



A REVIEW THROUGH DIALOGUE: RUTHANN KNECHEL JOHANSEN'S *LISTENING IN THE SILENCE, SEEING IN THE DARK: RECONSTRUCTING LIFE AFTER BRAIN INJURY*

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Abstract: As educators, we never know what stories our students may be carrying with them. This book holds insights and treasures for anyone who has been witness to or experienced the hard fight back from a near fatal trauma and the resulting loss of identity. As educators, researchers, and parents it is important to understand the difficult struggle of returning to life after suffering from a traumatic brain injury. This book is a beautiful and heart-wrenching testament to that struggle, and the ripple-effect through family, friends, and community when circumstance changes an individual's life in an

instant. Ruthann Knechel Johansen has opened up many spaces which allow for contemplation, examination, and ultimately a dialogue in response to her son's car accident and subsequent coma and traumatic brain injury.

Keywords: concussion; traumatic brain injury; poetic inquiry; life writing; arts-based research

Opening Spaces

When I first started to read Ruthann Knechel Johansen's (2002) *Listening in the Silence, Seeing in the Dark: Reconstructing Life after Brain Injury*, I was excited by the thought of engaging with a text I hoped would give me more insight into Traumatic Brain Injuries (TBI), and into my own process of healing from three Mild Traumatic Brain Injuries (MTBI). When I began to read the account of her son Erik's near fatal car accident, coma, TBI, and recovery, I was immediately pulled into her story. The book's introduction depicts the shattering circumstances she and her family faced not knowing if Erik would come out of his coma and, if he did, in what condition. Johansen refers to her son's second birth and while this is not a religious journey one realizes right away, that on some kind of spiritual level, it is a definite resurrection of sorts. Johansen repeatedly makes it clear that the journey through this second birth is not easy for anyone. She found herself in a "void or psychic-liminal space," totally unaware of how they were all to live through this reinvention of a life and self (Johansen, 2002, p. 2).

This book holds many insights and treasures for anyone who has been witness to or experienced the hard fight back from a near fatal trauma and the resulting loss of identity. As Leggo (2005) informs us, "I write autobiographically about experiences in order to understand who I am in relation to others, in order to understand my connection to communities and to the earth" (p. 115). Johansen's use of life writing has certainly done that and more. This book educated me as an academic and teacher, informed me as a survivor of an MTBI, and profoundly affected me as a parent, mother, and caregiver. I was cheering, crying, and ultimately listening to my own silence. Johansen's work is important not just as a piece that so aptly defines strength and courage in the face of loss and injury, but it is also a testimony to the human spirit and how deep the child-parent bonds run.

I often question what it means as a researcher to read and report on what I have read by other scholars. In responding to another person's book am I helping to inform others and myself of what still needs to be done? Am I looking for the "holes" in another's writing wherein I can fill the gaps? I question whether a work has enlightened me in some way, and what I could add to what has already been said. With Johansen's work I realize that in writing this review I would like to think that rather than looking for spaces that Johansen missed, I have found spaces that she has opened. I like to think that her willingness to be exposed and bare herself publicly to the bleakness of her family's initial circumstances and the voyage through it has made room for a dialogue to begin. While she has given me important material, it is only as good as what I choose to do with that information. In this case, I choose to share my response to the profound

portrayal of a family, thrown into turmoil on an ordinary Sunday afternoon, when their teenage son was trapped in the backseat of the car in which he was travelling and had to be extracted by the jaws of life, with my own poetry, my own lived experience. In this way, I reinforce the power of love, the power of togetherness and the power of community that Johansen repeatedly shows us is essential for getting through this kind of a situation and returning to life.

I hope in this call and response, the placing of her text next to my own writing, I will show how I was affected by her work. This is not intended to “upstage” the importance of her book, or the difficulty of her situation, but rather, to illustrate how exactly it is her work affects others. My intention is to co-create in this space something that at some point was lost for both of us - a sense of wonder. I will respond to her writing with my own poems, thus creating in this juxtaposition a written dialogue of sorts between author and reader, performer and audience, creator and witness. As Dobson (2012) tells us, “I maintain that poetry symbolizes the very breath and heartbeat of life” (p. 6). The power of this story has stayed with me long after I have closed the book.

