



When and how to enlighten citizens on genetics and hereditary cancer: a web survey of online video viewers

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Abstract

With the rapid expansion of genomic medicine, more citizens are compelled to think about genetics in their daily lives. This study aims to explore appropriate types of educational media and methods to enlighten activities for genetics and hereditary cancer. We presented an 18-min YouTube video on genetics and hereditary cancer to participants at a scientific event, Science Agora 2020, and administered a web questionnaire to investigate their opinions about when and how citizens should start learning about genetics and hereditary cancer. We recruited 133 participants who watched the video, and 26.3% (35/133) responded to the questionnaire. Most of them were evaluated to understand and appreciate the contents of the video. They identified websites, or videos as suitable learning media, irrespective of their sex, age, or profession. They highlighted upper elementary school or junior high school as appropriate educational stages to start learning about genetics and hereditary cancer to facilitate collecting their own genetic information by themselves. Our findings show that educational institutions should provide opportunities to learn about genetics and hereditary cancers, especially for upper elementary school and junior high school students, using learning media, such as videos, depending on their level or demand.

Keywords Genetics and hereditary cancer · Websites · Videos · Education

Introduction

It is estimated that 5–10% of patients diagnosed with cancer are due to genetic factors (Ngeow and Eng 2016). In Japan, one in two people will be diagnosed with cancer during their lifetime, and approximately 21,000 people in the AYA generation (adolescent and young adult) between the ages of 15 and 39 are diagnosed annually. Cancer control measure is a challenge for the entire nation, including young people (Katanoda et al. 2017).

In 2018, “the recommendation on the selection of core bases/ bases/ affiliated hospitals for cancer genomic medicine and the information transmission process in genomic medicine” was issued in Japan (Japan Agency for Healthcare Research and Development 2019). Moreover, since 2019, the “cancer gene panel test,” which analyzes hundreds of cancer-related genes at once so that the optimal treatment for each patient can be selected using the genomic information of cancer cells, has been covered by insurance.

The development of personalized cancer medicine using the genetic information of cancer cells is expected to accelerate (Kumaki et al. 2019). It is necessary to promote

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the genetic literacy of ordinary citizens and to establish a comprehensive system that can lead to more advancements in genomic medicine; however, such a system has not been developed yet (Kosugi 2019), and it remains insufficient for a comprehensive understanding of cancer (Ministry of Health, Labour, and Welfare 2015).

In Japan, “cancer education” focusing on cancer screening and prevention has been implemented in elementary, junior high, and high schools since 2014 under the “Comprehensive Support Project for Cancer Education.” Cancer education in schools is positioned as a health and physical education subject in the Courses of Study established, focusing on cancer screening and prevention with a strong emphasis on lifestyle-related diseases (Ministry of Education, Culture, Sports, Science, and Technology 2017, 2018). However, there are few references to human genetics and genomic medicine in the curriculum guidelines (Watanabe 2017). Therefore, most citizens have limited opportunities to learn about basic human genetics, which makes them prone to impaired judgments, misunderstandings, or anxiety, as they may be unable to make decisions about their own health and treatment based on genetic information. These can prevent them from acquiring correct knowledge, communicating with medical professionals, or learning by themselves about various diseases, especially cancer.

Recently, information technology has been rapidly advancing, and citizens can obtain more medical information by searching on the Internet (Ministry of Internal Affairs and Communications 2014). In the previous studies, comic books (Hiraoka 2016; Japan Agency for Medical Care and Development 2019) and dramas (Kobayashi et al. 2019) were used to educate the public about genetics. However, there are no reports on the use of video media, such as online video-sharing platforms, to educate the public about genetics and hereditary cancer. Therefore, this study aims to explore the suitable learning media and method of enlightenment activities for genetics and hereditary cancer. For this purpose, we launched the project “Genetic Cafe,” a public awareness project planned and run by genetic medicine experts. At the science event for the general public, “Science Agora 2020,” hosted by Japan Science and Technology Agency (JST), we presented a YouTube video under the name “Genetics Cafe: Let’s Know Genetics” to the participants and conducted a questionnaire survey for the viewers.

This study examined effective educational policies for genetics and hereditary cancer and explored appropriate types of educational media and methods of enlightening activities. The findings of this study can be used as a reference for the best educational strategies for promoting knowledge on personalized cancer medicine and genomic medicine to realize more effective health management and cancer prevention.

Materials and methods

In this study, we presented a video to participants at the “Genetic Cafe” in Science Agora 2020 to convey essential information about genetics and hereditary cancer. Then, we asked the video viewers to complete a post-viewing web questionnaire.

