

ATTITUDES AND BELIEFS ABOUT COLORECTAL CANCER AMONG MEXICAN AMERICANS IN COMMUNITIES ALONG THE US–MEXICO BORDER

Purpose: The purpose of this study was to examine Mexican American knowledge, attitudes, and beliefs about colorectal cancer and barriers to receiving colorectal cancer screening exams.

Design: We developed an open-topic focus group schedule that addressed knowledge, attitudes, and beliefs about screening for colorectal cancer and identified cultural issues to be considered when developing educational interventions to increase screening participation. Focus groups were used to elicit participant responses.

Setting: Two small communities (*colonias*) along the US–Mexico border.

Subjects: Mexican Americans ages ≥ 50 years.

Results: A total of 43 individuals (20 men and 23 women) participated in the focus groups, each of which lasted ≈ 90 minutes. Few focus group participants had ever heard of colorectal cancer or specific screening exams to detect early forms of cancer. Participants identified cost of medical care and embarrassment about receiving colorectal exams as barriers to screening participation. Respondents commonly expressed fatalistic attitudes about their chances of recovering from cancer, some preferred not to know if they had cancer or believed that they would refuse treatment if diagnosed with cancer. Nevertheless, many participants noted that strong support from family and friends or a strong will would allow one to survive cancer.

Conclusion: Interventions to improve participation in screening services for colorectal cancer should focus on reducing the influences of cost and embarrassment and improving levels of knowledge about colorectal cancer and the need for screening. (*Ethn Dis.* 2006;16:421–427)

Key Words: Attitudes, Beliefs, Colorectal Cancer, Fecal Occult Blood Test, Hispanics, Knowledge, Screening

From the Cancer Prevention Program, Fred Hutchinson Cancer Research Center, Seattle, Washington (GC BT RG); Department of Nursing (WO) and the College of Agriculture and Home Economics (AF), New Mexico State University, Las Cruces, New Mexico.

Gloria D. Coronado, PhD; Argelia Farias; Beti Thompson, PhD; Ruby Godina; Wendell Oderkirk, PhD

INTRODUCTION

Colorectal cancer is the third most common cancer and has the highest mortality of any cancer in the United States.¹ Substantial disparity in mortality from colorectal cancer exists among various US subgroups, including Hispanics. Hispanics experience higher mortality from colorectal cancer than non-Hispanics Whites and tend to present with more advanced disease (unpublished data, Li, March 2004). As is the case with disparities in other health conditions, the reasons for the ethnic disparities in colorectal cancer mortality remain poorly understood.

Colorectal cancer is preventable if discovered in a premalignant stage and is curable if found in an early malignant stage.² The US Preventive Task Force recommends screening for individuals age ≥ 50 years with the fecal occult blood test (FOBT), sigmoidoscopy, or colonoscopy to detect early colorectal growths (polyps).³ Data from national and regional sources indicate that Hispanics are less likely than non-Hispanic Whites to have ever received colorectal cancer screening. Data from the 2002 Behavioral Risk Factor Surveillance Survey show that nationwide, 34.5% of Hispanics have ever had an FOBT; this compares with 46.7% of non-Hispanic Whites. Similarly, whereas 39.0% of Hispanics have ever had a sigmoidoscopy or colonoscopy,

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49.9% of non-Hispanic Whites have had such a test.⁴

Little is known about Mexican American knowledge, attitudes, and beliefs about colorectal cancer. In one recent study conducted by Walsh et al, Hispanics were less likely than non-Hispanic Whites to have heard of a FOBT (58% vs 73%) or colonoscopy (57% vs 84%).¹ In the same study, compared to non-Hispanic Whites, Hispanics were less likely to think they needed any type of colorectal cancer screening if they felt healthy and were more likely to consider the tests to be embarrassing. Bastani et al conducted a study to identify knowledge about colorectal cancer and barriers to screening for several racial and ethnic groups, including Hispanics.⁵ Data from the study's focus groups showed that the most common barriers to screening among Hispanics were fear of finding cancer, the pain and discomfort associated with an endoscopic exam, and the feeling of being violated.

