DEALING WITH FAILURE IN PALLIATIVE CARE

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Abstract: In this article failure is considered from general, political and financial perspectives, Technological failure is discussed and educational, organizational and communicational failures are identified. In a Hospice setting, corporate staff failures are explored and the more painful personal and spiritual failures at the patient/carer interface are examined.

Key words: failure, palliative care, death, patient, carer

Introduction

Confronting Failure in Palliative Care is a challenging, daunting and uncomfortable experience. It involves "sounding soul depths" but there are significant rewards. In Palliative Care, our starting point is failure. We tend to inherit the clinical failures of others. Perhaps the motto of Mary Queen of Scots - "My end is my beginning" - could be corrupted to - "*Their* end is *our* beginning".

But what is failure?

- To fail is to fall short or be lacking in
- To fall away, to dwindle,
- To die (so Death is a failure)
- To prove deficient under trial or examination or pressure
- Not to achieve
- To be disappointed or baffled
- Not to be sufficient for
- To leave undone or to omit
- To deceive
- Failure is omission or lack of success

To be fallible is to be capable of making mistakes or liable to error. Failure comes from the Latin fallere - to deceive (This is not too far from the Latin *palliare* - to cloak from which palliative care is derived and so perhaps we should not be too surprised to experience failure in Palliative Care!).

If failure is lack of success, we ought also to define success. To succeed is to obtain one's wish or to accomplish what is attempted, to come after, to follow, to come into another's place. Success is prosperous progress, achievement, termination (which is not too far from ending, death, failure). Therefore perhaps success and failure are more closely linked than we imagine and we can conclude with J.M. Barrie that *We are all failures - at least all the best of us are* (Maxwell 2000).

The big picture

We do fail, we all fail but we find it difficult to acknowledge and confront failure and so we look for circumstances or others to blame. Don't we?

Isn't it comforting to have politicians and Health Ministers to blame for the *Big Problems* of resource allocation? We tend to look after cancer patients with Palliative Care needs and cancer has been high on the political agenda but shouldn't patients with non-malignant diagnoses also receive palliative care? Shouldn't Palliative Care be available to all who need it? Isn't it a Governmental responsibility to provide resources? We are currently in an age of expecting that everything that <u>can</u> be done for patients <u>should</u> be done with regard to surgery, chemotherapy etc. but we are already facing a crisis of resources. So who will make decisions regarding the sharing of resources, including:

- Palliative Care resources, in the future?
- Will the decisions be equitable?
- Who will advise the decision makers?
- What can we do?

Perhaps our role is, firstly, to provide evidence, (though characteristically we have been poor at pro-

viding an evidence base for what we do) to demonstrate by Needs Assessment exercises that patients with e.g. Neurological diagnoses like Multiple Sclerosis and Motor Neurone Disease, who could benefit, are being denied access to appropriate care.

Secondly, we need to educate the politicians and the Scottish Office through agencies such as the Clinical Standards Board for Scotland and the Scottish Partnership for Palliative Care.

Thirdly, we need to attract significant individuals to the cause, e.g. J.K. Rowling, who have an interest or personal experience, to increase the profile of previously neglected patients. We must be sure of this - we fail if we do nothing at a national level to highlight the plight of patients with non-malignant diagnoses and their need for Palliative Care.

We can also fail patients with Palliative Care needs, whatever their diagnoses, at a Regional level if there is no organized referral system or a lack of knowledge of basic Palliative Care and communication skills.

The influence of the Scottish Partnership for Palliative Care (SPPC 2001), the Clinical Standards Board for Scotland (CSBS 2002), the Scottish Intercollegiate Guidelines Network guidelines (SIGN 2000) and emerging Managed Clinical Networks (MCN) will help greatly but in our own regions we have responsibilities -

1. To ensure the Primary Health Care Teams (PHCT) and hospital staff at all levels are educated in pain and symptom control and communication skills and that a referral system is in place for those with Specialist Palliative Care needs.
2. Jointly to produce local standards, guidelines and protocols, thereby constantly improving quality of care.
3. To improve communication by letter/ telephone/ e mail to achieve seamless care.

Dealing with failure in a hospice setting

Within our own organizations we have even greater responsibilities. My experience is in Hospice care but I believe this can be extrapolated to other situations, as Hospices do not have a monopoly on death and dying.

