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Editor's Forum

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Discussions of death and dying in bioethics tend to focus on concerns about technology driven treatment in terminal illness, reluctance to recognise the prolongation of dying in such circumstances, and more recently in Canada, medically assisted death (MAID). The discussions relate to worries about the dying process in tertiary care settings but seldom contribute to our understanding of death itself.

Gary Frank's paper corrects a common misunderstanding that palliative care is for the dying who are on the brink of death. He describes the clinical picture of excellent palliative care for those with incurable illness long before they become terminally ill. This distinction between being incurable and terminal is frequently confused in clinical practice. Frank proposes that palliative care may act as a "supportive tradition" for the patient and family ensuring that the final stages of life are comfortable, meaningful, and even pleasurable. This is in keeping with older care based medical and nursing traditions around death that pre-dated modern curative medical care. When cure was a rare familiarity, the needs of the dying was the first step in providing good palliative care. It remains so today. Recognition that cure is not possible is an essential prerequisite to facilitate providing the dying patient and family with their needs. Today that recognition is often more difficult because of the incredible success of technology driven treatments. Frank describes the breadth of scope of good palliative care far beyond tertiary care hospitals and illustrates this beautifully with examples.

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In This Issue…

In contrast the paper by Daniel Garros presents the practical unfolding of a clinical palliative care approach within the confines of a tertiary care pediatric intensive care unit (PICU). While it might appear impossible to provide palliative care in this setting, Garros describes a successful program involving a committed multi-disciplinary team and active family involvement in care. The details he offers show a remarkable commitment to the intimate personal needs of the child and family in this technology dominated (often de-humanizing) environment. The professional collaboration and leadership needed to implement this quality of palliative care in this setting are considerable. The potential for conflict and confusion regarding goals of care in an intensive care unit (ICU) is high and may interfere with the provision of the care that Garros describes. Avoiding discussion of death and worries about death representing a collective professional failure may prevent this kind of quality palliative care in the ICU setting. The approach of Garros is a clear example of how to counter these common concerns. Accompanying this paper is a story written by Melanie Proskow, the mother of a child who died in the Stollery Children's PICU. The story speaks for itself.

In Derek Truscott's paper on metrics in health care he describes the use of feedback metrics in identifying expertise as being well established in professional sports. He states that although the benefits of metrics in medical practice and in health care provision may appear obvious because outcomes are not guaranteed, he cautions that feedback measurements per se will not improve care unless applied appropriately. Truscott warns of measurement problems relating to what is measured, how it is measured, and what importance is applied to each metric. For example, two major metrics in health care are death or quality of life but these may conflict with each other. Delaying death may worsen quality of life. Most metrics measure proxy values for good or bad health (both of which are vague and variable for most people) by using specific items that are measurable and reliable. But what do these reliable items actually mean for people? He states that impressive accurate metrics may not matter very much to most people's health – "hitting the target but missing the point". Truscott also describes the serious risk of "gaming the system" to improve the results of feedback and gives examples across a variety of systems. Finally he indicates that valuable resources may be diverted away from the actual provision of care to an ongoing process of metrics and performance evaluation without evidence of any benefit. He concludes that use of metrics is valuable if utilized to improve care rather than simply evaluating it. Only in this way can metrics satisfy the professional ethical duty to provide best care. A constant evaluative feedback loop without direct outcome assessment may have the opposite effect.

The Good Life in Palliative Care?

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> *et plurima mortis imago*
>
> "Death in sundry shapes appears", Dryden translation, 1697)
>
> (--Virgil, *Aeneid* 2,369)

In contemporary pluralistic societies there is no more agreement on what is a good death than there is on what is a good life (Meier, 2016). For some, a sudden death after a certain age seems preferable. Others hope for a gradual dying process that may allow one to "put [their] house in order" (Remnick, 2016). Some want to control the time and place of their death and so welcome the options of euthanasia or assisted suicide. Still others prefer to "take one day at a time". Other than the undesirability of being murdered against one's consent, there seems to be no consensus in society at large about what is or is not a good death. Whether or not it has always been thus is an interesting historical question –for which there is no simple answer (Walter, 2003).

Yet, despite this lack of consensus, people live and die with expectations of how things should be. These expectations may be implicit, even unconscious. They may also be unrealistic, having been shaped by the influences of an all-pervasive but unreflective commercial culture motivated primarily by consumerism. Indeed, such unmet expectations may themselves be a significant cause of pain and suffering (Illich, 1975). Yet there are communities, traditions, and subcultures (MacIntyre, 1981) that have more explicit and intentional views of death that are shared by their members, traditions that support the dying person and their family in dealing with death. Is Palliative Care one of these traditions (Thoresen, 2003)? I propose that it can be –but this is by no means guaranteed by the mere existence of palliative care as a medical specialty (Kellehear, 2016).

We die in many different ways and locations (Nuland, 1994). While sudden death will always exist, a growing number of Canadians experience chronic illnesses that involve an increasing need for care and medical intervention until they eventually die, most often in hospital --despite having previously indicated their preferred location of death to be home (Arnup, 2013).

