

**IN THE HIGH COURT OF NEW ZEALAND
WELLINGTON REGISTRY**

CIV-2015-485-235

UNDER	The Declaratory Judgments Act 1908 and the New Zealand Bill of Rights Act 1990
BETWEEN	LECRETIA SEALES Plaintiff
AND	ATTORNEY-GENERAL Defendant

**SECOND AFFIDAVIT OF RAJESH MUNGLANI
SWORN 15 MAY 2015**

RUSSELL McVEAGH

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I, **RAJESH MUNGLANI**, consultant, of Cambridge, United Kingdom, swear:

1. I am a Consultant in Pain Medicine practising in the United Kingdom. I have previously sworn an affidavit on 22 April 2015 in this proceeding. I refer to that affidavit.
2. I swear this affidavit in response to the affidavits of Dr Tony O'Brien and Baroness Ilora Finlay. I address each in turn below.

Dr O'Brien

3. Dr O'Brien questions the extent of my experience in cancer pain management.
4. I was appointed as a lecturer/senior research associate in anaesthesia at the University of Cambridge as well as an honorary consultant in anaesthesia at Addenbrooke's Hospital, Cambridge in 1995 following a period of time as a clinical lecturer in anaesthesia running my own neurobiology lab.
5. In 1996 I started up a new pain clinic, I dealt frequently with patients from Arthur Rank Hospice in Cambridge, cancer patients from Papworth Hospital and also patients sent from Bury Saint Edmunds from the hospital and hospice there. I usually treated 1 cancer patient per week. Such was the frequency, we often left an extra slot for treatment on my list because the number of patients was so regular and frequent. This did not include the outpatients that I saw, which were in addition.
6. I was given an honorary consultancy at Arthur Rank Hospice in recognition of my contribution, by Dr Tim Hunt who was the lead palliative care physician at the time. At one stage I was holding regular ward rounds at the hospice.
7. In 2000 I was invited to start a new pain service at the West Suffolk Hospital in Bury Saint Edmunds. There was great support both from the anaesthetic department and also from the palliative care physicians at Saint Nicholas's Hospice in Bury Saint Edmunds who had been regularly sending otherwise intractable cancer patients to me at Cambridge.
8. When I arrived at Bury Saint Edmunds, I was the only consultant who could do neurolytic blocks, complex facial injections and intrathecal neurolytic injections in a very large area of East Anglia and was regularly sent complex patients from far and wide. I appointed a clinical assistant in about 2007 and a further consultant in 2010 or thereabouts, but neither had the experience to deal with such patients. They were able to manage many of the general cancer patients but they would always leave the more complex ones for me.
9. In 2014, because of my increasing medicolegal and other work, I decided to give up paid employment in the NHS and give of my free time once a month. By this stage I had one clinical assistant, two pain consultant colleagues, a consultant psychiatrist and 6 nurses in the team that I had personally built up.
10. I still have regular phone calls about how to handle the most severe cancer patients.

RM Dm².

11. Dr O'Brien questions why I do not mention cancer work on my website. This is because it is my own private website which talks about my medicolegal and spinal trauma work. I am of the strong opinion that treatment of cancer patients should be done within a multidisciplinary environment of the NHS with no regard for money. I do certainly see cancer patients privately at the specific request of oncologists and palliative care consultants who know my skills and interest, but I do not advertise it.
12. When I was asked to write the article on suffering in cancer pain I wanted to make sure the article was up-to-date and chose as my co-author the leading pain consultant in Britain in cancer pain. He was the head of pain services at the Christie Hospital Manchester, the largest cancer hospital in Europe. He is no longer there, but subject to the usual formality, I expect him to be appointed to a large teaching hospital in London to build up the cancer pain services shortly.
13. In that way I hoped to combine both my long experience of dealing with difficult cancer pain along with the experience of one of the most highly regarded cancer pain doctors in the United Kingdom, to make sure our article was thorough and up-to-date.
14. Whilst my research and other articles have focused much on trauma and intractable pain, my own experience combined with that of my colleague I believe represents a considerable amount of experience in treating severe cancer pain that has not been able to be controlled by palliative care physicians.
15. At one point Dr O'Brien calls the article unbalanced. I do not accept that criticism as accurate. We were very careful to make sure we quoted some of the largest and most comprehensive surveys of cancer pain in Europe illustrating the persistence of pain in patients who had otherwise had care. That included some of the most up to date surveys available.
16. In my opinion, the argument that palliative care can control all these symptoms is simply not justified on the basis of the comprehensive reviews of cancer pain which we provided, much of which comes from the palliative care literature.
17. The decision to publish in the journal was based on the view that since the debate is taking place in a wider context than just the medical profession, it makes sense to reach a wider audience and inform it on the medical issues.
18. In paragraph 43.5 Dr O'Brien states that I have "catastrophised" the options into assisted suicide or else unbearable pain, sedation. He states the having cared for 100s of patients he has not come across such a decision.
19. The simple fact is, as mentioned in our article on pain and suffering in cancer patients, such decisions are much more common than many palliative care physicians would like to think.

Ref DMH. 3

Baroness Finlay

20. I have also read the affidavit of Baroness Finlay. She specifically refers to my article from paragraph 75 onwards. There is no doubt that the understanding of a patient's suffering is complex and she gives cases where suffering was undoubtedly intensified by other factors including previous abuse. I have little doubt that she is correct, I see the same in my patients both in those who have cancer and in those who have other serious pain conditions.
21. However, this does not detract from the point I am making that despite absolute optimum care from a palliative care and pain medicine point of view, even with psychological support there remain a number of patients who continue to suffer unbearably. She also calls for better training for palliative care physicians and doctors generally including GPs.
22. Whilst many patients do become used to the side effects of opioids, many do not, which is why they are referred to pain medicine for treatment as they cannot tolerate opiates.
23. I have had some prior contact with Baroness Finlay. In 2014 I was quoted in the House of Lords: "Dr Rajesh Munglani, the well known expert in pain management, writes that he frequently sees cases of excruciating pain that are unresponsive to powerful analgesics and can be alleviated only by very heavy sedation, to the point of unconsciousness." Following that, Baroness Finlay emailed me to say that her experience was at a variance to mine, and requested the data supporting my position, the frequency with which I see such patients, the types of opioid that are failing and the indications and protocol I use to sedate patients.
24. I responded to that email, setting out the evidence for my position. I also canvassed the views of my colleagues (which generally supported my position) and included those views in the response. Baroness Finlay does not refer to my response in her affidavit. A copy of my response is annexed at "RM1".

