



A tailored web-based communication intervention for cancer patients and their family caregivers

Background Information

The FOCUS Program

- In-person, nurse-delivered intervention for cancer patients and caregivers
- Strengthens communication and support
- Improves quality of life and reduces distress about cancer



(Northouse, *Cancer* 2007; Northouse, *Oncol Nurs Forum* 2002)

Interactive Web-based Program: Tailored for Patients and Caregivers



Sample 1 Tailored on:

- » Dyad type: Married Couple
- » Caregiver: Mary, wife
- » Patient: John, prostate cancer
- » Communication: High
- » Dyadic support: High

Introduction

When someone has cancer, it affects the whole family. For this reason, the patient and caregiver need to work together as a team. Let's look at what you told us and see how you're doing:

What you have going for you:

1. **Communication:** You have very strong communication. People who communicate well are better off in many ways. They have more support, stronger relationships, and higher quality of life. Here are a few examples of what you're doing really well:

- You share your feelings with each other.
- You know how important it is to be open.
- You are aware of each other's concerns about cancer.



Sample 2 Tailored on:

- » Dyad type: Mother / Daughter
- » Caregiver: Laura, daughter
- » Patient: Anita, breast cancer
- » Communication: Low
- » Dyadic support: Low

Introduction

When someone has cancer, it affects the whole family. For this reason, the patient and caregiver need to work together as a team. Here are some tips we made for you based on your answers.

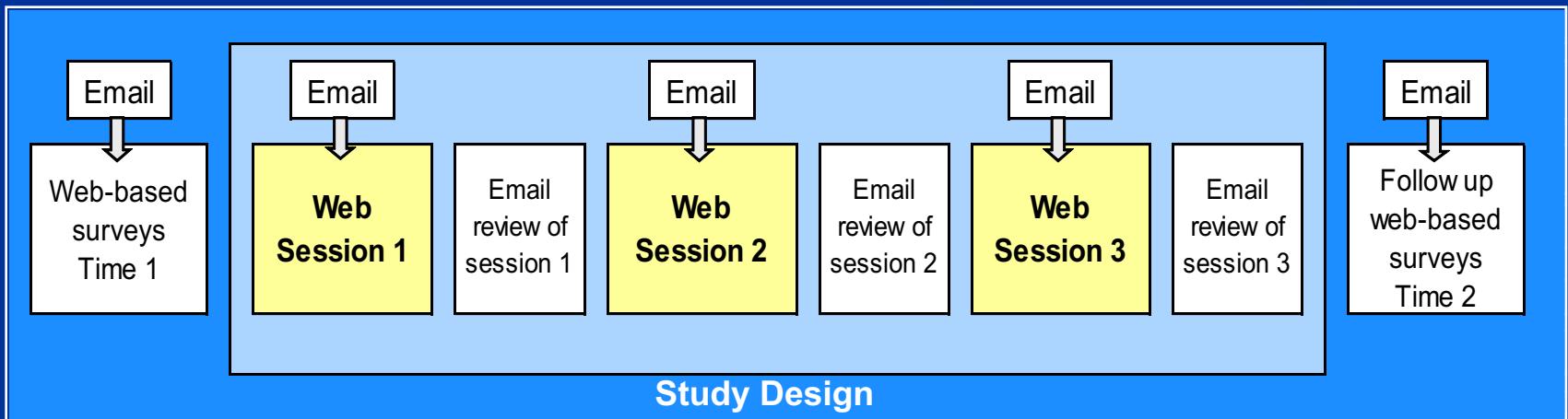
Working as a team means:

1. **Communication:** People who communicate well are better off in many ways. They have more support, stronger relationships, and higher quality of life. Good communication means you:

- Share your feelings with each other often.
- Talk about concerns such as sadness, fear, and worry.
- Listen to each other, without interrupting, even if you feel differently.

