

# CULTURAL PRACTICE OF AT-RISK PEOPLE OF COLORECTAL CANCER AND RISK REDUCTION IN INDONESIA: ETHNOGRAPHY STUDY

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## **Abstract**

The incidence of colorectal cancer (CRC) increases yearly, particularly in low- and middle-income countries. Avoiding risk factors serves to effectively and efficiently reduce CRC incidence. In this ethnography study, we explored the health behavior of at-risk people of CRC to reduce the risk in Palembang, Indonesia. Purposive sampling was used, and involved 9 participants. The data were collected using participant observation, in-depth interviews, and focus group discussions, and then analysed using thematic analysis. There were 9 themes that emerged: food preparation, food cooking, food consumption, moderate physical activity, health checks and medical treatment, trying traditional herbs, alternative therapy and spiritual power as treatment, controlling risky health related behaviours, cancer information, and self-health perspectives. Multiple-sectoral strategies and collaboration between academics, practices, communities, and government are needed to carry out risk reduction activities and increase awareness along with community empowerment and capacity building in accordance with cultural understanding.

**Keywords:** At-risk people, colorectal cancer, cultural practice, ethnography, Indonesia, risk reduction

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## Introduction

Colorectal cancer (CRC) accounts for the third highest incidence of malignant diseases worldwide (Bray *et al.*, 2018) and around 10% of the total incidence (Stewart and Wild, 2014). This continually increasing incidence remains 3 times higher in developing countries (Arnold *et al.*, 2016). The increasing CRC global burden is caused by an aging population and sedentary lifestyle (Favoriti *et al.*, 2016) including a westernized behaviour lifestyle (Tayyem *et al.*, 2016). Meanwhile in Indonesia, CRC was the most prevalent gastrointestinal cancer (Makmun *et al.*, 2014) whereby incidence rose slightly throughout 2013-2017 in Palembang, South Sumatra, Indonesia (Tiranda and Safitriana, 2018).

CRC can be detected through routine screening, early detection (Lowery *et al.*, 2016), prevention, and risk reduction intervention of modifiable risk factors (Meyskens *et al.*, 2016). The following ought to be taken into consideration in terms of emphasising a healthy lifestyle as primary prevention: regular physical activity, smoking cessation, reducing alcohol consumption, maintaining a normal body weight, and decreasing red and processed meat consumption (Richardson *et al.*, 2016). On the other hand, screening strategies essential to CRC are colonoscopy, fecal immunochemical testing (FIT) for occult blood, sigmoidoscopy plus FIT, and computed tomography colonography (Ransohoff and Sox, 2016). Unfortunately, CRC screening is less supported in Asia (Pourhoseingholi *et al.*, 2015) - especially in low- and middle-income countries due to the high cost of maintaining the necessary equipment, in addition to the necessity of having an expert to operate it (Lambert *et al.*, 2009).

The Ministry of Health of Indonesia has launched programmes to support the national medium term plan of Indonesia 2015-2019 focusing on promotion and prevention termed "GERMAS" programmes, whereby 3 activities which are being actively pursued are physical activity, consuming fruits and vegetables, and attending routine health checks. Moreover, the program employed the PIS-PK (Indonesia

Health Program with Family Approach) as an approach. Besides that, the government of Indonesia provides a program in the community under primary health care (PHC) coordination, Posbindu PTM (Integrated Development Post of Non-Communicable Diseases), with regards to screening and early detection of several non-communicable diseases, particularly cardiovascular disease, diabetes mellitus, and cancer (cervical cancer and breast cancer). Badan Penelitian dan Pengembangan Kesehatan (2012) of Indonesia showed that there were several challenges in conducting health service facilities for non-communicable diseases (including cancer): i.e. limitations of facilities, lack of the appropriate medicine and medical equipment, the lack of a number of health workers, and the lack of quality services.

However, there are limited studies on specific issues relating to the receipt of risk reduction interventions by those at risk of CRC, especially in Indonesia. As a consequence, the researchers recognized the need for a study to explore understanding and capture in what ways at-risk people perform risk reduction relating to situations and conditions following their social, cultural, and community beliefs. This study accounts for part of a research on community-based risk reduction regarding CRC in Palembang, South Sumatra, Indonesia. The objective of this study was to explore the perspectives of at-risk individuals regarding the cultural practice of CRC risk reduction behaviour. Accordingly, gathering the data concerning at-risk people on risk reduction based on cultural influences could render broader perspectives on health beliefs, values, and behaviour relating to CRC risk reduction.