SWORN at Cambridge, England this 15th
day of May 2015 before me:

D. Hargreaves (Solicitor)

A person duly authorised to administer
oaths by the law of England & Wales

R. Munglani
Rajesh Munglani

D. HARGREAVES
(SOLICITOR)

IRENA SPENCE + CO
MOUNTPLEASANT HOUSE
HUNTINGDON ROAD
CAMBRIDGE.

"RM1"

Dr Rajesh Munglani

Cambridge

13th August 2014

rajeshmunglani@gmail.com

Dear Lady Finlay

Assisted Suicide Debate

Thank you for your recent email on 22nd July to my secretary asking for clarification of my experience as a Consultant in terms of dealing with pain and suffering in patients; as you said your experience seems to be at variance with mine.

I am sure you have a lot to deal with so I have enclosed the main substance of your emailed letter as a footnote¹ and will do so with any other quoted material for convenience.

Whilst I hope my reply will assist you, I wish to point out that all the opinions I express are my own, and do not reflect on any of the institutions where I have worked or continue to work; furthermore in my clinical practice I fully respect the rights of Parliament and the GMC to legislate and regulate

¹ Dear Dr Munglani,

You were recently quoted in a House of Lords debate as follows "Dr Rajesh Munglani, the well known expert in pain management, writes that he frequently sees cases of excruciating pain that are unresponsive to powerful analgesics and can be alleviated only by very heavy sedation, to the point of unconsciousness."

As someone who has worked in palliative care for over 25 years and who has run a chronic pain management programme, my experience in Wales seems to be at variance with yours.

I would therefore be grateful if you could provide me the data behind your statement and the frequency with which you see such patients, the types of opioid that are failing and the indications and protocol you use to sedate the patients to the point of unconsciousness.

I look forward to hearing from you.

With kind regards,

Ilora Finlay

Baroness Finlay of Llandaff
House of Lords
Westminster, London SW1A 0PW

This is the annexure marked "RM1" referred to in the affidavit of Rajesh Munglani sworn at Cambridge, England this 15th day of May 2015 before me

Signature 

A person duly authorised to administer oaths by the law of England & Wales

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D. HARGREAVES
(SOLICITOR)
IRENA SPENCE + CO
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HUNTINGDON ROAD
CAMBRIDGE

respectively in this area and have to the best of my ability followed such laws and guidance without question, whilst still continuing to seeking to engage in debate on the subject.²

Dealing with the points you raise.

Do we see cases of unbearable suffering?

I was somewhat surprised by your email , I presume that you mean that you never come across patients who are suffering unbearably despite optimal medical management, if I have understood your email correctly.

One possible explanation is the differing roles we have.

As Consultants in Pain Medicine, we are only asked to intervene when other specialties are not managing to controls the symptoms of pain and so we tend to see pain at one end of the spectrum, that is uncontrolled by “conventional” means.

In this context, “conventional” would include those types of analgesics, hypnotics and other medications and infusions , which have undoubtedly improved pain control in palliative care settings including oral and transcutaneous opioids, benzodiazepines, ketamine, topical local anaesthetics etc.

Despite these major advances, as consultants in Pain Medicine we still see patients in severe distress; unfortunately they are often over-medicated and confused following quite natural attempts to control their symptoms and with little QOL³, or indeed no QOL.

Fortunately we are able to help some of these patients with optimisation of medication and on many occasions often using spinal delivery of the same drugs as mentioned above or the use of neuro-ablative techniques.

² *I have taken part in two theologically based meetings on Euthanasia , one at Bishop's House Coventry at the invitation of the Bishop and then subsequently at a theological training college in Cambridge **Dying Well: Faith and Compassion in Dialogue**. A conference hosted by: The Simeon Centre for Prayer and the Spiritual Life on 15th to 17th September 2011 at the Ridley Hall. Cambridge and have published one article on the specific subject and was also involved in a study which was published on End of Life preferences many years ago*

³ QOL Quality of Life I add these explanations for a reason detailed at the end of this letter.

In such situations we never work alone but in conjunction with our oncology and palliative care colleagues as well as other specialties as necessary including surgeons, rehabilitation professionals and others such as priests for spiritual support etc.

Unfortunately at least twice a year, we came across cases where, despite the interventions of everyone, patients suffer pain and distress and undoubtedly suffer, along with those around them including family and loved ones as well as attending medical and nursing staff.

In my experience it is in these situations, that comments “to put someone out of their misery” come from patients and their relatives or other phrases such as “I wouldn't let my dog suffer like that”.

The failure to control the suffering of an individual in such situations diminishes the individual; they are often over-sedated to the point of confusion, but in my opinion, in addition, undermine the role of the medical and other professions who are possibly ultimately powerless to act. I would make it clear that I do not personally sedate them to the point of unconsciousness; this has been observed in some cases in which I was asked to intervene, in the hospice setting over the years.

Since I was so surprised by your particular experience of not coming across such a situation in 25 years according to your email, I sent the substance of it to some of my colleagues in pain medicine without disclosing any contact details and I have enclosed some of the mostly anonymised responses below 4.

4

From: Rajesh Munglani <rajeshmunglani@gmail.com>

Subject: Assisted dying bill and do we see cases of unbearable suffering? Date: Tue, 22 Jul 2014 21:15:47 +0100

To: Pain Consultants <painconsultants@googlegroups.com>,

Dear Colleagues

I know this is a sensitive subject and strong views are held on it

Some of you may know I am not opposed to assisted dying and in fact am actually of the opinion in some cases the law should allow me to fulfil my duty of care to a patient by acting in a compassionate manner by relieving suffering to the point of death

Over the years I have come across not a few cases where patients have been in great distress and wishing to die due to uncontrolled pain or loss of dignity or both or else analgised to the point of unconscious in attempt to control suffering (terminal sedation)

One particularly distressing case was a consultant who taught me who had been unable to lie on one side due to severe pain, doped to the eyeballs in the hospice

The skin over the affected hip was dry and unwashed and in a horrendous state (the side he couldn't lie on due to severe allodynia from tumour infiltrating into the spinal root)

I did a bed-side paravertebral block in the hospice there and then and he turned over and slept properly for the first time in many weeks

Fortunately He died shortly after but he said he could not see the point in extending his life (neither could I for that matter)

Unfortunately in other cases my ministrations have not been as helpful

And patients have spontaneously expressed a wish die

Any way the reason for writing is that Baroness Ilora Finlay (who as you know is a palliative care consultant) has written saying to me saying the following

"Dear Dr Munglani,

You were recently quoted in a House of Lords debate as follows "Dr Rajesh Munglani, the well known expert in pain management, writes that he frequently sees cases of excruciating pain that are unresponsive to powerful analgesics and can be alleviated only by very heavy sedation, to the point of unconsciousness."

