

Health Information Project

Global Sage Meetings for

“Co-creating Health Information Right” Report

March, 2024



Table of contents

Introduction (Purpose and objectives of this report)	3
Part I- Keynote Lectures	4
1-1. Co-creating Health Information Right	4
1-2. Information as a Determinant of Health in the Modern Era	7
1-3. The Nature of Communication Through the Lens of the COVID-19 Pandemic and Related Topics	9
Part II - Discussion	12
1. Defining “Accuracy” in the Context of Health Information.....	12
2. Effective methods of conveying information	16
3. How We Should Consider Information Reliability and Validity	21
4. Necessary concepts for information co-creation	24
Acknowledgements	32
Meeting participants	33

Introduction (Purpose and objectives of this report)

Recognizing the movement toward information digitalization in recent years and the fact that health information can directly impact health, Health and Global Policy Institute (HGPI) held two meetings with health professionals, representatives of Government and industry, patients and patient advocate leaders, and experts in fields like philosophy, religion, and informatics for a global and multidisciplinary discussion on the nature of health information.

Our first meeting was held in July 2023 and focused on the accuracy and validity of health information. Keynote Lecture 1 was titled “Co-Creating Health information Right” and was given by Professor Takeo Nakayama, a member of the Kyoto University School of Public Health and an expert on health informatics. Professor Nakayama’s lecture examined the ideal structure of information surrounding health in the future and the nature of evidence based on the concept of health communication in Shared Decision Making (SDM), which is a necessary element in healthcare decision-making due to the multifaceted nature of information exchange in the modern era. Keynote Lecture 2 featured a lecture from Mr. Garth Graham, Director and Global Head of Healthcare and Public Health at YouTube, a video content platform used by billions of people today. Mr. Graham discussed the challenges and social responsibilities of platform operators given the widespread popularity of video content and highlighted current efforts to address those challenges. The discussion portion of the meeting looked back on the COVID-19 pandemic to examine issues related to accurate health information, which were shared from the perspectives of both information providers and recipients. Effective measures to bridge the gaps between these two parties were also discussed. Another theme of the discussion was the reliability and validity of information, with a close look at fundamental topics such as how individuals think, how society should position itself in the face of health information, and the characteristics of health information. Through this discussion, we were able to examine the true nature of health information as a social issue.

Our second meeting was held in October 2023 and focused on ideal methods of transmitting and receiving health information. Based on discussions on the nature of health information held during our first meeting, Chairman of the Japan Anti-Tuberculosis Association Dr. Shigeru Omi gave a keynote lecture in which he reflected on his position as a specialist during the COVID-19 pandemic and explored various topics, such as the balance between dialogue with the Government and the dialogue with the public during each phase of the pandemic. During the discussion, participants examined effective methods of communicating information and shared more specific methods of doing so, with a particular focus on items for information transmitters to keep in mind regarding the characteristics of health information, their responsibilities, and precautions for providing information. Among the items covered in that discussion, one of the most significant points raised was the need for the media and the Government to build a system for cooperation in the near future to establish the capacity to rapidly provide accurate information during emergencies. As Japan frequently experiences natural disasters and other crises, this must be done in advance, before emergency situations arise. The meeting concluded with a discussion on necessary concepts within information co-creation in modern society, where all citizens are frequently in contact with health information.

The discussions at these two meetings allowed us to discuss the nature of health information as a social issue that requires examination from both a medical perspective as well as the perspective of human nature. Our discussions were not held with the purpose of reaching a conclusion or for recommending solutions; rather, our objective was to crystallize and gather opinions and perspectives from a wide variety of positions. This report was also compiled based on this concept. We sincerely hope it serves as a useful reference for future discussions on health information.

Part I- Keynote Lectures

1-1

Co-creating Health Information Right

Takeo Nakayama

(Professor, Department of Health Informatics, School of Public Health, Kyoto University)

The common point between medicine and information: Uncertainty

According to William Osler, one of the fathers of modern medicine, “Medicine is a science of uncertainty and an art of probability.” Regarding decision-making, Claude Shannon, the father of information theory, said, “Information reduces uncertainty.” As we can see, “uncertainty” is the common factor among the definitions of “medicine” and “information.”

The importance of literacy in the age of social networks, as reaffirmed by the COVID-19 pandemic

During the COVID-19 pandemic, we saw the rapid spread of misinformation, which is incorrect information, and disinformation, which is fabricated information that is shared deliberately. Dr. Tedros Adhanom Ghebreyesus, Director-General of the World Health Organization (WHO), called this situation an “infodemic.” With society facing such circumstances, the topic of “literacy” among information recipients began to draw attention. Literacy can generally be divided into “information literacy” and “health literacy.” Health literacy can be further divided into “individual health literacy” and “collective health literacy.”

- ✓ Information literacy: The ability to utilize information for good decision-making without being influenced by it
- ✓ Personal health literacy*: The extent of an individual’s ability to find, understand, and utilize information that is useful for making decisions or taking actions related to their own or someone else’s health
- ✓ Organizational health literacy*: The extent to which an organization enables, in an equitable manner, the individual’s ability to find, understand, and utilize information that is useful for making decisions or taking actions related to their own or someone else’s health

*“Personal health literacy” and “Organizational health literacy” were redefined in “Healthy People 2030,” the U.S. equivalent of Japan’s “Health Japan 21.” Rather than referring to the ability to simply read information, as it did in the past, the term is now used to refer to literacy that is more in-depth.

The propagation of social media has driven a transition from an era in which most people were merely information recipients to one in which they can easily become information transmitters, as well. People must be conscious of the fact that transmitting information carries a greater responsibility than receiving it, but as it is currently used, the term “literacy” mainly refers to information recipients. What is being asked now is if all people are transmitting the information they receive reflexively, without properly digesting it, or if everyone understands basic principles like objectivity, transparency, and accountability.

The Original Meaning of “Evidence Based Medicine” (EBM)

While many people understand evidence-based medicine (EBM) to mean “healthcare that emphasizes scientific evidence,” in reality, it has been pointed out that EBM is an integration of the four elements described below (Straus SE, et al. *Evidence-Based Medicine E-Book: How to Practice and Teach EBM* (5th ed.), 2019).

- ✓ Best research evidence: Generalizations gathered using epidemiological methods on human populations
- ✓ Clinical expertise: Proficiencies, techniques, and intuitive judgment abilities that are based on the cumulative experiences of individual healthcare professionals
- ✓ Individual patient values: Patient desires, intentions, and values
- ✓ Circumstances: Patient individuality and diversity combined with the space in which treatment is provided (the clinical setting)

Professor David L. Sackett, who was upset that only the portion of EBM that emphasizes the use of scientific evidence in healthcare became widespread, pointed out that, “Evidence based medicine is the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett et al. *BMJ* 1996).



Photographed by: Kazunori Izawa

After Professor Sackett pointed out this nuance, Professor Tammy C. Hoffmann followed up with a warning, saying “Without shared decision making (SDM), EBM can turn into evidence tyranny” (Hoffmann TC, et al. JAMA 2014).

Shared Decision Making: A decision-making process in which patients and healthcare professionals communicate as equals

In SDM, conversations are held between patients and healthcare professionals to make healthcare-related decisions together, but SDM can be considered a new form of medical communication for harmonizing the limits of evidence (uncertainty) and diversity in values. Communication is fundamental in the process of setting goals while sharing information, goals, and responsibilities between patients and healthcare professionals. The concept of “patients and healthcare professionals transforming healthcare” is a concept of co-production, co-design, and co-creation, and will be important when thinking about the nature of healthcare in the future.

