Reading My Mother's Care

On the Fringes of a Compassionate and Empathetic Ethic

ANNA NATOLI

Ceci est un texte exploratoire de ma mère à qui des professionnelles de la santé ont prodigué des soins alors qu'elle était atteinte du cancer. Récemment en apprentissage comme éducatrice en soins médicaux, j'ai réfléchi sur la tension qui existe entre la collaboration interprofessionnelle et les soins en collaboration avec les interprofessionnels durant la formation médicale et les réalités vécues chez les patientes.

Must make a critical poetry, an analytic lyric, not a poetry that "decorates dominant culture" (to cite Michael Palmer) but one which questions the discourses.

This situation makes of representation a site of struggle.

(DuPlessis 145)

This is exploratory writing and reflection of the data and documentation of my mother's health records which tracks her care by healthcare practitioners and professionals as a patient/customer/client with cancer. It is an attempt to make visible my difficulty with my mother's death read adjacent to my frustration with my mother's care and is written in a style that lends voice to the tension between "[c]lean and reasonable scholarship about messy, unreasonable experiences" (Tamas paragraph 18). It is also a reflection on what I experience as a tension between the importance and significance, on the one hand, of interprofessional collaboration, a model of health-care which recognizes the importance of a multi-disciplinary healthcare team as a best practice, and interprofessional collaborative care, a model of health-care which recognizes the importance of a multi-disciplinary healthcare team to foster patient-centred care.1

And
listening to the patient
is only
now
becoming
a central
focus
for
health and social
care professions.

(Freeth et al. x.)

Interprofessional Care is the provision of comprehensive health services to patients by multiple health care professionals who work collaboratively to deliver the best quality of care in every health care setting. It encompasses partnership, collaboration and a multi-disciplinary approach to enhancing care outcomes and is the cornerstone of the HealthForceOntario strategy (Interprofessional Care).

bodies vacuous treated pathologic diseased studied

patient-consumer centered care patientconsumer stigmatized and

pathologized consenting to objects bodies

compassion and empathy patient-consumer-client-centered care

diseased patient

dis

ease of the

consumer

cared for by the healthcare system the professionals

in the healthcare system as an

this unnamed Mrs. u nfortunate 58 year old woman with a *metastatic* carcinoid tumor as well as a pelvic mass who does not believe she has cancer²

Of course,
even the most
conventional
of biomedics
would agree
that
a positive patient
is preferable,
but
beyond this the
patient has little determining effect
on the direction of
the story.

[Medical experts]

alone

are the narrators,

perhaps

even the authors³



Anna Natoli, "deeply hollow," clay, 2.5 x 2 x 2.25".

Photo: Richard Hovey.

and, on the other hand, the lived realities of person-/patient-centred care. The literature on interprofessional collaboration and interprofessional collaborative care suggests "high quality collaborative practice can increase professional satisfaction and the intrinsic motivation of team members' roles, aiding retention and reducing burnout" (Freeth et al. 12).

As a recent educator and learner of interprofessional education (IPE) and interprofessional collaboration (IPC), I witnessed a tension that often teeter-tottered between a corporate model of education of sound bites and checklists—about rather complex and dynamic social and professional relations—reduced to "workshops" about effective communication, conflict management skills and teamwork, and, an analysis of the psycho-social-philosophical relational dynamics of an ethics of care & self care (interprofessional collaborative practice) and person-centred care. Yet, and not surprisingly, the literature, and the literature guiding the educational direction of this initiative, 4 recognizes much more intimately the educational complexity of it within the existing bio-medical and empirical 5 paradigms of "medical" education.

