Fieldwork as a Bridge from Cancer Diagnosis to Survivorship

Celeste Baldwin, PhD, APRN, CNS
Francisco Conde, PhD, APRN, CNS
Cymbree Kawamura, MSN, RN
Lorraine Fleming, MSN, RN
Margaret Pascual, BSN Student
Andrea Wilburn, Research Assistant
Bridging the gaps in nursing care

- **Purpose:** Patient views
- **Theory:** Modeling/Role Modeling
- **Methods:** Qualitative inquiry
- **Results:** Content analysis
- **Conclusions:** Voices
Purpose of the Study

• Hawaiian Voices touched by cancer
• Survivor as defined by the patient
• Post-treatment lived experience
• What happens after the treatment bonds are broken?
• Real fears
Grounded Method

• IRB approval & Zung screening
• Consent, demographics, & incentive
• Trained nurse interviewers
• Face-to-face taped narratives
• Semi structured interview guide
• Field notes and memos
Grounded Theory as a Method

- Participants discuss their concerns
- Avoids preconceptions & researcher bias

“The researcher must enter the field as one who is naive, willing to learn from those who are the experts. The experts are the individuals or groups who can give the researcher insight into the substantive area.”

(Glaser, 2009)
Goals of Grounded Theory

- Hear from those who have lived the experience.
- Credible sources or actual survivors
- Emerging theory should predict behavior and lead to theory advancement
- Suggest further research
- Add to body of knowledge
- Elevate treatment in field of practice
MRM Theory

- Erickson-Tomlin-Swain
- “Model their world”
- Cultural view as told by the patient or ”talk story”
- Role of the nurse
- Affiliated individuation
Modeling and Role Modeling: A Theory and Paradigm for Nurses
Holism vs Wholism: Genetic & Spiritual Drive
Equilibrium of Self-care Concepts

- Hope
- Control
- Support
- Satisfaction
- Physical Health
Methods & Techniques

- 20 participants telling their stories
- Inductive process
- Memos and field notes
- Emergent and recurrent themes
- Coding data – looking for patterns
- Search for the “core category” that occurs over and over, as suggested by Glaser (1978)
- Theoretical saturation
- Correlation to the modeling theory
Semi-Structured Interview Guide: Setting the Stage

• “So, we are here today to talk about what it is like to have such a devastating disease and to have lived past the time when treatment occurred. In thinking of having cancer and making it through……..”

• Consistent opening statement to control interrater reliability
1. Tell me how it feels to be done with your treatment?

“Awesome - had it since I was born”

“I don’t look as far into the future”

“I don’t ever really consider myself done with treatment”

“It’s a blessing to know what you have”

“Not the same - a LOT more aware”

“Thankful that I am free right now”

“I survived the harsh treatment”

“I am very happy to still be here”

“Nothing better than having it behind you”
2. After going through this experience, how has it changed your life?

“It really brought a different perspective of living.”

“You realize after going through an experience like this, that we’re all just teetering on the edge.”

“I don’t bite my tongue anymore. I don’t go away from the situation saying: ‘oh, I wish I had said …’ now, I just say it.”

“Maybe pushier with doctors”

“Cancer was a gift, my life would be completely different”

“I don’t feel that it has changed my life, I’m still me”

“I can’t do the things I used to do everyday”
3. Are you doing anything different now, than before you were diagnosed with cancer?

“I changed my diet. I used to be a pig with sugar!”

“I can’t do the things I did before. I have a special diet to help swallow. A lot of scars”

“I believe in fate now”

“To me life is more important. I used to take it for granted”

“At first I would never go out because of the scarring. I don’t feel so bad now”

“People think I am drunk, but it’s my tongue”
4. How do you view your health now?

“Not on the same playing field now”

“My doctor gave me real “mental bracing” to really consider that he said “when you get into the boxing ring you cannot come out”

“No longer 400 pounds! I swim, I bike, I snorkel”

“I have real concerns about neuropathy”

“I try to eat healthy now and exercise”

“I monitor it constantly”

“I don’t have the capacity I had before”

“My husband is genuinely Ilokano and he likes internal organs, papa itan, pork, the steak…now, its brown rice, I take fruits”
5. Do you have concerns or worries about your health?

“I am constantly monitoring my conditions, my symptoms.

“I don’t think it’s gonna go down any further right now.”

“I went to the dentist and needed a gold crown. I said I don’t want to sink money into my teeth if I might not be around.”

“I don’t dwell on it. I think my chances of re-occurrence are high.”

“I worry about the cost. Six cycles of chemotherapy is $100,000.00.”

“Uh, I do worry. They say 1:4 breast cancer survivors have recurrence within five years.”
6. Do you consider yourself a survivor?

“Oh absolutely. I wouldn’t be here without that doctor”

“Yeah actually I would say yes, one of the hardest things to accept was that actually I’m someone who would live with this the rest of his life”

“I think there is a lot of freedom in that I have less worries. I don’t worry about what people think about how I look”

“Yes, actually I would say yes”

“Yes, I have survived not only the medical but personal issues”

“No not yet. I am still in treatments. Makes me worry because I feel too good”

“Yes, I have definitely survived something”
7. What is it like to be a cancer survivor?

“You have to put up a front, ya know? So you are not a burden; that everything is OK”

“I’ve lost everything. It feels like a switch went off. You learn too, who your friends are”

“I won’t feel like I am survivor until I am 90”

“For me, it’s almost like you hate to say it out loud and jinx it!!”

