

Courage, Cancer and COVID

Carol Kerrigan Moore, MS

Although the world is full of suffering, it is also full of the overcoming of it.” -Helen Keller

So here we are, in the midst of the most accelerated, far reaching pandemic of my lifetime, COVID-19. A global public health crisis, and a time of collective anxiety for a whole assortment of different reasons. At the time of this writing, the SARS CoV-2 virus has resulted in nearly 7 million confirmed infections and 400,225 deaths worldwide. US fatalities passed the 100,000 mark in May, 2020, while laboratory confirmed total cases numbered 1,891,690 as of June 6, 2020.¹ The US death toll remains the highest in the world. And here in Delaware, we have a reported 9,845 confirmed cases and 390 deaths.² Each one of these “cases,” each one of these deaths, was a person, not just a number.

This latest crisis comes on the heels of my own two year tumble into Cancerland. Like Alice in Wonderland’s trip down the rabbit hole. Or Dorothy’s journey from Kansas to Oz. Unfamiliar places accompanied by fear of the unknown, uncertain treatments, unexpected complications, life altering side effects, and a host of unanticipated life changes.

And just when things were getting back to “normal,” following my own expedition into Cancerland, the novel coronavirus arrived.

I read an article recently that talked about cancer patients now facing COVID-19 – and how a cancer diagnosis is a solitary experience of grief, at least at first – as opposed to the collective experience of a worldwide pandemic.

It’s like the whole world just got cancer...

I am worried, but not for myself, despite my potential status as an at-risk individual. I have concern for the world, and for those who have and will experience the worst this virus has to offer, and I feel for all those experiencing the significant sacrifices that are being made to try to “flatten the curve” to avoid overwhelming our health systems with more patients than there are beds and staff to take care of those affected.

I am concerned about those who are following directives to “shelter at home” while self-monitoring their worrisome symptoms, or waiting for COVID test results. This is a patient population that can be categorized as at-risk, since we know that respiratory status can decline insidiously and precipitously – without the usual warning signs – in patients who have the virus. I am currently sheltered from the direct impact of seeing the suffering first hand since I am no longer working in the health system and witnessing what is happening to the sickest patients inside those hospital walls. But I have seen the profound effects of previously undiagnosed COVID-19 outside the hospital setting, when I witnessed a person who was actively engaged in exercise and talking normally go into severe respiratory distress in seconds, requiring emergent care and hospital transport.

I understand the varying degrees of anxiety that health professionals and patients and the entire population may be experiencing. The fear of the unknown, and the lack of a clear roadmap to recovery, coupled with less than optimal resources, collectively exacerbate the challenges of treating a virus that we still do not fully understand. Testing availability in the US lagged at the

outset in comparison to many other countries, hampering our initial ability to assess who and where the outbreaks were highest. Due to the limited availability, tests were used only if patients met specific key criteria. The US response to the pandemic became a patchwork quilt of each state attempting to assess the problem, plan, and compete for scarce resources.

COVID-19 upended health care delivery and life as we know it. Sudden, massive, reactive change. With the resulting grief reactions. The necessary “stay at home” strategy and cancellation of elective procedures and messaging about COVID had the unintended consequences of delaying other needed care as people became fearful of going to practices or hospitals for other urgent or emergent needs. Cancer care is just one area that has been deeply affected by delays, and/or other changes in treatment plans necessitated by the pandemic response.

But a cancer diagnosis offers its own adventures into confronting one’s mortality, and that, for me at least, paved the way for a different perspective when faced with another (albeit worldwide) crisis. I am not living in fear. I am living in hope.

Hope that as in all crises, the helpers continue to emerge. Hope that our collective scientific wisdom and humane determination prevails. Hope that we leverage the learning from the first waves of this pandemic to foster innovations to overcome the many barriers to keeping infected patients and their caregivers and community members safe. Hope that more accessible testing, better turnaround times for results, and more effective medications and treatments will be available to help in the next waves of illness. Hope that an elevated focus on the most vulnerable populations stays at the forefront of planning and action. Hope that a safe, effective vaccine becomes a reality. Hope that the tremendous economic impact and polarizing turmoil will lessen over time.

