# The state of renal replacement therapy for children in South Africa: Data from the first report of the re-established National Renal Registry

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## Abstract

***Background:*** The South African Renal Registry (SARR) was re-established in 2010. The first report was produced in 2014. It revealed that only 3182 patients out of 43.6 million people who were dependent on the state for medical care, received renal replacement therapy (RRT) in 2012 (73 per million population).

***Aim:*** To describe the state of RRT for children in South Africa in 2012.

***Methods:*** From the SARR report and 2012 dataset, a cross-sectional study was performed of children under 14 years of age who received chronic dialysis, and incident renal transplants in 2012. Patient demographics, treatment modalities and outcome were recorded and RRT rates computed.

***Results:*** Fifty-nine children received dialysis in South Africa in 2012, a rate of 3.8 per million age-related population (pmarp). The mean age was 9 years 11 months. The most common cause of end stage renal failure (ESRF) was acquired glomerular disorders (83%). Ninety percent of the children received treatment in two of the nine provinces. Six children (10%) were treated in the only private dialysis unit. Eleven patients received kidney transplants (19%): six private and five public sector patients. Sixteen patients (27.1%) died: seven due to cardiovascular and three due to cerebrovascular events.

***Conclusion:*** There was a low RRT rate of 3.8 pmarp for children in South Africa in 2012. Private sector patients were likely to receive more optimal treatment. The poor performance of the state health sector can largely be ascribed to a deficiency of funding for RRT facilities and trained personnel.

**KEY WORDS**: children, developing countries, renal registry, renal replacement therapy.

Limited access to renal replacement therapy (RRT) for end stage renal failure (ESRF) for patients in the public sector in South Africa (SA) was reported in 2006.[1] Almost a decade later, the first South African Renal Registry annual report was published in 2014 (SARR Report 2012).[2] The report gave an overall account of data collected in 2012 for both adult and paediatric chronic RRT. It revealed that only 3182 patients out of 43.6 million people who were dependent on the state for medical care received RRT in the public (state-funded sector) in 2012. This is a treatment prevalence rate of 73 per million population (pmp). In comparison, 5377 of 8.671 million private sector patients received RRT, yielding a rate of 620 pmp.

Since 1994, with the advent of the new democratic South Africa, the national budget allocation for RRT has not been increased in line with the increased demand.[2] There are nine provincial Departments of Health (DOH) in SA which are responsible for funding RRT in the public sector, but not all provide such treatment. Public sector dialysis units have been forced to ration RRT, which has resulted in many patients being turned down for dialysis.[1] Private sector RRT is provided through health insurance schemes. ESRF is readily treated in this system because its treatment, including RRT, is classified by legislation as a "primary minimum benefit". There have been few advocates for children requiring RRT in SA, especially in the public sector. No dialysis registry reports on the state of RRT for children in Africa have been published previously. This study describes the extent and outcome of RRT in children in SA as reported in SARR 2012.

## Aim of the study

The aim of this study was to describe the prevalence, demographics, facilities for, and outcome of RRT for children under 14 years of age in SA in 2012.

## Methods

### *Study design*

This is a cross-sectional study of children who received RRT (chronic dialysis, and incident kidney transplants following a period on dialysis), in SA in 2012. Children who had received a kidney transplant before 2012 were excluded. The cut-off age of less than 14 years is used conventionally for paediatric treatment in SA and this age was used for this report.

### *Data collection*

Information for the study was based on the first report of the SARR in 2014 as well as existing data in the database of the SARR for 2012. A South African renal registry was re-established in 2010 at the instigation of the South African Renal Society and the South African Transplantation Society. This is a societal registry with no direct legislative requirements. All dialysis units in SA are required to download an electronic data collection programme and are requested to directly upload the relevant information of their patients in the beginning of a year and updated midyear. There are no incentives for performing the service. The collected information is transmitted to a central database server from which the registry manager collates the information for the registry. Access to the programme is password-protected to ensure that doctors and unit managers have access only to data of their own patients. For this study one researcher was given access to anonymized information of all children younger than 14 years prevalent in the registry for the period 1 January to 31 December 2012. Patient information was transferred onto an Excel spreadsheet for further analysis.

