An Ethical and Legal Commentary on Access to Renal Dialysis Programmes in Public Hospitals in South Africa: Reflections on Thiagraj Soobramoney versus the Minister of Health (Kwa-Zulu Natal) 1997

Manyangane Raymond Billa

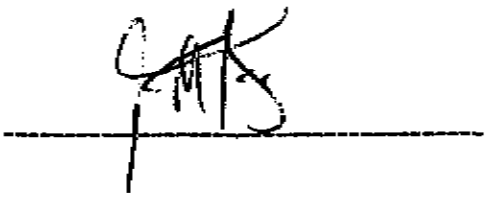
Student number: 502326R

In partial fulfilment of the degree of MSc Med (Bioethics & Health Law) Steve Biko Centre for Bioethics, Faculty of Health Sciences University of the Witwatersrand

Johannesburg, 2010

Declaration

I the undersigned, hereby declare that ***An Ethical and Legal Commentary on Access to Renal Dialysis Programmes in Public Hospitals in South Africa: Reflections on Thiagraj Soobramoney versus the Minister of Health (Kwa-Zulu Natal) 1997*** is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of references. It is being submitted for the degree of Masters in Science in the field of Bioethics and Health Law Steve Biko Centre for Bioethics, University of the Witwatersrand. It has not been submitted before for any degree or examination at this or any other university.



Signature

Date: 03 March 2010

Dedication

I dedicate this to my wife Makhotso, who has always supported me so graciously in every endeavour. Her own determination to excel in her studies, insight, encouragement, wisdom and tremendous intellect have provided me with a constant source of support. Without her encouragement I would not have finished this work.

To my two beautiful children Khensani and Tshepiso who are more special to me than can ever be imagined. I pray that they shall reach their full potential in their own pursuits in life.

Lastly I dedicate this to my mother, Modiehi, and my father in-law, Joe, whose belief in me has been the single most influential factor in my life.

I love you all deeply.

Abstract

The current exclusion criteria for accessing renal dialysis in South African public hospitals places great emphasis on the allocation of scarce resources. The case of Soobramoney at the Constitutional Court highlighted the ethical and legal implications of providing this scarce resource. Mr. Soobramoney was denied access to renal dialysis on the basis of scarce resources and he did not qualify for care due to not meeting the criteria set for renal care.

The Soobramoney case was considered mainly on the basis of scarce allocation of resources and offering treatment on an emergency basis. It was argued by the appellant that the state had an obligation to provide him with the treatment in terms of s 27(3) read with s 11 of the Constitution (para 14). This report takes a different slant and looks at the quality of life argument for increasing access to renal dialysis for those denied it based on current South African protocols.

In exploring this concept one would venture to offer a definition of 'quality of life' according to Brown as an overall sense of well-being. This includes an individual's satisfaction with their own lives (Brown, 2007: 72). A health related quality of life extends the definition to include the way a person's

health affects their ability to carry out normal social and physical activities (ibid).

A case is made for increasing access by developing programmes to cater for those in need of enhancing their quality of life. This is what is being motivated for in cases similar to Soobramoney, especially those with co-morbid disease. The quality of life argument is based on the fact that there are indications in literature that patients with end-stage renal disease rate their own quality of life to be as important as the quality of life of the general population.

Furthermore, there is no indication that the elderly live more miserable lives when they are on dialysis. The idea of respect for persons is highlighted - respect for the autonomous choices patients make concerning how they live their lives and including respect for them towards the end of their lives.

Finally, I reflect on some legal issues concerned with the Soobramoney versus the Minister of Health Kwa-Zulu Natal 1997.

Acknowledgement

I would like to sincerely thank my supervisor Prof. Donna Knapp van Bogaert for making me believe in me. For making me believe that the task of writing this report was within my abilities. Thank you for politely nudging me on.

Thank you to my other supervisor, Prof. Ames Dhai. Your words on every piece of work truly made me believe that I can do it. You spurred me on by telling me to keep the energy.

I thank all of you for your comments with every piece of work I submitted for correction and for the references you sent me.

Lastly I wish to thank staff in the Department of Health who gave me valuable advice and availed some material for this report. Particular thanks to Prof. Katz, Prof. S. Naicker, and Mrs. Dudu Mthombeni.

Table of Contents

Chapter 1

1. 1 Introduction

Kidney doctors lost their innocence in 1960 (Friedman, 1993: 1204-1205). We are informed that the words, 'prioritising, rationing and exclusion', which were previously alien to the lexicon of renal medicine, were introduced. Before this period, patients suffering from acute renal failure were doomed to death. The advances in renal medicine and the introduction of haemodialysis, we are told, led to the dilemmas we are facing today in treating patients with renal failure' (ibid: 1204). Friedman quotes Scribner and his dialysis team in Seattle, emphasising this dilemma:

> *... the power to forestall death in cases of renal failure raised troublesome issues of who would be treated and under what circumstances. Never before in the practice of medicine had the physician's decision on treatment so clearly been converted into a choice of life or death, as governed by policy, resources, and long-term budgets*

According to the last published Nephrology Report compiled by a group of academics from several universities in South Africa, the prevalence of

chronic renal failure is unknown in the country (Moshesh, *et al.* 2003: 1). In the South African circumstances, the problem is exacerbated by the limitation of resources leading to ethical problems a few of which I will explore in this research report. I will give a critical ethical analysis of the current government policy of rationing access to renal dialysis and kidney transplant to patients with end-stage renal disease. I will consider concepts like prioritising, rationing and exclusion. I will overview the problem of chronic renal failure in South Africa reflecting on such issues as socio-economic factors, disease prevalence, management protocols (including treatment options) and constraints e.g. funding and access.

This will be done by mainly reflecting on the now famous Soobramoney case. I will look at the ethical and legal implications emanating from this case. This will help us appreciate the problem of justice, health rights and allocation of resources in the light of budget limitations in the South African public hospitals.

1. 2 The Soobramoney Case

Mr. Thiagraj Soobramoney was a 41 year old unemployed man, who was diabetic, suffered from ischaemic heart disease and cerebrovascular disease which caused him to have a stroke during 1996 (Soobramoney vs. Minister of Health,97: 1). In 1996 his kidney also failed and thus had end-

stage renal disease. Mr Soobramoney's only hope for survival was then regular renal dialysis. He went to Addington Hospital, a public hospital in Durban for treatment but was denied treatment. He had earlier made arrangements to receive dialysis treatment from private hospitals and doctors, but when his funds were depleted, he was obliged to go to public hospitals.

The hospital said according to its treatment protocol, based on limited facilities, the patient did not qualify for regular renal dialysis. Mr Soobramoney approached the courts for redress. The hospital, in its argument before the court, stated that it did not have resources to provide dialysis treatment for all patients suffering from chronic renal failure. Their specialist in nephrology, Dr. Naicker told the court that additional dialysis machines and more trained nursing staff were required to enable it to do that. That could only be done if its budget was increased. This was however not possible as the provincial health department did not have funds for the service. The hospital had been following a set policy in regard to the use of dialysis machines (ibid: 15).

The healthcare budget as a percentage of GNP in "so-called developing" countries ranges from 0.8% to 2% compared to 10-15% in the developed world (Rizvi *et al,* 2007: 211). Most of the hospitals do not have the necessary nurse-patient ratios as there is a dire shortage of nurses in the

country. Naicker reports that work done by De Vecchi, *et al.* (1999)[1] indicates that the percentage of dialysis compared to the health budget is 1.8% - in Belgium, 0.7% in the UK and 7.3% for the US Medicare programme. She also informed the congress in Durban that according to the Bellagio Conference the cost of haemodialysis is 40 00-60 000 US dollars in the US and 100-200 US dollars per session in African countries (ISN Bellagio Conference, 2004).[2] In South Africa it costs 100-200 US dollars in private but access is free in the public service based on the exclusion criteria mentioned previously.

The patients who suffered from acute renal failure and could be remedied by renal dialysis had automatic access to renal dialysis. Those who suffered from chronic real failure like Mr. Soobramoney did not have automatic access to the programme. The guidelines stipulated that only those with end-stage renal disease (ESRD) and eligible for kidney transplant could be benefit from renal dialysis. Eligibility meant that a patient must be free of significant disease elsewhere, for example, ischaemic heart disease, cerebro-vascular disease, chronic liver disease and chronic lung disease. The preferred management of ESRD is renal dialysis and renal "replacement therapy. In "so-called developing" countries such as South Africa, the goal of the treatment options has been to 'have a circumscribed chronic dialysis program, with as short a time on dialysis as

[1] From Naicker presentation at Renal Congress, Durban, 2008
[2] From Naicker presentation at Renal Congress, Durban, 2008. (ISN –International Society of Nephrologists)

possible, and to increase the availability of transplantation (both living related and cadaver)' (Naicker, 2001: 263). As Mr Soobramoney was suffering from ischaemic heart disease and cerebro-vascular disease, he did not qualify for a kidney transplant.

The argument used before the courts were based on the provisions of the South African Constitution of 1996. Section 27(3) of the 1996 Constitution makes the following provision: "No one may be refused emergency treatment". Section 11 stipulates that 'Everyone has the right to life'. Mr Soobramoney had expectations, like all South Africans living in a now free and democratic society, that the state had an obligation to provide certain basic services to its citizens. In the Bill of Rights in Section 27, the Constitution makes the following provisions:

S 27. "Healthcare, food, water and social security"

(1) Everyone has the right to have access to –

(a) Health care services, including reproductive health care

(b) Sufficient food and water; and

(c) Social security, including, if they are unable to support for themselves and their dependants, appropriate social assistance.