Understanding IPE calls on not only the scope of health and social care professions, but also the academic basis of, for example, anthropology, sociology, geography, philosophy, economics, management and others. (Freeth et al. viii)

VOLUME 28, NUMBERS 2,3 35

body attacked by cancer ambushed by the care and empathy and compassion of the healthcare professional caring for cancer with the trauma of losing control of its function functioning

deceased the unfortunate circumstances leading to her death

care cared caredfor by from with-in *masculine* heroic narratives of science⁶

> interprofessionally in collaborative healthcare

in a system of disease focused care amongst

multifarious interprofessional collaborative voices specialists

General
consultant to see this
unfortunate unnamed Mrs.
whose history is
documented in the chart
In Patient

Assessment Mrs. Named
patient was seen between
11:00 and 11:
45am by Palliative Care
Services she does
complain of her
bone scan shows

interprofessionalism
modified: different
expert knowledges wrestle
for the power to determine
exactly what cancer is⁸

collaborative wrestling demonstrated in records of Mrs. unnamed 58 year old unfortunate woman

In addition to this recognition the phrase "learning with, from andabout",7 in the literature of IPC and IPE, it is assumed, provides the hinge on which interprofessional collaborative care situates health professionals, patients and friends and family, as part of the health care team, to learn with each other, from others and about others to facilitate collaborative patient-centred care. The phrase learning with, from and about leans in the direction of a deconstruction of the narratives of science that witnesses the erasure of bodies, people, persons, dynamic social and professional relations messy in the complexity of the everyday. It leans in the direction of opening up a discussion about a listening/hearing ethic—one that honours both the one listening and the one speaking, to include care of others as well as self – and yet falls short as listening/ hearing is grounded in the consumable: workshops about (non)verbal communication and the use of 'I' language; hierarchy and power and its effect on communication; a toolkit for the professional to manage conflict; how to communicate and resolve conflict to sustain effective and efficient teams; etc. These consumables and the checklists and toolkits that are the products of these consumables, facilitate not a critical analysis and/or reflection about the impact of social-political-philosophical discursive 'systems' and infrastructure on the effectiveness of interprofessional collaborative practice and collaborative patient-centred care but keeps the health care practitioner/professional in the busy-ness of self reflective practice (analyzing bias, prejudice, stereotypes, etc.) and "other-centredness."

The phrase, learning with, from and about, situated within a medical ethic and educational model, challenges, in part, the corporatization of medical and health care practice, for example, the allocation of an arbitrary amount of time 'appropriate' for discussions with patients about their care, because the responsibility is now situated in the behaviour and the appropriate use and integration of the consumable products made available to the health care practitioner/professional. The educational direction of IPE provides health care practitioners/professionals with the tools and toolkits to manage care within this arbitrariness, rather than facilitating a critical and analytical skill to challenge a systematic inheritance of business model as health care. This re-direction to an individualist/behaviourist model situates responsibility in the health care practitioner/professional's (in)ability repetitively documented well documented consultation transcribed practitioner/professional

dictated and accepted

medicalized care
controlling bodies
out of orderout of time⁹
this unnamed Mrs. unfortunate 58 year
old woman

pt went into x2
progressive decline
arrest @ 10:30 pm
(declared dead)
completed Death certificate
Sept. 22
pt died @ 22:30 h
release to morgue

where is touch flesh ears listening?
?touching upon
the fleshiness of pain
?touching upon
the fleshiness of subjects
?touching upon
the fleshiness of the
messiness of relational
dynamics?

medicalized care the masculine heroic narratives of science traced tracing pathologized bodies

Our eyes vision clarity reason :the illumination of enlightenment thinking advancing knowledge should not reason be used to probe the other with unforgiving Our eyes gestures ought look toward with each-other as our move to the rhythms of soft embraces, lightly softly touching upon communicating with



Sonia Natoli, "water on the shore," 2010.

to navigate in a health care setting that is motivated by profit rather than care, other-centredness rather than an ethics of care & self-care and models of communication rather than an ethic of listening/hearing. It is now up to the health care practitioner/professional to bandage messy social and professional relational dynamics with the use of these tools and toolkits without substantially disrupting the health care system.

As an understanding of IPE develops, those who engage in its practice will be called upon to build tools to ensure that it is both successful and effective. The result of such efforts will be to ensure that IPC is absorbed into the body politic of disciplinary education as part of the natural education and training of all health and social care professionals. (Freeth et al. viii)

That said there is a hint in the literature that nudges toward an initiation into a critical analysis of systems but it is problematically located in a causal analysis of the 'root cause' of quality assurance models, for example The Swiss Cheese model of prevention of error and Continuous Quality Improvement (CQI).¹⁰ This discussion is often located in the analysis of medical error facilitated by holes and gaps in the system, miscommunication between team members of collaborative care and a lack of adherence by patients about their care, for instance. This however is an interesting theoretical undoing of medical education. "A systems approach to healthcare error requires that we develop methods that address the processes contributing to error, not focus on individuals" and their behaviour (Leape cited in Baker et al. 14). Yet the system is full of persons and people mandated to work collectively and collaboratively across disciplines, processes, technologies and approaches/ethics of care.

