

The Person Within the Mask: Mask-Wearing, Identity, and Communication

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ABSTRACT

This autoethnographic exploration examines my seven-month experience wearing a mask after a stem cell transplant, October, 2019. The telling of my story includes the cancer-based context in which I began to wear a mask and a concentration on the interactions, behaviors, and happenings that occurred to me while mask-wearing. Although I make note of experiences during the COVID-19 crisis, most of the happenings from which I draw occurred pre-COVID. The focus of my reflections throughout the essay is given to identity de/reconstruction through the emotional experience that has in many ways defined my mask-wearing journey. Central ideas that are encountered throughout my story are victim/patient syndrome, isolation, dehumanization, disability bias, monitoring fatigue, sanctuary, and intimacy.

KEYWORDS: Cancer, COVID, Dehumanization, Identity, Isolation, Masks.

“Love takes off masks that we fear we cannot live without, and know we cannot live within.” – James Baldwin (1963)

The doctor leaned against the hospital room cabinet, half standing, half sitting. She looked directly at me as she said, “The results from the bone marrow biopsy indicate acute myeloid leukemia.” My gut response: “Impossible. I’m not the kind of person who gets cancer.”

Thus, began a year-long (at this writing) journey of identity deconstruction and reconstruction. The focus of this essay explores one aspect of my identity trek – wearing a mask. Wearing a mask became a new way of life after being diagnosed with acute myeloid leukemia (aml), July 2019, and receiving stem cells from a generous German donor in late October of that same year. With an eradicated immune system, my recovery (which I’m still in) demanded protection from people, animals, plants, dirt, and my own self. I knew that wearing a mask would present numerous logistical challenges, for instance, basic communication with others became more challenging. What I didn’t expect were the internal changes, in me. Whereas my public persona was constricted by wearing a mask, mask wearing also stimulated internal adaptations of my personal identity. The mask itself became a symbol of my identity journey. A constant physical reminder – all is not well. A periodic psychological reminder – I am not normal.

A unique aspect of this last years’ experience is the fact that the first three months of wearing a mask in public occurred before the coronavirus outbreak. During that time, I was simply a social anomaly. Since the outbreak, my donning of the mask has been within a culture where mask wearing is normative, though a hotly contested issue for some.

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In the following pages I use autoethnography to explore my mask-wearing identity trek. I begin by describing the context within which this journey took place, then identify specific behaviors and events that happened during this time, followed by extensive description and discussion of my inner experience. To this end, Ellis (1991) provides the following exhortation, applicable to all social scientists:

Sociologists can and should study how private and social experience are fused in felt emotions. Resurrecting introspection (conscious awareness of awareness or self-examination) as a systematic sociological technique will allow sociologists to examine emotion as a product of the individual processing of meaning as well as socially shared cognitions. (p. 23)

My Autoethnographic Approach

Autoethnography is a means of accessing and processing data from a most challenging context – the self. To this end, Tracey (2013) described autoethnography as, “the systematic study, analysis, and narrative description of one’s own experiences, interactions, culture, and identity” (p. 30). Over a three-month period, I took notes and sketched ideas about current events and past experiences regarding my identity journey wearing a mask. My notes tended to be somewhat brief, some written immediately after a particular experience, others only jotted down when someone or something jogged my memory. Ellis (1999) reminds us that all stories are partial and, as she so eloquently puts it,

Writing notes at the time the experience occurred would have been helpful but not absolutely necessary. If you’re writing about an epiphany, which you usually are in this kind of research, you may be too caught up in living it to write about it. (p. 674)

To tell and understand my story, I have drawn from a couple of different autoethnographic approaches. The first approach is more analytic, focusing on analysis and theoretical abstraction, with me as researcher operating more as critic or story analyst (Anderson, 2006; Bochner & Ellis, 2016; Tracy, 2013). When taking this approach, I’ve experienced a sense of distance between the person who lived the story (me) and that same person who is now analyzing the story (also, me). Analytic aspects of the present analysis form the two central sections of this essay. Early on in this process, I began separating my notes into two categories: one focused on behavior (my own or others’) and happenings; the other centered on my internal experience wearing a mask that was not always tied directly to one specific event.

The second approach I’ve integrated into this telling of my story uses systematic introspection in conjunction with, “the evocative, creative, and artistic elements and forms of storytelling” (Bochner & Ellis, 2016, p. 67). This approach is intended to evoke a response in the reader, and the storytelling itself becomes a means of discovery as the researcher/storyteller makes unanticipated discoveries in the process of constructing the narrative.

Evocative elements of this project emerge through *how* I tell my story and, more specifically, by providing access to my own emotional experience and struggle as I have deconstructed and reconstructed aspects of my identity. To this end, I have made every attempt to be open and authentic in my storytelling, and I have chosen often to use desert imagery to describe my experience since many happenings occurred while hiking in the Phoenix Mountains Preserve.

I've also chosen to tell my story using anecdotes that represent my masked experience, rather than providing a chronological report of masked events. As Jane Goodall recently stated, "...anecdotes are sometimes the key to unlocking a puzzle. They're terribly important" (Tippett, 2020).

Regarding the authenticity of my reported emotional experience, I've worked closely with my wife, Ann, in this storytelling. My tendency to minimize the negative is balanced by her keen memory and, at times, lasting visceral response to both positive and negative elements in the past. Additionally, my long-time friend, Ted, and I have had extended conversations about the concepts presented in this manuscript. Somewhat remarkably, I accompanied Ted through his own stem cell transplant for *aml*, just three months before I was diagnosed with the same, and he has been with me every step of the way of my own identity trek. His insights regarding my story, as told here, have been essential to my personal reflection. As Ellis (1999) reminds us, involving others who share a part in the story can be useful as one (re)creates one's own narrative.

A defining aspect of autoethnography is that the writing itself is a means of discovery (Bochner & Ellis, 2016). To explicitly acknowledge this process, I periodically pause the narrative for sections entitled: *Reflecting as I write*. In these spaces I report certain insights gained through the process of storytelling, itself. I also include the word, *Selah*, at the end of each section of storytelling. *Selah* is a word used in the Hebrew scriptures, particularly the Book of Psalms, which means *pause*. It is intended for emphasis and reflection. I use *Selah* to encourage emphasis and reflection on what we've just experienced together, and to create anticipation for what is yet to come. Williams (2003) reminds us that, "Every act of imaginative creation, in science as well as art, needs silence, a wariness about what looks easy" (p. 69).

