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# The challenges faced by rural paediatric patients undergoing haemodialysis in an urban area in South Africa

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Johannesburg, South Africa  
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# NMCH Dialysis Unit

Opened March 2018

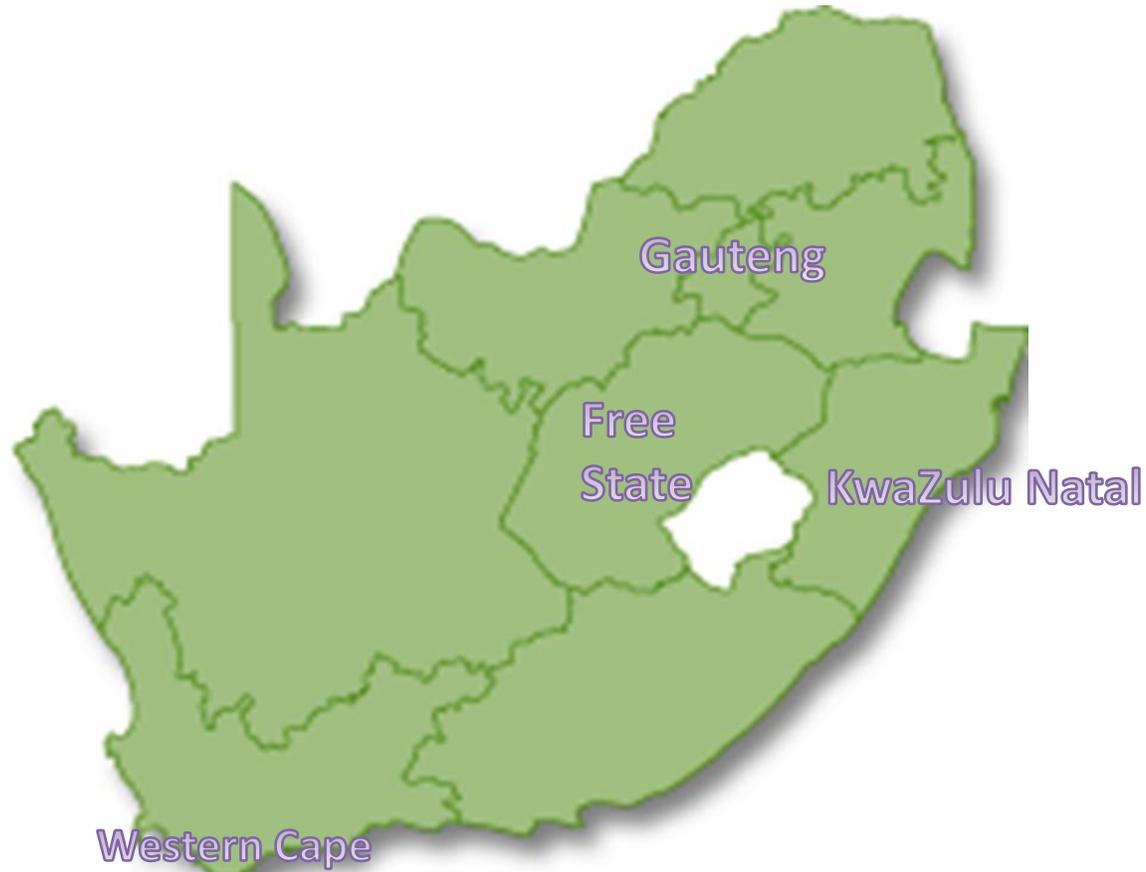
Provide acute and chronic PD, HD

- Including continuous modes in ICU

Currently has 18 chronic dialysis patients

- 7 PD
- 11 HD

# Introduction



- Nine state hospitals providing paediatric dialysis
- State hospitals which provide paediatric HD in SA
  - 5 in Gauteng
  - 1 in KwaZulu Natal
  - 1 in Western Cape
  - 1 in Free State
- Children who live outside of these areas and need HD must travel to these central areas for each session

