

Storying and Re-stor(y)ing Life-Threatening Illness

Research Team

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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

Research Question

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

What's in a story?

- inherently human expression
- establishes relationships
- feel greater agency
- understand a variety of perspectives
- constructs versions of reality and identity

(Ricoeur, 1986; Holloway & Freshwater, 2007)

Why Narrative Inquiry?

- a fulsome account of participants' experiences
- narrators control the talk
- storying and restorying can be readily understood
- narrative core to nursing practice (relational) and epistemology.

(Holloway & Freshwater, 2007; Tovey & Manson, 2004)

Cautionary notes:

- Intersection of the personal and the social
- personal narratives cannot be read as a transparent form of evidence but are constituted in and through broader social discourses (Scott, 1997, p. 20)
- Ethical challenges
 - Disclosing more than intended
 - Confounding the role and relationship of researcher
 - Protecting identities & anonymity

Methodology

- Constructionist assumptions
- Narrative inquiry (Riessman, C. 1993)
- Analytical approaches: as story analysts (thematic analysis; linguistic) and as story tellers (case narratives)

(Tovey & Manson, 2004)

Methods

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

Participants

- Participants living with:
 - Cancer 10
 - ESRD 13
 - HIV/AIDS 8
- 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

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



Case Study

Exploring how one individual makes sense of the uncertainty of a life-threatening diagnosis of breast cancer...

Nicole

- To invite the story
- To listen
- To hear
- To interpret
- The paradox...

Nicole

- 4 interviews (3 year period)
 - Age 59
- Diagnosed with breast cancer 1997
 - Twists and turns
 - A story within a story
 - a ten year “survivor”

Stories of Chronic Kidney Disease(CKD): Listening for the Unsayable

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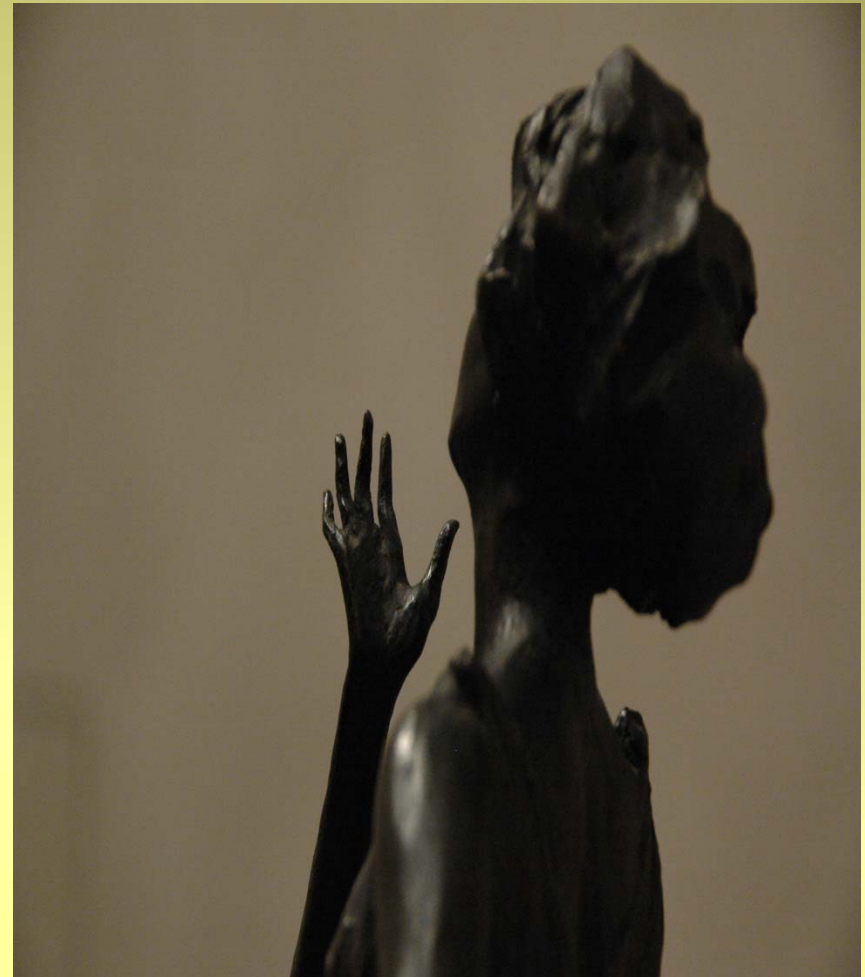


