

LIVING WITH DYING IN CHRONIC KIDNEY DISEASE

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“uplifting the whole people”

— HENRY MARSHALL TORY, FOUNDING PRESIDENT, 1908

Helen's Story



uvic.ca/illnessnarratives



What message about living and dying would you take from Helen's story?



Acknowledgements

- Canadian Institutes of Health Research, *Restor(y)ing Life Within Life-Threatening Illness* (Laurene Sheilds, PI; Anita Molzahn, Anne Bruce, and Kelli Stajduhar)
- Kidney Foundation of Canada & Kidney Research Scientist Core Education and National Training Program (KRESCENT)



Acknowledgements

- Copyright permission granted for use of photographs by Leland Makaroff and *Restor(y)ing* project
- The 14 people living with CKD who participated from 2008-2011



Objectives

1. Identify how CKD is not only a chronic illness, but also a life-threatening illness
2. Describe the stories of people with CKD in relation to perceptions regarding death and dying
3. Identify and discuss nursing strategies and interventions based on a palliative approach
4. Discuss the implications of these stories for end of life care in light of guidelines on end-of-life care



Outline

- CKD as a chronic disease, and a life-limiting illness
- Study design
- Themes emerging from the data
- Implications for care
- End-of-life care clinical guidelines



Background

Survival probabilities for people with stage 5 CKD:

- 75% at 1 year
- 50% at 3 years
- 35% at 5 years
- 17.6% at 10 years (USRDS, 2011, 2009)



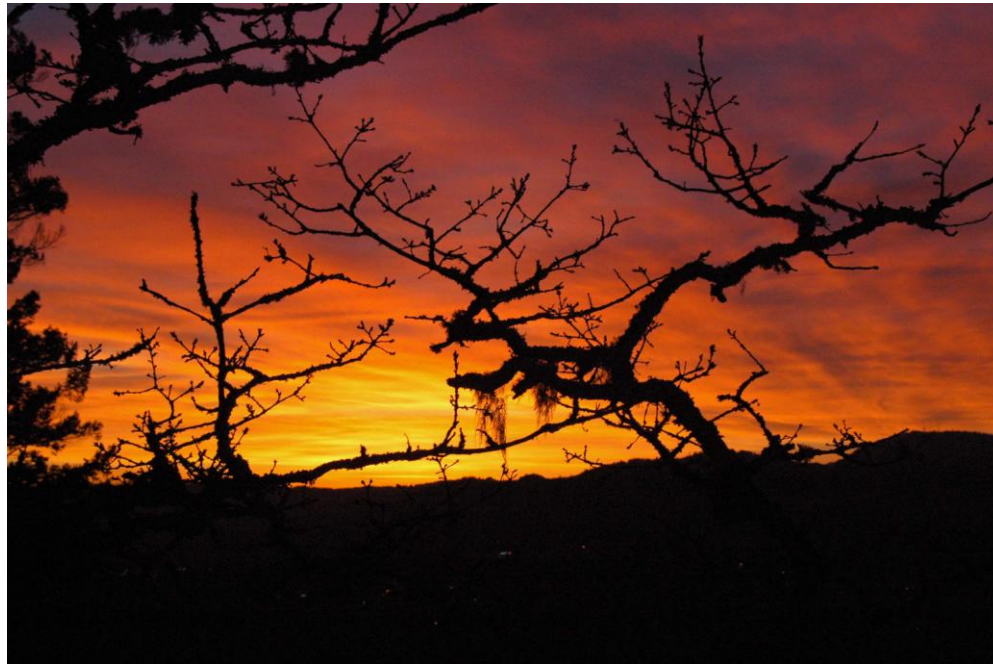
- Shorter life expectancy for those with cardiovascular disease and those who are not candidates for a renal transplant (Robert Wood Johnson Foundation, 2003)
- Conservative and palliative approaches may be appropriate for some



- Yet there is a “death denying culture” in dialysis facilities (Moss et al., 2002)
- CKD is both a chronic and life-threatening illness
- Little research on the perceptions of people with CKD about death and dying



Is there still a “death denying culture” in dialysis units today?



Literature Review

In the nursing literature, only three studies on the experiences of living with kidney failure had themes which reflected the life-threatening nature of kidney failure

Small number of studies addressing the qualitative experience of living with CKD

Concerns regarding threat to life are not raised



Literature Review

Davison (2010) studied 584 Stage 4 & 5 CKD patients' preferences for end-of-life (EOL) care

- 61% of patients regretted their decision to start dialysis
- More patients wanted to die at home (36.1%) or in hospice (28.8%) rather than in a hospital (27.4%)
- < 10% had a discussion about EOL care issues with their nephrologist in the past 12 months



Objective

To explore the experiences and perceptions that relate to death and dying among people with CKD



Study Design

- Narrative inquiry
- In depth interviews held four times over 3 years
- Purposeful and convenience sampling
- Advertisements in community and kidney-related newsletters
- Sample of 14 people living with CKD



Characteristics

- 10 men, 14 women
- Ages ranged from 43 – 80 (mean 66 years)
- Nine were on hemodialysis, three had been transplanted and two were managed conservatively



Characteristics

- Six participants had significant co-morbidities (five had cancer and one had HIV)
- Two participants lived in a rural setting and commuted for dialysis or received home treatment



Data Collection

- 27 interviews conducted over 2 years with 14 people living with CKD
- All but one participant engaged in two in-depth interviews
- Interviews ranged from 1-3 hours
- Participant asked to bring symbols of their illness that were photographed



Narrative Inquiry

- A fulsome account of participants' experiences
- Narrative thematic analysis
- Focus on “what” was being expressed, rather than “how” content was communicated
- Post-modern, social constructionist