(2) Further, "The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of these rights.

(3) No one may be refused emergency medical treatment" (my italics added).

Mr Soobramoney contended that as a patient suffering from terminal illness and as such requiring renal dialysis to prolong his life, the state had an obligation in terms of Section 27(3) to provide him with the service. He expected the state to provide funding and resources necessary to discharge the obligation.

In presenting judgement of the Constitutional Court judges, Judge P. Chaskalson argued that the appellant requested recourse from the courts on the basis of Section 27(3) which required him to be treated on an emergency basis. As the appellant's condition needed regular renal dialysis, not to secure his life, but to prolong it, he did not qualify in terms of the provision of the section. The hospital had argued also that to put Mr. Soobramoney on renal dialysis would deny other more deserving patients who qualified in terms of the criteria set by the Renal Unit of the hospital. It was stated that by using the dialysis machines in accordance with the guidelines, more patients would have benefited than would be the case if they were used to keep alive persons with chronic renal failure.

With this approach the outcome was said to be more beneficial as it was directed at curing patients and not simply maintaining them in a chronically

ill condition, the court documents indicated. The court ruled that he did not qualify and Mr. Soobramoney lost the case.

A second judge, Mr J Madala sought to consider the case on a different angle altogether, whilst concurring with Judge Chaskalson's conclusion however.

Justice Madala looked at the provision of the Constitution dealing with Section 11 – the right to life, which the appellant's lawyers placed before the court in his oral submission. Judge Madala asks the question, 'Should a doctor ever allow a patient to die when that patient has a treatable condition?' (ibid: 23). He says in the context of Mr. Soobramoney's case, the question to be answered is whether everybody has the right of access to kidney dialysis machines even where resources are limited (Soobramoney vs. Minister of Health,97: 23).

He further goes on to say that the provisions of the Constitution are forward-looking; these provisions are ideal and something to look forward to. The guarantees are not absolute, he maintains, but may be limited. In his judgement he states that the Constitution states in so many words that the state must take reasonable legislative and other measures, within its available resources to achieve progressive realisation of each of the rights mentioned therein. He says that the Constitution does make an admission

that it cannot solve all of society's problems overnight, but must continue trying to resolve all of society's woes.

As mentioned in the arguments placed before the court, he also concurs that one of the limiting factors in attaining these goals is limited or scarce resources. In other words, in the present situation in South Africa, the limited haemodialysis facilities, both machinery and personnel constituted limited or scarce resources thus, Soobramoney's case was denied.

Judge Albie Sachs also gave a separate judgement, whilst agreeing with both justices Chaskalson and Madala. He contends that the 'rationing of access to life-prolonging resources is regarded as integral to, rather than incompatible with, a human rights approach to healthcare' in all open and democratic societies. He avers that lack of principled criteria for regulating access to resources could lead to more difficulties than if none existed. He quotes a UNESCO publication to emphasise this point:

> *... Even in the industrialised nations where public tax-supported research has made a private biomedical technology industry possible, the literal provision of equal access to high technology care, utilized more often by the elderly, would inevitably raise the level of spending to a point which would preclude investment in preventive care for the young, and*

maintenance care for working adults. That is why most national health systems do not offer, or severely ration (under a variety of disguises), expensive technological care such as renal dialysis or organ transplant' (Brody, 1993).

He further states that if governments were to confer any benefit on any person unless it was to give equally to everyone else, the resultant option would be to offer the benefit to nobody. This would be disastrous he said (ibid: 32).

To 'reflect' in an ethics context, means to think, ponder, or meditate, on an issue which has been brought to one's attention, for example, *to reflect on one's virtues and faults* (Ado 1990: 74). My reflection in the context of the Soobramoney case means that I will consider it in its particular time and place, identify issues that were raised by the court and reflect back on them to see how the case impacted on the life of the claimant. This will also include identifying issues that the court failed to raise believing them to be irrelevant or simply non-issues in a legal sense. In doing this, I will demonstrate that perspectives of law and ethics are often quite different. I hope to show that there were flaws within the judgement made in the Soobramoney case. I will draw out points which I hope will demonstrate that there are many ways of looking at a problem and that the ethical issues I

raise may serve to provide further insight into the myriad of difficulties faced in decisions surrounding kidney dialysis and treatment.

In the next two chapters I will look at the case from legal and ethical perspectives respectively. I will then offer a reflection on the case. In my concluding chapter, I propose recommendations. Now let us turn to the Soobramoney case in which I provide a broad legal analysis.

Chapter 2

2.1 Legal Analysis

'The Soobramoney case was the first socio-economic rights case to reach the Constitutional Court.' (Hassim et al, 2007: 35) The author goes on to indicate that the state went on to defend this case successfully also.

As stated above, Mr. Soobramoney approached the Court seeking access to a renal dialysis service in the public sector hospital at the expense of the state after he was unable to fund this service at a private hospital. This service is provided for at state hospitals at state expense for those who satisfy strict medical criteria. Mr. Soobramoney did not meet these criteria and could not be accommodated at state hospitals for this reason. He needed medical eligibility for a kidney transplant to qualify for renal dialysis.

Mr. Soobramoney was unsuccessful at the Durban High Court, so he approached the Constitutional Court appealing his case challenging the denial of access on the basis of two constitutional rights (ibid: 35). These are the right to life in section 11 and the guarantee in section 27(3) that no person may be refused emergency medical treatment. The Constitutional Court decided that his claim had to be considered under section 27(2) that sets out the state's positive duties regarding the provision of health care services. In the Court's view, the state had indeed complied with section

27(2) constitutional duties because the guidelines according to which access to renal dialysis is limited are reasonable, and in Soobramoney's case, had been applied fairly and rationally. His claim was therefore dismissed. A week later he died from renal complications (ibid: 35).

The criteria for access to renal dialysis as set by the Department of Health in South Africa are as follows:

2. 2 **Exclusion Criteria for Renal Dialysis in South Africa**

The following exclusion criteria have been used as guidelines for public hospitals for putting patients on renal dialysis by the South African Department of Health in consultation with nephrologists and health administrators[3]:

2.2.1 Medical exclusion criteria

- Active, uncontrollable malignancy or with short life expectancy
- Advanced, irreversible progressive disease of vital organs such as:
- Cardiac, cerebrovascular or vascular disease
- Advanced cirrhosis and liver disease
- Medically or surgically irreversible coronary artery disease
- Lung disease
- Unresponsive infections e.g. HPV, Hepatitis B and C

[3] Exclusion Criteria which was adopted by the Department of Health as a guideline for all nephrologists in the public service institutions offering renal dialysis.

2.2.2 HIV and AIDS are not a medical exclusion criteria provided the patient has access to a comprehensive AIDS treatment plan including antiretroviral treatment and is stable for at least six months and the above exclusion factors are absent.

2.2.3 Age (provided above exclusion factors are absent) is not a contra-indication for chronic renal dialysis.[4]

2.2.4 Psychological Exclusion Criteria

- Any form of mental illness that has resulted in diminished capacity for patients to take responsibility for their actions.
- Active substance abuse or dependency including tobacco use.
- Obesity

2.2.5 Compliance

Patients with proven habitual non-compliance with dialysis treatment and lifestyle modification will be excluded or removed from chronic renal dialysis programmes.

The court had concluded that these criteria were reasonable and were satisfied that the appellant did not qualify for the service. They had considered this case under section 27(2) which dealt expressly with a right

[4] In the UK the median age of starting renal replacement therapy is 63 years and the median age of the population is 54 years (National Health Guidelines for Renal Dialysis. 2007, 6 October.

to access to health services and had ruled that his was not necessarily a case challenging a right to life. The Court had also decided that the case was not adequately covered by the right to life clause as it saw

> *section 27(3)'s purpose as ensuring that medical treatment is indeed given in an emergency .....decided that emergency medical treatment does not include chronic treatment for an ongoing state of affairs resulting from a deterioration of the applicant's renal function, which is incurable (paragraph 21). While renal dialysis may be needed urgently, it is not considered as emergency treatment (ibid: 36).*

Hassim, et al in her argument against the case states that 'if section 27(3) were to have been interpreted in accordance with Soobramoney's claim, the state's obligation to ensure access to health care services would have been severely compromised' (Hassim et al, 2007: 36). The authors further indicate that instead of fulfilling the provisions of section 27(2), the state would be forced to provide immediate health care services to anybody requiring this at any time this was demanded.

Some lessons are provided emanating from this case:

- that the Soobramoney case shows that the right of access to health care services does not impose a duty on the state to provide everything to everybody at once

- the " available resources " argument could be used to hold the state to account if it allocates a disproportionate share of the budget to a relatively small need leading to a limited access to health care services. The state cannot use this argument either if it spends vast amounts of funds on non-priority areas. This is an area of focus of the new administration in charge of government now to reprioritise funding to service delivery areas. The Minister in the Presidency responsible for Monitoring and Evaluation writes in his discussion paper, 'Recognize that there will always be limited funding and resources and yet be willing to commit to doing more with less and doing it on time (Chabane, 2009: 1).