Significance

- The Canadian Institute for Health Information (2011) found that the unadjusted five year survival rate for all individuals living with ESRD was 43.2%
- Consideration of CKD as a life-limiting disease is often not discussed
- Little is known about the experiences of living with CKD that are difficult to discuss, ineffable, and beyond words

Purpose

- To explore individuals' stories of living with CKD, particularly those experiences that are unsayable
 - The unsayable is that which is not expressed yet alluded to through language, and may be conscious or unconscious
- “What do people story or narrate as their experiences of the unsayable within CKD?”



Design

- A secondary analysis of the Re-stor(y)ing project
- Analyzed 46 interviews conducted over three 3 years with 14 people living with CKD
- Narrative inquiry
 - Narrative thematic analysis



Findings



Living with death: “We’re not looking at what’s coming”

Embodied experiences that were difficult to language: “I just can’t put words to it”

Unthinkable: “I really don’t think about it”

Unknowable mystery: “No one can say for sure”

Untold/ unheard: “They never told you”

1. Living with death

When you get to be 80 and more and more of your friends have gone you do have to say, more like, when am I going – rather than where am I going. That's what I think comes to my mind more than as I just said, how, how much longer will this kidney disease or whatever medicine I'm getting, keep me alive you know? I don't have anybody [at the renal unit] that I talk to intimately. ...

Interviewer: So you don't get to talk to anyone about this question of 'when'?

Brian: I don't think it's ever come up. Never. And I don't think I've ever talked to my family about it.

I even asked the nurse the other day, what are the signs from your point of view – the medical point of view – that life is coming to an end for me? Cause I'm seeing people going out forever and she said "uh, oh, we see signs" and I said, "well that's not good enough. What do you see?" She says, "well your blood tests, which have been very good lately."



Living with death

- CKD is life-limiting and most participants acknowledged this, yet a “culture of death denial” (Robert Wood Johnson Foundation, 2003, p. 61) prevailed
- An emphasis on life is socially constructed
- “It is important to remember that end-stage refers to the end of your kidney function (your kidneys are working at less than 15% of normal), not the end of your life.” (KFOC website, 2011)

2. Difficult to language embodied experiences

I never felt bad. I never felt sick. I never felt ill. I mean, yes, I had associated symptoms like joint pain. There were times I couldn't get out of a chair, the pain was bad (said in a whisper). I feel fine. I'm doing OK. I wasn't doing OK. It was real denial. You can look back and say that.



Difficult to language embodied experiences

- Some described a conscious choice about whether they discussed embodied experiences
- Other embodied experiences that were difficult to language were linked to suffering, such as physical pain or near-death experiences
- Suffering as an antecedent to the unsayable

3. Unthinkable

Ronald: I don't like that word "end stage."

Interviewer: What term do you use?

Ronald: I just say "renal disease," yeah.

Interviewer: Renal disease.

Ronald: I don't like to use the word "failure."