At the beginning, Johansen’s description of her relationship with her son appears to be nothing out of the ordinary. We see a very common teenager/parent interaction while she tries to engage him with his homework. Johansen (2002) acknowledges that, “Scenes similar to this typically occur in homes where teens reside” (p. 5). When circumstances change quickly it becomes apparent that this was the way that she needed to start, a bit stilted at the beginning and common place, in order to juxtapose the ordinary against the horrific events that were coming. In doing this she is able to build a place of heart and compassion on the side of the reader, when suddenly this common relationship and family are thrown into a parent’s worst nightmare. Johansen (2002) says herself, “My whole being inwardly leapt to gather his motionless and silent form into my arms” (p. 10). As we accompany her on this journey we come to understand on a visceral level the connection between parent and child when suddenly faced with life and death.

A poem found in:

Listening in the Silence, Seeing in the Dark (Johansen, 2002);

and

What a Wonderful World (Thiele & Weiss, 1967).

What is it you see
as you listen in the silence?
I see trees of green
red roses too
Can you see them

do you smell them?
*I see them bloom
for me and you*
I hold onto them for you
until you wake up.
*and I think to myself
what a wonderful world.*
The light of connection
is all we have.

What is it you see
as you listen in the silence?
*I see skies of blue
and clouds of white*
the softness of your cheek
brings me some light
*the bright blessed day
and the dark sacred night*
moves me through
my own darkness
*and I think to myself
what a wonderful world*
to a place of strength
of always remembering you.

What is it you see
as you listen in the silence?
*The colours of the rainbow
so pretty in the sky*
listen to a world
steeped in colour
*are also on the faces
of people going by.*
streaks of people
reaching out to you
*I see friends shaking hands
saying how do you do?*
feel us here waiting
*What they're really saying
is I love you.*
A whole world

to receive you back.

What is it you see
as you listen in the silence?
*I hear babies cry
and I watch them grow*
let your father's lullabies,
hold you
*they'll learn much more
than I'll ever know.*
we watch for a flicker
your potential flame to return
*And I think to myself
what a wonderful world*
the joy of waking
know you are never alone.

What is it you see
as you listen in the silence?
And I think to myself
Can you hear us
what a wonderful world.
calling you back
And I think to myself
Can you hear us
what a wonderful world.

The journey of accident and injury is one that no one ever chooses to take. But if or when it does happen, each individual, each family member, each family, responds in a deeply personal and unique fashion. In Johansen's experience, the whole family: mother, father, and sister, came together in order to support Erik as he struggled through the painful loss of bodily function, emotional awareness, and understanding of self; while at the same time trying to deal with their own complex emotions. Navigating through medical systems, rehabilitation, and eventually school, this was a journey that needed many players at different levels in order to work. From the doctors and nurses when Erik first arrived in emergency, to the rehabilitation center to which he was later transferred, to the principal of the private school to which Erik was allowed to return, it was a whole community that was required in order to help Erik find his way back into the world. Johansen found that people reaching out, bringing their own advice and experience was a gift from which she could build her own understanding and take strength: "As I regularly told Eric about the visits and telephone calls we received and

described the outpouring of support and concern for him, I realize that I was creating a hammock made of human love and stories in which we were metaphorically holding him" (Johansen, 2002, p. 42).

Hammock of Human Love

as found in *Listening in the Silence, Seeing in the Dark*

When my son was two
we would swing in our yard for hours
in the blue and white hammock
the one I bought one Sunday
on a whim at Canadian Tire
while looking for a new broom.
Tied between two cherry trees
we hung like marionettes
our imaginations pulling our strings
in a million directions.
We could fly
between the cloud dragons
who breathed icicles instead of fire
or try to rescue tiny reindeer
stuck between chimney and tree tops
all the while homemade cherry popsicles
melting before we could lick them clean.

Some days we would fall asleep
as my stories drifted away
down the street on a breeze
to our neighbour's yard
or maybe a park.
At night in summer heat
stars streaked across a world
he was still too small to hold,
our laughter, silliness and tales
keeping us from bedtime.

These were the memories I held
when on a Christmas Eve
one year later, our son,
not yet three
was rushed to emergency

his tonsils the size of a tractor trailer
choking him.

While we waited for the doctor
to return his fragile body to us
I imagined the sky dragons
we created circling above
protecting him.