The following information was collected for this study:

- Dialysis unit location and funding, specialist staffing and facilities, and number of patients treated.
- Patient age, gender and racial group.
- The cause of ESRF. Causes were grouped into four broad categories, namely glomerular disorders, inherited kidney diseases, congenital anomalies of the kidney and urinary tract (CAKUT), and other miscellaneous conditions.
- Clinical, laboratory and treatment information, which included the occurrence of anaemia, hyperparathyroidism (parathyroid hormone >88 pg/mL), and hypertension (blood pressure above 95th percentile of guideline levels).[3] Anaemia was defined as a haemoglobin (Hb) level < 11 g/dL for children <7 years of age and <11.5 g/dL for children ≥7 years of age.
- Information on drug treatment with erythropoietin-stimulating agents (ESA) and parenteral iron.
- Dialysis modality. Data were collected of the first dialysis modality recorded in 2012 only, thus excluding switches between modalities. Differentiation was made between haemodialysis **(**HD), manual peritoneal dialysis (PD) and automated peritoneal dialysis (APD).
- Information on incident renal transplantation and the period on dialysis before transplantation.
- Outcomes. The following were recorded: mortality and the cause of death, renal transplantation and continuation of dialysis.

Differential data were recorded for public and private sector patients.

Population statistical data were obtained from official statistics published by the South African government. Computations of RRT and transplant rates for children were done by the authors.

### ***Ethics***

Approval for the establishment of the SARR, including a waiver for individual written consent, was granted by the Health Research Ethics Committee of Stellenbosch University, Cape Town, South Africa (reference no. N11/01/028). Researchers are required to sign a confidentiality agreement before information from the registry is released for a study. Ethics approval for the study reported here was obtained from the Research Ethics Committee of the Faculty of Health Sciences of the University of Pretoria.

## Results

Fifty-nine children received RRT in SA during 2012. The age and sex distribution of the patients are depicted in Table 1. The mean age was 9 years 11 months (range 3 years 10 months to 14 years). Only seven children were younger than 5 years, while the majority (34, 58%) were older than 10 years. The male: female ratio was 1.5:1. Thirty-eight (65%) patients were African, 12 (20%) were of mixed race, seven (12%) were Caucasian and two (3%) were Indian.

**Table 1.** Demographics and treatment of 59 children with end stage renal failure (ESRF)

| **Age (years)** | **< 5** | **> 5** | **>10** |
|---|---|---|---|
| | Sex | | |
| Boys (*n* = 35) | 3 | 10 | 22 |
| Girls (*n* = 24) | 4 | 8 | 12 |
| | Aetiology | | |
| CAKUT | 2 | 2 | 5 |
| Glomerulopathy | 5 | 11 | 29 |
| Inherited | 0 | 5 | 0 |
| | Dialysis treatment modality | | |
| Peritoneal | | | |
| State | 3 | 8 | 19 |
| Private | 1 | 4 | 1 |
| Haemodialysis | | | |
| State | 3 | 3 | 13 |
| Private | 0 | 3 | 1 |

CAKUT, congenital abnormalities of kidneys and urinary tract

Children received dialysis in six of the nine provinces of SA, although there were paediatric dialysis facilities in only four provinces, two children (11 and 12 years old) received treatment in adult units (Eastern Cape and Mpumalanga). The provinces where children received treatment, and the number of patients who were treated in each province, are depicted in Figure 1. There were seven dedicated paediatric dialysis units run by paediatric nephronlogists in SA in 2012: six were in public sector teaching hospitals and one in the private sector. The private paediatric dialysis unit, which treated 10 of the 59 patients in this study, is in the northern part of SA in Johannesburg. There are also two public sector paediatric units in Johannesburg, at the Charlotte Maxeke Johannesburg Academic Hospital and the Chris Hani-Baragwanath Hospital. These three large paediatric dialysis units in Gauteng Province treated 75% of children in SA reported in this study. Most of the patients treated in these units lived in Gauteng Province, but some came from provinces where there were no paediatric or any dialysis facilities. The other large public sector paediatric dialysis unit is in Cape Town at the Red Cross War Memorial Children's Hospital. Most of the children with ESRF who lived in the southern part of SA were treated at this unit. Two of the paediatric units treated one and three patients, respectively.