Reflecting as I write:

I hiked today after finishing the first complete draft of this manuscript. As I ascended Shaw Butte, a 750-foot climb from our house, my mind was working over the manuscript like an eight-year-old deftly manipulating a jawbreaker side to side in his mouth. I was hiking at 11:30 in the morning in low 90-degree temperatures in order to avoid other people. As I entered the main trail from a spur that originates in our neighborhood, a man and a woman were huffing and puffing, trudging toward me. I decided to pull over, get a drink of water and let them pass. As I continued my hike I stayed 35-50 yards behind the couple in order not to be exposed to their breath stream. To maintain this distance between us I had to stop a couple of times to give these two hikers the chance to get farther ahead. In addition, I frequently put on my mask when I closed the gap between us or when we were in areas of the trail where the breeze died down (in my vivid imagination, stagnant air with COVID-19 droplets and aerosol slowly drifting toward me). When I reached the pinnacle of our mountain, I looked back over the trail from which we had come – there was no one there. If I had given this couple five more minutes to get farther ahead of me I could have hiked mask free almost all the way up. Taking time to pause (Selah) could have provided perspective as to where I had been and where I was about to travel. In the same way, I've come to realize that this essay represents the first time, since my diagnosis, that I've really paused to consider much of what I've experienced over the last eleven months. It has become an act of self-care and love that, through iteration after iteration after iteration, is providing perspective on my journey.

Beginning My Identity Trek: I Am Victim. I Am Patient

June, 2019, was a tough month. After finishing an exhilarating eight-day river rafting trip down the Grand Canyon, Ann and I found ourselves physically and mentally spent. She ended up with a respiratory infection that kept her down for three weeks. I attributed my own fatigue to caring for Ann, fighting off whatever she was infected with, and the stress of finishing a book manuscript on intimacy (Kelley, 2021). Mid-June I began taking ibuprofen to manage some achiness and help with my increasing exhaustion. These were symptoms I had experienced twenty-five years before when I contracted an autoimmune disorder – Still's Disease. Though I had been Still's-free for twenty years, I was still wary of my body's response when under pressure (a trigger for many autoimmune sufferers) and was sure that once I got a few projects off my plate and could relax that I would be okay. In spite of my rather easy-going, light-hearted public persona, I've never been good at handling stress. I am wound pretty tightly inside.

Reflecting as I write:

Looking at the previous sentence, I realize that wound represents both the past tense of "to wind," and the present tense of "to injure or hurt." As such, a rewording of this sentence is equally true – I am wounded pretty tightly inside.

In early July, Ann and I were finally getting the break we needed. We had begun a West Coast road trip to be filled with family, friends, wine tasting, and hiking. The trip would culminate in scenic Aspen, Colorado for a three-day conference. The perfect prescription for relieving my symptoms.

As we headed out to California I began increasing the amount of ibuprofen I was taking, but was still convinced that as I relaxed on our trip my body would recalibrate and I would soon be substituting good wine in Paso Robles for over-the-counter medication. Once in Paso, we were enjoying the company of Ann's cousin and her husband and I was relaxing, but my symptoms were intensifying. It appeared that even a good bottle, such as *Jubilado* from the Barr Estate Winery, couldn't halt the progression of what I was still convinced was my old autoimmune nemesis. Two days later, as we headed north to the coast of Oregon, I began taking acetaminophen to supplement the ibuprofen. True to my experience twenty-five years earlier, I was now having low to moderate fevers. On our second day up the Oregon coast, Ann took over the driving. This never happens. I drive, Ann navigates. That's the way we like it. So, this was a bit of a blow to me. I now sat passively medicated until we arrived at our friends' condo in Depoe Bay.

The Oregon coastline was stunning, but I was not doing well. We finally sought help from my doctor in Phoenix and he told me to go to urgent care. We did so, and I ended up being evaluated in the ER of a local hospital. My blood counts were so bad that they wanted to admit me, immediately, to a hospital in Portland. Thankfully, the ER doc had compassion on our situation and prescribed meds that would allow us to drive home in three days to see my own doctor at the Mayo Clinic. We left the ER with the doctor's words ringing in our ears: "You must make an appointment with your doctor before leaving the ER. Doug is not allowed to drive. You can't have an accident because Doug's blood can't clot. If you do run into trouble, you must tell the paramedics that Doug is immunosuppressed. If he begins to spontaneously bleed, get to a hospital!"

The morning after we arrived home, I went to see my general practitioner. He had seen the reports from the ER in Oregon and didn't even examine me: "What are you doing here? You should

be in the hospital. I've arranged for you to be admitted today. Your wife can go home and get your things after you're admitted."

*What is happening to us? This is a reoccurrence of Still's Disease, right?
I've handled this before and I'll handle it again. I just need some meds to
help tamp it down for a while and then I'll be fine.*

The first night in the hospital, even though I was on 50 mg of prednisone, I spiked a fever near 104 degrees Fahrenheit. Tests showed e-coli in my blood. That was good news, to me. We can "fix" e-coli through antibiotics. The doctors were not as satisfied. They wanted to know how the e-coli found its way into my bloodstream? Two days later, through a series of tests, it was determined that the real culprit was acute myeloid leukemia (aml). The leukemia had created a weak spot in my colon that likely let the e-coli pass into my blood. Ann and I were completely stunned by the diagnosis. As I mentioned at the beginning of this essay, "I'm not the kind of person who gets cancer." I wasn't sure who was the kind of person who gets cancer, but I was certain that it wasn't me.

Herein began the massive hits on my identity. I'm fit. I eat well. I practice prayer and meditation. I'm socially connected. I hike for my mental, physical, and spiritual well-being. None of this fit with my diagnosis. Interestingly, e-coli in my blood fit my identity of being strong and fit – "Not a problem, I probably ate something crazy. I'll get through this." – but I had no mental framework to understand cancer as part of my life. In spite of my biological mother and a half-sister dying of cancer, I have never considered cancer part of my family or personal story.

Enter victim/patient syndrome. My life suddenly felt like a runaway train – no breaks, no steering, no control – I was simply hoping it would stay on the tracks. Ann and I sensed an urgency from the oncology team. We were told there was no time to lose. Chemo should begin within 24 hours. As we talked with the doctor, who was now *my* oncologist, she explained the plan: "This is an aggressive cancer that in the long run does not respond well to chemo. You'll have five days of chemotherapy treatments to temporarily knock down the leukemia and you'll be hospitalized for a month or so. Then you'll be released to go home, but readmitted a few weeks later for another five days of chemo as we prepare for stem cell transplant."

