type (blog, email, social networking site, webpage) in the descriptions were examined; for the tweets, we considered their hyperlinks.

Textbox 1. Organ Donation Information Quality (ODIQ)

Does the video contain:

- a medically appropriate definition of brain death?
- several definitions of death?
- mention of at least two organs that can be donated?
- the organ donation card?
- other options of donation statements?
- the donation process?
- free of charge for medical procedures for the donor?

- misinformation or disinformation?

Data Analysis

We employed a combination of quantitative and qualitative methods to analyse the data. In YouTube, the videos were classified into three categories based on the ODIQ scores: Misinformation (videos with misinformation or disinformation), No Information (ODIQ score equal to zero) and Information (all other videos). We categorised videos in this way as misinformation videos tended to also include information.

We quantified the numerical results based on our research model (Figure 1), by conducting a one-way analysis of variance (ANOVA) in parametric variables (published year, uploaders, speakers, country, place, contact type, consent type, media format, religion, and narratives), and a Kruskal-Wallis test in nonparametric variables (duration, and views) to uncover differences among video groups. $P \leq .01$ was considered the significance threshold. We conducted post hoc tests (Multimedia Appendix 3) using SPSS version 29.0.10 [34].

We examined the narratives tied to organ donation found in YouTube video descriptions and comments, and in the tweets' content with quantitative and qualitative techniques. We processed text data with KH coder version 3 [35] to calculate word frequency. KH coder can summarise frequent terms in Japanese and their relationships with other terms, drawing co-occurrence networks. In this study, the networks were drawn as undirected and unipartite, calculated with the overlap coefficient [36], and the 60 strongest co-occurrences were represented as network edges.

We performed a qualitative analysis by labelling videos with annotations and observations, based on [37] and considered additional narratives based on our previous study (Multimedia Appendix 4). A researcher counted the narratives, considering a threshold of at least 17 (2.66% of 638) videos. We examined the top 10 YouTube videos in terms of views and comments to further verify narratives and quality of information. Moreover, we analysed seven videos that mentioned donation for research to provide the closest comparison to scenarios involving new research procedures. We also focused on frequent terms found with text analysis, reviewing their corresponding tweets.

Ethical Considerations

This study was considered exempt from ethical review by the medical board of Kyoto University as it was conducted on social media records and did not involve human data beyond measuring Internet activity. The analysed data did not include information that could identify concrete individuals, and findings related to medical conditions were reported in anonymous form.

Results

Time Dimension in Japanese Social Media

Figure 2 displays the quantity of YouTube videos from 2019 to 2023 (a) and tweets from 2018 to 2023 (b). Videos peaked in 2021 and 2022 (189/638, 29.62% and 165/638, 25.86%, respectively),

with no significant ($P=.053$) differences between groups. On Twitter, mentions of organ donation peaked in 2022 (21713/10000, 21.71%), 2020 (21093/10000, 21.09%) and 2019 (20731/10000, 20.19%). The topic of organ donation apparently peaked in 2022 on both social media platforms.

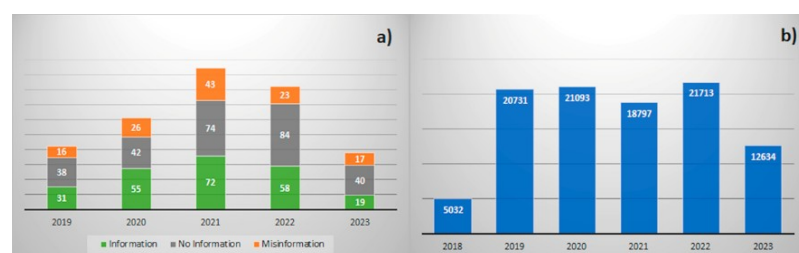


Figure 2. YouTube videos and tweets per year.

Individuality Dimension: Actors in Japanese social media

Table 1 shows overlapping actors identified in YouTube videos. Citizens (184/770, 23.89%), media (170, 22.07%) and unknown actors (121, 15.71%) uploaded most videos about organ donation. A one-way ANOVA demonstrated significant differences in doctors ($F(0.92, 34.81) = [8.41]$, $P<.001$), other medical staff ($F(0.28, 14.36) = [0.14]$, $P=.002$), associations ($F(1.23, 71.70) = [5.45]$, $P=.004$), citizens ($F(3.20, 127.72) = [7.97]$, $P<.001$), media ($F(3.12, 121.58) = [8.14]$, $P<.001$), and religious ($F(2.64, 70.29) = [11.93]$, $P<.001$), and educational ($F(0.63, 24.30) = [8.32]$, $P<.001$) actors. The Bonferroni tests available in Multimedia Appendix 3 specified differences in the means of doctors between Information and Misinformation ($P<.001$, 95% confidence interval (CI) = [.04, .16]), and Information and No Information videos ($P=.007$, 95% CI = [.01, .11]); other medical staff between Information and No Information ($P=.003$, 95% CI = [.01, .08]) and a moderate difference between Information and Misinformation ($P=.03$, 95% CI = [.00, .08]).

Other differences included the means of associations between Misinformation and Information ($P=.003$, 95% CI = [-.21, -.03]); citizens between Misinformation and No information ($P=.001$, 95% CI = [.06, .29]), and between Misinformation and Information ($P=.001$, 95% CI = [.06, .30]); media between No information and Information videos ($P<.001$, 95% CI = [.06, .25]); religious actors between Misinformation and No information ($P=.004$, 95% CI = [.03, .20]), and Misinformation and Information ($P<.001$, 95% CI = [.09, .27]); and educational actors between Information and No information videos ($P<.001$, 95% CI = [.03, .11]).

Table 1. Actors related to organ donation in videos based on ODIQ

Actor	IU ^a	NU ^b	MU ^c	TU ^d	IS ^e	NS ^f	MS ^g	TS ^h
Doctor	25 ⁱ	12	1	38	106	99 ⁱ	66 ⁱ	271
Medical student	0	0	0	0	4	3	1	8
Nurse	3	1	0	4	34	42	21	97
Other medical staff	12 ⁱ	2	1	15	30 ⁱ	14 ⁱ	8	52
Donor	2	1	0	3	67	91	55	213
Recipient	3	7	0	10	47	52	26	125
Donor relative	0	0	0	0	33	24	11	68
Recipient relative	0	0	0	0	16	22	9	47
Other patient	4	10	1	15	26	60 ⁱ	10	96

Other patient relative	2	0	0	2	21	36	6	63
Association	40 ⁱ	38	6 ⁱ	84	86 ⁱ	61	33 ⁱ	180
Citizen	59	71	54 ⁱ	184	116	143	84 ⁱ	343
Government	9	4	1	14	52	66	57 ⁱ	175
Media	42	93 ⁱ	35	170	54 ⁱ	99	51	204
Religion	16	37	31 ⁱ	84	27	46	42 ⁱ	115
Education	16 ⁱ	37 ⁱ	0	26	37	34	25	96
Unknown	48	51	22	121	8	15	5	28

^a Information Uploaders; ^b No Information Uploaders; ^c Misinformation Uploaders; ^d Total Uploaders; ^e Information Speakers; ^f No Information Speakers; ^g Misinformation Speakers; ^h Total Speakers; ⁱ Statistically significant differences.

Regarding speakers, citizens (343/2181, 15.72%) were mostly portrayed in YouTube videos, followed by doctors (272, 12.47%). We observed differences in doctors ($F(2.80, 153.08) = [5.81]$, $P=.003$), other medical staff ($F(0.80, 46.95) = [5.46]$, $P=.004$), patients ($F(2.18, 79.37) = [8.72]$, $P<.001$), associations ($F(2.78, 126.43) = [6.99]$, $P=.001$), citizens ($F(2.86, 155.73) = [5.83]$, $P=.003$), the government ($F(5.16, 121.83) = [13.46]$, $P<.001$), the media ($F(3.24, 135.52) = [7.59]$, $P=.001$), and religious actors ($F(4.09, 90.17) = [14.42]$, $P<.001$).

Bonferroni tests confirmed that the mean of doctors was different ($P=.004$, 95% CI = [.04, .30]) between Misinformation and No information; that of other medical staff was different between No information and Information ($P=.004$, 95% CI = [-.08, .06]); that of patients was different between No Information and Misinformation ($P=.001$, 95% CI = [.04, .23]), and between No Information and Information ($P=.003$, 95% CI = [.03, .18]) videos; that of associations was different between Information and No information ($P=.001$, 95% CI = [.05, .24]); that of citizens was different between Misinformation and No information ($P=.01$, 95% CI = [.03, .29]), and between Misinformation and Information ($P=.004$, 95% CI = [.05, .31]) videos; the mean of the government was different between Misinformation and No Information ($P<.001$, 95% CI = [.11, .33]), and between Misinformation and Information ($P<.001$, 95% CI = [.12, .35]) videos; that of the media was different between Information and Misinformation ($P=.002$, 95% CI = [-.30, -.06]), and between Information and No information ($P=.006$, 95% CI = [-.22, -.03]) videos; and that of religious actors was different between Misinformation and No information ($P<.001$, 95% CI = [-.22, -.03]), and between Misinformation and Information ($P<.001$, 95% CI = [.12, .32]) videos.

A sample of 91 users who tweeted 100 tweets with two retweets resulted in 70.32% identified as citizens, whereas among 95 users of 100 tweets liked eight times, 68.42% were identified as citizens. Among the citizens, two in each category were registered donors. Further, users with top likes manifested mostly in favour of organ donation, including a doctor and a politician, whereas another doctor unrelated to transplantation was not in favour (Table 2). Among users with top retweets, half were in favour, including a doctor and a politician, while another doctor was unclear and yet another was not in favour.