As someone who has worked in palliative care for over 25 years and who has run a chronic pain management programme, my experience in Wales seems to be at variance with yours.

I would therefore be grateful if you could provide me the data behind your statement and the frequency with which you see such patients, the types of opioid that are failing and the indications and protocol you use to sedate the patients to the point of unconsciousness.

I look forward to hearing from you.

With kind regards,

Ilora Finlay"

Before I reply and list the cases I have come across I want to gauge whether my experience of unbearable suffering in some patents is out of kilter with others consultants experience.

If you are happy to let me have specific anonymised cases and if in addition wish to put your name beside them let me know

Whilst I'm happy to be a voice crying in the wilderness if necessary, John the Baptist did come to a sticky end!

I look forward to hearing from you

Raj

The responses I obtained are below:

Subject: Re: Assisted dying bill and do we see cases of unbearable suffering?

Date: Tue, 22 Jul 2014 23:41:10 +0100

To: "painconsultants@googlegroups.com" <painconsultants@googlegroups.com>

In my many roles both in hospital palliative care and as informal consultant to the hospice, it is clear that there is neither a joined-up strategy to facilitate community nerve infusions (such as BPI or LPI or even ITI) or the servicing of IT implanted systems. It certainly true that I see many cases of opioid induced hyperalgesia (wrongly diagnosed as disease progression) and that just this evening I had a call from the hospice as they were running out of strong ketamine and could I suggest alternatives-a result of the UK's supply interruption courtesy of our friends at Pfizer. I have seen many many cases of opioid induced sedation and hyperalgesia (worse IMHO) and sometimes I have seen these patients in 'terminal agitation' given industrial doses of opioids and midazolam in the name of lessening distress.

WADR to Baroness Finlay, I doubt she could recognise opioid induced hyperalgesia and is almost certainly a doctor versed I. The Brompton cocktail. If that isn't sedating to death, I'm not sure what else qualifies.

In the end, a patient with a sacrum entirely invaded by tumor with an unstable pelvis, a late stage pancreatic cancer patient with huge coeliac and mediastinal mets or a young man with myeloma and 6 levels of vertebral collapse hasn't got that many options, and that's just this weeks caseload. When was the last time Illona was on call? Sometimes the 'double effect' phenomenon works to the patients and family's advantage. To claim otherwise is disingenuous.

.....
Subject: Re: Assisted dying bill and do we see cases of unbearable suffering?

Date: Tue, 22 Jul 2014 22:52:17 -0600

To: "painconsultants@googlegroups.com" <painconsultants@googlegroups.com>

Dear Raj

Greetings from the US and I hope this finds you well. Please don't get me started. This is very rich coming from a senior palliative care consultant - but only to be expected. This happens on a daily basis in hospices and also in hospitals. But what happens in that realm stays there. After all the patient didn't suffer and die of pain - this is the mantra that is drilled into the patients' family and they feel relieved. And in the eyes of many in the palliative care world (Sam you certainly are an exception and should be the role model), cancer with no treatment option = dying patient. It is the use of high doses of opioids and other drugs that put the patient on that slippery slope. Most of them need good assessment and an analgesic plan.

I am not in a position to champion the case of assisted dying simply because most of my patients want to live with better quality of life and that is my primary objective. Usually the patient realises at some point that his time is nearing and decides enough is enough - then I arrange for end of life care of their choice usually their own home. It is facilitating good end of life care for the patient and the family. However if the law permits I would do what is needed in the best interest of the patient on their instructions. We do that in intensive care when we confirm that the patient is brain dead; here it is easier because the patients themselves feel that their life is not worth living as they are suffering on a daily basis and there would be no answer to it.

Kindest regards

Dr Arun Bhaskhar

Subject: Re: Assisted dying bill and do we see cases of unbearable suffering?

Date: Thu, 24 Jul 2014 12:25:25 +0200

To: "painconsultants@googlegroups.com" <painconsultants@googlegroups.com>

It's now a few years since I stopped seeing cancer patients and it is disturbing to see that even though there may be improvement, things still haven't totally changed. There seem to be two separate threads here - one related to adequacy of pain relief (and the need for interventions) and the other to assisted dying. Both, however, seem to be related to the apparent inflexibility (?conceit) of some in palliative care in being unable to recognise their own limitations!

BW

Hi Raj

I have seen very few such patients, the only one I can recall: Businessman, 60-65s, just taking impressive pension and retiring to rural bliss finds he has lung cancer. Unilateral chest pain, opioids increased to the point that he is sleeping most of the day. Just about rouseable, but cannot keep awake to listen to or complete a sentence in reply. Intrathecal phenol neurolysis on a Wed. Slept all day Thursday, woke up Friday. When I saw him Friday evening he was sitting in the sun eating strawberries and drinking wine. He was euphoric and had very unrealistic ideas of what he would do on leaving the hospice. He then comes down to earth with a bump over the next few days. He still had to go through his final dying. I often think about him, because he had effectively been separated from his loved ones by the pain and medication, by waking him up again we gave him a further window on life, but inflicted the pain of separation a second time. On a slightly different tack I attach the text of a letter I fired off to the DT (unpublished!). Like you, I am not totally opposed to the principle of assisted dying, but who actually delivers the goods is crucial. Perhaps it would be better to find a softer name for the new category of licence, but the idea is still worth consideration...

Subject: Re: Assisted dying bill and do we see cases of unbearable suffering?

Date: Fri, 25 Jul 2014 11:32:40 -0500

To: "painconsultants@googlegroups.com" <painconsultants@googlegroups.com>

Licensed to Kill.