- the state will be held to account for not providing certain health care interventions simply because large numbers of people in need would require significant financial resources

Later cases, as we shall show hereinafter, 'have shown a greater willingness to ensure government proves its claim' (ibid: 37)

The following sections will consider how the South African courts have dealt with health rights, using the Soobramoney case as a prime study, but looking at other cases that came before the courts. This will consider 'aspects of socio-economic rights jurisprudence generally, and of health-

rights jurisprudence specifically that present cause for concern from a benefit-focused perspective' (Pieterse 2005: 86).

Pieterse further argues that despite the benefits that result from the litigations involving health-rights cases, some of these limit the health rights in our health-rights jurisprudence (ibid: 87). The following section would therefore be exploring some of the concerns he has identified as areas of concern arising from this case and other related ones like the Grootboom[5], Khosa/Mahlaule[6] and TAC2[7] cases.

The issues raised by the Soobramoney case was that refusal to renal dialysis by the hospital had infringed his right to life and not to be refused emergency medical treatment. The court held that his circumstances did fall within the ambit of the right not to be refused emergency medical treatment and that his right to have access to the relevant health care services was limited by resource scarcity and the competing rights of other patients.[8] When the case was appealed the Constitutional Court ruled that the rights to life and not to be refused emergency medical treatment were not applicable in the matter (ibid: 89). The court held that the rationing policy did not fall foul of s 27 (1) (a) mainly because it found the policy has been

[5] Government of the Republic of South Africa v Grootboom 2001 (1) SA 46 (CC)
[6] Khosa v Minister of Social Development; Mahlaule v Minister of Social Development 2004 (6) SA 505 (CC)
[7] Minister of Health v Treatment Action Campaign (No2) 2002 (5) SA 721 (CC)
[8] Soobramoney v Minister of Health, KwaZulu Natal 1998 (1) SA 430 (D) ('Soobramoney High Court') at 437A-D; 439E-440D.

rationally conceived and implemented in good faith by authorities who were better placed to take decisions of who was to receive treatment within the prevailing resource constraints. [9]

Pieterse (ibid: 90) notes that the Constitutional Court engaged more with the limits to s 27(1) (a) than with the content of entitlements it awards. He pays much attention to the concept of 'health care services' noting that the judgement seemed to accept that the claimed treatment fell within that concept. Pieterse (ibid: 107) further indicates that the court attempted to restrict the extent of the appellants entitlement by firstly awarding a narrow and specific meaning to s 27(1) (a) and secondly by limiting that right through section 27(2).

The state's decision not to make a judgement directing the hospitals to make the service available on the basis that it does not want to be seen to be second-guessing the rationing decision as it would do more harm than good and would be overstepping its institutional boundaries presents cause for concern. Pieterse correctly states that for the Court to accept that the State is unable to offer this service due to resource constraints is defeatist. It is clear that the Court did not go to the extent of verifying if the State was truly unable to offer the service considering resource constraints. With the new administration taking over government in April 2009, it is clear that the

[9] Soobramoney op cite note 2 at paras 25; 29-30 (per Chaskalson P for majority); 58 (per Sachs J concurring separately).

State intends to rationalise its services and reduce waste in all government departments. [10]Treasury is currently busy scrutinising all state expenditure with a view to prioritising the budget and allocate costs to pure service delivery. With this approach it is possible to determine that the budget could be better spent and government may allocate funds to appropriate services. Pieterse (ibid: 91) says

> *subjecting government assertions of resource scarcity to meaningful scrutiny allows for the undifferentiated 'tolling of the resource-bell' by the State in every matter where it falls foul of its socio-economic obligations, thereby stripping socio-economic rights of much remedial potential.*

The second defeatist stance according to Pieterse is the finding that Mr. Soobramoney's claim was untenable in the face of competing individual and societal demands for limited resources. Chaskalson's majority judgement tends to indicate that it would be very costly for the state to provide services to all people like Mr. Soobramoney. Similarly Sachs alluded to the limitation of rights in his judgement. He proposed that there should be a balance between entitlements or expectations without necessarily imposing limits to those rights according to Section 36.

[10] Several meetings have taken place between Provincial Treasury and institutions and government departments recently in Gauteng Province to determine where savings may be obtained in government budgets allocated within the province.

The implications of the judgement may also mean individual rights are sacrificed to the amorphous general good which could preclude virtually any adjudication of a claim to resources as enjoying constitutional priority over other claims we will explore. [11] This flies in the face of entrenching individual rights as espoused in the constitution.

The individual right pertaining to Mr. Soobramoney not interrogated by the courts that I wish to explore in this discourse is his desire for good quality of life that renal dialysis could offer. This right was limited when the state inferred that judging in his favour considering the scarcity of resources as argued by the hospital authorities would expose the state if more people in his position could litigate. The right to life could equally be defined as the right to quality of life. The court ruled that his case was not to save his life but rather to prolong his life.

The other case considered by the Constitutional Court was the Grootboom's.[12] This case decided that the State had breached its duties in respect of socio-economic rights (Hassim & Haywood, 2007: 37). It set the basic framework for future claims against the state regarding its positive duties in respect of all socio-economic rights, including the right of access to health care services, the same authors predicted. The applicant had been evicted from the vacant land they had occupied but when they

[11] Scott & Alson op cite note 13 at 252-253.
[12] Grootboom v Oostenberg Municipality 2000 (3) BCLR 277 (CC)

returned to their initial place of residence, an informal settlement, they found out that this was now fully occupied and thus became 'truly homeless' (ibid: 37). The High Court hearing their case decided that they could occupy a sports field next to the community centre they were camping pending an outcome of the main case at the Constitutional Court.

The High Court had ruled that the State had to provide shelter to children in terms of section 28(1) (c), which is 'an unqualified right as opposed to section 26. In the appeal against this decision, the Constitutional Court had ruled that the state had failed to devise and implement within its available resources a comprehensive and co-ordinated programme progressively to realise the right of access to housing.[13]

From this it is clear that the State has to develop reasonable plans to give effect to section 26(2) and section 27 (2) in the case of the Soobramoney case. In the Grootboom case these were:

- *sufficient flexibility to deal with emergency, short term, medium and long-term needs*
- *making appropriate financial and human resources available for the implementation of the plan*

[13] Paragraph 95

National government assuming responsibility for ensuring the adequacy of laws, policies and programmes, including the clear allocation of responsibilities and tasks, as well as monitoring programmes. (ibid: 39)

As stated earlier on, the new Administration in government seems intent on managing resources well and as such has a full ministry dealing with monitoring and evaluation of government programmes. Explaining the purpose of government's new long-term strategy, Manuel (2009: 2) writes, 'The Green Paper: National Strategic Planning is being tabled alongside a discussion paper on performance monitoring and evaluation. Together, they make clear that planning, coordination and performance management are interrelated. These functions call for close interaction and collaboration'

The authors have stated also in the case of Soobramoney that the State cannot spend vast sums of money on non-priority areas if the effect is to limit access to essential services like renal dialysis (ibid: 37). There has been an uproar over government ministers' and other officials' expenditure on luxury vehicles. It is said that such money could be spent on other government services. In its green paper on Strategic Planning 2009, the Minister in the Presidency writes, 'A key objective of national strategic planning is to prioritise the allocation of resources within a broad developmental framework. Another is to ensure greater efficiency in allocating and using resources' (Manuel, 2009:21)

The State was similarly made to implement a comprehensive PMTCT[14] plan in the TAC case before it as it was adjudged not to have had a reasonable PMTCT plan. [15] Similarly a question may be asked as to whether the State shouldn't be similarly compelled to have a look at implementing a 'reasonable' programme of renal dialysis for patients with conditions similar to Mr. Soobramoney who would have limited life-spans but require a better quality of life for their remaining years of a short life?

Just as the state had been oblidged to institute a PMTCT programme, there could have been valid reasons to allow people like Soobramoney access to renal dialysis programmes. The State could be compelled to introduce plans to reduce waste by improving its efficiencies so as to realise more funding for renal dialysis programmes. The denial of access to care would then be more clinical than resource constraints. The State has already embarked upon programmes to reduce waste in government departments as alluded to above.

Pieterse argues that not all decisions involving health care should be sacrosanct (Pieterse, 2005: 130). He argues that health care-related rationing decisions such as that challenged in Soobramoney, are not clinical, but political in nature (ibid: 131). Pieterse says as it is expected that

[14] PMTCT – Prevention of Mother to Child Transmission. This is a programme of providing anti-retroviral therapy to pregnant mothers and their newly-born children to prevent the transmission of the HI virus from the mother to the newborns during birth.
[15] Minister of Health v Treatment Action Campaign (No 2) 2002 (5) SA 721 (CC)

lawyers should not make medical decisions, similarly doctors should not make social decisions, quoting Parkins. [16] He goes onto show that the Soobramoney court fell into the trap of falsely equating a rationing decision as a medical/scientific one, and accordingly unjustifiably subjected the decision only to limited scrutiny. I will come back to this when I finally make a recommendation on how the matter may be addressed when looking at quality of life issues that were not considered by the court.