The Inpatient Unit

Great changes have taken place in Palliative Care since I started work at St. Columba's Hospice 18 years ago. Life was simpler then but Hospices have become more sophisticated and some people are beginning to ask if we now fail our patients by over-investigating, over-medicalising or over-physicalising death. The number of investigations (blood tests, microbiology, radiology) we perform has risen exponentially, particularly in the last 5years (Forth Valley Health Board, 2000) but there are situations we can improve dramatically - for example by treating hypercalcaemia, by commencing, discontinuing or altering the dose of drugs or by arranging a single fraction of radiotherapy to painful bony metastases - and, increasingly, we might be seen to be negligent if we do not attempt improvement.

What we must do is ensure that we discuss with patients and relatives the risks and benefits of each course of action and listen to what their wishes are. Hospices are not immune to Hospital infection problems and we have had serious difficulties associated with MRSA and Clostridium Difficile infections but by routinely isolating patients to avoid cross infection we are in danger of failing our patients and making them feel like lepers. We are bound by NHS guidelines (Health Advisory Group on Infection 1998) with regard to infection control and do adhere to them but we need to be innovative in our ways of dealing with the problem.

Could we be accused of failing by excluding relatives - by not permitting them to care for their loved ones within the hospice setting? Do we consider the Adults with Incapacity (Scotland) Act 2000 and the implications for involving relatives? We constantly need to ascertain their wishes and their understanding.

Are there symptoms we fail to deal with? Do we pay attention to the detail of pain and symptom control? Do we use the SIGN guidelines? Do we know our limitations and when to ask for help?

Isn't failing to ask for help a failure? Have we developed clinical and corporate governance? Do we do everything we can to minimize risk?

With regard to the timing of death, do we fail to have the relatives present if they wish to be there? Do we ensure up-to-date contact numbers at all times?

Day Care

If our patients are well, volunteer drivers collect them but if their physical conditions deteriorate they are transported by private companies for a fee. Should we be negotiating with the Health Board or Lottery for funding for a neglected area?

Day care is a therapeutic, social environment but do we fail our patients by "missing something" amongst the buzz? We've all had doorstep conversations regarding issues which patients would be reluctant to broach in a social group or for which they would even be reluctant to request a private chat. Are we able to provide "natural" regular one to one slots and private facilities to allow verbalization of deep feelings but prevent embarrassment or stigmatization?

Home Care

We may fail here by lack of availability - i.e. not providing a 24 hour, seven day a week service or we may fail by doing too much. We may be seen as "the Cavalry" coming in and deskilling or disempowering others - District Nurses, relatives, clergy. Do we fail by not having an in-patient bed or equipment available when required? Do we fail by not keeping abreast of new developments, drug regimes, lifting and handling techniques?

Are we victims of our own success? If we pull out all the stops in one situation do we unrealistically raise expectations of professionals or families in another? These thoughts may be familiar but we can still blame the organization, the management, the system for these failures.

Failure at the patient/carer interface

At Strathcarron Hospice we have a room called the Holly room. It is a family room and we place patients with young families there because it has a double bed and extra equipment. Our memories of patients we have cared for in that room are often coloured by feelings of failure. This is unlikely to have anything to do with the name Holly, though we are aware of associations with eternal life, pagan gods and prickly leaves! Sifting through the case sheets of patients who have died in Holly allows some common strands to be identified in relation to the theme of failure:

Patients' responses to failure

The transition from physical health to sickness and dependency brings many non-somatic consequences (Thomson 1976, Vanstone 1982). Patients progressively lose the ability to exercise power and influence in the ways used by physically healthy people but may develop alternative means of exerting power: A patient may report symptoms (e.g. pain, insomnia, infection) but refuse medication ("poisons"). Even if care is accepted it may not be validated as effective.

Physical disease may be accompanied by "malignant alienation", manifested when a patient is "out of sorts" with everything – self, world, God, family, carers. The carers can consequently become apprehensive of the patient and afraid to approach him. The patient then becomes more powerfully manipulative and selectively alienating, causing staff schisms.

The patient may subject the actions and attitudes of carers (both professional and family) to analysis and scrutiny, thereby potentially giving rise to mutual suspicion, defensiveness and hostility. Tensions may arise if the patient and family have different perspectives on treatment ("let illness take its course" vs "do everything possible to extend life"). Patient and relatives may differ in their respective standpoints in relation to faith, belief, and alternative therapies.