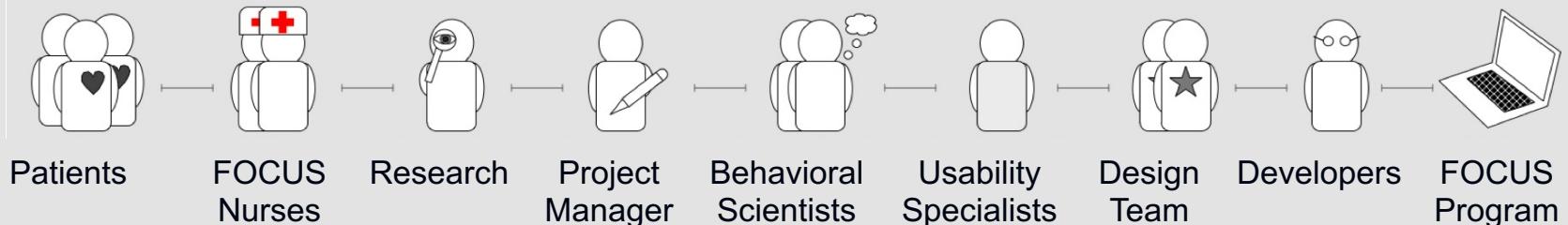
Translation: FOCUS on the Web

- Collaboration: Met with web experts
- Focus groups: Assessed web idea
- Usability study: Tested workability
- Phase II study: Pre and post-test

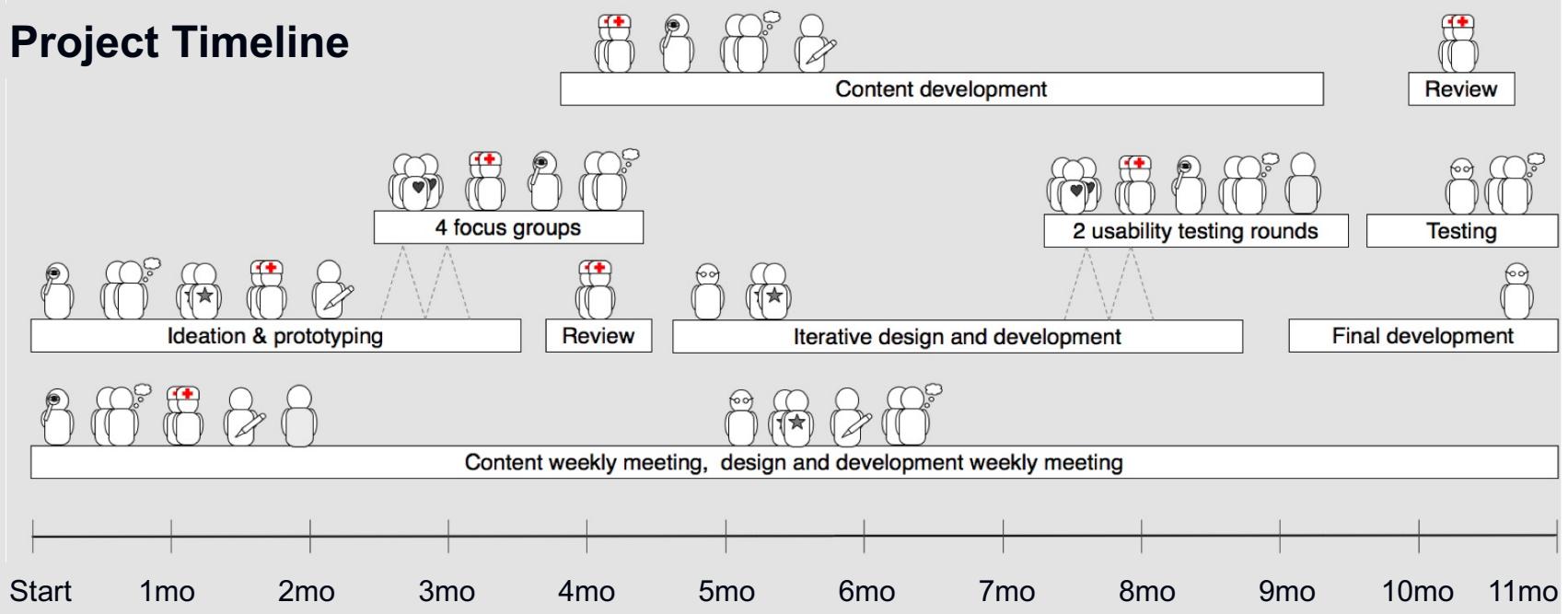


Development of Web-Based FOCUS Program

Multidisciplinary Team



Project Timeline



[About both of you](#) [Goals of the FOCUS program](#)[Finding out Laurel had cancer](#)[A cancer patient's story](#)[Building up your team](#)[Activities you can try](#)

We use all of this information, plus your answers to questions we ask during each session to build a program just for you.