Chapter 3

3.1 Ethical Issues arising out of the original case in context

The Soobramoney case highlighted a number of ethical issues involved in renal dialysis and renal transplantation and rationing this service. In a letter to the South African Human Rights Commission, following a complaint lodged by one of the patients at the Chris Hani Baragwanath Hospital, Katz writes, ' it is with great regret that nephrologists working in the public health service in South Africa have to refuse long term dialysis for people like Mr. X[17]. Unfortunately we are bound by the "official" guidelines by the National

[16] Parkin op cite note 149 at 870. See also ibid 867; 878; Einer Elhauge ' Allocating health care morality' (1994) 82 California LR 1451 at 1458; 1495-1596; Leonard M Fleck ' Just health care rationing: A democratic decision-making approach' (1992) 140 Univ Pennsylvania LR 1597 at 1599; Mechanic op cite note at 148 at 1734; Charles Ngwena 'Access to antiretroviral therapy to prevent mother-to-child transmission of HIV as a socio-economic right: An application of section 27 of the Constitution' (2003) 18 SA Public Law 83 at 88; Orentlicher op cite note 149 at 60.
[17] Name withheld to protect identity of patient as matter not in the public domain.

Department of Health'. [18] According to Katz, referring to the work by Moosa, at Tygerberg Hospital, discrepancies remain in trying to create equity in access to renal dialysis (Moosa, 2006: 1107-14).

From this it is clear that renal physicians, as stated by Kjelistrand and Dossetor, have to live with the question 'even though everyone rations and selects, does that make such selection just?' (Friedman 1993: 1205). The issue of justice is a vexing one for physicians generally, as their particular patient is their primary concern.

From the case review, the ethical issue which is most apparent is that of distributive justice. Particularly in the areas of distributive justice which concern the allocation of scarce resources with its sub-sets such as prioritisation, rationing, and exclusion we will see complexities arise (ibid).

Another important ethical issue brought forth in the original court case is that of medical futility. In such cases, the attending physician may be forced into a situation of denying a patient the form of care which is sought by the patient (or even both physician and patient). This is because the patient's condition is such that for example, renal dialysis would not prolong the patient's life as his or her underlying medical condition has been judged as

[18] Letter written to South African Human Rights Commission following a complaint by a patient who claimed he was denied renal dialysis care on the basis that he could afford this at the private health centres. He was actually not a good candidate like Soobramoney. He had comorbid disease – a vascular pathology.

terminal. The basis of the dialysis protocol is that any patient who is put on renal dialysis has to qualify for a renal transplant otherwise treatment by renal dialysis would be futile if it were not so.

Another ethical issue the Soobramoney case brought to the forefront is the role of the private health care sector – when funds run out for a subscriber's treatment the subscriber is summarily ousted from the medical scheme no matter the time of membership, contributions, age, gender, and medical condition. Should some benefits be on-going dependent on circumstances? This matter was not put under scrutiny by the Court during Mr. Soobramoney's presentation. He did not raise this as a matter for consideration. With the National Health Insurance policy being mooted by government, it would be appropriate to put the private health care funders and providers under scrutiny thus. This case involving the private funders is not pursued further as this discourse looks at the public sector hospitals in the main. I will now turn to an overview of each of these issues.

3.2 Allocation of scarce resources

In the letter I referred to above, Katz (ibid) states further, that the public hospitals cannot supply unlimited access to dialysis in South Africa as reflected in the preamble of the first non-racial guideline in 1996 which

reads, ' There is no country in the world that can afford high technology treatments that are available'.

The arguments brought before the courts by the hospital in the Soobramoney case adequately articulated the position that the State does not have sufficient resources to meet the needs for all those accessing its public hospitals. In order to ensure that those who require renal dialysis services and may benefit from these, the Department of Health had developed the guidelines to assist the hospitals to ration services and prioritise those who could benefit. The guidelines have already been referred to above. Explaining the advent of bioethics, Friedman states that 'given the limits on the number of patients who might be "accepted" for haemodialysis supported by grants and philanthropy, it became evident that rules were necessary to "allot the slots" equitably' (Friedman, 1993: 1205). Nephrologists in most countries are governed by this. In the US the Medicare programme was initiated and has a number of patients on the programme at State expenditure.

3.3 Distributive justice

Distributive justice is the next ethical problem identified in the Soobramoney case. This term refers to 'fair, equitable, and appropriate distribution determined by justified norms that structure the terms of social cooperation. Its scope includes policies that allot diverse benefits and burdens, such as

property, resources, taxation, privileges, and opportunities (Beauchamp and Childress, 2001: 226).

The authors go on to indicate that the term also refers broadly to the distribution of all rights and responsibilities in society, including, for example, civil and political rights. In this case we shall dwell on the rights of Mr. Soobramoney to receive care that was supposed to manage his health care problem which was a desire to access renal dialysis services at Addington Hospital when his funds were exhausted at a private facility. In terms of the guidelines he did not qualify for renal dialysis as the service was determined by justified norms which excluded him from the programme. The court had also concurred with the hospital that the policy so applied in excluding him was fair and reasonable. The authors explain that the problems of distributive justice arise under conditions of scarcity and competition to obtain goods or to avoid burdens (ibid: 226).

3.4 Medical futility

The guidelines developed by the Department of Health and supported by the nephrologists in the country in a way argued before the courts that Mr. Soobramoney would not benefit from the service he required as this was meant for people who were eligible for renal transplant. He did not qualify for this due to his medical condition. Providing him with this service would prolong his life but would deny other more deserving patients a slot on the

programme. In short treatment for him would be futile and it would be a waste of resources. Mr. Soobramoney actually died two days after case was concluded.

Though the withholding of treatment from Mr. Soobramoney was not stated to be purely on the grounds of medical futility, there is in my mind, sufficient reason to suspect this was implied. Schneiderman, et al (in Curzer 1999:760) though warn against withholding treatment on the basis of resource allocation citing medical futility stating,

> *'Arguments for limiting treatments on grounds of resource allocation should proceed by an entirely different route and with great caution in our present open system of medical care...'*

Mr. Soobramoney required renal dialysis to prolong his life and thus have a benefit of a qualitative life but did not require a treatment that preserved a permanent unconsciousness or that failed to end total dependence on intensive medical care and was therefore non-beneficial thus qualifying as futile (ibid: 759).

3.5 The role of the private sector

The other factor to consider ethically was the role of the private sector. As is the practice in the country that when the funds to care for one are exhausted in providing cover for self in the private sector, patients are invariably "dumped" onto the public service.

Mr. Soobramoney was initially treated at a private facility but had to go to the public service when he could not afford private rates when his medical funds were exhausted. The Constitutional Court also referred to the role of the private sector but never made any further comment or finding as the sector was not brought before the courts. The issue that needs further discussion is what should be the role and responsibility of the private sector once a patient had started treatment with them and could no longer afford their rates mid-way with the treatment plan. I will refer to this under recommendations and reflections in the next sections, though the envisaged national health insurance plan may be an answer. These ethical issues I consider to be the major ones which arose from the case in its original context. Now I will turn to reflect on the case identifying how these and other important ethical issues still have relevance.

Chapter 4

4.1 Ethical Reflections on the Soobramoney Case

In the first section of this chapter, I will review some comments concerning the Soobramoney case and provide a brief case summary. Then I will discuss the idea of respect for persons - respect for the autonomous choices they make concerning their lives. This will include references to the concept of medical futility and how it relates to the Soobramoney case. Then in the next section I will present my argument for the importance of the quality of one's life. In the following section, I will present objections to this argument. Finally, I will conclude that the quality of a patient's life is a manifestation of his or her own choice; what may or may not be my perceived quality of life may or may not be yours.

As medical professionals, we are obliged to respect the personal autonomous choices of our patients. Notwithstanding the problem of scarce medical resources, I will argue that healthcare professionals still have an ethical obligation to work towards respecting a patient's wishes regarding his/her quality of life. I will conclude by arguing that renal dialysis in end-stage renal disease when it can contribute to the patient's quality of life remains the ethical ideal towards which we should continue to strive.

Some ethical questions are relevant here - for example, the words of Judge Albie Sachs quoting Minow (1993)[19] in his judgement.

> *Interdependence is not a social ideal, but an inescapable fact; the scarcity of resources forces it on us. Who gets to use dialysis equipment? Who goes to the front of the line for the kidney transplant?'*

Judge Sachs asserts that a healthy life depends upon social interdependence in the form of clean air and water, good sanitation which all are supposed to be maintained by the state for the public good. This also includes healthy relationships and support provided by medical institutions. Naicker surmises, in agreement with the concluding remarks of Judge Sachs, that rationing of resources like renal dialysis and renal transplant programmes and deciding who should get the service, is best left in the hands of those best equipped to make the decision based on medical criteria (Naicker, 2008).[20] This however flies in the face of the remark made by Pieterse as commented on earlier in this discourse. I will refer back to this later.

Sadly, Mr Thiagra Soobramoney died two days after the judgement against his receiving dialysis was made.

---

[19] Minow, participating in an interdisciplinary discussion held at Harvard Law School in 1993.
[20] Presentation at Renal Congress, Durban. 2008.

Others, like Hassim putting weight to this argument on limited resources, state that the Soobramoney case recognises that the right to healthcare services does not impose a duty on the state to provide everything to everyone at once' (Hassim, et al.2007: 36).

Hassim, et al (ibid: 42) further states that there will be times when managing limited resources requires government to see to the larger needs of society rather than focusing on the specific needs of particular individuals within society. She concludes that in the case of Mr. Soobramoney, the 'available resources' argument meant that the state did not have to provide access to dialysis for people with Mr. Soobramoney's medical condition but that in another time and another case this may however change. No further cases similar to this have been brought before the courts yet to see how the court would interpret such a case in the light of other related health and social care judgements like Grootboom and Mahlaule/Khosa.