## Materials and Methods

### Study Design

An ethnography was employed to understand the social behaviour, health beliefs, and practices from a populace's point of view - either as individuals or as a part of a group or communities, institutions, or other settings

influenced by the culture or sub-cultures of where the at-risk people live.

### Participants and Setting

This study was conducted at the under-village of Silaberanti, a sub-district of Jakabaring, Palembang, South Sumatra, Indonesia. According to research by Tiranda and Safitriana (2018), the number of CRC patients at that location was the highest in Palembang. Purposive sampling was employed to select participants in following the inclusion criteria which were: (i) had not taken part in previous screening and early detection for CRC, (ii) at least 18 years of age (minimum age for informed consent in Indonesia), (iii) no issues with verbal communication, and (iv) residing in Palembang. In this study, at-risk people are referred to as individuals who have risk factors of CRC, including: family history (first, second, and third-degree relatives) as high risk people, and other moderate risk factors such as age, increased body mass index, inflammatory bowel disease, smoking, red meat intake, low vegetable consumption, low fruit consumption, and low physical activity. The total of 9 participants in this study consisted of 3 people who were high risk (from the family history of first-degree relatives on CRC), and 6 of them who were categorized as moderate risk.

### Ethical Considerations

This study was approved by the Ethical Review Board of Khon Kaen University (No. HE602164). The researchers explained to the participants that they could reject participation in the study or, if they decided to cease their involvement in the study, they had the right to stop at any time without any future discrimination. An informed consent form was given as an agreement of involvement accordingly.

### Instruments

The interview guidelines were developed by the researchers, then reviewed by an expert in community care. The main questions for the at-risk people of CRC were as follows: What are you doing as your daily living activities to prevent the risk of CRC? How do you keep

yourself healthier? Who do you think is at risk of CRC? Can it be prevented? If so, how?

### Data Collection

Participant observation, in-depth interviews, and focus group discussions were used to collect data. The study was conducted from November 2017 to June 2018. A grand tour was organised as the first step to involve people in community activities which was followed by selecting a gatekeeper. During participant observation and data collection, the participants were identified and recruited as a result of the gatekeeper's recommendations. In order to be aware of and understand the people's lives and daily activities, the researchers spent much time in the research location.

The researchers documented what had been learned during participant observation and recorded the information into field notes. The first author contacted participants and requested convenient times for interviewing with semi-structured questions taking 45-75 min and using a voice recorder. The transcripts were returned to the participants for response clarification and correction. Data saturation was achieved when there was no new additional information to be gained from the participants (Guest *et al.*, 2006). The current study achieved data saturation from the 9 participants.

### Data Analysis

Data analysis in qualitative research is sequential during data collection. The researchers performed transcription after interviewing each participant. The transcript was initially written in the Palembang language, then subsequently translated into English. The researchers aimed for data immersion by reading the data several times over, and read the transcription word for word and line by line to identify the main points as an initial coding. The researchers developed subcategories and categories of similar data based on the initial coding, and listed all transcript groupings into similar meanings as categorizations. Typology analysis was created by categorization, followed by matrix analysis to explain data. Lastly, thematic analysis was

carried out to identify and develop the arising themes.

### Trustworthiness

Trustworthiness of a study could be described as the quality of the data, interpretation, methods (Polit and Beck, 2014), consistency of credibility, transferability, dependability, and confirmability used in the study. After completing the transcript, responses were confirmed and clarified by participants in relation to the results of the transcription based on the participants' answers. In addition, the researchers engaged in prolonged contact with all participants to gain authentic data, then thick description was employed to achieve transferability. Field notes were made during participant observation and, once finished, the researchers re-wrote the field notes and expanded them into descriptions. This study employed data triangulation from various methods, i.e., participant observation using field notes and in-depth interviews to achieve dependability. Finally, the outcome findings represented the participants' perspectives and not the researchers' views and the resultant data triangulation as well as reflexivity were utilised to achieve confirmability.