**Figure 1.** The provinces of South Africa with dialysis centres and the number of children receiving dialysis in each in 2012. Dialysis centres. ° Units with paediatric facilities.

The population of SA was 52.27 million in 2012.[4] The overall RRT (dialysis and kidney transplantation) rate was 164 pmp.[2] Children under the age of 14 represented 29.6% (15.45 million) of the population.[4] The prevalence of RRT for children was 3.8 per million age-related population (pmarp). The number of children dependent on the state for RRT was 12.823 million, and on private health insurance 2.627 million.[2] RRT was supplied to 49 and 10 children in these groups, respectively. There is no statistical difference between these proportions: Pearson's χ[2] test *P* = 1.0. The RRT rates pmarp were 3.81 and 3.82, respectively.

The two most common causes of ESRF of the children in this study were glomerular disorders (83%) and CAKUT (8.5%). Glomerular disorders occurred mainly in the 34 children who were older than 10 years.

Thirty-four children (58%) had Hb levels below 11 g/dL; nine (15%) received parenteral iron and 14 (23%) received treatment with an erythropoietin stimulating agent (ESA). Hypertension was reported in 34 children (58%) and hyperparathyroidism in 27 (46%).

Peritoneal dialysis was the initial dialysis modality in 36 children (61%) (Table 1). This is the approximate prevalence rate for SA, mainly because of distances to renal units. The six private sector patients who were on PD were all receiving APD, compared to only four of the 30 (13%) patients being treated in the public-sector (*P* = 0.0001). Twenty-three children (39%) were on HD (Table 1) which was, in general, performed three times per week for 4 h. The duration on dialysis is depicted in Table 2.

**Table 2.** Renal replacement therapy in state and private sectors

| | **Duration of dialysis (mean, months)** |
|---|---|
| State | 18 |
| Private | 27 |
| Transplantation (*n*) | |
| State | 6 |
| Private | 5 |
| Deceased donor | 15† |
| Living donor | 12† |

† Recipients <18 years (SARR)

Eleven of the children on dialysis (19%) received kidney transplants during the year of study. This is a transplant rate of 0.7 pmarp, while the overall transplant rate was 4.7 pmp and that in patients 14 years and older 6.4 pmarp. Of the children who received transplants, six were private sector and five public sector patients. Thus 60% of 10 patients treated in the private sector compared to 10% (5 of 49) treated in the public sector received a transplant. This difference is statistically significant, *P* = 0.001. Private patients had spent an average of 1 year and 5 months and public sector patients 2 years and 4 months on dialysis before kidney transplantation.

Of the 248 kidney transplants performed in South Africa in 2012, 27 were in children less than 18 years old (11%) and 11 in children less than 14 years old (4.4%).

The mortality during the year of study was 27% (16 of 59 patients). These were all dialysis patients. The cause of death was reported in 10 children of whom seven (12%) died of cardiovascular disease and three (5%) of cerebrovascular events. Thirty-two children (51%) continued on dialysis.

## Discussion

This is the first report on the paediatric data of the SARR. The registry was established after the demise of the South African Dialysis and Transplantation Registry (SADTR) whose last report was published in 1994. During the hiatus between these reports, no data were available for renal replacement therapy in SA. All dialysis units in SA supplied data electronically to the new registry. The data on children reported here was extracted from the registry.