Reflecting as I write:

It has just dawned on me that to have this doctor become "my" oncologist meant – the cancer was real. There is a part of me that has continually wondered if all I've gone through was a huge mistake – I never really had cancer. In this regard, each time I meet with my oncology team and, at home, each time I put on my mask it is a reminder that cancer has been a "real" part of my journey.

Ann and I sat, dumbfounded. "Don't we want to see how well the chemo works before talking stem cell transplant?" I ventured. The doctor drew a large circle on the white board in my room, and a very small circle within it. "The large circle," she said, turning to us, "represents all the people who have *aml*. The small circle represents the percent for whom chemo alone works. Based on your genetic markers, you're not in that small group." I was suddenly...*patient*. I was now...*victim*.

Victim/patient syndrome, as I am using the term, is primarily characterized by the perceived loss of autonomy, ability, opportunity, and key identity anchors. My clothes were exchanged for a hospital gown. I had to be pushed in a wheelchair when taken for tests. My room was in a

pressurized wing of the hospital and I was not allowed to venture beyond it – in the next weeks and months I would repeatedly walk the circuit around the nurses’ station (95 steps for each lap) like someone preparing for a marathon on a high school track. My grandchildren weren’t allowed to visit me because they were too young (under age 12). My ability to work was severely limited. Food was prepared by others and served to me. I lost weight and my hair. As a high fall-risk (low platelets) I needed assistance to get out of bed. Experts were making decisions about my care, my life. And, if these shifts to my identity weren’t enough, I was given a mask – to be worn whenever outside my room.

We tried to find ways to gain some control of the situation. Ann, with the help of her brother and sister-in-law, began researching this disease and the treatments the doctors prescribed. Was there another way? Was there a better way? We tried to ask significant questions, but things were moving quickly and at times we felt paralyzed. Helpless.

It wasn’t until after my first hospitalization, when I was reading, *Anticancer: A New Way of Life* by David Servan-Schreiber (2017), that I began to understand how patient/victim syndrome was shaping my identity. Servan-Schreiber, an MD and Ph.D., who discovered his own brain cancer through his own brain scanning experiment, describes this identity transformation, as follows:

From the waiting room on the tenth floor of the oncology building, I remember looking down at people in the street—distant and oblivious, going about their everyday life. I had been cast out of that life, separated from its goal-oriented busyness and from its promises of joy, by the prospect of a probable early death. No longer wrapped in the comfortable mantle of physician and scientist, I had become a cancer patient. (p. 1)

Lying on the couch of our living room, as I read these words, I spontaneously wept. Servan-Schreiber had captured my experience – *cast out of that life*. No longer able to live behind his doctor and scientist masks, a new patient mask had been thrust upon him...and myself.

For someone who studies relationships, being forced into mask-wearing has provided a rare opportunity. Since the use of comedy and tragedy masks in ancient Greek theater, masks (literally and figuratively) have represented the emotional experience of individuals and their public personas (Tassi, 1993). In this regard, Goffman’s (1959) dramaturgic perspective encourages us to think of the presentation of self as performance. As Manning (2005) observed, “Each person, Goffman reminds us, is etymologically a mask” (p. 2).

Wearing a mask has come to symbolize my experience in certain ways. For the last seven months of my life I’ve had the opportunity to think about the masks I wear, how I wear them, and what I might be masking. Commonly, wearing a mask has been associated with the hiding of one’s true self, such as in the *Phantom of the Opera* and *The Man in the Iron Mask*. Yet, the masks we adopt and how we wear them also tell us something about who we are. The following pages explore this mask-wearing process of identity making.

Reflecting as I write:

This essay was originally titled, “The Person Behind the Mask.” However, this reifies the idea that the mask and myself are completely separate (the “real” me is somewhere behind the mask). I believe it is truer to speak of the person “within” the mask, integrating my sense of self with my mask-wearing experience.

Gear for the Journey: Wearing a Mask

I have not felt the luxury of choice experienced by many of those who have refused to wear a mask during the COVID-19 pandemic, often as a symbol of their individual rights. Wearing a mask was, and is, essential for maintaining my health. The stem cell procedure I underwent end of October eradicated my immune system. Each day, for the month post-transplant, I anxiously watched for my white cell counts to rebound so that I could be released from hospital. And, rebound they did. But, when I was released my white blood cells were far from normal. My numbers were low and the cells were still immature. To top it off I was taking immunosuppressant drugs to prevent rejection of my new German friends (my stem cell donor is German). As such, upon my release, I was given a number of instructions to protect my body as my immune system slowly rebooted: no fresh vegetables unless washed in a cleansing solution; no new pets; no new plants; no digging; and, *wear a mask* when in public or outside in the wind, near construction, or in the desert. The mask was intended as prevention from outside viruses, bacteria, and fungi. But, the mask was also intended as a sign to others to maintain some social distance (before social distancing was “in”) and as a reminder for me not to touch my face, especially my mouth and nostrils.

My friend, Ted underwent a stem cell procedure for *aml* a little over six months before I did. He wore a cool black mask when he was in public and when he drove his jeep, windows wide open, around town. *Okay, if Ted can do this, I can do this.*

Initially I felt quite conspicuous wearing a mask in public. With time, however, I became more comfortable wearing the mask into stores, especially when I could go outside to avoid close contact while my wife made the purchase. After the federal government’s admonition to wear masks in public, to arrest the spread of COVID-19, I became even more relaxed wearing a mask in public. As one passerby on a hiking trail called out, “Yo, Bro! Coronavirus. Good for you, Dude!” I thought, “If only COVID-19 was the biggest of my problems.”

Breathing through a mask is substantially different from breathing without one. My mask is fabric and high quality, with a valve for easier and cleaner exhalation. It has a filter layer between the internal and external coverings, and a strap that comfortably attaches around the ears. The thickness of the mask can at times feel constricting, especially when I am exerting my body. This has meant accepting that it will often be harder to breathe through the mask when active, and I’ve learned to carry lip balm because of the dehydrating effect of each breath when wearing the mask for a prolonged period of time.