The ways video content can benefit people's health and issues to address in the future

YouTube is a major platform where billions of people log in to view billions of hours of content every month. In Japan alone, videos related to health have amassed over 4 billion views. The advance of YouTube and other social networks has made it possible to provide information in real-time and at a scale that is certainly large enough to have an impact on people's health.

High-quality online information has three elements. It must be accessible (by being free and easy to discover), credible (by being based on the best sources of scientific information that are available), and easy-to-understand (by providing answers to questions that are clear and useful). Social networks are mainly operated by private companies and are superior to other platforms in terms of being accessible. However, it is difficult for social network operators to be involved in ensuring said information is credible and easy-to-understand. Because that information can impact people's health, one issue to address will be ensuring those elements are present.

Healthcare is not only something that exists within hospitals and clinics; it is part of our everyday lives. As individuals, we make decisions regarding various aspects of our lives such as what to eat or drink or when to exercise, and all of these choices impact our health. Operating an information platform to provide video content makes it possible for us to serve as a familiar presence that helps build knowledge and spark inspiration. In doing so, we aim to help people lead the healthiest lives possible and make decisions that are based on information. Highly-reliable, information-based, educational video content provided by healthcare professionals and public health organizations can help encourage people to lead healthier lives. As a platform operator, we think it is necessary to establish a system that allows them to do so in a systematic manner.

The limitations of enhancing literacy at the individual level and the social obligations of information platform operators

Before the internet and social networks existed, people generally obtained information from information providers they already trusted, like their parents or family doctors. However, we can now access information over the internet without knowing who is providing it. When people receive information from someone they cannot meet face-to-face with no assurance that the information is reliable, it is important for them to possess the literacy to choose which information to trust and which to disregard. However, intersecting factors like education and environment mean that raising information literacy at the individual level to certain standards is not something that can be achieved overnight. As such, the companies who operate social networks must engage relevant and like-minded stakeholders and work to ensure that each item that is shared can be trusted.

The need for initiatives for responsibly assessing and publishing content

We operate our platform with the intent of providing an ecosystem for sharing high-quality healthcare information. We have set rules for information providers with the goal of contributing to better health. For example, content that violates our policy is removed and information is subject to close inspection to ensure it is high quality. In addition to examining content, we also evaluate sources of information. Evaluations on other aspects like accuracy and accessibility are also conducted using fixed criteria.

When assessing information quality, however, reliability of the information source is not the only key indicator; it is also important to consider if the information encourages change toward healthier behaviors. A non-profit organization in the U.S. called the National Quality Forum (NQF) has presented recommendations that call on healthcare institutions to provide high-quality information. In addition to the importance of presenting information that is rooted in fact, they also stress the importance of encouraging people to adopt healthier habits.

From this perspective, after undergoing evaluation using objective criteria, content that is deemed to be high-quality is given a label that lets viewers know at a glance that the video is trustworthy. In Japan, a “Health and Medical Information” panel is displayed on videos and the site has been updated to include a “Health and Medical Information” section. These serve as proof that the party providing the information is trustworthy. For viewers, this provides a way to access information after confirming that it is coming from a reliable source.



Photographed by: Kazunori Izawa

The Nature of Communication Through the Lens of the COVID-19 Pandemic and Related Topics

Shigeru Omi

(Chairman, Japan Anti-Tuberculosis Association)

The three phases of the COVID-19 pandemic in Japanese society

The three-and-a-half years during which Japan confronted the COVID-19 pandemic can be divided into three phases. During the first phase, people had a shared fear of the unknown toward the disease and usable information was limited. However, all of society shared an awareness that we must somehow control the spread of infections and help prevent health services from becoming overwhelmed. People were encouraged to observe the “3 C’s Rule” (avoid closed spaces, crowded places, and close-contact settings) and it was a period of trial-and-error for all of our efforts.

By the second phase, during which the Delta variant emerged and Japan experienced its fifth wave, we had come to understand various aspects of COVID-19. For example, we knew the infections spread through shared spaces for eating and drinking or through the movement of young people who experienced relatively mild symptoms. At the same time, it was the period when the spread of infections was at its peak and healthcare demand was at its highest.

In the third phase, people began to show fatigue with COVID-19 restrictions and toward the state of emergency. This was when society reached a consensus that we should revert social, economic, and educational activities to the state they had been in before the pandemic.

These three phases saw Government operations transition between three administrations. The first phase roughly coincided with the Abe Cabinet; the second, the Kan Cabinet; and the third, the Kishida Cabinet.

Accurate information that was not conveyed

From the perspective of risk communication, I have the strong impression that most of the information regarding what was taking place within the Government and what experts were recommending was not accurately conveyed to the public.

Experts represent organizations that advise on infection control and are responsible for providing the Government with recommendations as to what measures will be necessary for individuals and for the nation. These recommendations are based on analyses of the situations surrounding the spread of infections or healthcare shortages. Only a small portion of experts’ activities consisted of answering questions before the Diet or at press conferences. We devoted a great amount of energy to compiling recommendations that were as scientifically sound as possible, that would convince as many people as possible, and that would receive as much support as possible. Aiming to achieve communication that is truly co-created, over 100 proposals were submitted during the COVID-19 pandemic.

In February 2020, at a time when each region did not have a policy for infectious disease control in place and the national Government had no policies attached to such efforts, a cluster of COVID-19 infections occurred on a cruise ship that had arrived at Yokohama Port. We experts thought that infections were already spreading to the community, and we knew that the virus could cause secondary infections in others, even during its incubation period or from people who were asymptomatic, and that the disease was not something that could be contained within six months or a year. All of this was told to the Government.

However, the Government and its officials were overwhelmed with responding to the cruise ship and there was no time to consider infectious disease control measures in each region. This meant that we, the experts, had to take the lead in disseminating information. Later, press conferences began to be held regularly, which gave the impression that experts were in charge of all decision-making. That was completely untrue. Had that been the case, all of our recommendations would have been adopted, but many were not. There were many other times when information based on insight from experts was not accurately conveyed, such as the recommended timing to seek a medical examination at a health institution. In another example, some expressed the opinion that experts were suppressing the PCR testing system.

We spent a significant amount of time gathering as many facts and as much data as possible to include in our recommendations so they would show clear evidence. However, in many cases, members of the media did not necessarily read the evidence and data included in those recommendations before disseminating their information. As a result, only certain portions of the recommendations were shared. Some members of the general public fully trusted the incomplete information being presented on TV and in other media, so the facts did not reach them. This resulted in a cycle that repeatedly reinforced incomplete information.



Photographed by: Kazunori Izawa

The fragmentation caused by information

In the early stages of the COVID-19 pandemic, many people thought the pandemic would end after half a year of patience, so they were worried but not divided. That worry eventually turned into frustration that a state of emergency was declared repeatedly and that various restrictions had been placed on activities. While this was going on, health professionals – who had always been at risk since the start of the pandemic – continued providing care while preventing nosocomial infections. Nonetheless, personnel shortages were blamed on a lack of effort among health professionals, causing frustration to gradually turn toward them. This also led to division.

The quality of healthcare in Japan is said to be top-class worldwide, but some said that the overwhelming lack of facilities for PCR testing meant PCR tests were not performed and that some infected people went overlooked. In reality, we were focused on people who were in poor physical condition and their symptoms, and we were providing people with diagnoses and treatments based on many clinical findings made using CT scans and other tools. This resulted in far fewer deaths compared to Europe and the United States.

