Communicating health information with the public: lessons learned post disaster

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Public health efforts are reliant on the dissemination of accurate scientific and medical information. Furthermore, open dialogue amongst researchers, policymakers, practitioners and the public can support the generation, dissemination, and use of scientific and medical findings. Information must be made readily available, accessible and usable if it is to support their informed decision making and efficacious action. However, access to health information can be stymied when faulty assumptions and expectations lead to a mismatch between the information provided to the public, and their skills and abilities. We know, from the repeated waves of adult literacy surveys undertaken in many industrialized nations, that significant numbers of adults in all participating nations have difficulty in using readily available materials to accomplish everyday tasks with accuracy and consistency.1 Recently, similar findings have been reported in Asian and African countries where health literacy measures were developed.2,3 Studies suggest that people with lower literacy skills are more likely to be residing in under-resourced areas, under-employed, poor, older adults and/or members of a minority group. Also, analyses indicate that this confluence of lower skills and marginalization may contribute to health disparities, which may worsen the double burden in low-income countries that struggle with high prevalence of communicable as well as chronic diseases.4

Health information materials and messages must be designed in a way that no one is left behind.5 With more than two decades of literacy research, we now know that health communication strategies must be augmented with findings from literacy and health literacy research. By highlighting the importance of information, literacy-related research argues that information should be well tested, clearly articulated, jargon-free, organized from the perspective of users, and carefully designed to be useful. This approach shifts the burden of literacy away from the receivers of information to the distributors of information, and the communication skills of the latter becomes important to establish stronger bonds of trust between the two in society.

This commentary draws some lessons learned from a brief case analysis related to the Fukushima disaster of 2011, involving an earthquake, a massive Tsunami, and nuclear accident. The case focuses on the nuclear disaster and the health effects of radiation contamination, both the scientific findings and public perceptions. In so doing, the importance of bridging the gap between scientific findings and beliefs through more rigorous communication analysis, planning, and dissemination is highlighted.
CASE BACKGROUND: PERCEIVED HEREDITARY EFFECT OF RADIATION EXPOSURE IN FUKUSHIMA

There is a persistent gap between scientific facts and people's belief about hereditary effects of the Fukushima nuclear accident. It was nearly 10 years ago in 2011 that the nuclear accident occurred after the massive Tsunami and earthquakes. Subsequently, the Fukushima local government launched a prefecture-wide epidemiological studies (Fukushima Health Management Surveys) to explore health effects of a low-dose radiation contamination. So far, the obtained results revealed no obvious effects with regard to the outcomes of pregnancies, but an increase in psychological distress as well as a temporal decline in pregnancy intention and breast feeding. Mothers’ particular concern about their children is persistent. Even four years after they gave birth (in 2011 to 2014), over 60 percent were worried about their children’s health status in general and over 30% about hereditary effects (influences on off-springs of their children). The same is true among residents of coastal areas in Fukushima, where the crippled nuclear power plant is located. Although the proportion is declining, 37% of respondents of the Fukushima Health Management Surveys in these areas indicated in a 2017 survey that hereditary effects were likely to occur. Furthermore, the Fukushima Health Management Survey and other surveys in Fukushima reported that lower educational attainment and lower health literacy were associated with a higher perceived risk of radiation exposure.

Children in Fukushima are growing with their parents’ persistent concern about their health, and protection measures that families decided to take. A 2014 survey among parents of children in various age groups from infants to junior high school students in Fukushima revealed that about 20% were concerned about radiation exposure, and over 20% of mothers of children less than 12 years old and over 10% of older children spent weekends in low radiation areas. The average age of Japanese women to give birth to the first child is around 30 years old. Students entering high schools (15 years old) at the time of the disaster in 2011 will reach the age 30 in 2026. Deliberate decline in concern about hereditary risk right after the disaster was observed in the reproductive age group in Fukushima, and further decline in the hereditary risk perception could not be achieved unless we appropriately address the concerns of current mothers and young people, who are the future parents. A survey among women’s college students in Fukushima, which was conducted four years after the disaster, showed that students’ confidence in having a normal childbirth was negatively correlated with their risk perception about hereditary effects of the radiation exposure in Fukushima. Most of them were high school students at the time of the disaster.