The purpose of this study is to present the findings from five focus groups conducted among Mexican Americans living in two small New Mexico communities (*colonias*) along the US–Mexico border. The focus groups addressed knowledge, attitudes, and beliefs about colorectal cancer and

Address correspondence and reprint requests to Gloria D. Coronado, PhD; Cancer Prevention Program; Fred Hutchinson Cancer Research Center; P.O. Box 19024; 1100 Fairview Ave. N, M3-B232; Seattle, WA 98109; 206-667-4216; gcoronad@fhcrc.org

barriers to screening for the disease. Findings from the focus groups identify cultural issues that need to be considered when developing educational interventions to increase colorectal cancer screening.

METHODS

Setting

This study took place in two underserved communities (*colonias*) of southern New Mexico. *Colonias* are generally unincorporated, illegally developed areas (areas divided without appropriate permits and housing set up without infrastructure), with poor housing, high unemployment rates, high poverty levels, poorly maintained roads and sanitation facilities, and limited services and programs for job training, health care, and education. The US Department of Housing and Urban Development (HUD) specifies that to be designated as a *colonia*, a community or neighborhood must be located within 150 miles of the US–Mexico border.⁶ Estimates of the number of designated *colonias* in New Mexico vary but are generally reported to be ≈ 137 , most of which (88%) are unincorporated.⁶ In a single county in southern New Mexico, Doña Ana County, estimates put the number to be ≈ 37 .⁷ *Colonia* residents are mostly Mexican American, most of whom work as seasonal farm laborers or in some other agriculture-related occupation.⁶

For the purposes of this study, we chose *colonias* that were served by a clinic because we planned to implement a clinic-based intervention. One *colonia* lies on the border of New Mexico and Texas and has a population estimated at 7904 (on the New Mexico side) of which 96.4% are Hispanic and 3850 (on the Texas side) of which 82.8% are Hispanic.⁸ The median household income for the community is reported to be \$22,547 and \$26,295, respectively.⁸ The second *colonia* we studied has

a population of 6117 of whom 64.5% are Hispanic according to the 2000 US Census Bureau; however this number is thought to severely underestimate the actual size of the population.⁸ Data from the US Department of HUD estimate the population at 17,000 (based on the number of household water connections).⁷ Reasons for the discrepancy are that many *colonias* have multiple housing units in the same lot, which are often hidden by gates and fences, and that housing unit numbers are difficult to identify, if existent. Moreover, households in the *colonias* are generally complex and characterized by fluid movement of people and housing units.⁹ The median household income for this community is \$22,692.⁸ The findings reported here are part of a larger study that sought to design and implement a clinic-reminder system to increase participation in screening services for colorectal cancer among Hispanics.¹⁰ The project was carried out collaboratively with investigators from New Mexico State University (NMSU) and the Fred Hutchinson Cancer Research Center (FHCRC) through a sub-contract with a local clinic.

Data Gathering

We limited our recruitment to individuals who were Hispanic and age ≥ 50 years. Focus group participants were recruited from the two *colonias*. Recruitment was carried out in two ways: 1) Spanish-language recruitment flyers were posted in local businesses and organizations (such as churches, grocery stores, and clinics); and 2) in-person recruitment was carried out by clinic health promoters and project staff familiar with the communities. During in-person and telephone contacts, clinic health promoters and project staff described the project and collected the names and telephone numbers of prospective participants.

Prospective participants were contacted by telephone one to two weeks later and were invited to participate in

a one- to two-hour discussion about colorectal health. Focus groups were held at the clinic health promotion office conference room or in a community center. Focus groups were led by the principal investigator (from NMSU) or one of several bilingual staff members (from NMSU and FHCRC), who were trained in focus group techniques and briefed on the discussion topics by the principal investigator (from FHCRC) who has wide experience in qualitative data methods. They were given instructions concerning listening skills, being flexible when necessary, accepting all ideas and opinions as valid, being nonjudgmental, understanding, and being sensitive to individuals who did not want to reveal information, qualities that are thought to maximize trust of the participants.

Before the discussion, the facilitators explained to the participants that information gathered in the focus group would be used for research purposes and that the discussion would be audio-recorded. Participants were assured that their names would not be associated with the tape. Written consent was obtained from all participants. The institutional review board at the Fred Hutchinson Cancer Research Center and the Office of Human Subjects Research of New Mexico State University approved the interview questions and the methods.