Why, then, did division among people occur? When people experience prolonged anxiety, they try to find some way to relieve it. This could be called their natural desire as living organisms. In the process of trying to relieve their anxiety, people who share similar viewpoints or perspectives gather and talk to each other. This amplifies certain opinions like, “Taking the vaccine will cause health problems,” leading to division among people.

Despite the fact that the information people obtained from TV or over social networks was fragmented, they perceived and accepted it as all the information that was available. I think this was a major influence that divided people during the pandemic. How can we convey accurate information in as clear a manner as possible, while taking the needs of information recipients into account? I have high expectations for today’s discussions on how to best co-create communication.

Part II- Discussion

1. Defining “Accuracy” in the Context of Health Information

1-1 Issues related to accurate health information that surfaced during the COVID-19 pandemic

The importance of having a full view of current circumstances when seeing or hearing various facts and events when the situation is constantly shifting during an infectious disease outbreak

- When the COVID-19 pandemic began, the media only reported on the severe circumstances in China, but most of the people being treated for COVID-19 in Japan had minor symptoms. The media only covered a single angle on the situation and did not provide a complete picture of the disease, which was still unfamiliar at the time. Both transmitters and receivers of information needed to know that the situation was uncertain and that the information being presented did not always give a complete picture.

Different healthcare provision systems gave different impressions of COVID-19

- During the early stages of the COVID-19 pandemic, the public was not told that the longer the time one took to receive treatment after developing symptoms, the greater the risk of severe symptoms. In regions with fragile healthcare provisions systems, people were unable to receive care after the onset of symptoms. This made it appear like COVID-19 was a frightening disease that rapidly caused severe symptoms, which resulted in a commotion. Even when different healthcare provision systems are responding to the same disease, differences in the environment or background surrounding treatment can distort how the disease appears to observers. How to best encompass this fact when transmitting information is a necessary perspective for information accuracy.



Photographed by: Kazunori Izawa

The impact of inaccurate information skillfully disguised as fact in the era of social networks

- Among the various claims and statements that were presented in definitive terms as facts on social networks, some were mixed with personal thoughts and wishes. These statements even confused healthcare professionals, who sometimes went so far as to ask for confirmation. We still do not have an answer as to how we can best confront such situations.

Hopes for future progress in efforts from public institutions in Japan to transmit accurate information

- For example, users who run a search for “vaccine ingredients” in Japanese will be linked to a Ministry of Health, Labour and Welfare (MHLW) website, but once there, they cannot reach lists of ingredients without spending a significant amount of time searching for them. Running that same search in English leads to the U.S. Center for Diseases Control and Prevention (CDC) website that provides a detailed list of ingredients and states, “Most vaccines don’t contain any mercury.” It also provides explanations to clear up common misinformation. There are high expectations for public institutions in Japan to follow their lead and be proactive about transmitting the information people want to find.

1-2 Successfully transmitting accurate health information: Perspectives from information transmitters

The desired future direction for the transmission of accurate health information

- While some people have firm standards for decision-making, others want someone else to make decisions for them. Considering this diversity among information recipients, rather than taking a single approach of either promoting public information transmission or curbing the spread of inaccurate information, it will be necessary to do both.

Potential methods of ensuring information is easy-to-understand, accurate, and detailed

- For information recipients, there can be somewhat of a tradeoff for information being easy-to-understand and accurate. For example, saying “one in six” may be more intuitive than “16.7%,” but some people would say “one in six” is inaccurate. How information is transmitted must be tailored to who is receiving it.
- When expressing percentages, there is room to consider methods of catching the eyes of readers and then working to encourage them to read more by using the phrase, “about one in X people,” which has greater impact. While ease-of-understanding is an important aspect of information, there are times information is presented in great detail to emphasize accuracy, which can make it difficult to understand from consumers’ points of view. One notable example of this is package inserts for pharmaceuticals. Expectations are high for the pharmaceutical industry to play a bigger role in transmitting health information in a manner that takes consumers’ perspectives into account.

The need to take the characteristics of information that is accurate and information that appeals to the emotions into account

- Information that appeals to the emotions may attract attention, but it is not always accurate. However, it is particularly effective at encouraging changes in attitudes or behaviors among recipients. When providing information, information transmitters must consider the strengths and weaknesses of both and disseminate information that contributes to people’s health.

The credibility of information that is co-created by information transmitters and recipients

- Expectations are high for major media outlets and other information transmitters to sometimes enforce standards like, “Information even a middle school student can understand,” and work to transmit information that is not only accurate but is easy-to-understand, credible, and useful. After considering the

intended recipients, the qualities of information must be tailored accordingly.

- In the current era in which people can access vast amounts of information, both good and bad, it is vital for the transmitter of each bit of information to be clearly indicated so those who receive that information can trust it.
- At times when circumstances are changing every moment, the information provided by healthcare professionals and the media may not always be correct. In one example, a TV program aired a statement saying, “Drinking green tea can reduce the number of COVID-19 viruses.” This was based on an exaggerated interpretation of the antiviral effects of green tea in a laboratory setting and was a case in which illiteracy on the part of the information provided at the TV station was on full display. Continuous efforts must be made to improve the literacy of information transmitters and update the information they have acquired.

1-3 Successfully transmitting accurate health information: Perspectives from information recipients

Preparations that information recipients must make to be able to access accurate information in the future

- In addition to efforts on the part of information transmitters, the transmission of accurate information also requires improved literacy among information recipients. Many people tend to be drawn to dramatic forms of information that tell stories, even when they are searching for information that is accurate. We could consider this problem to be rooted in both human nature as well as insufficient literacy among information recipients. To be prepared for future pandemics, improving literacy related to science and infectious diseases will be an important issue to address.
- On social networks, people display the tendency to try to exclude people who do not agree with their opinions from their communities. In the future, while ensuring information platforms are diverse, it will also be necessary to consider individual criteria that will not be swayed by all sorts of information.

Forms of social support needed to help patients reach accurate information, from patients' perspectives

- We should keep in mind that when patients pick and choose health information to make decisions, they are doing so under pressure. For example, in the field of oncology, progress in nationwide measures made under the Cancer Control Act have made a vast amount of accurate information available from



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sources like the National Cancer Center's Cancer Information Service. However, patients cannot become healthy with accurate information alone. Because they want to hear stories about people who recovered and have hope, patients tend to rely on sources of information with narrative elements.

- Sometimes, when they become patients themselves, even some highly literate people or physicians seek medical care with no clear scientific basis. Accurate information will not reach patients and those close to them unless it is provided alongside decision-making and emotional support that addresses the unconscious and intrinsic desire people have to get the information and results they want.
- For patients to reach accurate information, it is important for them not to become isolated. This is where peer support can play a role. If parties like patient advocacy groups and healthcare professionals work together to first provide patients with emotional support in facing their disease, it can become possible for patients to go and get the accurate information they need. Medical and nursing consultation support for patients generally begins with an assessment, but considering the perspectives of patients and other affected parties, it is also important for there to be support provided through peer support and empathy.

1-4

Building a Better Society of Information Co-Creation in the Future: Perspectives Needed for Bridging the Gaps Among Transmitters and Recipients

How to best transmit information to bring people who feel uncertain and undecided closer to accurate information, centered on the perspective of wellbeing

- When an information recipient selects information, their choices are changed by differences in the scientific expertise of information transmitters and their personal criteria (or, the presence or absence of such criteria). For people who are on shaky ground because they cannot determine what information is correct due to mismatches with their personal criteria, we should think about how to best transmit information from the perspective of bridging those gaps to further improve their wellbeing.