### Results

The characteristics of the participants in this study were as follows: 4 people were male and most of the participants were aged >32 years old (range 32 – 64 years old). From the marital status side, there were 2 single people, 1 widow, and 6 were married with children. All female participants were housewives and food sellers, and the male participants were waiters, pensioners, security guards, and an administrator at the parking plaza.

### Food Preparation

Food preparation is essential in augmenting the populace's health; most participants always went shopping at the market to buy their daily essentials. Purchasing such daily essentials was most commonly done at nearby stalls, and sometimes other family

members brought food to be cooked from the market. Participants cooked food freshly rather than storing it in a refrigerator.

*"I buy food at the stall near here, sometimes from my younger brother who works at the Silaberanti market - he sells coconuts there" (male, 36 years).*

*"Yes, fish and vegetables are bought at the stall near here" (female, 43 years).*

*"Yes, only for a day, the next day we go again to the market. We rarely keep things in the refrigerator. My husband does not like food like that" (female, 41 years).*

### Food Cooking

Food cooking consists of all the ways that the participants cooked their food; *brenghes pindang* boiling food, frying food, grilling food, and *sambal mentah* or raw *sambal*, a type of chili sauce, i.e. limiting the use of flavour additives or sugar and salt to give a savoury taste, and the use of low sodium salt (*lososa*).

*"Mostly pindang, because the eating habits of my husband include sauces, which is up to him" (female, 56 years).*

*"Fried foods, like fried fish and fried foods, like fried fish and fried sambal, but more frequently sambal mantah" (female, 41 years).*

*"While cooking we just add sugar and salt; that's enough to make it taste good" (female, 43 years).*

*"We buy our salt at the drug store; lososa (low sodium salt)" (male, 36 years).*

### Food Consumption

Food consumption means what people commonly consume in their daily lives; the most common foods they consumed were: *padang* cuisine, *brenghes pindang*, fried and grilled foods, usually fish and meat, *sambal mentah* i.e. a kind of spicy food, instant noodles - frequently bought away from the home, and fruits and vegetables.

*"While I worked the afternoon shift, I always consumed Padang cuisine food as*

well as Padang food: food cooked with coconut milk" (male, 32 years).

"Sometimes we buy small fish, my husband really likes patin fish. We buy it in small quantities. And when buying in a huge amount, the price is affordable for us" (female, 56 years).

"Now, there is plenty of duku (langsar), rambutan, and sometimes dragon fruit; those are the cheapest ones" (male, 62 years).

"We consume various kinds of vegetables every day and we never forget to prepare them" (male, 26 years).

Canned food and beverages are seen as fast foods which are often consumed by the participants. Drinking sweetened condensed milk, *ale-ale* (a fruit drink), and adding much sugar (2 spoons) to instant coffee was common.

*"The sugary drink I drink is just iced orange juice and I really like ale-ale"* (male, 32 years).

*"We use instant coffee; if it is not sweet enough we just add 2 spoons of sugar"* (female, 41 years).

*"A cup of milk or a sweet drink of condensed milk a day"* (female, 53 years).

### Moderate Physical Activity

Participants performed exercise as their regular physical activity, for instance, walking, jogging, running, gymnastics, cycling, using a treadmill, and fishing. The majority of the participants walked in the morning; some female participants walked to the market which often took 30 min or more. On the other hand, some participants partook of weekly gymnastics near their homes as well as cycling and using a treadmill. One participant believed that his activity, fish netting, was beyond or more intense than regular exercise.

*"On foot, it is not too far from here. It is located behind the post office, and I feel good while walking rather than using a motorcycle every day; I just want to move*

*my extremities - my body"* (female, 53 years).

*"I think I always do physical activity every morning (chuckle). When I wake up in the morning, I briefly do gymnastics on my own; once sweating, I'm finished"* (female, 56 years).

*"I do not do traditional physical activity; my activity (netting fish / fishing) is more intense than other activities"* (male, 56 years).

*"I bought a treadmill and bicycle to be healthier, because I have a history of illness"* (female, 36 years).

### Health Check to Medical Treatments

The participants believed that medical treatment might be effective in treating diseases. Medical treatment is their first choice when they get sick; some participants used over-the-counter medications and had health checks at the PHC, private clinics of medical doctors and other healthcare providers, and took antibiotics and analgesics to treat disease.

