

## THE DYING GAME

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### Abstract

Western medicine offers a health care system that is evidence based, outcome orientated, and frequently dominated by technological and pharmacological interventions. It aims to cure and when this is no longer possible it seeks to prolong a person's physical existence often at the expense of their spiritual and emotional well-being. This biomedical approach with its focus on the 'fleshy envelope' falls far short of the mark especially when directed to those who have a life-threatening illness or multi-system disease. Even with these illnesses, death is often considered an adverse event rather than a natural end to life. Human suffering is multi-dimensional and often beyond the reach of curative medicine, yet this approach to care remains the dominant paradigm for the majority of people who die within the hospital system, diverting attention away from the hard but real issue of life and death. Timely and appropriate preparation for death is rarely countenanced, leaving little if any time for the 'patient' and family to make the necessary journey towards wholeness and inner peace. Hospitals are not good places to die and will remain so until those who provide care reflect on their actions and agendas, and see a person's death not as the end of their life or as a failure of treatment, but as a profound transitional experience.

### Introduction

Over the past 30 years there has been a steady stream of literature in the scientific and lay press dealing with the so-called '*inhumanity of medicine*'.<sup>1-9</sup> According to Zeev Neuwirth, Professor of Medicine at New York University School of Medicine, the present health care system, 'has become a caustic and dehumanizing environment for patient and physician alike'.<sup>7</sup> At first, this damning assessment may seem unfair and misdirected given that the system of care of which he speaks can now cure or prevent many illnesses that were once life-threatening. It is a system of care that has resulted in a marked improvement in life expectancy and a better quality of life for most people. His criticism however has little to do with physical outcomes, but with a person's overall care experience within hospital – whether their psych-spiritual as well as their physical needs are respected and catered for. General speaking, it is all about the way people are cared for. Are they treated as people or as patients? Medicine's transition from a humanistic endeavour to a scientific enterprise is, according to Neuwirth, the cause of our current health care ills. He believes the transition has led to the human dimension of care being neglected in favour of what Daniel Callahan calls the therapeutic and research imperative.<sup>5</sup>

The aged, sick and dying are a particularly vulnerable group, and while they derive some benefit from the biomedical model of care it is often at the expense of their psych-spiritual well being.<sup>3,5-10</sup> I will say more about this later in the discourse but the following words, penned by Graeme Jones as he was dying of lymphoma, illustrate the nature of the problem faced by people who are dying. He says, 'It does seem bitterly sad that my fate, the fate of me, will be decided, indirectly, through the functioning of a fleshy envelope. I see the soul thus entrapped, as being the great and ultimate casualty of Cancer's mortal war.'<sup>11</sup>

Medicine, once a caring profession, had as its highest goal the alleviation of physical, emotional and spiritual suffering. Relief of physical pain has undoubtedly improved as a result of the latest technological and therapeutic advances, but evidence suggests the domain of psycho-spiritual care has been neglected and may even be a victim of our medical successes.<sup>10</sup> Patients burdened by emotional or spiritual distress do not benefit from interventions or therapeutic cocktails; what they want is for their doctor, and other health practitioners, to listen carefully to their concerns, to communicate clearly and to do all of this with a degree of compassion that says to the patient, they care.<sup>12</sup> This, according to Eric Cassell, is not as easy as it sounds, for the language that describes and defines a patient's (person's) suffering is different from the language of medicine. Too often, he says, there is an actual disconnect between case histories and the patient's narrative.<sup>13</sup>

### Doctor-patient communication

Doctors hear what they need to hear. Their prime concern is to gather information that will help with a diagnosis and the plan of treatment. Anything that is considered irrelevant to the clinical situation usually passes below the radar and remains unheard. This frequently includes a patient's struggle to understand what is happening to them, their confusion, anguish, fear, helplessness and their despair.<sup>10</sup> The more desperate the clinical situation the greater the risk of this disconnect and then, it is not because their cries go unheard but rather they are misunderstood. In my experience, patients nearing the end of life have great difficulty in finding words to adequately describe what they feel and frequently resort to metaphor. More than once, patients close to death have said to me, 'I want to go home'. If family is present when this is said, they often blanch at the thought of caring for their dying relative at home. What the dying person is usually asking for however is not that they be discharged, but that they be allowed to die.

