

Online peer-group activism for thalassemia health education during the COVID-19 pandemic: a case study from East Java, Indonesia

Annette d'Arqom and Danti Nur Indiasuti

Division of Pharmacology, Department of Anatomy, Histology, and Pharmacology, Faculty of Medicine, Universitas Airlangga, Surabaya, Indonesia, and

Zamal Nasution

Graduate Program in Institute of Population and Social Research, Mahidol University, Nakorn Pathom, Thailand

Abstract

Purpose – This study aimed to measure the effectiveness of online peer-group activism to promote thalassemia prevention among high school students of East Java Indonesia.

Design/methodology/approach – Twenty students were recruited as cadres and trained for thalassemia every weekend for four weeks, followed by creating health promotions via online media. The media was further disseminated among the students' peer groups for a week. The respondent's knowledge was measured before and after health promotion utilizing an online media mixed-methods approach that combined quantitative data using an online questionnaire and in-depth interviews for qualitative measurement. Descriptive and inferential analyses were performed using Graph Prism 5.00. Interview transcripts were analyzed to elaborate on the respondent's understanding of thalassemia.

Findings – The respondents had good basic knowledge about thalassemia; however, it was not in-line with their understanding, which increased after the online health promotion activity. Therefore, this approach is useful for disseminating health issues during the COVID-19 pandemic and can be implemented for broadening respondents.

Originality/value – This study showed the experience of online peer-group activism for thalassemia prevention in high school students. By empowering the peer group, health promotion is effective in increasing the knowledge and understanding of thalassemia. A similar approach can be proposed for other health issues.

Keywords Online peer group, Thalassemia, Good health, Well-being, Indonesia

Paper type Research paper

Introduction

The COVID-19 pandemic affects almost all aspects of human life, including the health promotion system [1]. The precautionary method of physical distancing is a challenge for health promotion practice. The online method of health promotion is a promising way to



deliver the message; however, due to Internet stability, boring language and other distractions, modification of the online method is necessary to ensure delivery of the message [2]. Moreover, promoting health issues by empowering peers has been proposed since 2013 [3].

Thalassemia is a genetic disease that reduces or abolishes globin production. This genetic disease is caused by a genetic mutation in the α -gene and/or β -globin genes, which encode the α -globin and β -globin chain [4]. Therefore, these mutations affect the hemoglobin level. The main symptom of this genetic disease is anemia, which varies from mild, which does not require any treatment, to severe anemia, which requires regular transfusions [5].

Prevention is the only way to stop the growth of this disease. Early detection before marriage and genetic screening with genetic counseling are necessary. Several countries such as Cyprus and Italy successfully reduced their thalassemia rates through prevention programs that have been introduced since 1980 and are now followed by Malaysia and Thailand [6]. Two main factors of the prevention program are mass education and the detection of thalassemia carriers in the population [7].

The detection system of thalassemia in Indonesia is still developing. In 2017, there were 8011 patients with thalassemia in Indonesia, which is projected to increase by 3,000 people each year. Treatment for thalassemia major reached IDR 2.15bn in 2014 and doubled to IDR 4.77bn in 2016 [8]. In 2007, in East Java, Indonesia, the rise in thalassemia patients was observed, from 170 patients in 2007 to 470 patients in 2015 [8]. Moreover, early marriage rates in Indonesia are increasing. Basic health survey (Riskesdas) 2010 data showed 0.2% of women aged 10–14 years, 11.7% of women aged 15–19 years and >56.2% of women aged 20–24 years were married [9].

Therefore, health promotion is necessary to disseminate the knowledge of the status and risk recognition of this disease from an early age, before marriage, to stop the development of thalassemia major. During this pandemic, an online platform can be utilized to empower the youth to spread knowledge about thalassemia among their peer group. A pilot project of this online peer-group activism was tested in July–September 2020 among high school students in East Java, Indonesia. This study aimed to measure the effectiveness of this approach to increase the knowledge of thalassemia.

Methodology

This study used the mixed-method approach, incorporating quantitative and qualitative analyses. The primary data were collected from the online questionnaire and an in-depth interview with the respondents.