Science Agora has been held annually since 2006, which is one of the largest science events in Japan sponsored by Japan Science and Technology Agency and a forum open to everyone with the purpose of connecting science and society through connecting parties from different fields, sectors, generations, and nationalities to promote activities in each region independently. Government officials, scientists, and citizens participate in this forum to present their ideas to connect society and science from their respective standpoints.

Creating the video

Video creation and overview

We chose YouTube, the world’s largest video-sharing platform (Visual capitalist 2019; Pew research center 2018), as a medium for presenting the teaching materials because it can deliver information to a wide range of viewers for free, can be viewed repeatedly, and can improve understanding through the use of multimedia including text, images, and sound (Honda 2000). We have created the video “Let’s learn about genetics and hereditary cancer!,” sponsored by Japan Science and Technology Agency 2020. The video creation period was from June to October 2020. The video was presented for 15 days during the period of Science Agora 2020 and the following week, that is, from November 15 to 29, 2020.

Selection of content items

The video consisted of two parts; the first was an introduction while the second was a lecture. The content items of the lecture were selected based on the “Recommendations on the Information Transfer Process in Genomic Medicine” by Japan Agency for Medical Research and Development (AMED) (Japan Agency for Healthcare Research and Development 2019) and previous studies (Sogawa et al. 2019).

The ten items were as follows: heredity, genes, causes of cancer, relationship between cancer and genes, medical treatment using genetic information, family tree, hereditary cancer, genetic counseling, certified genetic counselor,

and summary. Based on the previous study (Sogawa et al. 2019), we created eight main statements that included the key points for learning about personalized cancer medicine (Table 1). The contents were reviewed by the project staff.

We designed the flow of the video so that the viewer could clearly understand these eight main statements. We finally completed the video containing the 18-min lecture with 59 slides on genetics and hereditary cancer, following the 3-min introductory remarks. The video is available on the website of Science Agora 2020.

Web questionnaire survey

Target group

The respondents were participants in Science Agora 2020 who watched the YouTube video of “Let’s learn about genetics and hereditary cancer!”

Questionnaire survey procedure

The web questionnaire survey was conducted using a Google form from November 15 to 29, 2020. In this cross-sectional study, the participants agreed with the research purpose and completed a self-administered questionnaire survey after watching the video.

Selection of questions

The original draft of the web questionnaire was based on previous researches (Sogawa et al. 2019; Haga et al. 2013; Kihara and Kihara 2014). To evaluate whether the video viewers correctly understood the content of the video, we created a questionnaire consisting of five basic attribute items, eight knowledge questions, nine awareness questions, and one description question. The questionnaire consisted of a total of 23 items, including four items of basic attributes, eight items of knowledge, and eight items of awareness problems as questions that must be answered. The questions

other than the open-ended items were asked using the multiple-choice method or the rating scale method.

Ethical considerations

This study was conducted with the approval of the Research Ethics Review Committee of the Department of Medical Sciences, Okayama University (Lab. No. 2003-038). A check box for consent to participate in the study was provided in the web questionnaire.

Analysis

The total number of the video views was obtained from YouTube analytics. The results of the free description were analyzed qualitatively by thematic analysis, considering references in previous studies (Kihara and Kihara 2012).

Results

Attributes of the target audience

The total number of views of the video was 343, the estimated number of viewers (unique viewers) was 133, the number of respondents was 35, and the response rate was 26.3%. The respondents agreed with the purpose of the research and provided answers regarding the required items. Therefore, there were no analysis exclusions. Table 2 shows the respondents’ attributes, including gender, age, occupation, and self-learning experience regarding heredity.

Evaluation of the video and knowledge and understanding of the content

Table 3 shows the results for the video evaluation by the respondents. All respondents understood that “even if they had a hereditary cancer or were born with a predisposition to develop cancer, they would not necessarily develop cancer.” They also correctly recognized that they

Table 1 Eight main statements on learning about cancer genomics

Items
1. Cancer is a disease caused by genetic mutation.
2. Some healthy people are born with a tendency to develop cancer.
3. Approximately 5–15% of people diagnosed with cancer are born with a predisposition to cancer.
4. Even if you are “naturally susceptible to cancer,” it does not mean that you will definitely get cancer.
5. If one of your parents is “born with a cancer-prone constitutional DNA,” there is a 50% chance that you will inherit the constitutional DNA.
6. When considering hereditary cancer, the age at which the disease began is also important.
7. A “certified genetic counselor” can be consulted for advice on genetic issues.
8. Genetic counseling is available to anyone, regardless of whether they have the disease.