# Background

- First country on the continent to provide access to dialysis and kidney transplantation in the 1960's<sup>1</sup>
- Resource constraints in state sponsored healthcare<sup>2</sup>
  - Adult dialysis slots full: waiting times
  - Rationing / selection criteria for acceptance
- Total children on dialysis in SA: 94<sup>3</sup>
  - Forty-five on HD

1. Fabian J, Maher H, Bentley A, Gaylard P, Crymble K *et al.* **Favourable outcomes for the first 10 years of kidney and pancreas transplantation at Wits Donald Gordon Medical Centre, Johannesburg, South Africa.** SAMJ 2016, 106, 172–176.
2. Etheredge H, Fabian J. **Challenges in Expanding Access to Dialysis in South Africa—Expensive Modalities, Cost Constraints and Human Rights.** Healthcare 2017, 5(3), 38
3. Levy, C. Unpublished data



# Our patients

- “Crash landers”
  - Higher mortality
  - More expensive: acute lines / ICU stay<sup>1</sup>
  - Rural patients have less access to quality healthcare<sup>2</sup>
    - Poor referral to tertiary center
    - Poorer outcomes

1. Miller LM, Vercaigne LM, Moist L, Lok CE, Tangri N *et al.* **The association between geographic proximity to a dialysis facility and use of dialysis catheters.** BMC Nephrology 2014, 15:40

2. Rucker D, Hemmelgarn BR, Lin M, Manns BJ, Klarenbach SW *et al.* **Quality of care and mortality are worse in chronic kidney disease patients living in remote areas.** Kidney Int 2011, 79:210–7



# Our patients

Incidence is less than 30% of predicted

- ESPN/ERA-EDTA incidence of ESRD in children in Europe was reported as 5.2 pmarp<sup>1</sup>
- No SA registry
- Bhimma *et al.* estimated the incidence of ESRD in KwaZulu-Natal to be 1–2 pmarp<sup>2</sup>
- We are dialyzing 94 of an estimated 400 children with ESRD<sup>3</sup>

The lack of clinical skills, adequate laboratory services and radiography facilities may result in many patients not being diagnosed as CKD, and/or demising at peripheral hospitals, before they arrive at the tertiary center.

1. The European Society for Paediatric Nephrology, **The European Renal Association and European Dialysis and Transplantation Association Registry**. ESPN/ERA-EDTA registry annual report 2013 2015 [Available from: <http://www.espn-reg.org/>]
2. Bhimma R, Adhikari M, Asharam K, Connolly C. **The spectrum of chronic kidney disease (stages 2–5) in KwaZulu-Natal, South Afra**. *Pediatr Nephrol*. 2008;23(10):1841-6
3. Levy, C. Unpublished data



# Burden of dialysis

- Quality of life
  - Low overall
  - Lower in HD patients

Table 3. Mean HRQOL Scores for children and parent proxies for different modes of dialysis

