



Focus Groups to Describe Experiences with Cancer and Nutrition

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Introduction

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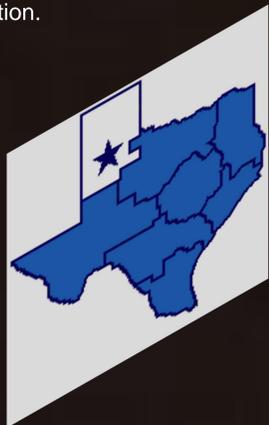
More than 11 million Americans are cancer survivors and 750,000 of them reside in Texas. The Cancer Nutrition Network for Texans (CNNT) was designed to address the many challenges to people living with cancer, whether they are survivors or care-givers. The information needs of the cancer survivor population focus on nutrition and symptom control, quality of life issues, and improved disease response. There is also a focus on education of the health professions directly in the area of nutritional needs of cancer survivors.

Aims and Methods:

A focus group study was conducted to gather information to develop education initiatives and outreach programs for rural West Texans affected by cancer particularly those in Public Health Region (PHR) 1. PHR 1 was targeted due to the lack of cancer survivor support services and the overall lack of nutrition and quality of life advice available in the rural underserved populations. Goals to optimize individual and community responses to cancer, to provide people and communities with resources and impart technical support to address long term survivorship issues. The sessions surveyed community members and gained input on medical access by having group members share health concerns, disparities, issues, and stories.

Results and Conclusions:

Five focus group sessions containing both caregivers and/or survivors of cancer were conducted. Conclusions include the continuing need for recent, evidence-based nutrition and personalized quality of life information for Texas cancer survivors and care-givers. Groundwork has now been laid to begin improvement of outreach delivery strategies and barriers of nutrition information.



Public Health Region 1 Map



Focus Group Format

This project was approved by the TTUHSC IRB and all focus groups were preceded by informed consent of all participants.

Focus Group Format:

Focus Groups conducted (Number of participants): Joe Arrington Cancer Center (7); Man to Man (8); Harrington Cancer Center (10); Joe Arrington Cancer Center (3); ACS Coping Group (4) Each focus group used the same 8 questions to elicit responses regarding cancer treatment and nutrition. 3 of the 5 groups had a mixture of various cancer types represented, however 2 were very specific: Breast cancer only and Prostate cancer only. Each participant was given a number by which to identify themselves with to allow for anonymity throughout the research process. The settings were informal to allow participants to feel comfortable in discussing their thoughts and feelings. While encouraged to answer questions during the session, all participants had the right to abstain from answering or leave at any time.

Focus Group Analysis

Focus Group Analysis:

All discussions were audio taped and transcribed to obtain specific quotes regarding nutrition information needs for cancer patients and/or caregivers. Each group was assigned a letter and when placed with the participants number, it allowed for all quotes to be easily traced to each particular discussion. Demographic forms were used to obtain the types of cancers represented at each group, treatment information that each patient received, along with the best ways to distribute information. Once all information was reviewed, a matrix with common themes among all groups was designed with supportive quotes for each theme.

Demographic results showed that:

- Among treatment options, surgery, chemotherapy, and radiation were all listed multiple times with surgery taking precedence.
- Individuals undergoing surgery only had fewer problems with eating or nutrition.
- Receiving information by website and email was favored over print media, TV, and phone.
- Ten out of 29 respondents traveled greater than 100 miles to receive treatment.
- Sixteen out of 31 respondents did not have a previous chronic disease before being diagnosed with cancer.
- Twenty-four out of 30 respondents felt nutritional supplements did not prevent cancer.
- Twelve out of 28 respondents felt nutritional supplements could be useful in treating cancer.

This information allows us to determine how best to approach nutrition information for cancer survivors/caregivers in rural West Texas.

Focus Group Analysis Methods

Demographic Information Form

The Cancer Nutrition Network for Texans
Demographic data for members of the focus group

Do not write your name on this form. You will be given a coded number to use with this form and to identify yourself when you make comments during the focus session. The list with the code numbers and these forms will be destroyed when the information has been fully analyzed in order to protect your confidentiality.

Code Number: _____ Session Number: _____

Check whether you are: a cancer patient ___ survivor ___ or caregiver ___

Do you (or your patient) live in Lubbock ___ or outside of the city ___?

How far was the distance traveled to receive treatment? _____ miles

When was the cancer diagnosed? _____

What type of cancer is it? _____

How is (or was) the cancer treated? _____

List any other chronic diseases you have (eg. diabetes, high blood pressure, etc.) in addition to cancer: _____

Does the cancer interfere with taking care of these other diseases? ___ Yes; ___ No.

Did you have any nutritional or eating difficulties resulting from the cancer (___ Yes or ___ No) and, if "Yes," were they temporary ___ or permanent ___?

Do you think dietary supplements such as vitamins, mineral or herbals help in preventing cancer? ___ Yes; ___ No

Do you think dietary supplements such as vitamins, mineral or herbals help in treating cancer? ___ Yes; ___ No

Has anyone tried to sell you nutritional products to treat cancer? ___ Yes; ___ No

Had you heard about the Cancer Nutrition Network for Texans (CNNT)? ___ Yes; ___ No

*Check which of the following is the best way for you to get your information: Newspaper ___; magazine ___; newsletter ___; television ___; website ___; email ___; telephone call ___.