The potential for real-world evidence to be utilized in information co-creation

- Providing daily updates of the nationwide estimated number of positive tests for COVID-19 and seasonal influenza by region improves public health and helps prevent the spread of infections.
- In a recent survey of approximately 1,000 physicians and 3,000 members of the general public, 59.0% of physicians and 44.4% of citizens said they would like for their data to be actively utilized. When asked their reason why, the most popular response was, "To improve my own health or treatment." Other respondents selected, "To create new and improved treatments" and "To confirm the effects of a medicine or the results of a treatment." The survey also found that many respondents felt that "Having data from Japan rather than from other countries will help build trust and a sense of security."
- In Japan, vaccination records and health information are not linked and establishing real-world evidence on a scale as large as in the U.K. and the U.S. will take time. However, if this can be achieved, it will be useful to both individuals and to society.
- Vaccine side effects or COVID-19 symptom severity can vary, even among family members. Utilizing and studying such events as forms of real-world evidence may help lead to future progress in personalized medicine.

The need to promote fact-checking practices that meet global standards

- In addition to transmitting accurate information and improving information literacy, it will also be necessary to fact check information that is transmitted. Japan did not have an organization that is certified by the International Fact-Checking Network (IFCN) until 2023. Looking at the number of items that are fact-checked, Japan only has a few hundred. This is far fewer than other countries such as Indonesia, where approximately 10,000 items were fact-checked. Moving forward, Japan must catch up to global standards.

- Japan should also add literacy education to public education programs. To popularize both fact-checking and literacy education together, Japan should actively participate in international conferences and similar events where parties like journalists, fact-checking and literacy educators, researchers, activists, and policymakers hold cross-disciplinary discussions to share best practices so we can acquire knowledge from around the world.

2. Effective methods of conveying information

2-1 Characteristics of health information that information transmitters should be aware of

- Because it directly affects people's lives and health, health information is characterized by its great influence on recipients. Furthermore, expressing certain opinions about diseases or patients may result in discrimination and prejudice. This means that among the types of information, health information is particularly sensitive. Information transmitters must be well aware of this fact.
- Healthcare is an enormous market which has private sector involvement. While healthcare is an issue for individuals and families, there are also public aspects to healthcare that involve the national Government and local governments. However, those aspects do not always directly benefit or satisfy patients and citizens. While understanding that this lack of balance is a premise, when disseminating information to diverse stakeholders, information transmitters must maintain both a sense of tension because they are handling information that is a matter of life and death and a sense of consideration toward patients and other affected parties.

2-2 Responsibilities and ethics that information transmitters (the mass media, government officials, health professionals, etc.) should pursue based on information recipients' positions



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- While health information accuracy is important, different recipients require different information. Because of this diversity, there are limits to defining accuracy in a uniform manner. This means information transmitters must clarify the purpose of information dissemination as much as possible before transmitting it.
- When transmitting information, health professionals must be aware that most recipients are members of the general public who have little knowledge about medicine. They must endeavor to use language and provide content that can be understood by everyone.
- As previously mentioned, and as often pointed out, there is information asymmetry among health professionals and patients. Government officials who transmit health information and formulate policies may not fully understand the concerns patients and citizens live with, creating another kind of information asymmetry. Patients have their own lives and values, and healthcare is not everything to them. The government must first understand this before disseminating information.
- Breaking down difficult-to-understand, technical health information to convey it to the general public in an accessible format is a key role of the media. They must also communicate the worries and concerns that patients and citizens feel toward healthcare to experts, health professionals, and the government. The media should position themselves between the two sides to serve as an information bridge.
- When the lack of information is overwhelming, like during the initial stages of the COVID-19 pandemic, the significance of information transmission from medical experts is believed to reside in their ability to provide accurate, up-to-date information after finding and confirming the accuracy of evidence in the stream of research papers being published. In addition to interpreting research paper content, it is also important for them to also explain conditions in real-world care settings to provide society with more immersive, practical information. In addition to conveying the information that has been clarified, another responsibility of health specialists is to take an overhead view of healthcare to identify what information has not been clarified.
- Health information can be disseminated by individuals or by teams. Both options have advantages and disadvantages. Using teams with several people allows for discussions on the information to be held in advance, before transmitting it. This makes it easier to compose articles that will receive acceptance from the public and helps protect single individuals from becoming the target of negative reactions (such as strong opposing opinions or abusive comments), which reduces strain on their mental health. One drawback of using teams is that it can become more difficult to manage or consolidate opinions. Individuals can transmit information immediately, but a person working alone can be deeply affected by negative responses.

2-3

Selecting means and methods of transmitting information to reach target audiences more reliably

- Early in the COVID-19 pandemic when information was scarce, one physician who was treating people in the frontlines of care published articles online to disseminate information. At the time, most of their readers were in their 40s, followed by people in their 30s, 50s, and 60s. They noticed that their articles were not being read by the younger generation of people in their 20s or under. The content of information being presented also changes depending on if the recipient has an underlying disease. As such, in a society with diversity among information recipients, the information that is transmitted will not be conveyed unless the party transmitting it envisions which specific target audience they intend to reach. In addition to transmission methods like TV, social networks, and video platforms, they must tailor the media or transmission methods they use to their target audience. For example, they might collaborate with influencers to transmit information.

- While newspapers and TV allow information transmitters to provide large amounts of information in short periods of time, these formats are prone to transmitter bias. On the other hand, video platforms allow them to deliver information instantly without cuts or edits, even when their videos are long. If information recipients have their own values and judgment criteria to determine if information is accurate, they will be able to obtain much more information from video content. This will expand the potential for the use of video content.
- The advantages of online media include the ability to provide detailed descriptions without worrying about word limits, and the ability to attach papers and other reference materials that provide a basis for statements. Over the course of the COVID-19 pandemic, there were dramatic changes to the properties and characteristics of the disease as well as in how we understood those properties. Over time, we also saw changes and differences in countermeasures and in the content of information transmitted by experts. Misinformation and disinformation spread easily, which could lead to confusion among citizens, so a number of efforts were made with a focus on online media to rapidly disseminate accurate information. First, when writing and publishing online articles based on interviews with experts, they were first compared with discussions held at the Novel Coronavirus Expert Meeting, its subcommittees, and statements made at press conferences held by experts who were on government committees. Also, the articles were disseminated by the day after the interview with detailed descriptions of the proof and the concepts that were reported in newspapers and on TV. This was an effective method of providing accurate information. However, the effectiveness of using online media to disseminate information has yet to be adequately evaluated and verified. In the future, we must evaluate online media as part of historical verification as other comparable events or new forms of media emerge.
- Misinformation and disinformation can be created in seconds. On the other hand, fact-checking takes an enormous amount of time and effort because articles from public institutions must be researched and experts must be interviewed before inaccuracies can be pointed out. It is best to work with a professional fact-checking organization so fact-checking can be performed quickly and efficiently and to ensure accurate information is disseminated.
- As for raising awareness toward diseases during school education, instead of using words like “children” or “elderly people,” it is better to use phrases that are easier for students to perceive and relate to, like “a 6-year-old girl” or “a 70-year-old man.”

2-4

Items information transmitters must be aware of regarding disclosing Conflicts Of Interest (COI) and handling slander or defamation

- The decision to disclose COI and to what extent depends on the medium used to disseminate information, but it is necessary to disclose as much as possible to ensure trust in the information provider and to avoid criticism for failing to disclose COI. Criticism toward the decision whether or not to disclose COI can cause distractions that prevent one’s key message from being communicated.
- Journalists are in positions that give them the ability to disseminate information, and that is one form of authority. This means that when making statements, information transmitters must assume that there will be some degree of reaction or disagreement. Even if a journalist is affiliated with a company, not all companies have systems in place to fully protect their employees, and transmitted content is often the responsibility of the individual. This means that in the end, they must have ways of defending themselves, such as relying on the police.

