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How compassionate, whole-person care cured me of a life-threatening disease

24 July 2018

HEALING | THERAPEUTIC
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Galia Barhava-Monteith, shares the story of her personal healing journey and how she was inspired to begin a quest to find the secrets of truly compassionate, therapeutic



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# A shock diagnosis

At the end of 2010 my life took a very different turn to what I had expected. I was diagnosed with early Stage 3, Churg-Strauss Vasculitis (CSV); A rare, and potentially fatal, autoimmune disease. My treatment followed the best medical protocols I could have asked for and the illness' progress was halted – I avoided organ failure, but found myself in the category of a 'chronic patient'.

Although the disease progression was stopped, the illness was still there lurking in the dark shadows, and had the potential of raring its ugly head at any moment. I felt that my whole life had now been propelled down a completely unpredictable path. I had no way of processing it and what it meant for me, my family and for the rest of my life. My treating physician, a kind and caring man – recognised he didn't know how to help me process this. And so he sent me to see another medical doctor, one that treats the mind and the body and who, said my specialist, had had considerable success with patients with complex conditions like mine.

It isn't an overstatement to say that the Whole Person Treatment Approach (WPTA) transformed my experience with my illness. Within 2.5 years from the end of the chemotherapy I was medication free. I was able to live my life free not only of physical symptoms, but also free of the anxiety and uncertainty of having this unpredictable and potentially fatal condition.

#### How could this be?

As an agent of change in my professional life, I became curious. I became curious as to why this profoundly beneficial and also relatively in-expensive way of treating people is not incorporated as part of care for people with chronic conditions. So I decided to undertake a doctorate to help provide some insights, which may play

some part in shifting the conversation. I decided to contribute to the discussion by producing an academically robust, yet practical piece of research that could provide a line of sight into the WPTA experiences of other patients with different types of chronic conditions. I also felt that by doing a doctorate with well-respected academic health researchers as supervisors, I would be challenged on my own assumptions and beliefs about what happens in the WPTA patient experience, which would help produce a more insightful piece of work.

This has been the case. As a patient, I was intrigued and fascinated by the 'what' of the WPTA approach; the idea that my illness was meaningful in the context of my own life, and even symbolic of my life's story.

What I found was that, it was the 'how' of the experience that mattered most for the people I interviewed -the ways by which the WPTA clinicians established the therapeutic relationships. It was the relational dimensions of these interactions that were in-of-themselves experienced as therapeutic. For me personally, this is exciting because it means that ANY clinician, irrespective of their perspective on the connections between mind and body, can incorporate much of these subtle yet powerful ways of being, into their clinical practice.

In undertaking the qualitative analysis of 29 interviews, I utilised a questioning technic aimed at generating practical insights. The four themes I constructed, attempt to communicate the essence of this experience in a pragmatic and implementable manner.

# The journey towards healing

In my mind's eye I visualise these four themes as a journey towards a direction of travel – patients who are freed from the burden of their chronic conditions. The first theme: "seeing patients as persons and explicitly acknowledging their unique history" – is the first step on the journey. Patients want, and need to be acknowledged as people with complex and broad lives that are, often, fundamentally altered because of their chronic conditions or symptoms. Clinicians who are able and willing to do so, are experienced by the patient as humanising and, dare I say it, healing, from the very beginning.

The second theme, or the next step in the journey is concerned with clinicians' ability to come across not as rigid professionals who have all the answers, but as people in relationships who are in-tune with the person in-front of them. I called this theme "clinicians bringing their whole selves into the therapeutic encounter" because in the interviews, participants made it clear that for them to open up to clinicians, the clinicians themselves need to be more open and authentic. When clinicians were able to do so, the care they provided was experienced as person-centred. Participants described it as if the clinician treated them as 'peers in a way', as people who can contribute to their own care, and not as if the clinicians were the ones with all the answers that the patients just needed to obey and follow.

For patients to feel this way, clinicians did not need to undertake many hours of intensive relationship building work. Often, the things that seem to matter most to the participants happened quite quickly, and within the first encounter. It was how clinicians phrased their questions, their body language towards the patient and the subtle, yet profound micro-actions that made the patients' feel they were being seen and heard. This experience of truly being listened to and feeling cared for, was something participants discerned very quickly from the very beginning.

