'THE PROS AND CONS OF TRUTH TELLING IN THE DYING PROCESS'

'A little sincerity is a dangerous thing, and a great deal of it is absolutely fatal'

~ Oscar Wilde

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The following is an excerpt from an interview with Dr. Elisabeth Kubler-Ross, M.D. one of the foremost authorities in the field of death and dying for over 20 years. Interviewer:

'Is there ever any justification for not being honest with someone who is dying, about the fact that they are dying?'

Kubler-Ross:

'You have to be honest, but you don't have to be totally honest. You have to answer their questions, but don't volunteer information for which they have not asked, because that means that they are not ready for it yet. Without miracles, there are many, many ways of helping somebody without a cure. So you have to be very careful how you word it. And never, ever take hope away from a dying patient. Without hope nobody can live. You are not God. You don't know what is in store for them, what else can help them, or how meaningful, maybe the last six months of a person's life are.'

The subject of truth telling is complex. Truth in itself, is subjective and at its core, a philosophical conundrum. The extent to which truth is subjective can be determined by what an individual's base reality is and how in touch with their own reality they are. Aside from this, we have the existence of what we perceive as facts and if a person is intermittently disassociated from their own reality, their ability to relay accurate facts as truth is quite diminished. Then we have the dilemma of what is fact. Most dictionaries describe 'truth' as the quality or state of being true: 'he had to accept the truth of her inevitable demise'. Therefore, it is that which is true or in accordance with fact or reality. Accordingly, a 'fact' is described as a thing that is known or proved to be true. 'The MRI clearly shows bone metastases'. Therefore, it is information used as evidence or as part of a report.

In medical terms, fact is accepted as what can be scientifically proven as an objective and verifiable observation, in contrast with a hypothesis or theory, which

is intended to explain or interpret facts. In a practical sense, when working with the dying, medical and allied health care staffers are generally accepted as the possessors of the 'facts'. They are assumed to be the authority on the subject matter at hand and patients and family often place themselves at their mercy. Both research data and the reality of repetitive experience with dying patients inform their possession of knowledge and their ability to relay what they see as facts in the form of truth. However - how, whether and when this truth is communicated to patients and families, is dependant on a multitude of factors. These factors include the depth of knowledge and accuracy of

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the facts, the quality of the practitioner's bedside manner, their sensitivity, compassion and personal ethics, their ability to assess what is appropriate for their patient, how they perceive the patient's mental and emotional state, the actual reality of the patient's state of being, the attitude of the patient and their family members, the spiritual and cultural beliefs of the patient and their family members and the institutions' policy and guidelines regarding 'truth telling' and 'fact imparting'.

Miyaji (1993) studied 'truth telling' amongst American doctors in the care of dying patients. He found that doctors inform patients of their disease using three basic styles: 'telling what patients want to know', 'telling what patients need to know' and 'translating information into terms that patients can take'. The study overviewed five basic normative principles; 'respect the truth', 'patients rights', doctors 'duty to inform', 'preserve hope' and the 'individual contract between patients and doctors'. As it can be deduced from these styles, there is a constant assessment and translating process occurring, which is based upon a host of independent and hard to pin down variables.

When we think about the pros and cons of truth telling both from a medical perspective and a family/friends perspective, we are essentially facing the same dilemma. What are the advantages or more acceptable reasons for lying? Because, if we are not telling what we perceive to be the absolute truth, then we are lying (with lying being an intentionally false statement) or, at the very least, covering up and being guilty by omission. When working with the dying and determining the level of 'truth telling' or 'truth trickling', the following factors come into play: the truth can be hurtful; the truth can shock; the truth can force someone into denial or, further into denial; the truth can stress a person to the extent that symptoms are worsened and the individual plunges into depression. And, appropriate timing in these sorts of situations is everything.

With families and patients alike, omitting certain parts of the truth can help avoid unnecessary conflict. The skill lies in determining what, when, how and why. Saxe (1991) declared that deception serves as a 'social lubricant', which safely separates individuals, their negative thoughts and their reactions to what might be a shocking reality. The truth, in any guise can be hard to cope with. For example, if a doctor speaks directly about the terminal disease of a patient then the individual or their family may view that doctor as officious, cruel or incompetent. Not everybody can hear all truths. And deception or, deception by omission is often required because it allows people to share information with each other without adverse reactions that diminish the quality of well-being and without causing undue duress and further trauma.

On the other hand, as we see in the case of poor Ivan Ilyich, lack of truth destroys trust, limits choice and creates distance between people. The Death of Ivan Ilyich is a tragic piece from the pen of Leo Tolstoy about a man who dies in a conspiracy of lies, truth withheld, and demoralising pretence. At the time, he wrote this work of fiction, Tolstoy was preoccupied with dying, as human mortality was for him, in large part, a

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philosophical dilemma. For Ivan, the evidence of lies becomes most apparent only as he begins dying, and notices the self-deceiving way he is treated by others. What tormented him most was the deception, the lie, which for some reason they all accepted, that he was not dying but was simply ill, and he only need keep quiet and undergo treatment and then something very good would result. The obviousness of lies surrounding his deathbed eventually awakens Ivan to the lies that have been present his entire life. As he dies, he accepts the meaningless of his former life and he accepts Christ. In this way, the death of the body is the death of falsehood—and the beginning of truth and life. It follows that some of the lies we tell ourselves can only be understood through the lens of our own physical demise. Ivan Ilyich dies with great anger toward those who should have given him the greatest comfort. He felt alienated and alone when he most needed the assurance of closeness and love. He had to suffer without comfort from the physicians he needed to trust and the family whose love he craved.

'Truth May Hurt But Deceit Hurts More'. (Fallowfield et al: 2002). This study focusing on communication in palliative care, goes on to say that most patients diagnosed with a life threatening illness want to know the truth regarding their situation to enable them to plan their remaining time with their loved ones. Yet, there has been an entrenched desire amongst medical staff to shield patients

from the reality of their patient's dire situation. This usually creates even greater difficulties for patients, their relatives and friends, and other members of the healthcare team. Although the motivation behind economy with the truth is often well meant, a conspiracy of silence usually results in a heightened state of fear, anxiety and confusion, not one of calm and equanimity. In palliative care practice dilemmas and conflicts about truth-telling may involve collusion between health care professionals and the patients' relatives to withhold the truth from the patient. The outcome of this behavior is much like Ivan Ilyich's fate.

In the everyday reality of life, truth is surely a fundamental right regardless of whether it is bad news from the doctor, the sudden end of a relationship, or being sacked from a job,. Yet, the way that truth is imparted to people with a life limiting illness must be guided by insight, mindfulness, sensitivity and compassion. Maximum consideration must be shown for the well being of the individual and their ability to deal with the truth in a way that does not further debilitate them or cause them undue anguish. In many cases, the dying are besieged with information overload and over medicalisation and are often left traumatised. Truth telling must be tempered with kindness, discernment, good timing and respect with full attentiveness to the individual's ability to process the information amidst the chaos created by their illness, medical treatment and emotions.

There is a way to tell the truth that honours kindness, compassion and innate

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concern. Yet the ethical duty of imparting the truth entails the unavoidable risk that putting it in the person's possession will cause pain. Ethics and compassion, truth and love – they should never be strangers. The bottom-line issue with telling the truth is always respect for the other person. Perhaps the golden rule is simple: treat the other person, as you would want them to treat you. So the question must always be about not whether to but how to communicate the truth – lovingly, respectfully, and kindly. As Ivan Ilyich realised, it is better to be loved in the context of a painful truth than to be treated with such disrespect and pretence that no one and nothing can be trusted.

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