- It goes without saying that there is a diversity of opinions in society, all of which must be respected. However, there are sometimes defamatory comments that are not directly related to the article posted, which is particularly common with online media. Comments that are malicious or defamatory to an excessive degree should be given serious treatment. For example, it may sometimes be best to consult a lawyer and consider legal action.

2-5 Perspectives on information co-creation among transmitters and recipients needed for modern communication

- As health communication studies have developed, information has come to be seen as something that not only flows in one direction from transmitter to recipient, but is also created between them by both parties. This is a major shift that represents a departure from the traditional model, which focused on “Providing citizens with scientifically sound information from experts so they can become knowledgeable and learn to take the right actions.”
- When citizens do not behave in accordance with the intentions of the transmitter, it is not necessarily due to a lack of knowledge among citizens. Each individual takes the course of action they think is right after utilizing their own knowledge and judgment criteria to interpret and understand the information they received. This became clear over the course of the development and spread of the internet and social networks. It will be important for health professionals and experts to not only to provide one-sided, scientifically sound, and correct information, but to also to transmit information after learning the thoughts and judgment criteria of patients and citizens.
- How information is communicated and who communicates it is more important than its content, and how that information is received by the recipient is even more important. In order to provide information smoothly, it will be important for experts and information transmitters to establish a communication network during non-emergency periods and to build public trust.



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2-6

The need to reinforce societal health literacy to compensate when individual health literacy is inadequate

- Health literacy refers not only to an individual's ability to gather and comprehend information, but also to society's ability to do the same. Given the presence of Social Determinants of Health (SDH), moving forward, in addition to the individual, we must pay attention to society's ability to gather and comprehend information – in other words, to societal literacy. If there is societal health literacy (i.e. such literacy within the context of healthcare), then it may lessen the impact of SDH on individual health status. This may occur, for example, if an individual's lack of health literacy can be compensated for by the people around them and by a social environment that facilitates the transmission of easy-to-understand information. Regarding the relationship between individual health literacy and health status, higher literacy is associated with better health. While evidence is still insufficient, it is also starting to appear that there are regional disparities in health literacy. For example, it has been shown that regional disparities in literacy are related to the quantity and quality of family doctors in the community as well as to social capital, which is the strength of social connections and trust in society or the community.
- One current challenge facing efforts to elevate societal health literacy is that health providers and experts do not always receive education on health communication despite the great significance of information transmission from such parties. While medical schools are currently expanding curriculums on interpersonal communication, it is not enough to prepare students to disseminate information through the internet and social networks. During the COVID-19 pandemic, a number of experts were able to effectively communicate with the public. Expectations are high that an educational system that uses such experts as role models will be established to help elevate societal literacy.

2-7

Identifying the best methods of transmitting appropriate information to citizens experiencing anxiety in the face of crises and developing an information dissemination system for that purpose

- During the COVID-19 pandemic, when reliable prevention and treatment methods had not yet been identified, discussions were held in the Government and among experts on if it was best to continuously provide information about the ever-changing virus and its symptoms, and whether doing so might cause the public to panic. The pandemic was not localized to Kasumigaseki or Nagata-cho, but was occurring in every region throughout Japan. It was local governments that were implementing countermeasures. This allowed us to affirm the importance of informing every community member of the facts, even the facts they do not want to know, while trusting them to make the right choices and take the right actions.



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In addition to scientifically sound information, it is necessary to also consider methods of disseminating information from a sociological perspective that takes the psychology of citizens into account.

- In the future, information from the national Government and local governments during crises should not only be disseminated by experts, but by multidisciplinary professionals including the media and experts in risk communication. During periods of non-emergency, these parties must collaborate and establish a reliable network for transmitting information in a smooth and effective manner. Establishing such an environment will also help to ensure psychological safety for information transmitters. It will also help experts avoid having their statements shortened or summarized in forms that do not convey their intent, which is the aspect of media exposure that troubles them the most. Combined with a psychologically safer environment, this will enable them to share information more proactively.

However, independence and impartiality are necessary aspects of journalism. As experts are employed by the Government and the media is the private sector, some are concerned that collaboration among these parties may prevent journalists from being able to guarantee independence and impartiality. This means it is necessary to have people or organizations who can serve as intermediaries between the media and experts, and who can match the information being transmitted to the information that society wants to know. While maintaining mutual respect for each other's positions, it will be important to co-create and transmit information in a manner that is matched to the needs of both transmitters and recipients in terms of content and delivery methods.

- Graduate schools of public health can serve as the key for promoting multisectoral collaboration in transmitting information. The philosophy and objective of such schools is training experts in community health and risk communication. They attract students from many fields that include health professionals and media representatives. After studying at graduate schools of public health and returning to their workplaces, they are likely to gradually transform real-world settings in both healthcare and the media. We have particularly high hopes that the government will create positions to actively recruit people who have studied health and risk communication.

3. How We Should Consider Information Reliability and Validity

3-1 How individuals and society should perceive and approach health information reliability and validity

- The root of the issue is understanding that there is no such thing as one right answer. Even if a piece of information is evidence-based, that evidence only represents what is currently visible, and nobody can say if it will still be correct in a few years or decades. This is especially true in healthcare. That is the world we live in, and we are trying our best to seek the truth given that fact. There is a Buddhist line of thought in which one begins by saying, "I am wrong," or "We know nothing." First, we should adopt this perspective as a society, because it might help foster information literacy.
- There is a concept called agnotology, which is the study of deliberate ignorance. Ignorance can be harmful or it can be virtuous. The former is harmful in that people with limited access to information are harmed by not knowing they are ignorant. The latter refers to ignorance when it is more useful not to become informed, or a state of ignorance that precedes the acquisition of new knowledge. Society and individuals must reaffirm the value of "virtuous ignorance."
- To begin with, in addition to scientific literacy, information recipients and society itself must also pay attention to physical and mental health as well as spirituality. Both health information and healthcare itself

are parts of people's everyday lives and are parts of human history, which makes it difficult to discuss healthcare as an isolated topic. Humanity has been dealing with the inevitable parts of life— namely, birth, aging, sickness, and death – since before the advent of modern medicine. Healthcare is related to all of these in the modern era, but none of them are complete with healthcare, nor can their narratives be contained within it.

3-2 The power of narrative in health information transmission

- In both clinical research and in citizen science, in which members of the general public participate in scientific research, narratives are a vital element that help researchers decide how to contextualize their research in explanations provided to collaborators. The value of narrative-based medicine, which uses a holistic approach that encompasses the entire daily lives of patients and families while keeping their backgrounds in mind, has been recognized for many years. Similarly, when transmitting health information, in addition to communicating accurate information that is based on scientific evidence, it is also important to determine how to tell a story that fits within a context that suits the recipient. There are high expectations for health information to be transmitted in a manner that keeps this narrative-based approach in mind.

