

## Dying to Know; Learning to Care

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*"Nothing in life is to be feared  
It is only to be understood"*

In writing this, Marie Curie could have been referring specifically to the care of people at the end of life. Since Victorian times death has become more hidden, often moved out of the view of most of the public and some of the professions. Cicely Saunders, the founder of the modern hospice movement was aware of this aspect of modern life and medicine when she created a professional discipline whose hallmark has been the combination of scientific understanding with personal concern. Readers of her work will know well that she identifies one of the key moments of her journey as her meeting and subsequent relationship with David Tasma, a 40 year old Jewish man who had survived World War II and the Warsaw ghetto. He spoke with her often about his life, his sufferings and what he wanted from his care-givers "I only want what is in your mind and in your heart" he told her, an oft quoted comment that addresses both the cognitive and interpersonal aspects of palliative care. Saunders was perhaps using a patient narrative to illustrate a point here. David Barnard and his colleagues, in their book "Crossing Over; Narratives of Palliative Care", identified seven overarching themes that emerged from their research into patient narratives at the end of life.

- i) There is no hard distinction between active treatment and palliative care and forcing patients to choose between them is hostile to good outcomes.
- ii) High quality palliative care requires a convergence of personal and institutional effectiveness.
- iii) Variations in socio-economic status are more likely to affect the quality of palliative care than the patient's diagnosis.
- iv) The definition of a 'good death' is highly variable.
- v) Patient or family centred care can appear more successful to the palliative care team than to the patient or family.
- vi) Relationships with patients, families and caregivers pass through many stages over time.
- vii) Professional caregivers as well as patients and families bring their histories of death and loss into the caring relationship.

Many years ago James and MacLeod published a paper entitled "The Problematic Nature of Education in Palliative Care". In that paper, whilst acknowledging that palliative care was emerging as a field of medical care in its own right, they identified that there were many aspects of palliative care that are problematic, particularly in the field of education. There are a number of those elements that remain problematic today. The aspects reviewed in that paper included the lack of a long tradition and adequate conceptualisation of palliative care; the significance of psychological, emotional and spiritual aspects of care; the importance of, but inadequate understanding of symptom control; the fact that palliative care is not curative in the accepted sense; the multi-professional nature of palliative care; the range of different settings of palliative care and the fact that palliative care givers have to perform their duties in situations where the emotional and psychological demands on them may be immense.

The relatively short life of palliative care to date means that there is not a long history of academic exploration and scrutiny. The essence

of hospice care, for example, is the provision of "good quality care." However, this good quality care is often ill-defined and difficult to measure. There is a danger that the physical dimensions of care may inevitably take priority over the other aspects that make up the totality of care because they lend themselves more readily to scrutiny and measurement. Because of this difficulty in measurement there is, for some, a difficulty in conceptualisation. Academic measurement is so often assessed in quantitative terms that qualitative evaluation is sometimes difficult to grasp. The Greco-Roman origins of western medicine suggest a medical model for illness; diseases are problems that have solutions. Many have argued that in developing its competence, western medicine has lost its caring. The emergence of palliative care is seen as a compassionate response to needs not being met by developed western medicine. As an emerging field however it is restricted by the poorly developed conceptualisation that often accompanies new areas of care. Our understanding of spiritual issues for instance is often sadly limited to religious beliefs or opinions without adequate reference to or exploration of the true significance and meaning of our spirituality. Despite the exponential growth in literature concerning spirituality there is still evidence of a lack of attention to detail and misunderstandings (Egan et al., 2011)

Although it can be argued that much of medical care is essentially palliative, in many medical interventions an outcome considered to be only palliative is neither desirable nor satisfactory. The non-curative nature of palliative care may not be an issue for those involved, some of whom have made a deliberate choice to care for people who are dying, however it remains an important issue to be addressed in palliative care education together with such aspects of the uncertainty of palliative care and the anxiety developed in the caregiver during his or her work.

Responding to the particular needs of individual people is fundamental to all medical care. The needs of people who are dying are likely to be more wide ranging than the needs of those who are not and in the delivery of palliative care those needs will be met by individuals and teams of different kinds. Listening to the patient's story and paying attention to the language used helps in the formulation of a diagnosis. This approach is also crucial as it allows a more valid formulation of particular needs and preferences the person has for their life and care. Only then can care can be tailored appropriately to meet the needs of the individual and remain true to the philosophy of palliative care.

