Maverick or Ethical? How far should we treat a dying patient in order to enhance their quality of life?

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Introduction

Throughout medical education, medical students are taught about diagnosing and treating disease. However, what about patients who are not treatable or unlikely to benefit from any pharmacological or surgical intervention? Indeed, chronic health such as heart and lung disease are never really 'cured', but are frequent attenders to the emergency department for symptom control. What about palliative patients? Palliative relates to any patient who has a progressive non-treatable irreversible illness that will take their life prematurely. This encompasses not just cancer patients but also those with neurodegenerative conditions such as MS or MND and, end stage heart and lung disease. In fact, even advanced dementia is now seen as a palliative diagnosis. Palliative is a spectrum which in cancer terms, implies the cancer has metastasised to other areas of the body. This could often cover a time span of several months to weeks (Commonly termed End of Life Care). When a patient appears to be 'dying', then this is often implied to be the last hours-days of life. In this time scale, it is appropriate to call this the terminal phase.

This is an ethical medical case involving a palliative cancer patient who had metastatic bowel cancer with a prognosis of weeks to live, but also suffered from chronic insomnia for about fifty years. I was asked to review to treat his insomnia in order to enhance his quality of life. He had requested anaesthesia in order to regain the energy needed to complete the churchyard garden before he died. Insomnia is the inability to have adequate restful sleep. This may be acute, over a few days or chronic if more than one month. 30-40% of the population may be affected with higher incidences seen with increasing age and among females,[1,2,3] and is deemed an important public health problem.[4]

Discussion

Propofol is the most widely used intravenous anaesthetic agent, being ultrafast and associated with rapid recovery and less hangover effect than other anaesthetics. It can be used for both induction and maintenance of anaesthesia in adults and children. It is rapidly metabolised by the liver and excreted in the urine. It is occasionally used in palliative medicine for terminal agitated delirium and for severe intractable vomiting.[6,7]

The recent death of the singer Michael Jackson from propofol (administered for chronic insomnia by his cardiology physician Dr Conrad Murray) brought biased media attention regarding the safety of this anaesthetic.[8,9] Although propofol is not recommended as a treatment option for chronic insomnia[8], a recent randomised double-blind, placebo controlled study on 103 adults with chronic insomnia, receiving either propofol or saline infusion, resulted in an improvement in the sleep pattern of 64 patients who received propofol, which persisted for six months afterwards with no adverse effects.[3] The risk argument against the use of this drug for the long-term treatment of chronic insomnia is unknown, as few studies have been undertaken.

Current evidence for managing chronic insomnia involves the use of Zolpidem, benzodiazepines and non-pharmacological methods such as cognitive behavioural therapy (CBT) & progressive muscle relaxation techniques.[10,11]

A new class of drug Ramelteon **(Rozerem®) is licenced in the USA for chronic insomnia and acts as a selective M-L1 melatonin receptor agonist within the suprachiasmatic nucleus of the hypothalamus, but was withdrawn in the UK and Europe in 2008 due to lack of convincing evidence of its efficacy.[12,13,14] However, a recent systematic review seems to show some clinical benefit for chronic insomniac suffers with this drug.[15]**

Discussion

The patient's quality of life was the driving factor which prompted the final decision to anaesthetise him, which is not an easy quantifiable marker because it is heterogeneous and subjective. For him, his dying wish was for the pleasure of a few hours sleep under anaesthesia. Because of his previous experience of anaesthesia prior to surgery, he knew it would re-energise him and allow him to work for 'longer hours,' to complete the church garden before becoming too unwell. There was considerable disagreement with some of the Macmillan nursing team who felt the patient was manipulative. Another objection raised was the negative impact it could have on the palliative care service, as well as setting a precedent for chronic insomniac sufferers who could demand the same treatment. Lastly, there was the risk to my professional career if the patient died under anaesthesia. Because there is no clear guidance or precedent for anaesthetic sedation in this niche patient group, there was therefore an element of medical risk taking. However, despite the many objections, the overriding objective was the safety, dignity and quality of life for this patient, thus the utilisation of a highly skilled consultant anaesthetist was employed.