Some illnesses can be predicted to end in death within a certain time frame, others are less predictable. And, of course, the continual development of new treatments may alter how predictable a disease really is. Palliative Care is an approach that does not focus on the prolongation of life but neither does it preclude it. So what then is a Palliative Care approach to death and dying? The *World Health Organization (WHO)* describes it as such:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.
Palliative care:
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement

counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO, 2019).

Although the modern hospice movement began with the work of Cicely Saunders in Britain in the mid-twentieth century, "expert and sensitive end-of-life care became an essential component of medical practice as early as 1772, and at times Dr. Saunders praised several of her predecessors" (Vanderpool, 2015). Prior to this there is also the history of monastic involvement in palliative care (Crislip, 2005). Throughout all of this history there is a common thread: good palliative care requires a focus on individual patients and their needs and wishes. This focus becomes more explicit over time and is very prominent in the writings of Saunders (Clark, 2005; Thoresen, 2003). Such a focus on the individual, however, occurs in a social context. Indeed, since the individuals in question are by definition increasingly dependent on others for the meeting of their most basic needs some sort of communal commitment to meeting those needs is essential. Thus, one potential criticism of the legalization of euthanasia and physican-assisted suicide is that, while the need to respect autonomy is clearly established, the responsibilities of the community to meet the needs of its dependent members is not.

The Palliative Care approach to these communal commitments is described in the WHO definition above and it is consistent with what most people say they want: to be *comfortable and cared for*, to not have dying prolonged (this is not the same as having life intentionally shortened), to have a sense of meaning, to be at peace with others, to be surrounded by those important to them (Byock, 2004). With this in mind, below is an example of what might be considered a good death in palliative care, in hospice in this case:

> Gloria is a 44 year old single woman. She was diagnosed with breast cancer ten years ago and has undergone multiple treatments for it: surgery, radiotherapy, chemotherapy and hormonal therapy. Three months ago she was diagnosed with new bone metastases but had no symptoms at the time. One month after that she saw her family doctor for a new right-sided abdominal pain. An ultrasound showed extensive liver metastases. Though she had hoped for the best, Gloria was not surprised at this news. She had been preparing for it mentally for a number of years and is now clear that she wants no further investigations or cancer treatments. Low dose oral morphine helps the abdominal pain considerably. After another month passes, Gloria calls her family doctor and tells her that she is having trouble managing at home alone. She is tired a lot and finds it difficult to bathe and sometimes to get dressed. She also complains of constipation. Gloria is not interested in going to the Emergency Department or even to her physician's office. She agrees to the homecare team coming to see her. After one month of daily visits from homecare and a few home visits from her family doctor, Gloria feels that, despite this much-appreciated support, she needs to be in a setting where she has around-the-clock assistance and care. She has discussed in-patient hospice care several times already with her homecare team and feels this is what she now needs. Homecare and her family doctor agree that it is at least reasonable to request an assessment for hospice and her family doctor does so. The hospice assessment team agrees that Gloria now meets the criteria for hospice admission and one week later she moves into her own room at a hospice near her home. Her closest niece arrives from Italy three weeks later with her cello which

> she plays for Gloria often. After five weeks of caring attention from a community of professionals, friends, and some family, Gloria dies peacefully in hospice a few hours after hearing her niece play Bach's fifth suite for cello, one of Gloria's favourite pieces.

This story is simple, a little romantic even, and it is also true and not uncommon. Like most things worthwhile, it takes some effort and attention to detail. This effort and attention are a result of the most basic and essential of human virtues: love and caring.

These virtues are, of course, not only found in Palliative Care! Thus, a good death can occur in many different circumstances (Kellehear, 2016) –even in circumstances normally dedicated to aggressively preserving life. One example of this is a simple but very helpful program initiated by critical care professionals in Hamilton, Ontario (Cook et al., 2015). The "Three Wishes Project" is a beautiful example of how simple caring gestures can bring meaning at the end-of-life --to both the cared-for and their caregivers, professional or not:

> …a project team member or bedside clinician sensitively elicited at least 3 wishes from the patients, family members, or other clinicians caring for the patients. We documented what the wishes were and whose wishes they were. When we introduced the project, our focus was how best to honor the patient. All wishes were for the patient or family… Wishes were classified into 5 categories: humanizing the environment (such as bringing favorite flowers or cherished momentos into the room), personal tributes (such as having a tea party or planting a tree in the patient's name), family reconnections (such as locating a lost relative or sponsoring a memorial meal), rituals and observances (such as blessings, renewal of wedding vows, or firework displays), and 'paying it forward' (such as organ donation, contribution to a significant charity, or unsolicited family donation to this project)… The project fulfilled an unmet need of dying critically ill patients and their families —'being known' in terms of one's life journey… The 3 Wishes Project brought a set of wishes to fulfillment for dying patients and their families. Most wishes were simple and inexpensive but were often described as invaluable. The project personalized the dying process. For the patient, eliciting the wishes encouraged individualized end-of-life care, guiding us to honor him or her. For the family, it helped to create enduring positive memories, countering the negative visual, auditory, and tactile stimuli propagated by technology. For clinicians, this project promoted interprofessional care, strengthening team bonds and exemplifying humanism in practice…
>
> The 3 Wishes Project aimed to integrate palliative care and spiritual care into critical care practice. Eliciting and honoring wishes fostered a community of caring, promoting patient-and family-centeredness as a core component of palliative care. It encouraged the verbalization and realization of unmet spiritual needs, whether secular or faith-based. Our findings underscore the drive that we all have to search for meaning, memories, and closure in anticipation of death while helping to create preparedness, comfort, and connections during the dying process (Cook et al., 2015).