VOLUME 28, NUMBERS 2,3 37

within the empathetic gesture of the listening'hearing trust warmth compassion returning with and to others irreducibility

we listen'hear touch upon'touching upon the delicacy of a nod.

speaking to bodies not with subjects identities subjectivities

?how to be recognized embodied subjectivities intersected by the context of social political discourses

?situated in our experiences of bodies travelling through the contemporary discourses of the politics of racism? ableism? sexism? homophobia? transphobia?

?within a model of interprofessionalism

So when I was told of myself my you myself owned by the fleshy intervention of the narrative of science bodies traced by the history of pathology the patient embodied by pathology her is subjectivityid entity



Anna Natoli, "woman scarred," clay, 11 x 6 x 6".

Photo: Richard Hovey.

On the one hand IPC and IPE is touted as addressing the 'behaviour(s)' of the health care practitioners/professionals by stressing the importance of a self governance methodology of reflective practice, with a preliminary look at the systems guiding and directing care (due to the complexity of differing clinical settings/environments this can only be a cursory discussion) and a nod to the challenges of delivering care. This falls short of developing highly critical, analytical and creative thinkers about the current and future direction of health care—not as a model of care but as a living ethic of well-being. On the other hand health care practitioners/professionals are responsible and accountable for the effective use of systems and processes which are modifiable (the addition of more defences or layers, layers of Swiss cheese to situate it within the Swiss Cheese model, to ensure the process is effective), not revisable.

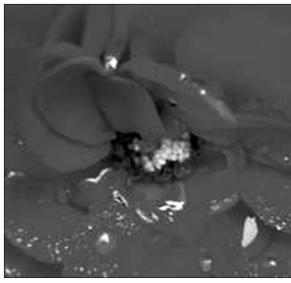
How then does this affect one's capacity to care, to care for others & self, to embody within the practice of health care a caring ethic—a listening ethic—as one navigates within a health care as business model (checklists and 'toolkits'), as bio-medical (pathologization and medicalization of bodies) and as continuous quality improvement? While interprofessional education and the "initiative to secure interprofessional learning and promote gains through interprofessional collaboration in professional practice" is a first step in changing social health care/medical practices, an analysis of the relations of the system of health care as business model, checks and balances of systems within a quality assurance initiative and healthcare as bio-medical would facilitate a much richer discussion (Freeth et al. 11).

the disfigured diseased object scientific cancerous body cognitive rationalized

bodyobject
about
me'my subjectivity cared
for
compassion
ately this
unfortunate unnamed Mrs. 58 year
old
caring about her
body

unfortunate 58 year old woman with [the following psycho-social characteristics of her cancerous and dis-eased body and mind]. She is an unfortunate 58 year old woman with 4 children. 2 of which live with her and her husband and 2 of which live outside the city. As this unfortunate 58 year old women she was born in Germany but grew-up in Canada; both her parents are deceased, as is one sister; she has one surviving sister.

Dictated. Accepted.



Sonia Natoli, "softly," 2010.

This initiative to integrate and/or embed¹¹ interprofessional education and interprofessional collaborative care into medical education, I am arguing, makes visible, the tension(s) I speak of above, in my mother's medical records and documentation particularly expressed in the use of the biomedical language of pathology as it navigates on the fringes of a compassionate and empathetic ethic. The best evidence of this is the often cited and 'dictated' superficiality of a naming convention that situates my mother's subjectivity and identity within the language of pathology—this

SCREAMING

who does not believe she has cancer

Where we listen from

close enough to smell and hear each other to touch and be touched accommodating the person's preferences for communicating.¹² Anna Natoli is interested in contributing to the scholarship about ethics from a feminist, gift-giving and gifting, grounded and eco-spiritual perspective to explore how relational dynamics of personal and interpersonal relationships might supplement the ought of a living ethic of wellbeing. Traversing writing practices she engages with narrative as a guide for what she calls embodied autofiction to develop an expression that better reflects this ought and to bridge intellectual and creative pursuits.

