

Cancer Survivorship Experiences of Rural Hispanics



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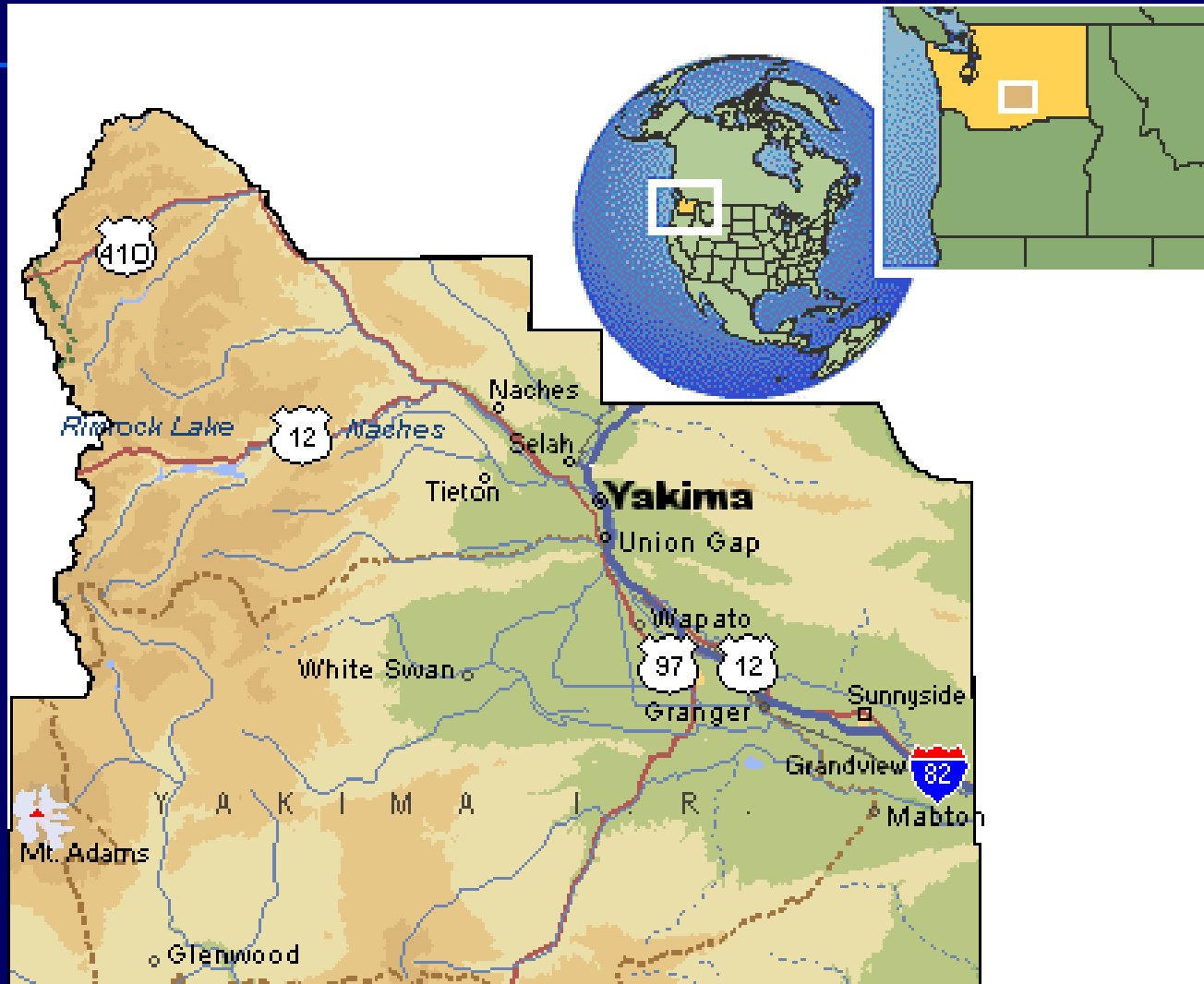
Objectives

- 1) Explore the experiences of Hispanic cancer survivors and family members of cancer survivors from two rural Washington communities.
- 2) Identify cancer-related information and resources useful for cancer survivors and community members at large.