The most memorable disconnect in my palliative care career occurred when a youngish man, dying of AIDS kept telling me he was 'full of shit.' It embarrasses me to admit that, initially I thought he was constipated and treated him accordingly. After several days I realized he was not constipated, and when I took the time to really listen, he told me he was 'full of shit' because of the shame and guilt he harboured following a regretful incident many years before.

Being fully present to a person's suffering is time consuming and exhausting. It can also be threatening to a doctor who is tied to a curative paradigm, particularly when he/she works in a 'pressure cooker' situation and has insufficient time to know the person they are treating, or time to reflect upon their actions. This exact scenario was described by Dr Edwards, a physician in the emergency department of one of Sydney's largest hospitals as follows:

'In order to deal with these aspects of my work, I have developed something like a Ned Kelly suit of armour – an outer shell that protects me from the bullets of misery, anguish and stress of people sick and dying; a mask that prevents too much eye contact, and therefore emotional connection, while at the same time preventing the emotion within me from escaping and being seen in the raw. This piece of armour protects me by putting some emotional distance between me and the patients I am dealing with...[B]ut this Kelly suit concerns me. Does it mean, by definition, that the system and specialty in which I work requires that I don the suit to work effectively, or have I put it on myself because I have become somewhat hardened to the human tragedy I deal with? And, more importantly whatever the answer to this 'chicken or egg' type question, how is this affecting me elsewhere in my interactions with patients as well as my day to day interactions with family and friends?'<sup>14</sup>

### The scientific imperative

The scientific or rational approach, where a doctor focuses solely on the physical well-being of their patient works well when the illness or injury that is being treated is 'curable'. If, for example, a person has a broken leg, they are prepared to suffer a system of care that treats them as a patient rather than a person. They do not mind too much if their doctor communicates poorly, as long as he/she does a good job. The issue of empathy and compassion is important but not as important as having someone who is technically and clinically competent. In cases where cure is possible, the end does justify the means.

The advantages of this form of care for those who cannot be cured has, however been rightly questioned. Those with chronic complex illnesses, the aged and the dying are unlikely to benefit from a cure-orientated paradigm. These people, particularly those who are dying are extremely vulnerable. They may be subjected to aggressive and futile treatment while their psycho-spiritual needs, which are immediate and overwhelming, are frequently overlooked by a system that is more concerned with the 'fleshy envelope'. One of the first to alert the world to this dilemma was Ivan Illich. 'Modern medicine', he said, 'has brought the epoch of natural death to an end.'<sup>11</sup> Illich's comments certainly rocked the medical boat, but his stance has been vindicated as present day evidence suggests the problem is probably worse now than ever before. This is epitomised in a comments made by one prominent physician in a prestigious medical journal about nine years ago. He was at the time referring to the care of dying children – another vulnerable group. This is what he said: 'Discontinuing aggressive care means giving up and, in effect, represents failure'.<sup>15</sup> About

the same time, the Chairman and head of the Human Genome Sciences delivered a similar message to the New York Times: ‘Death,’ he said ‘is a series of preventable diseases.’<sup>16</sup>

It appears that medicine’s successes have coloured its vision of what is possible and has crippled its ability to discern and to empathise with another person’s anguish. The clinical imperative to preserve life and prevent death has, it seems, become more important than the complex and time-consuming process of helping people cope with their suffering.<sup>7</sup>

The biomedical mode of care and the research aspirations to cure disease has, according to Daniel Callahan, ‘led to a conflict about the place and meaning of death in human life’.<sup>5</sup> Death, he says, has become public enemy number one and the medical profession’s discomfort with dying has resulted in this ultimate rite of passage becoming a maze of medical ritual. It now appears that death, once the natural end to life, has become the unnatural and unwanted end to a series of medical interventions and procedures.<sup>17-22</sup>

### The dying game

By way of an analogy I liken the care of the dying to a game of chess – a game where the skills and talents of the medical team are pitted against a strong but invisible foe, namely death. It is a game where death’s every move is matched by vigorous counter attacks until there are no counter attacks left and checkmate is inevitable. Despite this seemingly hopeless position, the medical profession rarely concedes defeat and continues its fight to the very end. It may lose the war but considers itself to have won a small but significant victory if it has succeeded in delaying death. As the game is played out there is a real danger that a patient’s and their family’s psycho-spiritual needs may be neglected only because they are seen as peripheral to the real battle. With this form of care there is always collateral damage, and most of this is incurred by the patients themselves and their families. Their psycho-spiritual, needs, as was the case with Graeme Jones, are sidelined while the battle between life and death continues to rage.<sup>23,24</sup>

