

# Narrative Inquiries of Life-threatening Illness

## Research Team

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- 31 participants who have met with us for 3 years

# Storylines of Life-threatening Illness

## Need for the Study

- People with life-threatening illness (cancer, end-stage renal disease, HIV/AIDS) living longer and healthier lives
- Experience of living in-between the promise of treatment and the threat of recurrence or progression of disease is not well understood
- Important for nurses develop a better understanding the experiences of living with uncertainty

# Purpose

- Explore stories of people living with life-threatening illness and to understand how these liminal experiences affect their understandings of health and living within the context of cancer, end-stage renal disease and HIV/AIDS
- Illuminate narratives, metaphors and metonymies used to portray these experiences, with an emphasis on the re-stor(y)ing process

# Why Narrative Inquiry

- Post-modern / Social Constructionist Perspectives
- Dialogical
  - Personal – Social (individual & meta narratives)
  - Participants – Researchers
  - Inscribed – Constituted
- Fluidity (Discursive Processes)
  - Story - Re-story
    - Narratives as Reflexivity
    - Narratives as Healing
    - Narratives as Political

# Methods

- Recruitment (newspaper, community, snowballing)
- In-depth Interviews (1.5-3 hrs)
  - 1<sup>st</sup> Interview – rapport, stor(y)ing of participants
  - 2<sup>nd</sup> Interview – representational symbols
  - 3<sup>rd</sup> Interview – deepening understanding
  - 4<sup>th</sup> Interview – reflecting back on the process

# Participants

- Participants living with:
  - Cancer 10
  - ESRD 12
  - HIV/AIDS 9
- Gender: Females 14  
Males 17
- Age: 37- 83 (Mean = 61.2)
- 1-50 Years Post Diagnosis (Median = 8 )

# Narrative Analysis

- Attending to the tensions, dialectics, and liminal spaces within stor(y)ing
- Exploring metaphor and metonymy
- Listening for the un-say(able) in how people living with life-threatening illness story and re-stor(y)
- Engaging in the multiplicity of story-ing/re-stor(y)ing, recognizing the fluidity of the story-ing process

# Research Question

How do participants living with cancer, end-stage renal disease or HIV/AIDS story and re-stor(y) perceptions of life threat?



# Cancer

## Turning Points: Milestones of Dates and Numbers

- Shock of diagnosis
- Intensiveness of treatment
- Post-treatment living

# ESRD

## A Silent Beginning

- Insidious onset
- Increasing burdens of illness
- Chronic *and* life-threatening illness

# HIV/AIDS

## A Death Sentence to...Living

- Date of diagnosis
  - Pre-anti retroviral treatment
  - Post-anti retroviral treatment
- Managing living day-to-day: Chronicity of Illness

# Narratives of Illness: Private Faces and Public Powers of the Big “C”

- Personal stories
- Meta-narratives
  - Social perceptions of threat
  - Language of war and battle
  - Dominance of the medical narrative
  - Survivorship
  - Shifting images of cancer

# Narratives of ESRD: Entanglement of Symptoms and Technologies

- Management of symptoms
- Support/resources available
- Meta-narratives
  - Life-review
  - “It could have been worse”; “I’m lucky”

# Social and Moral Narratives of HIV/AIDS

- Personal and Life contexts
  - Poverty
  - Housing
  - Patchwork of services and resources
- Meta-narratives
  - Stigma, secrecy, disclosure, fear
  - Shame, morality, sexuality
  - Performative advocacy

# The Stor(y)ing and Re-stor(y)ing Process

- Illusions of narratives as stable
- Rapid change
- Shifting cognitive and emotive responses
- Un/certainty and fragility of narratives

# Representational Symbols of Life-threatening Illness

- Research often relies primarily upon the spoken and written word
- Visual data may contribute understanding of experience other than what may be fully expressed via language
- “Visual representations of experience – in photographs, performance art, and other media – can enable others to see as a participant sees, and to feel”

(Riessman, 2008, p. 142).