Such endeavours aim to address,

> …conceptual dichotomies in the care of the terminally ill: natural and medicalized death, clinical care and research, and acceptance and denial of death. While these dichotomies may have been fundamental to the original hospice and palliative care movements, they could now undermine the progressive evolution of clinical care for the terminally ill (Zimmerman & Wennberg, 2006).

Or, as David Morris (1998) puts it,

> The consequences of this continuing modernist deconstruction of mortality have brought us to the current postmodernist impasse in which dying patients are trapped between two evils: a runaway medical technology of ventilators, surgeries, and organ transplants that can keep bodies alive indefinitely and –as if this prospect were not frightening enough-- an understandable but reckless public clamor for physician-assisted-suicide as the only alternative to such ignominious physician-assisted suffering.
>
> The impasse shows no sign of resolution. Nothing will stop the advance of biomedical technology, which brings great good along with its unforeseen dilemmas.

Where, then, is hope to be found in the midst of such seemingly intractable dichotomies and dilemmas? Since we cannot predict the future, and hope is by definition a future-oriented phenomenon, we cannot expect a precise answer to this question. And the more profound the problem, the more profoundly is this the case. In his remarkable study of the Crow Tribe's response to the cultural devastation they experienced in the late nineteenth century, Jonathan Lear, in words reminiscent of Paul of Tarsus (Rom.8:24-25; Heb.11:1; NIV, 2011), observes,

> 'what makes this hope *radical* is that it is directed toward a future goodness that transcends the current ability to understand what it is. Radical hope anticipates a good for which those who have the hope as yet lack the appropriate concepts with which to understand it' (Lear, 2006).

Nevertheless, adequately conceptualized or not, hopeful actions occur. I have already cited some of them above. After the rather pessimistic analysis of medicalized death given by Morris (1998) above, he too cites hopeful initiatives:

> Clearly there is room for improvement in our treatment of the dying patient. It is thus a hopeful sign that, amid the controversies and horror stories, physician Ira Byock is directing an ambitious community wide effort (the Missoula Demonstration Project) designed to rethink the contemporary way of dying.
>
> The basic shift in vision required for such rethinking, in Byock's view, comes when we abandon the traditional biomedical model focused on cure. 'Modern clinical training, procedures, recordkeeping, and economics,' he writes in his own critique of the deconstruction of mortality, 'constrain doctors and force them to approach dying as if it were strictly a set of medical problems to be solved.' Doctors wedded to the biomedical model of scientific problem solving may even deliberately avoid the word dying—which is scientifically imprecise—in favor of something more seemingly objective like multiple organ failure. Such biomedical euphemisms do

the patient and family a serious disservice in preventing a recognition that the process of dying (as distinct from accelerated medical treatment) is under way. The new model of dying that Byock proposes, based on the experience of hospice care, stresses what from a modernist point of view is an unimaginable end-of-life goal: personal growth and development. The Missoula Demonstration Project offers an experiment in creating a new community based biocultural model of dying… Dying, Byock believes, while by definition irreconcilable with cure, is highly compatible with healing. It is a time when patients, families, friends, caregivers, and even the wider community can experience meaningful connections and beneficial changes despite fears, conflict, and progressive illness… Hospice is the one organization today devoted to a philosophy of dying well, not just dying quickly or dying painlessly, and it has made a crucial contribution to whatever is positive and hopeful in postmodern illness. The first American hospice opened in 1974 in New Haven, Connecticut, inspired by and modeled on St. Christopher's Hospice outside of London, which founder Dame Cicely Saunders opened for inpatients in 1967. Since then, thousands of patients have lived their last weeks or months mostly at home, pain free, with dignity and with a chance for meaningful reconciliation, growth, insight, and healing.

In Canada, hospice palliative care has also had a positive, humanizing effect on the end-of-life experience of many patients and families. The ongoing challenge is to ensure this remains the case in the context of a contemporary culture, both medical and societal, that is not easily disposed to supporting such humane experiences. In response to these challenges, a renewed emphasis on the role of non-professional community involvement has developed. Not surprisingly, some public health leaders have been at the forefront of this movement (Kellehear, 2005), but they are not the only ones. Pallium Canada, a national palliative care advocacy and educational organization, has a strong partnership with the Compassionate Communities movement that is dedicated to fostering more community involvement in end-of-life care (Pallium Canada, 2019). The City of Edmonton, through its involvement in the Abundant Community movement (McKnight, 2010), is attempting to promote the public health of its citizens –including end-of-life care-- through a neighbourhood-based network of care and community re-vitalization (City of Edmonton, 2019). As well, the Parish Nursing Alberta movement is an example of faith-based communities promoting the health and well-being of their members –including at end-of-life. Community-based initiatives such as these are all positive, humanizing influences on end-of-life experience. Palliative care professionals should and often do promote and work together with them in pursuit of the best interests of patients. Other examples of this in Edmonton include partnerships serving the needs of vulnerable populations: the Palliative Care Outreach Advocacy Team (PCOAT), St. Joseph's Ministry, Pilgrim's Hospice, Ambrose Place, and George's House.