Japan holds a historical cohort data of atomic bomb survivors, which shows a long-term stigma around a regional radiation exposure. A study of survivors exposed to the atomic bomb in utero reported that the marriage rate tended to be lower with increasing exposure dose among both sexes. This was explained in part by discrimination due to people’s persistent belief about hereditary effects of radiation exposure. One might consider a need to minimize discrimination so that marriage prospects of young people in Fukushima are not similarly compromised.

This discussion uses the Fukushima experience as a case to draw health literacy lessons that can fill a gap between scientific findings and popular beliefs. It refers to the United States Centers for Disease Control and Prevention’s Clear Communication Index (CDC’s CCI), which is a tool to help assess and improve written health materials. The CDC’s CCI first
asks users to clarify the characteristics of their audience (their literacy and numeracy skills, prior experience with the topic, and ability to comprehend different information formats such as graphs) and the primary communication objective, followed by the items to score the main message, specific behavioral recommendations, levels of text and numbers used, and ways of explaining risk. This tool focuses on both health literacy and numeracy, and more importantly, it promotes interactions between the users (information developers) and their intended audience by asking the users to clarify the points mentioned above.

**LESSON 1: USE Plain LANGUAGE TO EXPLAIN COMPLEX CONCEPTS**

We in medicine and public health must consider the complexity of scientific and health information. For example, the Japanese Ministry of the Environment published “BOOKLET to Provide Basic Information Regarding Health Effects of Radiation”. In the booklet, the hereditary effect of radiation exposure is explained as “…there has been no evidence to prove that parents’ radiation exposure increases hereditary diseases in their offspring in the case of human beings. The International Commission on Radiological Protection (ICRP) estimates risks of hereditary effects as 0.2% per gray. This is even less than one-twentieth of the risk of death by cancer.” This passage, written in Japanese, is at the 9th grade level, as measured by the Obi-3, an internet tool to assess a text grade level. According to the health literacy toolkit developed by the U.S. Department of Health and Human Services Centers for Medicare & Medicaid Services, this grade level is categorized as between “average difficulty” and “difficult”. It should also be noted that unexplained technical words such as unit of radiation and abbreviations are used. A recent study reported that 95% and 46% of people in Fukushima knew the terms (e.g. sievert and ICRP), whereas the proportions were lower in other prefectures (e.g. 84% and 17% in Aichi prefecture without a nuclear power plant). As the CDC’s CCI recommends information developers to be aware of the health literacy level of their primary audience and “always” use words that the audience is familiar with, we need to carefully develop the health information by lowering the complexity of texts, and by avoiding technical jargons and offering clear explanations of scientific terms and measures.

**LESSON 2: BE ATTENTIVE TO NUMERACY COMPLEXITY**

The above passage in the Ministry of the Environment booklet also contains numerical information using a percentage written in terms of a number with decimal point and a fraction. The concept risk is noted as well, but not explained. This concept is classified as the most difficult numeracy information according to the “hierarchy of numerical complexity and comprehension” suggested by Apter and colleagues. Accordingly, a recent survey investigating people’s numeracy level in Japan reported that the proportion of respondents giving a correct answer was lowest for knowledge questions about chance/probability. On top of the difficulty in understanding risk, the above passage about hereditary risk requires people concerned about the Fukushima nuclear accident to convert unit and calculate what the risk proportion would be for their exposed radiation level (e.g. 0.14 μSv/hour in Fukushima city in 2018). The CDC’s CCI recommends that numeric information be presented with whole numbers that the primary audience is most accustomed to, that explanations be offered along with the number in such a way that the audience/reader does not need to undertake any calculations.
LESSON 3: COLLABORATE WITH THE INTENDED AUDIENCE

Health materials must be developed with rigor and follow a scientific process involving formative research, pilot testing with members of the intended audience, assessments and revision. A number of tools have been developed to help assess a variety of characteristics of texts that inhibit or facilitate comprehension and use. Various tools provide valuable insight for materials development, assessment, and/or re-writing. Some tools, such as reading grade assessments must be used for specific languages. For example, the Simplified Measure of Gobbledygook (SMOG) focuses on word and sentence length. Long sentences are difficult for many readers because they tend to contain clauses or asides that distract a reader from the main point. In the English language, word length is also an issue because longer words in English tend to have silent letters and so makes it difficult for weak readers. This is not true, however, in Spanish or Italian where every letter is pronounced. A number of other tools focus on broader components of text such as vocabulary, organization, or format. For example, the above mentioned CDC’s CCI consists of 20 scoring items to assess both text and numerical health information. The author has modified this tool to reflect the Japanese culture and translated it into Japanese as well as provided workshops to help health professionals use it. It proves useful for materials development as well as assessment.