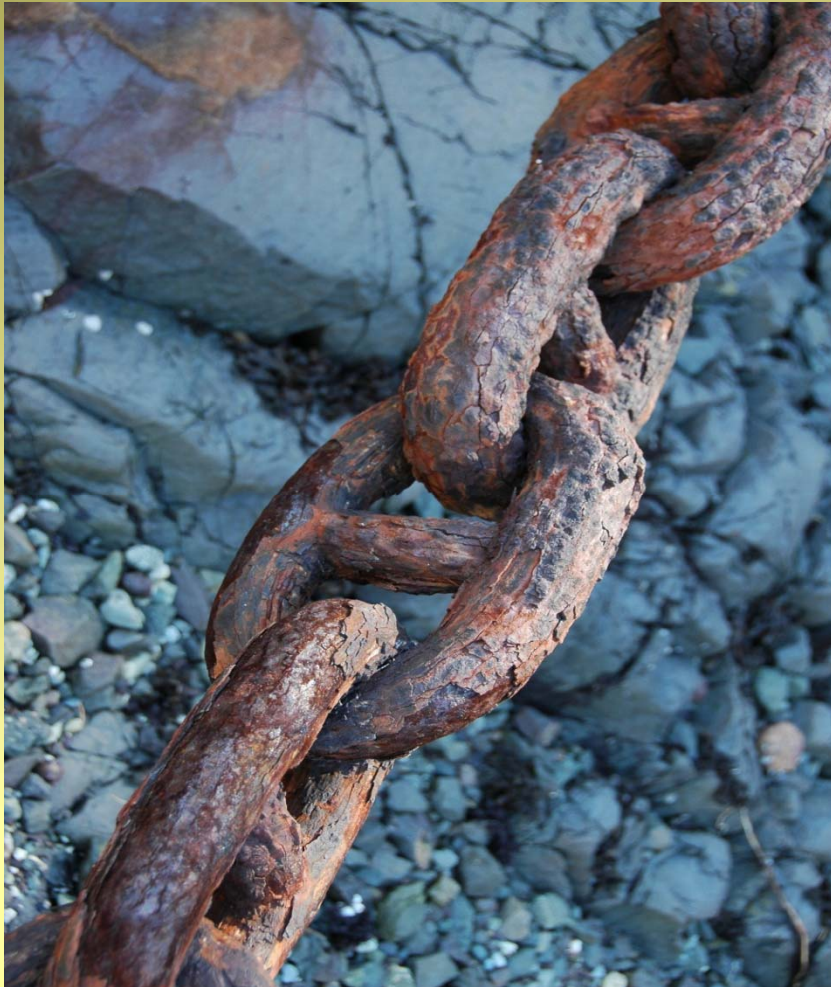
Interviewer: Just renal disease.

Ronald: Yeah.

Interviewer: Because "end" means "the end?"

Ronald: Well, yeah, I don't really think of it that way but I just think there should be a better term because I mean people are on dialysis for 20 years so "end" is very deceiving.

Unthinkable



- “The questions I want to ask about my life are not allowed, not speakable, not even thinkable” (Frank, 2002, p. 13).
- Topics ranged from the very idea of living with CKD to the possibility that this illness may hasten death

4. Unknowable mystery

Interviewer: So there's nothing you can do with this, this kidney. You can't talk to it, massage it, love it up.

Ryan: No, my wife was somewhere and there was a stone that says it's, it's good for kidney health or something like that so we don't believe in that stuff but we stuck it on my key chain anyway, yeah.



Unknowable mystery



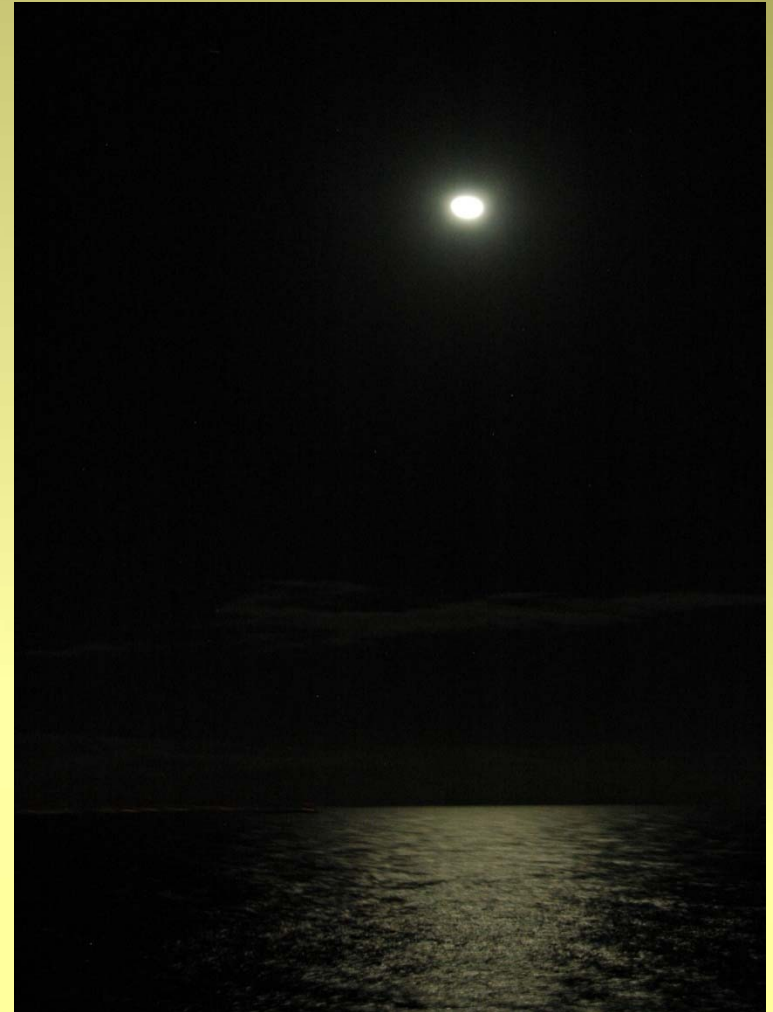
- Some existential beliefs and large life questions may not be expressible through oral or written language