The Assisted Dying Bill proposes that doctors be empowered to prescribe medicines to end life. Patients may wish to know their doctor's views. To this end, in the event that the Bill be enacted into law, I would urge the General Medical Council to create a new category of registration in addition to the existing licence to practice, licensed to kill.

Only those doctors so registered could fill the roles defined in the bill as "the attending doctor" or "the assisting health professional". Registration would be optional. The list of registered practitioners would be publicly available. The General Nursing Council could act similarly in respect of their members who wish to act as "the assisting health professional".

The point we are trying to raise is epitomised in your case

Unilateral chest pain, opioids increased to the point that he is sleeping most of the day. Just about rouseable, but cannot keep awake to listen to or complete a sentence in reply. Intrathecal phenol neurolysis on a Wed. Slept all day Thursday, woke up Friday. When I saw him Friday evening he was sitting in the sun eating strawberries and drinking wine. This is the problem we see very often; patients are drugged up to the point that they feel isolated and the family sees them as a shell of their former self. By the time they are referred to us, the damage is already done and it is often too late. When you do get them out of their "situation" two things happen - a) as you mentioned, patient comes out with unrealistic expectations and put the oncologist under pressure and b) the more common scenario, the penny drops that they are actually dying and often results in distress and related problems. We should endeavour to work together to provide appropriate levels of analgesia so that the quality of life is maintained as much as possible rather than adopt a strategy based on the belief that pain can be successfully managed by opioids as endorsed by the WHO ladder and the belief of many clinicians that there is no higher limit for opioid dosing. The article below is looking at a different aspect, but points towards the issue of tolerance and hyperalgesia in patients with advanced cancer.

Oosten, A. W., Oldenmenger, W. H., van Zuylen, C., Schmitz, P. I. M., Bannink, M., Lieveise, P. J., Bromberg, J. E. C. & van der Rijt, C. C. D.. 2011. Higher doses of opioids in patients who need palliative sedation prior to death: Cause or consequence?. *European Journal of Cancer* 47: 2341-2346. doi: 10.1016/j.ejca.2011.06.057.

BW

Dear Raj,

I had a patient several years ago, leiomyosarcoma left posterior paravertebral T5/6 level who despite maximal oral therapies, steroid blocks and finally an intrathecal pump was in severe pain for the last few months of life. He was also seen at the Marsden (John Williams very kindly organised the IT pump) The only additional treatment would be phenol ablation of the spinal cord or hypothalamotomy but access to these treatments are very difficult and the patient may not want to risk loss of motor function.

I have had calls from our local hospice over the years for pain procedures but some patients do not want to risk loss of motor function and due to

limited list capacity, a 2 week wait often means the patient has died before they can have the procedure. Baroness Finlay does not refer to the fact that patients may report their pain has improved because they are sedated rather than have improved pain control with higher dose opioids. Palliative care does rely on the sedating effects of opioids

to help patients manage their pain. Is this assisted dying or helping the patient manage their pain?

I would be interested to know if she manages patients on a one-to-one basis. We all know pain clinics who have received national awards but other hospital specialties in the same area are having to manage patients in severe chronic pain and this is why the interventional radiologist is an expanding service.

The assisted dying bill should enable doctors to avoid fear of sedating a patient to help them manage their pain and keep them comfortable. Assisted dying should not mean killing.

The current problem is that some doctors are fearful of giving adequate doses of opioids and patients are dying in severe pain. If she is concerned about abuse, every case of assisted dying could be referred to the courts or a local

The opinions of some of these very experienced pain consultants are fairly forthright and as you can see not one shared your view or had a similar experience.

Some colleagues privately expressed concern to me that your reassuring views of the ability of doctors to control all pain and suffering were being expressed at the highest levels of decision making of this country without the contrary experiences of other doctors also involved in the relief of pain and suffering, being taken into account. That is, that at times we *do* see cases of severe pain and distress despite all therapy and that this view should also be expressed to the non-medical Honourable Members in Parliament.

In fact I did not find a single pain consultant, of those who chose to respond in writing or communicated to me in private, who agreed with you despite the fact the consultants had opinions which lay on both sides of the assisted dying debate and also included the views of some of the senior pain specialists in this country, including one who has cancer pain as a major part of their practice of pain management.

What I want to emphasise, both for myself, and I think it is fair to say amongst the respondents is that we all see predictably, but thankfully not frequently, cases of patients coming from hospitals, hospices and also in the community, whose pain and distress is not relieved adequately. Indeed I would say that some are suffering terribly for long periods of time.

Fortunately we can help many, but there are clearly some we cannot without essentially making the patients significantly sedated. The great difficulty is if there does not seem to be an imminent prospect of dying, this often leads to great distress for all.

My own experience

practitioner (but they would need rapid access). The alternative is that patients obtain illegal drugs on the black market.

Kind regards,

Emma Chojnowska

Consultant in Anaesthesia and Pain Management

Over the years, in active clinical practice I have come across, despite the thoughtful input of palliative care and other specialities, one or two cases of cancer patients each year being in severe and uncontrolled pain. These include patients with tumours growing around and into the nerves and bones of the face, pelvic pain secondary to pelvic tumours invading the sacral plexus and paraspinal tumours growing in towards the spinal cord and spinal roots. The latter was in fact a senior consultant colleague who used to teach me (I recounted this case in my email to my pain consultant colleagues). He had specifically asked me to go in and treat him, as the hospice had failed to control his symptoms despite being there as an inpatient for several weeks.

A more difficult case has been a patient, though diagnosed with an abdominal malignancy, is still doubly continent but suffering from agonising rectal pain. He could still walk about and showed no prospect of dying at the time.

After a period of 6 months of futile treatment including trials of various medications and injections, spinal infusions to locate the source of pain and radiotherapy and various types of neurolytic block to the sympathetic chain, he began to express a wish to travel to Switzerland.

When I mentioned this case anonymously with an someone who opposed assisted dying and discussed what therapeutic options were left, including the use of intra-thecal phenol which of course would have made him doubly incontinent and possibly paralyse him, the opponent said to me that the patient "should be made to have the treatment even if he did not want to".⁵

⁵ This case was discussed (with the patient's permission) at the Bishop of Coventry's Colloquium on Euthanasia in 2010 which I had the privilege of attending and speaking at, along with others on both sides of the debate. This included Professor Nigel Biggar from Oxford and also Professor Badham from Wales along with barristers etc. Some of the delegates chose to put their thoughts into writing and this was published in the journal of observational pain medicine where my own paper was also published too. Just to clarify I have not identified the individual who actually said this.