PedsQL ESRD Domains	Child scores, mean (SD)					Parent proxy scores, mean (SD)						
	HD (n=14)	APD (n=8)	CAPD (n=5)	Total (N=27)	F*	p-value	HD (n=13)	APD (n=8)	CAPD (n=5)	Total (n=26)	F	p-value
General fatigue	60.3 (12.9)	63.3 (22.8)	90.0 (16.3)	66.7 (19.8)	5.9	0.01	59.6 (22.8)	62.5 (21.1)	80.0 (14.2)	64.4 (21.6)	1.5	0.24
About my kidney disease	56.4 (13.9)	71.2 (18.3)	71.0 (24.6)	63.5 (18.3)	2.4	0.11	59.2 (22.9)	56.2 (11.9)	75.0 (26.0)	61.3 (21.1)	1.3	0.30
Treatment problems	57.1 (13.6)	62.5 (22.2)	77.5 (20.5)	62.5 (18.7)	2.4	0.11	66.3 (16.4)	58.6 (25.0)	80.0 (18.9)	66.6 (20.4)	1.8	0.19
Family and peer interaction	48.2 (16.7)	51.0 (26.5)	53.3 (38.0)	50.0 (23.6)	0.1	0.91	46.1 (35.9)	61.4 (20.4)	60.0 (43.5)	53.5 (33.1)	0.4	0.66
Worry	52.3 (18.9)	49.1 (22.4)	49.0 (8.4)	50.7 (18.1)	0.1	0.90	54.8 (25.5)	51.2 (22.6)	53.0 (11.6)	53.4 (21.9)	0.1	0.93
Perceived physical appearance	43.4 (32.7)	52.1 (22.2)	70.0 (27.4)	50.9 (19.4)	1.5	0.24	48.7 (29.6)	51.0 (18.6)	63.3 (21.7)	52.2 (25.0)	0.7	0.51
Communication	62.1 (19.5)	61.2 (18.7)	79.0 (17.5)	65.0 (19.4)	1.7	0.21	70.8 (29.0)	76.2 (24.9)	86.0 (16.7)	75.4 (25.6)	0.7	0.51
Total	54.7 (9.7)	57.8 (15.3)	67.0 (10.4)	57.9 (12.1)	2.0	0.15	58.4 (18.6)	58.7 (9.9)	69.0 (12.7)	60.5 (15.4)	0.8	0.44

HRQOL = health-related quality of life; PedsQL = Paediatric Inventory of Quality of Life Core Scales; ESRD = end-stage renal disease; HD = haemodialysis; APD = automated peritoneal dialysis; CAPD = continuous ambulatory peritoneal dialysis.  
F-statistic and P values represent differences in mean scores between the various modes of dialysis for either group.

1. Obiagwu PN, Sangweni B, Moonsamy G, Khumalo T, Levy C. **Health-related quality of life in children and adolescents with end stage renal disease receiving dialysis in Johannesburg.** SAJCH 12(2):58



# Burden of dialysis

- Cost to caregiver
  - 27% of monthly income of HD patient spent on transport<sup>1</sup>
- Care Dependency Grant = R1 700
- SA households with inadequate or severely inadequate access to food 21,3% in 2017<sup>2</sup>

	PD	HD
Average age	12y2m (10m – 26y)	14y10m (3y9m – 28y)
% accompanied to hospital by a care giver	100%	25% (average age 17y)
Number of visits per month	1	12 (3 sessions per week)
Mean monthly family income = R2946.00 Mean number of people per family = 4 Mean amount available to each person per month before dialysis cost = R737.00		
Transport cost to the family per month	R145.00	R798.00
% of monthly family income spent on transport	4.9%	27.1%
Amount now available to each family member	R700.00 (R23.00 per day)	R537.00 (R18.00 per day)

1. Bello A, Sangweni B, Mudi A, Khumalo T, Moonsamy G *et al.* **The Financial Cost Incurred by Families of Children on Long-Term Dialysis.** *Perit Dial Int.* 38(1):14-17
2. Statistics South Africa. **General household Survey 2017.** Available at <http://www.statssa.gov.za/publications/P0318/P03182017.pdf> (Accessed October 2018)