Table 2 Characteristics of the target group

Characteristics	Answer	<i>n</i> (<i>n</i> = 35)	%
Gender	Male	13	37.1
	Female	22	62.9
Age	10s	1	2.9
	20s	14	40
	30s	5	14.3
	40s	8	22.9
	50s	7	20
Profession	Company employee	6	17.1
	Self-employed	5	14.3
	Health care worker	5	14.3
	Teachers	4	11.4
	Administrative staff	4	11.4
	Student	4	11.4
	Graduate student	3	8.6
	Researcher	1	2.9
	Other	1	2.9
	No answer	2	6.1
Self-study experience on genetics	Yes	14	40.0
	No	20	57.1
	I do not know	1	2.9

could consult a certified genetic counselor about their genetics. However, the percentage of the viewers who gave correct answers to questions about hereditary cancer rates was lower than that for other questions (Fig. 1).

Table 3 Questions and answers to the created video

Question	Answer	<i>n</i> (<i>n</i> = 35)	%
Did you understand the content of this lecture?	Yes	33	94.3
	Neither	2	5.7
	No	0	0
Was the content of this lecture easy to understand?	Yes	32	91.4
	Neither	3	8.6
	No	0	0
Do you think the content of this lecture is useful for your interest in “heredity” and “cancer”?	Yes	32	91.4
	Neither	2	5.7
	No	1	2.9
When do you think you need to learn the information you have obtained from the video?	When you feel the need	1	2.9
	Lower elementary school	1	2.9
	Middle elementary school	2	5.7
	Upper elementary school	10	28.6
	Junior high school	15	42.9
	High school student	5	14.3
After high school graduation	1	2.9	

Suggestions for effective educational activities

Table 4 shows the result of respondents’ perceptions of effective learning media for genetic and cancer education. Video was the only effective medium common to all surveyed age groups.

Appropriate educational stages to start learning about genetics and hereditary cancer

All respondents (35/35) answered that high school students could understand the contents of the video, while 85.7% (30/35) of them thought that junior high school students could understand the contents as well (Table 5). Additionally, 28.6% (10/35) and 42.9% (15/35) of the respondents stated that it was appropriate to start learning about genetics and hereditary cancer in upper elementary school and junior high school, respectively (Table 3).

Discussion

Most respondents understood essential information on genetics and hereditary cancer and that they could appropriately judge when and how to enlighten citizens on genetics and hereditary cancer.

More than 90% of the respondents from various backgrounds answered that the video was easy to understand and useful for those who are interested in genetics and hereditary cancer. In terms of learning media, the respondents from all age groups ranked videos highly and also mentioned websites and video-sharing platforms, such as YouTube. The results of the current study

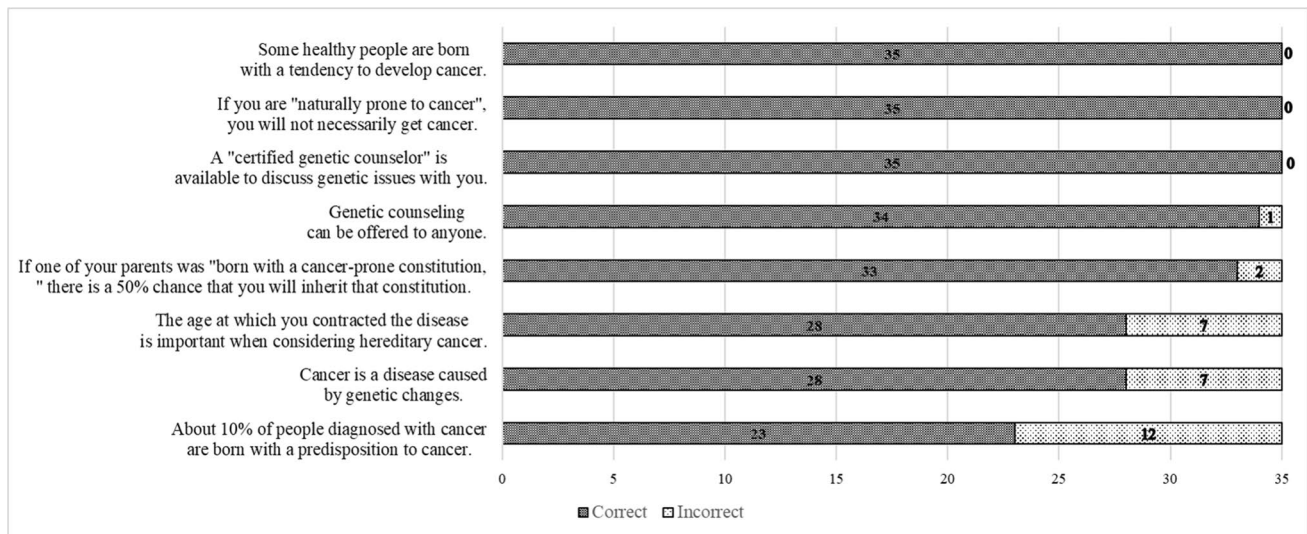


Fig. 1 Question and number of correct answers. Numbers in the graph indicate the number of people for each response. Number of correct answers to the questionnaire items after watching the video