Mark Bratton—a former barrister and currently a Priest organised the conference and reviewed all the other papers arising from it and also wrote the following about the conference "The articles included here were prepared for, and discussed at, a Colloquium on physician-assisted suicide and euthanasia held at the invitation of the Bishop of Coventry, the Right Reverend Christopher Cocksworth. The invitees included doctors, practicing barristers, philosophers, policy-makers and theologians representing a variety of different viewpoints. The aim of the 2-day gathering was to encourage frank discussion of the main issues with a view to promoting greater understanding of opposing positions, rather than to produce consensus. Papers were presented, questioned and commented upon with an emphasis upon seeking to understand why each individual held the views they did. At the end of the Colloquium, participants were asked to reflect on what they had shared and learnt, and invited to contribute to the set of essays published here"

The latter comment begs the question exactly what the purpose of medicine is—the simple mere prolongation of existence or in fact the maintenance of quality of life?

For many years, (whilst a Consultant at Addenbrookes and a Lecturer in the University running a pain research lab, an Honorary Consultant at Arthur Rank hospice for a time, lead clinician for the chronic pain service, and also subsequently as the lead clinician in Pain Medicine at the West Suffolk hospital Bury St Edmunds and associated with St Nicholas hospice) I came across such cases, not frequently, but regularly. I would submit this experience is not out of keeping with that of my colleagues.

In more recent years because of the expansion of my own medico-legal work I have taken more of the back seat, and now hold only an honorary contract at the West Suffolk Hospital having been a lead clinician there for 14 years and much of the cancer work is now dealt with by my excellent colleagues.

In fact one of them chose to reply and their comments are also given in the footnotes.

More general data as regards the presence of unrelieved pain in cancer

The next question to raise of course is what about the wider picture? Is the experience of pain consultants so radically different from other doctors, in seeing so much pain and suffering in dying patients?

It is interesting the literature from the pain and palliative care societies associations and societies without much dissent do seem to support the presence of pain as a significant feature in a proportion of cancer pain sufferers⁶. This view of the high levels of pain, especially in advanced

The papers can be freely downloaded from the Journal of Observational Pain Medicine website (www.joopm.com) but I will send my paper and that of Mark Bratton to you for convenience and I will happily send the rest.

⁶ **Prevalence of pain in patients with cancer: a systematic review of the past 40 years**

Abstract

Background: Despite the abundant literature on this topic, accurate prevalence estimates of pain in cancer patients are not available. We investigated the prevalence of pain in cancer patients according to the different disease stages and types of cancer.

Results: Fifty-two studies were used in the meta-analysis. Pooled prevalence rates of pain were calculated for four subgroups: (i) studies including patients after curative treatment, 33% [95% confidence interval (CI) 21% to 46%]; (ii) studies including patients under anticancer treatment: 59% (CI 44% to 73%); (iii) studies including patients characterised as advanced/metastatic/terminal disease, 64% (CI 58% to 69%) and (iii) studies including patients at all disease stages, 53% (CI 43% to 63%). Of the patients with pain more than one-third graded their pain as

disease was also confirmed in the British Pain Society's own publication on treatment of cancer pain.⁷ My reading of the literature and experience suggests that this continues despite all the therapies and interventions we have to offer. Thankfully the incidence of severe pain that is uncontrolled is small but for that individual patient of course, dominates their whole existence. The National Cancer Institute at the NIH in the US again cites the high level of pain experienced and thankfully most pain (but unfortunately not all) can be controlled⁸.

moderate or severe. Pooled prevalence of pain was >50% in all cancer types with the highest prevalence in head/neck cancer patients (70%; 95% CI 51% to 88%).

Conclusion: Despite the clear World Health Organisation recommendations, cancer pain still is a major problem.

Ann Oncol (2007) 18 (9): 1437-1449. Also cited at <http://www.medscape.com/viewarticle/564770>

⁷ Extract below from **The British Pain Society's Cancer Pain Management**

A perspective from the British Pain Society, supported by the Association for Palliative Medicine and the Royal College of General Practitioners Jan 2010

10.2 Epidemiology of cancer pain in the community

10.2.1 Prevalence

Systematic reviews (Hearn, 2003; van den Beuken-van Everdingen, 2007) have demonstrated that **cancer pain is common and its prevalence is related to the stage of illness:**

- 48% of patients with early disease.
- 59% undergoing cancer treatment.
- **64-74% with advanced disease.**

These findings are in keeping with those in the recent European Pain in Cancer (EPIC) survey of 11 European countries, which indicated an overall pain prevalence of 72% of patients with cancer in the community. The rate was slightly higher in the UK at 77% (Breivik, 2008).

10.2.2 Pain severity

Most research on cancer pain severity has been conducted in secondary care settings (Klepstad, 2002; Yates, 2009). Using a 0-10 numerical rating scale, hospitalised cancer patients typically report:

- mean scores for worst pain of 4.8.
- mean score for average pain of 3.7.

⁸<http://www.cancer.gov/cancertopics/pdq/supportivecare/pain/HealthProfessional/page1>

The highest prevalence of severe pain occurs in adult patients with advanced cancer. Chronic pain is an issue in cancer patients, with up to 33% continuing to have pain after curative therapy. During active cancer treatment and in advanced disease states, tumors cause most pain. However, survivors are affected more by pain related to modalities such as surgery, chemotherapy, or radiation therapy than by cancer-related pain. One summary provides an excellent review of troublesome symptoms in cancer survivors, including pain. Although cancer pain or associated symptoms often cannot be entirely eliminated, appropriate use of available therapies can effectively relieve pain in most patients. Pain management improves the patient's quality of life throughout all stages of the disease. Patients with advanced cancer experience multiple concurrent symptoms with pain; therefore, optimal pain management necessitates a systematic symptom assessment and appropriate management for optimal quality of life.[3] Despite the wide range of available pain management therapies, data are insufficient to guide their use in children, adolescents, older adults, and special populations.[4]

A presentation of the American Cancer Society states 75% of Cancer patients suffer pain though though added 90% could be controlled with optimal treatment (in which case, by implication there is lack of control in 10%)⁹ .