And, though it is easy to forget in this age of specialization, professionalization, and anomie, if one has the good fortune of adequate resources, especially social supports, it is entirely possible to have a good death, with or without any organizational intervention:

> In late July [2016]… Cohen received an e-mail… saying that [Marianne] was suffering from cancer… Now, it appeared, she had only a few days left. Cohen wrote back immediately:
>
> 'Well Marianne, it's come to this time when we are really so old and our bodies are falling apart and I think I will follow you very soon. Know that I am so close behind you that if you stretch out your hand, I think you can reach mine. And you know that I've always loved you for your beauty and your wisdom, but I don't need to say anything more about that because you know all about that. But now, I just want to wish you a very good journey. Goodbye old friend. Endless love, see you down the road.'
>
> Two days later, Cohen got an e-mail from Norway:
>
> 'Dear Leonard
>
> Marianne slept slowly out of this life yesterday evening. Totally at ease, surrounded by close friends. Your letter came when she still could talk and laugh in full consciousness. When we read it aloud, she smiled as only Marianne can. She lifted her hand, when you said you were right behind, close enough to reach her. It gave her deep peace of mind that you knew her condition. And your blessing for the journey gave her extra strength. . . . In her last hour I held her hand and hummed 'Bird on the Wire', while she was breathing so lightly. And when we left the room, after her soul had flown out of the window for new adventures, we kissed her head and whispered your everlasting words. So long, Marianne . . .' (Remnick, 2016).

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DYING in HOSPITAL, A PEDIATRIC PERSPECTIVE

The New Paradigm - Palliative Care is for the Living!

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Contrary to the commonly accepted view, palliative care is not about a good death experience, rather a good life for patients with life threatening or life limiting conditions.

The *World Health Organization* (WHO, 2002, 2018) defines palliative care as the prevention and relief of suffering of adult and pediatric patients and their families facing the problems associated with life-threatening illness. These problems include the physical, psychological, social and spiritual suffering of patients, and psychological, social and spiritual suffering of family members.

Differences of opinion exist about whether use of the term "life-threatening" (where a cure is possible) or the term "life-limiting" (no realistic hope of cure) is more appropriate; what matters in the life trajectory of children with such conditions is to enhance their life as much as possible, utilizing common principles of palliative care such as pain management, dyspnea control, proper mobilization, age appropriate playing time, etc. This type of care can be provided to varying degrees in tertiary care facilities, in community health centres and even in children's homes.

Active total care of the child's body, mind and spirit, also involves giving support to the family.

In this way palliative care begins when life threatening illness is diagnosed and continues regardless of whether or not a child receives treatment directed at curing or alleviating the disease. In fact, palliative care may be concomitant to the treatment of the active disease. Even in the critical care environment this approach can be applied to the overall management of the patient.

Health providers must evaluate and alleviate a child's physical, psychological, and social distress. This involves a multidisciplinary approach that includes the family and makes use of available community resources. In the Stollery Children's Hospital, child life workers have an extremely important role, normalizing the young child or teenager's life as much as possible. By using age appropriate activities, and programs that involve the individual as well as the family, within the limits of what the illness will allow, the day to day life of the child is enhanced. Social work, spiritual care and the specialized palliative care service contribute other important members. But it is not always necessary to have a specialized team directly involved to provide good palliative care. The pediatrician, family physician and the intensivist can fulfill this role with assistance in many cases (Davidson, et al., 2007).

Is my child dying?

In some complex life threatening conditions it may be difficult to discern when a child is actually dying. For patients who may still benefit from disease modifying or life-sustaining treatment, every effort should be made to continue this treatment in combination with implementation of palliative care measures. When life-sustaining treatment is deemed ineffective, more harmful than beneficial for a patient, or when it is no longer desired by the patient and family, it is essential that the patient not be abandoned. In this situation there is a provision of receiving comfort-oriented treatment to prevent and relieve suffering and maximize quality of life. Failure to provide this end of life care is medically and ethically indefensible (WHO, 2018).

Improved quality of palliative care has been associated with improved patient outcomes, and is associated with financial risk protection for patients and their families with reduced costs for the health care systems (Knaul, et al., 2017).

Improved patient outcomes include better control of pain and other symptoms, decreased spiritual distress, enhanced quality of life, improved patient and family satisfaction, and reduced number of physician office visits, emergency department visits, hospitalizations and days in the intensive care unit at the end of life.