Table 2. Top users identified on Twitter

Username	Likes	Type	In favour of donation?
@aaaaa	82 004	Citizen	Yes

@bbbbbb	37 095	Citizen	Unclear
@cccccc	27 028	Doctor	No
@dddddd	24 162	Unknown	Yes
@eeeeee	18 709	Citizen	Yes
@nnnnnn	12 824	Government	Yes
@ffffff	12 315	Citizen	No
@gggggg	10 564	Doctor	Yes
@hhhhh	10 310	Citizen	Unclear
@iiiiii	10 172	Patient relative	Yes
Username	Retweets	Type	In favour of donation?
@bbbbbb	16 392	Citizen	Unclear
@jjjjj	7 674	Doctor	Yes
@hhhhh	7 415	Citizen	Unclear
@aaaaa	6 964	Citizen	Yes
@cccccc	6 350	Doctor	No
@kkkkk	5 471	Citizen	No
@dddddd	4 491	Unknown	Yes
@nnnnnn	3 270	Government	Yes
@lllll	2 448	Citizen	Yes
@mmmm m	2 192	Doctor	Unclear

Place Dimension: Countries, Regions, and Place Types

Places identified in YouTube videos were mostly closed spaces (332/1317, 25.2%), hospitals (242, 18.37%) and open spaces (205, 15.56%) according to Table 3. We observed significant differences in hospitals ($F(2.46, 147.74) = [5.28]$, $P=.005$), medical offices ($F(0.72, 40.24) = [5.70]$, $P=.003$), closed places ($F(3.44, 155.78) = [7.02]$, $P=.001$), open places ($F(2.31, 136.81) = [5.37]$, $P=.005$), and unknown locations ($F(3.25, 78.30) = [13.18]$, $P<.001$) across ODIQ groups. Bonferroni tests uncovered differences between the means of hospitals in Misinformation and No Information ($P=.004$, 95% CI = [.04, .30]) videos; medical offices in Information and Misinformation ($P=.006$, 95% CI = [.02, .15]) videos; closed places in No Information and Information ($P=.001$, 95% CI = [.06, .27]) videos; open spaces in No Information and Information ($P=.006$, 95% CI = [.03, .23]) videos; and unknown locations in Information and No Information ($P<.001$, 95% CI = [.08, .23]), and Information and Misinformation ($P=.005$, 95% CI = [.03, .22]) videos.

Table 3. Places, locations and countries in YouTube videos based on ODIQ

Place	Information	No Information	Misinformation	Total
Hospital	74	107 ^a	61 ^a	242
Medical Office	26 ^a	15	3 ^a	44
Educational Institution	24	11	13	48
Home	48	77	31	156
Religious building	7	2	3	12
Other closed space	100 ^a	163 ^a	69	332
Nature	69	80	33	182
Open space	57 ^a	103 ^a	45	205

Unknown	57 ^a	24 ^a	15	96
Location in Japan				
Hokkaido	12 ^a	2	1	15
Tohoku	3	5	0	8
Kanto	18	26	9	53
Chubu	14	14	5	33
Kansai	6	8	3	17
Chugoku	6	4	1	11
Kyushu / Okinawa	17 ^a	4	1	22
Unspecified	134	171	84	389
Country				
Canada	8	7 ^a	12 ^a	27
China	29 ^a	76 ^a	61 ^a	166
India	6	2 ^a	8 ^a	16
Israel	5	3 ^a	8 ^a	16
UK	18 ^a	28	23 ^a	69
US	54	86	57 ^a	197

^a Statistically significant results

Most identified Japanese regions were Unspecified (389/548, 70.98%), followed by Kanto (53, 9.67%). Significant differences included Hokkaido ($F(0.28, 14.36) = [6.24]$, $P=.002$) and Kyushu and Okinawa ($F(0.537, 20.70) = [8.23]$, $P<.001$), where pairwise comparisons detailed differences between the means of Hokkaido in Information and No Information videos ($P=.003$, 95% CI = [.01, .08]); and Kyushu and Okinawa in Information and No Information ($P=.001$, 95% CI = [.02, .10]), and Information and Misinformation ($P=.004$, 95% CI = [.02, .11]) videos.

Countries with significant differences were Canada ($F(0.45, 25.39) = [5.72]$, $P=.003$), China ($F(10.93, 111.87) = [31.02]$, $P<.001$), India ($F(0.27, 15.32) = [5.76]$, $P=.003$), Israel ($F(0.25, 15.34) = [5.16]$, $P=.006$), the UK ($F(0.96, 60.56) = [5.07]$, $P=.006$) and the US ($F(4.17, 131.99) = [10.04]$, $P<.001$). Bonferroni tests specified differences between the means of Canada in Misinformation and No Information ($P=.003$, 95% CI = [.02, .12]) videos; China in Misinformation and No Information ($P<.001$, 95% CI = [.11, .32]), Misinformation and Information ($P<.001$, 95% CI = [.25, .48]), and No Information and Information ($P<.001$, 95% CI = [.06, .24]) videos; India in Misinformation and No Information ($P=.002$, 95% CI = [.02, .10]) videos; Israel in Misinformation and No Information ($P=.005$, 95% CI = [.01, .09]) videos; Serbia in Misinformation and No information ($P=.003$, 95% CI = [.01, .04]), and Misinformation and Information ($P=.004$, 95% CI = [.01, .04]) videos; the UK in Misinformation and Information ($P=.005$, 95% CI = [.03, .19]) videos; and the US in Misinformation and No information ($P=.009$, 95% CI = [.03, .26]) and Misinformation and Information ($P<.001$, 95% CI = [.11, .35]) videos. Furthermore, on Twitter, Japan was mentioned 7,486 times and China 2,640 times.

Activity Dimension in YouTube Videos and Tweets

The average ODIQ of 638 videos was 0.68, with significant differences in terms of brain death definition ($F(2.46, 147.74) = [5.28]$, $P=.005$), several death definitions ($F(19.42, 68.96) = [89.44]$, $P<.001$), organs ($F(22.75, 79.56) = [90.79]$, $P<.001$), donation card ($F(23.21, 67.16) = [109.73]$,

$P < .001$), other donation statements ($F(30.91, 75.52) = [129.94]$, $P < .001$), and the donation process ($F(1.26, 23.67) = [16.94]$, $P < .001$).

Pairwise comparisons uncovered differences between the means of brain death definition in Information and No Information ($P < .001$, 95% CI = [.10, .20]) videos; death definitions in Information and No Information ($P < .001$, 95% CI = [.32, .46]), Information and Misinformation ($P < .001$, 95% CI = [.18, .35]), and Misinformation and No Information ($P = .002$, 95% CI = [.03, .21]) videos; organs in Information and No Information ($P < .001$, 95% CI = [.35, .50]), Information and Misinformation ($P < .001$, 95% CI = [.10, .28]), and Misinformation and No Information ($P < .001$, 95% CI = [.14, .32]) videos; and donation card in Information and No Information ($P < .001$, 95% CI = [.35, .49]), and Information and Misinformation ($P < .001$, 95% CI = [.24, .42]) videos.

We observed differences in the means of donation statements in Information and No Information ($P < .001$, 95% CI = [.42, .56]), Information and Misinformation ($P < .001$, 95% CI = [.24, .42]), and Misinformation and No Information ($P < .001$, 95% CI = [.07, .25]) videos; and donation process in Information and No Information ($P < .001$, 95% CI = [.06, .14]), and Information and Misinformation ($P = .002$, 95% CI = [.02, .13]) videos. Information videos presented ODIQ elements more than Misinformation videos, being the most frequent donation statements (115/638, 18%), organs that can be donated (99, 15.51%), donation card (98, 15.36%) and several definitions of death (91, 14.26%). Further, we observed significant differences ($F(8.50, 53.03) = [50.91]$, $P < .001$; $F(1.68, 22.34) = [23.87]$, $P < .001$) between types of donation statements, being family consent the most frequent in Information videos (60/638, 9.40%), whereas Internet was the least frequent (25/638, 3.91%).

Regarding video duration and views, we found significant differences ($H(2) = 37.38$, $P < .001$; $H(2) = 14.79$, $P < .001$). Post hoc tests identified differences between the means of duration in No Information and Information (-69.46, $P < .001$), and no Information and Misinformation (112.57, $P < .001$) videos; and views in Information and No Information (53.76, $P = .003$), and Information and Misinformation (65.73, $P = .004$) videos. By reviewing the 10 most viewed videos, we verified that six were classified as No Information, three as Information and one as Misinformation, including three transplant short videos by a medical association, two news reports, two webtoons (digital comics), a reaction video from Tik Tok, a promotion campaign video and a comedy dialogue. One of the webtoons contained information and the other misinformation, whereas the comedy dialogue contained information on organ donation.

We examined frequent words employed in video descriptions (a) and their comments (b) in ODIQ based groups (Figures 3-5). Word frequency is reflected in node size, whereas the stronger the tie strength, the thicker the lines. Nodes without colour do not belong to a particular group. It should be noted that some words with similar meaning in English have multiple ways of expression in Japanese. In Information videos, a cluster in green corresponds to organ donation as borrowing life uploaded by associations, whereas another cluster of descriptions uploaded by diverse actors (mostly associations) in yellow requested to register as donors. A word group in purple mentioned the lung and heart and is connected to a group in red corresponding to the Organ Transplant Network and YouTubers uploading videos about kidney transplantation. This content is also tied to a cluster in blue about old organ donation promotion videos released by Advertising Council Japan and uploaded by multiple accounts. Other frequent words include 'China' and 'donor'.

As for comments, most of them are proactive towards organ donation. A group in green includes the terms 'before', 'brain death', 'donor', 'China', 'family' and 'talk', linked to a group in yellow that views organ donation as negative. A group in purple includes recommendations to seek medical help. Another cluster in blue talks about 'expression' of 'intention' to donate, whereas a cluster in orange shows a positive reaction towards the old promotion videos. Further, other words include 'Japan' and 'oneself', reflecting organ donation as something that must be thought of and known individually in Japan.

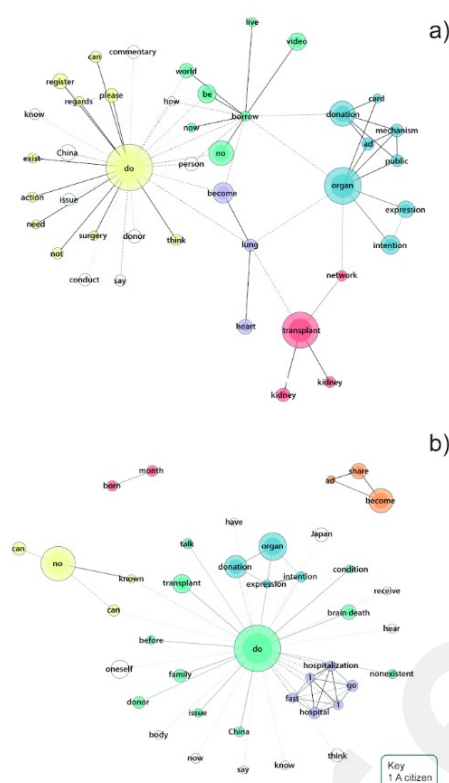


Figure 3. Descriptions (word frequency 30-800, tie strength 0.96-1) and comments (word frequency 120-4 000, tie strength 0.7-1) of YouTube Information videos.

Regarding descriptions of No Information videos (Figure 4), a group in green involves news reports by Epoch Media group YouTube channels (the term 'Tang Dynasty'), an American organisation **with a branch office in Japan**, about accusations of organ trafficking from some New Religion practitioners in China, and linked to a group of interviews in yellow involving requests to surgeons to avoid international organ transplantation. Other terms include 'United States' and 'donor registry'.