3-3 Remarks on management provided by the Government or by health institutions during pandemics

- Michel Foucault coined the terms “biopower” and “biopolitics” in the 1970s. In short, these concepts argue that nation states once regulated their subjects through punishments or imprisonment, but now imposes health on them or forces them to live in biomedical health instead.
- During the COVID-19 pandemic, information regarding the right actions for citizens to take was transmitted through the media and other information resources by the Government and by healthcare institutions, and citizens listened. We also saw anger among the public during the pandemic, even in developed countries. Before we can determine if healthcare-related information was received accurately, we must first recognize the tension between individuals and the state and other institutions with authority to serve as a premise for considering the transmission of health information.
- A contemporary Italian philosopher named Giorgio Agamben uses two terms to refer to life: bios and zoe. To put it simply, bios refers to the vivid manner in which humans live their lives, while zoe refers to an animalistic way of living. He also refers to people with only zoe as “Homo Sacer.” Homo Sacer are people who exist outside of the protection of the law and can be killed without it being considered a sin, but cannot be used as a sacrifice to the gods during religious ceremonies.
- When healthcare professionals managed patients or society during the COVID-19 pandemic, were patients drained of their bios? Did it result in modern Homo Sacer who were only allowed to keep living?
- When people in Japan observed behavioral guidelines such as masking, it was not because they were forced to do so by law, but because doing so became the social norm. While certain aspects of this could be considered good examples, it may also be safe to call it a state in which citizens were observing only their biomedical health. Expectations are high for experiences from the COVID-19 pandemic to serve as opportunities for each citizen to reconsider the question, “What is the purpose of living?” and gain perspectives on both bios and zoe.



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3-4

The education, lifestyles, and perspectives necessary to build literacy and acquire critical thinking

- People have an innate desire to hang onto or grasp something, and one aspect of Buddhist thought considers “faith” to be “a mind without doubt.” This is a similar sentiment to being open-minded and listening to the voices of others rather than clinging to any specific piece of information. To avoid being misled by conspiracy theories and similar narratives, people must keep an open mind without holding a rigid belief in any particular opinion, and religious studies, philosophy, and liberal arts are useful for attaining that.
- Having faith that is based on having an open mind is to have a perspective that is similar to critical thinking. If someone trusts in something with a closed mind, they may begin to distrust other information. This may make them vulnerable to conspiracy theories that doubt every bit of information provided from sources like the mass media with statements like, “The Government must be connected behind the scenes” or “Everything they say is wrong.”
- The foundation of critical thinking is a healthy lifestyle. Finding small forms of happiness in our everyday lives over the course of activities like cleaning up, greeting each other in the morning, reciting sutras, and sharing meals forms the foundation for critical thinking and allows us to open up our minds and say, “No matter what happens, life is good.” Rather than only using one’s head, critical thinking should combine both mental and physical cultivation. It is important to foster physical health, mental health, and critical thinking from early on in life, accompanied by physical and mental nurturing, and we should look forward to building a world in which we can feel wellbeing based on this.
- In the future, introducing mental health education at schools may help children learn about systems of the mind, emotions, and feelings to help them grow and enjoy better mental health. Knowing the mind means knowing what one is feeling in the moment, and it means knowing oneself. It is important to decide which actions to take based on this knowledge. Furthermore, having the mental ability to set criteria that allow us to make decisions for ourselves is the foundation for receiving information.

4. Necessary concepts for information co-creation

4-1

The mental conditions of people who must acquire information and make decisions under extraordinary pressure

- Patients have to make decisions under great psychological pressure. When someone is diagnosed with cancer, for example, they experience various uncertainties about their future, such as what will happen to their disease, work, and daily life, or even if they will be able to continue living in the first place. It has been said that approximately 20% to 40% of people with cancer are in a state of depression. We must remember that they have to make decisions and select information under severe psychological duress.
- Within health information, information that is based on scientific evidence lies on one end of the spectrum while narrative-based information lies at the other. Generally speaking, evidence-based health information does not give people the hope to live. For example, not very many cancer patients feel encouraged if their doctor tells them, “The five-year survival rate is 40%.”
- When people feel anxious or burdened with thoughts like, “I don’t want to take anticancer drugs” or “Anticancer drugs seem hard on you,” human nature may lead them to seek information that relieves these feelings and they may be drawn to inaccurate information like, “Anticancer drugs have been banned.”
- We must always be aware that people are at risk of making mistakes in evaluating information when they have been diagnosed with a disease or are facing a pandemic, disaster, or other crisis.

4-2

Human nature means people are more drawn to hopeful narratives than to evidence-based information that makes them confront reality

- When viewing health information, health professionals see the “forest” while patients see the “trees.” The “forest” represents the vast medical knowledge of health professionals that allows them to see the patient’s prognosis from an overhead point of view. Patients, on the other hand, only have the limited information they receive at medical consultations, so they must make decisions while only being able to see the “trees.” This is why people are attracted to information that is narrative-based and familiar, and



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develop the tendency to rely on it. They might hear information like, “Some people are still full of energy even after their cancer diagnosis,” or “They are working hard in their everyday life and are staying positive while they face their diagnosis” and find it more inspiring than evidence-based information. This is human nature.

- About 20 years ago, when there was still little access to video platforms, TV had a great degree of influence. For example, when a popular information program said, “Eating bananas increases white blood cells,” bananas immediately sold out at hospital shops. When struggling with a disease, people are easily drawn to information that is easy-to-understand, uplifting, and encouraging. We must not disparage or ridicule people who are drawn to pseudo-medical information like this. Given the various forms of pressure they face, people may feel timid and fear their doctors will scold them if they ask questions. Among both laypeople and physicians, there are cases in which people develop the tendency to trust inaccurate information. We must acknowledge this aspect of human nature and consider ways of providing accurate information to those who need it.
- Misinformation also spread during the COVID-19 pandemic. For example, one person claimed to be a cancer patient who recovered from COVID-19 by taking Ivermectin. This was an example of narrative-based information being disseminated with full confidence in its accuracy because it was based on personal experience. Cases like this show that we must recognize that there are limits to the effectiveness of providing evidence-based information alone.
- A group of physicians prepared materials for a rehabilitation facility managed by recovered drug users called the Drug Addiction Rehabilitation Center (DARC). After as much discussion and consideration as possible, the materials were presented to the affected parties in full confidence. Those materials included data on the very high infant mortality rate for mothers under the age of 25, which was meant to help raise awareness so support could reach those who need it. However, seeing this information made one of the people in attendance experience a traumatic flashback and they broke down in tears. Science and medicine are based on a framework that assumes there are solutions to problems. This means that presenting a solution to someone with a problem can carry the risk of being hurtful to that person. As this example shows, it is also crucial to keep in mind the importance of including narratives from the viewpoints of the parties most affected.

4-3 Limitations on the degree to which science and medicine can influence behavioral change

- When we consider public masking during the COVID-19 pandemic, we see that even though there was evidence that masking was an effective medical countermeasure, the perception of masking among the general public and the extent to which people were actually encouraged to wear masks was a different story. As such, this topic also requires discussions from the perspective of social science. In a similar manner, discussions must also be held on society’s understanding and acceptance of genomic medicine. As we can see, there are limits to holding discussions that examine only the accuracy of health information or the presence or absence of evidence; we must also think about how society understands information.
- In research in citizen science following the Fukushima nuclear accident, there was initially much discussion regarding how to interpret radiation risk when the Government presented a report with recommendations from scientists. As this example demonstrates, controversy can occur even when scientific data is presented. Because of this controversy over the interpretation of scientific data, the Government adopted an extremely forgiving (and possibly irresponsible) stance that the interpretation of data must be left up to “individual philosophy.” Ultimately, discussions on the reliability of health information question scientific theory itself, asking “What exactly is science?” We can consider the

years of the COVID-19 pandemic to have been a period during which we questioned what it means for scientists to reliably transmit information.

