Overview of the Qualitative Research Process

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Uses of Qualitative Research in Community Based Research

• Exploratory/Formative Research
  – Ethnographic studies
  – Development of interventions
  – Development of study methods
  – Development of surveys

• Outcome Evaluation
Phases of Qualitative Research

- Research Design
- Data Collection
- Data Analysis
- Deliverable
I. Research Design
Research Design

- Research objectives
- Define data collection & analysis methods
- Deliverable
II. Data Collection
Common Qualitative Data Types

- Interviews
- Observation
- Visual (Video/Image)
Common Qualitative Interview Types

- Focus Groups
- Key Informant
- Cognitive Interviews
Qualitative Interview Structures

• Informal
  – General conversations in the field
• Unstructured
  – Interview setting with no guide
• Semi-Structured
  – Interview setting with a guide
• Structured
  – Interview setting with a set interview schedule
The Semi-Structured Interview

• Has structure and purpose

• Goes beyond the spontaneous exchange of views that take place in everyday conversation

• Relies on a careful questioning and listening approach

• Not a conversation between equal partners

• Remains flexible to explore new avenues of inquiry
Semi-Structured Interview Guides

• Topical structure
• Questions should be open ended, not leading
• Probes/prompts can be built in to questions
• Questions can be prioritized
• Should be organized and easy to read
Example Semi-Structured Interview Guide

YWI FG questions

Primary purpose: To improve understanding of what young women are concerned about and where are the informational and support/services gaps (info/support available, but they did not get it as well as things they wish were available but was not). Additionally, would like to get a sense of where young women are getting important information and how else they might accept it.

Questions (in blue) are the most salient questions for our young women's focus groups/K1 interviews.

1) Remembering back to the time around your diagnosis and early treatment, what was/were the most difficult thing(s) for you (emotionally/physically) regarding your diagnosis and treatment of breast cancer?

Factors that disproportionately affect young women

A. Reproductive and sexual issues

1. Menopause/Infertility
   a. Did the topic of long term risks, such as premature menopause or potential infertility (not being able to have children) after treatment, ever come up?
   b. If yes to menopause, did you get information about what to expect physically and how to handle symptoms?
   c. Do you feel that you got enough information? What else would you have wanted?

2. If yes to potential infertility
   a. Women dx, at a young age, may still be thinking about having children or having more children. Did your doctor talk to you about potential fertility issues?
   b. If no, did this ever come up as an issue for you? (moderator we are looking to see if either both of the following: if participants wanted to preserve fertility or if they discussed this w-doctor)
   c. If yes, what information was given to you and when did you receive it? (note looking if women were given the range of options) Do you feel like you get all the information you needed? That this was an appropriate time to get this
Conducting Qualitative Interviews

• The interviewer needs to have a methodological awareness of the interaction
  – Sets up the interview
  – Uses systematic questioning & probing techniques
  – Reflects on the aim and mode of questioning
  – Focuses on the dynamics of the interview
  – Pays critical attention to what is said
  – Circles back to a topic for clarification or expansion
Qualitative Interview Skills

• Able to set aside his/her own agenda and filters
• Presents him-/herself as cordial but not intimidating, and non-judgmental
• Recognizes and avoids biases
• Able to critically analyze situations
• Knows how to obtain valid and reliable data
• Can think abstractly

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Building Rapport

• You only have a short time to create an interaction that goes beyond polite conversation or the exchange of ideas
  – Relationship is marked by respect, interest, attention, and good manners on the part of the interviewer

• You must be able to establish an atmosphere in which the interviewee feels safe to talk freely about his or her experiences and feelings
  – Relationship is friendly but not a friendship

Steinar Kvale (1996)
Irving Seidman (1998)
III. Data Analysis
Qualitative Data Analysis

• Two levels of coding:
  – Level 1: Structural Coding
  – Level 2: Thematic Coding

• Coding work done using NVivo Software
Qualitative Data Analysis: Structural Coding

• Structural coding:
  – Follows the interview structure. Each question is assigned a structural code.
  – This allows the generation of structural code reports which show participants responses to a particular question.
Qualitative Data Analysis: Structural Coding

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Coding Summary Report

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<tr>
<td>Name</td>
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Total Users: 1

Internals\YWI FG- #1-nvivo

Node Coding

| Tree Nodes \ I. Factors that disproportionately affect young women\a.MostDifficultThings |
|---|---|
| References | Coverage |
| 2 | 4.67% |

Character Range: 62260 - 64070

Reference 1:
Participant 6:
One of the things you ask people about... one of “the worst things” or whatever, I forget how you phrased it. For me, it’s the anxiety... um, that I carry. I, I’m... the complete opposite of you (laughs)! Every day I think it’s comin’ back!

Participant 9:
I was EXTREMELY anxious, before the cancer.

Group:
(Mixed comments 52:54...)
Qualitative Data Analysis: Thematic Coding

• Thematic coding:
  – Themes that arise from structural coding
  – Pre-determined themes
Qualitative Data Analysis: Thematic Coding
Qualitative Data Analysis: Thematic Code Reports

Coding Summary Report

Project: YWI-FG's
Generated: 12/1/2011 2:49 PM

Coding By
Name: JG.13
Initial: JG
Total Users: 1

Internals\YWI FG-#2-nvivo

Node Coding
Free Nodes\LeavingFamilyBehind

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</tr>
<tr>
<td>Reference 2</td>
<td>0.23%</td>
<td>6020 - 6366</td>
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Participant 2:
For me it was, um, my mom went with me, to my doctor’s appointment when I was diagnosed. I felt a lump on my own, and I had to come out. So I had a lumpectomy, first, and two days after that surgery I got the results... um, from the biopsy. And I remember, the first thing I said to my mom, when we got into the car, she could take me home was, “I don’t have life insurance.” And that scared the heck out of me, because who’s gonna take my student loans, my car payment, all those other things? I was thinking, “I’m gonna die, and I’m gonna leave my parents with $40,000 in debt. What up with that?” And I remember that being my first fear, was, “Well, now I can’t even get life insurance.” And then the next thing was, “Well, I’m twenty-six years old. I’m single, I live on my own, and I want kids some day. So how’s that gonna happen with the treatment?”