An open-topic schedule was used to guide the focus groups, leaving the facilitators considerable freedom to explore issues that emerged in the discussion. The following topics were addressed: What is colorectal cancer? Who can get colorectal cancer? How do you think someone knows that he or she has colorectal cancer? What puts someone at risk for getting colorectal cancer? How can you prevent yourself from getting colorectal cancer? What are some factors that make it difficult for you to prevent yourself from getting colorectal cancer? How is colorectal cancer treated? Four focus groups were

Table 1. Themes and subthemes related to colorectal cancer screening

Themes	Subthemes
Knowledge, symptoms and risk factors of colorectal cancer	Colorectal cancer tests Colorectal cancer symptoms Risk factors
Attitudes and beliefs about colorectal cancer	Fear Fatalism Treatment ineffective Early detection helps
Prevention and early detection	Eating habits Exercise Checkups Detection tests
Barriers to detection	Cost of medical care Embarrassment
Ways to cope with cancer	Mental and spiritual strength Willpower Support from family and friends
Other	Alternative treatments Desire for information

conducted in Spanish, and one was conducted in English.

A total of 43 individuals (20 men and 23 women) participated in five focus groups, each of which lasted ≈90 minutes. Group sizes ranged from four to 18. All who attended agreed to sign a consent form and participate in the discussion.

Data Analysis

Analysis of the information was based on the audiotapes and the field notes taken by the note-takers and facilitators. (Facilitators were those who led the focus groups.) After the focus group sessions, transcripts were made of the tapes and field notes. Transcripts were written in English and were reviewed by the other staff present at the focus group. Audiotapes were shared only with the project staff and were erased after transcription to help maintain confidentiality.

Analysis of the information was made following principles of qualitative research suggested by Morgan and Krueger.^{11,12} In each interview, a matrix of the main topics was created. From the matrix, staff independently identified and coded common themes that ap-

peared throughout the interviews. All authors met to review all the themes that were identified. In cases where authors disagreed about a theme, the item was discussed until a consensus was reached. Where consensus could not be attained, the opinion of the focus group facilitator prevailed. To maintain the richness of the information obtained during the interviews, we translated and present direct quotes in the results section. Although the specific words may not have been repeated by all participants, the meaning was expressed and widely affirmed during at least one of the focus groups. Where divergent opinions were expressed, they are noted in the text.

RESULTS

From the focus group analyses, a number of themes were identified (see Table 1). Each theme had a number of connected subthemes.

Knowledge, Symptoms, and Risk Factors

The first major theme discussed was knowledge of colorectal cancer, its symptoms, and risk factors associated

with colorectal cancer. Few people had heard of colorectal cancer or the tests used for screening; indeed, not knowing about colorectal cancer was cited twice as often as knowing about it (Table 2A).

The focus group participants had a variety of ideas of the symptoms of colorectal cancer. Some participants cited pain in the stomach area, blood in the stool, general bleeding, and painful bowel movements. A few noted that it had no symptoms or that it could not be felt (Table 2B).

Participants had a number of ideas about risk factors associated with colorectal cancer. The most frequently cited risk factor was nutrition, although the specific dietary intake varied. A common response was that eating “hot, irritating foods, such as chilies and hot sauce” contributed to colorectal cancer. Others thought that eating too many animal byproducts and/or fats contributed to colon cancer. Still others thought eating too many starches was a risk factor (Table 2C). A common response was drinking alcohol (Table 2D) and another response was heredity (Table 2E). Digestive problems were also given as risk factors. Ulcers, heartburn, gastric distress, colitis, constipation, and diarrhea were cited (Table 2F). Stress was mentioned a number of times as a risk factor for colorectal cancer (Table 2G) and other risk factors mentioned included smoking and the use of medications (Table 2H).

Attitudes and Beliefs About Colorectal Cancer

Fear of finding cancer was a common theme in respondents. Respondents were particularly concerned about a finding of cancer, even though the reason for a visit to a doctor might have another purpose (Table 3A). Fatalism was a strong component of attitudes and beliefs about cancer. Many people mentioned they were unlikely to fight cancer because they would die anyway. The idea that “it is in God’s hands” may best summarize these attitudes