In addition to the scoring items, the index has four introductory questions focused on characteristics of the targeted audience and the main message to convey, making sure that the developers engaged in needed formative research. This implies that a rigorous assessment with pilot testing of the developed materials among intended audience is required even at a time when an urgent response is needed after a disaster. Such pilot testing can also promote participatory development of health information in community. According to Sandman PE, the concept of risk consists of both technical portion “hazard” and non-technical portion “outrage”. Quantitative risk assessors focus on the hazard and affected communities focus on the outrage. As Sandman recommends, epidemiologists should involve people in the process of designing scientific evidence, implementation of evidence-based practice and interpretation of scientific evidence when creating and disseminating health information in the community. Studies have shown that health interventions developed in collaboration with members of the intended audience are more likely to appropriately address their needs and can even lead to capacity development within the community. Without clear understanding of the audience’s needs and demands, behavioral recommendations that are specific to them can not be effectively conveyed.

IMPLICATIONS FOR HEALTH COMMUNICATORS

These lessons learned in the aftermath of the Fukushima experience also call for improved readiness of health professionals to communicate scientific facts, directions, or general information in a way that is accessible to all in the community. Right after the Fukushima nuclear accident, confusing messages with regard to the reference level, designation of evacuation areas, and health effects led to people’s distrust of the national and local governments. When the messages did not meet the needs of audience and their distrust toward the government was shaped in the early phase of the Fukushima case, subsequent health communication between professionals and a community was interrupted. One such example is the “alarmist interpretation” of the increased rate of thyroid cancer among children in Fukushima. This type of “risk” indicators is the most difficult numeric
Although specialists explained that the high incidence rate was largely due to the “screening effect” of the region-wide screening, the message did not reach the community members. As a result, the implementation of school-based screening is still in operation, though it is under debate. On the contrary, such routine screening among healthy people has been no longer recommended in Korea since the screening effect was detected.

In Japan, public health nurses are the gatekeepers of community health and they conduct community diagnoses and plan and implement health promotion activities. Many of the nurses work for local governments and health centers and are the first responders when a disaster occurs. Sadly, communication to these key professionals was not well developed and, as a result, these professionals were not well equipped to communicate with their clients. A survey among public health nurses in Fukushima prefecture in 2015 reported that 14% answered that the hereditary effect was likely to happen in their region, and 77% had faced difficulty answering questions about radiation. Similarly, teachers are the major informants about radiation at schools. The Japanese government published standard textbooks on radiation for students at elementary, junior high and high schools. However, a survey similar to the one among nurses was conducted at schools in Kagoshima prefecture with a nuclear power plant, and 79% of teachers answered that they had anxiety about having to address students’ questions about radiation.

Identification of and involvement of stakeholders in communities to promote multilateral communication in the earlier phase is recommended. As such, nurses and teachers should have been the first professional groups to be thoroughly briefed and educated about the scientific evidence so that they could then “translate” what they learned to their communities. Such strategic implementation of the multiple layers of “translators” is recommended for effective and efficient risk communication. One possible strategy is to formulate an emergency health literacy team to help implement a multiple-layer communication system to work from the early phase of a disaster.

CONCLUSION

This commentary focused the case of hereditary risk perception in Fukushima and three health literacy lessons learned: use of plain language, attentiveness to numeric information, and needed rigor in health information development. These lessons indicate the needs of awareness raising among health professionals about the gap between science and community, identifying and empowering key “translators” in communities, and collaborating with community residents including children and young people. People with lower literacy skills are to be found in all parts of the world. Health literacy promotion among both health service users and providers can lead to better health outcomes and equity as stated in the United Nation’s sustainable development goal 3. No one should be left behind and information must be geared for the greatest possible ‘accessibility’.

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