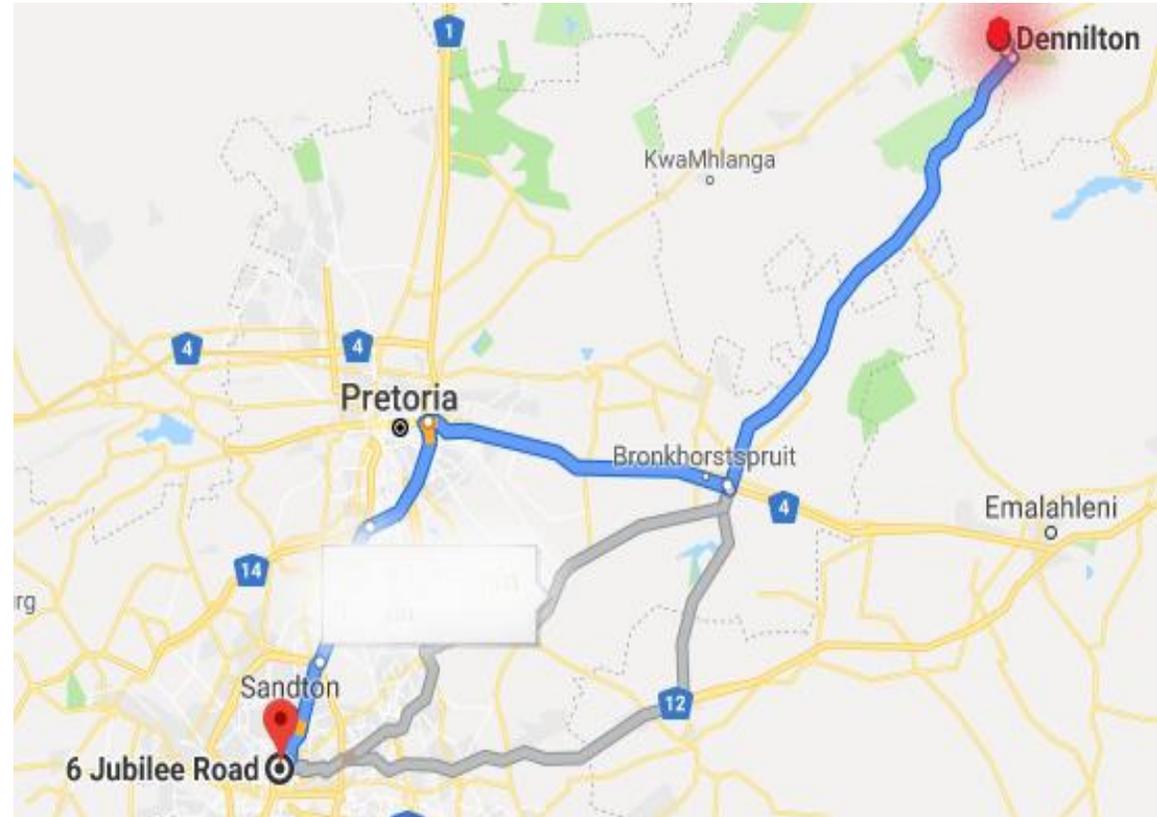
# Patient distance from dialysis centre

- 69% come from within 175km of our center
- 90% live within 50km
- 25% live between 175-300km away
- 6.25% live more than 300km away  
( All the above include both PD and HD)
  
- Furthest HD patient lives almost 200km away



# Patient TM

- 12 yrs female
- Lives in Dennilton (193km)
- ? primary diagnosis
- Failed PD
  - Recurrent peritonitis
- T/P x1 Feb 2017
  - Nephrectomy April 2017: vascular complications
- HD 3x/wk 4hr



# Summary of issues

- Mom unable to find full-time work
  - Primary caregiver
  - 2 adults 5 children, 2 grand children
  - Depends on child support grant
  - Buys in CBD to sell back at home at mark-up
- Diet non compliance
  - Leaves home at 3am on HD days
- TM has missed a lot of school
  - Repeating grade 4 (should be in 6)
  - Difficult with all the travelling

# Conclusion

In South Africa, patients living in rural areas compared to those living in urban areas have poor access to RRT.

Their outcomes are worse on HD.

The challenges facing our patient and family:

- The time they leave their home and the distance to be transported to their dialysis centre.
- Burnout on the guardians and patient.
- Patient missing school due to 3 x / week HD.
- Patient developmental growth

# Recommendations

SA Health Department needs to consider building satellite clinics in those hospitals with no HD facilities

Early diagnosis and referral of patients:

- Education of families
- Education of HCW
- Streamlining referral processes

Thank You

Any questions?