Respondents of this study were high school students aged 16–18 years. Inclusion criteria were high school students who agreed to join the activity. Participants who were not high school students and did not complete the survey were excluded from this study. Due to large-scale social restrictions, the selection of the eligible high school was based on the nearest distance from the researcher's address. The communication with the school was supported by the teachers who actively responded to the request. The concept of this activity was further discussed with the vice principals and student affairs officers. Further, the school proposed a list of 20 students and obtained consent from the parents. Those students were recruited as cadres who would disseminate the information regarding thalassemia to other students. They were trained intensively every weekend within a four-week period regarding thalassemia, including thalassemia symptoms, treatments, screening, preventions, blood donors and psychosocial aspects. The training was performed by the pharmacologist, clinical pathologist and psychiatrist using webinar Zoom[®] and education video on YouTube. Further, the cadres were divided into four small groups based on their project, which were education video, news article, Instagram and poster. Each group was mentored by a medical doctor and lecturer from the Faculty of Medicine, Universitas Airlangga. Further, their

projects were disseminated to their friends for a week, and on the last day, four cadres presented information on thalassemia to 67 students.

The knowledge of respondents on thalassemia was measured by using a set of questionnaires before and after the online activity. The questionnaire consisted of two sections, which were basic information of the respondents and a closed-ended question on thalassemia knowledge. In-depth interviews with five respondents were performed to elaborate on the respondent's answer after the online activity using a phone or social media. They were chosen by purposive sampling from the pool of respondents who agreed to conduct interactive communication. Quantitative data were analyzed using Graph PRISM version 5.00 (La Jolla California USA), and interview transcripts were analyzed to elaborate the respondent's understanding regarding thalassemia.

Ethical consideration

Ethics approval was obtained from the Faculty of Medicine, Universitas Airlangga No. 200/EC/KEPK/FKUA/2020, and also, parents' informed consent was acquired before the study.

Results

Characteristics of respondents

A total of 83 responses were received, but only 57 questionnaires were valid and used in the final analysis, corresponding to an effectivity rate of 69%. The respondents were aged from 16 to 18 years old, with 50.88% in the 11th grade and 49.12% in 12th grade. The majority of the respondents were female (77.19%) and the rest were male (22.81%). A total of 70% of the respondents were involved in school club activities such as school committees, journalism, choir and so on. Regarding thalassemia, 80.70% of the respondents had heard about thalassemia before; however, only 14.04% of them knew someone with thalassemia (Table 1).

Characteristic	N	%
<i>Age(years)</i>		
16	24	42.11
17	28	49.12
18	5	8.77
<i>Sex</i>		
Male	13	22.81
Female	44	77.19
<i>Grade</i>		
11 th	29	50.88
12 th	28	49.12
<i>Club activity</i>		
Yes	40	70.18
No	17	29.82
<i>Heard about thalassemia</i>		
Yes	46	80.70
No	11	19.30
<i>Knowing thalassemic patients</i>		
Yes	8	14.04
No	49	85.96

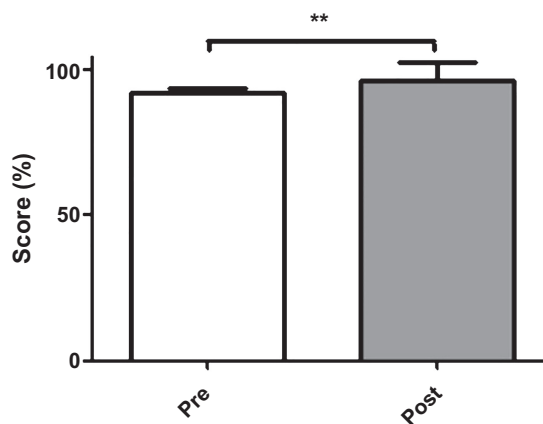
Table 1.
Characteristics of
respondents

Knowledge about thalassemia

Twelve questions regarding the definition, symptoms, screening, treatment and psychosocial aspects of thalassemia were measured before and after a week of online promotion activity. The results showed that the respondents had good basic knowledge about thalassemia (Table 2). After the online peer-group activity, an increase in the knowledge of the respondents was observed (Table 2). The mean of the score between pretest and posttest was significantly different ($p\text{-value} < 0.01$) (Figure 1). However, there was no significant difference between knowledge and age, sex, grade or club activity (Figure 2a-d). Nevertheless, the