¹"For over 30 years interprofessional education has been promoted in policy documents as a means to enhance collaboration, reduce service fragmentation and promote high quality client care (for example, DHSS, 1974; WHO, 1998; DOH, 2001; Health Canada, 2003)" (Freeth et al. 12).

²"When what she said didn't fit their fixed ideas, they went on as if it did. Resistance, they called that when you didn't agree, but this bunch didn't seem that interested in whether she had a good therapeutic attitude. What were they listening for, inasmuch as they listened at all? How that Dr. Redding stared at her, not like she'd look at a person, but the way she might look at a tree, a painting, a tiger in the zoo" (Piercy 84-85).

³Stacey 12, emphasis mine.

⁴See footnote #1.

⁵Empiricism (empirisizem) n. the scientific method of proceeding by inductive reasoning from observation to the formulation of a general principle, which is then checked by experiment (*The New Lexicon Webster's Dictionary of the English Language* 309).

⁶Ibid. p. 11.

⁷See Richard Hovey and Robert Craig (under review). "Understanding the relational aspects of learning with, from and about the Other: If it were only that easy!," *Nursing Philosophy* for an insightful discussion about rethinking the phrase *with, from and about* to *about, with and from* that accounts for the how of collaboration: "[c]ollaborators begin by first learning *about* one another, then progresses to learning *with* that person within some context. Learning with another person opens up the possibility of learning *from* the Other when the participants are willing and open to share new perspectives" (1).

8Stacey 30.

⁹"The time is out of joint" (Hamlet cited in Derrida 1994: 1).

¹⁰The explication of these models falls beyond the scope of this paper. I maintain a more generalist approach in this paper to facilitate the exploratory writing of the text.

¹¹I want to thank Richard Hovey for engaging with me on numerous occasions about the distinction between integration and embedding and a hermeneutic approach to education and healthcare.

¹²O'Brien and O'Brien 16-17.

References

- Baker, G. Ross and Peter Norton. "Making Patients Safer! Reducing Error in Canadian Healthcare." *Healthcare Papers: New Models for the New Healthcare* 2 (1) (2001): 10-31
- "Derrida, Jacques. Of Grammatology (1967)." *Thought-jam.* Wordpress. Web. 12 February 2010.
- Derrida, Jacques. Specters of Marx: The State of the Debt, the Work of Mourning, & the New International. Trans. Peggy Kamuf. New York: Routledge, 1994.
- DuPlessis, Rachel Blau. *The Pink Guitar: Writing as Feminist Practice*. New York: Routledge, 1990.
- Freeth, Della, Marilyn Hammick, Scott Reeves, Ivan Koppel and Hugh Barr. "Forward," "Introduction," & "The Spectrum Illuminated", Effective Interprofessional Education: Development, Delivery & Evaluation. Malden, MA: Blackwell Publishing Ltd, 2005.
- Hovey, Richard and Robert Craig. "Understanding the Relational Aspects of Learning With, From and About the Other: If It Were Only that Easy!" *Nursing Philosophy*. (under review).
- Interprofessional Care. Government of Ontario, 2007. Web. 09 February 2010.
- O'Brien, Connie and John O'Brien. A Little Book About Person Centred Planning: Ways to Think About Personcentered Planning, Its Limitations, The Conditions for its Success. Toronto: Inclusion Press, 2002.
- Piercy, Marge. Woman on the Edge of Time. New York: Fawcett Crest, 1983.
- Stacey, Jackie. *Teratologies: A Cultural Study of Cancer*. New York: Routledge, 1997.
- Tamas, Sophie. "Writing and Righting Trauma: Troubling the Autoethnographic Voice." Forum Qualitative Sozialforschung/Forum: Qualitative Social Research 10 (1) Art. 22 (2008): 24 paragraphs. http://nbn-resolving.de/urn:nbn:de:0114-fqs0901220.
- Vasseleu, Cathryn. Textures of Light: Vision and Light in Irigaray, Levinas and Merleau-Ponty. New York: Routledge, 1998.