### End-of-life care

Let us now direct our attention to some published data that relates to end-of-life care. Time will only allow me to review a few studies, so I have selected those that focus on the aged, people with dementia and those who are dying. They all relate to care within hospitals for that is where the majority of deaths occur and where the ‘dying game’ is most frequently played out.<sup>25,26</sup>

To the best of my knowledge, there is only one paper that looks at the number of doctors seen by terminally ill patients in the course of their illness – a surprising fact given that importance attached to the doctor-patient relationship. This study was published by palliative care workers from the UK and was prompted by a distressing account from one patient who received confusing and conflicting messages from a number of different hospital doctors. The study determined the number of doctors seen by 50 cancer patients during the course of their illness and was calculated from patient and/or family recall supplemented by a search of hospital and out-patient files. The final count is, according to the researchers, likely to underestimate the actual number seen, but despite this the results are staggering. The median survival time for these 50 patients was 28 months and during this period the median number of doctors seen was 32. The minimum number was 13 and the maximum 97.<sup>17</sup>

Apart from the obvious question, why so many doctors, it was the therapeutic value of the visits that was called into question. Continuity of care, difficulty with communication and lack of information were identified as the main problem areas. This is evidenced by a statement made by one patient who said, ‘you have to start all over again with each one.’ Seamless medical care is clearly compromised when so many doctors are involved. Patients were given medical advice but this was frequently misunderstood by the patient and family. A not uncommon scenario when matters of life and death are being considered and when lack of time (as was the case with most out-patient visits) did not allow the doctor to give anything but the bare facts. The frightening thing about this study is that the large doctor contingent may represent the tip of a very large iceberg with patients seeing many other health care workers such as nurses, social workers, occupational therapists etcetera. One can only speculate on the effect of these visits on an ailing person’s limited physical capacity, their quality of life and their way of life. What suffers is something Graeme Jones described as precious normality or what I call ‘life’.

The next two studies looked at the care dying patients received during their final admission to hospital.<sup>18,19</sup> Both are retrospective studies and while one originates from the USA and the other Australia, they adopt similar methodology permitting valid comparisons to be made. The major difference between the two was with the range of primary diagnoses. Thirty percent of deaths in the USA cohort resulted from cancer and 60% from cardiovascular disease whereas all deaths in the Australian study were from cancer or other haematological malignancies.

Of the 200 people that died in the US study more than half were admitted or were transferred to an intensive care unit. The majority of these patients were connected to a ventilator and most died while still attached. Twenty five percent of the 200 patients had CPR and a similar number continued some form of artificial feeding or hydration up to the moment of death. In the Australian study of 100 deaths, significantly fewer patients were admitted to the ICU, 7% died while attached to a ventilator and only 2% had CPR. On the other hand, more than half were still receiving active treatment (chemotherapy and/or antibiotics) at the time of their death, 78% had tests performed in the last two days of life and 50% had an intravenous infusion running at the time of death.

At first glance both studies suggest that the care given to those dying is, not only aggressive but also inappropriate and futile. On closer analysis however the underlying problem appears not only with the strategy adopted, but with the clinicians' unwillingness to acknowledge that their patients were dying and to adjust treatment accordingly. With both cohorts, the recognition of impending death and the implementation of a palliative care plan occurred very late in the course of the illness, often a matter of days before death. In most cases the palliative care plan did not exclude the withdrawal of futile treatment or the cessation of pointless interventions such as blood tests. According to the authors of the US study, 'this pattern may represent a lack of clarity or ambivalence about the goals of care and a concern about doing nothing.' They conclude by suggesting that the maintenance of active and aggressive treatment may be for symbolic reasons – to avoid the perception of abandonment. Surely there are better ways for doctors to show that they care. The advice given by Dr. Francis Peabody as far back as 1927 is as pertinent today as it was then. He said, 'the art of caring for people is to care for people.'