Mr Soobramoney's only hope for survival was regular renal dialysis. All that Mr. Soobramoney requested was to have what he considered as a good quality of life that renal dialysis could have provided. The arguments presented by the doctors who opposed his case were that he did not qualify for renal dialysis in terms of guidelines set in the public sector. Mr. Soobramoney had a pre-existing medical condition that disqualified him

from accessing renal dialysis. In terms of the protocol one needs to qualify for a renal transplant in order to be eligible for a renal dialysis. Mr. Soobramoney's pre-existing medical condition disqualified him from this programme.

The argument I wish to advance, though not included in his argument before the courts, is that people in Mr. Soobramoney's situation do not necessarily request a cure from their medical condition. Rather, what they desire is an enhanced quality of life. "There is no reason to welcome death until life becomes unbearable" (Epstein 1998: 748). Mr. Soobramoney may have known that death was inevitable however, but he sought relief through the courts purely to prolong his life, and consequently to enhance the quality of life he had remaining.

Dr. Martin Luther King Jnr. is quoted as saying 'The quality, not the longevity, of one's life is what is important.' (Brown et al 2007: 72). In exploring this concept one would venture to offer a definition of 'quality of life' according to this author as an overall sense of well-being. This includes an individual's satisfaction with their own lives (ibid: 76). A health related quality of life extends the definition to include the way a person's health affects their ability to carry out normal social and physical activities (ibid: 72).

By approaching the courts Soobramoney was under the assumption that renal dialysis does enhance a quality of life. Brown, et al (ibid: 83) further explain this assumption

> *Dialysis treatment is promoted as a means of maintaining or improving a patient's quality of life and well-being. This inevitably results in patients electing to commence dialysis in the expectation that their lives will be significantly improved as a result of undergoing treatment.*

In the next section of this chapter, I will discuss the idea of respect for persons - respect for the autonomous choices they make concerning their lives. This will include references to the concept of 'quality of life' and how it relates to the Soobramoney case.

4.1.1 Respect for persons

Immanuel Kant (1829 -1913), as discussed by the philosopher James Rachels (1987: Chapter 10), set forth the idea of respect for persons. Kant's work greatly influenced the course of moral philosophy and in particular, the then-unknown field of bioethics. In *The Metaphysics of Morals* (4, 429) Kant argued that humans have "Intrinsic worth". By that he means that because we are human we have something which exalts us

above the animals and the rest of creation – this intrinsic value or worth makes us valuable "above all price". Because we have intrinsic worth, we have moral standing, which, for example, plants and animals lack. Because we have moral standing we are morally valuable. And as human beings we should never be used as means to ends.

An outline of what Kant (ibid) says is that [only] people have conscious rational aims and hence [intrinsic] goals; only people are rational agents; humans are free agents capable of making our own decisions So we rational beings are beyond value since we are the sources of value. For Kant, treating others as ends involves a strict duty of beneficence. This means that when we help and not harm others, in so far as possible, we further their ends and respect their rationality. If we did not do this, then we would hinder their ends, and would use and manipulate them.

From the theories of Kant, Mill and W. D. Ross, Beauchamp and Childress (1991) developed their theory of "principlism" which is based on four principles: autonomy (respect for persons), non-maleficence, beneficence, and justice.

In biomedical ethics we look at all the principles in varying degrees to describe and define the moral obligations between the patient and the

doctor or health professional. We understand that in this relationship persons are not to be harmed.

Here, I will look at beneficence as it relates to the Soobramoney case.. Beauchamp describes beneficence in two forms, positive and negative beneficence (Beauchamp 2001: 165). He defines beneficence as 'taking positive steps to help others' (ibid: 166). The relationship between the patient and the doctor is that of the patient approaching the doctor to receive help. In another definition, beneficence is described as 'an obligation to help others further their important and legitimate interests (ibid: 166). These interests are what bring a patient to the doctor as the patient requires healthcare from the doctor or health facility.

The request of Mr. Soobramoney was to be offered renal dialysis as his important and legitimate interest. The renal physicians, in terms of utility, were expected to work as 'agents to balance benefits and drawbacks to produce the best overall results for him' (ibid: 165). His autonomous choice to request renal dialysis to prolong his life was denied on account of scarce resources and that he would not benefit from the service considering his medical condition. He had made a conscious and legitimate decision knowing that renal dialysis was able to meet his medical needs. The state hospital in turn, decided that despite the previous benefit he received from

the private institutions he could not access service at the public hospital facility.

In the Hippocratic work of *Epidemics* we are told that "as to disease clinicians should make a habit of two things, to help or at least to do no harm" (ibid: 176). By not helping Soobramoney (via providing dialysis) a harm was probably caused because he subsequently died soon after the court ruled against him and renal dialysis could have helped by prolonging his life.

4.1. 2 Respect for persons and quality of life

End of life decisions are complex matters to deal with in the South Africa population. This is so considering the past history of this country which led to the skewed allocation of resources based on race. The imbalances of the past have been carried over in the new democracy. So allocation of scarce resources does compound the ethical challenges faced by both clinicians and administrators in public service hospitals.

Public hospitals make decisions to maximize utility of the resources on the basis of triage – refusal of patients with likelihood of survival ..... and futility – withdrawal of therapy..."(Hodgson, 2006: 73-75) It is said that in case of intensivists at Critical Care Units, physicians have to make end of

life decisions and involve families in such discussions. Family members are involved together with the team and are "being called upon to make a momentous/irreversible decision, so that they are not left with a burden of guilt" (ibid: 74). Studies done in France indicate that family members do not want to be involved in such decision-making processes but even though such studies have not been done in South Africa, the impression is made that the results would not differ (ibid). The futility of treatment though, is a decision largely made by the clinicians in a paternalistic fashion in most cases.

In the same article Hodgson (ibid) cites examples of practices in Critical Care Units in the public service. He reports that it is indicated that decisions on futility are based on criteria that are seldom described or written and when made, may or may not be discussed with the family depending on circumstances of the case. We could say a treatment is futile if it will fail to maximise the patient's quality of life (ibid: 46) as put by Hofmann and Schneiderman (2007)

> *The University of California, San Diego Medical Center, for example, defines a treatment as futile when it "has no realistic chance of providing a benefit that the patient would ever have the capacity to perceive and appreciate, such as merely*

> *preserving the physiologic functions of a permanently unconscious patient, or has no realistic chance of achieving the medical goal of returning the patient to a level of health that permits survival outside the acute care setting ... The cardiologist wants to help the patient maintain a strong cardiac output, a nephrologist wants to make sure the patient's kidney function is adequate, and the pulmonologist concentrates on lung capacity and viability.*

This is what I would like to explore looking at the current protocol to deny elderly patients and people in the same position as Mr. Soobramoney access to renal dialysis care.

The question to ask is –"Is dialysis futile in elderly patients and those with co-morbid disease?"

In answering the question I pose I above, I wish to refer extensively to arguments raised by Papadimos describing the duties of care-workers to patients described as 'outliers', meaning those patients who exhaust the resources of the state hospitals due to the lengths of stay in hospitals or co-morbid conditions they have.

Patients with end-stage renal disease requiring dialysis fit this description generally and Mr. Soobramoney was a fitting example in particular considering he had pre-existing co-morbid disease. Another definition of an outlier (Papadimos, 2004: 11) is given below:

> *An outlier, in this context, is a human being, who suffers an incredible physiologic, emotional, and financial burden; who, in turn, will cause health care providers and administrators economic and psychological stress. An outlier can be recognized, an outlier will cost money, and an outlier will tax emotions. Why stay engaged in their care?*

Papadimos (ibid: 3) goes on to say,

> *Struggles with obligation regarding the care of outliers consume the consciousness of many health care providers, including the authors. Morality, responsibility, good will, duty, acting on principle, justice, and treating people as an end in themselves, as viewed by the authors and supported by the philosophies of Immanuel Kant and G.F.W. Hegel, are explored as a basis for a physician to never disengage from the care of outliers.*

To 'never disengage from the care of 'outliers' as mentioned, looks to the work of major philosophers such as Immanuel Kant. As Kant ([1797] 2005) articulates in his Second Formulation of the Categorical Imperative,

> *Act in such a way that you treat humanity, whether in your own person or in the person of any other, always at the same time as an end and never merely as a means to an end*

In the context of the Soobramoney case, a renal physician has an obligation to the patient that requires that his or her own personal clinical decisions are not based solely on issues such as availability of resources. Rather, treating a person as an end in his or herself requires that physicians ought to respect the decisions of the patient as a person of dignity and worth and never disengage from their patient's care.[21]

Hegel, according to Papadimos (2004: 21), introduced the concept of "right", which is extrapolated here to mean a patient has a right to health care. At the same time, we are reminded that we are all part of society and live according to moral law – meaning that we live according to a set of rules. 'This moral law involves, according to Hegel, "... identity of my will with the will of others"' (ibid).

[21] The second formulation of Kant's Categorical Imperative also leads to the imperfect duty to further the ends of ourselves and others. If any person desires perfection in him or herself, then it would become a moral duty to seek that end for all persons equally, so long as that end does not contradict perfect duty.

The renal physician has a moral duty to help a patient with end-stage renal disease coming to the hospital requiring assistance. It is the responsibility of that physician to attend to the needs of that individual, whether it is Mr. Soobramoney or someone younger with no co-morbid disease. Taking care of outliers is something many providers and institutions do not like, or even are required to do, but in doing so they provide society with an example of a "beneficent action having moral worth " (Papadimos, 2004: 17).