- It may be safe to assume that people experienced greater fear and anxiety regarding radiation because radiation symptoms do not manifest immediately like with infectious diseases. After the Fukushima nuclear accident, 90% of telephone consultations about radiation came from people living in Tokyo and Osaka, some of whom were experiencing psychosomatic symptoms caused by anxiety. Sharing scientific data on measurements of radioactive contamination using units like becquerels or sieverts did little to help improve such symptoms. Rather, those people hoped to receive narrative-based information that would give them hope. While scientists tend to prioritize transmitting information that is based on data, there are times when doing so can aggravate feelings of anxiety or despair. However, information transmitters must provide information to people based on the principle that they want to help. It may be best to establish information transmission guidelines in advance, during periods of non-emergency.
- Human beings are regulated by biology. In diagnostic imaging, for example, images exist as a form of reality. As critic Hideo Kobayashi points out, human beings are not only defined by biology, and all of their symptoms cannot be explained no matter how much diagnostic imaging is performed. In a world where we have technology and IT like diagnostic imaging, nobody has a clear answer as to how to accumulate wisdom and then add understanding and interpretation. While it may be impossible for us to achieve perfect happiness, we may require attitudes that allow us to approach happiness; it is important for us to know what would make us feel a sense of understanding and acceptance and say, “Well, if that is the case, then I’m okay with dying.”

4-4 Neuroimaging as a form of narrative and its utility in the field of psychiatric disorders

- In healthcare settings, a variety of test data has started to be shared with patients and other affected parties to help achieve early detection. In the past, judgments were made based on general feelings of being unwell or were based on the senses, but this “objective self” has been gradually replaced with data. Tools like neuroimaging and neuropsychological test scores have made it possible to obtain scientific data in psychiatry, a field where there have traditionally been few objective diagnostic criteria. This can be seen, for example, in neurodegenerative diseases where the underlying cause is believed to be in the brain, such as dementia.
- At the beginning, there was a great amount of discussion (especially overseas) that viewed the overemphasis and proliferation of neuroimaging in the field of dementia in a very unfavorable light. Reasons that were mentioned included: (1) the unreliability of diagnostic imaging; (2) the belief that early detection of dementia would only lead to early despair, given the lack of a cure; and (3) the belief that detecting diseases through neuroimaging would lead to people becoming impoverished for aging, which has traditionally been considered a natural phenomenon. For example, one person was given a brain scan as part of a comprehensive medical checkup for their employer. While they approached the scan with a lighthearted attitude, they were only told, “You have brain atrophy and may have dementia” without being given adequate time to mentally prepare themselves for the reality of aging. This can cause people to enter a state of intense anxiety and depression later on in their daily lives.

Over the past decade, there has been a positive shift in the meaning of “neuroimaging” in the field of dementia. First, diagnostic precision has improved and diagnostic classifications for dementia have become clearer. These allow health professionals to more fully inform patients of the future course of the disease, making it more predictable for both parties. It has also become possible to provide tailored care for each disease, which enables people living with dementia and their families to prepare both mentally and in their environment.

Communication gaps and disconnects in discussions on aging, end-of-life care, and death resulting from the Japanese cultural value of avoiding being a burden on others

- When people in Japan today think about aging, end-of-life care, and death, many want to avoid becoming a burden on their families or children. In fact, when they are asked, “What is important to you with regards to where you will spend your final days or where you will receive end-of-life care?” over 70% of the public said, “I don’t want to burden my family or others close to me.” From the perspective of information transmission, two aspects of this attitude can be considered problematic.
- First is the possibility that this attitude toward avoiding being a burden to others is a factor for communication gaps. Inspecting this attitude, we see there are various emotions that lie beneath the surface and contain the true feelings of the affected party. For example, they may want to be independent, or they may feel sorry, ashamed, or embarrassed out of consideration or concern for the other party. There is also the possibility that the person saying, “I don’t want to be a burden on anyone” does not realize their own true feelings. If they just say, “I don’t want to be a burden” without noticing those true feelings, then the other party may take those words at face value, so these words can cause gaps in communication.
- Second, in addition to communication gaps, this attitude toward avoiding being a burden may cause people to cut off communication. For example, even if someone’s treasured family member tells them, “I don’t want to be a bother,” and they reply “That won’t happen,” the conversation might end there, and both parties might be unable to bring it back up again to explore the issue further. In short, it may be possible that if people are too careful about not bothering others, it can lead to communication being cut off and result in even further isolation.
- In a way, hesitancy toward burdening others may lead to hesitancy toward relying on others, and such feelings may cause society to become a place where people are forced to help themselves. In other words, people may become hesitant to ask for information from people who are more well-informed and instead try to access information on their own using the internet and social networks, which have become commonplace in the modern era. This may be a factor that is preventing people from accessing accurate information.
- Historically, this attitude that emphasizes not bothering others in the context of aging, end-of-life care, and death dates back to the Heian period, but there are few materials on it from modern history. This attitude was always present in the past in Japan, but there may have been other values that controlled it or had a greater degree of influence, and this may have suppressed this attitude a small amount. This attitude may have been influenced by other concepts, as well. For example, the Confucian concept of filial piety – in which it was expected of children to care for their parents – may have lessened feelings of being a burden to others. It may also be possible that people thought that passing away would have a positive impact on various people, as told in Buddhist stories of being reborn in purity, and this may have led them to view passing away in a different light than being a burden. These values related to filial piety or being reborn may no longer seem very realistic to people in Japan today, and the disappearance of these concepts that had previously suppressed the attitude toward being a burden let it come to the forefront. This change in recognition may not have taken place on the individual level, but may have become a prevalent norm or value in the modern era. As previously mentioned, this oversensitivity toward the recognition of being a burden may lead to gaps or breaks in communication and is preventing the effective co-creation of information. History also shows us that it is impossible to lose this attitude, so we must consider how to best live alongside it.

4-6

The growing amount of inaccurate medical information online and the need to develop and discuss an environment for controlling it

- While pseudo-medicine with no scientific basis is nothing new, in recent years, a vast number of people get their information from video platforms. More people than ever before are now hearing inaccurate information such as, “Anticancer drugs are banned in the United States,” or “The WHO has banned anticancer drugs.” Some believe this information and pass it on to those around them using social networks. In addition, many of the people who appear in the videos that transmit this inaccurate medical information seem ordinary and friendly. This eases the viewer’s sense of caution toward doubting what they have to say, so people tend to believe them.
- The companies that operate online video platforms have reinforced rules to prevent people from accessing videos that spread pseudo-scientific or inaccurate medical information, and have introduced designs that prioritize videos that point out inaccurate information created by health professionals.
- We are living in a “spider’s web of information,” where inaccurate information is all around us and everyone stands a chance of falling for it. For example, when patients with kidney disease read an article in a health magazine that claims massaging the kidneys can heal them, they might ask their nephrologist about how to massage their kidneys. In such cases, patients think they have found a precious bit of information that is going to help them attain better health and are unaware that they have been caught in the spider’s web of misinformation. Working together with people in various positions including health professionals, the mass media, patients, and affected parties, we must actively transmit discussions like those held today to society and make the world a place where the spider’s web of misinformation is clearly visible.

4-7

The widening information gaps among people who actively seek health information and people who are uninterested

- In addition to transmitting accurate information, the party doing so is also very important, and a network must be established to create mutual links among members of the general public (namely, patients and other affected parties) to make it easier for that information to be accepted as narratives. While they are not specialists, the “members of the general public” we refer to here are people who think about healthcare on a daily basis. It will be beneficial to establish a network among affected parties to foster information sharing, but those parties will be constricted by the allure of knowledge – once they know something, they cannot go back to a time when they did not know it. This means that steps must be taken to regularly update the knowledge possessed by people who have already acquired some information.

