THE POETRY OF LIVED EXPERIENCE: A DISABILITY POETICS WORKSHOP THAT COLLABORATES WITH MEDICAL PRACTICE

Click here to go to the Workshop page @ HEALhealthcare.ca

INTRODUCTION

Hello there, my name is Shane Neilson. I am a mad/autistic poet and physician from New Brunswick with an interest in disability poetics.

I have encountered ableism repeatedly in my travels as both physician and patient. Something I've thought about a lot is how might we change the attitudes of health care practitioners around the ill? One way is didactic – to provide evidence around degrees of satisfaction and different outcomes amongst disabled folk. Another way is to have trainees meet disabled people and learn from their experience. Using the arts is another means to allow health care workers to imagine into disabled experience.

The purpose of this workshop, then, is to encourage medical practitioners to use arts-based methods so that the limits of understanding the lived experience of patients can be understood.

The workshop will take about an hour to complete.

I start you off with a video performance of a poem by Nisha Patel. Nisha's poem is followed by some questions designed to get you thinking. Then you will have two opportunities to write poems.

In conclusion, Patel will bring us home with another video performance. Both video performances are unique to this workshop, and I am very glad that Nisha collaborated with me.

Finally, my thanks to HARC.

Click here to watch this introduction.

This project is part of the Hearts-based Education and Anti-colonial Learning resource, an initiative of the Health Arts Research Centre, and funded in part by Indigenous Services Canada.

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National Collaborating Centre for Indigenous Health

HARC The Health Arts Research Centre

WORKSHOP

Please click here to view “When I Learned that I am Disabled” by Nisha Patel. For reasons of accessibility, a transcription of the poem is below. Please consider purchasing Patel’s ***Coconut*** from NeWest Press direct from the publisher, the link to do so is here. Nisha’s work is so exciting!

...I am writing about getting through five days
of paranoid anxiety. Getting through my brain
not working the way it is supposed to, did you
know that disability is a social construct? That
the majority define what it means to be able to
thrive, that lack is problematized only because
we want it to be a weakness. That in an accepting
society we are all a little disabled, but no one has
been told they are less. No one is left wanting
more. Equals, in law and morality, before god. In
a society where my brain doesn’t work the way
it’s supposed to and that’s okay, we’re all worth
our weight in good days. And my good days
are not worth less than your good days. That
you having more good days doesn’t make you
more good. Or deserving of more days. When
I Google VAMPIRES I am not looking for a
way to live forever. I am looking for a way to be
remembered for something more than my body.
If a diabetic is bitten at the neck and drained,
does her pancreas get immortalized too? What
about my serotonin receptors? Or my elevated
adrenaline? Does my heart still want to beat too
fast, or is it stuck not beating for anything at
all? When I Google COVID SYMPTOMS for
the 60th time in 400 days, I am not looking
for a reason to save myself. I am looking for a
way to save others from the pharmacy counters
that take too long, or the insurance paperwork
that asks too much, the pills you can split by
hand, or the big ones you swallow whole, I
am looking for ways to reassure myself that
there is hope. When I Google DISABILITY
the Government of Canada says: “Disability
Benefits includes disability pensions and
children’s benefits, savings plans and a gasoline
tax refund program.” And I guess that does not
sound so bad when it’s called a benefit. When
I learn I am disabled, I take insulin invented a
100 years ago in the same thighs I cut open at
16 under the fog of manic depression. I fight
the ache of my ovaries, the beast behind breasts
that bashes the gate of my ribcage, I fight the
rush of blood to my sides as beg to never
become a woman again, I say no to the birth
control pills because being fat is a liability. I
say yes to the IUD that renders me crippled for
two weeks, unable to move anything below my
pelvis. I say no to the SSRIs that try to kill me. I
say yes to the antipsychotics that try to stop me
from killing me. I go outside. Being disabled
means I am no longer a series of questions in
an emergency room, a misplaced picc line, or
an x-ray’d lung that proves the diagnosis wrong,
I know that knowing something is wrong is
better than knowing nothing at all, living in
anger or fear of sudden death, because people
like me die sometimes and no one cares, and I
am lucky that when I die I will notice, I will feel
a sigh of relief, I will know that I did my best
and if it wasn’t enough it isn’t my fault. That I
tried. That trying when your body fails is a gift
to yourself. I am not afraid to die. I am afraid of
who I might fail to be if I live in fear of death.
When I Google WAYS TO SAY I LOVE YOU
WITHOUT SAYING I LOVE YOU I know that
going to bed, and waking up, is one of them.

DISCUSSION QUESTIONS: (If you are alone, ask and answer these yourself. Take notes! They might help you later when you write your poems. If you are part of a group, then ask and answer the questions together):

1. **What are you struck by in this poem, either visually or in terms of the language? In terms of the narrated experience?**
2. **What kinds of barriers are faced by disabled people?**
3. **Is there a benefit to witnessing lived experience in a creative/performative, rather than biomedical, way?**

EXERCISE 1: Set a timer for ten minutes, but don't start it yet. First, read these instructions:

- **Write a poem about chronic illness or disability.**
- **Adopt the voice (or voices) from your experience with patients. Do not identify them in your piece. Just start writing.**
- **Your work can rhyme if you want, if you think it'll help; it can be in form, like a sonnet; free verse is good too.**

Okay, now start the timer! Go!

When you're done, and if you're part of a group, then share your work with one another! Remember, take care to ensure that the lived experience of the patient is respectfully discussed and remains unidentified during discussion. Point out the memorable parts of one another's poems. Mention how you felt when writing the work. If you are completing the workshop by yourself, then move on to the next exercise. Don't worry – you'll have your turn to put on your thinking cap.

EXERCISE 2: Set a timer for ten minutes, and like the previous exercise, don't start it yet. The instructions are:

- **Write a poem about chronic illness or disability that either is your own, that may be your own, or that involves someone close to you.**
- **Write as you wish, in any way you like.**

Okay, now start the timer! Go!

Ask yourself, or the group generally: **Did it feel somehow different, writing from this prompt as opposed to the one before? If yes, why do you think so?**

Some other questions to think through:

1. **What are some limitations in play when writing about the experiences of others?**
2. **Do you think these same limitations apply when offering care to disabled patients?**
3. **Does the special access to experience offered by the second prompt somehow offer what feels like more authentic work?**

CONCLUSION: As you consider how you might understand disabled experience better, if at all; as you reflect on how arts-based methods generally might get at the heart of what's essential in medical education; as you think, WOW, WHAT A GREAT WORKSHOP; but mostly, as you ponder how to improve caring for disabled people, please click here to view a final poem by Patel titled "Field Notes I and II."

Field Notes I, by Nisha Patel

University Wellness Services | Mental Health Centre

Date: March 4, 2013

Session number: 1

Client stated that she finds it very difficult to feel happy - she
feels like she is going through the motions in life.

Field Notes II, by Nisha Patel

University Wellness Services | Mental Health Centre

Client's Name: Nisha Patel

Client stated that she experiences regular and intense changes in mood client decribes
client notes client considers client consultanted client is on the wait list client strongly
feels she needs to be assessed and on medication client experiences intense suicidal
ideation client stated that there is little that holds her back client states client will

August 8th, 2013