Goals of the FOCUS Program

This Is where we start. We use all of this information, plus your answers to questions we ask during each session, to build a program just for you. **The goals of the program are to help you:**

- **Work together** as a team to deal with the cancer.
- **Share your thoughts** and feelings with each other.
- **Get better** at talking to each other about the cancer.
- **Learn new ways** to support each other.
- **Practice problem solving** so you can deal with issues that come up the future.
- **Find resources** to help you cope with your concerns.





A question for Laurel

How did you feel when you learned you had cancer? Choose up to 3.

- Fearful
- Worried
- Shocked
- Overwhelmed
- Angry
- Anxious
- Sad
- Helpless
- Guilty
- Relieved
- My reaction isn't on this list

Submit Answer



Why feelings matter

Your feelings are normal. It's common for **both** patients and family members to feel a lot of different emotions. Even though family members are not sick or facing treatment themselves, cancer also affects their lives.

Here's what we've heard from other patients about the reactions Laurel chose:

- **Fearful:** There's a lot that patients might be afraid of after a cancer diagnosis: Patients might fear dying, suffering, losing their hair, or what the diagnosis means for their family.
- **Worried:** Many patients worry about their treatment - what it's like, how to pay for it, and how it will change their everyday life. Many also worry about the effect their cancer and treatment will have on their life and family.
- **Shocked:** No one expects to hear the word "cancer" when they enter a doctor's office. Even if tests are done, many people have hope that the results will be negative. When patients learn it's cancer, they may feel overwhelmed and shocked.





Dan's story

When I first found out I had cancer, I was terrified. I couldn't help but think - am I going to die? What will happen to me and my family now?

I kept my thoughts to myself for days. I'm not a talker. I just don't like to. We don't talk about touchy-feely things in my family. We deal with getting through the next day, you know? That didn't work for me with this cancer thing. One day I broke down. I decided I had to tell my brother, Owen, what was up. At first I could hardly talk about it. I got too uncomfortable and changed the subject. Slowly, I figured out that if we were gonna get through this thing, we had to talk about it. It wasn't easy at first, but we knew it was important so we made a big effort. It's a little easier now- we can both share feelings ok. We're getting better at it.

Turns out, talking about it is the best thing I can do. It doesn't make the cancer better, of course. But it does make me feel better. It's just nice to know I'm not doing this alone.



Focus Group Feedback

- Positive response to content
- Positive response to program targeting patient-caregiver pair
- Suggestions about design
 - Color scheme
 - Contrast
 - Font size
 - Program features (ie check boxes, line spacing)
- Reassurance from pairs in which one person had little internet experience
- Reassurance about web-based delivery of cancer program

Usability Testing

- Procedures:
 - Test working prototype with representative content and navigation features
 - Test representative users when possible
 - Facilitator moderates session, prompting participants for feedback
 - Note-taker observes session
 - Videotape (ie Silverback, eyetracking software)
- How many participants do you need?
 - Popular reference: 80-85% of usability problems can be uncovered by having 4-5 individuals test the interface (Nielsen 1993). Some have questioned this # in recent years...

Results from Usability Survey (n = 16)

	Mean (SD)
I thought that this program was easy to use	6.6 (0.5)
I would choose to use this type of program in the future to complete an intervention that aims to improve my health	5.9 (1.0)
The program was too complex	1.1 (0.3)
I would need help from a technical support to be able to use this program	1.1 (0.3)
The program ran smoothly	6.3 (0.8)
The program was inconsistent (there were parts of the program that seemed out of place)	2.3 (1.7)
I think that most people would learn to use this program quickly	6.4 (0.8)
Using this program felt awkward to me	1.3 (0.4)
I felt very confident using this program	6.6 (0.6)
I needed to learn a lot of things before I could get going with this program	2.3 (2.1)
Total Usability Score	89.5 (8.3)

(Adapted from Brooke, 1996: SUS Quick & Dirty Usability Scale)

Qualitative Feedback from Usability Tests

- Favorable, sometimes emotional, response to program content.
 - Program brought patients and caregivers “*closer together to really discuss and not just guess.*”
 - Program led to communication about previously unshared feelings, stimulating “*discussion that you might not have or you might not even think of.*”
 - “*When you’re prompted, you can talk about it a little deeper.*”
- Acceptance of web-based intervention
 - “*There is something non-threatening about the computer asking a difficult question.*”

FOCUS Demonstration

Mail Message



Mail Properties

From: <focusstudy@umich.edu>
To: <dzulman@med.umich.edu>
Subject: Welcome to FOCUS, Michele
Attachments: Mime.822 (4 KB) [View] [Save As]