#### Dementia and end-of-life care

My experience in caring for dementia patients at the end of their life is limited, as is my knowledge of the medical, legal and ethical complexities associated with the various treatment strategies available at the this time. I am referring to such things as the continuation of treatment that was once efficacious (e.g. medication to control blood pressure and cholesterol levels, and aspirin to prevent strokes), the role of antibiotics for infection, the appropriateness of artificial feeding and hydration and the diagnostic value of laboratory tests and X-rays. I suspect the problem is much the same for this group of patients as it is for those described previously – there is a reluctance to cease medications or to withhold investigations for fear this may be misinterpreted as giving up. The matter is contentious but society will have to come to grips with the question of how best to treat this vulnerable group of people as they near the end of their life. Failure to do so could lead to them becoming the victims of ill-considered or inappropriate treatment as one recent study confirmed.<sup>20</sup>

The choice of treatment and the clinical pathway adopted for dying dementia patients is as much a moral, ethical and legal issue as it is a medical dilemma (the same is true for those who have had a stroke or closed head injury – recall the Terri Schiavo case). A good example of the dilemma faced is the use of artificial feeding. The medical rationale behind enteral feeding is to help maintain nutrition in someone who has difficulty swallowing and to prevent pneumonia that could result from inhaling ingested food or fluids. The ultimate aim is to prolong life. Despite the rationale, evidence now suggests that survival is not prolonged and aspiration is not prevented in those who are tube fed.<sup>21</sup> To make matters worse there is also a high incidence of complications associated with tube feeding, but we continue to recommend and implement this form of care. Why? Because of the possible moral, ethical and legal consequences if we do not.

The same dilemma exists with those who have difficulty swallowing and, for whatever reason, are not tube fed. These patients are frequently given thickened fluids which are thought to be nutritious, easier to swallow than solids and other fluids, and less likely to be inhaled. But again there is scant evidence to suggest that any of this is true. From the 'consumer's' point of view, thickened fluids are not appealing to

the eye or the taste buds and, if body language is anything to go by, they are rarely approved of by the person who is made to swallow them. So once again an unpleasant treatment option is persisted with, not because it is better for the person but because it is thought to be the lesser of two evils.

### Patient and family perceptions of end-of-life care

One can only wonder how patients feel and how families respond to the forms of end-of-life care that have been described. Dr Joanne Lynn, a passionate advocate for the aged and the dying in the USA asked 3357 surrogate decision-makers about the care their loved ones received around the time of their death. In 40% of cases family were not satisfied with the medical care and 60% felt their loved ones psych-spiritual needs were unmet.<sup>22</sup> Sadly, this is a common response. In a recent US survey of almost two million hospitalized patients, satisfaction with emotional and spiritual care received one of the lowest ratings of all clinical care indicators and was rated to be most in need of quality improvement.<sup>23</sup> In another study involving two hundred cancer patients, 75% expressed dissatisfaction with the medical system, saying it failed to meet their emotional and spiritual needs.<sup>24</sup>

Evidence suggests the dying game is not in a dying person's best interest nor is it perceived favourably by family. Doctors, however will persevere with aggressive and inappropriate treatment while ever death is considered to be the enemy. They may see this treatment as life-saving, but it is, in reality, death-prolonging. Such an approach is not only futile; it fails to recognize the very personal nature of suffering and is therefore unable to meet the real needs of the person dying and their family.<sup>10</sup> Fifteen years have passed, but the words of the Regius Professor of Medicine at Oxford University are as true today as they were then: 'There is no doubt the current medical system is highlighting our deficiencies. Oncology is a good example. Patients are subjected to the most intensive protocols of chemotherapy, some of which require them to be taken to death's door in an attempt to eradicate their tumours...patients are pushed to the extremes of their endurance, and not always for reasons that include a careful appraisal of what is meant by quality of life.'<sup>3</sup>

### The cost of end-of-life care

It is difficult to put a cost on all of this, but clearly there is an emotional cost to patient and family, and also to the medical system as a whole and those who work within it. While this is undoubtedly a most important issue, the financial cost to the community cannot be ignored. Without going into detail, evidence suggests that hospital inpatient costs increase rather than decrease as death nears. When costs are tallied for the last twelve months of a person's life, the average cost increases exponentially in the three months before death with more than 40% spent in the last month of life.<sup>25</sup> The question that needs to be addressed is whether patients and the community are getting value for their money and if not, why not? Is the therapeutic and research imperative contributing to better end-of-life care or do they divert attention from the real needs of patients and families. And finally, what effect does this approach to care have on the mindset of those that implement it and on the system of care generally?