The mask can also feel constricting in the same sense that shoes do for some of us. Personally, I can’t wait to kick off my shoes when I get home from work— free and toe wiggling fresh! In the same way, once away from others, taking off the mask feels fresh and free, more fully engaging of the senses.

Just the other day my wife went to have her hair cut and colored and she wore a mask the entire time, as did the stylist. Upon her return, she reported that the mask she was wearing, a beautiful handmade cloth mask, simply felt too claustrophobic and she asked the stylist for one of the more ephemeral paper masks. I have also felt this claustrophobic feeling when wearing a mask for an extended period of time. For me it is akin to looking out of a mechanical bubble, watching the rest of the world go by. The mechanical sensation is partly a result of the mask’s inflation and deflation with each inhalation and exhalation. It’s one of the many factors (which I discuss later) that can contribute to a sense of dehumanization.

I have also had to adjust to the fogging of my glasses in cooler weather. I have been a contact-wearing person since my twenties, but certain effects of my medications have left my eyes a little dry, and so I’m now wearing glasses. This has meant, not only shifting my identity, at least

temporarily, to glasses-wearing, but experimenting with numerous iterations of mask-wearing protocol, especially when on the trail – glasses perched on top of the mask, glasses perched behind the mask, mask pulled down to nose tip, mask pinched tightly around the nose, glasses removed altogether.

Reflecting as I write:

Today while hiking, another mask-wearing insight. Spitting on trails is common as dust, bugs, and saliva buildup need to be expectorated. Today, as I neared the top of the trail, I had my mask hanging from my left ear and as I turned my head to the right to spit my mask swung up in front of my face! Fortunately, I sensed what was happening and stopped the procedure mid-motion before I filled my mask with spit. Catastrophe averted! On the way down, I practiced my new protocol (which I highly recommend you practice at home): turn, hold (until the mask reaches its full extension in front of your face and begins to retreat), spit.

An additional logistical issue is that going anywhere requires a tremendous amount of forethought. Getting out the door is much like trying to leave the house with an infant in tow: Do I have the bottle? The playpen? Diapers? Wet wipes?.... In my case, because I must stay out of the sun, it's more like: Do I have my mask? Sunscreen? A broadbrimmed hat? A long sleeve shirt? Lipbalm? Neck gaiter?

I should also note that I have two high-quality masks, one all black which I primarily use for hiking, the other a montage of color that I playfully refer to as my party mask (see figure 1). Having the two masks has been helpful to me given the loss of nonverbal facial cues. Like adding an emoji to a text message, my party mask sends a happy, joyous message that often opens positive, casual conversation: “I love your mask!” “Thanks, I really like the colors!” Interestingly, I recently misplaced the party mask after a short camping excursion and was without it for a few days. Even though I still had the black mask, I felt mild anxiety without the party mask, similar to what many of us experience when we're without our phone for a few hours. Evidently, having both masks available represents a sense of safety and security for me as I continue to work out my identity and, of course, maintain fairly stringent health practices.

Reflecting as I write:

As I write “work out my identity,” I'm struck by the idea that to some extent our true identities, true selves if you will (Kelley, 2021), are buried deep inside us and that various experiences, from finding love to journeying with and through cancer, can allow our identity to work itself out.



Figure 1. My Two Masks and Sun Protective Gear

Pictures from the Trail: Mask-Wearing Behaviors and Happenings

Here I paint a few pictures that represent how my mask-wearing interactions are often altered from my normal communication preferences and tendencies. The first shift in interaction dynamics that I became aware of was the increased difficulty for others to hear me through the mask. My mask, with its fabric exterior and filtering material in the middle, muffles my voice slightly and, of course, obscures my lips from view (a critical visual element that aids hearing). I have a hard time projecting my voice under normal circumstances, so this is a foundational problem. A particular memory that highlights this effect is when I would check in for my tri-weekly blood draws shortly after my hospital release. Perhaps the staff person who checked me in on the oncology floor saw too many patients with masks each day or simply didn't work at remembering returning patients, but each time I checked in was like a brand new experience with her: "Name." "Douglas Kelley. That's k-e-l-l-e-y." pause. "Telley?" "No, K(percussive)elley! K(percussive)-E-L-L-E-Y!"

Though this repeated scenario was mildly annoying, it became rather comical over time. More important to me were the times I experienced constriction of personal interaction due to the *masking* of my facial expressions. One day in the Lost Dog Wash Trailhead parking lot, a woman said to me, "Can you keep the noise down a little?" She was smiling and, I thought, most likely joking. I love humor and connect with people through play, so I enthusiastically responded with a big smile and appropriately crinkled up my eyes as best I could – only to realize that my mask, sunglasses, neck gaiter, and hat had prevented my nonverbal response from getting through to her. As if to confirm my realization, she put words to my unavailable nonverbal cues, "I'm joking. It's just so quiet out here."

The masking effect of my mask and sun-protective clothing has been so profound, that at times my neighbors haven't even recognized me as I've walked our neighborhood. Many of us learned as children that it is not polite to stare at other people. But, without somewhat gawking at the tall, rather mysterious figure stalking the streets, my neighbors have no way of knowing that I am buried or hiding under this obscuring costume.

Others' reactions to my mask-wearing have mostly been benign to positive. Other than a few children who haven't taken the do-not-stare rule to heart, responses from children and adults have not been negative, offensive, or embarrassing. Many I meet on the trail make brief eye contact, give a slight nod, or make a slight gesture with the hand to recognize the presence of a fellow human being. Others speak to me as we pass, "Beautiful morning," "Have a great day," and yesterday hiking in 90-plus degrees a woman with a big smile offered, "We're some of the five people crazy enough to hike in this heat!" Pre-COVID-19, in particular, non-masked persons tended to be helpful, giving me more space and letting me go first, whether I was in a line at a store or on the trail. However, many people in a store or on a trail simply pass me by without making eye contact.

Reflecting as I write:

My first instinct was to write the penultimate sentence, as follows – "Others have spoken to me as we pass, as if I was normal." My friend, Ted, and I have spent a great deal of time talking about "normal." Of course, we can never really go back to normal. And neither of us desires to. We have learned and changed too much through this process to want to return to life the way it was. People often speak of a "new normal." But, life is still changing so quickly for us (e.g., periodic bone marrow biopsies, medication adjustments, energy fluctuations) that any new normal is fleeting, at best. For now, with Ted thirteen months out from transplant, and me seven months out, it seems too early to think of any kind of lasting norm – Ann and I are readjusting our relationship every 6-8 weeks, my energy and focus for work continue to fluctuate, and my deep contemplative faith is constantly morphing with each phase of recovery.