5. Untold/unheard

[The acute pain doctor] referred me to the chronic pain team so I don't know, I don't think he mentioned that he was signing off but someone else was signing on. So it's just those little details that somehow care professionals leave out that you know again I think they assume that we know or they use language, they use the medical terms for things which I can understand but most people wouldn't be able to. You know they need to sort of get down to the patient's level and talk more human-like instead of - standing at the foot of your bed, towering over you and saying oh this and this and this.

Untold/unheard

- That which is unsayable *for* people is distinct from that which is unsayable *to* people living with CKD
- Was certain information shared but perhaps in a manner that was inaccessible to or unheard by participants?



Implications

Nurses:

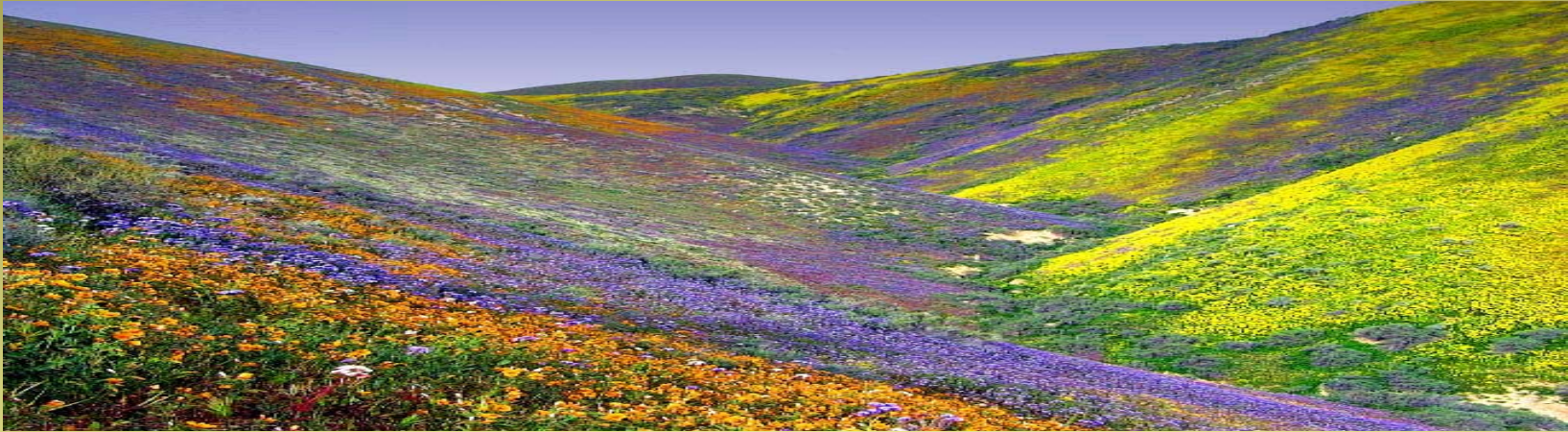
- may assume that what is significant for patients *can be said*. However, not all experiences can be fully expressed in language
- may attend to experiences that are challenging to language through offering to listen and bear witness
- need ask themselves if they are willing to engage in conversations that may be unresolvable
- can be aware that the information that they provide may not always be “hearable” by patients. A mismatch of communication and receptivity may leave people feeling like they were not told important information related to their health

Liminal Spaces



How do people living with life-threatening illness narrate liminality and liminal experience?