Monday - October 4, 2010 1:00 PM

Hello Michele,

Thank you for agreeing to participate in the FOCUS Program. Here's what you can expect over the next 8 weeks:

- **Step #1: To start, you and Angie will fill out a survey online.** These surveys will help us build a personalized program just for you.
- **Step #2: You and Angie will work together at the computer to do the 3 FOCUS sessions.** You'll do one session every 2 weeks. We'll send you an email when it's time for each session.
- **Step #3: When you have finished all 3 sessions, we'll ask you to fill out another survey so we can learn more about you and your thoughts about the program.**

Don't worry about remembering all of this, we'll send you an email when it's time for the next step. If you have any questions or need to contact us, you can always use the "Help" button on the FOCUS website.

A few important notes about the survey:

- It will take you about 30 minutes to finish.
- If you need to, you can stop and take a break. The survey will remember where you stopped so you can come back later.
- You should answer these questions by yourself, Angie doesn't need to be with you.
- Use the "Help" button or call (734) 615-4017 if you have trouble filling out the survey.

To get started, click the link below to fill-out your survey.

www.focusstudy.org

Please use the following password to log on to the FOCUS website.

- Current Password: focus



FOCUS

Helping Families Through Research

?

Help

Welcome to FOCUS.

Please Log In.

Your Username

Your Password

Login

Click below if:

I forgot my password.

I forgot my username.

I need help logging in.



Development Mode (Session Time out 15 mins)

Helping Families Through Research

?

Help



Logout

Welcome Michele.

S U R V E Y

Start



FOCUS

Helping Families Through Research

Development Mode (Session Time out 15 mins)

?

Help



Logout

Thank you for participating in the FOCUS program. Please complete the following survey so we can build a program just for you.

- **Please answer the questions by yourself**, without talking to Angie.
- **Each section has specific instructions**. You will need to read the instructions and answers so you know how to answer the questions in that section. For example, one section may ask how things are going in the past week, another will ask about the past month.
- **You will need to answer nearly all of the questions to continue**. In order to build a program just for you, it's important that you answer the questions. There are a few questions you can skip if you don't want to answer them. Those questions are marked "optional."
- **It's usually best to give the first answer that comes to mind**. There are no "right" or "wrong" answers with these kinds of surveys. If you are unsure about how to answer a question, please choose the answer that is closest to how you feel.
- **You will not be able to go back and change your answers after you click "Next Page."**
- **You are welcome to take a break if you need one**. Please pause for a short break if you need one while you're doing the survey. The survey will remember where you left off so you won't have to start over.
- **It should take you about 30 minutes to complete the survey**.
- **Our privacy policy is the in "Help" menu for you to review**.

If you have any questions or comments, please contact Ann Schafenacker, RN, MSN (Study Coordinator) at (734) 615-4017 or annschaf@umich.edu.



FOCUS

Helping Families Through Research

Development Mode (Session Time out 15 mins)



Help



Logout

What is your age?

What is your birth date? Please pick the month and date from the list, then type four digits for the year.

January

1

Are you male or female?

Male

Female

What is your ethnicity? Please mark one.

Hispanic or Latino (Cuban, Mexican, Puerto Rican, South or Central American or other Spanish culture regardless of race)

Not Hispanic or Latino

FOCUS Baseline Questionnaire

- **Sociodemographics**
 - Age
 - Sex
 - Race/ethnicity
 - Patient-caregiver relationship
 - Spouse/partner, friends, parent-child, siblings
 - Living together or apart
 - Marital status
 - Education
 - Employment
 - Household income

FOCUS Baseline Questionnaire

- **Baseline Health**
 - Type of cancer
 - Type of treatment
 - Stage of disease
 - Physical/emotional/social well-being
 - Risk for distress
 - Scale includes demographics, health history, current concerns, symptom scale

FOCUS Baseline Questionnaire

- Assess baseline levels of outcome variables...
 - **Benefits of illness** (positive impact of illness on patient/family/relationships)
 - **Effective communication** (Lewis Mutuality and Interpersonal Sensitivity Scale)- assesses open communication and ability to share feelings about the illness
 - **Social support** (7-item measure of dyadic support)
 - **Self-efficacy** (Lewis Cancer Self-Efficacy Scale)
 - **Emotional distress** (Profile of Mood States- frequently used among cancer patients and their caregivers)
 - **Quality of Life** (FACT-G)

FOCUS Baseline Questionnaire, con't

- Positive impact of cancer diagnosis

Some patients say that in spite of difficulties that occur with an illness such as cancer, good things have come from it. Other people don't see anything positive coming from their illness. We would like to know about your experience. **How much do you agree with the following statements?**

Having cancer has...