My own mask-wearing behavior has been surprising to me. I'm fairly extroverted and I have a propensity to play and try new things. But, donning a mask in public (not for fun with friends, but because I have to), I suddenly find myself reticent to engage others. Because of others' difficulty in seeing and hearing my verbal and nonverbal communication behaviors, I initiate conversations less often and sometimes physically withdraw in order to avoid potential interaction. When chatting with a neighbor, rather than indulging my normally talkative self, I often cut the conversation short to finish my walk.

Part of this effect is due to what I have termed, *monitoring fatigue*. When outdoors talking with someone, especially someone who is not masked, I am constantly monitoring my environment and my body. I was somewhat of a high self-monitor (Fuglestad & Snyder, 2009) pre-diagnosis, but after stem-cell transplant I have become ultra-sensitive to what is happening in my body, what potential threats exist in the environment, and potential communication challenges. Wind, dust, neighbors walking their dogs, children (as one doctor called them, "walking petri dishes"), neighbors slowly moving closer as they talk, a cough from a conversational partner – all potentially threaten my compromised immune system. Face-to-face conversations can now be exhausting – I am on constant alert.

Wilderness Experience: Isolation, Dehumanization, Disability Bias, Monitoring Fatigue, Sanctuary, and Intimacy

My emotional experience of mask-wearing has been somewhat complex, as is typical of all emotional experience. In my recent book, *Intimate Spaces: A Discussion about Discovery and Connection* (Kelley, 2021), I report that when asked about intimacy in a variety of contexts (talk, sex, play, grief, conflict, forgiveness), study participants tended to identify intimacy behaviors (e.g., sharing, affection) and then articulate their experience of those behaviors (e.g., feeling safe, close). In similar fashion, we have just looked at behavioral elements associated with my mask-wearing. And, now, explore my emotional experience of those behaviors.

To understand my experience, I offer a few assumptions about moments and the nature of emotion. The mask-wearing moments I experienced are exactly that, moments. These moments have made it into the current telling of my story because they represent something significant in my emotional experience, my connection with others, or the shaping of my identity. Borrowing from Owen's (1984) theme criteria of repetition (of words), redundancy (of ideas), and intensity, and my own description of intimate moments as mindful, reciprocal, and meaningful (Kelley, 2021), I approached understanding my mask-wearing experience by looking for that which occurred repeatedly, was emotionally intense, felt meaningful, and somehow revealed a sense of presence with others (or lack thereof).

Emotion is multi-faceted. It includes aspects that are both affective and cognitive (Guerrero, 2013). That is, emotions are sensory feelings we experience along with the cognitive processes that identify what those feelings mean. Our core affect (Russell, 2003) can be described in terms of valence (positive/negative or pleasure/displeasure) and arousal (or activity; active/passive). But to understand what an active negative experience means, one must understand the experience at some deeper level. This often occurs when we name or label our emotions. For example, the sentence, "What I'm feeling is intense and undesirable" highlights negative affect that is highly active, but "I'm so angry I can't see straight!" provides meaning beyond identifying the experience as something we like or dislike, find pleasant or unpleasant, is active or passive.

Emotions are also typically experienced in clusters (Guerrero & Cole, 2015) that are positive, negative, or mixed. For instance, in my recent experience, there have been so many people on the trail (I counted more than 100 on a recent 75-minute hike) that I frequently feel frustrated at having to wear my mask – *All of you people are causing me to miss out on the feeling of fresh air on my face and the joy of breathing freely*. At the same time, I feel thankful and joyful that I am well enough to be hiking a mountain with a 750-foot change in elevation. All this is to say, that as I describe my emotional experience wearing a mask, I'm presenting it in a way that embraces its messy, non-binary, clustered nature.

"Who is that masked man?" This classic line from the epic 1950s television show, *The Lone Ranger*, paints a picture of much of my mask-wearing experience – unknown and alone. Of course, the mask itself is a physical barrier. The human face is remarkably designed – eyes and mouth forward-oriented for reception and signaling of verbal and nonverbal cues. We are, indeed, relational by design (Kelley, 2021) – infants' attention naturally drawn to recognition of the human face (Otsuka, 2014), and identity developed as they watch the responses of others to their own selves (Cooley, 1922).

Much of this primary orientation of self to other, of which I was accustomed for 62 years, was now suddenly wrested from me on a regular basis. As previously noted, this disorientation has often caused me to withdraw and resist engaging others. Engagement feels too unpredictable; too difficult to communicate clearly both verbally and nonverbally; too uncertain. This tendency to withdraw also negates one of my foundational identity anchors (Buzzanell, 2003, 2010) – I am

playful and funny. The mask limits my ability to connect to others using the verbal and nonverbal nuances necessary for play and humor. As the previous story with the woman in the parking lot illustrates, all of the verbal and nonverbal cues necessary to engage others humorously are now less available to my playful personality.

The physical barrier of the mask has at times facilitated a sense of isolation and loneliness. One might expect isolation to be an issue while hospitalized, but Ted and I have discussed how isolation continues and is, in some ways, worse once you come home. My friends checked in on me frequently when I was in hospital, in crisis. Once back at my house, these check-ins became less frequent. Also, because a hospital room is a quasi-public space, it's easier to pop in on someone while they are confined to their hospital bed than it is to show up unannounced at their home. Thus, my sense of isolation has in some ways grown since being home and been amplified by the fact that often when I am with others, whether friends or strangers, I wear a barrier that restricts access between us.

Reflecting as I write:

Writing about isolation, I'm struck by the joking Ted and I have done about getting healthier. Recently, I sent him a screenshot of my online portal at Mayo – I had no appointments scheduled, no upcoming tests. As happy as I am that I'm doing well, there is a sense of loss. Mayo has been a place of face-to-face (mask-to-mask) contact, especially as we remain coronavirus quarantined.

The mask has also had dehumanizing effects. Some of this is due to the physical shape of the masks. The front of some masks, in contouring to one's nose, look more like a bird's beak. Others take on the appearance of an expressionless emoji or cartoon character as they flatten across one's face. Of my two masks, the black looks a bit menacing to me, like Darth Vader, or more formal at the very least. The party mask with its varied colors is much more fun, but still reminds me of something one might wear to a costume party or as a deranged archnemesis of Batman.