Comments to these videos include a cluster in green with the word 'touched', linked to a cluster in yellow reacting towards the organ-trafficking videos. The word groups in red and blue show positive reactions towards short videos released by a Japanese medical association regarding organ transplantation. The comments towards organ donation seem more proactive than negative.

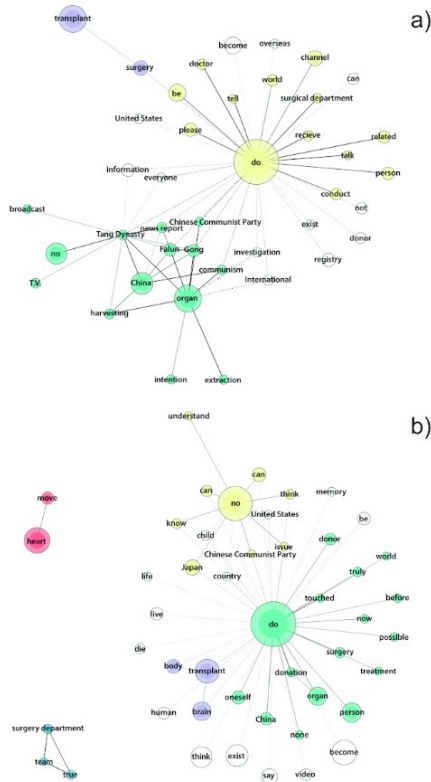


Figure 4. Descriptions (word frequency 60-1 500, tie strength 0.95-1) and comments (word frequency 120-4 000, tie strength 0.5-0.9) of YouTube No Information videos.

Misinformation video descriptions were the most fragmented, with a word group in yellow requesting money donations to support Epoch Media Group channels tied to a group in red including the word 'fact', and to a group in blue including the term 'China'. Another group in purple connects some New Religion practitioners to the word 'Japan', calling to stop organ harvesting. Another cluster includes the terms 'brain death', 'death', 'donor' and 'harvesting' in videos uploaded mostly by Epoch Media Group channels and a few unknown actors.

In contrast, a word group in lime green described a video by a different New Religion about resilience during the COVID-19 pandemic with a global outlook and with a positive attitude towards organ donation. Further, a cluster in pink describes videos uploaded in Japanese channels dedicated to urban legends, which included stories of medical negligence during organ donation. Other terms include 'Chinese Communist Party' (CCP).

As for comments in Misinformation videos, a cluster in green shows a positive reaction towards the Epoch Media Group videos, including the persecution of Uyghur Muslim minorities in China as a human rights issue. A word group in red ties organ donation with the terms 'lottery' and 'trade'. Other words include 'crime', 'death penalty' and 'Japan', which characterise organ donation in negative connotations.

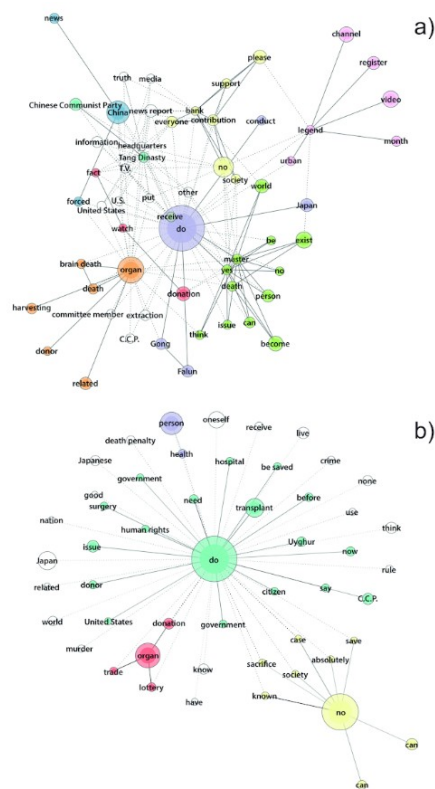


Figure 5. Descriptions (word frequency 30-750, tie strength 0.6-1) and comments (word frequency 150-6 000, tie strength 0.65-0.85) of YouTube Misinformation videos.

With regards to Twitter, a group of top words in green indicates donation intention statements through donation card, driving licence and health insurance card, with mention of 'China', 'consent', 'dignity', 'donor', 'hospital', 'Japan', 'money', and 'society' (Figure 6). A group in yellow indicates the consent of Japanese families and parents, including the terms 'human', 'pay', 'prolonging life', 'trade', and 'usable'. Other terms seem to show more positivity towards donation ('good') and include 'blood donation' and 'brain death'.

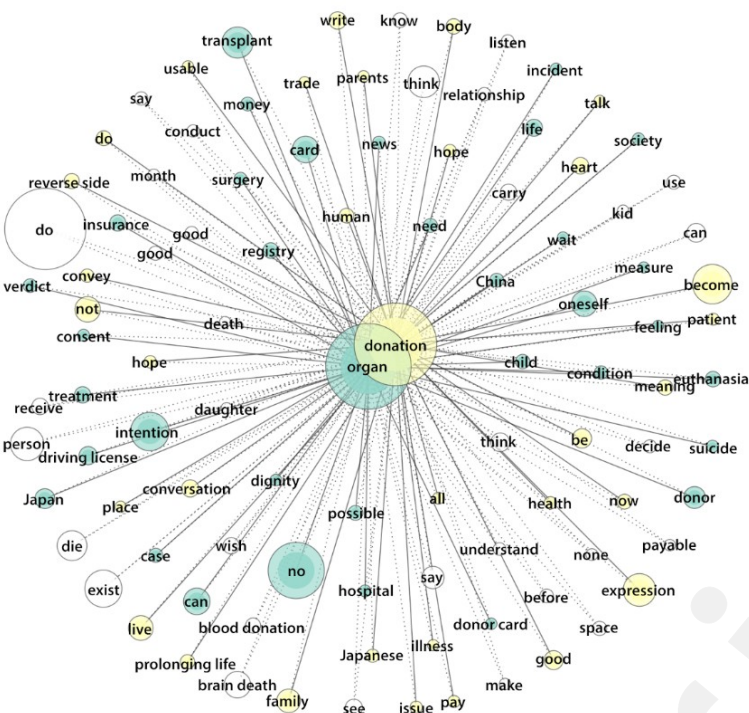


Figure 6. Top words in Tweets (frequency 1 750-125 000, tie strength 0.6-1).

Relations Dimension: Hyperlinks Beyond YouTube and Twitter

On the case of the 638 YouTube videos, 319 (50%) included social media hyperlinks, 317 (49.68%) links to webpages, 46 (7.21%) included an e-mail and 25 (3.91%) a link to a blog. The ANOVA test showed significant differences in social media links ($F(4.75, 154.50) = [9.74]$, $P < .001$) and e-mail sharing ($F(1.63, 41.02) = [12.87]$, $P < .001$) across ODIQ groups. Post hoc tests estimated a difference in the means of social media links between Misinformation and Information ($P = .002$, 95% CI = [.06, .32]), and No Information and Information ($P < .001$, 95% CI = [.07, .28]) videos; and of e-mail sharing in Misinformation and No Information ($P = .001$, 95% CI = [.03, .17]), and Misinformation and Information ($P < .001$, 95% CI = [.07, .21]) videos. Most social media links were to Twitter and YouTube, with fewer to Amazon and Facebook.

With regards to Twitter, most links in the sample of 100 000 tweets were to news media reports, including 1 061 (1.06%) tweets from Yahoo news, 784 (0.78%) from the Japan Broadcasting Corporation (NHK) and 625 (0.62%) from Asahi News, one of the five largest newspapers in Japan. The highest time peaks seem to correspond to a news report from Mainichi News (another large newspaper in Japan) about uterus transplantation research by Keio University and a YouTube video about body donation. Another link to a company of health insurance containing preparations before death (including organ donation statements) was tweeted 1 130 (1.13%) times.

Narrative Analysis: Organ and Body Donation on YouTube and Twitter

Table 4 compiles the narratives related to donation found in the 638 YouTube videos, with new ones compared to those compiled in Multimedia Appendix 3. The ANOVA tests showed a significant difference in favour ($F(6.90, 114.45) = [19.14]$, $P < .001$), economic ($F(2.13, 50.59) = [13.39]$, $P < .001$), and organ trafficking ($F(1.63, 41.02) = [12.87]$, $P < .001$). Pairwise comparisons verified a difference in

means of narratives in favour between No Information and Misinformation ($P<.001$, 95% CI = [.10, .32]), and No Information and Information ($P<.001$, 95% CI = [.18, .40]) videos; in economic issues between Misinformation and No Information ($P<.001$, 95% CI = [.07, .22]), and Misinformation and Information ($P<.001$, 95% CI = [.07, .22]) videos; and in organ trafficking between Misinformation and No Information ($P=.004$, 95% CI = [.04, .25]), Misinformation and Information ($P<.001$, 95% CI = [.25, .47]), and No Information and Information ($P<.001$, 95% CI = [.13, .31]) videos.

Table 4. Main narratives tied to donation in YouTube videos based on ODIQ

	Information	No Information	Misinformation	Total
Narratives in favour				
In favour	81 (12.69%)	75 (11.75%)	7 (1.09%) ^a	163 (25.54%)
Connecting lives	9 (1.41%)	8 (1.25%)	1 (0.15%)	18 (2.82%)
Ganbaru	6 (0.94%)	10 (1.56%)	3 (0.47%)	19 (2.97%)
Green Ribbon	14 (2.19%)	15 (2.35%)	0 (0%)	29 (4.5%)
Helping others	13 (2.03%)	4 (0.62%)	1 (0.15%)	18 (2.82%)
Narratives against				
Against	9 (1.41%)	4 (0.62%)	4 (0.62%)	17 (2.66%)
Economic Issues	14 (2.19%)	18 (2.82%)	26 (4.07%) ^a	58 (9.09%)
Organ trafficking	20 (3.1%) ^a	85 (13.32%) ^a	56 (8.77%) ^a	161 (25.23%)
Unclear narratives				
Mechanistic view of life	6 (0.94%)	6 (0.94%)	5 (0.78%)	17 (2.66%)

^a Statistically significant results

Regarding religions mentioned in the 638 videos (Table 5), we found statistically significant differences in Christianity ($F(0.29, 17.19) = [5.50]$, $P=.004$), Islam ($F(1.61, 48.64) = [10.55]$, $P<.001$) and New Religions ($F(3.90, 63.80) = [19.43]$, $P<.001$). Bonferroni tests specified differences in the means of Christianity in Misinformation and No Information ($P=.007$, 95% CI = [.01, .10]), and Misinformation and Information ($P=.008$, 95% CI = [.01, .10]) videos; of Islam in Misinformation and Information ($P<.001$, 95% CI = [.06, .21]); and of New religions in Misinformation and No Information ($P=.001$, 95% CI = [.04, .21]), Misinformation and Information ($P<.001$, 95% CI = [.13, .30]), and No Information and Information ($P=.004$, 95% CI = [.02, .16]) videos.