Another interesting thought introduced by Papadimos is brought to the fore concerning the rising numbers of the ageing population as voters in the United States of America. A scenario is painted of this growing population who may be able to force the government to allocate resources to cater for the number of patients who may require dialysis as a collective will. This group, it is said, may ultimately make the physician their primary negotiator for allocation of these resources. This would fit in with the Hegelian philosophy of self-determination. The authors however do not offer solutions on what to do concerning allocation of scarce resources in this challenging situation. They do however pose a few thoughts proposed by Papadimos quoting Singer (1997: 24):

> *... decisions over resource allocation can be mitigated through three general strategies: 1) don't do things that don't work; 2) don't do things that do*

work, but the patients don't want done; and 3) don't do things inefficiently...

The answers to these comments should be that 'these concerns should not be translated into a plan for evasion of care of outliers, but should result in a well-planned approach to staffing, securing of funding, and locating alternative funding sources for these patients' (ibid: 26).

The current protocol for renal dialysis programmes is still exclusivist but due regard needs to be taken to review the situation especially regarding the aged and those with co-morbid disease. There is a need to shore up the renal dialysis programmes so they are not only efficient but consider the needs of patients in a resource-constrained environment. The partnerships between the public and the private sectors should be pursued e.g. in sharing resources where the private sector has a financial advantage and in cases where public service physicians can assist the private sector with issues involving futile care (Hodgson, 2006: 74). The advent of National Health Insurance, as envisaged by the Ministry of Health, could probably provide an avenue for expanding this programme of private-public partnerships.

4.1. 3 Arguments pro and con the quality of life in context

In considering renal dialysis for cancer patients in his essay, Epstein (1998: 753) argues that the fact that a patient suffers from cancer should not be

the reason for denying them access to renal dialysis care. Similarly, I wish to contend that despite the fact that Mr. Soobramoney had pre-existing medical conditions, he had a right to access renal dialysis to enhance his quality of life. Due to rationalisation of scarce resources Mr. Soobramoney could not access this care in the public sector. He could no longer afford the costs of paying for this service in the private sector.

Renal dialysis is considered to be a life-long treatment and life-saving in the absence of renal transplant. Also as indicated above, the percentage of patients on renal transplant in the country is quite low. The advent of anti-retroviral drugs is however changing this as Venter (2008: 182) states:

> *Kidney transplantation has been established as the most effective form of renal replacement therapy from a cost and quality of life perspective in the developed world. The first year after the transplant can be more expensive and may have a slightly higher mortality, but after the first year, expected survival is 10 - 15 years longer than in patients on dialysis, and the intervention is significantly cheaper. While cost-effectiveness in the developing world is less well described, the renal transplant programme in South Africa has a long history, with expansion in the last decade driven from the private sector*

HIV infection was an absolute contraindication to organ transplant but now the availability of anti-retroviral therapy is rapidly changing this. In a similar way as the availability of drugs has added to a much improved quality of life for patients with HIV/AIDS, patients in need of renal replacement programmes, like the elderly and similarly debilitated patients, also have a need for renal dialysis to improve their quality of life.

There are reasons advanced why renal dialysis should not be provided for cancer patients, which may justify some people supporting denying the elderly with debilitating diseases renal replacement therapy. The reasons advanced are, dialysis may be thought to be futile; it may be thought to result in poor quality of life for patients with cancer; dialysis may be withheld from patients with advanced cancer because of cost (Epstein, 1998: 744).

'Today however the ethics of treatment or non-treatment strongly embraces the principle of self-determination. This approach has largely replaced the approach of paternalism' (ibid: 744). Epstein indicates however that it is only when the treatment is deemed futile that the physician makes treatment decisions. Dialysis however is understood to be an effective treatment in modifying the course and symptoms of end-stage renal disease.

Patients who opt for this form of therapy therefore are hopeful that this will alter the course of their disease and enhance their quality of life. I suggest that physicians may not be aware of the patient's desire for a better quality of life for a number of reasons. The first one is that a patient's quality of life is subjective; what is a good quality of life for one person may differ from that of another. In this regard, a patient's perception of his or her quality of life may differ from that of his or her physician. Secondly, the patient with a short amount of life remaining, but with an acceptable quality of life, may value that time more than the physician realizes; there is no reason to welcome death until life becomes unbearable. Finally, even when death would be welcomed by a patient, the physician may be able to "choose" for the patient a relatively pleasant death instead of an unpleasant one. In this way, a physician can contribute not only to a patient's quality of life, but his or her quality of death as well.

There are indications in the literature that patients with end-stage renal disease on dialysis rate their quality of life to be almost as good as does the general population: 'it appears that quality of life on dialysis is clearly acceptable and is not in itself a source of misery from which death is sought' for a number of elderly patients on dialysis (Epstein, 1998: 749). Mr. Soobramoney was hoping for a less-miserable life when he approached the courts as he desired to continue dialysis which he could no longer afford due to financial problems.

There is no doubt that renal dialysis does add an additional financial burden to any health care system. For example, in the Medicare programme in the USA it has been shown that more elderly patients have been put on renal dialysis and this seems to be costly mainly due to the high number of patients on the programme (ibid: 750). With this programme, more lives are being saved without offering a cure. The elderly on the programme continue to receive treatment for other illnesses they suffer e.g. cancer. That being said, Epstein (ibid: 750) argues that dialysis in cancer patients with end-stage renal disease is a reasonable cost-effective treatment whose benefits outweigh its burdens in the majority of cases. By benefit, he refers to the personal quality of life benefit derived from this procedure.

Latos (1999: 637) advises that the mode of dialysis in the elderly should be individualised taking into consideration both medical and psychosocial factors. Decisions concerning dialysis should not be treated differently from decisions about benefits and burdens of any other medical treatment. Dialysis should be a therapeutic option available to all people, including people with cancer, to be used when the benefit to the patient exceeds the burdens of treatment. In general this will include all but those near death. Each case must be decided on its own merits, and it is the competent and informed patient or proxy who should make the decision (Epstein, 1998: 753).

On average, we can say it is true that elderly persons do less well than younger people after risky medical or surgical procedures. Renal dialysis, on the other hand, is not considered a 'risky procedure'. A point that should be noted is that at no age - the "young" or the "old" (and in recognition that the distinction is arbitrary) will any impairment or procedure affect *all* individuals in the same way. Using age alone as a status on which to base the type of care provided is most likely not built on a solid foundation and may reflect a societal bias against older people in general (MRC 1994: 37).

Whenever a patient's perspective on his or her quality of life – its value and worth – is known, I suggest that respect for that particular persons dignity and worth and their own opinion concerning their quality of life outweighs other factors when considering the provision of renal dialysis (Cain 2002: 300).

The case involving Mr. Soobramoney was about his right to emergency care. He argued that he was denied this basic right. Behind this right was a desire for quality of life, which as I stated earlier was not articulated during the court hearing.

The argument forwarded by the doctors at King Edward VII Hospital was that in offering him dialysis to save his life other more deserving younger

patients who stood a better chance to survive and receive a renal transplant would be denied.

Williams, a British health economist who did a study on the cost-effectiveness of coronary bypass grafting, recommended that resources be "redeployed at the margin to procedures for which the benefits to patients are high in relation to costs" (Williams quoted in Beauchamp, 2001: 210). A question following this analysis was however how quality of life can be determined. From this, the concept of quality-adjusted life years was developed. This is referred to as a health-related quality of life (QALY).

Proponents of cost-evaluation assessment believe that 'saving the life of a younger person is likely to bring more QALYs than saving the life of an older person'. This argument says that age plays a role in considerations of quality of life, which is more compromised in the elderly (ibid: 211).This feature favors life-years over individual lives and the number of life-years over the number of individual years.

Arguing against this, Beauchamp quotes Harris who states "QALYs are 'life-threatening device' because they suggest that life-years rather than individual lives are valuable" (ibid: 211) He says that adaptation of QALYs fail to recognise societal and professional beneficence that is ethically required when rescuing individual lives.

Hutchison, *et al.* (2007)[22] quote from a very large study on ICU admissions for patients with end-stage renal failure (ESRF) and non-ESRF patients in the United Kingdom In this study the ESRF patients had far more readmissions to ICU than non-ESRF cases but the lengths of stay were comparable to the non-ESRF patients. Most of the ESRF patients were younger and had severe illnesses compared to the non-ESRF cases. The analysis that patients were younger was an indication that there could be discrimination against older patients for receiving dialysis. This strengthens the notion that generally older patients have difficulty accessing renal dialysis according to the authors, supporting the same point I made earlier. But this also emphasizes the point that services like renal dialysis are seen as more beneficial to the young compared to the elderly and much sicker patients considering their live years and improved quality of life.

There was also greater post-ICU mortality with ESRF patients. Such patients fared badly in the longer term compared to the other cases even though this was a younger age group. Those against quality of life would indicate that patients with ESRF with severe illnesses and co-morbid diseases and of a much older age do not enjoy a better quality of life considering the number of hospital ICU readmissions and higher levels of mortality post-ICU.

[22] Analysis based on authors' research report in Critical Care Forum published online and downloaded from Pubmed. See reference list.

There are studies that indicate that the aged tend to present late for renal dialysis (Navaneethan et al, 2008: 1186). There are other factors like race, physician referring, physician rationing, medical insurance and distance to dialysis centre which have an impact on the care of the aged. Most elderly Black patients live in rural areas where access to health care is still limited. Some of the physicians take long to refer the patients to the renal care centres. Some of the patients are not referred because physicians may decided against referring patients to renal physicians as a form of rationing resources preserving this for younger patients. These are some factors that need to be considered when making decisions about allocation of scarce resources like renal dialysis before care is denied to patients with end-stage renal failure who are elderly and have co-morbid disease.