Central, here, however, is that both masks restrict expression of emotion, a key characteristic of what it means to be human. We dehumanize others, and ourselves, when our perception is that they, or we, only experience a limited range of emotion (Oelofsen, 2009). In essence, we dehumanize when we treat others, or ourselves, mechanistically and animalistically (Haslam, 2006; note my previous description of mechanistic aspects of the mask). In this regard, I have been particularly drawn to certain science fiction stories where computers or automatons are humanized by being endowed with emotion or emotion-like characteristics. Listen to Hal, the computer from *2001: A Space Odyssey*, as he is being disconnected:

I'm afraid. I'm afraid, Dave. Dave, my mind is going. I can feel it. I can feel it. Mind is going. There is no question about it. I can feel it. I can feel it. I can feel it. I'm a... afraid. (Kubrick, 1968).

My own emotional struggle to stay human came in part from regular reminders that my body is in many respects a machine. After removal of lymph nodes in the neck, I had a visible incision with stitches and protruding drainage tube that left me Frankenstein-esque. I also lived for four months with a triple lumen catheter, consisting of three tubes (lumens) with bright red caps, protruding from my skin above my right pectoralis muscle. To shower, I taped Glad Cling Wrap over the top of it. To sleep, I moved it from side to side depending on my position. To dress, I looked for shirts where the three lumens didn't seem too pronounced. To draw blood, I simply

unbuttoned my shirt and the attending nurse would deftly draw my life-giving fluid from one of the lines. Those who knew me well joked about me being the bionic man. Ted and I celebrated together when we each had our triple lumen catheters removed. Human, again! Free!

Of course, the body is a machine, of sorts. An amazing machine that still leaves me in awe as I contemplate my survival and the body's ability to adapt. But the temptation for me has been to allow a mechanistic mentality to dull my more human aspects, especially my experience of emotion and, subsequently, my sense of identity. The mask, at times, has triggered these internal struggles. When wearing a mask it is difficult for my conversational partners to see or hear my emotional expression. Subsequently, at times when talking with others I have chosen not to provide a fuller range of emotion and, like the rote movements of a machine or pre-programmed responses from Siri or Alexa, to simply continue through the motions of the interaction – no meaning attached.

Another form of dehumanization that I have experienced comes through invisibility. Invisibility has often taken the form of being unrecognizable. Like a familiar stray dog roaming the neighborhood, I pass house by house, fellow walker by fellow walker, with scant recognition from others of me as a person. This creates a sense that I'm living in a bubble, looking outward to the rest of the world that appears to be functioning normally. At times, this sense of hiddenness breeds feelings of loneliness, while at others it creates sanctuary (to be discussed momentarily).

Dehumanization has also occurred through disability bias. When I am masked, and Ann and I are walking the neighborhood together, it has not been uncommon for me to be conversationally bypassed – others looking more often at Ann, than myself, even though we're standing near each other. I assume this occurs because it is more rewarding for others to talk with Ann's emotionally expressive face, rather than my masked and muted countenance. This effect may be amplified by the fact that, due to my high-risk status, I typically maintain greater distance between myself and conversational partners than do other conversers. These factors make certain turn-taking cues (such as, taking an audible breath and opening one's mouth) less available for my use and, as such, conversation with me may feel more awkward and uncertain to others. My diminished ability to use facial and vocalic cues also makes it more difficult for me to participate in a quickly moving conversation, so it is easier to withdraw, to be content as a nonentity, than to exert the energy necessary to stay in the conversation.

Disability bias has affected me in other ways, as well. When on the trail, I often take off my mask unless people are nearby. Trying to get my mask in place, hooked around my ears under my broad brimmed hat, while holding water bottle and hiking poles, has at times cut a comic figure. Like the prototypical sitcom dad, I appear loveable, but inept. At times, my capable and competent persona has suffered as I fumble with my gear and two young twenty-somethings go trail-running by...apparently free from physical encumbrances. Case in point, one rather stunning morning, I had paused my hike to take pictures of a fallen barrel cactus whose root system couldn't handle the top heaviness incurred from spring rains. A young couple was coming down the narrow path and as I was trying to get my mask and glasses back on and get off the trail to properly social distance, I ended up stumbling over a rock. The couple politely inquired, "Are you okay?" as they passed, but I was left feeling embarrassed and inept – "Check out the old guy. How nice that he's out doing what he can!"

At other times, help from others has facilitated my sense of being disabled. Patient. Victim. I'm used to being strong on the trail. I'm the first to move aside to let others pass. I'm eager to offer information to those who seem lost. But now as I, mask bound, approach others, many move aside to let me proceed unfettered. I appreciate these thoughtful acts. In fact, I find myself, at times, resenting those who do not give me sufficient space ("Can't you see I'm wearing a mask?!). But, at the same time, I prefer being the strong one who helps or makes way for the other.

My experience of disability bias is heightened when I'm being treated as though I am weak, small, and fragile. A poignant event occurred one day as I was moving out from the trailhead. Two women, engaged with a dog, were oblivious of me and were blocking the trail. A third woman, coming in from having completed her hike saw me with mask, hat, sunglasses, neck gaiter, poles, and gloves and said, "Ladies, let's move aside. He's afraid." She was smiling at me and seemed to be thinking she was helping, no sarcasm or malintent was evident. The other two women edged over to the side of the path with the large dog and I said "thank you" as I passed. While I appreciated these acts of kindness, I was transported back to grade school days where a teacher might help a smaller child who is having trouble seeing a track meet over the taller children, "Johnny, are you trying see? Everyone, make a space for Johnny in the front so he can see the race."

These accounts represent my experience of centripetal energy. Centripetal energy can be understood as a relational force, connecting partners with one another (Baxter & Montgomery, 1996). However, my reference here is to an internal, identity-based experience of centripetal force. A pulling inward. A growing smaller. Like a massive whirlpool spinning broadly at the top, but slowly pulling jetsam and flotsam, kelp, seaweed beds, and unsuspecting boaters down into the depths where there is little to no light. This can become a dark and frightening place. Indeed, in this way, centripetal force can hold my victim/patient syndrome in place –energy spiraling inward, I become smaller and smaller, less autonomous and able.

