

Cost and Value of Cancer Care

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Introduction: The question of why?

The first thing that people often say when they find out that I want to specialise in oncology is “Why?” “Why work in a profession where you know you’ll have to continuously give people bad news and help them through what in most cases would be the most traumatic experience of their lives?” There’s no one real answer to that question, much like there’s no one answer as to why I wanted to become a doctor, my want to study medicine and specialise in oncology comes partly from an intuitive knowing that I would enjoy the field more than anything else I could do with my life. There is one answer I usually give though, and that is simply that I *hate* cancer. A diagnosis of cancer causes more grief and destroys more patients’ lives than any other in medicine; it places a huge strain on their families and conjures up deep fears of suffering, pain, a huge loss of dignity and death. I hate what it does to patients and their families through the immense psychological trauma it causes, and I know that I want to be there helping them fight it and helping them through what is a terribly trying moment in their lives.

That’s the real reason I want to specialise in oncology. The hidden cost that cancer has on patients and their families is the psychological grief it causes them. You can bandy around monetary statistics about what cancer care costs in terms of direct medications and research, but you ignore the true suffering of patients, something as medical students we’re increasingly being taught not to do. Therefore, this paper shall concentrate on some of the hidden costs of cancer care in Australia, and why it’s important to patient care to recognise them.

Economic costs: An important but narrowly focused look at the cost of cancer care.

There is no doubt that the cost of health care has increased exponentially as the prevalence of chronic disease has increased. Data from the US shows health care funding as a percentage of GDP has increased from 5% in 1965 to 16% in 2004.¹ In Australia, where 9.5% of GDP is spent on health care, 6% of that is related directly to cancer treatment.² This figure is \$2.7 billion², which whilst still a significant amount of money pales in comparison to the cost of cancer care in the US, where \$74 billion is spent directly on cancer care and drugs prescribed by oncologists accounting for a staggering 40% of total drug expenditure.¹ Despite this spending, the prevalence of cancer increased by 34% in the period of 1990-2000³ and cancer remains the leading cause of DALYs in Australia.²

Research: The scientific community researching cancer is stunted in Australia.

There is no doubt that an improved health related quality of life is an important endpoint in any clinical trial.⁴ However, the process involved is expensive and costly to patients as well as governments. US figures show it can cost upwards of \$1 billion US to bring a drug to market after its discovery¹, and this cost carries through to the patient. Studies have shown that chemotherapeutics in aggressive clinical trials can cost up to 40% more than in a control group, adding an extra 10% onto the total cost in trial patients.⁵ These increased trial costs threaten to hurt patient recruitment into an already stressed system within Australia.⁶ Medical students should understand and appreciate that recruitment of patients into clinical trials is an important part of health care and advancing the science of medicine as a whole. It has been an ongoing concern of the AMA that

Australia lacks the infrastructure to research drugs from discovery to trial⁷, a concern mirrored in the fact that adolescents and young adults are poorly recruited into clinical trials in Victoria.⁸

Health Care in Australia: The system and its inequities.

Managed care has the potential to help focus health care in Australia through reducing fragmentation of the health care system.⁹ However, health care policy in Australia, with its curious mix of private and public health sectors, is limited to trying to improve public access to health care and bring them onto a level field with the private sector.¹⁰ Indeed, 50% of patients with breast cancer are treated in the private sector.¹¹ Despite this system, and funding initiatives like the \$190 million pledged in the 2004/5 Budget to strengthening cancer care, severe inequities exist in Australia.² It is unacceptable that a Territory capital in Darwin *does not provide a radiotherapy service, and patients must fly four hours to receive treatment.*² Or that Indigenous Australians have a 9 times greater risk of dying from cervical cancer, which magnifies out to *18 times in rural areas.*¹² It has been shown that having private health insurance improves survival in colorectal and breast cancer patients in NSW.¹³ As students, we should realise that despite Australia being a first world country with a very good standard of health care, strong problems with our health care system still exist. A goal of health funding then, has to be addressing these inequities in our system if we are to reduce the cost of cancer care.²

The Real Burden of Disease: The cost of a cancer diagnosis on the patient and their families.

