Learning to be a dying person: Being outside/inside cancer treatment systems

by C. Ann Syme

"What my aim is at this point, and I find myself finding it difficult, finding what that goal is. Because when you're healing, that's a thing to look forward to and it moves you forward into your future. But if you're not moving that way, you're not moving towards a future that's being without an illness, I don't know how you can say (what) that direction is. I'm not sure I have the vocabulary for it. It's all sort of stalled, sort of static."

The woman who spoke these words has died of cancer. The day she said this she had just learned that the cancer she had was incurable. I open with this account to introduce the concern and focus of my study. This is what I call the 'liminal space'. Jane* came to this space after being through the cancer treatment system, learning what it was to be a person with cancer, learning how to be a cancer patient with colon cancer, learning that the chemotherapy, surgery and radiation therapy she had could not rid her of her cancer, and now being faced with learning to be a person who would die of cancer.

Liminality is a concept arising out of anthropology, describing a betwixt and between place and persona between a past and future state (Turner, 1969; van Gennep, 1960). Meyers (2008) explores liminality through the lens of existential philosophers Sartre and Merleau-Ponty's reflections on being and nothingness. Liminality is also taken up in sociology in terms of inter-polar spaces between cultures (Fanetti, 2005) and in thinking about porches as thresholds and transitioning spaces (Walker, 2005). Liminality is also explored in health care literature relating to chronic illness (Frankenberg, 1986), and as a space experienced by people facing life-limiting diseases (Bruce et al., in press). Finally, liminality is explored for people with cancer in terms of a process (Little, Jordens, Paul, Montgomery, & Philipson, 1998) and as a life-long way of being after being diagnosed with cancer (Navon & Morag, 2004).

This study explores liminality as a particular space that opens up for some people leaving cancer treatment centres and, being faced with dying because of their cancer, how they go on. As a concept liminality is rooted in the betwixt/between living/dying and expressed by people like Jane, as an ambiguous space and self. I will also demonstrate that, in some particular and observable ways, it is a space shaped by the cancer treatment system and how people are constituted and constitute themselves as cancer patients and, subsequently, as dying persons. This will be carefully explored, as liminality itself is a rather ineffable concept, particularly as this applies to a dying person, and difficult to *expose* in an empirical manner. However, liminality is also a space that lies between two expert systems, and is, therefore, shaped by and experienced through how these systems are and how these systems are taken up by people who find (or lose) themselves in a liminal space. Therefore, while

liminality is not a new term to be used in cancer or other life-limiting diseases, the ways in which liminality is positioned in this study are new territory for cancer palliative care research and nursing.

* names of participants are changed to protect anonymity

Background

This research project attempts to explore how some people exiting the cancer treatment system after unsuccessful treatment find or lose themselves in a liminal space, as a sort of parenthesis between the expert systems of cancer treatment and the emerging expert system of palliative care, and between a self as living self and a self as dying. In this space meaning becomes diffuse and self as dying is ill defined. Although the preceding sentences describe this space, they do not, as this work seeks to do, add the layer of problematizing the liminal space. What is the problem with liminality? In this study I explore this question with the aim to contextualize the space of liminality and the problem it poses from the perspective of the individual who finds or loses himself in this space, and explore the features of the expert cancer system that contribute to liminality in the particular ways that I will argue cancer systems do.

While the biologic/cellular and bodily stories give meanings to cancer, the voices that attend these stories are not equal. The biologic/cellular story of cancer is caught up with the science of the disease and with this in the dominance of medicine over the person, as a patient's bodily and personal experience of the disease. In this weighted meaning-making space, there is a person with cancer trying to make sense of their situation—who they are, what is becoming of their bodies, and how their narratives will be indelibly shaped and, ultimately, truncated through their experience. These narratives and sense-making spaces are ones that are shaped by medical dominance and the institutions that lay claim to understanding how this disease is manifest and how, when it appears in a person's body, it is addressed. When this institutional and medically dominant interest is withdrawn, people may tumble into liminality—a space between expert systems. This is a space that seems to be, so far, beyond the reach of expert institutional shaping, and is the living/dying space where people lack a narrative to take themselves forward.

Questions that led me to my research

There are two questions leading this study and shaping and forming what this research addresses.