These improvements tend to be greatest when palliative care is initiated early in the course of life threatening illness. In some cases, provision of palliative care has been associated with prolonged survival. Less data are available on outcomes of palliative care for children than for adults. However, pediatric palliative care has been associated with improvements in health related quality of life, emotional well-being and family satisfaction (WHO, 2018).

What do the families want at the end of life for pediatric patients?

Meyer, et al. (2006) have published a study describing the results of interviews with families of children who have died in hospital, and they expressed the following “needs” at the end of life:

- Honest and complete information
- Ready access to staff
- Communication and care coordination
- Emotional expression and support by the staff
- Preservation of the integrity of parent-child relationship
- Faith

Conclusion

A lot can be done to enhance the quality of life of a child or teenager whose life is likely to be shortened by a chronic and/or acutely life threatening debilitating condition. Principles of palliative care should be applied in parallel to the active treatment of the child’s condition. In the dying hours, a lot can be done to improve the experience of a dying child in the ICU. The families who have experienced this tragedy can offer insight and knowledge for caregivers. The following story is about a teenager who died in the Pediatric Critical Care Unit at the Stollery Childrens Hospital, narrated by his mother.

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A SUPER-HERO WITH A SMILE!

Melanie Proskow, Mother

November 10, 2004 I was going to deliver my babies. Our medical team had spent hours and hours with us to save my children and me; I had pre-eclampsia. First to be delivered was Jacob; only 1 ½ pounds at 26 weeks gestation. I quickly got a glimpse of his head and blew a kiss as a team of at least 10 whisked him off to the NICU with my worried husband in tow. Then next I delivered my angel Sarah, who had died 2 days before. She was so peaceful and so very beautiful. While we said good bye to her in one part of the hospital, Jacob was a couple floors up continuing the fight for his life.

Jacob looked so very tiny in the isolet with so many tubes and lines attached to him and he was intubated. I had no idea what any of it meant. Every time a monitor beeped, a med was given or something needed to be done they taught me all about it. We were thrown into a world that we honestly did not know anything about. Jacob spent 102 days in the NICU. During this roller coaster time he grew to 6 pounds, had two surgeries, countless tests and procedures and was finally ready to go home. During the NICU stay was the first time we saw his magical smile. A smile that said "hey mom, I am going to be OK". I did not know at the time how much that smile would be a part of our lives and a major communication tool.

Just before Jacob turned one, he had his first seizure. He was diagnosed with Seizure Disorder, Spastic Quadriplegic Cerebral Palsy, Global Developmental Delay and Legally Blind. The many specialist caring for him taught us what this all meant and worked with us to give Jacob the *best quality of life that he could have*. I counted each day as a blessing. We could have lost him at birth as well. He fought and we fought along side of him.

Jacob's beautiful smile continued to touch so many. Even with all the challenges he faced on a daily basis *he had a great life*. He loved to be with family and friends. He loved camping, boating, quadding, going to school, cuddles, music and so much more. There were very few days in his life that he did not start and end with a smile. He was surrounded by love and thrived in it.

He needed several surgeries through the years, many tests and procedures. However, no surgeries or test were done without a lot of conversation. We all had one goal: to give Jacob the *best quality of life we could*. I think we all did a pretty good job of that!

When Jacob was seven his world became brighter. He became a big brother. Sweet Lily Hope entered our world and loved her brother from the moment they met. They had a bond like I have never seen. Jacob's biggest smiles were for his sister. Lily happily went to every appointment with us. She always helped with Jacob and was so proud of her big brother.

As Jacob got older things got more complicated. Due to pain and health issues he could no longer go to school. His care away from home also got harder and his trips back to see family just a couple hours away lessened. So, we adapted; family came to us. Holidays were spent in our home. Through it all he continued to fight and smile.

In 2016 we faced our biggest surgery yet; it lasted over 7 hours. After already having over 20 surgeries I thought we were prepared. Pain was in control and we had such high hopes that this surgery would give him a better quality of life and take away so much of the pain he suffered from. Unfortunately, just over a week after surgery Jacob went into respiratory distress and was rushed to the Pediatric Intensive Care Unit (PICU). Things changed hour by hour; like being on a roller coaster. Once again, our teams worked with us to make the best decisions for our son. He ended up being intubated for three weeks. He was finally extubated to a BIPAP machine. This was now our new normal. He needed BIPAP every night and sometimes all day when he was unwell. Hospital stays were hard on us all. Jacob and I are separated from Lily and Kris. We learned to make ourselves at home in the hospital. Family naps were taken, movie night still continued and music was always playing. Holidays were spent in the hospital including Jacobs 12th birthday. We used our own blankets and Jacob was always surrounded by his numerous stuffed animals. Most of which were *super heroes just like him.* It was at this time that discussions came up about our goals of care for Jacob. We had to start thinking of what was best for him and his quality of life.

Once we went home, we saw a difference in Jacob. He was not as strong and continued to have issues with his breathing. A couple more surgeries were required to help correct some back complications. During this time, I felt we lived more in the hospital then at home. While I was so very thankful for everyone who did everything they could to make our days easier and to help Jacob it was hard on us all. A special nurse practioner who holds a special place in our heart referred us to Make A Wish. We did get out of the hospital and our pediatrician agreed; if we were going to go now is the time to do it. In June of 2017 we headed to Florida. It was not easy traveling but Jacob loved it all and was so happy! The memories made on that trip fill my heart with happiness. Our family got to be just that, a family.

