



Learning To Be a Dying Person

Organizing transitions in palliative care: Being outside/inside cancer treatment systems

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BACKGROUND

Reflexivity

I come to my interest situated in both my life and history, but also in the context of my work in the cancer system, in which I am frankly disturbed by the invisibility of the struggle that cancer patients transitioning to dying selves seem to experience, and the consequent lack of support they seem to be offered.

Questions to Consider...

- How does a person become a cancer patient?
- What shapes this new self for the person who has discovered this disease in their body?

Transitioning to becoming a cancer patient

There is a self without cancer who is compelled by the diagnosis to learn and add a new self with cancer or 'cancer patient' and an in-between transitional space filled with testing, waiting, uncertainty, anger, grieving, yearning, and all things people are likely to experience when mortally endangered as they are with facing a cancer diagnosis.

Transitioning to being a treatment patient

- As people transition to becoming a specific type of cancer patient, treatment options are made clear to them by the oncologist.
- Here now a further differentiation of the person may begin with an identification with their treatment – the mastectomy patient, the bone marrow transplant patient.
- Foucault (1970) describes this as a discursive formation, where language, actions and context create and maintain the structures which shape our thinking and speaking.

Transitioning out of treatment

- Finally, people as cancer patients of all types and sorts transition to one of two not so very distinct groups: the 'survivors' or the 'non-survivors'. To become a survivor is what engaging with the cancer treatment system is all about – the cure, the eradication of the cancer. Yet in reality, there are very few adult cancers which are truly cured.

Transitioning to being a dying person

- For those not moving towards the insecure survivorship self, there is perhaps a more anxiety-provoking transition to be made to a non-survivor person, that is the person who will die from their cancer.
- It is this cancer patient person learning to become the person dying of cancer I am particularly interested in better understanding. How do they accomplish this particular transition? What can we learn about their needs in this learning-self-as-dying space?

RESEARCH QUESTIONS

1. How does the transitional patient organize a **self** that engages with the liminal space between cancer treatment and palliative care?
 - ❖ What contributes to this organization of this self?
 - ❖ How is this self and space made visible through language and/or narratives that are used around this transitional self and space?
2. If question 1 can be understood, then where ought this transitional space (between cancer treatment and palliative care) to be located - inside or outside the cancer treatment centre?
 - ❖ What are the benefits for patients (and families) with either locale?
 - ❖ What are the benefits for the contributing sectors of the health care system from either locale?
 - ❖ How is either option brought into relief by language and discourses that come both from the transitional patient, their families, oncology team members and selected text surrounding the organization of these two areas of concern?

METHODS

Philosophical Hermeneutics & Discourse Analysis

- The meanings of cancer are wholly caught up in how the disease has been socially constructed.
- This is what Gadamer (1975) refers to as historicity, and to which Foucault (1988) calls the political technology of the self.
- Historicity describes how words and language are more than letters and sounds, but rather they conjure in our minds a picture which includes our thoughts and feelings about what we read and hear not only containing our history as person, but also the histories that the word has come to possess through its many and often differently situated understandings.
- Foucault's (1988) addition is that how the self is constituted is not merely a matter of chance but produced out of power and privilege.
- It is my intention to explore with patients and their families, as well as with oncology clinicians how they describe transitioning from curative cancer care to palliative care, and how patients move or are moved through this transitional or liminal space.
- Foucault (1988), in his examination of political technology situates the constitution of self in the context of the state and its aim to support and strengthen itself.
- That is to say, what we do, and how we decide upon things is not only related to a personal history and meanings, but also the power and politics of the social networks in which we exist.

DATA COLLECTION PROCEDURES

Patient and Family Participants

- Patients and family members will be interviewed separately to gain an understanding of the exclusivity and/or mutuality of their perceptions of how they describe the shaping of themselves or their loved one as they move from treatment of their cancer to palliative care.
- Interviews will be taped and transcribed for later analysis, and field notes will be taken at the time of the interview.
- It is hoped that six (6) patients and their family members will agree to participate.

Patient and Family Questions

- How did you recognize that the curative treatment phase of your cancer care (your loved one's cancer care) was concluded?
- What did this call forward in you (or your loved one) to meet with this new phase?
- Was there anything that particularly shaped your (or your loved one's) response to being in this new 'after treatment' phase?

Oncology Clinician Participants

- Oncology clinicians working in the cancer centres will then be interviewed, focusing on how they account for patients' movement from curative cancer treatments to palliative care.
- This interview will take place after I have taken time to preliminarily engage with the patient's and family's text, therefore the questions listed below are, at best, tentative.
- It is hoped that six (6) participants will be recruited from various disciplines but most necessarily inclusive of nurses and oncologists as they seem specifically to be engaged with each and every patient.

Oncology Clinician Sessions

- How do you understand how patients move from cancer treatment to palliative care?
 - When does this happen?
 - What does this look like?
 - Why does this happen the way it does?
- How do you think your work in the cancer system contributes to the organization of this transition and the patient's sense of self in this transition?
- In your mind, what else shapes this transition and the transitional patient?

EARLY UNDERSTANDINGS

Patient concerns are that when they finish their treatment they often feel abandoned by the system when they are discharged from BCCA...

Speaking with surviving family members who have lost a loved one to cancer, they share that they truly wished that their loved one had more time to adjust to being a dying person, and that in not having this they felt opportunities for growth and closure were missed...

For some, the battle language of cancer gets in the way of healing opportunities for cancer patient and their families...

NEXT STEPS...

I have now received my ethics approval so will begin data collection within the next couple of weeks. Then, I will be analyzing and writing, analyzing and writing, analyzing and writing, analyzing and writing...

