Sample chapter

Excerpts from

Why We Revolt

A patient revolution for careful and kind care

Victor Montori
This sample chapter of ‘Why We Revolt’ is taken from Victor’s original book, first published in 2017 by The Patient Revolution, Rochester, Minnesota, USA.


Copyright @ 2020 by Victor Montori

Distributed by Kaleidoscope Health and Care, London, UK.

hello@kscopehealth.org.uk

Contents

Hello. Why are you reading this?

Revolt

Cruelty

Reactions:

Charlotte Augst
Suzette Woodward
Nish Manek
Alf Collins and Martin Marshall
This is a book about why we should put care back into healthcare. It’s a reminder that we have to notice how care is given in order to make it better.

Our mission at Kaleidoscope is to work with others to build a future which is kind, connected and joyful. We couldn’t be more proud to be working with Victor to do so.

If you would like to know more about what else Kaleidoscope does, we’d love to hear from you.

In the meantime, enjoy the book. And let it bring hope, elegance, and revolution to where you are.

Rich Taunt and Ted Adams
Kaleidoscope Health and Care
@kscopehealth
"Caring is not meant to be efficient, it is meant to be elegant."

Revolt

Orwell proposed that one must write, among other reasons, to “see things as they are, to find out true facts and store them up for the use of posterity.” This book arises from my need to do just that. And what I see is that healthcare has corrupted its mission, it has stopped caring, and I am not going along with it.

It is time for a patient revolution to bring about careful and kind patient care for all.

If someone gave you this book, they were probably hoping to advance such a revolution. I hope you can do the same.

Keep this copy, get the full book, and give it to someone else.

Thank you, and take care.

V
Cruelty

It was late at the premier teaching hospital in the country, and we were overworked and overwhelmed. Those patients in most trouble had made it in, but many waited outside, a domino line from the threshold of the emergency room to the edge of the hospital. Those inside were on stretchers in the treatment areas. They were in the hallway, on chairs, or on the floor. It was the era of hyperinflation and terror in Lima, Perú. I was one year away from graduating from medical school.

A corpulent and inebriated man came in with a large scalp laceration. One of my colleagues began to clean the wound. She misjudged that he would not need local anesthesia. He responded abruptly and violently, taking a bottle with some coloured antiseptic solution and hurling it at her head, missing narrowly. Her scream and the red vitreous splash everywhere acted as the Bat-signal. Other doctors in training came rushing to her treatment bay. They first tried to restrain him. Soon, the gang in white coats was holding him down and beating him up. When it was over, the man had the original laceration and the swollen, bruised, and cut face the class of 1995 gave him.

What that patient received in punches, we delivered verbally to anyone who complained and whom we chose not to ignore. This was our emergency room, and these people, the patients, were here to bother us, to interrupt us, to make our day more difficult. We dehumanised the “laceration,” the “foreign body,” or the “appendix” without seeing the destitute and illiterate patients behind those labels. These subhumans were not only unfortunate and fortuneless but, in our eyes, were also careless, irresponsible, and stupid.
Like a potent drug, equal parts efficacy and bitter pill, our emergency room could save a life while demeaning it.

Decades of psychological and sociological research explain the behavior of this white-coated mob. But what about the hospital rounds led by senior clinicians? A student six years my senior wrote a graduation thesis in which he noted that these rounds, when at the patient’s bedside, almost never acknowledged the patient’s existence: no greeting, small talk, explanations, nor elicitation of worries. Perhaps a question, but its purpose was to solve the diagnostic puzzle. Perhaps an exam, but it was to detect a sign. The patient as object, the subject barely noticed.

Yet, no one told us we, the trainees, were lacking in care. We ran a complex system of redistribution by which we asked more affluent patients to bring extra supplies that we would store and use to help poorer ones. We would use one patient’s social assistance card to get free supplies for another who narrowly failed to meet the program’s requirements. Thanks to this work, patients received tests, treatments, and operations; they got better and went home; and we received recognition. Perhaps we cared, but frankly, most of our work was completed to impress our senior residents and attending physicians with our resourcefulness and efficiency.