In fall of 2017 Jacob suffered from another respiratory infection, leading to the PICU again. Our teams had worked with us to make sure we had many tools at home to keep him there as long as possible. Until spring of 2018 we were in and out of hospital. Every visit our doctors talked to us more and more about his goals of care. I saw him getting weaker. I saw him loosing his fight. For a child that never spoke a day in his life he had so much to say and *we had to listen to him*. At home he was tired, needing a long nap to recover from a simple walk. I had such fear for when the next respiratory season would hit. I feared my boy would not be able to continue that fight. But that fear was realized much earlier then I thought. On May 13, 2018, Mother's Day, Jacob's breathing got worse and oxygen needs were higher on continuous BIPAP; I could tell his lung had collapsed.

We were immediately taken by ambulance into the trauma room as we had been in the last couple visits where everyone worked hard to stabilize him and off we went to the PICU. At this point walking into the PICU I felt we were with family. We knew everyone and they knew us. They knew what helped Jacob and what didn't. He had a simple cold. But to Jacob a simple cold threatened his life. I could see he was tired. His body was tired of fighting. The doctors saw it too. We spent the next couple of weeks watching him weaken. Watching his body tell us it was done.

The staff in the PICU made sure we recorded Jacob's heart beat, we recorded Lily singing a song to Jacob, we took Jacob and Lily's fingerprints to make jewelry and most importantly we spent time as a family. We had numerous friends and family visit. On his sick nights family would sleep in chairs with us to keep watch over Jacob. As Jacob got more tired and his body started to show signs of shutting down he became more at peace. I talked to Jacob for hours making sure we were listening to him. On June 1st, Jacob's dad's birthday we talked with our doctors. We knew this would be the last night we would spend as a family. The PICU brought in another hospital bed into Jacob's room. We turned on the star gazer light that shone stars on the ceiling. We wrapped Jacob in a special *superman cape*. Jacob, Kris, Lily and I spent the night cuddling and just being a family. Our nurse came in the room minimal times to let us be. Lily described our room as beautiful and she brought her cousins in to show them. We all took turns cuddling up to Jacob. We prayed. I tried to make sure I would remember what it felt cuddling my boy and feeling his warm little body against mine.

The morning came too soon. The sun shone into our room. Jacob woke up again so peaceful. He gave us one final smile and it still told me he was going to be OK but this time I knew it meant he would be OK in heaven with his sister Sarah watching over us. His smile said thank you for letting me go when I was ready. Thank you for loving me. With our family, priest, pediatrician, PICU staff and our intensivist we watched Jacob so very peacefully go into a coma. We played music. We continued to cuddle. We remembered so many good times. *He spent his last hours as he did his life. Surrounded by love.* As he took his last breath he was being cuddled in bed with Lily on one side of him and me on the other. Kris had his arms around us all. The peace I saw on his face that day helps heal my heart. After he passed we spent some time with him. With the nurse I helped change his clothes and clean him. We tucked him into bed with his superhero blanket and his superman in his arms we said good bye. Lily crawled in bed with him and said her final good bye and told him how loved he was. The three of us walked out of the hospital that day with his empty wheelchair and a part of our hearts broken. I picture Jacob in heaven now walking on legs that work, dancing in a pain free body, singing with a beautiful voice and still facing every day with a smile. Jacob touched so many lives. His strength continues to help me and his story helps me continue on. I am not sure why Jacob chose me to be his mom but I thank God everyday that I was blessed with him.

Every Breath You Take: Ethical Considerations Regarding Health Care Metrics

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> *Every breath you take*
> *Every move you make*
> *Every bond you break*
> *Every step you take*
> *I'll be watching you*
> (Every breath you take: Sting,1983)

I am a psychologist specializing in psychotherapy. In particular, I am interested in what it takes to be a good psychotherapist. In seeking answers to this question, I have been drawn to the literature on expertise (Ericsson, 2018). This research has reached a consensus that in order to learn how to do something well we need feedback. Simple examples come from sports where it would clearly be preposterous to attempt to get good at baseball, for instance, if we never knew whether or not we were scoring runs.

However, even in sports, where outcomes are clearly defined, a goodly amount of superstitious thinking was until quite recently alive and well. In the 2003 book, *Moneyball*, Michael Lewis recounts how the collective wisdom of baseball insiders was often flawed. Many of the metrics used to evaluate players—stolen bases, runs batted in, batting average—were not actually associated with winning baseball games. Lewis describes how the Oakland Athletics Major League Baseball team took advantage of better metrics to assemble and coach a team that could compete with much more highly funded teams. Their approach often flew in the face of the beliefs of many baseball scouts and executives, yet enabled them to shock the league by making the playoffs in 2002 and 2003.