Table 2. Focus group comments: knowledge and risk factors

Subject	Comments
A. Knowledge of CRC	"Truthfully, I don't know what it is—I don't have any idea how it is." "What is it? Good question!"
B. Symptoms of CRC	"...and she said it was only a pain when she sat down...like as if she was sitting on a stick...but she never told me she had other symptoms..." "What happens is that the lower part of the intestines start rotting... right?" "...if one never had hemorrhoids and then suddenly feeling a little ball in the rectum, something abnormal..."
C. Risk factors for CRC: Diet	"I like chiles ... that's one of the things [that causes colorectal cancer]." "A lot has to do with what one puts in—what was given to animals—what we are eating—animal byproducts—they are recycled, so we are eating that." "The people who suffer from that, it's from a lot of starch and bread." "Yes, we eat a lot of red meat, starch, and bread, and don't eat enough fiber."
D. Risk factors for CRC: Alcohol	"It is one of the illnesses that beer [causes]." "Liquor is probably a big risk."
E. Risk factors for CRC: Heredity	"... cancer is hereditary. Even if a person takes good care of themselves, if it's in the family [they are at risk] ..."
F. Risk factors for CRC: Digestion	"If you have diarrhea, you get colitis and colitis gives you cancer. Everybody accepts that colitis gives you cancer." "I think it maybe comes from constipation." "A lot of people have told me that [it comes] from hemorrhoids."
G. Risk factors for CRC: Stress	"Stress gives you a lot of constipation and bowel movements and that gives you cancer because you worry about the whole world." "When there is something wrong with the nervous system you get ulcers and gastritis, which can cause cancer."
H. Risk factors for CRC: Medications	"People that take a lot of medications can cause cancer to themselves because the body can react differently to the medications."

about cancer (Table 3B). Some participants believed that treatments would make cancer worse or spread the disease, and that treated cancer would eventually return (Table 3C). Other individuals believed that early detection and treatment at early stages would help (Table 3D).

Prevention and Early Detection

Participants generally believed that a number of behaviors and factors could prevent colorectal cancer. The most prevalent idea expressed was that a diet high in fruits and vegetables and low in fats and sweets can prevent colorectal cancer (Table 3D). Another factor frequently mentioned was the importance of exercise. Seeking checkups or consultations with physicians were mentioned by many individuals as a good way to help detect cancer early (Table 3C). Tests of detection were focused on the doctor's office and/or clinic. Few participants had ever heard of an FOBT or sigmoidoscopy/colonoscopy. None identified the

screening test by name. Even fewer knew that the test could be done in the home (Table 3C).

Barriers to Detection

Lack of access to insurance, whether it was private insurance, Medicare or Medicaid, was a strong barrier to receiving tests for early detection or for prevention. The lack of insurance kept many individuals away from physician offices. Personal embarrassment was also mentioned by both men and women as a reason for not being likely to seek colorectal screening (Table 3E).

Attitudes About Ways to Cope with or Survive Cancer

When asked about ways to cope with cancer, a common theme was that a strong will to live could allow one to survive and to want to fight harder. Several focus group participants stated that having a supportive family and friends increases one's chance of surviving colorectal cancer (Table 3F).

Other

Two other themes emerged throughout the interviews. Participants spoke often of traditional cures for illness in general and also for colorectal cancer (Table 3G). A second miscellaneous theme was that although tests were deemed important, few participants mentioned FOBT, sigmoidoscopy, or colonoscopy as good tests to be used for colon cancer detection.

Finally, nearly all participants in all of the focus groups wanted to know more about cancer. They repeatedly stated that they had trouble obtaining information, especially in Spanish, about various cancers as well as general healthcare problems. Some mentioned that talking with providers about cancer was often difficult because providers spoke only English.