1. *How does the transitional patient organize a self that engages with the liminal space between cancer treatment and palliative care?*

My interest in this question is how the self takes shape and is shaped for people who find themselves liminally situated after unsuccessful cancer treatment. The answer is sought in the language they, their family members and the oncology clinicians who care for them use to express this self and space, and in the shaping forces for this self and space that can be seen in the discourses. The second question presumes on this first liminal space being made visible, and asks:

2. *If question one can be understood, then where ought this transitional space (between cancer treatment and palliative care) to be located—inside or outside the cancer treatment centres?*

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Methods

First, I applied Giddens' (1990, 1991) work in terms of his arguments about expert systems in modernity, as these relate to the nature of cancer institutions and the ways in which patient persons interact with them and reflexively create their self-narratives. Giddens' work concerning the reflexivity of self-narrative in modernity was also used, as a lens on people's experiences of being cancer patients and becoming liminal persons. Next, I used Foucault's (1988, 1989) thinking as it relates to unearthing the power effects in discourse and how these effects were sought out in the accounts and data. Here, the notion of medical dominance, as it relates to becoming and unbecoming a cancer patient, was explored. Finally, Gadamer's (1976, 1989) philosophical hermeneutics were used to explore the complexity of meaning in language used by participants and found in writings about cancer care and liminality. Additionally, Gadamer's notion of how language forms and shapes the self was explored, as it is through conversations that the support for people in liminal places was shown to be a critical nursing skill.

Findings and meaning making

My findings were organized according to patient participant accounts of how they became cancer patients, how they were discharged from the cancer system, and how they found or lost themselves after disengagement with the cancer treatment system. Alongside those patient and family perceptions, I explored with clinicians to see how they saw their behaviour shaping the discourse around patient care, paying attention to the clinician language and clinician perspectives of how people became constituted as cancer patients. Each portion of the findings is thought of in terms of patient participants' sense of progression and, also, the findings are grouped into three themes in terms of the concept of aggregation as very much an organizing technology.

People become *aggregated* as cancer patients—they become grouped and labelled in different ways. This gathering in is not merely a disciplinary activity or a system effect, but also how patients rethought of themselves and gathered in new perspectives of being, not only a person with cancer, but of *becoming* a cancer patient. Similarly, when treatment ended, the notion was that cancer patients, after being so attentively shaped, were disbanded and let go, *un-becoming* a cancer patient, and leaving a sense of uncertainty and unraveling of the self that I label *disaggregation*. Finally, some of the people with cancer, after taking leave of the treatment system, found or lost themselves in what I refer to as my liminal space where there was, from their perspective, no aggregating force whatsoever.

Becoming a cancer patient—aggregating

I share an account from Mary that exemplifies what I call becoming or being aggregated cancer patients.

"My doctor sent me for an x-ray after a long time of wheezing and kept saying it was my asthma and finally sent me for an x-ray and it came back and it had a nodule on it. They didn't want to explain the nodule until I came to see the doctor. This was in early May and we were told to wait until July 4 for a CT scan, so we phoned the private health clinic in Vancouver and had one done there and then and that's when we knew. The radiologist took some time with us. He put his hand on my shoulder and said, 'I'm very sorry.' And I knew; I just knew. I knew what it was. I knew I was incurable and that we were on a trip."

Mary is being self-surveillant about what seems to be happening to her. She knows something is wrong, but she cannot seem to get the satisfactory attention of anyone in authority. Her body is signaling that there is something wrong, the coughing won't go away. She receives the sinister, but very inadequate label, the nodule. And she

pulls all the strings she can to get at the expert opinion she feels she needs to get to as quickly as she can. She knows that they know something, but she just cannot seem to get them to tell her. And when she finally gets the expert opinion she's looking for, she says she already knew. Gathered under the expert clinical gaze of the radiologist, she gains proof to her bodily story that she actually has cancer. She was accurate.

What is interesting is that Mary feels reassured, like knowing that she has cancer is better than worrying whether or not she might. The accounts also showed an interrelationship between the person and their situation, and as collective as we might want to think becoming a cancer patient might be, it's obvious that a person's history, their sense of self, very much shapes this first transition.

Accessing expert systems was a very interesting phenomenon. According to Giddens, it is a crucial point of connection in which trust may be either built up or broken down. It is what binds the lay actor into the trust relationship with the expert and that's what Giddens would call face-work (1990). Face-work functions to reduce the concern that the human operators, the flesh and blood folks, within an abstract system have the necessary knowledge and skills to deliver what the abstract system represents. Think of getting on the airplane to come to this conference. Here is some face-work described by a family member:

"Going to the cancer clinic, that first experience, I think that's when we knew we'd entered a new world, because there's people with no hair and they're young and they're old and they're all filling out forms and it's sort of like in the future, walking through void spaces, some knowing where they're going and some not. You know it was a very unusual experience."

Unusual, indeed—how people experience this becoming or aggregating force is very important to how they enter into and experience their care.

Un-becoming a cancer patient—disaggregating

When cancer patients were discharged from the cancer clinics there is what appears to be a breakdown in their cancer patient narrative.

Listen to how Jane feels the aggregating forces being withdrawn and senses her narrative unwinding:

"That was a really big bump, too. There was a meeting when the results of the CAT scan and the CA numbers were going up and so the oncologist said that there was a recurrence. But I was asymptomatic and then after that I was symptomatic and that was the other shoe dropping. The minute you are symptomatic, you're in, you're not in that same path. You get sent home with a book from the palliative care centre that has a DNR, which is hard to look at, and she began to cry."