And, hope that, in the midst of it all, we are reminded of the truly important things in life.

Each other.

We will move through the grief and loss of life, and of life as we knew it, together.

Don Berwick, MD, a founding member of the Institute for Healthcare Improvement, and President Emeritus, has a famous saying: “*Hope is not a plan.*”

Fortunately, we each have an unusual personal opportunity to turn hope into action in this crisis.

We can follow and stay abreast of the recommended precautions, and help our family members and friends follow them too. We can wear masks, to protect each other from asymptomatic or pre-symptomatic spread in the community. We can practice physical distancing. We can empathize with and support those on the front lines who are testing and treating and caring for patients, with the attendant fatigue and distress that occurs due to the unending demands of an infectious disease that has spread fast enough and far enough to be a pandemic. We can be sensitive to those who have been unable to work from home due to the essential “in person” nature of their jobs, and those whose workplaces have experienced significant interruptions and, for some, closures. We can advocate for the proper equipment and resources, and work with or donate to organizations supporting marginalized and underserved individuals. We can check on friends and family and our neighbors.

As a state, we can continue to *identify* our most vulnerable populations, and *use* that knowledge to guide our efforts to address the ongoing health disparities and inequities that have been

magnified in this crisis. Leaders need to fully identify and engage early and often with key stakeholders during planning processes to proactively identify and resolve potential barriers, and engage in shared decision-making when implementing change.

We can all listen, and fully acknowledge the social injustices that have been brought to the forefront on the backdrop of this pandemic, with their own longstanding impacts on public health. We can be agents of change. We can ACT. We can help.

I am grateful to be a sounding board for my former colleagues and friends and family members as they face unprecedented change amidst the other inevitable challenges. These challenges include the collateral damage of families often not being able to be present with their hospitalized loved ones or residents of assisted living, long term care facilities, and hospices, even when they are dying. Residents of all types of communal living facilities have endured months of limited social interaction with fellow residents, family and friends—losing precious time with their loved ones, time that can never be recovered.

And for months, we have lost the ability to gather together in person to mourn the many losses we are enduring...or to celebrate the major milestones in life—graduations, weddings, new babies...and the little things, like sharing a hug and an evening with friends.

Everything that I have learned (often the hard way) about facing and allowing and processing the emotions and challenges that a cancer diagnosis brings, has ironically helped to prepare me for what we are now collectively facing. This novel virus has, in its own way, demonstrated with brutal clarity how interconnected we all really are: locally, nationally, and globally.

So I'm letting go of what I cannot control, and spending time writing, researching, listening, and problem solving with friends locally and across the globe. I'm practicing self-care. I'm witnessing unprecedented levels of teamwork here in Delaware as public health officials and staff, policy makers, community members, health professionals, and concerned citizens work together to save lives. And I'm filled with gratitude that I'm still here to be able to do all of these things.

"The power we discover inside ourselves as we survive a life-threatening experience can be utilized equally well outside of crisis, too. I am, in every moment, capable of mustering the strength to survive again--or of tapping that strength in other good, productive, healthy ways." -Michele Rosenthal

"In every crisis, doubt or confusion, take the higher path - the path of compassion, courage, understanding and love." -Amit Ray

References

1. Centers for Disease Control and Prevention. (2020). Coronavirus Disease 2019 (COVID-19). Retrieved from: <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html>
2. Delaware.gov. (2020). Delaware's Response to Coronavirus Disease (COVID-19). Retrieved from: <https://coronavirus.delaware.gov/>

This is an Open Access article distributed under the terms of the Creative Commons Attribution Non-Commercial License (<https://creativecommons.org/licenses/by-nc-nd/4.0/>) which permits unrestricted non-commercial use, distribution, and reproduction in any medium, provided the original work is properly cited.