Questions	Correct answer (%)	
	Pretest	Posttest
Q1 Thalassemia is a genetic disease that can be inherited from one or both parents	89.47	100
Q2 Thalassemia is a blood disorder caused by impaired hemoglobin production	91.23	96.49
Q3 Thalassemia is an infectious disease	89.47	87.22
Q4 Symptoms of thalassemia vary from asymptomatic/mild, moderate and severe symptoms	92.98	100
Q5 The main symptom of thalassemia major is anemia, which is weakness, fatigue, lethargy, pale face, sometimes with yellow sclerae	92.98	98.25
Q6 Thalassaemic major can be prevented by not marrying another with a thalassemia trait	92.98	94.74
Q7 Not all anemia is thalassemia, thus examination by health personnel is necessary	94.74	98.25
Q8 Thalassemia screening includes a history of thalassemia or repeated transfusions in family members, a history of anemia, physical examination and blood tests	91.23	96.49
Q9 Thalassemia major requires life-long blood transfusions to maintain hemoglobin levels	87.72	100
Q10 Blood donation is needed to ensure the availability of blood supply for those who need it, including thalassemia	94.74	94.74
Q11 Stigma/negative views from society, economic burdens, physical changes are factors that can cause psychological problems in parents and survivors of thalassemia	91.23	94.74
Q12 Government and community support, especially in their immediate environment, is needed by thalassemia survivors and their families	94.49	98.25
<i>Mean</i>	92,11%	96,64%

Table 2.
Percentage of the correct answer



Source(s): * $p\text{-value} < 0.01$

Figure 1.
Comparison between the pretest and posttest scores

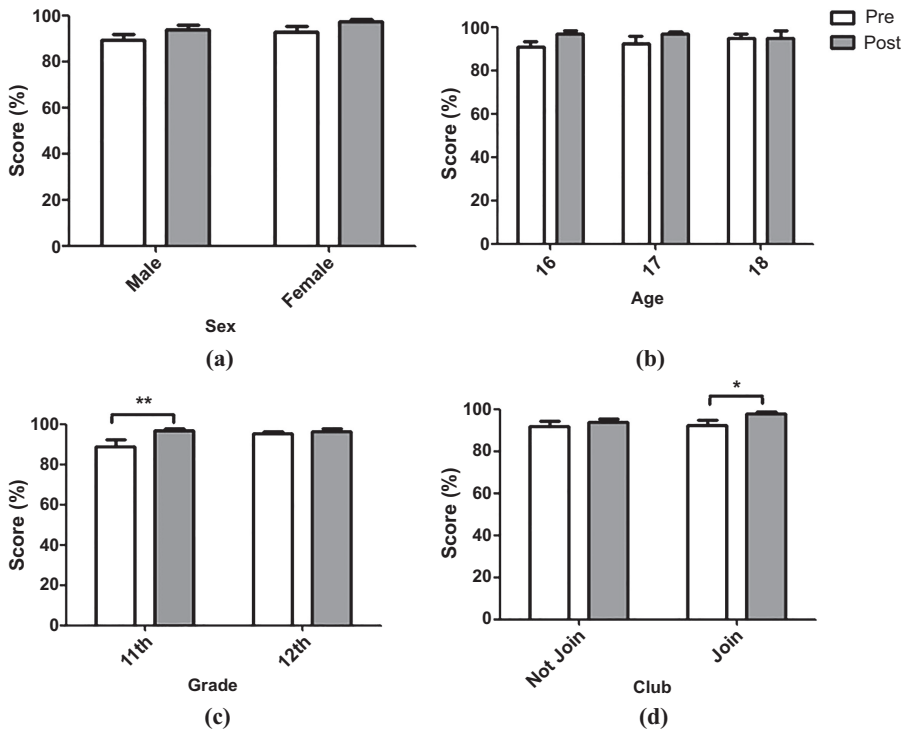


Figure 2. Relationship between sex, age, grade and club activity with knowledge of thalassemia

Source(s): * p -value < 0.05, ** p -value < 0.01

increase of knowledge was found in the 11th grade and students who joined club activities after the thalassemia health promotion (Figures 2c and 2d).

Interestingly, after elaborating with an in-depth interview, their good knowledge was not in-line with the understanding regarding this disease, as respondent 1 and 23 said:

I know Thalassemia from the television show and this disease is inherited from the parents, however, I always think that this disease is infectious. And we need to avoid interaction with the patients.

My friend in elementary school is a Thalassemia patient. So, I know Thalassemia since that period. But I did not understand what it was until I joined this activity.

The respondents admitted that before filling the pretest, they searched and read about thalassemia on the Internet. Moreover, respondent 3 conveyed her curiosity regarding the mechanism of mutation in thalassemia.

Based on the information that I got from the internet, thalassemia is a genetic disease. But how does it occur in the first place? What factors drive this mutation. If we know, maybe we can prevent it from happening.

The respondents also never thought of undergoing a blood screening in order to know the genetic status of thalassemia, as stated by respondent 2:

I think I do not have Thalassemia, since I never felt any anemia. And I do not have any family history of Thalassemia. As I know from the television show, the children will get thalassemia if the parents have this disease. My parents do not have any symptoms, so I guess I will not get this disease.