Major Themes Emerging

- Awareness of death as a consequence of CKD
- Close calls
- Contemplating suicide or withdrawal from dialysis
- Family support for survival
- Putting plans in place while living life to the fullest



Awareness of Death as a Consequence of CKD

- All of the participants were very aware that death was a possible consequence
- Some were calm, others emotional, some fearful, others noted “it doesn’t scare me at all”
- Noticed that people in their CKD community were dying: Helen: *“I've been trying to think of how many people I've seen go since I've been there...”*



Brad: *“Cause I really don't think about, you know, [that] I'm dying ... I'm sure a lot of people worry about dying. I particularly don't and I don't want to die. I'd like to live forever but I've led a good life, a happy life. When I have to go, I can. We can go here, something can drop on our heads. I'm not going to agonize over that.”*





Advanced directives discussions

- “...*time to go, I’m going to go.*”
- “...*you have a choice, I’m a full code!*”
- One participant commented that he *felt sorry* for his physician



“Close Calls”

- Participants described "close calls"
- Experiences where they were faced with significant health events that nearly cost them their lives

“ ‘Ray, Ray, Ray,’ he says, ‘this isn't a countdown sacrament! It's a sacrament for the living!’ ”

- CKD not as bad as previous life experiences





Helen: *"I could hear my doctor...And he was telling all my family to come in and see me because I was dying and they wouldn't get a chance if they didn't come then. I thought I was in a black tunnel and I clawed my way up this tunnel because I wasn't going to die. I finally managed to get my head out of this tunnel... There wasn't anything. I wasn't even covered in blankets - I don't know where the tunnel came from. And my nurse was sitting there - he was a nice young man, he was holding my hand ...)."*



Contemplating Suicide or Withdrawal from Dialysis

Talked about withdrawal from dialysis as “suicide”

Most thought about ending their life due to:

- the unpredictability of CKD,
- the relentless nature of the “work,”
- the influence on their overall quality of life



Participants knew that withdrawal from dialysis would mean death

- Reported situations where they saw that other patients made that decision

Brad: *"I found that terribly difficult to understand. You know they went home to die. But I suppose some people's lives could be so miserable they don't think there's anything to live for."*



Story of Cynthia



Family Contributions to Survival

Participants described the efforts that family members put into keeping them alive

Stories about:

- Transportation to dialysis treatment
- Serving as a home dialysis partner
- Providing distraction, support, and sometimes housing



Helen: *"I think almost everybody does....I wouldn't have to sit there for four hours. It'll all be over. I could just rest - but do I know that I can rest? Does anybody know? Does anybody know what happens when we die? Cause I sure never met anybody that came back to tell. So I'm not sure that you do get to rest. I'm not sure anything really happens when you die you know The other reason is do I really want to do this to my family? No. You know, I mean they've been very supportive."*



Putting Plans in Place for Death While Living Life

Planning their deaths while at the same time living their lives (e.g., music at funeral, ashes)

A pragmatic approach

Bob: *“You make up a will real quick.”*

Financial considerations

Ronald: *“You don’t have to pay the inflation rate because it’s all paid.”*



Live life to the fullest

Doing “work” while at dialysis, such as funeral arrangements for in-laws

Writing their life stories, family history, or biography



Ken: *“You can't just sit there and dwell on the bad - oh I'm going to die, I'm going to die, I'm going to die ... You've got to live for the here and now and plan for the future. If something goes wrong, it goes wrong. But be ready for that, right.”*



Bea: *"So I spoke to her and I said to her, look, consider it a life sentence, not a death sentence, and it will help you deal with it...and try and deal with it as an inconvenience while you continue your life...It's quality of life, not just quantity. I don't want at the end of either of our lives to say, damn, wish we'd done that while we had the chance."*



Reflecting on these findings, what do you think are some of the implications for practice?

Are there aspects of individuals' stories that we are either uncomfortable with or we do not want to hear?



Implications for Care

- Mortality rates in CKD are higher than cancer
- Some argue that there is limited recognition of probability of death among patients (Davison & Simpson, 2006)
- Typically, significant symptom burden, low levels of functioning, unpredictable exacerbations, & sudden death (Davison, Murtaugh & Higginson, 2008)



Implications for Care

- 5 of 14 participants died shortly after interviews
- Participants were aware of death as a possibility, and were comfortable discussing topic



Engaging in the Questions

Providers may have difficulty discussing sensitive topics themselves

- 88.9% of Spanish nephrology nurses reported EOL care as a demanding task
- 92.6% would like more education regarding EOL
- 44% would only initiate conversation when the patient raised the issue
- 9% would never discuss the issue (Ho, Barbero, Hidalgo, & Camps, 2010)



Entering into Stories

How can we facilitate discussions of death and dying if we are not comfortable?

Future education of nurses and nursing students

Listening to patients and hearing their stories with greater awareness of realities of living and dying with CKD

Raising EOL discussions in relation to hope
(Davison & Simpson, 2006)



End of Life (EOL) Care

Participants knew of the option to withdraw from dialysis, even if it was not discussed on the unit

Approximately 20% of people on dialysis choose to withdraw from treatment (Kidney End-of-Life Coalition, 2012)

Some viewed withdrawal from treatment as suicide



Palliative Approach to Care

While trajectory of CKD is not always predictable, EOL planning is warranted

- Out of 710 dialysis patients, 45 had near death experiences (Lai et al., 2007)
- Application of principles of specialized palliative care (Stajduhar, 2011)



Robert Wood Johnson Foundation Guidelines (2003)

Growing recognition for the need for advance
care planning

Clinical practice guidelines have been updated
(Moss, 2012)



Resources for End of Life Care

<http://www.kidneyeol.org/Files/AddressingEOLCareInESRD.aspx>



Discussion: Implications for EOL care



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