	Not at All	A Little	Some	A Lot
Led me to be more accepting of things.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Helped me take things as they come.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Brought my family closer together.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Made me more sensitive to family issues.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

FOCUS Baseline Questionnaire, con't

- Patient-caregiver communication about cancer

Each family has their own way of experiencing the patient's illness. There are no right or wrong ways. **Please let us know to what extent each of the following sentences applies to you and Angie now. Choose the response that best describes how you both are now.**

Always True Frequently True Sometimes True Seldom True Never True

We keep the communication open between us about the cancer.

We understand how each of us is feeling about the cancer.

When we don't understand what the other is feeling about the cancer, we try to figure it out together.

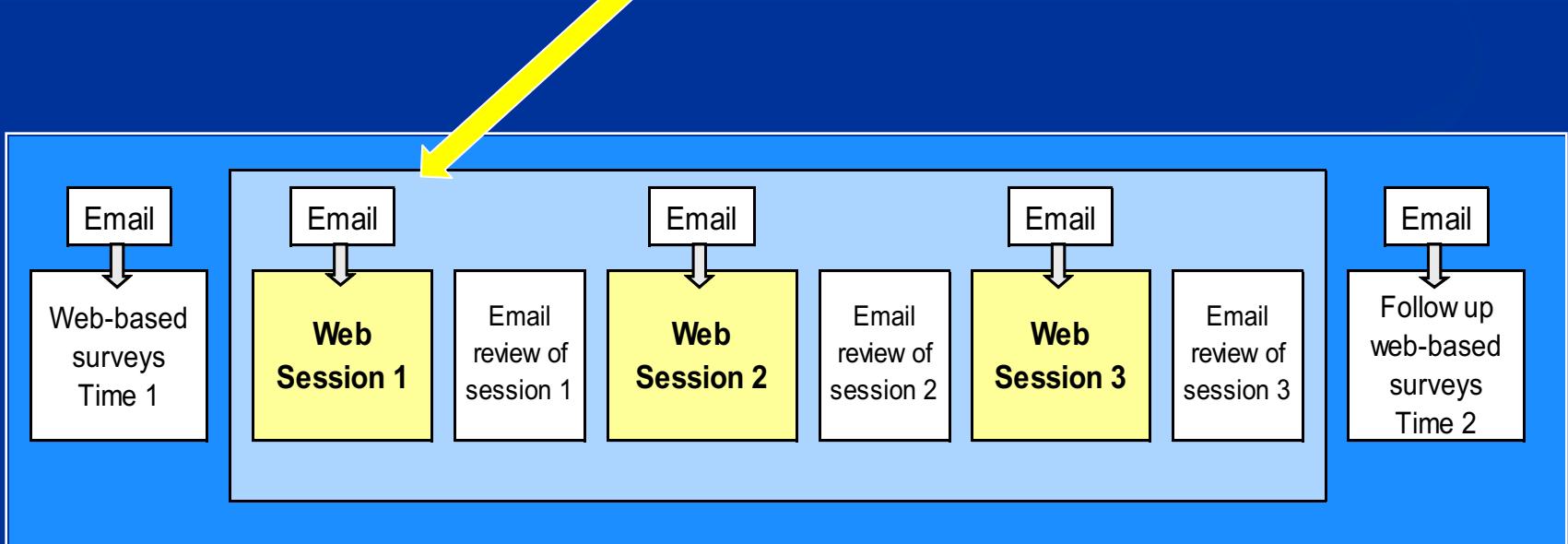
Thank you.

Thank you for taking the time to complete this survey. Your participation in our research on cancer and families is very valuable.

In one week, you'll be able to start your first FOCUS session. We'll send you an email with a link to the session at that time. If you have any questions or concerns please contact Ann Schafenacker RN, MSN (Study Coordinator) at (734) 615-4017 or annschaf@med.umich.edu.

Next Page

One week later...



Mail From: <focusstudy@umich.edu>

File Edit View Actions Tools Window Help



Mail Properties Personalize Message Source

From: <focusstudy@umich.edu>

1/11/2011 10:29 AM

To: Zulman, Donna

Subject: It's time to start your first FOCUS session

Hello Michele & Angie,

Thank you both for completing your surveys. Now, it's time for your first FOCUS session. Click the link below to go the FOCUS website.

www.focusstudy.org

Just a reminder, you need to be together to do Session 1.