- Photographs are interpretive
- Generating an image itself may be considered a construction of reality
- Photographs are an extension of “self-portraits, a reflection of the self” (Kruse, 1999, 144-145)
- Photos can evoke emotions, thoughts, and imagination prior to them being languaged
- Become “seeable” in a manner that goes beyond the “sayable”



# Our Use of Representational Symbols

- Our language shifted from “representational object” to “representational symbol”
- At 1<sup>st</sup> interview, we asked participants to think of a symbol that represented their experiences of living with HIV/AIDS, ESRD or cancer
- At 2<sup>nd</sup> interview, we asked about the significance of their symbol and we took photographs
- At 3<sup>rd</sup> interview, we asked participants about their thoughts of their symbol

# Diversity of Symbols

<b>3 oil paintings</b>	<b>Hand-drawn symbol of French cross</b>	<b>Food (apples)</b>
<b>7 photographs of loved ones</b>	<b>A wig</b>	<b>A chain (gold)</b>
<b>3 pieces of music</b>	<b>Picture of airplane</b>	<b>A cross on a necklace</b>
<b>2 books</b>	<b>Copy of his flight engineer's wings</b>	<b>Hoya plant</b>
<b>A Chinese proverb</b>	<b>Charts of PSA blood work results</b>	<b>Hydrangea flower arrangement</b>
<b>A limerick</b>	<b>A small bluish-green dragon(angel)</b>	<b>A document folder</b>
<b>A poem</b>	<b>Cushions on a futon</b>	<b>Embroidery of a "phoenix rising"</b>
<b>Memories from a grandmother</b>	<b>A piano</b>	<b>A basket of rocks</b>
<b>Bag with picture of Jimmy Hendrix</b>	<b>A painter's hook</b>	<b>Hopes for a Jeep Cherokee to pull a small trailer</b>
<b>A necklace with 2 charms</b>	<b>A white cotton nightdress</b>	<b>A yoga mat</b>
<b>A small white teddy bear with a pink and blue ribbon</b>	<b>A coffee filter</b>	

# An Evolution Towards Visual Analysis

## Five approaches to visual analysis

1. Interpretation by participant
2. Team visual analysis
3. Poetic analysis
4. NVIVO
5. Patterns

# 1. Interpretation by participant

“Why did you choose this particular symbol?”

“What do you see?”

“How does it reflect your experiences?”

“What is difficult to put into language or words?”

“How does this object convey what is beyond words?”

# Interpretation by Bob

*Well, I actually came up with a couple of things. And one would be a chain, if you're chained down. I mean, you might as well just carry this [dialysis] machine around with you...*

*It just slows you down. It's like a weight. So yeah it's...yeah it can be just being the chain around your neck, it's just...*



*It's not very heavy. It's just there. Actually I picture a, yeah, actually when I picture a chain I don't mean a real heavy thing you pull a car around with. Actually it's for some reason it's just a chain around your neck that you might see a cross on. And I'm not religious. ...And it's just something that's yeah it's a fine chain, it's not a heavy one. It's just but it's there...*

## 2. Team Visual Analysis

- Interpretation by research team
  - Discussed each participant one at a time
  - Described/showed representational symbol

# Example of Team Analysis: Connie

*I thought my, I couldn't identify my HIV with a "thing" because it wasn't living. My HIV is alive, it's trying to kill me um and if I fertilize myself and water myself and take care of myself well I'll end up blooming. And when I don't I end up just – well I could die or just hibernate.*



- Negotiating uncertainty (of HIV)
  - not a clear distinction between life and life-threat
  - she has to be more alive than the HIV
  - living beyond expectations



# 3. Poetic Analysis

- Using participants' texts to create a poetic rendering of their meaning making

## Rocks

Small rocks picked up along the way,  
piled like an altar on the back of the toilet.

I spend a lot of time at this altar  
since my colon cancer  
and marvel at God's sense of humour.

Me, a fastidious man,  
now I crap and it's all over the place.

