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SUFFERING: THE NIGHT-SIDE OF LIFE

Author: Jackie Hazelhurst

Perhaps it was a response to approaching middle-age, or perhaps it was serendipity, however in the summer of 2017 – long before I had considered studying medicine – my mother enrolled in a chaplaincy course. Her previous career of physiotherapy had been safely rooted in the realms of science, but chaplaincy provided no such solid ground. Chaplains work with the intangible and nebulous, with matters of meaning and hope; in a phrase ‘the human spirit’ or ‘wairua’.(1) Despite their many differences, chaplains and doctors share two crucial similarities: both are rarely sought out by people that are well, and both are primarily concerned with alleviating suffering. Throughout this essay I will draw from medical anthropology to consider a range of definitions of suffering, using the literature of Cassell, Tate, and Pearlman. I will then apply these principles to a patient case study, exploring the concepts of grief in unexpected death and “the dark night of the soul”. Finally, I will consider how suffering and grief can be meaningfully acknowledged and engaged with in a clinical practice setting and identify lessons for my future practice. Trauma – described by Indigenous scholar Eduardo Duran as a “soul wound” – and the suffering it provokes are facets of our humanity. (2) Acknowledging and addressing this pain lies at the heart of medicine; as in the words of Thomas Egnew, “all patients will eventually need a skilled physician-healer”.(3)

Defining suffering and grief:

Eric Cassell, perhaps the most authoritative voice on the subject of suffering, challenged the classical reductionist model that focussed primarily on the body and physical disease. He defined suffering as “*the state of severe distress associated with events that threaten the intactness of the person*” and appreciated the vast array of reasons people suffer beyond simply an experience of pain (for example, in the face of uncertainty, indignity or the loss of ‘what could have been’).(4) Although his work on suffering was highly influential, in the years since it has been widely revisited and revised. Wellmer challenged the idea of a

single autonomous self, asserting that ‘*a person is never fully coherent*’;(5) Braude contended that there is a truly subjective element to suffering that cannot be explicitly defined,(6) and Svenaeus argued we must consider the lived experience of suffering, describing suffering as a mood; a state that determines “*the way the whole world appears to us*”.(7) Although I am doubtful words can ever fully capture something that is first and foremost experienced rather than articulated, the definition I favour is the framework laid out by Tate and Pearlman. They proposed that suffering requires two necessary conditions; (a) a loss of a person’s sense of self, and (b), a negative affective experience.(8) This definition provides a simple and elegant understanding of suffering while retaining Cassell’s original intent.

In illness it is not just the patient that suffers, but also their whānau, friends, and care team. Grief, which can be defined as “*the primarily emotional/affective process of reacting to a loss*”, has no physical cause and yet is clearly a form of suffering.(9) C. S. Lewis captured this experience in his description of life after the death of his wife; “There is a sort of invisible blanket between the world and me”.(10) A skilled doctor acknowledges the suffering of the patient and their wider support network, as well as recognising the emotions the interaction provokes in physician themselves.

A case study in suffering: KH

In clinical practice, as in life, the hardest days don’t come advertised that way. On the day I met KH I wasn’t meant to be on the child oncology ward at all - I was shadowing a Paediatrics registrar who happened to be called to ward A6 to assist with a challenging catheterisation. KH had been admitted only a few weeks earlier with a painful hip after a fall ice skating. Her parents initially suspected this was a ploy to get time off school. However, KH left the hospital with a diagnosis of a pathological hip fracture and metastatic rhabdomyosarcoma. While the prognosis of metastatic rhabdomyosarcoma in children varies, the

5 year survival is typically 20-32%.⁽¹¹⁾ When I met KH, the large tumour that spanned her upper femur and hip was causing urinary outlet obstruction, compounded by her reluctance to urinate due to radiation burns. Although in intellectual terms, catheterisation was the best option to relieve her discomfort, KH was extremely distressed despite her father and grandmother's desperate attempts to comfort her. The uniquely high-pitched wails of a child in anguish – a sound from childhood I had long since forgotten – stayed with me as I drove home that night.

In the days following our encounter I read KH's patient notes, in part for a logbook entry I had to complete, and in part in the hope I would understand why my interaction with her – although short – had provoked such strong feeling inside me. In some respects, this was explained by our similarities. Our grandparents had immigrated to New Zealand from the same country and spoke the same mother-tongue, we both had sisters and the same colour hair. However, that didn't account for the deep sadness captured in the notes of her clinicians and wider multi-disciplinary team, which mirrored my own. Death is always challenging, but the death of someone that is "not supposed to die", such as a child, makes the grieving process particularly difficult. An unexpected death may come in many forms, including a traumatic death, or dying by suicide. It challenges the rules we use to make sense of the world and this changing lens through which we interpret our lives is in itself a loss we grieve.