A very recent study suggests that in patients who survive cancer, persistent pain is a major problem in 5-10% despite therapy including long acting opioids, and of course the problems with opioids are also highlighted ¹⁰.

Reflective practice to improve management of pain in cancer

The apparent failure of conventional pain management in cancer should cause us to reflect on our practice and all the factors that might be contributing to the persistent experience of pain. That is we should carefully analyse the situation of the patient and their pain in relation to the diagnosis, and see how it can be improved and make sure, as you say appropriate that protocols are being followed.

⁹ **American Cancer Society available here**

<http://www.cancer.org/acs/groups/content/@ohio/documents/document/acspc-023667.pdf>

In this lecture it states the following :

About one-third of cancer patients in the U.S. suffer from significant pain. Although pain is often thought of as happening in advanced stages of the disease, it may occur at any stage for many reasons:

Impact of Cancer Pain Impact of Cancer Pain **Nearly 75% of patients with advanced cancer have pain.** Of the people with cancer who have pain, about 40-50% describe it as moderate to severe and another 25-30% describe it as very severe. Cancer Pain can have significant impact on the physical, emotional, and psychological aspects of life: Suffering, decreased quality of life, feeling a lack of control. **He goes on to states that with optimal treatment 90% should achieve relief. NB not 100%**

¹⁰ J Clin Oncol. 2014 Jun 1;32(16):1739-47. doi: 10.1200/JCO.2013.52.4629. Epub 2014 May 5.

Pain in cancer survivors.

Glare PA¹, Davies PS², Finlay E², Gulati A², Lemanne D², Moryl N², Oeffinger KC², Paice JA², Stubblefield MD², Syrjala KL².

Pain is a common problem in cancer survivors, especially in the first few years after treatment. **In the longer term, approximately 5% to 10% of survivors have chronic severe pain that interferes with functioning.** The prevalence is much higher in certain subpopulations, such as breast cancer survivors. All cancer treatment modalities have the potential to cause pain. Currently, the approach to managing pain in cancer survivors is similar to that for chronic cancer-related pain, pharmacotherapy being the principal treatment modality. Although it may be appropriate to continue strong opioids in survivors with moderate to severe pain, most pain problems in cancer survivors will not require them. Moreover, because more than 40% of cancer survivors now live longer than 10 years, there is growing concern about the long-term adverse effects of opioids and the risks of misuse, abuse, and overdose in the nonpatient population.

Yet despite adequate resources, as the footnote below shows, some patients continue suffer significant pain¹¹

Analysis of whether current therapies can be expected to control all symptoms

It is clear that many reviews show that most analgesic drugs do not work in most patient. This was specifically highlighted in a major article and editorial in the BMJ.¹² That does not stop us trying to help but we have to understand the limitations our treatments and ability, including poor efficacy and side-effects.

It is recognised that opioids in whatever form, do not provide the desired relief in many cancer suffers and though rapid acting opioids can be very useful for break through pain, there are issues as

¹¹ Epidemiology of cancer pain and factors influencing poor pain control

Mellar P. Davis, Declan Walsh, Abstract

Pain is one of the most commonly experienced and feared symptoms of advanced cancer. Most cancer patients experience pain, usually of moderate to severe intensity, and most also have a number of distinct pains. The most common type of pain is related to bone metastases. Neuropathic pain occurs in one-third of patients, alone, or as a mix of nociceptive and neuropathic pain.

The failure to manage pain properly is due to several factors. In developing countries, it is likely to be related to geography and limited resources. Legal restrictions also present barriers. In developed countries, failure to manage pain properly is usually related to a "disease" rather than a "symptom" model of care, which minimizes symptom management. Other factors include lack of physician education and failure to follow existing guidelines. Patients fear addiction, drug tolerance, and side effects. **Despite adequate resources, pain is still undertreated.**

¹² BMJ 2013;346:f2690 doi: 10.1136/bmj.f2690 (Published 3 May 2013)

Expect analgesic failure; pursue analgesic success

Most analgesic drugs work well but in only a small percentage of people. Andrew Moore and colleagues argue that we need to move away from a focus on average response and seek out what works for each patient

Professor Andrew Moore , Sheena Derry , professor Christopher Eccleston , Professor Eija Kalso .

The first part of the article starts as follows

"A 2003 newspaper article caused considerable grief for the pharmaceutical industry. Entitled, **"Our drugs do not work on most patients,"** it claimed that most drugs worked in only 30-50% of people. While that surprised journalists and the public, it was not news to professionals, including the then editor of the BMJ.

The Editorial that accompanies the article is given here

BMJ 2013;346:f3666 doi: 10.1136/bmj.f3666 (Published 5 June 2013)

Balancing benefits and harms

Fiona Godlee

"Unfortunately in the balance between benefits and risks, **it is an uncomfortable truth that most drugs do not work in most patients.** On the positive side, Andrew Moore and colleagues say that if we can embrace the fact that most treatments fail, we will deliver better and safer care. But this needs a radical shift in the way we evaluate and use drugs (doi:10.1136/bmj.f2690)."

regards to dosing, particularly in patients already on higher doses of the same opioids in a sustained release formulation.¹³

The recognition that cancer patients continue to suffer despite the availability of best practice and current drugs has led to the trialing of newer cannabis derived agents because of these continuing unmet needs¹⁴

¹³ Crit Rev Oncol Hematol. 2011 Dec;80(3):460-5. doi: 10.1016/j.critrevonc.2010.12.002. Epub 2011 Jan
The use of rapid onset opioids for breakthrough cancer pain: the challenge of its dosing.
Mercadante S.

Abstract

Breakthrough cancer pain (BTcP) has been defined as a transitory increase in pain intensity on a baseline pain of moderate intensity in patients on analgesic treatment regularly administered. This review provides updated information about the use of opioids for the treatment of BTcP, with special emphasis on the use of new rapid onset opioids (ROOs). Due to its slow onset to effect oral opioids cannot be considered an efficacious treatment for BTcP. Parenteral opioids may provide rapid onset of analgesia, but not always available particularly at home. Different technologies have been developed to provide fast pain relief with potent opioid drugs such as fentanyl, delivered by non-invasive routes. Transmucosal administration of lipophilic substances has gained a growing popularity in the last years, due to the rapid effect clinically observable 10-15 min after drug administration, obtainable in non-invasive forms. Fentanyl is a potent and strongly lipophilic drug, which matches the characteristics to favour the passage through the mucosa and then across the blood-brain barrier to provide fast analgesia. Transmucosal, buccal, sublingual, and intranasal fentanyl showed their efficacy in comparison with oral morphine or placebo and are available for clinical use in most countries. All the studies performed with ROOs have recommended that these drugs should be administered to opioid-tolerant patients receiving doses of oral morphine equivalents of at least 60 mg. The choice of the dose of ROO to be prescribed as needed remains controversial. The need of titrating opioid doses for BTcP has been commonly recommended in all the controlled studies, but has never been substantiated in appropriate studies.