If you have any questions or need to contact us, please use the "Help" button on the FOCUS website or contact Ann Schafenacker, RN at (734) 615-4017 or annschaf@umich.edu.

Thank you,

The FOCUS Team



Welcome to FOCUS.

-Please Log In.

Your Username

Your Password

-Click below if:

[I forgot my password.](#)

[I forgot my username.](#)

[I need help logging in.](#)



Development Mode (Session Time out 15 mins)
Helping Families Through Research | [Help](#) | [Logout](#) | [Debug](#)

**Welcome Back.
Please select what you would like to do.**

SESSION 1

You and Your Family

Start

SESSION 2

Dealing with Concerns

Start

2 weeks after Michele & Angie
complete Session 1

SESSION 3

Supporting Each Other

Start

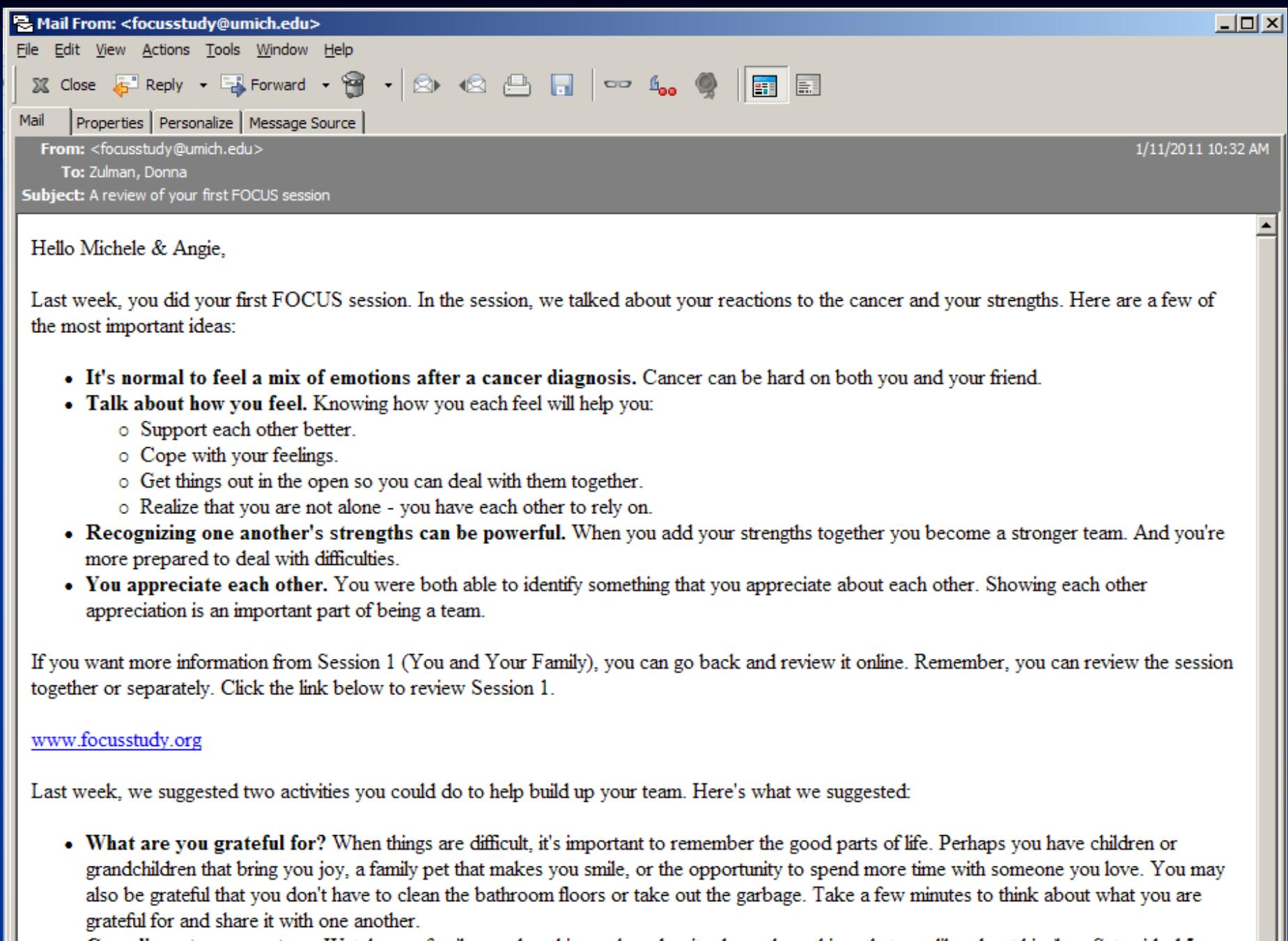
2 weeks after Michele & Angie
complete Session 2

Begin FOCUS Demonstration

Session 1:

- Reacting to cancer diagnosis
- Working as a team
- Recognizing strengths and appreciating each other

Screenshots from Session 2



Welcome Back.

