“You Don’t Have to Make a Meal Out of It”: Using mixed methods to explore diet among long term cancer survivors

Katherine Clegg Smith, PhD
Associate Professor
Johns Hopkins Bloomberg School of Public Health
Tales from the field of mixed methods research
Sharing emerging experiences
A case study of diet among cancer survivors

Mixed methods for discovery
Mixed methods and interdisciplinary research

The value of multiple perspectives

Challenges of doing mixed methods research

How to make it work
Eating for Life: Dietary Behaviors Among Long Term Cancer Survivors

5R21CA152789-02
What is the problem that I am trying to solve?

http://dccps.nci.nih.gov/ocs/prevalence/prevalence.html
What is the problem that I am trying to solve?

On the face of it – this is not a problem. But.....

http://dccps.nci.nih.gov/ocs/prevalence/prevalence.html
Cancer survivors face elevated health risks

- Cancer recurrence
- More likely to report poor or fair health, psychological disabilities, limitations to tasks of daily living, and inability to work (Hewitt et al, 2002)
- Increased incidence of chronic illnesses: heart disease, osteoporosis, hypothyroidism, dementia (Khan et al, 2011)
- Lifestyle factors and treatment both play a role
We sometimes think that a cancer diagnosis is a wakeup call, but.....
We sometimes think that a cancer diagnosis is a wakeup call, but.....

Cancer survivors are no more likely to give up smoking, reduce alcohol consumption or become more active

22 May, 2013 | By The Press Association

The post-treatment behaviour of cancer survivors is not necessarily going to see them give up smoking, cut down on alcohol or exercise more often, according to new research in the British Journal of Cancer on

In the first large-scale study in the UK to look at smoking, alcohol and physical activity, the researchers discovered that cancer survivors were less likely to give up smoking or cut down on alcohol, and were more likely to exercise less frequently than those who were cancer-free over a four-year period. The researchers also found that cancer survivors were more likely to live a more relaxed and sedentary lifestyle.

Why? What? How?
Mixed methods to bring multiple perspectives to a problem
Phase 1

Clinical
Phase 1:
Qualitative Interviews with Cancer Care Team

Phase 2:
Multiple Data Collection with Patients

QOL (Quant)
Cancer narrative (Qual)
Identity exercise (Qual)

24 Hr Recall (Both)
Dietary interview (Qual)
Key questions for Phase 2

• Is cancer a defining characteristic for people 3 or more years past diagnosis?
• How do people conceptualize of their cancer experience?
• How well are people doing in terms of meeting dietary recommendations?
• What are the barriers to eating well?
• Are people aware of the healthiness of their diet?
Phase 2: Data collection with survivors

• 60 long-term survivors (breast, prostate, NHL)
• 4 data collection points
  – Time 1: Structured QOL, Sociodemographics, Identity exercise, semi-structured cancer history interview, assisted 24 hour dietary recall
  – Times 2&3: 24 dietary recalls
  – Time 4: Feedback of dietary information & semi-structured dietary discussion
Participant Characteristics

• 29 people have completed at least time 1:
  – 20 breast; 6 prostate; 3 NHL
• 49-74 years; 17 still working
• Up to 16 years post diagnosis (mean = 5 years)
• 2 current smokers, 21 overweight or obese, 9 not physically active, 19 drink alcohol
Perceived health-related Quality of Life (SF-12)
Who am I?

Example #1 (breast)
• mother
• sister
• nurse
• friend
• conscientious
• cancer cheerleader
• volunteer breast center
• volunteer mission of mercy
• gardener reader

Example #2 (prostate)
• handsome
• energetic
• thoughtful
• loving
• caring
• entreprenuerial
• funny
• determined
• focused
• positive
Only 4 of the 29 participants have mentioned ‘survivor’ or cancer.

Cancer or survivor was never mentioned before #5 on people’s list.
Example participant: 114 (prostate)

• Interviewer: Do you consider yourself to be “cancer survivor”?
• 114: No.
• Interviewer: Okay. What does that term mean to you?
• 114: It just hit me and that was it, you know.
• Interviewer: Yeah. What do you think the term cancer survivor means?
• 114: My wife is a cancer survivor.
• Interviewer: Okay. And why do you say that?
• 114: Because she had, she almost died.
How well are people eating?