Reference 2 Coverage: 0.23% Character Range: 6020 - 6366

Participant 3:
My biggest fear was, I had, at the time she was three, my daughter, and, um, all I could think of was, “I’m gonna die, and my daughter’s gonna grow up without a mom.” And I won’t have a chance to teach her and show her everything that I wanted her to have and to know.” And I could cry, just thinking about it now. (Chuckles)

Total References: 2 Coverage: 1.04% Total Users: 1
Qualitative Data Analysis: Thematic Code Reports

I. FACTORS THAT DISPROPORTIONATELY AFFECT YOUNG WOMEN

a. Most Difficult Things

FG1:
- Anxiety/concern about recurrence — (111)
- Anxiety about the unknown — do I have something else? (1) — The unknown. Before you get that info, you know, there’s some other aura, like, hiding out somewhere in there, you know?
- Transition off treatment, what is normal now? (111) — “Right after you’re done with chemo, or, the period when you’re done with treatment, if people haven’t had chance to reorient or whatever, and then you’re just sort of supposing it to be normal, but you’re not quite normal. It’s a slight anomaly, and some patients just feel...”
- Support groups for those with BRCA gene (11) — “I join the support group. If not, I want other people who have that gene, and that’s the goal. It’s tough, because you have to go through that.”
- Support group for those transitioning off treatment (11)

Want more:
- More follow-up guidance for those with BRCA gene (11) — “Well, having the BRCA gene, I know (232,242), or whatever it is, but it seems like... I wish there was more follow up, where they guide me, at least to a specific group. Do you know what I’m saying? Just a little bit more observation.”
- Support groups for those transitioning off treatment (11)

FG2:
- How to start the process and figure out where to go for treatment — 1
- Fear of the big journey ahead of her — 1
- The cost because didn’t have life insurance — 1
- So I had a lynchectomy, first, and two days after that surgery I got the results... um, from the biopsy. And I remember, the first thing I said to my mom, when I got into the car, she couldn’t have her home now. I don’t have life insurance, but that scared the hell out of me, because what’s going to happen to her? And it scared the hell out of me, just thinking about it. And then, the cost of...”
- Worried if she’d be able to have kids — 1
- I am 29 and 25 years old. Is I am single... I live on my own, and I want kids some day. So that’s what I was thinking, that... what is that going to happen with the treatment?
- Fear of dying and leaving children — 11
- “It’s the biggest fear now. I had, at the time, was three, my daughter, and um... I’ll come back to this two. I’m gonna do...”
- “I can’t do that to her, and with what I was thinking about that. I wanted her to have a...”
- “I didn’t have insurance, so...”
- “Worried about what’s going to happen to her?”
- “I didn’t have insurance...”
- “So, you know, the insurance was going to just kill me. I’m gonna be leukemia, or...”

FG3:
- Finding resources on how to talk to her kids about it — 1
- I think having children, that was the
Qualitative Data Analysis: NVivo

- NVivo is just a tool – it does not do the analysis for you.
- Good for project archives.
- NVivo has an array of reporting and other features
IV. Deliverables
Deliverables

• Code Reports (Structural or Thematic)
• Thematic Analysis Write-Up Report
• Presentations
Thematic Analysis Write-Up Report

YW1 – FOCUS GROUP THEMATIC ANALYSIS
Joshua Gagne
Survey & Data Management Core

1. FACTORS THAT DISPROPORTIONATELY AFFECT YOUNG WOMEN

a. Most Difficult Things

Remembering back to the time around your diagnosis and early treatment, what were the most difficult thing(s) for you (emotionally/physically) regarding your diagnosis and treatment of breast cancer?

This question was discussed in all 4 groups.

- Anxiety/concern about recurrence (4) – (4 participants from 1 group).

- Transitioning off treatment, what is “normal” after treatment? (3) – (3 participants from 1 group). One participant stated, “Right after you're done with treatment, if people haven't had chemo or radiation or whatever, and then you're just sort of supposed to be normal, but you're not quite normal. My oncologist actually said they used to have support groups just for people during this transition time. I don't know what happened to those support groups…

Another participant reported, “I think the misconception is, I think people think, once I get through all this, I want to go back to normal. Like, that's the goal, is to be 'back to what I was, before.' It's not like that. You are completely changed and different and you know, I kind of just took that expectation off myself, because I felt... you know what I'm saying... Like, you're not... my life is completely... you can't go back. It's a 'NEW normal.'”

- Fertility issues and being rushed into fertility decisions (3) – (3 participants from 3 groups). One participant stated, “Well, I'm twenty-six years old, I'm single, I live on my own, and I want kids someday. So how's that gonna happen with the treatment?”

Another participant said, “I mean, I think it’s one of the hardest things. I mean, after being diagnosed, is NOT having children and having people say, ‘okay, you need to decide right now what you’re gonna do, because we can get you fertility, maybe…’ um, so I ended up saying (? 11:23 - Elizabeth S.) no, it at Brigham and Women’s. But, you have to decide right now, and this is very early on in your cycle, and if you decide to go and freeze, that’s fine, but it will delay your treatment. So, decide right now.'
Deliverables

- Deliverables used to:
  - Inform/develop grants/further research protocols
  - Inform/develop interventions
  - Inform/develop surveys
  - Develop professional presentations/poster
  - Develop manuscripts