Only 59 children received RRT in SA in 2012. The RRT prevalence rate of 3.8 pmarp is much lower than that in developed countries. Global prevalence rates in the developed world range from less than 20 to about 80 pmarp for children 0–14 years of age.[5] RRT rates in developing countries vary considerably. In large parts of the developing world, including Africa, the rates are unknown.[6]

Despite all provincial departments of health being responsible for funding of public health-care in SA, only four of nine provinces have paediatric dialysis facilities. Forty-three of the 49 children (88%) receiving RRT in the public sector in 2012 were treated in two provinces, namely 34 in Gauteng Province and nine in the Western Cape Province. Because many patients have to commute to other provinces for treatment, parents and patients have to expend substantial time and money in order for patients to receive dialysis. This is especially problematic for a child at school. Increasing the number of dialysis units would ease this burden.

Health registries are extremely important in planning the management of disease. They supply information on burden of disease, treatments and outcomes.[7] Because of the paucity of registries, limited data are available for RRT from developing countries with the exception of Latin America.[8] For this reason the establishment of the SARR is a significant achievement. It is apparent from available registries that RRT rates differ vastly worldwide. Dialysis is provided almost universally in the USA and Europe, resulting in high RRT rates.[9] The RRT rate for children is also high in the developed world. The rate from 12 registries in Europe in 2002 was 62.1 pmp for patients under the age of 20.[10] For children 0–14 years the incidence of RRT varied widely across Europe from 1.8 to 9.8 pmarp.[11] This is in stark contrast with countries in which it is provided partially or not at all.

There are several reasons for the disparity of RRT access between countries and these are related mainly to the high cost of treatment.[6] Even in wealthier countries, such as those in Europe, the prevalence of RRT varies according to the macroeconomics of countries.[11] Patients are not accepted into replacement programs due to rationing of resources. A process of “microallocation” in which some patients are selected for treatment is applied.[8] This applies also in the public sector of SA.[1] This system is especially applied in the case of younger children, who are seldom considered for chronic dialysis in SA because of their poor long term outcome and small likelihood of undergoing a successful kidney transplant.

In SA, the government provides dialysis partially for patients dependent on the state for healthcare. Eighty three percent of the population of SA is dependent on the state for medical care,[2] but limited resources are allocated for dialysis resulting in a disappointingly low therapy rate. Dialysis for children is especially restricted. The primary limitation is the acceptability of a patient for kidney transplantation.[1] Once accepted, a patient receives comprehensive treatment, including the possibility of transplantation. Alongside this state or public system in SA is one of private insurance health care in which dialysis is provided based on medical criteria applicable in developed countries. Ten children (17%) in this study were treated in the single private unit, and 49 in seven public sector units. The latter also treated some private patients because of the remoteness of the private unit. The difference in rates is apparent in dialysis, but also in transplantation; 60% of private patients receiving a kidney transplant in 2012. Ironically, legislation obligates the private system of insurance/medical aid schemes to provide RRT, including dialysis and kidney transplantation, because treatment of ESRF is classified by law as a “prescribed minimum benefit”.[12]

South Africa is classified in the medium category of the United Nations Human Development Index (HDI), and as an upper-middle-income economy by the World Bank.[13, 14] It is one of the two wealthiest countries in Africa and should arguably have a higher RRT prevalence rate; for example the RRT (dialysis and transplantation) prevalence in Brazil, which has a similar per capita income to South Africa, is 1136 pmp[8] compared to 164 pmp in South Africa. Likewise SA's kidney transplantation rate is similar to that of India, which has a much lower HDI.[15] Such comparisons are problematic but nevertheless serve to highlight vast differences between countries, and the plight of countries outside the developed world.

The RRT (dialysis and transplantation) rate for children was disproportionately high compared to that in the whole population – 3.8 pmarp vs 164 pmp, given that only approximately 1% of ESRD occurs in children. This is partly due to a higher transplantation rate in children because of prioritization of children for cadaver kidney transplantation and the readiness of parents to donate a kidney to a child. South Africa has an active deceased donor transplantation programme, which supplies the majority of kidneys. Organs are distributed mainly locally because of great distances between units. All the major centres perform transplantation on older children, but only three centres perform transplantation in younger children, the one private (Johannesburg) and two public sector units (Cape Town and Johannesburg). Despite this established infrastructure, the transplantation rate in both adults and children, which is commensurate with the RRT rate, is disappointingly low. This probably also indicates a lack of resources.