*"For just a common disease i.e. a headache, I take Bodrex to reduce symptoms. For a cough, I buy Formula 44 and sometimes Komix sachets"* (male, 36 years).

*"I absolutely trust in medications at the hospital, because they are handled by the experts who have plenty of experience related to disease"* (male, 32 years).

*"If I get a severe sign and symptoms of disease, then I go to the PHC"* (male, 56 years).

*"When we get sick, we go to the doctor and get cured"* (female, 36 years).

However, not all participants believed and trusted in health service medications. Some participants remained sceptical and non-trusting of health services and their medications, as well as being disappointed in the PHC services.

*"Medications given by the PHC were not effective; I got gout from the medications*

*given to me by the PHC nurses” (male, 56 years).*

*“I understand that the given medication can treat the disease but it consists of a chemical material” (male, 62 years).*

### **Trying Traditional Alternatives, Herbs, and Spiritual Power Treatments**

Besides the application of medical treatments, some participants also believed in and tried traditional alternatives, herbs and spiritual treatments. These traditional alternatives were Chinese medicine, propolis, massage, and coining (*kerokan*). Meanwhile, for traditional herbs, they used *jamu*, *jintan hitam*, *sari kurma*, *benalu* root, and ginger water. Lastly, for spiritual power, 1 participant believed that diseases are sent by jealous people and that shamans (*wong pinter*) may be called upon to treat such diseases.

*“We tried Chinese medicine; for Rp 1.200.000, we got jamu. I really hope that I’m always healthy in order to take care of my husband” (female, 56 years).*

*“Three drops a day of propolis can be used as a prevention for many diseases” (female, 36 years).*

*“I just do coining; when I get a common cold I do cupping” (male, 56 years).*

*“There are many kinds of leaves: cinnamon, satin tails, cloves, creat, and sappanwood” (male, 62 years).*

*“We think that disease is sent by a jealous person. So, we tried consulting with a shaman (wong pinter) - he was from Bangka” (male, 36 years).*

*“We also tried the shaman; he came to our home and asked for Rp 50.000 per massage” (female, 56 years).*

*“Herbs are medications consisting of natural compounds which have been proved and are rather better than generic medication” (male, 32 years).*

*“I drink ginger water frequently; it is created from 3 shredded pieces of it” (male, 62 years).*

Conversely, some participants were unconvinced by the use of herbs and were

uninterested in such use. The reasons given were that they remained doubtful about the herbs’ advantages; they felt hesitant about current substances like *jamu*, were unwilling to try herbs because no symptoms had emerged, and the price was high.

*“I have my doubts; I am not sure if it is safe or not, but based on their explanation it is great” (male, 32 years).*

*“Nowadays, jamu is ground or in powder form. You can see the seller’s hand, it does not show any change; years ago, turmeric was grated manually” (female, 43 years).*

*“Someone has informed me about the herb’s benefits, but I am not sure. Is it useful or not?” (male, 36 years).*

### **Controlling Health Risk Behaviour**

Smoking and consuming alcohol as part of health risk behaviour and subsequent health risk prevention may change health behaviour and limit the need for cancer screening. Most participants’ family members were active smokers - including their school-aged children. Meanwhile, for alcohol, 1 participant had stopped consuming alcohol for almost a decade.

*“I stopped smoking because I was coughing up blood, and then I went to see the doctor” (male, 62 years).*

*“I decided to stop smoking when my father passed away due to lung disease” (male, 36 years).*

*“My husband and my children are smokers, and commonly use 1 pack a day” (female, 41 years).*

*“Not anymore, it was years ago. I stopped drinking alcohol in 2004” (male, 56 years).*

### **Cancer Information**

The participants gathered information related to cancer as well as other people’s views on cancer. They sourced cancer information by themselves via the internet and other social media. They also got information during Posbindu PTM activities and shared

this with the CRC community. However, they lacked an understanding of cancer risk prevention.

*"I do not really know; I only know it is 1 disease. Yes, it is 1 kind of disease, a dangerous disease and there is no therapy to cure it" (male, 32 years).*

*"No, I do not. We never get information related to it, never" (female, 36 years).*

*"The nurses at the hospital did not care about it; we found out for ourselves" (male, 36 years).*

*"We never knew how to prevent cancer, because there was no health promotion about the disease" (female, 42 years).*

### Self-health Status

The participants believed that they were in a healthy condition so they thought there was no need for a health examination even though they might be worried and unsure about their exact health condition.