Table 5. Religions in YouTube videos across ODIQ groups

Religion	Information	No Information	Misinformation	Total
Buddhism	6 (0.94%)	4 (0.62%)	7 (1.09%)	17 (2.66%)
Christianity	4 (0.62%)	5 (0.78%)	9 (1.41%) ^a	18 (2.82%)
Confucianism	0 (0%)	1 (0.15%)	0 (0%)	1 (0.15%)
Islam	7 (1.09%) ^a	27 (4.23%)	21 (3.29%) ^a	55 (8.62%)
Judaism	0 (0%)	0 (0%)	1 (0.15%)	1 (0.15%)
New Religions	9 (1.41%) ^a	36 (5.64%) ^a	32 (5.01%) ^a	77(12.06%)
Shinto	1 (0.15%)	2 (0.31%)	2 (0.31%)	5 (0.78%)

^a Statistically significant results

As for seven videos on donation for research, five were uploaded in 2022, one in 2021 and one in 2020. They were uploaded by three citizens (two funerary staff), two educational actors, two media channels, one association and one religious actor. Five videos highlighted citizens; four doctors, donors, associations; three other medical staff, educational and media actors; and one a medical student, a nurse, a recipient, a donor relative, other patient, a government functionary and a religious actor. All showed locations in Japan, whereas three showed the Kanto region. Three were classified as Information, two as No Information and two as Misinformation. Those classified as Information were mostly in favour of organ donation, explaining ways of showing consent and mentioning consent from the family. A video by a funerary staff also shared on Twitter explained the history of body donation and the donation process.

Another video uploaded by an inheritance consultation staff mentioned body donation as part of end-of-life care, how to register for body donation, and organ donation as a gift of life according to the JOTN, being one of the few that mentioned the organ extraction process, body preservation and the lack of costs of organ donation for the donor. People in the comments reacted with curiosity. A video by an association highlighted several experts discussing international aspects, donation as normal, the donor coordinators' role in research, and donation as transplantation as part of a specific course at the undergraduate level in a Spanish university. Thus, the activity of donation is articulated with education and research, whereas the research results were related to heart and lung transplantation.

In No information videos, we observed negligence as a deterrent for body donation. A news report showed how a donor had requested that their body be used for medical education, but after a few years, the university had cremated the body without contacting the family first. A comment argued that donation was for profit. Another video by funerary experts discusses a university which did not preserve the body correctly. The staff, as experts on death, were able to detect issues in the preservation workflow and body management while acknowledging the emotions of the bereaved relatives. In turn, most comments sympathetically argued about human error and the need for unified guidelines and proper training to handle body donation.

Religion was mentioned in one Misinformation video, and organ trafficking was mentioned in a news report, which prompted reactions of fear, sadness, and anger in the comments. Another video was similar to one of the Information videos about donor coordinators and normalised organ donation, but it also included the for-profit (economic) narrative and racist content.

With regards to Twitter, Figure 6 shows that some prominent narratives included death with dignity ('dignity') in preparations for a good death, a mechanistic view of life ('usable'), and economic ('pay', 'payable' and 'trade'). Top commenters in terms of retweets supported blood donation, euthanasia and organ donation - including from children, - expressed through donor cards, mostly in line with a mechanistic view of life. They also mentioned Night Doctor, a Japanese drama; Never Let Me Go, a novel by a Japanese author about a fictional future in England; and the anime Angel Beats!. Others discussed trafficking organs in China and respecting the donors' anonymity. Few worried that organ donation was not possible for them as a parent did not agree, or they either lived alone or had an illness.

Top commenters in terms of likes also mostly favoured blood donation, euthanasia and organ

donation expressed through written documents, as well as the green ribbon and a mechanistic view of life. Never Let Me Go and Angel Beats! were mentioned. Few users mentioned body donation, economic issues, and organ trafficking in China. Some expressed anxiety about not being able to donate due to family or illness.

Discussion

Communication of Organ Donation Across Dimensions

With regards to YouTube, doctors, and other medical staff (notably donor coordinators) mostly uploaded Information videos. Associations and citizens uploaded little misinformation, whereas the media, religious and educational actors mostly uploaded videos without information. Doctors and citizens were less present in misinformation videos; other medical staff and associations were portrayed mostly in information videos, and patients, government, media, and religious actors were present mostly in videos without medical information on organ donation. The public's interest and participation in dissemination of organ donation-related information seem to be greater than the doctors', which contradicts the findings in [13], although the numerous mentions of heart transplantation and appearances of heart transplantation experts support the interest of this medical group.

Misinformation was low in hospitals, medical offices, and unknown locations, whereas videos without information mostly showed closed and open spaces, which were more urban than rural. In particular, Hokkaido and Kyushu and Okinawa are regions with high cultural and ethnic diversity in Japan; thus, a relationship seems to exist between the dissemination of medical information on organ donation and diversity.

Canada, India, Israel, the UK and the US were mostly mentioned in Misinformation videos, whereas China was mostly mentioned in No Information videos, followed by Misinformation videos. Israel was often involved in opposition to organ trafficking in the accusations against China distributed by Epoch Media Group, and China was prominent on both YouTube and Twitter. A New Religion was frequently featured in No Information and Misinformation videos by these media, employing the narrative of Gotai Manzoku in organ trafficking accusations, which was linked to Buddhism and 'Chinese culture'. Further, the news reports employed Christian imagery and Christian and Islamic communities in China as victims of organ trafficking.

Epoch Media Group was founded by New Religion adherents in New York in 1999 as a newspaper called The Epoch Times, which expanded into multiple media in over 30 countries, including Japan, with the objective to restore the religious rights of the outlawed New Religion in China [38]. It pivoted to the far right when reporting on migration from the Middle East to the European Union in 2015 [39]. In the US, at the height of the group's ad spending, its videos collectively gathered some 3 billion views on Facebook, YouTube and Twitter, ranking 11th among video creators across platforms and outranking other traditional news media [40]. Its links with the far right may be the reason why India, Israel, and the US are often quoted in its content as governments in these states have escalated their far-right rhetoric and actions in recent years.

Regarding organ donation, some New Religion adherents have accused the Chinese government of organ harvesting from prisoners since 2006 [41]. Much less is mentioned about how members avoid modern medical treatments because they believe that illness is caused by karma [42]. It was

reported that their leader envisions science as an immoral religion as science was employed by the Chinese government to discredit Qi Gong, the basis of exercises in some New Religions and spiritual practices in China [41]. However, irregularities on organ acquisition by Chinese researchers were found in a journal paper [43] and reported by the Japanese channels of Epoch Media Group; thus, this media does not always disseminate misinformation. It does not share their religious beliefs with outsiders; instead, it seems to use talking points and imagery from other religions to oppose organ donation in Japan. The implication beyond social media environments is the recent coalitions of some Japanese New Religions practitioners supporting conservative politicians based on practices learnt from the American far right [44] that could eventually influence legislation. This would oppose the interests of medical actors, patients and researchers.

Information Quality on YouTube and Twitter

Donation statements that seemed to be more accepted and common were card-based and relying on family consent, but not through the Internet. A few people voiced their distrust of My Number, an ID registry intended for e-governance, extending their distrust to the Japanese government. Historical records show opposition to such systems, both analogical and digital, whereas laws protecting internet data are not highly effective, and the risk of discrimination that could result from data breaches [45].

Regarding proactive narratives of donation, our data show 'helping others' among donor relatives and the public, which was a finding previously recorded among medical students [20]. They also show that the indirect way of communication common among the Japanese favours indirect support for organ donation, such as in a symbol (e.g. the Green Ribbon). Old TV commercials on YouTube about organ donation may have appeal partly due to nostalgia-based trends in social media that involve graphics, music and multimedia. This nostalgia can be linked to different time periods in Japan, but the original airing time of commercials uploaded by the Advertising Council Japan and by some citizens ranges between 1999 and 2007. This timeframe roughly corresponds to the end of the economic bubble in the 1990s, before environmental disasters such as the Kumamoto Earthquake and the Fukushima nuclear reactor failure in 2011. Thus, in comparison to the increasing economic inequalities and environmental damages of later years, this period seems to embody comfortable, prosperous and safe for Japanese people [46].

In terms of emerging methods to communicate organ donation, we noted three YouTube videos in a channel managed by a woman kidney donor and a woman kidney recipient. This channel communicates kidney illness and treatments, interviewing all actors involved and normalising organ transplantation. Moreover, we found a video of a medical practitioner discussing the medical drama *Night Doctor*, where one of the protagonists opposes organ donation by their relative. However, they change their mind once they interact with actors involved in the donation process. Although emerging methods to communicate organ donation can be categorised as entertainment education, *Night Doctor* is particularly relevant as it takes advantage of a charismatic character with whom the viewer can identify or empathise and sends them into a journey where they emerge changed. This technique has been employed successfully to improve science literacy and public health using dramas across the world [47].

Information videos were the least viewed (Ranks = 283.19), followed by No Information videos (Ranks = 336.96) and Misinformation videos (Ranks = 348.93). Yet, the top seven viewed videos

about organ donation included a video with Information and six videos with No Information, which were short videos taken vertically (as with a smartphone) uploaded by a medical association; they included a young doctor answering a technical question (e.g. how do you preserve a heart for a transplant?), and requested people to comment and ask more questions about the topic. Reactions to these videos were widely positive and pro-donation, and the number of views (4,729,206) of the top No Information video surpassed those of the top Misinformation video (1,753,898). This suggests that employing viral formats can surpass the popularity of science Misinformation, even when the latest is tailored for prioritisation by social media algorithms [48].

Indirect messages of opposition to organ donation in both social media seemed to employ economic issues and organ trafficking frequently, which helps us further our understanding of public opinion (as seen in [11]). Such economic issues involve not only suspicions of enrichment by donation actors but also economic inequalities that would ensure that resources will be more accessible to the top 10% [49] or to men [50] in Japan. Thus, we detected a need to include information on the donation process and costs more constantly and openly to the public. Moreover, tools to foster a more equitable distribution of organs should be available to allocate more organs to places with high populations of people with target diseases and increase the accessibility of organ donation services in rural areas [51], as well as economic aid for mid and low-income patients and a gender perspective [52]. Having more transparent reporting of organ transplantation donors and recipients across gender, income and geographical regions could help develop such programmes.