Occasionally, this churning would be interrupted. Mostly at night, when the hospital was quiet and slow. A sudden frameshift. An abrupt double take. The clinician suddenly noticing the person in the patient. A chair pulled. A chat.

Lines thrown from one boat to another. Permission to board.

“Who came to visit you today? Who is in that picture at your bedside?”
For an instant, the boats approached, abutted, and their wakes kissed.

Soon, they must diverge, drift, and sail away.

The clinician stands up as a new admission, a “pneumonia”, rolls in.

Cruelty seems to require that we, as clinicians, dehumanise patients, consider them not like us, not our kin. That we treat their suffering and dependent selves as a subspecies, as an extreme form of “them” with nothing in common with our humanity. Nothing in their name, their appearance, or their circumstance is able to bridge their distance from us. They are beds, diagnoses, samples, case numbers, or statistics. The expression in their eyes, the warmth of their heart despite their impossible circumstances, and the picture she keeps by her bedside of her granddaughter in a faraway city are all desperate gestures reaching for the reset button to make one human notice another.

Cruelty requires policies and procedures that discourage people, even the kindest, from noticing. One set of such policies defines jobs very narrowly. I get paid to do this, not to worry about the design limitations of a system in which I am no more than a replaceable part, a part that will be replaced if I don’t do what I am expected to do. I am just following orders. Policies that retain professionals who become uninterested in the concrete downstream consequences of their actions on individual people, and thus behave unprofessionally.

Cruel policies affect how the work is done. Impossibly busy appointment schedules and heavy patient loads force clinicians, even the kindest, to see patients as a blur, noticing nothing particular about any of them. Policies that place vast distance between the
administration and the hospital ward, between the receptionist and the bedside, between the decision-maker and the petitioner. This is a distance from which Ana, Jose, and Susan cannot be distinguished from each other or from other patients, all of them solidly “them.”

The clinician leans forward, unhurried.

Lines thrown, closer.

His eyes instantaneously sign a one-clause contract: “We are here now, for you and your care only.”

He questions and gets answers. They make answers.

Boats moored together. Permission to board.

Unhurried touch. Examined. Reassured.

With cruelty always a possibility, for a moment, care happens.

The “pneumonia” that rolled in? That is Ms. Seminario. The picture used as wallpaper on her smartphone? That is of her oldest daughter, Carmen. Ms. Seminario is afraid, short of breath, alone. She dreams of getting better so she can resume her life and embark on an often-postponed new quest. She is getting better for her children.

The clinician leans forward, unhurried.
A reaction

Charlotte Augst

What strikes me upon reading Victor’s work is that, at its heart, it is a call to listen: to listen to those who are in pain, afraid, struggling with ill health and its treatments. It has proved hard to foster this culture of listening, of respect and partnership, in health and care.

National Voices is small – what can our contribution be? How can we make it easier for those who decide how health services work to listen to the experiences, wisdom and aspirations of those who use and need services? Or maybe: how can we make it harder to ignore this perspective?

This is the call to action I am hearing and responding to: strengthen National Voices’ ability to speak confidently and authoritatively about what people living with ill health know and want. Take the insight and aspirations of citizens and patients into decision-making rooms. Start and conclude all our involvement with the question: what’s it like for those who need care? Is the change we are talking about going to make a difference to what people tell us isn’t working? How will we know?

We have great access to the people who try to reform health and care. And we are the centre of a network that directly supports and advocates for people living with ill health. We are ideally placed to be the hearing aid the system needs to listen better. Let this revolt be a listening one.

Charlotte Augst (@CharlotteAugst)
Chief Executive, National Voices
A reaction

Suzette Woodward

I read Victor’s book with profound sadness because I recognised it and I recognised myself within it. It is a beautifully crafted book that draws you in page by page.

The sadness is matched though with hope. The hope that caring for each other really matters and it is possible. I had the pleasure of watching an unhurried consultation between a relative and a competent, careful and kind clinician. He took the time to really understand what mattered and talk through at length the different options. He listened, he heard and he advised but most of all he cared. There is a mass of evidence to show that compassion, kindness, joy, gratitude and caring matters.