*"Because I am still young, I have no idea of any kind of disease I may have; I feel strong, and also I am a little fat because I only eat and sleep" (male, 32 years).*

*"Surely I will have a lot of confirmed diseases if I go to see the doctor; I'm afraid of learning that I have a disease, absolutely" (male, 36 years).*

*"I am afraid to find out if I have any diseases; you get a disease; just let it be; I am afraid it will always haunt me for the rest of my life" (male, 32 years).*

*"I am afraid that if they diagnosed me, I would have a disease. I am afraid it will haunt me all my life" (male, 56 years).*

*"I have not felt any symptoms until now, but thank God, I am still healthy. However, I am unsure. Am I indeed healthy or not?" (female, 41 years).*

### Discussion

The purpose of this study was to explore what was done by at-risk people to reduce the risk of CRC. The results of this study provide an

understanding of the efforts made by those at risk of CRC to reduce the risk of the disease, including preventing and controlling the risk factors.

Preparing healthy food is one way to prevent cancer. The majority of the participants prepared their own food by shopping at the market; meanwhile, other participants minimized the use of food additives and preferred to use low sodium salt which does not directly cause cancer in predetermined amounts. *Pindang* is a traditional food from Palembang and a dish that refers to a certain sour and spicy fish soup which was commonly consumed by the participants. Spicy food *sambal mentah* was a major kind of consumed food among the participants. Lv *et al.* (2015) found that spicy food, in particular fresh chilli pepper, which is high in bioactive ingredients can reduce the risk of cancer more than non-fresh spicy foods. In addition, Chen *et al.* (2017), stated that a high level of spicy food consumption, i.e. food containing capsaicin as an irritating agent, was linked to developing the risk of cancer,. Moreover, small fermented shrimp paste or *belacan* or *terasi* is commonly used in a soup dish which is 1 of the important and well-known ingredients of *Pindang* foods in Indonesia. However, *belacan* or *terasi* is associated with cancer (Arshad *et al.*, 2005 cited by Ghazali *et al.*, 2012) and has a high level of salt and arsenic in the salted and fermented food (Sharif *et al.*, 2008). Unfortunately, there is no recommendation or guideline by the government concerning the amount of daily shrimp paste product consumption in Indonesia.

Further, consuming fish was a necessity for several participants and their family members and is inversely linked to CRC (Wu *et al.*, 2012). Fish also contains selenium, vitamin D, and n-3 fatty acid which can inhibit colon carcinogenesis (Xu *et al.*, 2015). Some participants often bought food from outside the home rather than eating home cooked food and had a lower consumption of fruits and vegetables. One participant frequently consumed *Padang* cuisine which is rich in taste comprising succulent coconut milk and spicy

chillies. Indonesia is a world leader in coconut products and the population's dietary practice of consuming coconut products is high. Coconut milk contains saturated fat and a high intake of fat is associated with the risk of colon cancer (Dahm *et al.*, 2010). Another frequent method of cooking in the daily diet was fried and grilled food. Pietrzyk (2017) explained that consuming fried fast food is associated with a high risk of CRC, with a high glycemic index. Nevertheless, half of the participants were not consuming vegetables and fruits, soft drinks, and sugar-sweetened beverages frequently. Excess intake of sweetened drinks and carbonated drink can lead to increased weight and obesity and is linked to the risk of CRC. Participants need to know that healthy dietary behaviour is influenced by knowledge, belief in diet, and prevention (Palmquist *et al.*, 2011) which can reduce the cancer burden by two thirds (Willett, 2005).

Frequent physical exercise might prevent CRC. Most participants chose walking as their daily exercise and also took part in weekly gymnastics. One participant (male, 56 years) believed that his daily activity of netting (fishing) was beyond or more intense than general physical activity. Moderate physical activity in daily life for at least 20 min or 1.5 h weekly of vigorous activity is recommended to reduce the risk of CRC (Greenward, 2015). Notwithstanding, half of the participants remained unable to participate in exercises due to financial problems, insufficient time to exercise, and their responsibility of doing household chores. Even at the weekend, they used their time to rest and relax in their leisure time away from their daily activity. In their study, Kang *et al.* (2014) described fatigue, poor health, insufficient time, and lack of information as obstacles to exercise. Community action and multiple policy opportunities with a cultural and needs approach in providing an environment for exercise contributes to CRC risk reduction (Kushi *et al.*, 2012).