In addition, other studies (see: Klang, Bjorvell & Cronqvist 1996; Levinsky 1999; Riley & Pristave 2001) appear to indicate that the elderly have valued their lives better after being put on dialysis. The goals for elderly patients undergoing dialysis may be different from those for younger age groups. Long-term survival (greater than 10 yrs) is often not anticipated-nor is it expected. However, some individuals and their families may have unrealistic expectations of just what dialysis can accomplish (Weins 1998: 19). For example, although dialysis will ameliorate uremic symptoms and improve congestive heart failure, it will not prevent the progressive vasculopathy or neuropathy associated with diabetes. In addition, the

changes in lifestyle required by dialysis, coupled with the trade-offs of potential debilitation, may not be appealing for some patients. Nevertheless, several studies have provided strong evidence for acceptable survival and quality of life among elderly dialysis patients. Many individuals feel that dialysis offers them the chance to spend increased time with family and friends, and some rank their health at least as good as others their age (Latos 1996: 644).

Thus renal dialysis, not being a cure for end-stage renal disease can still assist in letting those not qualifying for a renal transplant add some value to the last days of their lives. Such patients need to be afforded this basic need before their deaths. Mr. Soobramoney sadly was denied this desire.

One may conclude by stating that renal dialysis for the older person in end-stage diseases when it can contribute to the patient's quality of life should remain as an ethical ideal towards which we should continue to strive.

Some studies done however yield different results concerning quality of life on renal dialysis (Brown et al, 2007: 75). The authors state that while dialysis supports life, it does not necessarily improve quality of life and that the majority of patients on renal dialysis rate health related quality of life as being less than "good" as deteriorating health impacts on the amount of time they can spend at work or other activities and the impact it has on

family life. They indicate that some patients on dialysis feel short-changed – that their expectations have not been met and that life on dialysis is not living (ibid).

The authors conclude by advising that it is essential not to forget the importance of quality of life in assessing someone who is receiving dialysis and always seek to improve it. They suggest that this is the role that palliative care can play in their management and that of support for the families. Did Mr. Soobramoney and his family receive this? Now let us look at the recommendations as we conclude this discourse on the Soobramoney case.

Chapter 5

5. 1 Conclusion & Summary

In summary, this is a reflective discourse on the case of a patient, Mr. Soobramoney who approached the courts to demand that he be put on renal dialysis treatment at state expenditure after he had exhausted all his funds whilst being treated by renal dialysis for his end-stage renal failure at a private facility.

He went to the Constitutional Court when he failed to win his case at a supreme court in Durban. He had sought refuge in the Constitutional Court on the basis of emergency care (Section 27(3)) but the court heard his case under a different section of a right to life. His case was dismissed. He died soon after the case was concluded.

The court heard that he needed renal dialysis to prolong his life, and for my discourse, interpreted as requiring an enhanced quality of life. He was denied this right to life on the basis that the service was limited as a scarce resource and that the guidelines provided by the hospital were reasonable. Pieterse, who has been quoted extensively in this discourse, argues that some of the litigations in the health-rights cases limit health rights in our health-rights jurisprudence (Pieterse, 2005: 86). He holds that the state did

not go to the extent of verifying whether it was truly unable to offer the service considering constraints. The court's decision is also criticised for stating that individual rights are sacrificed to the amorphous general good which could preclude virtually any adjudication of a claim to resources as enjoying constitutional priority over other claims thus infringing on individual rights like that of Mr. Soobramoney.

Following the Grootboom case it is clear that the State has to give effect to Sections 26(2) and 27(c) by developing reasonable plans to address shortcomings in its service delivery in health care like renal dialysis. This can be as it was compelled to do in the TAC case on PMTCT.

The Constitutional Court erred by not wanting to make comments on what they termed as medical or scientific decisions arguing that this is sacrosanct and is best left in the hands of clinicians. Pieterse ably argued rationing of health care-related decisions are not clinical but political and should have been handled by the Court.

In reflecting back on the Soobramoney case I highlighted quality of life issues emphasising that humans should not be used a means to an end. They need to be respected as persons and not to be harmed.

Hospitals make decisions to maximise utility of resources based on triage and futility as seen in renal dialysis care and critical care units. Thus end of life decisions in terminal care are difficult to make but when taken tend to be made in a paternalistic way by physicians. Families are not normally involved in such decision-making processes, but they should be included.

In looking at medical futility I identified that there are studies that looked at futility of care of patients defined as "outliers". These are patients who exhaust state funds during their care and cause physiologic and emotional burdens in addition to the financial one.

Whilst recognising this I made a point, quoting the studies made on 'outliers' that physicians do not need to disengage from their care but rather need to recognise that continued care may improve the quality of their lives and help ease inevitable death. This I feel is important and following Brown (2007: 72), I defined quality of life as a concept that relates to a person's overall sense of well-being which includes that individual's satisfaction with their life and relates to their ability to take pleasure in every day activities. I further indicated that health-related quality of life extends this definition to include the way a person's health affects their ability to carry out normal societal and physical activities.

Further it became clear that quality of life is a subjective feeling for patients. Those patients requiring treatment which enhances their quality of life value greatly the remaining time of their life years. They value life until it becomes unbearable and that physicians have a role to play in assisting patients to have a pleasant death too. Simply put, physicians need to respect the patient's wishes for a type of treatment envisaged if it will improve their quality of life.

There are theories that base quality of life on QALYs, quality of life-adjusted years. Some studies using this theory tend to be biased towards the young when making treatment decisions. The studies made on patients with end-stage renal failure (ESRF) show that the aged tend to do far worse than the young on renal dialysis. There are more readmissions to intensive care units for those with (ESRF) than those without showing that such patients spend more time in hospital than those without the disease.

Thus arguments against quality of life indicate that renal dialysis does not enhance this. The patient's uremic symptoms may be relived but their other comorbid conditions like vasculopathies remain. Also there are many other life's inconveniencies involved with renal dialysis.

5.2 Recommendations

The main recommendations from a legal perspective centre on giving effect to Section 27 (1) (a) and Section 27 (2). With the advent of a National Health Insurance we should be able to achieve universal coverage for all. Porter and Teisberg (2006: 328) state that universal coverage and value-based competition will produce dramatic improvements in efficiency and effectiveness of health care. They advocated for changes in insurance rules and regulations. This is what NHI will achieve in our country. More patients with renal disease will hopefully benefit as more centres offering renal dialysis in the private sector will now be available to the indigenous population. Perhaps with this there could be a review of the protocols for renal dialysis.

Public-private partnerships to increase access to renal health care that are currently in place should be strengthened as we noted such a facility being opened at Mankweng Hospital, Polokwane where the former Minister of Health commented thus, "The purpose of this project is to research cost effectiveness and efficiency of Telemedicine in expanding access to quality healthcare, particularly targeting poor people living in remote areas" (Tshabalala-Msimang, 2007: 2).

As suggested by Pieterse, the courts should begin to make rulings on medical decisions without abrogating these to the medical profession only. Just like they are able to pronounce on political and socio-economic matters before it, the Constitutional Court should be able to decide a matter on medical issues brought before it as no profession should be sacrosanct. This way the courts should interrogate the defence on allocation of scarce resources based on medical criteria to see if the departments are indeed spending the allocated resources appropriately.

The other point looks at the role of the private sector in renal care in particular, but overall health care generally. The tendency for the private sector to 'dump' patients on the public service should be reviewed. There should be mechanisms undertaken to determine whether a patient who first presented to a private facility, and once having exhausted their funds, should be 'dumped' onto the public service. Some form of criteria should be developed to determine who should be transferred to the public hospitals to conclude treatment or should stay in the private facility even if they cannot afford the care as they will not be required to pay for the service. This could be covered under NHI.

On the ethics side, apart from the general criteria set, there should be an assessment made of the patient's perception of quality of life if they require

renal dialysis or a similar treatment. Patients in Mr. Soobramoney's case should be evaluated to determine if they would be able to improve their quality of life if put on renal dialysis even if they do not qualify in terms of the protocol generally adopted by renal physicians. All patients requiring renal dialysis should however also be counselled thoroughly on this type of care as it is not in all cases where the quality of life may be enhanced as we read that at times the uremic symptoms may be improved but other vasculopathies remain.

Lastly, as it was the case with the PMTCT programme and the HIV/AIDS programme, consideration should be given to establish a renal care programme, fashioned along the Medicare programme, to look after renal care service in the country. The number of renal care units arising in the country under the auspices of private industry e.g. some pharmaceutical companies may be required to look after the public service clients.

Although over 12 years old, this case still has relevance to the people of South Africa. Reflecting back on it gives us an opportunity to reconsider issues such as the fair distribution of medical resources, the role of the public sector in health care, decisions concerning who decides if a treatment is futile (and why), and the respect for a patient's view on the quality or not of his or her remaining life. In this thesis, I have attempted to

highlight these and other ethical issues in the legal context of the case of Thiagraj Soobramoney versus the Minister of Health KZN (1997).