When I explore with Jane what her sadness and bereavement is about, I sense two things. One, Jane knows she's dying and this rejection is highly personal. Jane knows that the cancer clinician not only rejects her because there is no further interest in her cancer, but the clinician is also signaling that he or she is not interested in her symptoms and, ultimately, in her suffering. Jane's biologic cancer story has ended and so has the clinician's interest.

Giddens (1991) is helpful here. He would say that Jane's impending death, for the clinician, is a technical matter. What death then becomes is a matter of deciding at what point a person should be treated as already having died. Jane's not there yet. She has not caught up with the medical fact of her death. Yet, for the cancer system, Jane has, for all intents and purposes, already died, and she, herself, has no narrative to take her forward.

Un-aggregating—liminality

Here, I draw from the accounts about the space between cancer treatment systems and the next potential abstract system, palliative care. People were asked to reflect on what they thought was going to happen next after being discharged from the cancer system. Knowing they had incurable cancer that was beyond treatment, where did they feel themselves to be? This was the most difficult question I put to people, and one that, for many, required that I stop recording and give people some time to gather themselves. Responding to my exploration of what this space felt like, Jane reflected most movingly on the liminal space in which she found/lost herself.

"...and I have been spending quite a bit of time figuring out what the aim is and what my aim is at this point, and I find myself, um, I find myself finding that difficult finding what that goal is. Um, because when you're healing that's a thing to look forward to and it moves you forward to your future. Um, but if, um, you're not moving that way, you're not moving towards a future that, um, is being without illness, I don't know how you can say what direction that is? I'm not sure I have the vocabulary for it. It's ah, sort of stalled, sort of static."

Familiar to Jane is the healing place, something to move forward and story herself toward. Unfamiliar to Jane is the place where there is no healing, the place of not being without illness. She cannot say death. This is a place for which Jane has no words and she does not know how she will move forward in this space of utter strangeness. This space is also framed as an in-between space flanked by two poles. The proximal pole is what is known—the here and now of being a person with cancer that may be healed. The distal pole is not clear at all, and where the stepping-off place is what Jane calls a “stalled and static place.” It is the dying and death place, but Jane has not yet found these words, she cannot story herself forward in this space.

Goal-less, with the experience of losing a healing direction, Jane cannot see what to look forward to. The future Jane is moving towards is obscure and she is rendered aimless. Directionless, if Jane is not healing she is not moving into a future without cancer. But Jane cannot bring her vision around to her future with cancer, the incurable and progressing disease she now knows she has. Motionless, within this space Jane tells us she is stalled and static. This space escapes her linguistic horizon and she, consequently, has no words to speak herself forward into some direction. She has lost her story, biomedically *and* bodily, and in terms of Giddens' (1991) conception of self-narrative, cannot go on. She is neither here nor there, she feels that she is living and somehow not living in a way she has never encountered before.

Caring in the liminal space

How might the liminal patient be supported in an unwanted departure from the treatment centre and an unwilling approach of either palliative care experts or, perhaps, death itself? If, in fact, the transition of a cancer patient to a dying person requires a cognitive or, perhaps, a linguistic threshold of acceptance or a liminal pause or parenthesis, does the cancer treatment centre have the culture to form this imagery in this existential space? Can a person with incurable cancer story themselves into being a dying person while still in the treatment centre?

To try and understand this, I looked at what happens in this space outside of cancer treatment centres, first in terms of palliative care, and then in terms of two ‘solutions’ the cancer control system has generated: patient navigators and clinical pathways.

Palliative care—the next expert system

Syme and Bruce (2009) looked at the development of palliative care in Canada. They took a critical perspective and looked at the

development of hospice in its original social movement being something that augmented what was then a very disinterested expert medical system, which was focused on curing and correcting. Over time, the hospice movement evolved towards the expert medicalization of dying with palliative care being mainstreamed into health systems, and the care of the dying person becoming more gathered under yet another expert medical gaze.

Researcher Margaret O'Connor (2007) explores the effect of the evolution on palliative care. She says, “Perhaps the historical discourse about dying could be viewed as a discontinuous discourse, once a shared, communal, family activity and regarded as human beginnings and endings, it is now, not only separate and hidden from the community and family, but has become a medical event in the hands of those who have made care of the dying their specialty, with its own particular language and discourse. The personal and human bodily story of life, and here, death, has been supplanted by a medical or biological story” (p. 236).