Motivation

- Compared to non-Hispanic Whites, Hispanics in U.S.:
 - are diagnosed with more advanced cancers
 - experience greater cancer-related morbidity and mortality
- Compared to urban populations, rural populations:
 - face unique barriers to accessing health care
 - experience poorer health outcomes

Location of the Yakima Valley



Recruitment

- Participants recruited from Sunnyside and Toppenish, WA via:
 - Flyers
 - Radio
 - Church services
 - Health fairs

Data collection

- 5 focus groups conducted by trained Spanish-speaking facilitators between February 2006 and October 2007
- 41 participants (31 women, 10 men)

Data analysis

- Audio-taped sessions transcribed, translated into English
- Matrix of main topics created from each session
- From matrix, 3 staff members independently identified and coded key words and common themes
- Themes and key words reviewed/discussed, consensus reached

Focus group participants

Focus Group	Date	Female	Male	Total
#1	Feb-06	3	2	5
#2	Feb-06	6	2	8
#3	Mar-06	7	1	8
#4	Sep-07	8	4	12
#5	Oct-07	7	1	8
		31	10	41

Overview of Themes

- Experience with cancer
- Experience with physician
- Information and resources

Experience with cancer

Reactions to cancer diagnosis

- Fear
- Helplessness
- Sadness
- Strength & Courage
- God's will
- Hope

Experience with cancer

Challenges faced after cancer diagnosis

- Concern for children
- Financial concerns
- Lack of support from spouse
- Depression & psychological effects
- Isolation/lack of support in the community

Challenges faced after diagnosis

Lack of support from spouse

“[She] didn’t get operated for cervical cancer, supposedly because the husband told her that he wasn’t going to be an idiot anymore. ‘If you’re going to get your uterus taken out, you’re no good to me anymore.’ And they’d rather let themselves die.”

Challenges faced after diagnosis

Isolation

“Well ... that is why one gets depressed more, because you don't get to talk to other cancer survivors in order to get advice...”

“Why, I ask you here, does no one get together anywhere? We are always in our houses, stuck in our houses. There comes the depression, there comes nervousness, there comes illness of the brain, of everything.”

Experience with cancer

Beliefs about causes of cancer

- Genetics
- Smoking
- Environmental causes (chemicals, pesticides)
- Sun
- Physical trauma
- Riding horses (prostate cancer)
- Operations on cancerous tumors

Beliefs about causes of cancer

Riding horses

"... two uncles of mine passed away from prostate cancer, and in Mexico, ... since they were very young ...well they transported the horse dressings... they say, but I don't know, that that is what affected them. And that is why... they got [prostate] cancer, ...they were always on horses."

Beliefs about spread of cancer

Operations on cancerous tumors

“There is cancer...and if they operate they don't stop it, it scatters...you need to know where the cancer is. If they operate and they don't know where it is at, like in my sister's case, they operated and it scattered...”

Experience with cancer

Beliefs about cures for cancer

- Natural remedies and herbs
- Smoking cessation
- Faith in God
- Eating healthy

Experience with physician

Level of satisfaction with physician

- Trust and confidence in physician
- Physician was:
 - unavailable
 - rushed for time
 - insensitive
 - negligent
- Could not understand physician

Level of satisfaction with physician

Physician was negligent

"The doctor that I had ... she ignored me completely. She did not want to run tests on me, did not want to do anything to me. Finally I switched doctors. What I am hearing, is that the majority have to go through one or two doctors ... here in the clinic before they are able to find out that they have something."

Level of satisfaction with physician

Physician was negligent

"...my mother-in-law... her physician ... he never wanted to tell us anything. He would get mad, yell, and tell us that she was going to be released. But that is not the response we were looking for and after...he said he has going to go on vacation and was going to pass the case on to a female physician."

Information and resources

Useful information for community

- Prevention messages
- Importance of early diagnosis
- How to find specialists
- Where to go for treatment
- Disease (causes) and methods of treatment
- Treatment side effects

Information for community

Treatment side effects

“When they give us the medications ... they only tell you ‘you are going to take this pill for this amount of time, one daily, and that,’ but they do not tell one the consequences . I took Tamoxifen for five years and now ... I have osteoporosis. Something the doctor did not warn me about, did not even say to me ‘you are going to suffer from this ...’ ”

Information and resources

Useful resources for community

- Formation of community support groups to:
 - Connect cancer survivors to one another
 - Offer support for those newly diagnosed
 - Offer hope

Resources for community

Community support groups

"... if nobody is sick with cancer in the family ...well, it takes them like by surprise, right?... [support groups] are very nice because ...it is good to know ...what steps to take... one is more prepared. Even the people who do not have it and who do not suffer from it, it is good to be informed."

"... information and for one to know how to act when things happen to us in the clinic ... so if we are not comfortable with the situation there... one can be informed on one's own account."

Conclusions

Findings

Participants identified need for cancer support groups in their communities

Solution

Cancer survivor support groups organized in Sunnyside and Toppenish

Conclusions

Findings

Misconceptions exist regarding causes of and cures for cancer

Negative experiences with physicians reported - participants felt neglected and ignored

Solution

Support groups can serve to provide useful, accurate information

Support groups can help teach individuals to be more assertive/proactive with physicians