Victor calls for a revolution and conversations to spread that revolution – in his words “we can decide that we want a different future and act to achieve that future.” I love the saying ‘Plant trees you will never see’ – for Victor this is building cathedrals that may take generations to complete.

All it takes is for us all to open our hearts and minds and act so that we can all be good ancestors and echo beyond our time.

Suzette Woodward (@suzettewoodward)
A reaction

Nish Manek

“...the patients were here to bother us, to interrupt us, to make our day more difficult.”

I want to say I’ve never identified with the sentiment above. But I’d be lying.

My first reaction to Victor’s writing was one of guilt. I started my career seeing patients ‘in high definition’, aspiring to deliver the elegant care that he describes. But the truth is, on a difficult day in general practice, his call to deepen and decelerate care feels impossible. What happened along the way?

Victor’s stories, told in a beautifully lyrical way, raised so many questions. How can we consistently create space to deliver kindness in healthcare, instead of it being a luxury?

How can we preserve continuity in general practice, so that we don’t erode the opportunity to learn more about the person behind the patient?

But alongside the guilt, there was hope.

This book serves as a powerful reminder to clinicians. A reminder of why we went into healthcare, of the privilege it is to be stewards of our system, and of the power of role modelling kind, careful, and elegant healthcare.

Read it, absorb it, and let’s think about what we can all do, person to person, to kickstart a revolution.

Dr Nish Manek (@nishmanek)
GP trainee, Cambridge
A reaction

Alf Collins and Martin Marshall

Kind, thoughtful, compassionate, honest, unhurried, elegant. Mull over those words for a while, let them tumble through your mind for a few moments. Now, how do you feel? Now, how about these words: performance, data, targets, workforce crisis, waiting times...?

Social scientists talk about framing - the way in which groups with common interests and aims describe and communicate reality. But much more than that - framing is the way those groups of people perceive reality - the way things really are.

For all the right reasons, we have put processes, systems and structures in place to commission, provide and regulate healthcare but in doing so, our lexicon has changed. Arguably, our language has shifted from a focus on healthcare as a mission towards healthcare as an industry.

Victor Montori recognises this and has written a bold, thought-provoking book that should be a call to action for all of us. Victor warns that our healthcare lexicon has shifted and so too has our reality. Healthcare has become industrialised and the danger is that compassionate, elegant, kind and unhurried care is being squeezed out in the process. The greatest impediment to high quality care in the NHS is the lack of time in the consultation.

Many have argued that if we want to progress healthcare, we can only learn so much from industry. No-one has argued this as convincingly as Victor. We urge you to take the words in this book and make them part of your language. And in doing so, your reality.

Alf Collins (@alf_collins)
Clinical Director, Personalised Care, NHS England and NHS Improvement

Martin Marshall (@MarshallProf)
Chair, Royal College of General Practitioners
What’s your reaction to the stories in this book? What resonates with your own story?

PatientRevolution.org

Stories can inform, infect, irritate, and ignite a chain reaction that makes the status quo unsustainable.

Stories are the first step in a push for healthcare that is careful and kind to each patient and community.

Our mission is to arm people to tell their stories and help them tell those stories in consultations and hospital beds, in their communities, and in the rooms where leaders decide policies.

Join us.

At our website (PatientRevolution.org), we offer tools to help you tell your stories and change industrial healthcare toward careful and kind care for all.

As you read this book, you may want to share your own stories with me.

Do so.

Send me your stories:

victor@patientrevolution.org
Victor Montori, MD, MSc (Lima, 1970) is a professor of medicine, a highly cited researcher, and a diabetes doctor at the Mayo Clinic, USA. To share your stories or send Victor a note: victor@patientrevolution.org

Victor wrote Why We Revolt as a series of personal essays to describe what is wrong with ‘industrialised healthcare’, how it has corrupted its mission, and how it has stopped caring.

Victor founded The Patient Revolution, a non-profit organisation, to translate the book’s ideas into action. To join and contribute to The Patient Revolution: patientrevolution.org

This book contains excerpts from the full book. It is published by Kaleidoscope Health and Care, a social enterprise with a mission to work with others to build a future which is kind, connected and joyful. To find out more: kscopehealth.org.uk