Later when I held him
trying to settle
the small wriggling frame
that was trying to outsmart
the pain of surgery,
I found the tales
that had tied us together
in summer
now brought him back to me.

In the morning bright
but weary we held
our Christmas gift close
as he opened his eyes
into a new adventure.

His breathing regular,
his heartbeat strong
he told us stories,
until we swung quietly
holding each other
in the hammock of our love.

While Johansen shows us what kind of dedication it takes not just for the patient, but all those involved; from the family to the healthcare professionals, the hours and even years involved in healing in order to recover from a TBI, she also clearly shows the deficits within a system that does not always work. Early on, while one doctor was informing the family of the severity of the injury and loss of function of parts of the brain, Johansen began to realize her helplessness in the situation: "Through them the doctor conveyed his authority and expertise as my own sense of powerlessness to aid my son increased hour by hour" (2002, p. 18).

While her son went through this in the 80's, and while there have been tremendous advances in the understanding and rehabilitation process for TBI, there are still huge gaps in patient care. Whether medical or rehabilitative, educational or institutional, without compassionate care from those who work in these areas, navigating the road forward can be difficult if not impossible. Without family support or strong advocates, patients sometimes get the minimum amount of care. As Johansen witnessed herself, patients could be left unattended for hours with no one to reach out to bring them back from a chasm of un-identity, that space between initial concussion and the gradual re-integration into a body that is able to function in some capacity in this world.

In her short article about critical care treatment after a life-threatening illness, Misak (2004) also found, in experiencing the transition from ICU to a general ward that, "The transition from having someone at your bedside 24 hours a day to someone checking you once in the night is unsettling, at the very least, and utterly frightening at the most" (p. 358). Misak goes on to suggest how a Critical Care Intervention team could help alleviate some of this stress, while Rocker, Cook, and Shemie (2006), recommend multidisciplinary teams to care specifically for TBI patients in order to improve both quality of care, and long term outcomes. Trying to work through a system that is torn between patient care and institutional finances, when life is hanging on the edge, is dependent on the medical expertise needed for survival.

The medical system has also come to realize how important the connection of patients with that of loved ones and their community is in order for them to advance past the initial precipice of despair and death. Life has changed since the time when doctors made house calls. Communities have shifted away from neighbours, churches, doctors, and teachers who knew you from birth to death. Instead, we go to walk-in clinics and hospitals that are understaffed. Johansen found they had to learn to navigate a system, to:

learn to read the signs, language, and ways of organizing medical knowledge. We had to construe meaning for medical information encoded in specialized jargon and cryptically hidden in case notes usually not available – or, if available, virtually undecipherable – to patients or their families. We had simultaneously to tolerate the depersonalization of our son and resist the routine that turned him into an object analyzed by medical professionals. (Johansen, 2002, p. 25)

Undecipherable

As found in *Listening in the Silence, Seeing in the Dark*

I will never sit in silence again
the world as I have known it gone,
my burgundy nails call me
to remember rich deep moments
but all I see are fingers,
flower stems turned outward
toward a sun
that hides behind different trees,
reaching limbs, searching
for warmth that eases pain.
I can't crawl out
from behind a continual buzzing
the vibration of my brain
rebellious against the pace I keep,
I rebellious against the life I didn't ask for,
life rebellious against a backdrop
that wasn't supposed to yet be staged.

I can never sit in silence again.
The paper bag I wear over my head
to hide the uncertainty
of being present
doesn't block out the road rage
I feel in my kitchen
or my laundry room
or hallway.
The clicks and creaks
of the house settling
into another cold winter
have become Trojan horses
ready to attack my head
as I try to escape
into a moment of calm.

I will never sit in silence again.
Instead the prayers
I never knew as a child
the ones I heard others speak

or repeat or drown in
or force down my throat
at the beginning of the school day
yell at me that God is laughing
in my face because I have become
a jokester, a trickster
trying to understand the destiny
laid out for me
while I walk backwards
into the living room of my dead ancestors.