### Summary of Dietary Recall Data
(based on responses from first 21 participants)

<table>
<thead>
<tr>
<th></th>
<th>Recommendation</th>
<th>Average value</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Calories</strong></td>
<td>Variable based on age, gender, and physical activity level</td>
<td>1,780kcal</td>
<td>478kcal; 3,850kcal</td>
</tr>
<tr>
<td><strong>Fiber</strong></td>
<td>25g for women; 38g for men</td>
<td>Women: 18.4g</td>
<td>Women: 1.7g; 56.0g</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Men: 16.1g</td>
<td>Men: 5.1g; 54.8g</td>
</tr>
<tr>
<td><strong>Calcium</strong>&lt;sup&gt;1&lt;/sup&gt;</td>
<td>1,000mg if 45-50; 1,200mg if 51 or older</td>
<td>802.8mg</td>
<td>153.7mg; 1779.2mg</td>
</tr>
<tr>
<td><strong>Sodium</strong></td>
<td>1,500mg</td>
<td>2,902mg</td>
<td>590mg; 7,361mg</td>
</tr>
<tr>
<td><strong>Cholesterol</strong></td>
<td>Less than 300mg</td>
<td>312mg</td>
<td>25.5mg; 1060.0mg</td>
</tr>
<tr>
<td><strong>Saturated fat</strong></td>
<td>Less than 10% of kcals</td>
<td>10.8%</td>
<td>0.03%; 30.04%</td>
</tr>
<tr>
<td><strong>Vitamin D</strong>&lt;sup&gt;2&lt;/sup&gt;</td>
<td>15mcg or more if 70 years or less; 20mcg or more if older than 70 years</td>
<td>70 years or younger: 5.9mcg</td>
<td>70 years or less: 0.3mcg; 30.0mcg</td>
</tr>
<tr>
<td></td>
<td>71 years or older: 2.9mcg</td>
<td>30mcg</td>
<td>71 or more: .18mcg; 8.2mcg</td>
</tr>
<tr>
<td><strong>Fruits and vegetables</strong></td>
<td>2.5 cups or more</td>
<td>2.8 cups</td>
<td>0 cups; 8.1 cups</td>
</tr>
<tr>
<td><strong>Alcohol</strong></td>
<td>Women: 1 drink per day maximum (14g) Men: 2 drink per day maximum (28g)</td>
<td>Women: 4.6g</td>
<td>Women: 0g; 51.5g</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Men: 13.1g</td>
<td>Men: 0g; 60.1g</td>
</tr>
</tbody>
</table>
Considering the context & taking a close look at individual eating patterns: P114

### SUMMARY OF MEALS

#### Day 1

<table>
<thead>
<tr>
<th>Time</th>
<th>Meal Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00 a.m.</td>
<td>Oatmeal, milk, banana, raisins, grapes, small chocolate wafer cookie, water, and tomato juice</td>
</tr>
<tr>
<td>1:00 p.m.</td>
<td>Tangerine, mango, chocolate wafer cookie, and water</td>
</tr>
<tr>
<td>6:30 p.m.</td>
<td>2 dinner rolls, butter, 2 cups garden salad with spinach, parmesan cheese, artichoke hearts, bell peppers, broccoli, cabbage, carrots, cauliflower, cherry tomatoes, cucumber, blue cheese, 10oz tuna, salsa ½ a baked potato with sour cream, broccoli, cauliflower, onion, peppers, zucchini, scotch, and water</td>
</tr>
<tr>
<td>10:00 p.m.</td>
<td>Tangerine and water</td>
</tr>
</tbody>
</table>

#### Day 2

<table>
<thead>
<tr>
<th>Time</th>
<th>Meal Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00 a.m.</td>
<td>½ a bagel, American cheese, tomatoes, red sweet peppers, white onions, broccoli, cucumbers, 2 small chocolate wafer cookies, tomato juice, water</td>
</tr>
<tr>
<td>1:30 p.m.</td>
<td>Pistachios, almonds, fat free cool whip, 2 scoops Breyers completely chocolate ice cream, fudge, strawberries, 2 cups baked Tostito’s, spinach dip, onion dip, vegetarian chili with cheese, tangerine, grapes, sunflower seeds, and water</td>
</tr>
<tr>
<td>7:00 p.m.</td>
<td>3 slices of cheese pizza, sautéed onions, bell peppers, cauliflower, and mushrooms, fat free parmesan cheese, and water</td>
</tr>
</tbody>
</table>