¹⁴ <http://www.gwpharm.com/cancer-pain.aspx>

This comes from the website of GW pharma makers of Sativex, which is derived as you know from Cannabis Cancer Pain

Over one-third of patients with cancer, and around three-quarters of those with advanced disease, have chronic pain. Currently available opioid therapies do not yield sufficient relief in a substantial proportion of these patients and there is a clear need for new treatments.

Chronic, unremitting pain in deep tissues that results from cancer adversely affects a disproportionately large portion of the population. Worldwide, more than 12.7 million people are diagnosed with cancer each year (WHO cancer factsheet 2008) and it has been estimated that by 2020 that figure will rise to more than 16 million people a year. The prevalence of cancer pain directly correlates with the stage of disease, with more than 70% of patients in the advanced stages of cancer reporting pain (World Health Organization, 1996). In particular, patients with breast and prostate cancer, both of which have a propensity to spread to bone, more often experience pain than patients with uterine and cervical cancer. Pain as an initial presenting symptom will occur in 20-40% of patients. Severe pain occurs in 20-35% of the cancer population and significantly impairs activities of daily living. The mean incidence of pain in a sample of 5,410 patients (across 22 studies) in various stages of cancer was 51%, whereas among 9,007 patients (across 38 studies) with advanced metastatic or a terminal phase of cancer, the mean incidence was 74% (Bonica, 1990).

Currently, opioids are the principal agents employed in the management of cancer pain, but the therapeutic benefit of their prolonged use is frequently offset by the development of undesirable effects such as constipation, sedation, respiratory depression and tolerance (Kehl et al., 2003).

Other symptoms as well as loss of autonomy as a motivator for request for assisted dying

It is clear that even if one is able to control most symptoms of pain in about 90% of patients with optimal availability of best practice, including protocols and drugs and of course clinicians willing to provide such care (which is not always the case), the simple fact is some patients continue to request assisted dying because they have lost the will to live.

Their quality of life, in their own eyes, has been so destroyed, particularly with loss of function and bodily image, they see little meaning in continued existence. I have particularly observed this in patients with head and neck cancers, and those with pelvic cancers where there is double incontinence and loss of sexual function. I have seen similar views expressed in other non malignant cases, in the case of severe breathlessness and also motor neurone disease.

The recognition that some patients have had enough, despite adequate pain control is recognised in the literature. In particular fatigue, including "fatigue with life" does seem to be a persistent issue when pain is eventually and thankfully controlled, this is discussed in my own article and discussed elsewhere¹⁵.

¹⁵Munglani R Reflections on Pain Suffering and Euthanasia Journal of Observational Pain Medicine – Volume 1, Number 1 (2012) ISSN 2047-0800 downloadable from here

<http://www.ioopm.com/index.php?journal=ioopm&page=article&op=view&path%5B%5D=5&path%5B%5D=46>
Cancer. 2014 Feb 1;120(3):425-32.

Prevalence and characteristics of moderate to severe fatigue: a multicenter study in cancer patients and survivors.
Wang XS, Zhao F, Fisch MJ, O'Mara AM, Cella D, Mendoza TR, Cleeland CS.

BACKGROUND:

The effective management of fatigue in patients with cancer requires a clear delineation of what constitutes nontrivial fatigue. The authors defined numeric cutpoints for fatigue severity based on functional interference and described the prevalence and characteristics of fatigue in patients with cancer and survivors.

METHODS:

In a multicenter study, outpatients with breast, prostate, colorectal, or lung cancer rated their fatigue severity and symptom interference with functioning on the M. D. Anderson Symptom Inventory numeric scale of 0 to 10. Ratings of symptom interference guided the selection of numeric rating cutpoints between mild, moderate, and severe fatigue levels. Regression analysis identified significant factors related to reporting moderate=severe fatigue.

RESULTS:

The statistically optimal cutpoints were 4 for moderate fatigue and 7 for severe fatigue. Moderate=severe fatigue was reported by 983 of 2177 patients (45%) undergoing active treatment and was more likely to occur in patients receiving treatment with strong opioids (odds ratio [OR], 3.00), those with a poor Eastern Cooperative Oncology Group performance status (OR, 2.00), those who had >5% weight loss within 6 months (OR, 1.60), those who were receiving >10 medications (OR, 1.58), those with lung cancer (OR, 1.55), and those with a history of depression (OR, 1.42). Among survivors (patients with complete remission or

Other issues

I fully understand that you have not asked my opinion in the matter of assisted dying but I hope you will bear with me whilst I take this opportunity to say that I am not unaware of the arguments about exploitation of the vulnerable, and the slippery slope hypothesis. However it does seem in places like Oregon, it is the articulate white middle classes, who always have had the privilege of deciding their way in the world, who most ask for assisted suicide rather than the other more vulnerable groups according to my reading of the literature.

At present, in this country, those who are articulate and have the knowledge, means and money are able to go off to Switzerland and continue to exercise the autonomy they have always had throughout their life. It is the poor and vulnerable who do not have the ability to make such choices. Furthermore, as has been highlighted in the recent Court cases, it does seem unfair (whatever one's views), that those who are physically handicapped are often unable or less able to exercise the freedom of choice to be able either to commit suicide or go to Switzerland compared to able bodied people.

The presence of facilities in places like Switzerland has allowed this country to "duck the issue" for a number of years and clearly now this is rightly being addressed again in Parliament against a background of overwhelming public support and warnings from the Supreme Court that there must be some change in the law.

I am also aware that some of the Medical Royal Colleges have come out against assisted suicide and understand their reasons for doing so. However the BMJ along with many doctors in their personal opinion are in favour of some change in the law. I think the recent Editorial in the BMJ is a significant contribution and is also given as a footnote to this letter. I think the arguments presented there are coherent, reasonable and an important contribution to the debate¹⁶.

no evidence of disease, and not currently receiving cancer treatment), 29% of patients (150 of 515 patients) had moderate=severe fatigue that was associated with poor performance status (OR, 3.48) and a history of depression (OR, 2.21).