### Care versus cure

Patients' suffering at the end of life is well-recognised but the medical profession's capacity to address this in a compassionate and caring way is compromised by a health care system that is focused on cure. Modern medicine looks for solutions and flounders when there are none, as is the case when a person is dying. What these people want is for us to be present to their suffering – to be silent, to stay and to hear their grief. Or as the late geriatrician Richard Kalish recommended, 'Don't just do something, sit there.' The reason why doctors and other health care workers find this hard is complex and varies from one individual to another. The following however may contribute to a doctor's preference for the medical model:

- An underlying fear of death
- The medical training they receive
- Difficulties in making an accurate prognosis and determining when death is inevitable
- Fear of failure
- A moral, legal and ethical obligation to preserve life
- Community expectations
- Patient and family expectations (perceived or real)

Caring for the dying is not a game nor is it a battle. It is a time when the medical profession should stop intervening and help patients (and their families) prepare for the final stages of their journey. Paradoxically, the very cessation of inappropriate life-sustaining treatment can herald a form of care that invites dying patients to begin their final journey while at the same time presenting doctors with the opportunity to engage in meaningful dialogue with them and to partake of their own inner journey.<sup>27</sup>

In a recent study, a number of oncologists' were asked to reflect on the most recent in-patient death they were involved with. The results indicated two markedly different approaches to end-of-life care. There were those who viewed psycho-spiritual issues as important and others who did not. The former were not afraid to deal with the 'tough' questions, felt they had a more positive influence on the patient's and family's acceptance of the dying process and viewed the whole process as satisfying. Satisfaction with their role and their job overall, was much better when compared to those who maintained a more distant relationship. The latter often described a sense of failure in not being able to alter the course of the disease and suffered accordingly.<sup>28</sup>

There is a clear message here. Doctors who are not trapped by a biomedical model of care are more likely to respond to the psycho-spiritual needs of their dying patients and are less likely to be lured into the dying game and to resort to futile or inappropriate treatment. For these doctors, preparation for death is not perceived as giving up nor is death considered a failure of treatment. Because they are comfortable with the reality of death they are more likely to abide by the principles outlined below; principles that espouse a dying person's right for comfort, control, autonomy and independence.<sup>29</sup> Their right for care at a time when it is most needed.

- To know when death is coming and what to expect
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptoms
- To have choice and control over place of death
- To have access to information & expertise
- To have access to spiritual & emotional support
- To have access to palliative care
- To have control over who is present and who shares in your death
- To ensure wishes are respected
- To have time to say goodbye
- To be able to leave when it is time to go

The following experience described by Dr Bartholome, as he was dying of cancer, illustrates what is possible if the medical profession adopts a holistic model of care; a model that supports the dying person as they get on with the real business of living and dying. It may seem ironic, but living in the shadow of death is not so much life-threatening as life-changing. Dying is a transitional experience where the person often receives many unexpected gifts. Death then, is not just the end of life; it is a profound and complex human mystery. As Viktor Frankl said, 'As the outer life fades, the inner life becomes more intense.'

It's been a little over a year now since I discovered I have a fatal disease. In trying to explain to family and friends what, having this period of time meant to me, I have found it helpful to characterise it as a gift. It has allowed me time to prepare my family for a future in which I will not be physically present to them. It has given me the opportunity of tying up all the loose ends that our lives all have. I have been provided the opportunity of reconnecting with those who have taught me, who have shared their lives with me, who have touched my life. I have been able to reconnect with those from whom I had become estranged over the years, to apologise for past wrongs, to seek forgiveness for past failings.

But even more than all these, this gift has provided me the opportunity of discovering what it is like to live in the light of death, to live with death sitting on my shoulder. It has had a powerful

effect on me, my perspective on the world and my priorities...I like the person I am becoming more than I ever liked myself before. I am free of the tyranny of all the things that need to get done. I realise more than ever before that I exist in a web of relationships that support and nourish me, that clinging to each other here against the dark beyond is what makes us human...I have come to know more about what it means to receive and give love unconditionally... I wish that the final chapter in all your stories can have a chapter in which you are given the gift of some time to live with your fatal illness.<sup>30</sup>

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