Traditionally, measuring the BOD has been used to help guide funding and policy making.¹⁴ Whilst it remains an important measure of the economic cost, with US data showing a loss of \$115.8 billion due to lost productivity from cancer (a figure which only spirals out to \$232.4 billion if the cost to caregivers is included).¹⁵ However, this approach only looks at the monetary costs of cancer care and doesn't delve into the psychosocial side. Studies have looked at the impact cancer has on families, and shown that the largest cost of cancer to caregivers is the labour cost, with the more a patients' ADLs are hampered by the disease the more it impacts on families.¹⁶ It is important for students to understand this and work with inter-disciplinary teams such as those made up by OTs and social worker's to help try and reduce this burden on families. This becomes especially important when one considers that studies have shown that the well-being of the patient and partner are interrelated.¹⁷ It is well known that psychosocial aspects are an equally important part of managing patients with chronic illness.¹⁸ However, despite this knowledge treatment is compounded by the fact that 17-25% of cancer patients could be diagnosed as clinically depressed¹⁸, yet despite this physicians commonly are poor at recognising psychological problems in cancer patients.¹⁷

Barriers to treatment success: The burden of lower socio-economic status and being rural.

It is well known that there are many inequities in health care, with race, gender, age and social class being just a few.²⁰ Socially disadvantaged patients experience worse physical and mental outcomes, and often access health care services less.²¹ These facts are well known and taught in medical schools worldwide. However, in Australia there remains specific challenges in health care imposed by the large rural population which students may often be unaware of. Examples include 89% of rural women with breast cancer reporting problems specific to being rural.²² Other glaring issues surround Indigenous populations, who often have a lack of access to palliative care and often defer surgery due to an obligation to kinship and community roles.¹² The socially disadvantaged are also less likely to receive surgery for lung cancer, a statistic born out of not only lower socio-economic

status, but stigma as well, with the lower class being more likely to smoke and therefore not only increase their risks, but being labelled as an untreatable case because of this.¹³ In addition, because of poor funding and resources, in Australia there is an 18% disparity in patients who should be receiving radiation therapy and those that actually do.² Once again compounding the issue, there is an increased propensity towards more aggressive medical treatment in the last few years of life in cancer patients²³, which can impact upon rural citizens who have further to travel to receive treatment. Shockingly, rural citizens are not only diagnosed later, but *are 35% more likely to die within 5 years of diagnosis*.² With only 64% of patients reaching a 5 year survival after a diagnosis of cancer²⁴, this shocking disparity should highlight to students the need to train a rural workforce and understand the issues surrounding being rural in Australia.

Breast Cancer: An opportunity to delve into the hidden cost of cancer care.

Breast cancer is a very well studied cancer in a lot of aspects of care, which is not only due to its large prevalence in the community (it affects 1 in 8 women in developed countries)²⁵, but the significant impact it has on the victim and their families. Breast cancer was the first cancer to actively set up support groups, and these have been shown to increase survival and well-being in women with the disease.¹⁹ And indeed, women with breast cancer are high utilisers of health care services, an important factor as psychosocial interventions have been shown to reduce medical costs.²² Whilst this is an important part of health care, it is important for students to understand that the real cost of breast cancer care includes both disruptions to family planning, and body image. Family planning is a huge issue to women with breast cancer, particularly younger women. To put this in context, I'm going to use this opportunity to share the experience of a young woman with breast cancer whose diagnosis has completely changed her ideas on what is important to her;

The patient was only 35 at the time of her diagnosis, (and statistics show that breast cancer in younger women is associated with a worse outcome)²⁵ and despite battling the disease for a year and remaining positive despite the looming prospect of a double mastectomy, the thing to really hit her and which demonstrates the hidden cost of cancer care – is the impending operation to remove her ovaries. She is childless. There is a vast difference between not having children because you're too busy to actually being told "You can't have children". The news has impacted on her psychologically worse than the actual diagnosis of cancer has, and shows that students must understand and appreciate that patients are people too, and that just curing them of their disease is never the end of the story.