Regarding body donation on YouTube, the acknowledgement of mistakes in the donation procedure and other medical mistakes, in addition to the skilful handling of emotions such as anger and grief by those featured in the videos, seems useful to prompt proactivity in the comments, even for videos without medical information. In addition, the more complete the ODIQ information, the more positive the public's comments.

On Twitter, organ donation was mentioned, together with death with dignity, as preparations for a good death by some businesses and citizens. Given the high number of older individuals dying in Japan and the continuous professionalisation of funerals, death-related businesses have boomed with a net worth between 700 and 891 billion yen as of 2005 [53]. Despite the profit component, it is expected that death-related businesses and their clients will contribute to normalising preparations for a good death in public conversations, and this may include options such as organ and body donation for research.

Towards a Strategy for New Medical Research Procedures

Given our findings, we propose the following aspects to implement new medical research procedures such as RAP.

Pivoting from the dyad of donation-transplantation to a research focused scenario, we must first consider how research is conceptualised. Reciprocity-based messages work best for organ donation [54], and, according to the collected social media data, proactive narratives of donation are linked to prosocial behaviour (e.g. connecting lives, helping others and, to a lesser extent, borrowing); thus, the proposed research should have a prosocial and reciprocity dimension in lines with *kyosei*. Data acquired for medical research should not be considered as the researchers' property but as

borrowed data.

One issue with research databases is the idea that, somehow, they should be eternal, which is largely impossible due to technological changes and constraints. Thus, thinking about research data as borrowed data keeps in mind its temporality, whereas those that oversee it can be considered as stewards and not owners. Short and long-term approaches to data stewardship and storage should be implemented. To avoid loss, mismanagement and weaponisation of research data, people from diverse backgrounds should steward it, receiving frequent capacitation to ensure the data's fair treatment and its technological safety. Decisions regarding data allocation to specific research projects should also be taken collectively.

In addition, clear documentation must be available on the obtained organ, tissues and their related data, together with research outputs, including communications with the public. This information and the donation workflow, costs and actors involved should be easy to access by donors and their relatives. An anonymised version should be made public, not only in the local language, but internationally. Further, some interested patients and relatives may also be trained to steward the data.

Regarding the management of donation programmes for research, aiming for diversity and horizontal organisation among actors seems to increase the chances to identify issues before the programme is implemented. Specialised donation coordinators should be trained to understand enough of the programmes' medical, management and economic aspects so that they can communicate them to patients, relatives, media, and the public. Researchers and other actors in the donation programme ecosystem could be trained to handle emotions such as anger and grief in worst-case scenarios (e.g. when mishandling of research samples occurs). They can also cooperate with insurance and funerary staff to manage such scenarios.

In terms of potential donors, the number of cases of excessive influx of body donations in Japanese universities has been increasing - particularly in the Kansai region, - due to the perception of this act as a social service and due to the rise in thinking openly about death caused by the global environmental crisis [55]. Our data point to people interested in organ donation who have been diagnosed with cancer or other illnesses and who think that they are unable to donate. Such cases could be canalised to RAP.

Regarding cultural aspects, those that want to implement new medical research procedures should be mindful of New Religion narratives. If the target population for research programmes has a low degree of critical thinking and religious knowledge, increasing religious literacy through multi-religious educational programmes is recommended as many Japanese cannot distinguish between mainstream religion ideas and those of New Religions [56]. Representatives of Buddhism, Shinto, Christianity and Islam could collaborate in these programmes.

In terms of communication and promotion, using local and familiar contexts (such as those in TV ads by the Advertising Council Japan) may appeal to Japanese adults and youngsters. Researchers should pay attention to popular cultural products that disseminate information and misinformation of medical science topics. Further, medical actors should be more proactive in mitigating misinformation by adopting integral communication strategies that include indirect support (e.g. green ribbon), viral formats (e.g. short videos) and longer communication formats (e.g. interviews

with multiple actors and discussion of science topics tailored to the public).

Last, promoting new medical research procedures could include partnerships with living donors who have some ability to communicate medical topics, or who may be interested in receiving training to do so. Other partnerships could be forged with funerary and insurance experts, some of whom also promote their services in the ENDEX, the end-of-life exhibition, which provides a yearly space to openly discuss death and preparations for a good death in Japan.

Regarding the strengths and limitations of our analysis, the combined quantitative and qualitative method allowed us to discern multiple aspects, including communication actors, time frames, locations, activities, and hyperlinks, disclosing a thorough description of content across two platforms that focus on different types of formats and target different audiences. However, this research into the Japanese context may not apply to other countries and regions; thus further research on a global scale is recommended. Finally, we did not consider other individual differences such as motivation. Given that public opinion was often either in favour or against without stating reasons, further focus group and interview research involving the public is recommended.

Conclusions

We examined the communication of organ donation in Japanese social media through a multidimensional framework. Based on our findings, we provided recommendations towards organ and tissue donation for medical research purposes, such as in RAP. Our conclusions are as follows:

1. Time dimension:
 - a. While YouTube videos peaked in 2021 and 2022, tweets were numerous between 2019 and 2022.
2. Individuality dimension:
 - a. Associations and unknown actors uploaded, and citizens and doctors appeared more in information videos.
 - b. Media- and education-related actors uploaded, and citizens, doctors and media actors appeared in more videos without information.
 - c. Citizens uploaded and appeared more in misinformation videos.
 - d. Most users of average retweeted and liked tweets were identified as citizens.
3. Place dimension:
 - a. Most places identified in YouTube videos were closed spaces, hospitals and open spaces.
 - b. Most Japanese regions in the videos were unidentified, followed by the Kanto region.
 - c. A high number of information videos showed locations in Hokkaido, and Kyushu and Okinawa.
 - d. Most mentioned countries on Twitter were Japan and China.
4. Activity dimension:
 - a. Organ donation was associated with borrowing life and the donor registry in information videos, with comments being mostly positive.
 - b. Organ donation was mainly associated with accusations of trafficking by American media in videos without medical information and with misinformation.
 - c. While comments to no information videos were mostly proactive towards donation, comments to misinformation videos were negative.

- d. Few videos and tweets versed on organ donation processes and costs.
- e. YouTube videos about body donation were mostly favourable.
- 5. Relations dimension:
 - a. On YouTube, most hyperlinks pointed to Twitter and YouTube, and, to a lesser extent, Amazon and Facebook.
 - b. On Twitter, most links pointed to news reports by Japanese media.
- 6. Recommendations:
 - a. Consider research data as borrowed data.
 - b. Make management of donation programmes horizontal and diversified.
 - c. Be mindful of science -misinformation and popular -culture trends.

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Conflicts of Interest

The authors declare no conflicts of interest.

Abbreviations

CCP: Chinese Communist Party
JOTN: Japan Organ Transplantation Network
NHK: Japan Broadcasting Corporation
ODIQ: Organ Donation Information Quality
RAP: Rapid Autopsy Programme

Multimedia Appendix 1: [Actors Classification]

Multimedia Appendix 2: [Place Classification]

Multimedia Appendix 3: [Post hoc Tests]

Multimedia Appendix 4: [Narratives related to organ donation]

References

1. Ministry of Health, Labour and Welfare. *Trends in leading causes of death*. 2023. URL: <https://www.mhlw.go.jp/english/database/db-hw/populate/dl/E03.pdf> [access September 5, 2023]
2. Pujadas E, Beaumont M, Shah H, Schrode N, Francoeur N, Shroff S, et al. Molecular profiling of coronavirus disease 2019 (COVID-19) autopsies uncovers novel disease mechanisms. *The American Journal of Pathology*. 2021; 191(12): 2064-2071. doi: 10.1016/j.ajpath.2021.08.009

3. Hooper JE, Williamson AK. Autopsy in the 21st Century. *Cham, Switzerland: Springer Nature Switzerland*, 2019
4. Nakazawa K, Kizawa Y, Maeno T, Takayashiki A, Abe Y, Hamano J, et al. Palliative care physicians' practices and attitudes regarding advance care planning in palliative care units in Japan: a nationwide survey. *American Journal of Hospice and Palliative Medicine*. 2014; 31(7): 699-709. doi: 10.1177/104990911350732
5. Nather A, Mandy FSY, Ning T, Kaiying W. Tissue banking in Asia Pacific region: past, present and future. *Cell and tissue banking*. 2018; 19: 229-240. doi: 10.1007/s10561-018-9697-y
6. Kadota M. Status and challenges of organ donation in Japan. *International Symposium on Organ Donation in Japan and Spain – Possibilities of the Spanish Model*, Tokyo Japan, 2022 January 25. URL: <https://www.youtube.com/watch?v=Q5ycV2jYetY> [access September 19, 2023]
7. Soyama A, Eguchi S. The current status and future perspectives of organ donation in Japan: learning from the systems in other countries. *Surgery today*. 2016; 46: 387-392. doi: 10.1007/s00595-015-1211-6
8. Yagisawa T, Mieno M, Ichimaru N, Morita K, Nakamura M, Hotta K, et al. Trends of kidney transplantation in Japan in 2018: data from the kidney transplant registry. *Renal Replacement Therapy*. 2019; 5(1): 1-14. doi: 10.1186/s41100-019-0199-6
9. Fuse M. Kyosei. In: Kothari A, Salleh A, Escobar A, Demaria F, Acosta A, editors. *Pluriverse: a post-development dictionary*, New Delhi, India, Tullika Books, 2019: 226-228.
10. Saita N, Sasaki M, Okate K, Sato S, Azuma R. People's perception on organ transplantation and human death- using religious factor scale for view of death and life. *Japanese Society of Nursing Proceedings. Comprehensive Nursing*. 2006; 37: 427-429.
11. Maeda S, Kamishiraki E, Starkey J, Ikeda N. Why are autopsy rates low in Japan? Views of ordinary citizens and doctors in the case of unexpected patient death and medical error. *Journal of healthcare risk management*. 2013; 33(1): 18-25. doi:10.1002/jhrm.21114
12. Yasuoka MK. *Organ donation in Japan: A medical anthropological study*. Lexington Books, 2015.
13. Ogawa M, Fujita T, Fukushima N, Nakatani T, Kitamiura S, Imamura Y, et al. Regional survey of tissue donation among the general public and medical staffs around Osaka, Japan. *Transplantation Proceedings*. 2016; 48(7): 2423-2428. doi: 10.1016/j.transproceed.2016.02.088
14. Yoshikawa M, Yoshinaga K, Imamura Y, Hayashi T, Osako T, Takahashi K, et al. Transplant procurement management model training: marked improvement in the mindset of in-hospital procurement coordinators at Hyogo prefecture, Japan. *Transplantation Proceedings*. 2016; 48(7): 2437-2441. doi:10.1016/j.transproceed.2016.02.087
15. Okita T, Hsu E, Aizawa K, Nakada H, Toya W, Matsui K. Quantitative survey of Laypersons' attitudes toward organ transplantation in Japan. *Transplantation proceedings* 2018; 50(1): 3-9. doi: 10.1016/j.transproceed.2017.11.011
16. Nawa N, Ishida H, Sugino H, Katsuragi S, Baden H, Takahashi K, et al. Analysis of public discourse on heart transplantation in Japan using social network service data. *American Journal of Transplantation*. 2018; 18(1): 232-237. doi:10.1111/ajt.14527
17. Huguet Cañamero E. The normalization of Organ Donation discourse in the press. *Organ donation in Japan and Spain - Possibilities of the Spanish model*. URL: <https://www.youtube.com/watch?v=sUHIcd9SvPE> [access July 21, 2023]
18. Akabayashi A. *Bioethics Across the Globe: Rebirthing Bioethics*, Springer Open, 2020: 13-26.
19. Murakami M, Fukuma S, Ikezoe M, Izawa S, Watanabe H, Yamaguchi H, et al. Knowledge does not correlate with behavior toward deceased organ donation: a cross-sectional study in Japan. *Annals of transplantation* 2020; 25: e918936-1. doi: 10.12659/AOT.918936
20. Hamano I, Hatakeyama S, Yamamoto H, Fujita T, Murakami R, Shimada M, et al. Survey on

