

Holding Secrets While Living with Life-Threatening Illness: Normalizing Patients' Decisions to Reveal or Conceal

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Connor's Story (Bladder Cancer)

When I first went in to have my bladder scraped...we [spouse and I] didn't tell anyone because we just thought that it was going to be a day procedure and ... that's the end of it. But as it turned outit was more life threatening than we thought... so at that point we just had to tell the family. And then you're forced to decide about disclosing to more people—particularly when you've got to disappear from work for [a few] months. I haven't told my children the whole story though--no, no. I still want to protect them and I don't want them to feel any worse because they worry.....



Nancy's Story (Chronic Kidney Disease)

When I was 21, I was screened because my sister had polycystic kidney disease. At the time, I was in school studying biology and genetics, and we studied this specific, genetic kidney disease. I read in black and white, “50/50” chance, but it hadn’t entered my mind that this could be me. Then, here I am in the ultrasound and the tech is measuring, measuring, measuring.

“What are you measuring?” I ask. “You’ve got lots of cysts” – which she wasn’t supposed to say. I burst into tears- I had been keeping it, like a secret, from myself.

Need for the Study

- Living with serious illness is fraught with challenges of *what* to share, *with whom*, and for *what purpose*.
- Communicating openly and directly about illness is not always easy- fear of disclosure, stigmatization, or privacy keeps some people silent.
- Assumptions that secrets about health/illness are negative
- Instead, we assume that secrets are normative; most people conceal information and “ all stories contain secrets” (Ayres & Poirier, 2003, p. 116)

Purpose of Study

- To understand the role of keeping secrets and how they act for people living with life threatening illnesses of advanced cancer (AC), chronic kidney disease (CKD), and HIV-AIDS.

Research Questions

1. What role does keeping secrets play for people living with illness?
2. How do secrets act for people living with life threatening illnesses of advanced cancer, chronic kidney disease (CKD), and HIV-AIDS.

Our Methodology

- Dialogical Narrative Analysis (Frank, 2010)
- Narrative inquiry (Riessman, 2008)
- “...human life depends on the stories we tell: the sense of self that those stories impart, the relationships constructed around shared stories and the sense of purpose that stories both propose and foreclose” (Frank, 2010, p. 3).

N= 32 participants; plus Advisory (**N= 8** representing population)

Participants

- HIV-AIDS (8)
- CKD (14)
- Cancer (10)

Age & Sex

- 14 women
- 18 men
- 37 -83 years old

Three Interviews

- #1 interview
- #2 photo
- #3 phone

Data analysis

- Coding for secrets and stigma- NVivoTM
- **Thematic analysis**
- **Dialogical Narrative Analysis**
- Going further: “thinking with stories”/versus thinking about stories.
- **What is at stake in stories?**
- **How do stories guide what to do in order to hold your own?**
- **What does the story make imaginable?**
- **3 major storylines** (how stories act and affect teller)
 1. **connecting-isolating**
 2. **protecting-harming**
 3. **empowering-imprisoning**
- **3 exemplar cases**
 - Christopher (HIV-AIDS)
 - Connor (Cancer)
 - Nancy (CKD)
- **Interpreting how stories act**



Christopher's Story Living with HIV/AIDS

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Interpreting how stories act

Stories of holding secrets act:

- To connect and isolate
- To protect and harm
- To empower and imprison



Discussion & Conclusion

- Secrets act as a social practice along continuums of: connecting-isolating; protecting-harming; and empowering and imprisoning.
- Along the continuums, the function of concealing information about illness is perceived as both + and –
- Ongoing assessment is needed on the impacts on secret-keeper and recipient
- Patterns of secrecy are part of living with serious illness (avoid mis-interpreting as being dishonest or lack of acceptance)
- Nurses can acknowledge that people have choices about revealing & concealing health information. Stay open, question and explore with cautious curiosity.

Thank-you!

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2. Frank, A. (2010). *Letting stories breathe: A socio-narratology*. Chicago, IL: University of Chicago Press.
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