DISCUSSION

Rates of colorectal cancer screening are low in the general population and

Table 3. Focus group comments: attitudes and beliefs

Subject	Comments
A. Fear	<p>"I think that a lot of the reason is the fear of the doctor telling you that you have cancer. When I go to the doctor my pressure goes up; but I don't have pressure problems; it's just the fear."</p> <p>"...you are afraid that the doctor is going to tell you that you have cancer, so a lot of times you don't go because you are scared."</p>
Fatalism	<p>"Some people feel that if they are going to die then they will die, if you feel you're going to die in one month or six months, some people would rather not do anything for it."</p> <p>"I have a friend that was 37 and got cancer. He received chemotherapy, and when he was done with that treatment he went for a full checkup. He came back from the doctor looking sad and I asked him what was wrong. He said that the treatment didn't really help and that the cancer was back again. I don't understand because he was only 37, he didn't drink or smoke he lived a good life by eating healthy and exercising, but he still got cancer. It scares me that this could happen to anyone."</p> <p>"... if you have cancer, forget it, [chances are] 50-50 that you will die."</p>
B. Treatment	<p>"Cancer brings death. The treatments are very harsh."</p> <p>"If I get cancer, it would be better that I am going to die."</p> <p>"I had a friend who had cancer, treated it, and was really sick. He finally got a little better and the cancer came back even worse. He died about six months later."</p>
C. Early detection	<p>"Finding it [cancer] in time, yes, I think it's like everything, get your checkups on time."</p> <p>"We have a neighbor that got cancer of the ovaries...she got all of the treatments...now she doesn't have anything...she has gone forward and the cancer has gone away."</p> <p>"I think if you get it in time, you can prevent it, that's why you're supposed to see the doctor and get checked."</p> <p>"Only when we go to the doctor's is that test done. They are the ones that check us for that [colorectal cancer]."</p> <p>"The only way you know is if the doctor checks you and tells you that you have that one [colorectal cancer]."</p> <p>"[It can be detected through] analysis that can be done on one, blood tests."</p> <p>"I don't think there is a way you can check for cancer at home."</p> <p>"Only when we go to the doctor's is that test [for colorectal cancer] done."</p>
D. Prevention	<p>"We need to start eating right; maybe we eat foods that are high in fat too much and that could be one of our problems."</p> <p>"If we eat a lot of fruits and vegetables and we don't eat meat and if you don't eat a lot of sweets, it will keep your bowels open."</p> <p>"We also need to start exercising, even if it is just a walk around the block after you eat or a bike ride; we need to start doing this in order to stay healthy."</p> <p>"Walking, something to do around the house."</p>
E. Barriers to early detection	<p>"That [lack of insurance] is one of the most important things, very important. This state needs to give insurance to all."</p> <p>"One doesn't have economically the means. Make the examine more affordable."</p> <p>"Why sometimes we don't go to have the test done, I think also because of decisiveness, excuses, or procrastination. We don't like it. We put it off until later..., and because I don't have a car, and because I have the children, and I can't complete it with the money [I don't have]."</p> <p>"Sometimes we are embarrassed so we don't go to be checked."</p> <p><i>A male participant emphasized:</i></p> <p>"Because they [men] are too macho. See, I am a macho man; I don't like anybody to look at my rectum, that is the truth. If I were a woman, women are more use to it."</p>
F. Coping with cancer	<p>"... [Survival from cancer] depends on the mentality of the person, what they want to do...if I want to live, I am not going to eat ...or not do anything or the cancer will eat me..."</p> <p>"... [One's survival] depends on each person's self worth, even if just a little bit.... They don't want to eat any more. What will happen to a person if they don't eat? It depends on the will to keep on living, everything depends on that."</p> <p>"Because if you have the love of one's family, the love is stronger than any illness...they ask me what is...they want to know why I want to keep on living, and I say because of my wife and children with love, anything is possible."</p>
G. Traditional remedies	<p>"...many times us Mexicans, sometimes we do not go [to the doctor]. A swig of herbs with seeds...and with that it [the pain] goes away."</p> <p>"The remedies that my grandmother would give me [were] herbs, they're good and hopefully we continue with those..."</p>

The results of this report support the idea that Hispanics have low levels of knowledge about colorectal cancer and face unique barriers to greater screening participation.

are reported to be particularly low among Hispanics. The results of this report support the idea that Hispanics have low levels of knowledge about colorectal cancer and face unique barriers to greater screening participation. Our findings corroborate those of other research showing that lack of access to health care is a barrier. Unlike attitudes and beliefs reported for other groups, Hispanics in our sample held fatalistic beliefs about their chances of surviving cancer and believed that one's will to live and support from family members would protect them.

A surprisingly small number of focus group participants had heard of colorectal cancer, despite being the age for which routine screening is recommended. This finding is concerning because previous research has linked having a low level of knowledge about cancer to having a small likelihood of participating in screening.¹³ Specific misconceptions about the causes of colorectal cancer were noted in some previous investigations. A common belief, for example, stated by our participants was that having hemorrhoids increases one's risk of developing colorectal cancer, a finding also reported for Hispanic female participants in focus groups conducted by Royak-Schaler et al.¹⁴ Other misconceptions existed about the causes of cancer, such as the belief that eating too many chilies or that having ulcers or gastric distress can cause colorectal cancer; these findings were not supported in other research.