Therefore, after the online activity, their understanding regarding thalassemia and its prevention was increased as stated by respondent 55 and 23:

I never learned about Thalassemia at school, so I just know that we can stop Thalassemia by finding the right soulmate. I always thought that genetic disease is a condition that needs to be accepted. With the high cost of treatment, prevention is the best way.

My friend has thalassemia, but not the severe one. Sometimes, his face looks pale and he is easily tired. I need to tell him about finding the right person to be his wife, otherwise, his children might get the major one.

This activity broadened the knowledge of the student as stated by respondent 3:

I am very happy to be able to spread the good things in this pandemic situation. I hope this activity can be sustained and more participants can join, as I know that this knowledge should be spread.

This online peer-group activity regarding thalassemia not only increased knowledge but also brightened spirits, as mentioned by respondent 1:

I am glad the university and my school hold this event; it enlightens my soul to be more graceful and accept the condition. We need to learn to form the Thalassemic patients that always have the spirit to keep walking even though they need a transfusion every month.

The online thalassemia promotion conducted by the peer group made it understandable and removed the language barrier as respondent 23 said:

This activity is easy to follow and I can understand what they said. I can also ask without hesitation. Even though I feel offline discussion will be better, but during this pandemic, offline activity was impossible.

However, since the duration of the activity was similar to the school period, respondent 55 felt a burden in having to complete both tasks from the school and the thalassemia promotion.

I need to admit that this activity has a positive impact on us. However, with the school online platform, the numbers of the task are increasing. So, it was quite difficult to make a balance between the school task and this activity since we need to follow the tutorial and make some content.

Moreover, unstable Internet access was a burden in this activity, as admitted by respondent 2.

The difficulty in this activity is the internet access. My laptop and phone signal are really bad sometimes, especially when I watch YouTube or Zoom with video. As we know in this situation, we use the internet for most of the activity.

Discussion

The COVID-19 pandemic has pushed all sectors of human life to be creative and innovative. Due to physical distancing, health promotion needs to find an alternative way. Webinars might be a solution to this pandemic; however, their effectiveness to deliver health promotion is still questionable [10]. The health approach to the young generation needs creativity and utilization of technology, such as social media to reach them [11]. Moreover, the design, concept, timing of webinars and the optimal Internet/broadband connection are necessary to obtain effective digital learning [12].

This study showed thalassemia health education can be performed by empowering the youth and utilizing digital technology. Our findings showed the basic knowledge of the respondents was good (92.11%) and increased after the online activity (96.64%); however, this might be biased since the respondents were able to access the information prior to completing the questionnaire. However, some students were still confused regarding

thalassemia not being an infectious disease, which can be observed from a decreasing score of question number 3 from 89.47% to 87.22%. Surprisingly, after an in-depth interview, it was found that their knowledge was not in-line with their understanding, especially regarding thalassemia transmission, screening and prevention. The willingness to do the screening is one point that needs to be emphasized during health promotion. Taken together, the online peer-group activity was a prospective method to promote health issues among high school students, not only increasing the knowledge but also their understanding.

Peer groups have a big impact on adolescents and affect their behavior [13]. Therefore, empowering the peer group for health promotion is a good strategy for increasing the acceptance and understanding of the health issue [3]. Moreover, the WHO in its report emphasized comprehensive sexuality education, which includes understanding the risk of genetic diseases, such as thalassemia, due to consanguine marriage [14]. A peer-group approach was shown to be effective in delivering sexual health promotion in high school students [15]. Furthermore, it will be a great advantage if health promotion, such as thalassemia, can be integrated into the school curricula to stop the growth of thalassemia major [16]. Since promoting health is not only the responsibility of the government but also all of humanity, including academics and youths [17], health promotion should not be stopped due to the COVID-19 pandemic.

Conclusion

Even though the students have a good knowledge regarding thalassemia, their understanding is not enough to force them to undergo thalassemia screening and control their marriage. The measured knowledge in this study might be biased since the respondents were able to access the Internet to find the information before filling the pretest. However, this study shows that by empowering the students, the health information can be spread easily within the peer group, since the barriers can be eliminated, including the language barrier. An online platform is an effective method to perform health promotion during the COVID-19 pandemic, such as for thalassemia prevention.

Recommendation

A similar approach, empowering peer groups and utilizing digital learning, might be useful for other themes and can be delivered to other groups of respondents. The timing of the activity should be taken into consideration since the respondents are students who have other scheduled activities. Moreover, the cadres from this activity can be empowered to promote thalassemia to other schools in the future.

Conflict of interest: There is no conflict of interest.

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Corresponding author

Annette d'Arqom can be contacted at: annette-d-a@fk.unair.ac.id

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