I will never sit in silence again.
Instead I throw pebbles
onto a beach
listen to the splash
of bigger fish
chasing the rope pulling me
as I try to wiggle free
of the hold it has around my head,
I can't quite cut loose
of the thread
strangling me.
I go down again
relieved that the flash of water
takes away the pain
of not breathing

I will never sit in silence again.
I will wear black socks to bed
to keep down the noise
of feet scraping blankets,
keep the TV just loud enough
so that the mumbling voices
drown the drone
in my head.
I notice a drone following us
down this country road of a script
written before I arrived,
where I discovered
I didn't love you
because of the arrows

you were throwing at me
while I wasn't looking.
It is too painful to think now
that the silence hurts more
than my broken heart
and somewhere along this road
we were both lost.
I will never sit with you again in silence.

While Erik's road to recovery was filled with some fairly significant people (doctors, therapists, educators, and friends) it is the journey itself that becomes the crux of the book. With the loss of consciousness, language, and memory, the question that stands out from the book is what is it that actually defines who we are and gives us our sense of self? The juxtaposition of Erik at the beginning of the accident, in a coma unable to respond for himself, becoming more and more just a body being cared for and a file number on a page, and the person who eventually grows up to lead a full independent life, is profound. As we watch Erik first regain consciousness and reach out to his father, a poignant moment, we see that inside this broken shell there still remains an individual trying to be found. The problem is that the person who was in there is scattered at best, and everyone around him has to be introduced to this new way of his being in the world while the road back is extremely long.

Johansen takes us through Erik's recovery, or at least the most significant parts, step by step, which is important in understanding the length of time and the intensity of attention needed in order to help him progress. As Erik begins to walk and returns to life at home everything has changed. He has outbursts, uses inappropriate language, and fails to understand social cues that were once second nature to him. He cannot function academically anywhere near the level that he could before, but because of everyone's willingness to adapt in order to bring him home he is able to succeed. Eventually Erik is able to graduate with his class and is accepted into a college program. It is apparent through this story that the individual who was lost on so many levels, the soul that was housed in this body and had fallen into a kind of limbo becoming virtually invisible, could be found again. As we watch Erik come back from this edge we grow to understand what it is that makes and shapes who we are.

Hanging on the Edge

A lemming doesn't know
not to jump
only to follow
and when there is no

movement, he stands still.
But me,
I can't say I have yet learnt
when to stand still,
I have only learnt to climb
to hold my breath
and know it is ok
to reach out of bounds.

Long ago I imagined myself
a mountaineer of sorts
trying to touch heights
that I saw from so far away
the tops were barely visible,
yet I knew I could make it to the top
and as I went I gathered strength
as a whole community came along
to build a platform together on which to stand.

Now after too many head injuries
when I find that language
makes me stumble
and I can't seem to decipher
the directions I need to know
to find the way back down,
like the lemming
I am left hanging, waiting,
for some kind of movement
to begin.

The only difference between us
my determination to survive
keeps me from following the
next guys signal to run.

Johansen's epilogue is dedicated to Erik's critique of the book, which gives some very important insights into the experience of relaying someone else's story and forces Johansen to go back and look at what she is conveying, as opposed to what Erik was experiencing. Having read her manuscript, Erik begins to question if she still sees him as the scattered remains of his former self. He seems genuinely surprised and hurt by the fact that both his mother and father might not see him as a complete and recovered

being which is how he views himself. As she comes to understand what she has been holding onto, that being the son she felt she lost, she realizes that she stopped seeing Erik as a completely healed individual. He was not that shattered, scattered self anymore, even though he was different. "Apparently to Erik past and present former ability and altered ones were all one fabric," as he had gone on to create a new life, full of potential (p. 210). Johansen realizes that, "As I had continued writing watching closely, looking backward, Erik proceeded living forward, becoming author of a more important sort" (p. 210).

Johansen has given us a beautiful account of her family's journey through TBI. Beautiful, despite the tragic circumstances in which this happened, for her rich language speaks when her son cannot. She has opened herself up and shares the terror, the frustration, the joy, and complexity everyone in this family experienced. This book makes us think about what it is that is important to hold onto in life and how fleeting it all can be. In a moment the house can be gone, the body missing, the soul invisible. We must keep implementing change in order to make these transitions back to self easier for everyone involved. This book is for everyone, for we all are affected in some way as we do not live in isolation. I am happy to have had a moment in which to sit alongside Johansen and be witness to her struggle. This has been a moment to engage in dialogue with her text in order to find a better understanding of my own situation. I am grateful for the gift that has come from this work.

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