CONCLUSIONS:

The current study statistically defined fatigue severity categories related to significantly increased symptom interference. The high prevalence of moderate=severe fatigue in both actively treated patients with cancer and survivors warrants the promoting of the routine assessment and management of patient-reported fatigue

¹⁶ Editorials BMJ

Why the Assisted Dying Bill should become law in England and Wales

BMJ 2014; 349 doi: <http://dx.doi.org/10.1136/bmj.g4349> (Published 02 July 2014) Cite this as: BMJ 2014;349:g4349

Tony Delamothe, UK editor, Rosamund Snow, patient editor, Fiona Godlee, editor in chief

It's the right thing to do, and most people want it

Lord Falconer's Assisted Dying Bill is expected to receive its second reading in the House of Lords this month. *The BMJ* hopes that this bill will eventually become law.

The bill would allow adults who are expected to live six months or less to be provided with assistance to end their lives.¹ Two doctors must be satisfied that the person is terminally ill, has the capacity to make the decision to end his or her life, and has a clear and settled intention to do so. This decision must have been reached voluntarily, on an informed basis, and without coercion or duress. Both doctors must be satisfied that the person has been fully informed of the palliative, hospice, and other available care options.

Once both doctors have countersigned the declaration that the person wants to end his or her life, the attending doctor can prescribe the life ending medication, which would be dispensed only after a "cooling off" period of 14 days (or six days if prognosis is less than a month). The person would administer the medication themselves. This is what differentiates "assisted dying" from "voluntary euthanasia," where the doctor administers the lethal drug(s).

What are the arguments for such a law? **People should be able to exercise choice over their lives, which should include how and when they die, when death is imminent. In recent decades, respect for autonomy has emerged as the cardinal principle in medical ethics and underpins developments in informed consent, patient confidentiality, and advance directives.² Recognition of an individual's right to determine his or her best interests lies at the heart of efforts to advance patient partnership.^{3 4} It would be perverse to suspend our advocacy at the moment a person's days were numbered.**

As shown by harrowing personal accounts, some terminally ill people want the option to call "time."^{5 6 7} And the majority of the British public want the option too. The 2010 British Social Attitudes survey shows that 82% of people are in favour of a change in the law on assisted dying.⁸

What are the arguments against such a law? People opposed to the bill cite the difficulties of establishing that someone has less than six months to live. Yet most studies suggest that doctors consistently overestimate rather than underestimate prognosis.⁹

Another argument is that individual choice should be limited when it has a profound effect on others. But we already accept people's decision to reject life saving treatments, if they have mental capacity, regardless of any effects their subsequent deaths may have on those they leave behind. The Falconer Bill allows for the secretary of state to issue codes of practice on the assessment of mental capacity, "recognising and taking account of the effects of depression or other psychological disorders that may impair a person's decision making."

Those who oppose a change in the law often shift their arguments to hypothetical victims, some of them glimpsed at the bottom of a slippery slope. It's therefore important to say who will and will not be affected by the new law. The Assisted Dying Bill does not cover people with disabilities who are not terminally ill, other people with non-terminal illness, people who are not mentally competent, or children. That much mentioned victim—the elderly lady who believes she has become a burden to others and offers herself up for assisted dying—will not qualify.

Passing the law would not represent a leap in the dark: the US state of Oregon, on which the bill in England and Wales is closely modelled, has allowed assisted dying since 1997. Last year, 122 dying Oregonians were given life ending prescriptions; 71 took the life ending medication and died. Altogether, "assisted deaths" accounted for 2.2 per 1000 total deaths in the state.¹⁰

Extrapolating Oregon's figures to England and Wales, each year about one patient per general practice of 9300 patients would discuss the issue of assisted dying; each general practice would issue one prescription for life ending medication every five or six years, and every eight to nine years one patient per general practice would take life ending medication.

Oregon's experience confounds claims that assisted dying legislation impedes the development of palliative care. Oregon is now regarded as a national leader in palliative care.¹¹ Tellingly, the Oregon Hospice Association, initially opposed to assisted dying, found "no evidence that assisted dying has undermined Oregon's end of life care or harmed the interests of vulnerable people."¹² In 2011 the European Association for Palliative Care concluded that palliative care in European countries with legalised assistance to die is as well developed as it is elsewhere.¹³ Some doctors are unhappy about the part they would be asked to play. However, the bill makes robust allowance for conscientious objection—a provision that has worked well for the almost 50 years of the Abortion Act. Discovering what "the average doctor" thinks about assisted dying, however, has been difficult, with professional bodies going through extraordinary contortions to avoid asking individual members for their opinions.

Ultimately, however, this is a matter for parliament, not doctors, to decide. Last month the UK Supreme Court upped the ante. Its president said that unless parliament satisfactorily addresses the Suicide Act 1961, which prevents doctors helping patients to end their lives, the court could force change upon them by declaring the act incompatible with the European convention on human rights.¹⁴ Let us hope that our timid lawmakers will rise to the challenge.

Notes

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Footnotes

- Competing interests: We have read and understood BMJ policy on declaration of interests and declare the following interests: for the past five years, TD has been publicly declaring his support for a legal option for terminally ill adults of sound mind who want to die.
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My own opinion is that it is important that treating clinicians be kept completely separate from a multidisciplinary team who would dispassionately assess any request for assisted suicide. In particular, the multidisciplinary team should include a palliative care consultant or a pain consultant and also a psychiatrist, and should assess for and offer any remaining therapeutic options and examine for any conflicts of interest including financial pressures. Thankfully in this country, the latter is less likely to be the case than in the United States.

I am also in favour that, if assisted suicide is legislated for in some form, then just as we have midwives to help human beings entering the world, there should be a similar role and specialty to help human beings make a peaceful transition for those leaving it and again I think it appropriate that doctors remain outside this role.

Finally I looked on the Internet and found that it was Lord Carey who quoted me and so I hope you do not mind that I have sent him a copy of this reply, so that he will be aware that you contacted me.

Please do not hesitate to contact me if I can be of further assistance.

With my very best wishes



(amended version 9th January 2015)

CrossRefMedline

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