Liminality

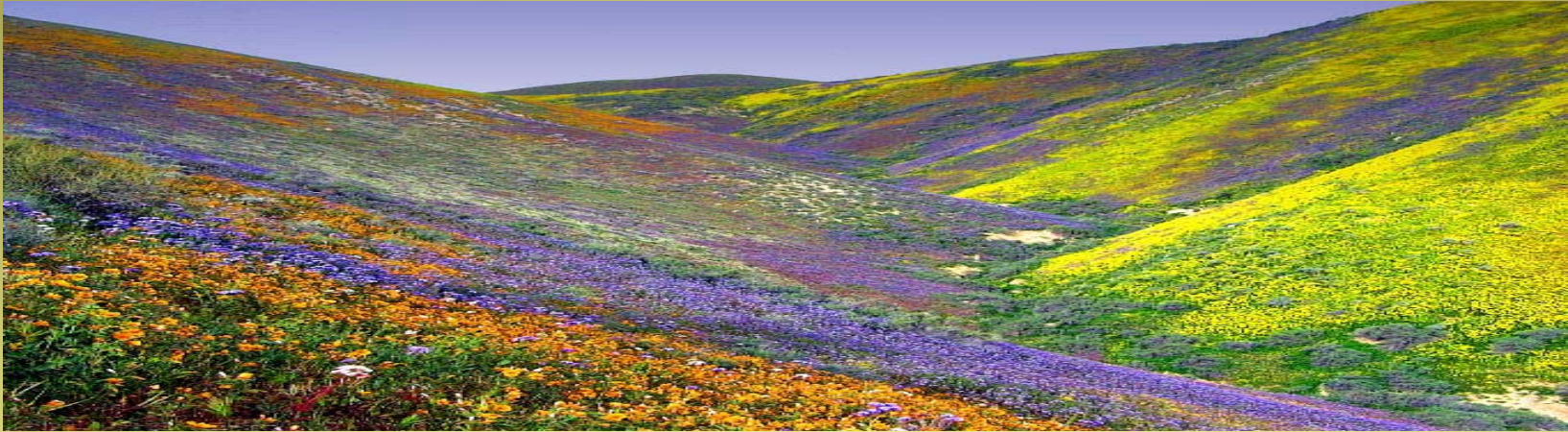


- Liminality is an in-between and uncertain experience sometimes described as being 'betwixt and between' (Turner, 1967/2008).

Liminal spaces in-between

- - waiting for diagnosis following tests
- - in-between diagnosis and surgery
- - monitoring blood work
- - waiting for kidney transplant
- - anniversaries of 5 year mark
- - hoping and fearing

Liminality



- Liminality is an in-between and uncertain experience sometimes described as being 'betwixt and between' (Turner, 1967/2008).
- Un-say(able) and metonymic aspects of liminality

Storying liminality ~ 3 storylines

- Holding opposing stories
- Narrating (in)consistencies
- Storying and being storied

Holding opposing stories

- Both believing and not-believing
- both 'wanting-to-know and not-wanting to know'.

Narrating (in)consistencies

- Certainty and uncertainty co-exist

Storying and being storied

I went in to get some eye care ... and we were doing a swab to see if there was anything bacterial or fungal or anything that would grow that would give them a hint to what was going on. I went into an eye care centre in (name of the city) where there's a fairly significant prevalence of HIV um and this woman screamed at me when she found out I was HIV positive. She said, "they should have marked it on the chart". And it was marked on the chart but she said, "they should have marked it on the chart; they should have told me, I should have known; people in the waiting room should have known!" And she was just screeching this and so people in the waiting room did know by the time she was finished screeching and uh then she left me sitting there sort of like, oh my gosh, she doesn't understand that you don't get HIV from sitting next to somebody from doing an eye swab or anything like that. I just - couldn't get out of there fast enough but it's like you don't know when to expect it.

Discussion

Implications for practice

- - recognizing the complexity of liminal experience
- - considering ways of engaging with people as they negotiate between stories of health and illness.
- - to listen without needing to resolve ambiguities or inconsistencies
- - investing time to listen and understand
- - recognizing that stories change and are often partial
- - people often narrate stories that allow them to take control of their reality through storying what is meaningful for them