attitudes toward brain-dead and living donor transplantation in medical students: a cross-sectional study in Japan. *Clinical and Experimental Nephrology* 2020; 24: 638-645. doi: 10.1007/s10157-020-01878-9

21. Tsubaki M, Tougo S, Kobayashi M, Arakawa S, Yoshida K. Narrative review on attitudes toward organ donation of undergraduate nurse students. *Japan Journal of Nursing Science*. 2020; 17(1): e12291. doi: 10.1111/jjns.12291
22. Uchida K, Mukai M, Miyagi M, Fukushima K, Uchiyama K, Nakayama A. Management of regional bone bank during declaration of a state of emergency concerning the COVID-19 in Japan. *Cell and Tissue Banking*. 2021: 1-7. doi: 10.1007/s10561-021-09908-w
23. Miyagawa Y, Ito R, Masukawa K, Miyashita M, Yamagiwa T. 新型コロナウイルス感染症対策の現状と課題。 Palliative Care Research. 2022; 17(2): 59-64. doi: 10.2512/jspm.17.59
24. Statista. Share of people who use YouTube in Japan in fiscal year 2022, by age group._URL: <https://www.statista.com/statistics/1071780/japan-youtube-penetration-rate-by-age-group/> [access October 3, 2023]
25. Statista. Share of people who use Twitter in Japan as of fiscal year 2022, by age group. URL: <https://www.statista.com/statistics/1077538/japan-twitter-penetration-rate-by-age-group/> [access October 3, 2023]
26. Rieder B. YouTube Data Tools, Ver. 1. Digital Methods. URL: <https://tools.digitalmethods.net/netvizz/youtube/> [access September 19, 2023]
27. Tweet Binder. Tweet Binder. URL: <https://www.tweetbinder.com/> [access September 19, 2023]
28. Author, Yamanaka T. Sustainable design in YouTube- a comparison of contexts. *Int J Affect Eng.* 2018;17(1):39-48. Doi: 10.5057/ijae.IJAE-D-17-00010
29. Author, Park HW. Information Circulation Among Spanish-Speaking and Caribbean Communities Related to COVID-19: Social Media-Based Multidimensional Analysis. *Journal of Medical Internet Research*. 2023; 25: e42669. doi:10.2196/42669
30. Numbergenerator.org. Number generator. URL: <https://numbergenerator.org/numberlitrandomizer> [access September 1, 2023]
31. Japan Organ Transplantation Network. The gift of life. Things to know and consider Organ Transplants. URL: https://www.jotnw.or.jp/files/page/en/index/doc/english_gift_of_life.pdf [access May 30, 2023]
32. Murakami M, Fukuma S, Ikezoe M, Iizuka C, Izawa S, Yamamoto Y, et al. Effects of structured education program on organ donor designation of nursing students and their families: A randomized controlled trial. *Clinical Transplantation*. 2016; 30(11): 1513-1519. doi: doi.org/10.1111/ctr.12845
33. Altay S, Berriche M, Acerbi A. Misinformation on misinformation: Conceptual and methodological challenges. *Social Media + Society*. 2023; 9(1): 20563051221150412. doi:10.1177/20563051221150412
34. IBM Corp. *IBM SPSS Statistics for Windows, Version 28.0*. Armonk, NY: IBM Corp, 2021.
35. Higuchi K. A Two-Step Approach to Quantitative Content Analysis: KH Coder Tutorial using Anne of Green Gables (Part I). *Ritsumeikan social sciences review*. 2016; 52(3): 77-91.
36. Vijaymeena MK, Kavitha K. A survey on similarity measures in text mining. *Machine Learning and Applications: An International Journal*. 2016; 3(2): 19-28. doi:10.5121/mlaij.2016.3103
37. Park HW, Lim YS. Do North Korean Social Media Show Signs of Change?: An Examination of a YouTube Channel Using Qualitative Tagging and Social Network Analysis. *Journal of Contemporary Eastern Asia*. 2020; 19(1): 123-146. doi: 10.17477/jcea.2020.19.1.123
38. Loucaides D, Perrone A. The media giant you've never heard of, and why you should pay attention. *The Conversation Review*. 2023; 11: 1-11. doi: 10.1016/j.conrev.2023.100030

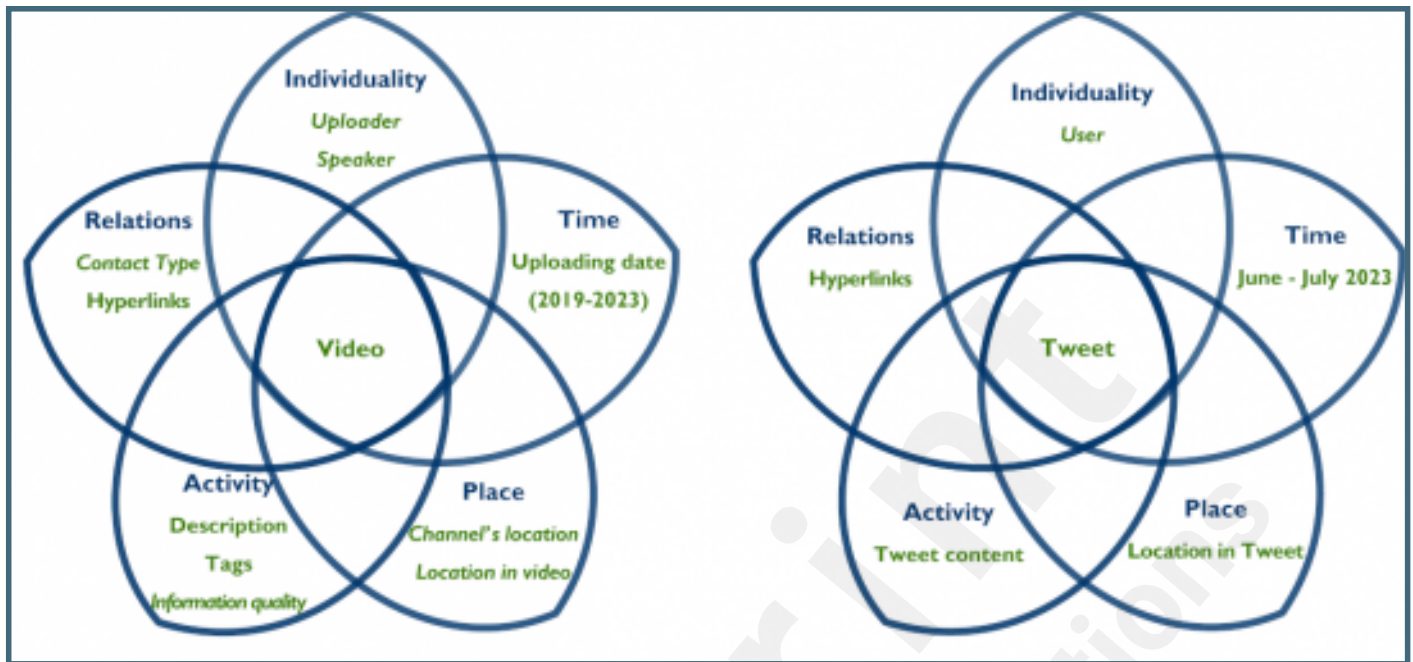
- attention. 2022. *Open Democracy*. URL: <https://www.opendemocracy.net/en/epoch-times-media-giant-youve-never-heard-of-and-why-you-should-pay-attention/> [Access March 9, 2024]
39. Perrone A, Loucaides D. A key source for Covid-skeptic movements, the Epoch Times yearns for a global audience. *Coda*. URL: <https://www.codastory.com/disinformation/epoch-times/> [access November 6, 2023]
40. Zadrozny B, Collins B. Trump, QAnon and an impending judgment day: Behind the Facebook-fueled rise of The Epoch Times. *NBC News*. URL: <https://web.archive.org/web/20190823004157/https://www.nbcnews.com/tech/tech-news/trump-qanon-impending-judgment-day-behind-facebook-fueled-rise-epoch-n1044121> [access November 6, 2023]
41. Lewis JR. *Falun Gong: spiritual warfare and martyrdom*. Cambridge University Press. 2018.
42. Van Zuylen-Wood S. Maga-land's favorite newspaper. *The Atlantic*. 2021. URL: <https://www.theatlantic.com/politics/archive/2021/01/inside-the-epoch-times-a-mysterious-pro-trump-newspaper/617645/> [access March 19, 2024]
43. Robertson MP, Lavee J. Execution by organ procurement: Breaching the dead donor rule in China. *American Journal of Transplantation*. 2022; 22(7): 1804-1812. doi: 10.1111/ajt.16969
44. Hall JJ. New Religious Movements and Conservative Politics in Japan: An Overview of Electoral and Non-Electoral Political Activities of Happy Science and the Happiness Realization Party. *Bulletin of the Institute of Japanese Studies, Kanda University of International Studies*. 2023; (15): 274-260.
45. Orito Y, Murata K, Young CA. e-Governance risk in Japan: Exacerbation of discriminative structure built in the family registration system. *ETHICOMP 2013 Conference Proceedings: The possibilities of ethical ICT*. 2013: 362-370.
46. Keliyan M. Postmodern Japan Middle Class Related Mythology and Nostalgia. *Slovenská politologická revue*. 2012; (2): 91-106.
47. Singhal A, Cody MJ, Rogers EM, Sabido M. *Entertainment education and social change*. Lawrence Erlbaum Associates, inc, publishers. 2004.
48. Son J, Lee HK, Jin S, Lee J. Content features of tweets for effective communication during disasters: A media synchronicity theory perspective. *International Journal of Information Management*. 2019; 45: 56-68. doi:10.1016/j.ijinfomgt.2018.10.012
49. Tamura M, Kakihara H, Wakutsu N, Sakoda S. Health Care Inequality And Business Cycles In Japan. *Value in Health*. 2016; 19(3): A267. doi: doi.org/10.1016/j.jval.2016.03.777
50. Kim Y, Ahmed E, Ascher N, Danguilan R, Hooi LS, Hustrini NM, et al. Meeting report: First state of the art meeting on gender disparity in kidney transplantation in the Asia-Pacific. *Transplantation*. 2021. doi:10.3390/ijerph19148356
51. Zeng Z, Tao W, Ding S, Fang J, Wen J, Yao J, et al. Horizontal Integration and Financing Reform of Rural Primary Care in China: A Model for Low-Resource and Remote Settings. *International Journal of Environmental Research and Public Health*. 2022; 19(14): 8356. doi: 10.3390/ijerph19148356
52. Mannon RB, Reed EF, Melk A, Vinson A, Wong G, Ahn C, et al. A multi-faceted approach to sex and gender equity in solid organ transplantation: The Women in Transplantation Initiative of The Transplantation Society. *Frontiers in immunology*. 2022: 5238. doi: doi.org/10.3389/fimmu.2022.1006855
53. Tanaka D. Working of funeral homes: Between dignity of death and commercialism in work for the dead. In Suzuki H (ed.) *Death and Dying in Contemporary Japan*: 83-101. Routledge. 2013
54. Hirai K, Ohtake F, Kudo T, Ito T, Sasaki S, Yamazaki G, et al. Effect of different types of messages on readiness to indicate willingness to register for organ donation during driver's license