#### Day 3

<table>
<thead>
<tr>
<th>Time</th>
<th>Meal Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:30 a.m.</td>
<td>Oatmeal with milk, raisins, apple, sweet n’ low, cinnamon, salt substitute, tomato juice, and water</td>
</tr>
<tr>
<td>1:30 p.m.</td>
<td>¼ cup black bean soup, sour cream, sunflower seeds, tangerine, 2 small chocolate wafers, and water</td>
</tr>
<tr>
<td>6:00 p.m.</td>
<td>Baked, breaded chicken breast, vegetable medley, stuffing, medium chocolate cookie, and water</td>
</tr>
<tr>
<td>9:00 p.m.</td>
<td>Pistachios and water</td>
</tr>
</tbody>
</table>

# Dietary Feedback to P114

<table>
<thead>
<tr>
<th>Nutrient</th>
<th>Dietary Guidelines for Americans 2010</th>
<th>Recall 1</th>
<th>Recall 2</th>
<th>Recall 3</th>
<th>Average</th>
<th>Meeting Dietary Guidelines?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total calories</td>
<td>2,200 – 2,400 calories</td>
<td>2,277 kcals</td>
<td>3,875 kcals</td>
<td>1,631 kcals</td>
<td>2,594 kcals</td>
<td></td>
</tr>
<tr>
<td>Fiber</td>
<td>38g or more</td>
<td>25.0g</td>
<td>54.8g</td>
<td>20.2g</td>
<td>33.3g</td>
<td></td>
</tr>
<tr>
<td>Calcium</td>
<td>1,200mg or more</td>
<td>1,305mg</td>
<td>1,979mg</td>
<td>788mg</td>
<td>1,357mg</td>
<td></td>
</tr>
<tr>
<td>Sodium</td>
<td>1,500mg or less</td>
<td>4,248mg</td>
<td>4,626mg</td>
<td>3,891mg</td>
<td>4,255mg</td>
<td></td>
</tr>
<tr>
<td>Cholesterol</td>
<td>Less than 300mg</td>
<td>265mg</td>
<td>183mg</td>
<td>185mg</td>
<td>211mg</td>
<td></td>
</tr>
<tr>
<td>Saturated fat</td>
<td>Less than 10% of calories</td>
<td>10.1%</td>
<td>12.1%</td>
<td>9.8%</td>
<td>10.6%</td>
<td></td>
</tr>
<tr>
<td>Vitamin D</td>
<td>20mcg or more</td>
<td>18.2mcg</td>
<td>10.7mcg</td>
<td>13.4mcg</td>
<td>14.1mcg</td>
<td></td>
</tr>
<tr>
<td>Fruits and Vegetables</td>
<td>2.5 cups or more</td>
<td>7.4 cups</td>
<td>5.7 cups</td>
<td>1.7 cups</td>
<td>4.9 cups</td>
<td></td>
</tr>
<tr>
<td>Alcohol</td>
<td>2 drink maximum per day 1 drink = 14g of pure alcohol (e.g., 12oz of regular beer, 5oz of wine or 1.5oz of 80 proof distilled spirits)</td>
<td>20.16g</td>
<td>None</td>
<td>.25g</td>
<td>6.8g (less than a drink per day)</td>
<td></td>
</tr>
</tbody>
</table>
Extract from feedback interview with P114

Interviewer: *Do your doctors ever talk about healthy eating or ask you about your eating habits?*

114: No, because they know I eat healthy. I mean, they’ve ask me what I eat so – not as extensively as you have. Yeah, but I’m – I eat, think of what I eat, pistachios and – if they took the salt off then it would be totally healthy but then again I eat almonds, they have no salt, and I eat some other nuts besides this. And I think that’s healthy, eating nuts, it’s good form of protein.
Challenges posed

• Working with methods that are outside of one’s comfort zone
• Not necessarily a linear or straightforward story to tell with the data generated
• Time intensive – both data collection and analysis
• As a qualitative researcher – how do I keep up and involved?
Learning from experience

• Organizational systems are key
• Iterative analysis – how are the pieces fitting together
• Talking with the team - building meaning
• What questions are being answered? Which ones are not?
A successful exploratory mixed methods project • Will probably emphasize the preferred 'flavor' of the lead researcher • Our study is primarily constructionist with an emphasis on the experiences of the impacted • Should appropriately stretch the skills and perspectives of the research team to address new questions or established questions in new ways • Integrating dietary assessments with established quantitative QOL assessments and qualitative survivor data – ultimately to inform intervention development