Ulster Med J 2017;**86(2):**143-144

James Logan Prize Essay

The Importance of Holistic Care at the End of Life

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Accepted: 12th of November 2016

PREFACE

James Alexander Logan, a second-year medical student at the Barts and The London School of Medicine and Dentistry, died in February 2001 after a painful illness. A Trust was set up in his name in 2003 to promote education in the recognition and treatment of cancer pain and it provided funds for an annual essay prize, open to those undergraduate medical students of Queen's University, Belfast, who had completed their fourth year palliative care teaching. The first competition took place in 2010 and the winning entry appeared in the Ulster Medical Journal in 2011.

The Trust itself was dissolved in 2014 but the essay prize continues and the Trust's website can still be accessed at http://www.jameslogantrust.org.uk/

INTRODUCTION

No man is an island
Entire of itself;
Every man is a piece of the continent,
A part of the main;
If a clod be washed away by the sea,
Europe is the less,
As well as if a promontory were,
As well as any manner of thy friends
Or of thine own were;
Any man's death diminishes me,
Because I am involved in mankind,
And therefore never send to know for whom the bell tolls;
It tolls for thee'

MEDITATION XVII
Devotions upon Emergent Occasions
John Donne

This 17th Century poem by John Donne is a rare piece of literature that transcends generations, cultures and ages. This is partly because it deals with the universal theme of death and partly because the central message is, and always will be, true. That central tenet is that all human beings live their lives as interconnected entities and the invariable presence of death must be considered in the context of these connections. This essay seeks to explore how a holistic approach is required to optimise palliative care for not only the dying person's physical needs but also, for their relational existence.

BIOPSYCHOSOCIAL-SPIRITUAL

The most widely accepted model of care and research is George Engel's 1977 Biopsychosocial model[1]. This model was unique as it was the first time that healthcare providers were challenged to view service users within their wider context and not just as diagnostic and therapeutic challenges. More recent advances on this model have encompassed spirituality which is a sensible and necessary addition particularly in end of life care[2]. This essay will use the Biopsychosocial-Spiritual as a basis to explore how holistic care can be achieved at the end of life.

BIOLOGICAL

The biological needs of service users are largely dependent on the underlying illness. As the intent of treatment changes from curative to palliative many medical issues may arise. The most common challenges facing clinicians tasked with end of life care are pain, nausea, vomiting and breathlessness[3]. Multidisciplinary teams are assembled to optimise symptom control. Advances in therapeutics over the last century means that doctors have a significant arsenal of drugs to help ensure symptom control. While opiates remain the mainstay of treatment for pain at the end of life, many useful drug and non-drug adjuncts now exist. Complementary therapies are increasingly becoming integrated into end of life care. Although the quantitative evidence base for many of the treatments is still being collected there is certainly vast anecdotal evidence of its benefit. These complementary therapies which include acupuncture, aromatherapy and massage therapy, amongst others, can be used for not only symptom relief but also for psychological well-being[4].

PSYCHOLOGICAL

The psychological component of the Biopsychosocial-Spiritual model recognises the complex interplay of mind and matter. Emotional turmoil, lack of control, depression, despair and anxiety are all recognised manifestations in end of life care. The origins of these psychological issues are manifold but misgivings about diagnosis, treatment and the future should be addressed. The psychological theory

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of 'concreteness' is often employed to alleviate distress[5]. Concreteness stops service users dwelling on abstract questions about the future and encourages consideration of the concrete past and present experiences. There is an innate interplay between the psychological and the biological which is particularly well illustrated in palliative care. For example, if a service user is particularly dyspnoeic because of their underlying disease they may become increasingly anxious which will perpetuate the dyspnoea. This may continue until the point of exhaustion. However, simple interventions such as opening windows, use of fans, and use of medications can be made to improve either the underlying pathology or the anxiety which will in turn improve the dyspnoea. This is just one example of how management with a holistic approach can ameliorate the end of life experience for a patient.

SOCIAL

Humans are innately social entities. Interpersonal relationships allow us, as humans, to fulfil our innate need to belong. Relationships are dynamic systems which evolve over time and circumstances. We live our lives with many varied relationships including spousal, family, friends and neighbours. In end of life care consideration must be given to these connections and importantly to the person at the centre of these. Effective communication is absolutely essential for nurturing relationships at the end of life. Stress and grief are often potent catalysts for conflict in families. Often, sincere open conversations can help alleviate some of the conflict. This role should be undertaken by all members of the multidisciplinary team but often trained counsellors are required to address complex disputes. Where children are involved, efforts should be made to include them. Children will bring a unique set of questions and challenges so all communication should be age-appropriate. Another, often overlooked, relationship is the therapeutic relationship. In practice this means shared decision-making between service users and clinicians as well as transparency with the individual and the individual's family. Holistic care at the end of life then, not only extends to the individual, but to the many varied interconnections they have formed.

SPIRITUAL

Spirituality is something which is difficult to define with many definitions from different perspectives. In essence, it can be thought of as 'a person's search for meaning'. Traditionally this has meant a religious belief in one or more deities. As our society grows so too does the boundary of spirituality. Many more minority religions are now part of society as well as an increasing number of atheist groups. Spiritual care at the end of life is seen as a vastly important issue by healthcare providers. There is an abundance of formal research and a systematic review by the department of health in order to equip providers with the best possible tools to provide holistic end of life care[6]. An evolution of services is taking place that better reflects our changing society. Spiritual care has increased in visibility in the last two decades. Previously spiritual care was equated with religious care and the provision of chaplains was seen as zenith. Now, a broader concept of spirituality has been adopted and is seen as the remit of not only the chaplains but of all healthcare staff. Although the Liverpool Care Pathway is now discredited, one of the positive aspects was that it included a question about spiritual and religious beliefs[7]. This question often prompted discussions within families about a subject that they may have found difficult to broach. So, although spirituality is a complex and challenging aspect of end of life care, it is paramount to providing quality holistic care.

CONCLUSION

This essay has outlined the principles of end of life care using the biopsychosocial-spiritual model as a framework. However, it is inaccurate to conclude that rigid provision of care according to this model would provide sufficient care. Death, like life, is a matter of individuality. Service users should be granted autonomy in all aspects of their care with continued input and feedback from the family. Exemplary end of life care is not about rigid guidelines but rather supporting the individual and their family on their personal journey.

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