Please select what you would like to do.

SESSION 1

You and Your Family

Review

SESSION 2

Dealing with Concerns

Start

SESSION 3

Supporting Each Other

Start

2 weeks after Michele & Angie
complete Session 2



Development Mode (Session Time out 15 mi

Helping Families Through Research

[? Help](#)

[? Logout](#)

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Michele



Before we begin the session

Please look at the picture on the left.

Where is Michele sitting? Click the person in the picture who is sitting in the same place as Michele .

This will tell us which direction your questions will come from. When you have chosen, click "Ready to Begin".

[Ready to Begin](#)

Welcome back!

Before we get started with your second session, we'd like to remind you that it's **important to work together at the computer**.

Just like the first session, **we'll ask you to answer questions by yourselves and together**. Please:

- Answer your own questions.
- Be honest.
- Respect each other's opinions.

If you'd like more help using the program, click the "Help" button in the upper right corner of your screen.



In this session we'll:

- Talk about how the past few weeks have gone.
- Talk about how your family is coping with Michele's cancer.
- Offer some problem-solving tips and resources.
- Look at your communication style.
- Talk about common communication road blocks and ways to get around them.

First, we have a couple of questions about how the last few weeks have gone.



This question is for Michele

Cancer can be difficult for families to handle. Think about your relationship with Angie. Which three of the following cancer-related concerns do you think have been most difficult? (Choose up to 3.)

- Handling financial issues
- Dealing with the healthcare system
- Dealing with work
- Managing the household
- Handling concerns of children
- Managing symptoms
- Figuring out how to tell others
- Asking others for help
- Worrying about the future
- Dealing with strain on our relationship
- Dealing with the cancer risk for family members
- Making tough decisions
- I haven't faced new challenges
- Our challenges aren't on this list

Submit Answer



The same question for Angie

Think about your relationship with Michele. Which three of the following cancer-related concerns do you think have been most difficult? (Choose up to 3.)

- Handling financial issues
- Dealing with the healthcare system
- Dealing with work
- Managing the household
- Handling concerns of children
- Managing symptoms
- Figuring out how to tell others
- Asking others for help
- Worrying about the future
- Dealing with strain on our relationship
- Dealing with the cancer risk for family members
- Making tough decisions
- I haven't faced new challenges
- Our challenges aren't on this list

Submit Answer



Working on concerns together

It's common to go through tough times after a cancer diagnosis. The concerns you shared with us are listed on the right. Below, we'll talk about two of your concerns in more detail.

Later on, you'll be able to talk about all of the concerns you chose.

- **Cancer makes work hard.** Some patients feel too sick to work. Family members often take a lot of time off from work to help their loved one. People may feel like they are falling behind and can't catch up.
- **Cancer and its treatments can be difficult for everyone.** Patients may feel sick, have very little energy, and might lose their hair. It can be hard for family members to watch their loved ones go through that. Many family members struggle to figure out how to help. Cancer symptoms and treatment side-effects can make life really tough for everyone.

How might you cope with these concerns together?
What can you do to help each other?

Michele chose:

- Dealing with work
- Managing symptoms
- Figuring out how to tell others

Angie chose:

- Asking others for help
- Worrying about the future
- Dealing with strain on your relationship



Take a few minutes to talk about your answers

- What are some specific examples of the concerns you chose?
- How were your concerns similar? How were they different?
- What, if anything, surprised you about each other's concerns?

Michele chose:

- Dealing with work
- Managing symptoms
- Figuring out how to tell others

Angie chose:

- Asking others for help
- Worrying about the future
- Dealing with strain on your relationship

Work together to
find ways to
address your
concerns.