The incidence and prevalence of ESRF in children in SA and therefore the true need for RRT are unknown. The incidence of chronic kidney disease (CKD) in Sub Saharan Africa is thought to be higher than is known.[16] The need for RRT therefore is probably greater than is appreciated. This is because several risk factors for CKD in children are more common in Sub Saharan Africa, such as intrauterine injury, malnutrition, schistosomiasis, post-infectious glomerulonephritis and HIV-associated nephropathy.[16] This is also in keeping with a South African study in which focal segmental glomerulonephritis was the most common cause of CKD, stages 2–5.[17] Because of the greater exposure to immune-stimulating antigens, CAKUT is relatively less common than glomerulopathies in the developing world.[16] Also, children in our environment with CAKUT either die young or develop ESRF after childhood.

Thirty-four of the patients in this study were anaemic (58%) but only 23 of them (68%) were receiving effective treatment in the form of parenteral iron or an ESA. This suggests deficient budgeting for RRT in SA as both treatments are expensive. In the NAPRTCS report of 2008 90% of children on dialysis in the USA were receiving an ESA.[18]

The outcome of patients in this study was dismal. Sixteen (27%) of the 59 children died during the year of survey. This compares poorly with outcomes in the developed world. In Europe the crude 2-year survival in 0–19 year old patients on dialysis was 94.2% in the period 1995–2000, and 92.7 in the US in the period 2004–2007.[9, 18] Exact comparison is not possible because of the nature of the current study which was a snapshot (period prevalence) study, but survival in the developed world is clearly superior. No data for the rest of Africa regarding RRT for and mortality of ESRF in children are available.

The prevalence and outcome of RRT for children in SA, both dialysis and kidney transplantation, falls far short of that of the developed world and much of the developing world. The inferior management in the public health sector can largely be ascribed to a lack of financial and human resources and unrealistic budgeting. Treatment seems to be deficient also in the private sector. The re-established SARR should provide the much-needed information to plan a national dialysis policy for efficient and equitable care. It is proposed by the authors that a national registry such as the SARR, for children with CKD stage 3 or more, be developed and funded by the state. Such a registry would provide vital information on the epidemiology of chronic renal failure in children in SA. It would also facilitate early identification of risk factors for progression and encourage the institution of reno-protective treatment. Ideally, identified children should undergo pre-emptive kidney transplantation which is a more economical option than dialysis. It would be wiser to invest in a registry that can provide information for planning equitable and quality renal care for children in SA, than to spend money on a service that has unknown boundaries.

A summit meeting was recently held between stakeholders in the care of patients with ESRF and the South African National Department of Health. From this meeting a report was issued which highlighted the gross deficiency of RRT and placed much of the onus of improving access to RRT on the South African government.[19] Some initiatives may improve the treatment of ESRF in future. The SA government has proposed a new model for healthcare in South Africa in which public sector patients will be treated in private facilities.[20] The current report highlights the plight of children for whom treatment of ESRF is especially deficient in SA, and for which special considerations for RRT would be required. In addition, the first steps have been taken towards the establishment of a renal registry for Africa.[21]

## Conclusion

This extract of the SARR database revealed that there are severe shortcomings in the care of children with ESRF in SA. Dialysis and kidney transplantation rates are comparatively low. There is a deficiency of resources allocated by the government for RRT. While RRT prevalence rates did not differ, treatment of children in the private sector was superior to that in the public sector. Private patients received the preferred form of dialysis, spent a shorter time on dialysis and were more likely to receive a kidney transplant than public sector patients. The registry and this report should inform the health authorities and stimulate the provision of better and more equitable RRT for children in SA.

## Conflict of Interest

The authors declare that they have no conflict of interest.