Failure and carers

When confronted with these manifestations of patient power, carers can be subject to feelings of failure. Exceptionally long involvements or exceptionally short involvements are familiar stressors. Other stressors for carers include:

- Young patients with dependent family members
- Synchronous life-threatening illnesses in the same patient
- Criticism of care, particularly if unjust
- Unanswerable spiritual issues
- Quest for therapy outwith our resources e.g. "healing" or "wholeness" by alternative/complementary/unorthodox means

- Refusal of mediation in intractable family tension.

Corporate failures can be corporately admitted but at our deepest levels as carers we all have personal failures which we are reluctant to admit even to ourselves. We may make gaffes. We may fail to respond to cues when we feel out of our depth, unable to cope or when we fear our intervention may worsen a situation, perhaps especially in the spiritual or psychosocial realms. In addition, our own personal (professional/domestic) baggage may impact negatively on our ability to deliver effective care and the asset of sensitivity may degenerate into the liability of hypersensitivity. The conscientious worker may become the workaholic, unwittingly demeaning other colleagues. Little is known about the impact on individuals of a life-time career in Palliative Care, this being the first generation which has worked solely in this area of medicine but perhaps the key is in how we deal with our own vulnerability. *I will be forced to pay attention to my own suffering and need if I am to be of service to anyone else* (Campbell 1986).

The discipline of pastoral theology has rightly highlighted the theme of the "Wounded Healer", (Campbell 1986). *The wounded healer heals because he or she is able to convey both an awareness and a transcendence of loss*. (Church Times 1997). Henri Nouwen (1972) relates this, not only to the experience of disability, but also, and possibly more importantly, to the task of care-giving. So professionals who seek to deliver care in the face of apparent failure can draw on spiritual resources and also on principles closely related to professional caring:

- Acknowledge patient autonomy
- "Come into another's place" or "wear another's shoes" – see from another's perspective, possibly with the help of fellow-professionals to re-evaluate both failure and success, and what these may actually mean to patients.
- Be realistic, acknowledging that we fail because we are human.
- Promote mutual support within the caring team – foster realism about our own personal and professional strengths and weaknesses.
- Ensure appropriate peer support networks exist to prevent "natural" failures progressing to burn out or serious mental/physical illness.
- Set limits - demarcate boundaries for professional activity and personal leisure and recreation.

Palliative care purports to offer comfort, reassurance and hope where there is apparent failure (life-threatening illness) and those who deliver Palliative Care are confronted by failure both in and around them. By enabling patients and carers to identify and utilise their own personal and spiritual resources, failures can be challenged. As good palliation can offset the adverse effects of illness, so the personal and spiritual resources of carers and patients can extenuate feelings of failure.

Death

With the prospect of impending death as the outcome of life-threatening illnesses, patients and their carers may reflect on the question of what death might mean. For some death is soothing, welcome, an adventure but for many death is a failure, feared because of its inevitability, the uncertainty both of its timing and what lies beyond it and the variation in its quality. The acceptance by past generations of dying as "God's will" is no longer a satisfactory explanation to many but, as the illness advances, there can be a shift in perspective whereby the final outcome comes to be regarded as a friend, bringing ultimate release from pain, dependency and disease and even by some as "the final healing".

The ideal, frequently but by no means universally achieved in specialist palliative care, would be to provide opportunities in the ending of life for forgiveness, reconciliation, hope, and the expression of deep emotions. The pursuit of these issues may well involve reflections by patients, family and staff on perceived failures in their lives which could become overwhelming but, by acknowledging and confronting failure, perhaps we can all better understand it, learn from it and begin to "fail forward" (Maxwell 2000) thereby achieving a measure of success.

A final thought

Antonio Machado beautifully describes failure transformed:

'Last night I dreamed-
-blessed illusion-
that I had a beehive here
in my heart
and that

the golden bees were making
white combs and sweet honey
from my old failures.'
(translated by Robert Bly) (O'Donohue 2000).

Acknowledgement

I would like to thank the Rev. Stuart Coates, Hospice Chaplain, Strathcarron Hospice for inviting me to consider the concept of Failure in Palliative Care and for his advice and helpful comments on the manuscript.

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Editorial Note

'Dr. Downs' article is adapted from a talk which she originally prepared for a conference organised by the College of Health Care Chaplains, but which, due to unforeseen circumstances, she was unable to deliver.