- renewal in Japan. *Transplantation*. 2020; 104(12): 2591-2598. doi: 10.1097/TP.0000000000003181
55. Ukai H. . Yahoo News. <https://news.yahoo.co.jp/expert/articles/2b855e05a138399e557870fbd0a2f5292c9b7e26> [access November 6, 2023]
56. Sakurai Y. The Unification Church and its Japanese victims: the need for “religious literacy”. *Nippon.com*. <https://www.nippon.com/en/in-depth/d00845/> [access November 6, 2023]

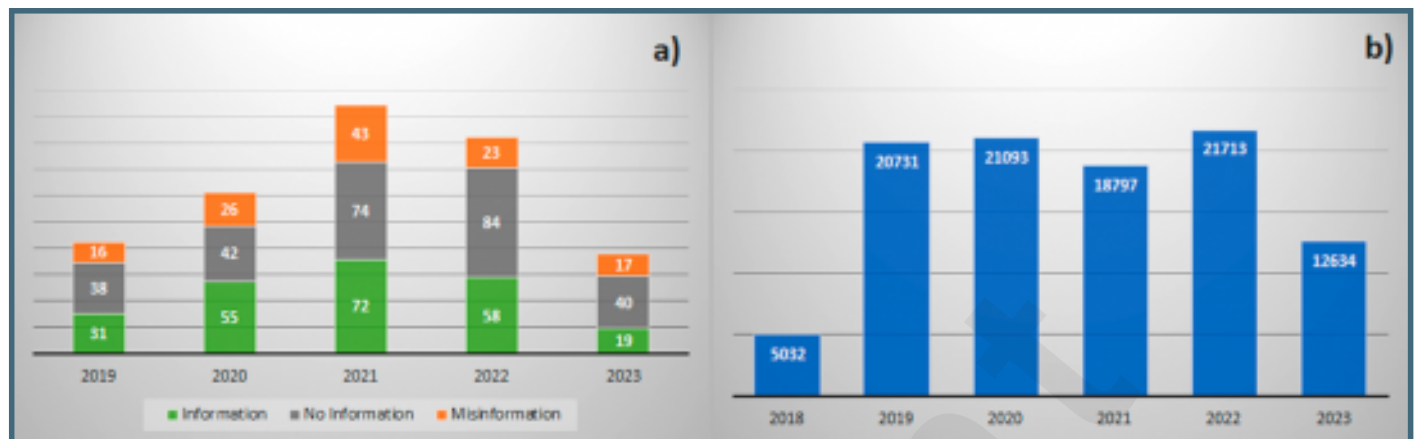
Supplementary Files

Figures

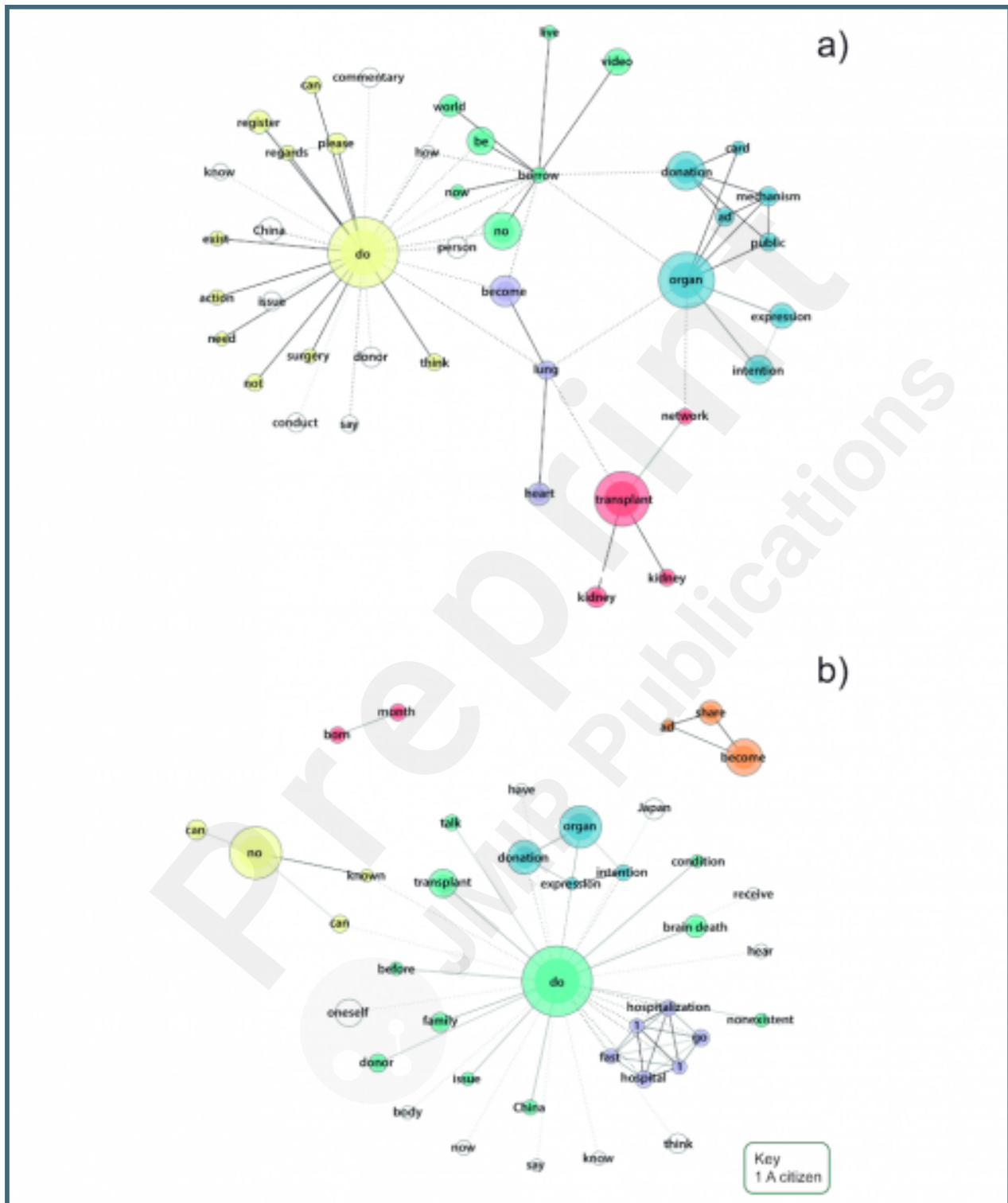
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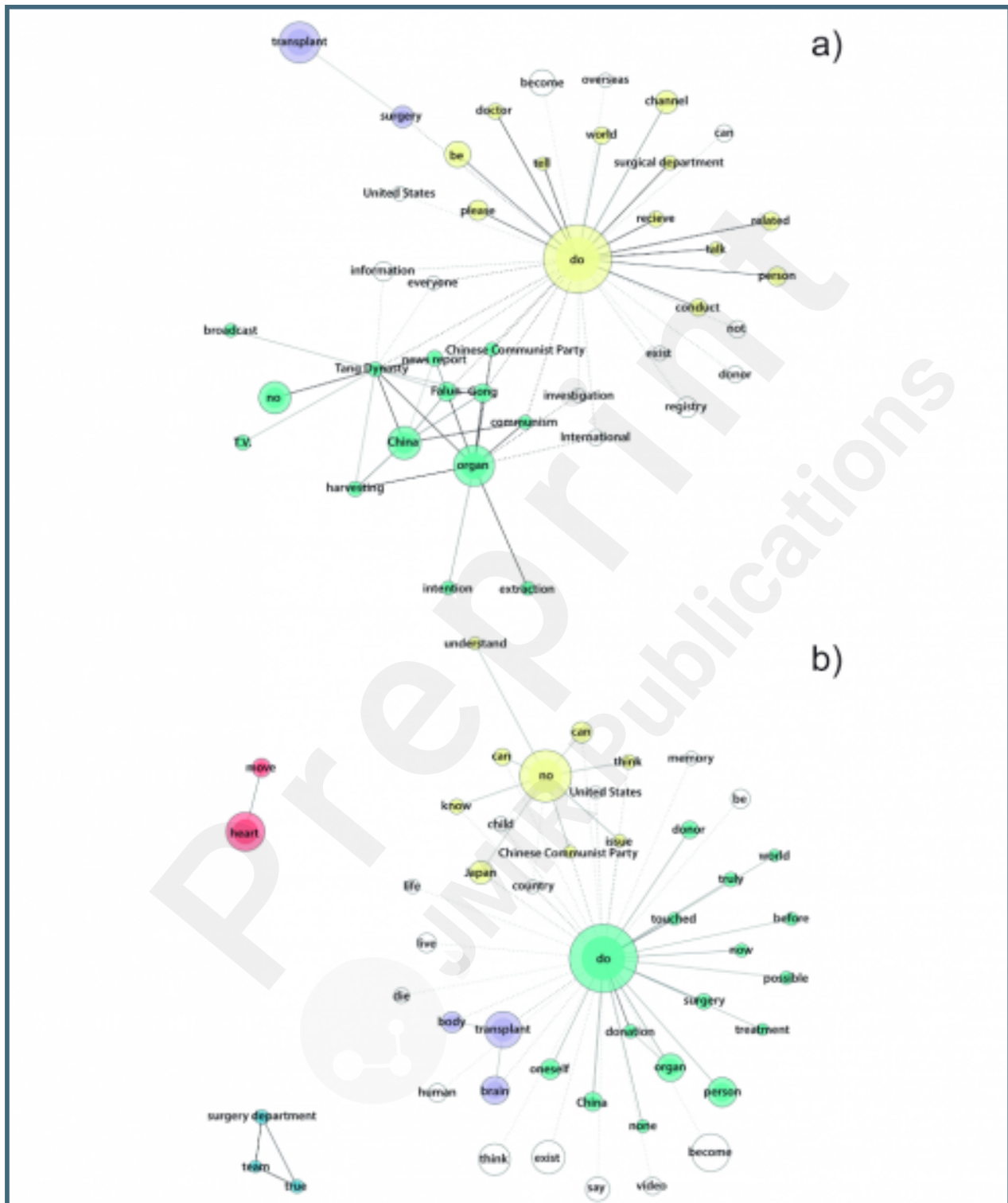
YouTube videos and Tweets per year.