To that end I named the third theme "negotiating first encounters" where I unpicked how the subtle yet sophisticated listening practice was experienced. Within this theme I described ways of listening that underpin this experience. These are:

- The art of listening
- The heart of listening
- The act of listening
- The craft of listening
- Observing and acknowledging

Drawing on my career working in organisations, and coaching senior executives to help them bring about positive change – I know how scary it can be to fundamentality change thoughts and beliefs that underpin how we see the world and how we behave. Thoughtful, mindful and deliberate ways of carefully communicating while on this journey underpins the success or otherwise of such efforts.

This is why, for me these three themes all speak to behaviours and practices that can be undertaken by any and all clinicians who work with people with chronic conditions. Shifting their self-concept from passive patients, to people who can find a way forward for their lives.

This way of practicing, can, in my view, bring about change for how clinicians think about health and illness – and of their patients. I propose that when clinicians reorient their practice towards the whole person, and endeavour to listen attentively to the story the patient wants to tell, their beliefs about dualism, reductionism and the aetiology of illness will be challenged and even fundamentally changed. My research crystallised to me that powerful change can be brought about by doing first, and trying to understand 'what happened here?' later.

My fourth and final theme – or the end of the journey, addresses the change brought about through experiencing the WPTA specifically. It explicates the ways patients themselves experienced the altering of their own beliefs about their own illness as a consequence of this approach. I must reiterate here, that this was only possible after clinicians' established the mutual trust and respect with their patients.

"A door into understanding" is how participants described this experience. Their words spoke of having experienced a profound and transformative as well as educational process. They described how they had gained an understanding of the connections between their personal histories, emotional experiences, and even spiritual states and their physical symptoms and conditions.

They described seeing themselves, finally, as integrated. They detailed the power in being able to identify 'life' situations which contributed to flare-ups in their conditions and create strategies to avoid those. Be them Asthma, eczema, hives, chronic pain or any number of other conditions the participants had. They now felt as if their illnesses no longer dominated them and described how they were able to live their lives to the fullest. Participants told me how they gained a sense of freedom and of hope.

In a world where change is accelerating – and in healthcare AI and Robotics are already seen to be encroaching on the domains of the highly regarded medical specialist – diagnosis and surgery, the human aspect of care is what these changes can never replace. I believe these changes provide an urgent imperative to bring about a shift in *how* clinicians are trained and practice.

### To the future...

Bringing about these shifts in clinical practice can be done. It can be done through incorporating examination of the mind body duality which philosophically underpins modern medical and clinical practice into the formal education of clinicians. It can be done by insisting on systemic reflection of the power of relationship in the context of healthcare. It can be done by exposing more clinicians and health policy makers to these ways of practice and gently guiding them towards incorporating aspects of this practice into routine care approaches.

And what about me? I aim to speak and write to my research with as a broad an audience as possible. I also actively seek opportunities to professionally engage with the medical and health community in helping bring about a change both on a one-to-one level working with clinicians, as well as on a systemic level working with managers and health policy makers. After concluding nearly four years of research, I see this way of practice as having the potential to transform not only the lives of patients, but of clinicians as well.

### Galia Barhava-Monteith

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6 Responses to "How compassionate, whole-person care cured me of a life-threatening disease"

# Peta Joyce says:

July 25, 2018 at 3:36 pm

Bravo Galia! I love the way you transformed your personal experience into a very important piece of research, and simplified the 'magic' of a healing client/physician relationship down to a few simple principles essentially about being human.

### Galia says:

July 26, 2018 at 5:17 pm

Thank you Peta – My intent was to produce a scholarly work with the capacity to influence practice. All ideas on how to best achieve that are really welcome!

#### Claire says:

July 24, 2018 at 9:22 pm

Hi, is it possible to have a link to the primary research/thesis in this write up please? Looks excellent and useful for my research work.

Thanks,

Claire

# **Robin** says:

July 24, 2018 at 9:26 pm

The author's email address is at the beginning of the article

#### Barbara says:

July 24, 2018 at 7:42 pm

Dear Galia,

I'm an MD from Ljubljana, Slovenia, in the process of writing up my PhD in medical anthropology "Understandings of healing in biomedicine – reflections of physicians-teachers" (qualitative research, interviews with clinicians + (auto)etnoghraphy). I feel we share some experiences and a lot of passion and dedication to the subject. I would love to dialogue with you, to learn more about your work and projects, please let me know if we could do it over skype sometime in August.

Wishing you all the best Barbara

## **Robin** says:

July 24, 2018 at 8:01 pm

Barbara, we have forwarded your message to Galia. If you want to connect directly, her email address is at the beginning of the article  $\ensuremath{\mathfrak{C}}$ 

"When all members of an organization are motivated to understand and value the most favourable features of its culture, it can make rapid improvements."

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