Participants had their health checked at the nearest public or private healthcare services, while some symptoms of diseases emerged. One of the participants was sceptical and distrusted health services. Contrariwise,

traditional herbs, complementary therapy, alternative medicine therapy, and spiritual power (*dukun* or *wong pinter*) remained as being believed and trusted by the participants due to cultural beliefs. The traditional herb *jamu* may improve health. *Jamu* is a traditional herbal healing from Indonesia and it is predominantly a herbal medicine made from natural ingredients. The participants used the herbs themselves 1-3 times a week routinely incorporating shredded turmeric and red ginger which was seen as a prevention for many diseases. *Jamu* as traditional medicine in Indonesia, has become a part of the people's cultural habits even though there is a lack of research supporting its usefulness in health. Increasing *jamu* consumption in the community is caused by the back-to-nature trend in individual healthcare. That is to say, people believe in traditional herbs over man-made medication as it consists of natural ingredients. On the other hand, *jamu* does not render adverse effects on its user, the price is reasonable, and it is readily available (Prabawani, 2017, citing Muslimin, 2009). Conversely, healing using magic and spells or evil spirits is alive and well throughout Indonesia, and many believe in rituals that can cure disease. Delays in diagnosis and treatment are commonly caused by people consulting traditional healers as their first choice (Iskandarsyah *et al.*, 2014); limited access, the high cost of medical care, culture, and distrust of health care services influence individuals to choose an alternative therapy (Assan *et al.*, 2009). Accordingly, there is a need for a wide-reaching campaign with culturally sensitive awareness to encourage people's understanding in the use of medical treatment or traditional and alternative therapy.

The most striking fact was parents allowing their children to smoke and not prohibiting them from smoking; this influence increased exposure to second-hand smoke, thus augmenting the risk of CRC over time. The smoking participants were conscious of the dangers of smoking yet continued in the behaviour, although they had tried to stop smoking without success. Family support, the environment, workplace, knowledge, and

healthcare services have an essential capacity to encourage smoking cessation. Anderson *et al.* (2015) stated that the awareness of at-risk individuals regarding CRC remains low, despite the increase of information concerning risk factors. An effective strategic program is required to support smoking cessation and prohibit second-hand smoke vulnerability.

Social media is an important source used to obtain information and raise awareness. One study by Xu *et al.* (2016) confirmed that information provided by social media was useful in the prevention, screening, and treatment of cases for cancer promotion, information, and education. Most participants really believed that they were in great condition and that they did not need to check up on and routinely maintain their health status. In the present study, some participants were aware and conscious of health risk factors due to having a health history of several diseases causing trepidation at a health examination. On hearing bad results, it would haunt them for their entire lives. Providing sharing-type groups might be beneficial for at-risk individuals in terms of sharing and discussing issues relating to their health conditions and what should they do to reduce the CRC risk.

## Limitations

Although this research satisfied its aims, there are some limitations. The data represents the cultural practices of at-risk people in 1 sub-district in Palembang, South Sumatra, Indonesia, though the results may still be applicable to supporting the development of community-based cancer risk reduction in particular areas in Indonesia.

## Conclusions

The present study explored the situation regarding health behavior in reducing the risk of CRC. Cultural competencies are also needed in terms of providing information to the public by adjusting the education curriculum in

accordance with the latest issues and the present Indonesian government program. Cross-sectoral collaboration between academia or education, health care providers, local government, and the community are needed to increase awareness in carrying out activities. There needs to be discussion between communities and the relevant stakeholders in determining what and how to encourage and better an at-risk individual's health behaviour in conjunction with cultural activities in the community as well as improving community health literacy. There needs to be an increase in capacity building for relevant stakeholders, health volunteers, NGOs, and others that play a crucial role and are actively involved in reducing the risk of CRC in the community.

All in all, knowing and understanding the health behavior of at-risk individuals amid conducting CRC risk reduction gives a clear description and explanation to healthcare providers, government, and communities in terms of developing effective strategies that can be applied to the promotion, prevention, and risk reduction regarding health behaviour with consideration of the cultural and belief related approach to increase health awareness.

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