"Moneyball" is now shorthand for using metrics to make better decisions in domains ruled by unproven traditions. Education and law enforcement have shown particularly enthusiasm (Muller, 2018; O'Neil, 2016), with healthcare not far behind (e.g., Glorikian & Branca, 2017; Nash, 2014; Norton, Li, Das, & Chen, 2018). The idea that we can improve our effectiveness by gathering better information about aspects of the patient's condition that influence the outcomes we seek is alluring. Indeed, one doesn't have to look very hard at the practice of psychotherapy to uncover batty beliefs in need of being moneyballed. (I'm talking to you, peddlers of past life regression therapy.)

The Upside of Metrics

The value for practitioners of using metrics is pretty obvious. Health care professionals are expected to know if we are helping and not harming our patients. Yet, if we are honest, we often don't know if our routine practices are effective.

Consider a typical visit to a general practitioner. The patient arrives and communicates a complaint. The physician takes a history and conducts an examination. Sometimes diagnostic tests are performed or ordered. A solution is proposed based on some combination of medical practice guidelines (when available) and the physician's knowledge, skill, and experience. It is assumed that if the patient does not return it is because their complaint was resolved. Patients actually often fail to return because their complaint did not respond to the prescribed remedy and they lost faith in the doctor's ability. If physicians received routine outcome metrics they would have feedback that could be used to practice more ethically and effectively.

Metrics can also be used to guide practice for rare and complex cases that the typical health care professional might encounter infrequently in their careers. Similarly, practice guidelines that incorporate signs and symptoms needing attention allow effective practices to be shared among all practitioners (e.g., Chapman, Black, Drinane, Bach, Kuo & Owen, 2017). Better decisions can be made by orienting practitioners to the aspects of care that matter for the patient's health and well-being. The provision of care thus becomes more reliable, efficient, and effective.

Who are Metrics for?

It might seem self-evident that metrics are intended to influence the behaviour of health care providers. Curiously, however, access to metrics alone does not improve patient outcomes. Some have likened it to giving a stopwatch to a runner. Being in possession of information about how fast we are running doesn't in and of itself make us faster.

And so it goes for health care providers. While we might like to think that all of us are in this profession for altruistic reasons, many are content to simply do their job. Others of us may be doing the best we are able, in which case nothing will improve our outcomes. Still others might respond to feedback by trying to do things differently but misguidedly, such that our outcomes worsen. A significant number have untapped talent, act on feedback in productive ways, and improve. The net result is no change for the group as a whole.

Threats to our reputation, status, and professional pride do tend to improve outcomes, but not always in ways that we might wish for (Olivella & Siciliani, 2017). In an infamous US example from the 1980's, surgeons and their affiliated hospitals were provided feedback on their patient's mortality rate (Epstein, 2006). One hospital was put on probation for receiving a low "grade" and the following year received the highest grade. Success! Or was it? It turns out that the surgeons, instead of improving their practice, turned away the sickest patients. A patient that dies at home, or on someone else's table, did not "count" against them. If they had sufficient doubt about the patient surviving a procedure, therefore, they simply would not perform it. Unfortunately, this is not an isolated incident (Bevan & Hood, 2006), although the impact overall is less clear (Chen & Meinecke, 2012). More on this later.

Some have proposed that metrics be made public so that patients might make informed choices (Mak, 2017). This takes metrics outside the realm of enhancing performance and into that of social ideology. Patients are assumed to be interested in quality health care and to be rational actors in a "health care market place." The flaw in this thinking is that human beings are not particularly rational when it comes to making decisions about spending money (Kahneman, 2011). Indeed, people are not sensitive to information about provider effectiveness and tend not to base their health care decisions on it (Moscelli, Gravelle, Siciliani, & Santos, 2018).

Various political rulers have tried influencing the behaviour of health care administrators in an attempt to impact outcomes. In the 2000s the job security of UK health care managers was tied to performance targets that were publicized in the form of rankings and ratings, known as "naming and shaming" (something that had been applied to schools and local government in the previous decade). It turns out that, like the health care professionals they are charged with managing, administrators are sensitive to reputation. They are also sensitive, not too surprisingly, to the threat of job loss. It does seem to be the case that performance targets do genuinely improve if opportunities are made available for managers to repair their reputation. (Propper, Sutton, Whitnall, & Windmeijer, 2010).

The Downside of Metrics

Overall then, a bit of a mixed bag when it comes to the upside of metrics, although there are some good reasons for using them. But there are also a number of very serious concerns. The first is problems of measurement.

Most significantly, we almost always collect proxy metrics because we usually cannot directly impact ultimate outcomes. Take the example of the two most important outcomes for most people: quality of life and mortality. Quality of life is a by-product of a life well lived. It cannot be achieved directly. The same for mortality. We die from disease or injury, so these are what we measure. The trouble begins when, by selecting one target, we necessarily displace another. Quality of life and mortality matter to varying degrees across patients and circumstances. Indeed, it is often the case that prolonging a patient's life will adversely affect the quality of it. Which then should be given priority over the other?