'Hope' is painted on one rock  
kept for unknown reasons  
reflecting what is sacred.

But I too have a sense of humour  
and appreciate this gift from God  
an attitude of hope,  
solid as a rock.

Symbol by Colin



## Nightdress

I picked this up in a Mexico City market,  
white, bleached cotton, just so nice.  
very expensive too....

... memories...

Symbol by Kate



I didn't know that you swelled up. And I put this  
on,  
it was something I was able to wear when I got  
home from hospital

I could go out wearing something like this.

I can't remember when I last wore it but I kept it,  
now tattered, but still there, and it continues.

The more I think about it, it's really a good  
symbol.

I visualize me in that dress in the fall,  
out in the tomato patch.

# 4. NVIVO

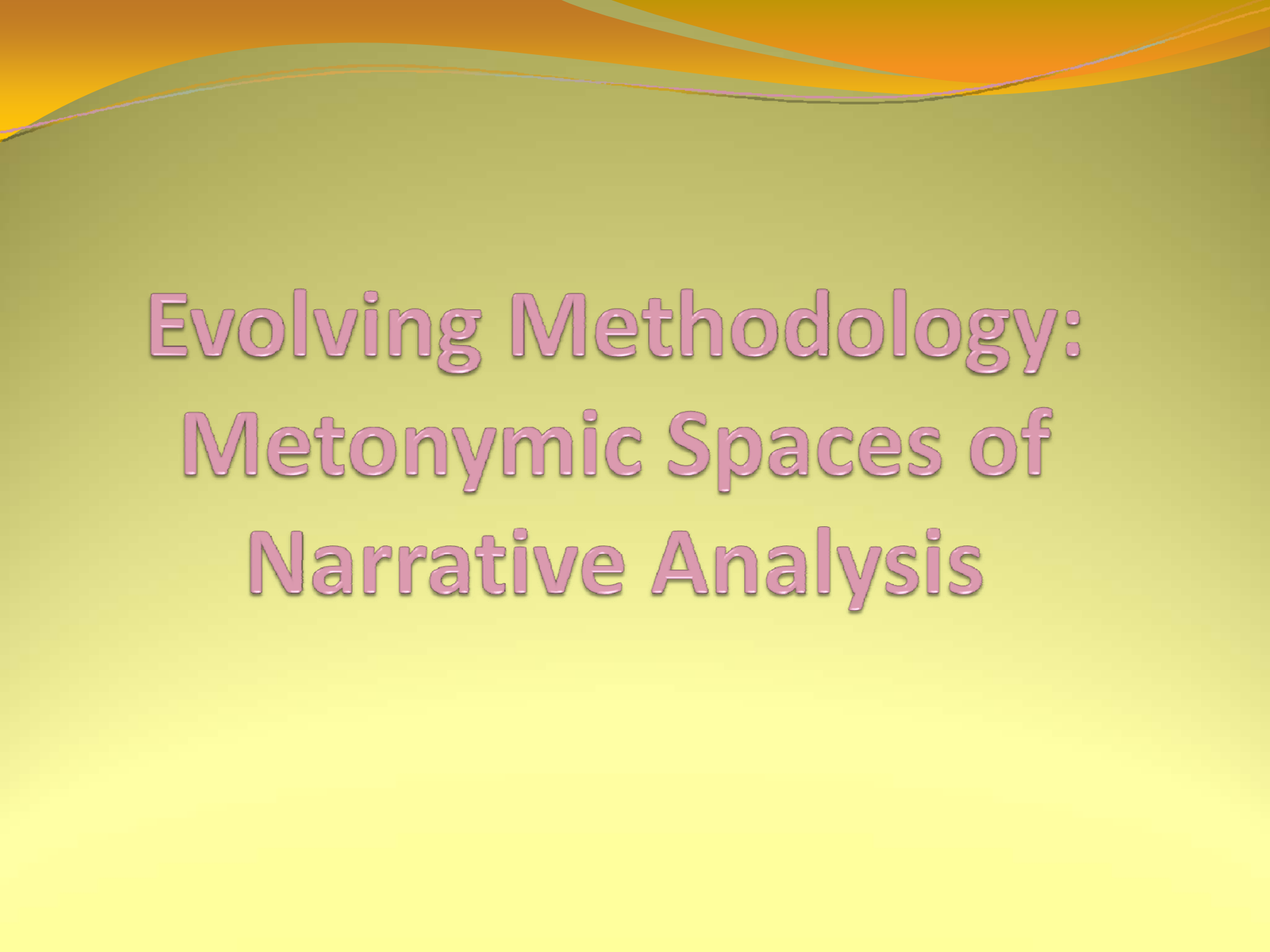
- We are currently coding 1<sup>st</sup> and 2<sup>nd</sup> interviews for all references to:
  - representational symbols
  - metaphors