Table 4 Responses to suggestions for effective educational activities

Total	N	What type of media would you like to use to obtain the information you got from this lecture? (Multiple answers allowed)				
		Age				
		10s	20s	30s	40s	50s
Home page	22		9	2	5	6
Video	21	1	8	3	7	2
Manga	15		6	1	3	5
Books	15		6	2	3	4
Lectures	11		2	3	4	2
Pamphlets	10		5	1	4	
Posters	5	1	2	1	1	
Other	3		1	1		1

Table 5 Responses regarding understanding genetics and hereditary cancer by educational stage

	Question	Answer (n = 35)		
		Understand	Do not understand	Do not know
Do you think it is possible to understand the knowledge gained from this lecture for each option?	Lower elementary school	1	23	9
	Middle elementary school	5	17	11
	Upper elementary School	16	7	10
	Junior high school	30	0	5
	High school student	35	0	0

support those of previous studies (Huang and Penson 2008; Prochaska et al. 2017) showing that social media and mobile health technologies, including the Internet, play an important role in finding health information for

cancer prevention and treatment. In addition, the existing literature highlights that cancer genetics education using videos is useful for people with visual impairments or those who cannot read for some reason (Boudreault et al.

2018). The fact that video distribution services can be distributed to a wide variety of people around the world in prior studies suggests that they need to be incorporated as a familiar medium for respondents in the future (Tackett et al. 2018). In summary, effective enlightenment activities should incorporate the use of educational videos.

In this study, 28.6% and 42.9% of respondents said it would be appropriate to start learning about genetics and cancer in upper elementary school and middle school, respectively, and most respondents realized the importance of early education on genetics and cancer. Our results are in line with those of several previous studies (Watanabe et al. 2019) that have described the effectiveness of education for upper elementary school and junior high school students. Other studies have reported that early education interventions will have a strong effect on prevention and health promotion behaviors in the future (Campbell et al. 2014) and that school teachers feel the need to teach genetics in cancer education to their students (Yamada-Kurebayashi et al. 2023).

The extant literature points out that the implementation of cancer education at school can bring about a ripple effect on the guardians, leading not only to cancer prevention for the students themselves but also to educational effects for their families (Yokoyama et al. 2018). Therefore, it is important for medical and educational institutions to work together to promote genetic education in schools.

Limitations

This study has the following limitations. First, we could not verify whether the respondents had knowledge of the existence and mechanism of hereditary cancer before watching the video, because we did not compare the results before and after watching the YouTube video. However, since all respondents answered correctly, it is unlikely that the YouTube video had a negative impact on them. Hence, future research should verify the knowledge and understanding of the respondents before watching the video.

Secondly, there may be a bias of the respondents including medical professionals, teachers, graduate students, and researchers, who are expected to be particularly interested in science education, although the Science Agora 2020 event was designed for the general public.

Finally, we did not conduct statistical analysis, because this study is a preliminary survey to see what kind of opinions would emerge from the respondents, and the number of respondents was small. Therefore, it is necessary for future research to expand the target audience to examine whether the results of this study are useful for other ordinary citizens.

Conclusions

The study's findings highlight the importance of learning about genetics and cancer, especially for elementary, junior high, and high school students, using learning media such as videos that match individual characteristics. In the future, it is hoped that more people will get interested in genomic medicine and genetics, especially cancer, through various media, leading to more effective health management and cancer prevention.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s12687-023-00663-x>.

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Author contribution This study was initiated and designed by Reimi Sogawa and supervised by Shinji Kosugi and Akira Hirasawa. Material preparation, data collection, and analysis were performed by Reimi Sogawa, Noriyuki Yamashita, Mariko Kochi, Mashu Futagawa, Fumino Kato, Yusaku Urakawa, Yayoi Tanimura, Hideki Yamamoto, Shuta Tomida, and Akira Hirasawa. The first draft of the manuscript was written by Reimi Sogawa and reviewed by Takahito Wada, and the final manuscript was approved by all the authors.

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Data availability All data generated or analyzed during this study are included in this published article.

Declarations

Ethics approval The questionnaire and methodology for this study were approved by the Research Ethics Review Committee of the Department of Medical Sciences, Okayama University (Lab. No. 2003-038).

Consent to participate Informed consent was obtained from all individual participants included in the study.

Consent to publication Informed consent was obtained from all individual participants included in the study.

Conflict of interest The authors declare no competing interests.

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