Despite having little knowledge of colorectal cancer, most participants in our study were able to identify commonly accepted cancer prevention strategies, such as eating a healthy, well-balanced diet and exercising regularly. Participants also frequently stated that receiving regular medical examinations is an effective way of detecting cancer at an early stage and that if cancer is detected early, an individual has a greater chance of surviving. Nevertheless, specific procedures such as FOBTs, colonoscopies, or sigmoidoscopies, were generally unknown to most participants. Many participants expressed interest in learning more about colorectal cancer.

Participants in our study had pessimistic attitudes about their chances of surviving cancer. Many stated that they would rather not know if they had cancer; others stated that if they had cancer, they would decline treatment, explaining that treatments are ineffective and that cancer may return even if treated. These beliefs reflect the concept of fatalism (*fatalismo*), which is the feeling of hopelessness and powerlessness resulting from the belief that events are determined by fate or by something over which one has little or no control.¹⁵ Findings from previous research suggest that fatalism is common in under-served populations, those with low incomes, with low levels of education, or those who have limited knowledge of cancer.¹⁵ Our study participants had limited knowledge of cancer and lived in under-served communities with scarce healthcare resources. Fear and fatalistic attitudes about developing cancer or recovering from it are reinforced in communities where screening is rare, and cancers are often detected in late stages. Fatalism has been identified as a barrier to screening participation among Hispanics when other types of cancer have been examined.¹⁶⁻¹⁸

Our findings show that cost of medical care is the most commonly reported barrier to screening for colorectal cancer. Cost was also reported as a deterrent to screening in studies

conducted by O'Malley et al, Reynolds et al, and Carpenter et al.¹⁷⁻¹⁹ Cost and lack of healthcare coverage were identified as barriers for Hispanic women in research concerning screening for cervical^{20,21} and breast cancers.^{22,23}

Our findings also indicate that embarrassment was seen as a barrier to screening for both women and men and was thought to be particularly problematic for men. Bastani et al similarly concluded that embarrassment was a deterrent to screening participation,⁵ a conclusion also reached by Walsh et al and Royak-Schaler et al in their studies.^{1,14} In all these studies, screening procedures were described as embarrassing, uncomfortable, and an invasion of privacy. Data from the study conducted by Bastani et al show that Hispanic women identified discussing certain parts of the body as taboo.⁵ These findings support the notions of embarrassment (*vergüenza*) and modesty (*modestia*), common characteristics among Hispanics.^{24,25} Moreover, as demonstrated in research by Modiano et al, Hispanics may be uncomfortable answering physicians' questions they consider private.²⁶ Hispanic men also are thought to view sickness as a sign of weakness,^{5,26} and may view the colonoscopy/sigmoidoscopy procedure as a symbol of being sexually violated.²⁷

The importance of a supportive family and friends is best illustrated in participants' discussion of ways of coping with cancer. The high value Hispanics place on family and the tendency to refer to family members as sources of strength as well as material, emotional, and informational support (*familismo*) has been documented in several previous investigations.^{25,26,28,29}

Somewhat surprising was the importance of willpower and mental and spiritual strength needed to cope with cancer. To the best of our knowledge, such constructs have not been associated with Hispanics nor reported before.

A final area mentioned quite frequently was complementary treatment.

Some participants believed taking herbs or other plants considered medicinal in nature could be useful treatments for cancer. A few also thought a trip across the border to Mexico would result in inexpensive tests and treatments.

Summary

Given the increasing size of the Hispanic population, developing interventions to reduce the burden of disease will become increasingly important. The findings from our study demonstrate that intervention to improve participation in screening services for colorectal cancer should focus on reducing the influences of cost and embarrassment and improving levels of knowledge about colorectal cancer and the need for screening.

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AUTHOR CONTRIBUTIONS

Design concept of study: Coronado, Thompson, Oderkirk
Acquisition of data: Coronado, Farias, Godina, Oderkirk
Data analysis interpretation: Coronado, Farias, Thompson, Godina, Oderkirk
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