References

- Aldo, AV. 1990. *A Dictionary of Ethics.* Irvine, California: Progress Publishers.
- Beauchamp, L. and Childress, F. 2001. *Principles of Biomedical Ethics.* (4th Ed.): New York: Oxford University Press
- Brody. 1993. Biomedical Technology and Human Rights, UNESCO, Paris: 233. In Minister of Health vs. Soobramoney
- Brown E, Chambers EJ, Eggeling C. 2007. *End of Life Care in Nephrology-From Advanced Disease to Bereavement:* Oxford: Oxford University Press
- Cain, P. 2002. Cardiopulmonary resuscitation. In: KWM Fulford, DL Dickenson and TH Murray (Eds.). *Healthcare Ethics and Human Values.* NY: Blackwell Publishers: 298-303.
- Chabane C, 2009. A Green Paper on – *Improving Government Performance: Our Approach.* www. the presidency.gov.za.
- De Vecchi et al, Dratwa M, Wiedemann ME. 1999. Nephrology Dialysis Transplantation. Table – Dialysis Costs Related to Health Care Costs.
- Elhauge E 'Allocating *health care morally'* (1994) 82 California LR 1451-1544.
- Epstein AC.1999. Should cancer patients be dialysed? *In* Curzer HJ. (Ed.). *Ethical Theory and Problems.* Wadsworth Publishing Company, London.

▪ Fleck LM. *Just Health Care Rationing: A Democratic Decision-making Approach.* University of Pennsylvania LR, 140: 1597-1636.

▪ Friedman E. A. 1993. Ethical Problems in Dialysis and Transplantation. *New England Journal of Medicine*, 328:1204-1205.

▪ Government of the Republic of South Africa v Grootboom 2001 (1) SA 46 (CC).

▪ Grootboom v Oostenberg Municipality 2000 (3) BCLR 277 (CC)

▪ Hassim A, Heywood M, and Berger J. (Eds). 2007. *Health and Democracy: A guide to human rights, health law and policy in post-apartheid South Africa.* Cape Town: Siber ink: 33-34.

▪ Hofmann PB and Schneiderman LJ. 2007. Physicians Should Not Always Pursue a Good "Clinical" Outcome. *The Hastings Center Report,* 37(3). Retrieved: 27 July 2008. Available at: http://www.proquest.com/

▪ Hodgson RE. 2006. The management of death in the ICU. "The South African perspective". *Critical Care and Resuscitation*, 8: 73-75

▪ Hutchison CA, Crowe AV, Stevens PE, Harrison DA and Lipkin GW.2007. Case mix, outcome and activity for patients admitted to intensive care units requiring chronic renal dialysis: a secondary analysis of the ICNARC Case Mix Programme Database. *Critical Care*; 11(2):R50. Published online 2007 April 23.doi:10.1186/cc5785. Accessed 20 July 2008 at www.pubmed.nih.gov/

▪ Kant, I. (1829 -1913). 2005. *Groundwork for the Metaphysics of Morals.* TK Abbott (Trans). L. Denis (Ed.) NY: Broadview Press.

▪ Katz I. 2008. Business Plan Proposal for Kopanong Dialysis Unit (Vaal Triangle). Submitted to Chris Hani Management and Department of Health – 2008.

▪ Katz I. 2008: Complaint lodged by patient at Human Rights Commission – alleging denial to renal dialysis at Chris Hani Baragwanath Hospital. File no: BW099663490.

▪ Khosa v Minister of Social Development 2004 (6) SA 505 (CC).

▪ Kjellstrand CM, Dossetor JB (ed.). 1992. Developments in Nephrology: Boston: Kluwer Academic, in Friedman E. A. 1993. Ethical Problems in Dialysis and Transplantation. *New England Journal of Medicine*, 328:1204-1205.

▪ Klang, B., Bjorvell, H., and Cronqvist, A. 1996. Patients with chronic renal failure and their ability to cope. *Scandinavian Journal of Caring Sciences*, 10(2): 89-95.

▪ Latos DL. 1996. Chronic Dialysis in Patients Over Age 65. *Journal of American Society of Nephrology;* 7(5):637-646

▪ Levinsky, NG. 1999. Quality and equity in dialysis and renal transplantation. *New England Journal of Medicine*, 341 (22): 1691-1693.

▪ Mahlaule v Minister of Social Development 2004 (6) SA 505 (CC).

▪ Manuel T. 2009: The Green Paper: *National Strategic Planning*: www.thepresidency.gov.za

▪ Medical Research Council (MRC). 1994. *The Health of the UK's Elderly People.* London: The Council: 37.

▪ Minister of Health v Treatment Action Campaign (No2) 2002 (5) SA 721 (CC).

▪ Minow. 1993. Participating in an interdisciplinary discussion held at Harvard Law School, "Session I: Applying Rights Rhetoric to Economic and Social Claims" Economic and Social Rights and the Right to Health (Harvard Law School Human Rights Program, Cambridge MA 1995) 1 at 3. In Minister of Health vs. Soobramoney, 1997.

▪ Moosa MR, Kidd M. (2006), 'The dangers of rationing dialysis treatment: The dilemma facing a developing country', Kidney International 70: 1107-1114.

▪ Moshesh F. 2003. Nephrology Report. (Retrieved 29 September 2004) Available at: http:www.doh.gov.za/mts/reports/nephrology.html

▪ Naicker S, 2001. *Africa*. In Levinsky NG (Ed). *Ethics and the Kidney*. Oxford University Press. 255-263

▪ Naicker S. 2008. *Ethics & Economics of RRT in Africa and the Developing World*. SA Renal Congress Presentation. Durban.

▪ Navaneethan SD, Aloudat S and Singh s. 2008. A systematic review of patient and health system characteristics associated with late referral in chronic disease.*BMC Nephrology*, 9(3): Downloaded at www.biomedcentral.com/1471-2369/9/3 on 05.07.2008.

▪ Ngwena C 2003. 'Access to antiretroviral therapy to prevent mother-to-child transmission of HIV as a socio-economic right: An application of section 27 of the Constitution. *SA Public Law*, 83-102.

▪ Papadimos TJ and Marco AP. 2004. The obligation of physicians to medical outliers: A Kantian and Hegelian synthesis. *Journal of the British Medical Council,* 5 (3): Retrieved 5 July 2008. Available at: http://www.pubmedcentral.nih.gov/.

▪ Parkin A. 1995: 'Allocating *health care resources in an imperfect world*' (2002) Modern LR: 867-878.

▪ Pieterse M. 2005. A Benefit-Focussed Analysis of Constitutional Health Rights – a Dissertation for Doctor of Philosophy. School of Law: University of the Witwatersrand: Johannesburg

▪ Porter ME, Teisberg EO. 2006: Redefining Health Care – *Creating Value-based Competition on Results:* Boston. Harvard Business School Press.

▪ Riley, JB., Jr. and Pristave, RJ. 2001. Patient's rights in receiving or rejecting dialysis care. *Nephrology News and Issues,* 15 (9): 49-51.

▪ Rizvi SAH, Naqvi SAA and Ahmed E. 2007. Renal Transplantation in Developing Countries. In: *Kidney Diseases in the Developing World and Ethnic Minorities.* EN Nahas, RS Barsoum, J Dirks and G Remuzzi (Eds.). New York: Taylor and Francis: 211 – 241.

▪ Scott C; Alston P '*Adjudicating constitutional priorities in a transitional context: A comment on Soobramoney's legacy and Grootboom's promise*' (2000) 16 SAJHR 206-268.

▪ Singer PA. Resource allocation: *beyond evidence-based medicine and cost effectiveness analysis.* ACP J Club. 1997; (127): A16-A18.Retrieved 5 *July* 2008. Available at:http://www.pubmedcentral.nih.gov/

▪ South African National Health Department, South African Renal Society, South African Transplant Society and South African HIV Clinicians Society. 2007. *National Health Guidelines for Chronic Renal Disease.* In Guidelines for Renal Replacement Therapy in HIV-Infected Individuals in South Africa.3-18.

▪ Thiagraj Soobramoney versus Minister of Health (KZN). 1997. Constitutional Court of South Africa, Case CCT 32/97.

▪ The Constitution of the Republic of South Africa, 1996. Act 108 of 1996.

▪ Tshabalala – Msimang, M. 2007. Address by former Health Minister Manto Tshabalala-Msimang at the Telemedicine Project Launch at Pietersburg Hospital.

▪ Venter WDF, Naicker S, Dhai A, Fabian J, Wadee S, Britz R, Paget G and Meintjies G. 2008. Uniquely South African: Time to consider offering HIV-positive donor kidneys to HIV-infected renal failure patients? *South African Medical Journal*, 98(3): 182-183.

ANNEXURE B

GAUTENG PUBLIC HOSPITALS THAT PROVIDE RENAL DIALYSIS SERVICES

Name of the Hospital	**Haemodialysis**	**Peritoneal Dialysis**	
Chris Hani Baragwanath	x	x	
Dr. George Mukhari	x	x	
Steve Biko Academic	x	x	
Charlotte Maxeke Johannesburg Academic	x	x	
Helen Joseph	x	x	
Kalafong	closed		
Tembisa	no	no	
Natalspruit	no		
Sebokeng	closed		
Tambo Memorial	no		
Leratong	x		
Heidelberg	no		
Kopanong	no		
Germiston	no		
Dr Yusuf Dadoo	no		
Tshwane District	no		
Mamelodi	no		
Pholosong	no		
Jubilee	no		
Odi	no		

Please note that the indicator 'x' stands for those hospitals which have renal dialysis