Steps for solving problems

We keep encouraging you to talk about your feelings and concerns. Although talking is important, sometimes it's only the first step. **Here are steps that might help you address your concerns:**

1. **Share your concern.** Try to give examples of what you mean.
2. **Come up with some ideas to try.** Talk about how you can work together to deal with the concern.
3. **Choose an idea** you want to try.
4. **Talk about how things went** after you've tried it for a few days.
5. **Try another idea** if things haven't improved.

Sometimes it's hard to come up with strategies to try on your own. Fortunately, there are resources to help you. Read about some of these resources on the next page.



Ways to get help

Here are just some of the people and places you can turn for help dealing with your concerns. First, here are general resources that might help.

General resources for common concerns

- **Things to try:**
 - ▶ Talk to the **social worker** at your cancer center. You may find out about local services that can help.
 - ▶ Join a support group, either online or in-person, to learn how others have handled similar problems.
- **Where to find information online:**
 - ▶ [The National Cancer Institute](#).
 - ▶ [American Cancer Society](#).
 - ▶ [Cancer Care](#). You can also call the Cancer Care hotline at 1-800-813-HOPE.
 - ▶ [The Wellness Community/Cancer Support Community in Ann Arbor](#).
 - ▶ [Gilda's Club/Cancer Support Community in Royal Oak](#).

Click each of the concerns below to see some resources that might help:

- [Dealing with work](#).
- [Managing symptoms](#).
- [Figuring out how to tell others](#).



A question for both of you

Think about the way you usually talk about the cancer. Read these descriptions of different communication styles. Together, decide which one best matches how you talk to each other about the cancer.

- Both of us are open about our feelings. We're comfortable talking about the cancer and how it affects us.
- One of us is more open about our feelings than the other. We are different in how comfortable we are talking about the cancer.
- Neither of us is very comfortable talking about our feelings. We like to keep our feelings about the cancer to ourselves.
- None of these describe us.

Submit Answer



Your communication style

You've told us one of you prefers to talk more than the other. That's common among cancer patients and their family members. The important thing is to keep working on it. Research shows that people who share their feelings have an easier time coping with the cancer. They also tend to have happier, more fulfilling lives because they:

- Get more help dealing with their concerns.
- Let their feelings out, which makes them feel less stressed.
- Feel supported by their loved ones.





Talk about your style

Spend a few minutes talking about your communication style:

- What are you comfortable discussing about the cancer?
- What, if any, topics about the cancer would you like to talk about more?
- What could you do, together, to work on sharing your feelings about the cancer?

Results for Phase 2 Pre-Post Test

Instruments/Variables N=38 dyads	Time 1 Mean (SD)	Time 2 Mean (SD)	Effect Size	Change P-Value
Patient: Benefits of Illness	2.6 (0.7)	3.1 (0.6)	.50	<.01
Patient: POMS-Fatigue	11.3 (4.1)	9.6 (4.1)	.43	.02
Patient: FACT-G QOL-Physical	21.6 (4.8)	23.4 (4.1)	.37	<.05
Patient: FACT-G QOL-Functional	20.0 (4.8)	21.6 (4.7)	.39	.02
Caregiver: Benefits of Caregiving	2.6 (0.8)	2.8 (0.8)	.34	<.05
Caregiver: Self-efficacy	141.2 (16.5)	147.8 (16.9)	.54	<.01
Caregiver: Dyadic Support	4.2 (0.7)	4.4 (0.5)	.34	<.05
Caregiver: POMS-Anxiety	8.8 (4.0)	7.9 (2.4)	.38	.03
Caregiver: POMS-Depression	7.6 (3.5)	6.7 (2.0)	.38	.03
Caregiver: POMS-Anger	7.8 (2.4)	6.7 (1.8)	.58	<.01
Caregiver: POMS-Total	58.8(17.9)	54.1 (11.0)	.47	<.01
Caregiver: FACT-G QOL-Total	85.8 (12.5)	88.5 (11.0)	.37	.03

Means (SD) and Change Scores from R21 Tailored Web-based Study

Qualitative Feedback from Phase 2

We conducted a qualitative study with 16 of the patient-caregiver dyads to learn more about their experience.

What they liked most:

- it facilitated their communication or brought them closer together (43%)
- it was easy to use, convenient, and could be done at home (40%)
- it provided new information (17%).

They also liked:

- working on the program together (100%)
- email reminders (100%)
- having a “Help” button available.

Suggested changes:

- 41% said “nothing”
- 24% said some content was repetitious
- 25% wanted more content
- 5% wanted an indicator of program length
- 5% wanted content more relevant to their phase of illness.