It has a familiar ring. If, indeed, palliative care has become, in this way, like a cancer system in terms of being an expert medical system, what can be seen or understood about the features of this positioning? Learning about this next expert system, cancer patients had been conditioned to our very well oiled, efficient and highly esteemed cancer treatment system. It's small wonder that cancer patients leaving the cancer system were either vaguely unaware or utterly aware of the next expert system and encountering it, found palliative care comparably disappointing. But they also found palliative care intrusive. It was not a space they were ready to take up and they preferred to linger in liminality.

Patient navigators

Patient navigators were originally envisioned as providing access to the cancer system, most particularly to the under-served populations that were not accessing cancer screening or cancer care. This original vision has latterly developed to one of an overall navigation for cancer patients. What has been criticized, particularly by Thorne and Truant (2010) in this gradually accelerating movement is that the conception that a health care system that needs to be navigated speaks to a larger issue than mere way finding. I find it interesting to reflect the solution of navigators is very much a cancer system-generated solution mirroring the very inherent characteristics of the cancer control system, the “siloeed” aggregation of patient types. This time it is not a tumour type, and lacking this depiction, has become directionless and lost or, as I've described, has become liminal.

Clinical pathways

Clinical pathways are developed to support clinicians to provide consistent and measurable standards of care. Clinical pathways are, again, a system-generated solution to patient movement and care, the most prominent of which is the Liverpool Care Pathway, when we think of palliative care. This tool was developed in the U.K. originally, as a basis for end-of-life education for care providers and, more recently, has been used as a template to standardize how patients and their families are cared for at end of life, including how they experience the transitions between expert agencies. In a multi-centred study of the effects of applying this clinical pathway, outcomes of improved symptom burden and documentation have been shown (Ellershaw & Murphy, 2005). It strikes me that this tool represents an extension of the evidence-based and structured approach to patient care that the expert cancer system has been shown to provide. If this is so, there are definitely some pros and cons to this way of shaping care. But there also is a part of me that feels a little concerned about how packaged this approach may feel to people and families as a technology of moving them through. However, this pathway is framed as improvement to an organization that is currently seen as abandoning patients. Perhaps, then, it's a useful first step.

Nurses caring in liminal spaces

For people who come to this space, like Jane, I believe it is only when the collective and comprehensive self is appreciated and honoured, is there any space for support or guidance, and that this care would need to be provided with a highly empathetic, but very light hand. For Jane, her care needs are about dwelling in the liminal space and being lost in herself as she does. What Jane needs is accompanying, listening, clarifying, supporting, the skill and other-centred and other-interested posture, the language simple, accessible and absent where required. The conversation, in this space, strikes me as an ultimate example of a fusion of horizons where the two who are engaged in this space learn and create the horizons of who they are as they speak their ways about it, both willing to enter into the conversation and be changed by it (Gadamer, 1976). In the cancer centre, oncology clinicians may take up this work. Here is the liminal space so clearly appreciated by oncology nurse Kate.

"So, they come to a place of feeling disappointed, and I think it's at that point that it is probably the hardest phase for them, is when they start to see that things have moved on. It's scary. They don't know how fast it's going. They don't know what it means, and they don't know what it's going to look like."

And here, this space so delicately explored by Kate,

"Well, to be honest, I have sort of come to a place of acceptance with myself, so I deal with it. I try to put myself in their shoes. I have to try to understand what's happening for them."

Kate knows cancer in a way that allows her to connect with patients and help them to weave their own story or, alternatively, understand when their stories falter and do not seem to go on. She knows liminality and can work in the liminal spaces, so employing

oncology nurses in this work would create a different conversation than the one that patients have just had with their oncologist.

However, people in liminal spaces might actually need to step away from the cancer clinic for a time before they're ready for any engagement about who they are and where they are, no matter what that engagement is.

Or people in liminal spaces may need to step entirely away from the cancer clinic and their cancer clinic situation experiences of battling and loss and have their liminal needs supported elsewhere. So, what would liminal care look like if it was outside of the cancer system? Could liminal care be provided by home care nurses who could be cued to this critical conversation with an oncologist and asked to make a home care visit? Or could palliative care nurses working in palliative care programs be cued that patients have had this difficult conversation and take leave from what patients have framed as their intrusive institutions and have this conversation with them? This research only can pose these questions and cannot answer them. But like any good piece of research, I can lay out what is learned and what needs to be studied next.

Closing

While our expert systems busy themselves with the shaping of patient persons and wrestling with system issues of treating and moving cancer patients or dying persons, people live and breathe and story themselves in the liminal spaces. Cancer, home care or palliative care nurses, perhaps, can meet patients in their liminal space, but if, and only if, they're able to leave behind the organizational sequestering of expertise and power and tread lightly and carefully in those person-sacred places. In the words of D.H. Lawrence, then, "Be careful and be gentle about death for it's hard to die. It's difficult to go through the door even when it opens" (1994, p. 607).

Thank you very much for your attention and your caring spirit. ❧

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