The issue of fertility conservation in women with breast cancer is complex and often strategies to help try and save reproductive function can increase cancer recurrence, less than 10% of women previously diagnosed with breast cancer become pregnant, a substantial cost that any student has to recognise can impact on their patients lives and wellbeing.²⁵ This fact highlights an important part of patient care, in that care is primarily directed towards surveillance for cancer recurrence, yet co-ordinated care often does not extend beyond a short follow up period and research showing that early detection of recurrence does not increase the likelihood of salvage.²⁴ In fact, so narrow minded is this monitoring strategy that 60-99% of breast cancer survivors report fear of recurrence, which impacts negatively on themselves and their families.²² There is a phenomenon known as "learned helplessness", often developed by partners of cancer patients which encompasses feelings of guilt and worthlessness as they watch their partner suffer, particularly if there has been inadequate symptom control, and fear of recurrence can exacerbate this problem.²⁴ Another important issue in the management of a chronic disease such as breast cancer is symptoms such as fatigue, with 70% of patients reporting fatigue 1 month after surgery and 50% 1 year after surgery, yet despite this obvious and glaring statistic, 40% of patients are not offered recommendations on how to deal with fatigue, despite there being strategies in place to help improve it.²² As medical students, it is once

again critical to understand the importance of understanding a patient's problems and what can be done to address them, understanding which starts by listening to patients and their problems rather than making assumptions.

Sexual Dysfunction: *A under taught and under recognised problem of cancer patients.*

It is prudent to highlight another major psychological problem in the cost of cancer care, and that is psychological problems caused by sexual dysfunction, a common and underappreciated problem for survivors. In breast cancer patients, 21-39% will experience some sort of sexual dysfunction, with body image disruption crucial to this.¹⁹ These issues are often seen very soon after surgery or adjuvant chemotherapy, and hence last the course of treatment for the patient.²² Cervical cancer patients report worse outcomes, with statistics ranging from 44 to 79% of radiation therapy patients and 6-19% of radical hysterectomy patients reporting problems such as lack of lubrication, tenderness and post-coital bleeding.¹⁹ Men with prostate cancer report similar and perhaps worse psychological problems, with even biopsy resulting in sexual difficulties.¹⁹ In conjunction, 78% of retropubic and close to 100% of perineal prostatectomy patients report ejaculation difficulties and erectile dysfunction, a cause of significant psychological morbidity.¹⁹ Students must be aware of these issues and not be shy in tackling them or broaching them with patients, as open discussion of them is sure to improve health related outcomes for patients.

Indigenous Australians: *The broad gap in health outcomes is excruciatingly obvious in cancer care.*

Finally, it would be prudent to wrap up this discussion on cancer care with a look at the most socially disadvantaged group of Australians, the Indigenous Australians. There is limited data on cancer incidence in Indigenous populations, yet despite this what little data is known is frightening.¹² Indigenous Australians are 6 times more likely to develop primary liver cancer, have a later diagnosis, slower uptake of services and have worse compliance for treatment regimens.¹² The likelihood of death from cancer in the Indigenous population can be 30% higher², a statistic which can't just be explained away with people of lower socio-economic status having worse health outcomes.¹³ Part of the problem lies in a general lack of access to services, but there are also large and glaring issues in language and culture, not only due to the unfamiliar environments of hospitals but also because Indigenous concepts of health encompass one's place in the community, so health is seen as being able to carry out their normal roles, an important factor in treatment.¹² Students *must* be aware of these cultural issues and how to address them, else we make the gap in health care wider than it already is.

Conclusion: *The medical students of today will pioneer changes in Australian health care.*

As has been highlighted by this essay, despite the large advances in medical care in Australia, there remains quite a way to go, particularly in Indigenous health care and communication skills. It is of critical importance that medical students understand that the cost of cancer care isn't just measured in economic terms, but in the impact it has on families of their livelihood and the considerable psychological morbidity it causes. Recognising the significant distress that cancer patients and their partners suffer and aiming to ameliorate this is crucial, and central to this is improving communication skills to allow students to acknowledge problems and talk with patients about them. Without these essential communication skills, the cost of cancer care in Australia will never truly be brought down, as the hidden cost on patients and their families is the real burden, and looking at it from a purely economic sense is narrow-minded and detrimental to patient care. The students now, who will be our doctors within a few years, will recognise this, and the cost of cancer care will improve because of it.

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