A trigger that can move me into this emotional whirlpool is monitoring fatigue. Ironically, on Day 100 (100 days post-transplant is a big deal), a month before the COVID-19 epidemic was having much effect in this country, Ann and I had gone out to do some shopping at Costco, but I had forgotten to bring my mask (we now keep extra masks in both cars). Our options were: I could sit in the car while Ann took care of our needs; we could go home and get the mask and return; or, we could just go home. *Wait a minute. We're celebrating Day 100, dammit! Let's just do this thing and I'll stay away from people.* And that's exactly what we did. However, not without a great deal of angst on both of our parts. For me, once in Costco, the monitoring fatigue felt overwhelming and precipitated a stream of internal, irrational monologue. I was constantly aware of the people around me ("Don't people have jobs! Why are so many people here?!"), people bumping into me ("Can't people tell I'm immune compromised?!"), children (Why do people bring these walking petri dishes to a store?!), and coughs, sneezes, and sniffles anywhere in the store ("Why would you go shopping if you're sick?!""How do you know that is just allergies?"). As soon as we had our main items, I was out to the parking lot away from people. The experience was disappointing, because I've always enjoyed running errands, tasting samples, and having casual conversations with store employees and other patrons (connecting as one human family – life is good!), but the high self-monitoring now felt exhausting. My self-monitoring was no longer the standard replaying of what I said to someone in passing or wondering if I should have worn a hat, it was monitoring of a nature that potentially had life and death ramifications. At times, it felt like one misstep could make a life or death difference. I realized that as much as it felt good to do something that felt normal, the fear and weariness of self- and other-monitoring overwhelmed these positive feelings. (I should note that since COVID-19, many stores and restaurants have implemented procedures that are safer for me and help me feel safer. That said, I still haven't been in a store or restaurant for over two months – as COVID-19 numbers are increasing in much of the country, at this point in time, the hyper monitoring and risk simply outweigh the pleasure I might receive.)

Reflecting as I write:

To bring this point home, today, I received a text that friends of ours have been exposed to COVID-19 from someone they allowed to come into their

home. They have now been tested and we are awaiting the results. One misstep....

A consequence of monitoring fatigue and feeling small is that of frequently adopting an internal defensive posture. When I see someone coming toward me, who I imagine may be holding an untoward attitude regarding my mask and head-to-toe covering, I find myself preparing a quick retort. If they were to say something like, “Hey, Bud, that’s a bit much isn’t it?” I’m ready to put them in their place, “Actually, the experts tell us that the trail can be high risk because people are breathing hard,” and, “I’m six months out from a stem cell transplant and kicking your butt on the trail. What’s your excuse?” In reality, I have never gotten to use any of my snarky comebacks because no one has ever asked me about my extensive sun and germ-protective attire. Even casual friends in the neighborhood have never asked.

Although, I have not gotten to use my well-rehearsed rejoinders regarding my appearance, my defensive posture has also been evident in my felt need to explain. Standing outside talking with a neighbor on a 75-degree day, covered head to toe with sun-protective clothing and mask, I’m tempted to offer, “By the way, because I’m immunosuppressed I have to wear this mask, and I can’t have any sun exposure so I’m stuck wearing this crazy outfit.” Ann and I have joked about getting me a t-shirt that says something like – *Don’t ask. I just had a stem cell transplant.*

One time this internal sense of boldness came out directly. On a hot day while hiking with my wife, we passed a young man with a dog and, apparently, no water. I was quick to comment on the dangers of hiking with a dog on a hot Spring day without sufficient hydration. Where did that come from? I don’t normally make such comments to strangers. In this case, I think the anonymity of the mask, instead of causing me to withdraw and feel small, emboldened me to speak to this fellow stranger.

It is notable that I often feel slightly startled when someone directly talks to me in a store or on the trail. Simple comments that seem like “normal” conversation catch me off guard – “Beautiful day,” “A great day to be alive,” “Enjoy your hike.” My surprised responses illustrate for me how isolated I can feel and how at times I view myself as “different,” less “human,” less “able bodied,” “patient” – *Oh. You’re talking to me, like I’m a regular person.* These are wake-up calls for me to reflect as to how I am constructing my identity. Have I been buying into a view of myself as victim and patient? What is it, then, that makes me...*me*? Often, my surprised response to someone’s kind words has been a reality check that I’m not living as “normally” as I thought.

Reflecting as I write:

The words I use above reflect my own biases about what it means to be a “regular” or “normal” person. I need further reflection as to what these words mean to me: different, human, able-bodied, patient.

Less noticeable, at first, wearing a mask has also prompted positive experiences with self and others. An exception to feeling surprise when people engage me as “a regular person” has occurred a few times when I have encountered other hikers who are equally sequestered behind their sun gear and mask. On these occasions there are nods of mutual recognition and short discussions about staying protected, always with at least a mention of what it is that is putting us more at risk (e.g., allergies, medications, cancer, autoimmune disorders). I have felt camaraderie during these times and a certain sense of generosity as most of these conversations have been characterized by a gratefulness that we are able to be out on the trail. I am thankful for a conversation with two women who described their practice of stepping six feet off the trail to allow

hikers to pass – “We’re happy to give more able-bodied hikers space, and to take time to water, refuel, and just look at the fabulous mountains.”

At times my mask-wearing has served to create a positive sense of sanctuary. As the COVID-19 quarantine was put in place, many of the trails I was used to hiking became cluttered with people. I soon had to change my routine in order to avoid too many people on the trail. One of the lasting effects of this has been to create a personal sanctuary as I walk or hike. This seems especially true when I choose to go out during hotter parts of the day in order to avoid others. During these times the heat, mask, and protective clothing serve to create an insulated space where I can be alone with my thoughts. This is valuable time for self-reflection and prayer.

My own faith is Christian-contemplative in nature. There is long history of desert spirituality in the Christian tradition (as there is in most religious traditions) and, although my desert experiences with the mask have been mostly urban, the mask and my additional protective apparel have at times created a deep solitude. This solitude has allowed for fresh perspective on the world that I am walking through. At other times, I have experienced my masked solitude as a *with-God* moment – intimacy – like two lovers so engaged in the *now*, that the rest of the world ceases to exist.

Ann and I have experienced masked intimacy, as well. To use a term from Sandra Petronio’s work on privacy (Petronio, 2002), Ann “co-owns” my masked self, as well as the person within the mask. In *Intimate Spaces* (Kelley, 2021), I discuss co-owning private relational spaces as a means of achieving intimacy. Ann has not only been let into the private spaces described in this essay, she has taken a certain amount of responsibility for them (“Do you have your mask?” “Should you have your mask on here?” “Does it feel like too much to meet Ron and Julie at the restaurant?” “You seemed reserved in our time with Scott and Elaine. Are you okay?”). And, wonderfully, we have engaged in some mock kissing with one another, playfully pressing our mask-covered lips together.