## References

1. Moosa MR, Kidd M. The dangers of rationing dialysis treatment: The dilemma facing a developing country. *Kidney Int*. 2006; 70: 1107–1114.
2. Davids MR, Marais N, Jacobs JC. South African Renal Registry Annual Report 2012. *South African Renal Society. Cape Town* 2014; 1 (1): 1–19.
3. National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents. The fourth report on the diagnosis, evaluation, and treatment of high blood pressure in children and adolescents. *Pediatrics* 2004; 114: 555–576.
4. Statistics South Africa [Internet]. Mid-year population estimates 2013. STATSSA; [updated 2013 November 07; cited 2016 March 02].
Available from: http://www.statssa.gov.za/publications/P0302/P03022013.pdf
5. Harambat J, van Stralen KJ, Kim JJ, Tizard EJ. Epidemiology of chronic kidney disease in children. *Pediatr. Nephrol*. 2012; 27: 363–373.
6. Jha V, Garcia-Garcia G, Iseki K et al. Chronic kidney disease: global dimensions and perspectives. *Lancet* 2013; 382 (9888): 260–272.
7. Liu FX, Rutherford P, Smoyer-Tomic K, Prichard S, Laplante S. A global overviewof renal registries: a systematic review. *BMC Nephrol*. 2015; 16: 31.
8. Obrador GT, Rubilar X, Agazzi E, Estefan J. The challenge of providing renal replacement therapy in developing countries: The Latin American perspective. *Am. J. Kidney Dis*. 2015; 67 (3): 499–506.
9. Liyanage T, Ninomiya T, Jha V et al. Worldwide access to treatment for end-stage kidney disease: a systematic review. *Lancet* 2015; 385 (9981): 1975–1982.
10. van der Heijden BJ, van Dijk PC, Verrier-Jones K, Jager KJ, Briggs JD. Renal replacement therapy in children: data from 12 registries in Europe. *Pediatr. Nephrol.* 2004; 19 (2): 213–221.
11. Chesnaye NC, Schaefer F, Groothoff JWet al. Disparities in treatment rates of paediatric end-stage renal disease across Europe: insights from the ESPN/ERA-EDTA registry. *Nephrol. Dial. Transplant*. 2015; 30 (8): 1377–1385.
12. Medical Schemes Act of 1998, Pub. L. No. 131. (20 November 1998). 13. United Nations Development Programme [Internet]. Human development report 2013. UNDP; [updated 2015 August 29; cited 2016March 02]. Available from:
http://hdr.undp.org/sites/default/files/reports/14/hdr2013_en_complete.pdf
14. TheWorld Bank [Internet]. TheWorld Bank – countries - South Africa. WBG; [updated 2016March 02; cited 2016March 02]. Available from: http://data.worldbank.org/country/south-africa
15. Garcia-Garcia G, Harden P, Chapman J. The global role of kidney transplantation. *Curr. Opin. Nephrol. Hypertens.* 2012; 21 (3): 229–234.
16. Kayange NM, Smart LR, Tallman JE et al. Kidney disease among children in sub-Saharan Africa: systematic review. *Pediatr. Res*. 2015; 77 (2): 272–281.
17. Bhimma R, Adhikari M, Asharam K, Connolly C. The spectrum of chronic kidney disease (stages 2-5) in KwaZulu-Natal. South Africa. *Pediatr. Nephrol.* 2008; 23 (10): 1841–1846.
18. North American Pediatric Renal Trials and Collaborative Studies [Internet]. NAPRTCS 2008 Annual Report. NAPRTCS; [updated 2008 October 01; cited 2016March 02]. Available from:
https://web.emmes.com/study/ped/annlrept/Annual%20Report%20-2008.pdf
19. MoosaMR,MeyersAM, Gottlich E, Naicker S. An effective approach to
chronic kidney disease in South Africa. *S. Afr. Med. J*. 2016; 106 (2): 156–159.
20. National Health Insurance [Internet]. National Health Insurance – Green Paper. NHI; [updated 2016 January 20; cited 2016 July 22].
Available from: http://www.nhisa.co.za/A_legislation.asp
21. Davids MR, Eastwood JB, Selwood NH et al. A renal registry for Africa: first steps. *Clin. Kidney J.* 2016; 9 (1): 162–167.