# 5. Patterns

- Once we have completed coding, we will look across the data for patterns
  - Within illness groups
  - Across illness groups
  - Content (i.e. 7 photographs of loved ones)
  - Meta-narratives (i.e. survivorship)

# Lessons Learned

- Examining our intention regarding incorporation of visual images in qualitative research
- Shifting of language towards symbols as metaphors
- Analysis is more complex than we anticipated
- It is not about the objects in and of themselves but
  - about the meanings that we create,
  - and the culture in which we live



# **Evolving Methodology: Metonymic Spaces of Narrative Analysis**

# Narrative Analysis

- Conceptual
- Visual
- Thematic
- Metonymic



# Metonymies

## 1. Content or Narrative

- *I'm not religious so I hate the word spiritual. Ughh..... It's so generic....(long pause). Funny enough I believe, in a weird way, that there is a God, you're gonna' hate this... a guardian angel over my head, considering all the things that happened to me, including this [HIV], that I've survived this*

## 2. Methodological Metonymies

# Methodological Metonymies

## Metonymies

- Personal ( ) Social
- Homogeneity ( ) Diversity
- Outsider ( ) Insider
- Reader ( ) Text
- Illuminate ( ) Obscure

# Personal ( ) Social

*When I get my blood work back, you know, my close friends...if I say, oh yeah, my viral count is undetectable. Which basically means if I got my blood tested for HIV I would be negative...But only my sister wants to understand the numbers involved. And I try and tell people this. It's all about numbers for me. This is how I have to live, by numbers. How my immune system works, CD<sub>4</sub> count, my viral load. They're really not interested in that...But kind of you want a bit of acknowledgement for adhering to the drug program and everything.*

# Homogeneity ( ) Diversity

*That is the hardest...I think that is...the hardest part, is living with the uncertainty. When you're first diagnosed you think you're going to die – within a minute and a half – in the general scheme of life. You know you're sitting in your doctor's office and you've had the tests and you come back and he says well, it is XXX. And that's the first thing you think – well, that's it, I'm gonna die. And my doctor was very funny cause he said, Jeannie, we're all going to die! (laughs) And then he laughed and I laughed and then we went on.*

# Outsider ( ) Insider

*I don't tell people I was HIV positive. The secret was owning me...So I had to come out of the closet even though...you're not concerned about yourself so much...They get a worried look on their face and they're worried that you're going to die.*

# Reader ( ) Text

*A lot of people who get diagnosed with a potentially terminal illness, it becomes you. You know, your cancer becomes you to your friends. Your (whatever) disease becomes you; um if you let it. .... When I was diagnosed and went through [treatment] I came out the other side and the feeling that I had was, I'm broken; and I don't know if I will ever be fixed. .... It has taken four years for me . . . to get 'fixed again'*

# Illuminate ( ) Obscure

*So maybe I am  
still in denial,  
maybe I am  
enlightened,  
who knows?*



# Metonymies as Rigor...

- Personal ( ) Social
- Homogeneity ( ) Diversity
- Outsider ( ) Insider
- Reader ( ) Text
- Illuminate ( ) Obscure



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