The range of individuals in those teams allows palliative care to be multi-disciplinary and multi-professional in a way that other specialties in medical care are not. Within hospice/palliative care teams difficulties occasionally arise in the grey area between medical

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and nursing functions as roles become blurred. There is a difficulty of sharing knowledge in the care setting. The complexity of palliative care knowledge and its use as a basis for action present a particular challenge for those faced with the task of explaining aspects of palliation to others. This task may be yet more challenging because others in the team may not have adhered to the same “framework for understanding” which is essential for sharing if understanding is to take place. The implications here for palliative care education are significant. The task is not solely one of teaching palliative care but also of encouraging those involved to understand fully and to be able to articulate to others their theories and bases for action and to develop in other caregivers a framework for the understanding of practice. Palliative care cannot be seen solely in terms of skills and knowledge – it must include those processes that can be identified as metacognitive and reflective as well [2]

## Learning to Care

Frederick Hafferty, in his book, *“Into the Valley”* identified specific problems in medical training related to feelings inculcated during that training. He noted the variability with respect to affect that can be traced to the tension between medicine’s dominant values of detachment and distance and the lay values of concern and affectivity. His study characterised individuals wrestling with these concepts; they were unable to resolve the emotional difficulty of practising clinical medicine without enjoying any formal institutional support for their continued efforts to maintain a sense of self as sensitive, caring and reflective social beings. Over time he suggested it was easy to tire of the struggle. The emotional and psychological demands of palliative care are immense. The distance and detachment that are possible and perhaps even desirable in other forms of medicine are not so in palliative care. Indeed there is a case for arguing the opposite; that is that engaging with people who are sick is an essential feature of palliative care. Further, to tire of the struggle to be caring and sensitive as a consequence of the overwhelming demands, would be a negation of the principle theme of palliative care practice.

MacLeod investigated how doctors perceived they had learned to care [4] During the interviews in one study doctors retrospectively identified “turning points” at which they first perceived some notion of what it means to care for someone who is dying. The doctors often used poignant language and a number wept when recollecting the strong feelings associated with these critical incidents. They felt that their training had been inadequate in preparing them for such care. This situation should no longer be acceptable in our universities. This situation was identified in a slightly different form, decades earlier by Francis Peabody (1927). The practice of medicine in its broadest sense includes the whole relationship of the patient with his physician. Even at that time, students were taught a great deal about the mechanism of disease but very little about the practice of medicine. “The training is too scientific and the students do not know how to take care of patients”. Has there been sufficient change? Treatment of disease may be entirely impersonal but the care of a patient must be completely personal. Sadly though, there have even been suggestions that being empathetic ‘takes too long’ in a busy day. The pressure of work leads to doctors primarily treating disease; the conditions are not conducive or favourable to establishing a personal relationship. Peabody writes of a ‘great group of patients in which it is not the disease but the man or woman who needs to be treated...The good physician knows his patients through and through and his knowledge is bought dearly. Time, sympathy and understanding are needed. The reward is to be found in that personal bond which forms the greatest satisfaction of the practice of medicine...The secret of the care of the patient is in caring for the patient.’

Janssen and colleagues (2008) address how we teach medical students the art of caring for the person rather than simply treating the disease- a question particularly relevant to end-of-life care where, in addition to the physical needs, attention to the psychosocial, emotional, and spiritual needs of the patient is paramount. They investigate how we learn to care and develop caring human relationships, describing the development and display of empathy in adulthood and the developmental impact of human interaction. They also clearly outline evidence of situational barriers to effective education about care in medicine including role models, ward culture, and the socialization process. They propose a model for medical education based on patient contact, reflection, self-care, role model development, and feedback that will see students learn the art of human care as well as the science of disease management.

Caring itself can be thought of as behavior or as a motivation. As behavior it is often thought to mean “looking after people and seeing to their needs”. As motivation it can refer to being fond of someone, feeling sympathy or empathy for them, being concerned for their well-being or having a professional commitment to seeing to their needs. It could be argued that the best caring professionals show both of these aspects of care. To identify what caring means to patients themselves, Janssen and MacLeod (2010) sought the voices of people who were dying. The importance of care was illustrated through descriptions of the benefits of caring behavior and the negative consequences of uncaring behavior. They suggest that in order to demonstrate the empathy and compassion expected and assumed of medical graduates and engender a feeling of being cared for among their patients, doctors need to invite and develop a relationship with those they are caring for. This is primarily a human interaction – reciprocal in many ways, that needs to be attended to in just as much detail as aspects of disease management.

In his book *“The Illness Narratives”* Arthur Kleinman outlines his understanding of how the interpretation of illness meanings or narratives can contribute to more effective care. He sets out a practical clinical method that practitioners can (and should) apply to provide more effective and humane care [of chronically sick people]. He writes that his ‘alternative therapeutic approach originates in the reconceptualization of medical care as (1) empathic witnessing of the existential experience of suffering and (2) practical coping with the major psychosocial crises that constitute the menacing chronicity of that experience.’

Empathy is an elusive concept in medicine. Empathy is what we see or feel when we look at a picture, read a book, listen to music or experience a play. Empathy is much more than just knowing what we see or feel though, it is the image and the emotion generated by the picture or the music, the book or the play. Empathy helps us to know who we are and what we feel. William Blake wrote:

*“Can I see another’s woe,  
and not be in sorrow too?  
Can I see another’s grief,  
and not seek for kind relief?”*

True empathy focuses on the impact that disease and its treatment have on a patient’s ability to lead a meaningful life. Specifically it involves caring for the fate of another human being – the concept of empathy is relevant to the care of people who are dying because more than anything they are people in need.

It is these aspects of the caring relationship that need to be attended to.

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