There is also the problem of precision being inversely related to importance. This is known as "hitting the target but missing the point." The most important things in life—good health, happiness, love—are the most difficult to measure. The more reliable and valid our measure, the less important the resulting metric is. We can know with great accuracy what the exact time is, for example, but have no idea if our time is well spent. Even mortality has a signal-to-noise ratio too low for it to be used as a valid metric of health care quality (Scott, Brand, Phelps, Barker, & Cameron, 2011).

The use of metrics can also have unintended consequences (Armstrong, 2011; Mau, 2019; Smith, 1995). In particular, it is common to become fixated on the proxy measure and lose sight of the outcome. Some refer to this as "treating to the test" and it is surprisingly easy to do. In my field of psychotherapy one of the more common metrics asks the patient if we talked about the things they wanted to talk about. In session I often ask myself this very question. (An occupational hazard of being a professor is loving the sound of my own voice.) To the extent that the patient's agenda is related to outcomes—and it is highly—this represents good practice on my part. But there are other proxy metrics that are far less valid yet no less seductive. Attempts to treat diabetes by aggressively controlling hemoglobin A1c turned out to be misguided and the source of unnecessary anxiety and expenditures (Prasad & Cifu, 2015). We ought to take great care to measure what matters, because what is measured is what will matter.

One of the more pernicious unintended consequences of measuring health and health care is that resources are necessarily diverted away from providing care. Using resources for performance measurement of health care, rather than its delivery, can only be justified if the former has an influence on the latter. Sadly, this metric is rarely calculated, let alone acted upon.

The most troubling concern with metrics may have no direct solution. A psychologist studying the impact of planned social change in the United States and an economist studying monetary management in the United Kingdom both arrived at similar observations that have become eponymous laws. Campbell's law states: The more any quantitative social indicator is used for social decision-making, the more subject it will be to corruption pressures and the more apt it will be to distort and corrupt the social processes it is intended to monitor (Campbell, 1979). Goodhart's (1984) law states: Any observed statistical regularity will tend to collapse once pressure is placed on it for control purposes.

Campbell's (1979) and Goodhart's (1984) law tells us that when a metric is used for control it becomes corrupt by fostering "gaming" (efforts to cheat the system) and outcomes are degraded. This is a very serious problem that calls the whole enterprise of metrics into question. Examples abound (Campbell; Muller, 2018). Police departments held accountable for the percentage of crimes solved fail to record every complaint or postpone recording complaints until and unless they are solved. Recording the number of the enemy left dead on the battlefield during the Vietnam War competed with and even supplanted more traditional goals of warfare to the detriment of the US war effort. Educational performance contractors who were paid based on students' improvement on standardized tests taught items taken directly from the final test to be administered, rather than actually tutoring students on math, science, and reading.

A Way Forward

When Sting was asked by BBC Radio about his song, *Every Breath You Take*, he said, “I didn’t realize at the time [I wrote it] how sinister it is. It sounds like a comforting love song. I think I was thinking of Big Brother, surveillance, and control. One couple told me ‘Oh we love that song; it was the main song played at our wedding!’ I thought, ‘Well, good luck.’”

Broadly speaking, there are two strategies available to mitigate the inherent downsides of metrics (Poku, 2016). The first is to divorce metrics from any system of reward or punishment, thereby eliminating incentives for gaming while maintaining the quality of outcomes. The second strategy is to implement safeguards to minimize corruption and distortion of metrics used for accountability.

“Safeguards” are simply a euphemism for policing. We know this contributes to a health care system that ultimately fails patients and society, in large part by degrading occupational satisfaction for health care professionals. If metrics are used to evaluate, they should be applied to systems – not providers. In any event, many important outcomes are not sensitive to individual providers’ actions; they are a product of the effectiveness of systems. Thus, not a great strategy in practice.

We should instead insist that the benefits of collecting and analyzing metrics outweigh the burdens of doing so. Health care managers ought to be responsible for reviewing the utility of metrics. If the system of collecting and reporting metrics does not improve outcomes, the system should be changed. For instance, the outcome sought may not be amenable to improvements in quality of the care provided. The OECD estimates that only half of deaths from ischaemic heart disease, for example, are amenable to healthcare, while most deaths from hypertensive diseases are (Kiernan & Buggy, 2015). A system that held providers accountable for outcomes related to ischaemic heart disease should be modified to include hypertensive diseases instead or scrapped.

Ideally, health care metrics should be generated and utilized collaboratively. Enlisting health care providers, and patients when possible, to identify meaningful targets results in better metrics and better outcomes. While many metrics in anaesthesia, for example, are relatively easy to collect, they matter less to patients than a normal recovery, no morbidity, and absence of vomiting and pain. Indeed, postoperative vomiting is the greatest concern of patients undergoing ambulatory surgery (Kiernan & Buggy, 2019). Plus, attempts to legislate the use of metrics without enlisting providers collaboratively, tends to be counter-productive (Urbach, Govindarajan, Saskin, Wilton, & Baxter, 2014).

Ultimately, metrics should only be used to improve the quality of care provided, not to evaluate it. Normative and formative information for provider or system, coupled with support and training, can enable individual and institutional learning. Doing so would uphold our ethical obligations to provide the best care possible.

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