The concept of the "dark night of the soul" comes from a poem by the 16th-century Spanish poet, St John of the Cross.⁽¹²⁾ The phrase often is used in relation to a loss of faith, but more broadly describes a collapse in meaning in life, or a change to the conceptual framework of the world that can occur in response to a traumatic event. Many parents who have lost children find themselves unable to conceptualise both their faith and the death of their child. This itself is a form of suffering, as a component of their identity is forever lost. I saw a glimpse of this in my encounter with KH, where while KH's father tried to calm her, her grandmother stepped back to pray in the corner of the hospital room. It was a striking image, but I couldn't help but wonder whether her faith would remain in the event of KH's death. A form of faith has been shown to be protective for those exposed to the death of a child ⁽¹³⁾ – but how can one keep hold of their faith in the face of tragedy? This is a question not even

my mother, adept in spiritual care, can answer.

The role of the physician in suffering:

A biomedical approach, including placing our faith in medications or surgery, will not relieve the grief and suffering associated with illness. Instead, we begin by following our instincts of compassionate care and listening. Tate and Pearlman give three suggestions for how clinicians can ameliorate suffering in patients and their whānau: "(1) *seeking to understand their patients' lived experience*; (2) *inquiring into their patients' experiences by paying particular attention to their loss of relationships, roles, and narrative*; and (3) *actively listening and exploring the words and stories that their patients share*."⁽⁸⁾ Humans are narrative creatures who use stories to make sense of human acts and agency. The formation of a narrative, guided by the physician, can be a powerful form of healing. For children such as KH, a narrative is required to make sense of they are experiencing pain, why they can no longer go to school the way their friends can, and why life suddenly looks so different. For KH's parents, a narrative can provide an indication of the road that lies ahead – providing an ability to plan and be the best parents they can be in the time that is left. However, the challenge for clinicians with both patient and parent is to balance hope with honesty. Honesty without hope is cruelty. Hope without honesty is a lie. Learning to navigate this challenge skilfully is the work of a lifetime.

Lessons for my future practice:

Repeatedly bearing witness to suffering can cause significant stress for healthcare professionals, with far-reaching biopsychosocial impacts. In a study of Canadian palliative care physicians, 38.2% of respondents reported a high degree of burnout, mirrored by many other studies.⁽¹⁴⁾ However, encouragingly, statistics vary widely based on the interventions that are provided within the workplace. A systematic review of 59 studies found a reduction in symptoms of burnout when physicians were given opportunities for '*learning meditation, improving communication skills, peer-coaching and art-therapy based supervision*'.⁽¹⁵⁾ Burnout is not an inevitability and resilience can be developed and maintained throughout a career – regular supervisory meetings will be an important component of my future practice.

So how can I as a physician respond to suffering without succumbing to it? In myself, I recognise a temptation to look away, because to truly engage with the suffering of another who is dying requires confronting my own mortality. However, I keep returning to Remen's words; *"The practice of medicine is a special kind of love"*.⁽¹⁶⁾ To be there in a person's final months, to witness the pain of themselves and their loved ones, is to bear witness to some of their most vulnerable and precious moments. In the case of KH, the opportunity to be a part of her joy as well as her pain, and to see the immense love and resilience of her family is an invaluable privilege. Medicine is a gift for both patient and physician.

Concluding remarks:

As many medical students do, I worry that I will not be able to shoulder the weight of witnessing great suffering. However, I draw upon the knowledge that, often, to be a healer is to be a listener, which is something I know myself to be. When we as clinicians allow ourselves to be moved by our patients we also open ourselves to the many lessons they have for us. To care for KH and her whānau has meant grappling with the knowledge that undeserved tragedies occur every day, and could happen to me and the people I love. This has also been the most confronting part of medical school. Brain tumours, miscarriages, unexplained crippling pain; these are experiences that I have witnessed not as a medical student, but as a colleagues and friend. The separation between doctor and patient is an imagined one. In Susan Sontag's classic text, 'Illness as Metaphor', she writes, *"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick... sooner or later, each of us is obliged, at least for a spell, to identify as citizens of that other place"*. As physicians, we will always be both healers and in need of healing, rendering us all inescapably, intimately, human.

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