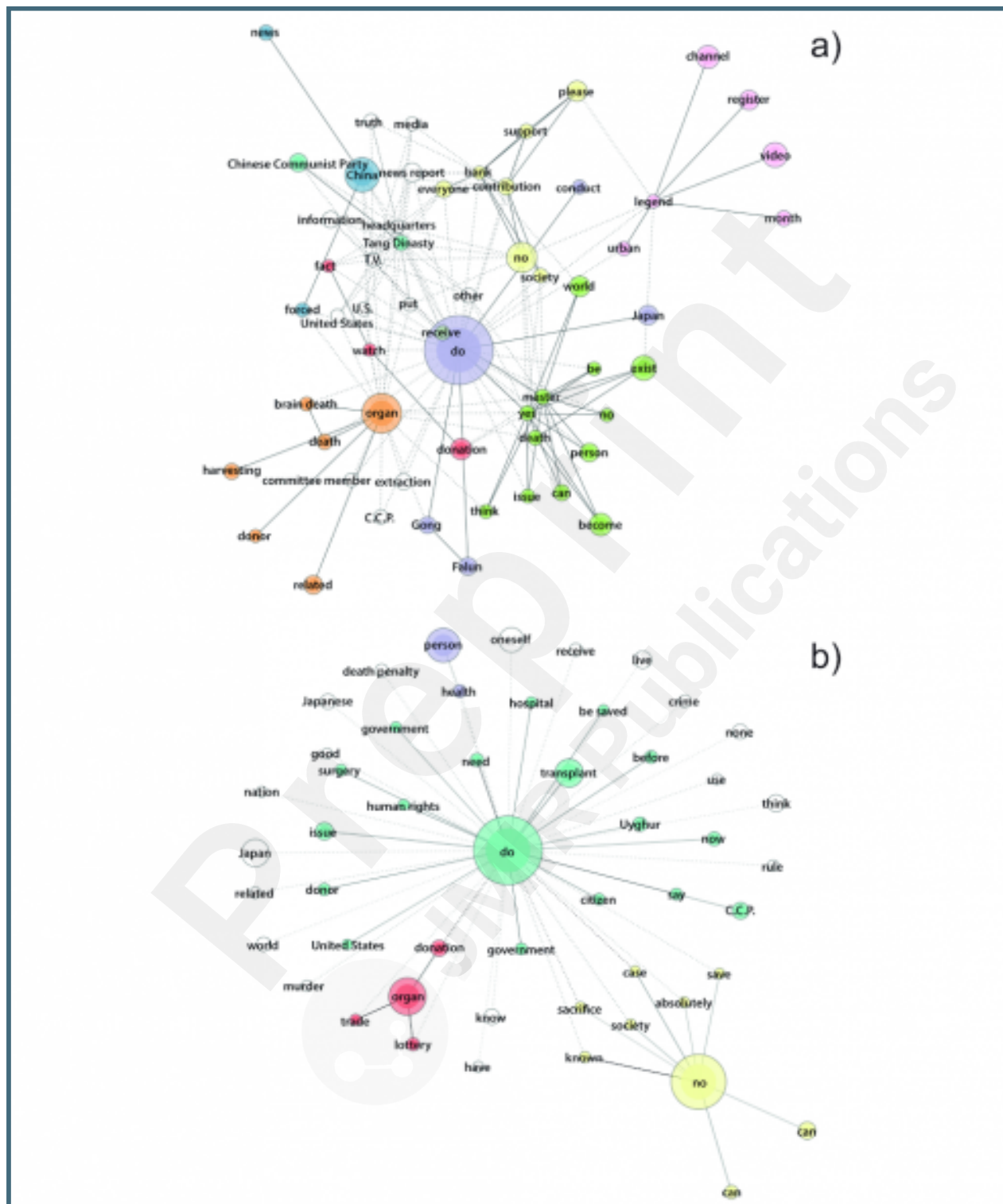
Descriptions (word frequency 30 to 800, tie strength 0.96 to 1) and comments (word frequency 120 to 4000, tie strength 0.7 to 1) of YouTube Information videos.



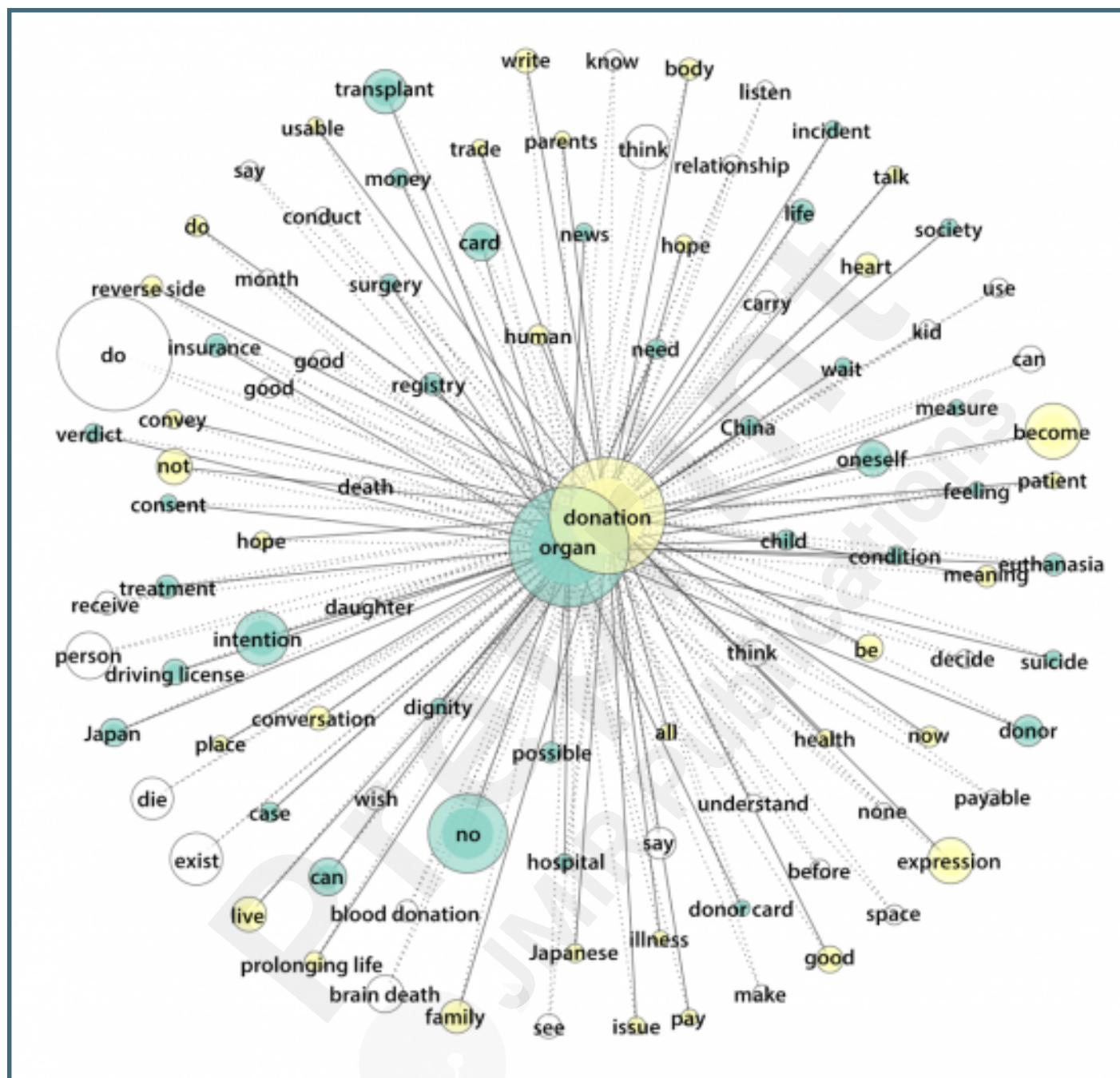
Descriptions (word frequency 60 to 1500, tie strength 0.95 to 1) and comments (word frequency 120 to 4000, tie strength 0.5 to 0.9) of YouTube No Information videos.



Descriptions (word frequency 30 to 750, tie strength 0.6 to 1) and comments (word frequency 150 to 6000, tie strength 0.65 to 0.85) of YouTube Misinformation videos.



Top words in Tweets (frequency 1750 to 125000, tie strength 0.6 to 1).



Multimedia Appendixes

Actors classification.

URL: <http://asset.jmir.pub/assets/558e034632a91dd85788c3dfabb0d346.pdf>

Place classification.

URL: <http://asset.jmir.pub/assets/0e747bef2647f90943bee0bb05f60d4e.pdf>

Posthoc tests.

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Narratives related to organ donation.

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