A few weeks post-procedure, this case was discussed by the hospital Clinical Ethics Committee (CEC) because of the uniqueness of this procedure. Ironically, they voted against this procedure being ethical as it was felt the potential for harm of anaesthesia outweighed the good; that it could set a precedent, and may not be the best use of limited resources (Justice argument). However, it was pointed out by another consultant anaesthetist on the ethics committee, that the use of propofol by a skilled anaesthetist and under controlled conditions was a very safe drug.

Had the ethics committee given a consensus before the procedure, it is probable that the patient would not have received his wish to be anaesthetised for his chronic insomnia. What impact this may have had on his morale and wellbeing is speculative.

Case Presentation

Mr BW is a 73 year old who was diagnosed with Dukes C carcinoma of the colon in 2007. He initially underwent surgical resection of the tumour and later received chemo-radiotherapy for metastatic spread to both the lungs and liver. He describes having insomnia for about fifty years, and has undergone every investigation and treatment options, all to no avail. On average, he slept about 2-3 hours a night.

A referral was made by the Macmillan nurse to myself to treat him for his chronic insomnia. The patient stated that the only drug that initially worked was a barbiturate, back in the 1960s. Currently, he was taking Temazepam 20mg, Lorazepam 2.5mg & Promethazine 25mg, with no real benefit. Despite having a prognosis of weeks, Mr BW insisted on working on average four hours a day maintaining the church gardens, which he has been doing for the last ten years.

However, he felt that the chronic insomnia compounded his fatigue, impeding his ability to work longer. He was determined to complete the church gardens by Christmas 2012, after which, he would then be ready to die.

Mr BW frequently requested during consultations anaesthetic sedation in order to enable a full nights sleep. This, he believed would 're-vitalise' him, as he described always feeling refreshed on two previous occasions following general anaesthesia for surgery. His request was initially resisted as it was not deemed a reasonable option. Instead, a barbiturate, Phenobarbitone 30mg, was commenced orally along with dexamethasone (steroid) 6mg for daytime energy, which did help. The patient was non-compliant, insisting that he didn't want any medication that would sedate him during the day. The next option was to switch to a short acting barbiturate, Amibarbital 120mg, but again, he disliked it.

Because the patient was desperate to regain some sleep in order to fulfil his dying wish, it was eventually agreed that an anaesthetic opinion would be sought for a one-off non-repeatable sedation. The anaesthetic consultant agreed to sedate him for one night only and his admission arranged when the anaesthetist was also on call at the hospital. He was sedated with an infusion of propofol, with cardiac monitoring for six hours. He awoke, initially feeling a bit drowsy, but in the afternoon, he was back at the church ground mowing the lawn and saying he felt 'refreshed.'

The hospital communications officer became aware of this planned admission and obtained the patients consent for Anglia TV news to tell his story, which he consented to. He was filmed both prior and after his sedation which was then broadcasted that evening.[5]

Remarkably, post-anaesthesia, he lived for a further five months and died peacefully at the local hospice in March 2013.

Ethics

The four principles of ethics are autonomy (right to self determine), Beneficence (do good), Non-maleficence (no harm) and justice (same treatment for all), underpins the way we practice medicine. Deciding whether any treatment is beneficial is determined by the *good* being greater than the *harm*.

Summary

We seemed to have lost a fundamental skill in modern medical training, and that is the *art* of medicine, which was very much an attribute of the *old apprentice* medical training of bygone years, whereby you learnt, were inspired and motivated by our clinical teachers. Is this something that perhaps needs to be reintroduced in modern clinical training? We have lost the skill to *think outside the box*, to innovate, to inspire, and to be willing to take risks for our patients-providing of course the benefit outweighs the harm. It is not solely medical knowledge that makes good doctors. It is also your communication, compassion and empathy which are harder to evidence base. Patients aren't just interested in how much you know, but also how much you care.

If this were your patient, would you have anesthetised him?

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