“I am a fighter not a survivor”

“It’s a unique journey that unless you go through it, it’s hard to appreciate. Once you are through it, it’s like yeah!”

“It’s given me freedom and self-confidence”
7. What is it like to be a cancer survivor?

(continued)

“Well I don’t know; I just feel God put me here and you know that’s what he made me go through, so I’m just accepting it as part of my life”

“It’s like you are part of a group that went through this; and it’s like not the end of the world”

“I don’t feel different or special; I’m happy...I’m still me!!!”

“It’s wonderful. The opportunity to know what you have. It’s a blessing”

“That there is life after that diagnosis. It’s important for people to know that”
8. Is there any advice you would give to nurses when caring for cancer survivors?

“I think sensitivity is important, cause everybody is unique. Everyone’s journey is very, very different”

“Thinking that they will get it and knowing nurses are smarter than that”

“Accept people as they are and not like they are going to die”

“Just try to stay upbeat”

“They are doing a great job!”

“Don’t just come in and say I have your medicine. Talk to us and touch us”

“Try to stay upbeat, be aware of your feelings”
8. Is there any advice you would give to nurses when caring for cancer survivors? (continued)

“The nurses are the best, I mean unbelievably good”

“They are very caring, it’s a Hawaii thing ya know?”

“There is something that happens in the brain that you just are not as articulate”

“Chemo fog is a very real thing”

“You can tell who really cares”

“The nurses here vs mainland catered to my needs better”

“Don’t lose your sense of humor. We need to see humor, camaraderie, and support”
9. Are there any other things you would like to add or discuss as we close?

“They really beat me up and tore me up. I had a really nasty time. I was wrapped up in bandages. Cut me from my ear to jaw and down with half my throat cut out. Then they give you a silence of the lambs type mask for radiation”

“We are not cancer patients here for treatment only, we are human beings who happen to have cancer!”

“You are walking in a different world ya know as a patient? Walking into that medical realm and navigating through the system is tough”

“You learn who your friends are”
9. Are there any other things you would like to add or discuss as we close? (continued)

“The oncologist refused to see me because I was referred by a P.A. It was because of insurance. She had me on the table and told the oncologist MD to sign off. They have to be better than that”

“Cancer is very devastating. I am very appreciative”

“Some nurses tend to get burned out”

“The power of touch is very strong”

“Cancer is just a speed bump!”

“Cancer is not a death sentence or the end of the world”

“Don’t be afraid to hug us! We need physical contact!”
9. Are there any other things you would like to add or discuss as we close?
(continued)
“Nurses need to be competent, control the situation, and have compassion. If you don’t have all three then you don’t belong with patients”

“Nurses are more of a healthcare provider than the doctor. They are the care. Follow up and call us so we know what is happening”

“My nurse ya know, her word was good and her word was honest. I love nurses”

“Cancer carries a stigma, a label, but you are not alone”

“Nurses can never show or be disgusted with the stuff the patient is going through. Go in and lay it on the line”

“Nurses need to educate themselves on their patient before they see them...look at the chart!!”
## Results: Demographics

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<th>Frequencies (%)</th>
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<td>Time since cancer diagnosis</td>
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Results: Role of the Nurse

- **Unconditional Acceptance:**
  Most of the participants felt the nurses had this, but have a desire to be “touched more” and cancer is not a “stigma”

- **Nurturance:**
  Patients felt they are humans first and happen to have cancer

- **Facilitation:**
  Participants want the nurse to communicate all of the steps
Results: Self-Care Sub-concepts

- **Hope:**
  - Most: normal levels of hope
  - High uncertainty about the
  - Some not able to call themselves a survivor
  - Survivor view vs national organizations varied

- **Control:**
  - Most felt in control of daily life
  - High control \(\rightarrow\) increased support

- **Support:**
  - High support \(\rightarrow\) high satisfaction

- **Satisfaction:**
  - Most satisfied with care
  - Requests for increased touch from nurses

- **Physical Health:**
  - Many changes to activity levels
  - Many changes to diet
Literature Search

• **Affiliated Individuation:**
  – Innate need for humans to “attach” to another

• **Research:**
  – Bowlby first defined in infants
  – Winnicott, Kline, and Mahler supported “the infant ‘needs’ it’s mother”
  – Study presumes MRM applies to any age group

• **Findings:**
  – Cancer survivors may “need” the nurse
  – The patient simultaneously is close to yet separate from the nurse
  – Like “an infant ‘needs’ its mother”

• **Future Study:**
  – Further exploration needed
  – If patient perceives this need un-met, does this lead to feelings of abandonment?
Results: Equilibrium – Homeostasis

- Cancer causes a change in balance of self-care
- Any component out of balance disrupts self-care homeostasis
- Nursing care is critical to maintaining equilibrium
- How nurses should provide for the affiliated individuation needs of the patient during survivorship is uncharted waters requiring further study
Results: Survivor Voices

• Participants:
  – Most are thrilled to be a survivor
  – Unsure of timeline
  – NCI survivor definition may not fit the patient’s view

• Being a Survivor:
  – Does not come without a fight
  – Is heavily dependent upon the 5 Self Care sub-concepts in harmony
  – Human touch and compassion are high on the list of patient priorities
“Aloha for you kokui”

“Mahalo” or thank you to our partners