On the other hand, people who are the most difficult to provide with accurate information and intervention would be the farthest from such a network, and conversely, that distance only grows the more the network is expanded. This ends up dividing communication. To co-create information in the future, we must examine methods of overcoming that division among people who are interested in health information and those who are not.

4-8

The potential for easy-to-understand narratives to alter the accuracy of evidence-based data and diagnoses

- After the launch of disease-modifying drugs for dementia, studies are being conducted to closely reexamine cases in which Alzheimer’s disease was diagnosed using conventional neuroimaging and amyloid

Positron Emission Tomography (PET) scans. These studies are currently finding many cases in which conventional neuroimaging resulted in diagnostic errors. Physicians serving in clinical settings diagnose a great number of patients using complex data from sources like long-term follow-up and observations, so it is very interesting to see there are diagnostic results that differ from neuroimaging findings.

- While it is important to communicate narratives effectively, we should not lose sight of the need to transmit accurate, evidence-based information. We must also take note of the fact that narratives which can be conveyed to people more easily can sometimes alter information that is based on evidence. For example, if someone uses functional neuroimaging and tells a patient that there are brain function abnormalities or a disease while pointing at glowing areas, the patient may believe them. Researchers who spent many years developing functional neuroimaging are surprised to see these images interpreted in such a sweeping manner, and this has become concerning for many scientists. However, when data is interpreted to create narratives and is documented as text, the process of breaking down that information into something more accessible for the sake of providing explanations can lead to events that scientists did not anticipate. This includes the transmission of information that was not originally intended.
- Objective explanations backed by data and narratives that are close to subjectivity generally align with what German philosopher Karl Jaspers (1910-1969) referred to as “explanation and understanding.” When one physician was asked why scientists tend more toward “narratives that are close to subjectivity” or “understanding,” they replied, “As scientists, we want to avoid mistakes no matter what, and we do not want to admit when we were wrong.” In other words, when we enter into the realm of “understanding,” we face a dilemma in which mistakes become inevitable and the scope of interpretation becomes enormous. How to best bridge the gaps between explanation and understanding may become an issue in communication in the future.

4-9

Communication that becomes fragmented due to there being a small number of transmitters and many receivers, and overcoming this challenge

- The layout at the venue where the meeting was held featured several speakers and many audience members, and resembled a Buddhist sermon. While attempting to invent and improve methods of information transmission is a good thing, in a setting like the one used at the venue, it is considered a given that the speakers’ statements – or more specifically, the information provided by the information transmitters in attendance – are correct. (In a Buddhist sermon, that information would be Buddhist teachings.) Unless there were changes to that layout, there would be fragmentation in communication between the information transmitters and recipients, and this can be viewed as a structural limitation to information co-creation.
- While Buddhism shares the teaching of the Buddha to help people attain enlightenment, the path to doing so is different for each person. In other words, information recipients cannot always attain enlightenment with the righteousness of the information transmitter alone. If we substitute this into the context of healthcare, where the goal is health and wellbeing, we can conclude that each individual can seek their own method. While each individual has a different method of interpreting information, it is important for them to attempt to make better choices in the future by making those methods even more reliable, such as by examining them with an understanding of tradition, having repeated discussions, or by using evidence. Speakers/information transmitters have information, but in reality, that information is not absolute, and by chance, anyone could be in the position of transmitter while anyone could be in the position of receiver. It is also worth noting that the speakers and the audience as a whole are a group of people who just happened to gather at the same place. Adopting a perspective like this with the understanding that the transmitter and recipient are aiming to co-create information is one method of overcoming fragmentation.

Furthermore, the people who gathered at the meeting and took part in the discussion were people who have been giving serious consideration toward the nature of health information as professionals. Even in a discussion among professionals, opinions clashed and it was not easy to come to conclusions. Moving forward, communicating this fact to society may be one way to avoid having such meetings become one-sided discussions that oppose other perspectives.

4-10

Understanding the optimism and pessimism in the background of brain neuroimaging, concern toward becoming a burden, and AI

- Whether it is about interpreting the results of neuroimaging or researching attitudes toward being a burden to others, there is a mixture of optimism and pessimism throughout society. If hope goes too far, it can turn into hype, so how video content and the media are used will be extremely important. While one participant shared the personal belief that the reception of new technologies like AI can be viewed with a degree of optimism, some philosophers reject techno-optimism.

For example, when considering if diagnosing dementia using neuroimaging or large language models (LLMs) is optimistic or pessimistic, we must also consider a more multi-layered perspective in addition to the rejection of techno-optimism. In *Moralizing Technology*, Dutch philosopher Peter-Paul Verbeek supports the empirical turn, and French philosopher Bruno Latour argues that we must consider more empirical aspects rather than just techno-pessimism. How should we convey the fact that the tendency to view oneself as a burden and narratives in clinical settings are not monoliths of optimism or pessimism, but a complex mixture of both? And, can that be considered wisdom? If so, what kind of wisdom would it be? As previously mentioned, what Karl Jaspers describes as the knowledge of understanding may not be containable by clinical knowledge. It is unclear as to whether the view of the self as a burden is rooted in optimistic emotions or pessimistic ones. It is because this is unclear that we must consider matters at a more foundational level.

- While “I don’t want to bother you” sounds like the right thing to say, one study began by asking if that is actually the case. Positive and negative aspects are always present in the background of this attitude, and the contexts and backgrounds of this attitude in situations related to aging, end-of-life care, and death are different from those in other public spaces, so by nature, it should carry a different meaning. Despite the differing contexts for both of these spaces, we are left with the impression that there is some overlap in their meanings and in the awareness behind them. From person to person, the positive and negative aspects that lie behind the view of the self as a burden vary in content, and research to clearly identify each aspect is still ongoing. In fact, the aforementioned study was able to reveal the true feelings of parents who said they did not want to burden others at the end of their lives in one or two cases out of around 200 people, and their children were happy to learn their parents’ true feelings. By identifying and effectively disseminating cases like these, it may be possible to deepen conversations on life and death in parent-child relationships, so we must examine methods and tools for doing so in the future.

4-11

The transformed nature of health information creation and the continuing socialization of personal health data

- In addition to perspectives on information transmission, we should also include perspectives from the side of information producers; namely, those who handle development and management operations for electronic medical records and the creation of big health data. While the tools we use to transmit information have changed and grown more diverse with the development of social networks and video platforms, it also seems that the way we produce information is changing, as well. It is likely we must also transform communication to suit these changes in how information is produced. For example, various

forms of health information are being digitalized one after another, and such information is accumulating. While there are few examples from Japan, overseas, it is becoming increasingly common for manufacturers of electronic medical records to create them together with patients. So, in addition to the ongoing digitalization and accumulation of health information, the quality of that data is also changing. The gradual accumulation of health information data (or, to phrase it in terms of the relationship between the objective self and subjectivity, the accumulation of the “objective self”) may form an objective group and change subjectivity in society and society’s way of thinking. Therefore, while discussing how information is transmitted, we should also continue discussing how information is produced.

4-12 The co-creation of common values based on a recognition of positions and realities given by chance

- Even when various parties including health professionals, patients, and long-term care providers are in the same setting, they each have their own position and viewpoint, and members of each group tend to align with each other according to those positions. However, there are times people form groups after being placed in situations and environments. Whether it is in the context of healthcare, physical characteristics, being born in Japan, or being born in a country that is at war, this reality is the same: people cannot change the positions they are given. This results in differences in perspectives and values. While these differences are entirely up to chance, it may be that conflict arises because we perceive these values as being all the values that exist. While keeping in mind that we have differences which are given to us by chance, what will be important is if we can share and co-create values while recognizing and embracing diversity without aligning ourselves in groups according to those differences.

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