UnMasked Reflections

Having thus recounted my mask-wearing behaviors and happenings, and explored my mask-wearing experience, here I offer a few thoughts to complete the overall depiction of my mask-wearing identity trek. It is important to emphasize that my predominant experience of mask wearing has been positive, or at least benign. I have generally not experienced wearing a mask as an undue burden. Certainly, part of this is due to the fact that I was able to watch Ted go through each stage of the stem cell process six months ahead of me. Part, as well, is due to my generally optimistic, positive outlook on life. However, my innate curiosity and reflexivity have also kept me keenly aware of the changes to my public persona and inward identity reported here. As such, my experiences of isolation and dehumanization have been significant. Certainly, I experienced these elements of my journey as the constant push and pull of relational dialectic tensions, such as autonomy-connection, openness-closedness, and public-private (Baxter, 1990; Petronio, 2002; Rawlins, 1992).

An undercurrent through much of this essay is the temptation to think the “real” person is behind the mask. Of course, this rings true in certain respects. Someone may say, “That ‘person’ at work isn’t really me” or, as one of my intimacy study participants offered, “...because you are allowing someone to know you on a different level than others. You can take off the mask and be you. When you are silly and having fun you find a different [kind] of love for someone” (Kelley, 2021).

So true. But how we wear our masks, or which masks we choose to wear, also says something about who we are as persons (Jacobsen & Kristiansen, 2014). The social roles we play

have something to say about us in that we have taken on those roles and played them in particular ways (intentionally or not). Mask wearing was thrust upon me. And I have chosen to mostly embrace it and be conscientious in my practice of mask wearing due to the potentially grave consequences of not doing so. But this has been my personal response. Ted has been wearing a mask twice as long as I have. We share some of the mask-wearing experiences described in this essay and differ in others. Ted and I are both positive and upbeat and have embraced our cancer experience as part of our journey. So, both of us have endured wearing a mask in mostly positive ways. However, Ted is much freer and less fear-based than I am, so he has experienced less of a sense of dehumanization behind the mask.

Reflecting as I write:

Ted just contacted me and, after reading a draft of this manuscript, is now wondering if some of his early choices to be mask “free” were in response to the dehumanizing effects of the mask – the desire for more direct connection and to feel normal.

Mask wearing still doesn't feel natural or normal to me. Yet, whereas I have chosen not to be defined by the fact that I wear the mask, it has been important for me to accept that mask wearing is a significant part of my life at this time. To give perspective to this tension, I have also struggled not to align my identity with cancer. In the early days of trying not to let cancer define me, I couldn't even say the word, “cancer.” I always spoke of my “condition,” “situation” or, maybe, “illness.” Overtime, I realized that real health and strength came in being able to say that cancer is/was part of my journey. So, am I a cancer survivor? Yes. Gladly so. But I typically don't think of myself that way. I more naturally think of myself as a husband, father, friend, teacher and writer who has successfully journeyed through numerous obstacles in his life (as we all have) – I've twice hiked the Grand Canyon rim to rim in a day; I've been separated from my wife and participated in rebuilding a stronger marriage with her; I've been diagnosed with acute myeloid leukemia, received a stem cell transplant, and am currently doing all I can to live healthily.

Reflecting as I write:

As part of this identity struggle, you might have noticed that when I refer to acute myeloid leukemia or use the acronym, aml, I never capitalize it. In my mind capitalization gives the disease too much respect or too much power over me. I assume this may change with time.

I finish these reflections by offering a word that has held a special place in my life over the last couple months – spaciousness. As I described previously, centripetal force has described much of my identity experience when wearing a mask. It is too easy when I put on the mask to spiral inward, becoming smaller and smaller. Centripetal force isn't a negative force. It is necessary. Relationally, it can be connecting, pulling two individuals toward one another. But it needs to be balanced with centrifugal tension. A moving outward. In the case of my identity – spaciousness. The temptation is to equate spaciousness with casting off the mask, feeling the sunlight on my face, breathing the fresh crisp air. And I have done this, at times. Notably, one day on the trail I watched a young man come flying by me, running on toes, arms out to the side, wild curly hair, no shirt, tattoo down the spine and side and arm and, once a ways past me, stopping to raise his arms and hands in the air as if to celebrate the spaciousness of life. Beautiful. I want that.

But, I can also choose to wear a mask spaciously. And I have done this, too, in my better moments. Gaining a more spacious perspective can change our behavior in positive ways. This has

taken on two different expressions for me. The first is spaciousness as engagement, as relational generosity. In contrast to centripetal withdrawal, spaciousness for me has meant engaging others while mask wearing, whether passing the time, being polite, or having a meaningful conversation. It has meant generously offering emotional expression to others through letting someone see my eyes, pulling my mask down for a brief moment to smile, or simply expressing verbally how I am feeling.

My second expression of spaciousness has been one of wearing the mask lightly. That is, a spacious worldview has provided me perspective. This has been evident in appropriate mask humor (when wearing my black mask: “Luke, I am your father.”) and self-deprecating humor (“Does this mask make me look fat?”) to connect with others and help them feel comfortable. In essence, from a spaciousness perspective, the mask is small potatoes. Not unimportant, but dwarfed by greater themes of love and connection with others.

Both of these spacious expressions, as I am relating them here, feel safe. This is essential. Lack of safe space results, once again, in pulling away, withdrawing, feeling small and protective. In sharp contrast, feeling safe results in standing in the great expanse, feeling small, but with a heightened awareness of personal worth and place. The opening quote from James Baldwin (1963) speaks to this, “*Love takes off masks that we fear we cannot live without and know we cannot live within,*” and he goes on, “I use the word ‘love’ here...in the tough and universal sense of quest and daring and growth.” As I’ve argued, elsewhere (Kelley, 2019, 2021), full love creates safe space for intimacy (discovery and connection) and personal transformation.

My masked-identity trek has led me through a wilderness strewn with the seeming indifference of medical challenges and coronavirus quarantine; yet, love, a daring and growth-producing love, has been hiding in the spaciousness of this quest. Masked and unmasked, may we all continue to live with such spaciousness – grateful and loving, generous with ourselves and others.

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