Matrix of Common Themes Among Focus Groups

Emotional/Psychological	Gustation/Eating	Support Importance	Physical Effects	Information Problems	Sources of Information	Dietary Supplements
Trying to keep my life as normal as possible (A6)	He got to where I couldn't cook for him (A6)	The group here kept me going (A6)	Constant diarrhea (A6)	No one in a smaller community did not get any information (A7)	This little bible helps...for little drinks during the stay and things like that (A6)	I can't say it helps or I can't say it doesn't help (A6)
Emotional upheaval and the difficulty handling your emotions (A7)	You eat whatever will stay, whatever doesn't fall on the cardboard (A6)	My grandchildren...help keep me busy (A5)	Nauseating (A5)	Most of it's trial and error...there was no specific information or counseling (A5)	[There was an] informative class that gave us books that had all of the information in it about some of the symptoms and what to expect in going through chemo (A6)	Some of these supplements can be very detrimental or counteractive to other medications (A7)
Biggest challenges was her accepting (A2)	I had no support group...it's a hot tougher when there's no husband, children, sisters or brothers (A4)	Her brain just doesn't work like it use to. She is not able to problems solve and her memory is bad (A3)	[Facilities] are better than they were but still long ways to go (A5)	A friend got nothing but a stack of papers and none of it was put in any kind of form (A6)	I don't think that supplements help in treating or prevention of cancer (B5)	
Doesn't want anyone to see her or what she looks like (A2)	The thing to not dwell on (sorry because) I suspect that may have caused my cancer (B4)	Emotional support like this group essentially saved my life (C3)	You actually go into a chemo bag...you truly can't remember stuff (A4)	Would really have appreciated someone talking to me to tell me what to expect (A6)	Some little recipe cards (A5)	I wonder if it's been effective...I don't know (B7)
Losing my modesty during treatment (A5)	Since I been on chemo, I developed some sort of lactose intolerance (A4)	Family was surrounding her and supporting her (C10)	Vomiting and Constipation (A2)	Useful information (their process of their illness, things that are out there. And recipes for smoothies (A1)	I've always taken a multivitamin but I don't know if it's working (C4)	
It felt like a death sentence (A4)	Any type of good diet won't hurt you (B3)	Ensure and my husband got me through (C4)	Problems with protein (Bov)(A2)	There has to be a reason...whether it's a person or place (B7)	Her doctor suggested the 'See Food Diet'...if you see food and list it, then eat it (B3)	Somebody was a shabby dealer...I couldn't tell any difference though (C5)
She had difficulty meeting nutritional needs...in dealing with considerable pain issues (B1)	Only time I had difficulty was after surgery for something else (C1)	Family has helped with positive thinking (C7)	Milk products...just don't work for me (A2)	Any information for me that would clarify some of these themes (B8)	A website connected to the hospital...that way you would feel more comfortable (A6)	If all of those products did what they said they did then there wouldn't be any sick people (C2)
Hard to think that there's not a cure...I thought I couldn't do this (C4)	[I prepared meals as usual and the site as usual] (C2)	Highly recommend [support group] (D1)	No significant change in weight (B5)	Most doctors don't say anything about about nutrition (B8)	A class came in very handy (A6)	Take a multivitamin, but I took it before the cancer (D3)
Depression and anxiety set in (C3)	I couldn't hardly eat anything, sweet or sour...it didn't matter (C6)	Friends became my family...I was single at the time...I didn't know what I was going to do (B2)	She did lose considerable weight (B3)	Any information for me that would clarify some of these themes (B8)	Give a book before the 1st chemo treatment (A4)	I'm almost at the point where I don't want to take any supplements (B3)
Knowing other people had the same problem was helpful (C4)	I didn't want anything (C7)		I lost 40 lbs at first (B8)	Some of that information [on the internet] scared me (B7)	I knew that based on the information that was given to me that if I needed the help, it was there (A4)	I wonder if we create some of our own problems with supplements I've don't know what's on them (B3)
I was scared not knowing what was going to happen (D1)	She had an all liquid diet (C7)		Treatment caused me weight loss...but following surgery I gained weight because I couldn't work out as I normally do (B5)	One on one counseling would be nice (D1)	Mostly from my doctors (C3)	But they're safer than pharmaceuticals (B4)

Focus Group Findings

- Diverse nutritional problems among cancer survivors
- Need for personalized nutrition counseling
- Patients had to figure out nutrition regimens themselves and sought information from the internet
- Nutritional problems and physical side effects result more from treatment than the cancer
- Recommend computer access in the cancer center
- Primary concern is how to keep cancer from recurring
- Unexpected large number of people that did not support use of supplements
- Depression, withdrawal, and fear were common emotions during the treatment process

Supportive Quotes of Findings

Supportive quotes from participants:

- A website connected to the hospital...that way you would feel more comfortable (A6)
- Most of it's trial and error...there was no specific information or counseling (A5)
- Would really have appreciated someone talking to me to tell me what to expect (A4)
- Most doctors don't say anything about nutrition (B8)
- I had mouth and throat sores so I couldn't eat or drink anything (C10)
- [Treatment] has weakened me down (D2)
- There just wasn't that much nutritional information out there (E2)

Also, among the men's prostate group and the breast cancer only focus groups there was a camaraderie noted among the participants. They seemed to speak much more openly about their problems and everyone participated during the discussion.

Conclusion

After all data was reviewed, it appears that people are still having significant trouble acquiring cancer nutrition information. We also found that while the cancer diagnosis may take an emotional and physical toll, it is the treatment of the disease that has the most devastating effects. Overall, cancer supplements were thought to be of importance in the treatment process of cancer but not in the prevention. This information can be utilized in order to develop better methods of delivery for nutrition information. Due to the increasing survivorship of cancer patients, there is a definite need for a well developed, collective source of cancer nutrition guidelines and general information in West Texas.