Evaluating the accuracy and completeness of ANZDATA recorded cause of death amongst transplant recipients

Melissa Levy, James Sindone, Bree Shi, Mark Dennis, Rajesh Puranik, Steve Chadban, Tracey Ying

Kidney Centre, Royal Prince Alfred Hospital

Disclosures

Nil disclosures

Background

- Kidney transplant recipients (KTRs) have increased mortality compared to the general population.
- Registry data is essential in guiding understanding of cause and timing of death.
  - Contingent on reporting procedures.

Background

- ANZDATA (Australian and New Zealand Dialysis and Transplant Registry)
  - Captures data on patients receiving maintenance Kidney Replacement Therapy in Australia and New Zealand, including kidney transplant recipients.
  - Data capture form allows for a single cause of death to be reported (according to 84 codes).

AUS. & N.Z. DIALYSIS AND TRANSPLANT SURVEY

DATE OF DEATH CAUSE OF DEATH (Record from list)

Study aims

1. To evaluate agreement between ANZDATA-recorded cause of death with the cause of death determined by a panel of physicians on review of clinical notes.
2. To gain greater understanding of the complexities of death in kidney transplant recipients by including secondary cause of death assessment.

Methods

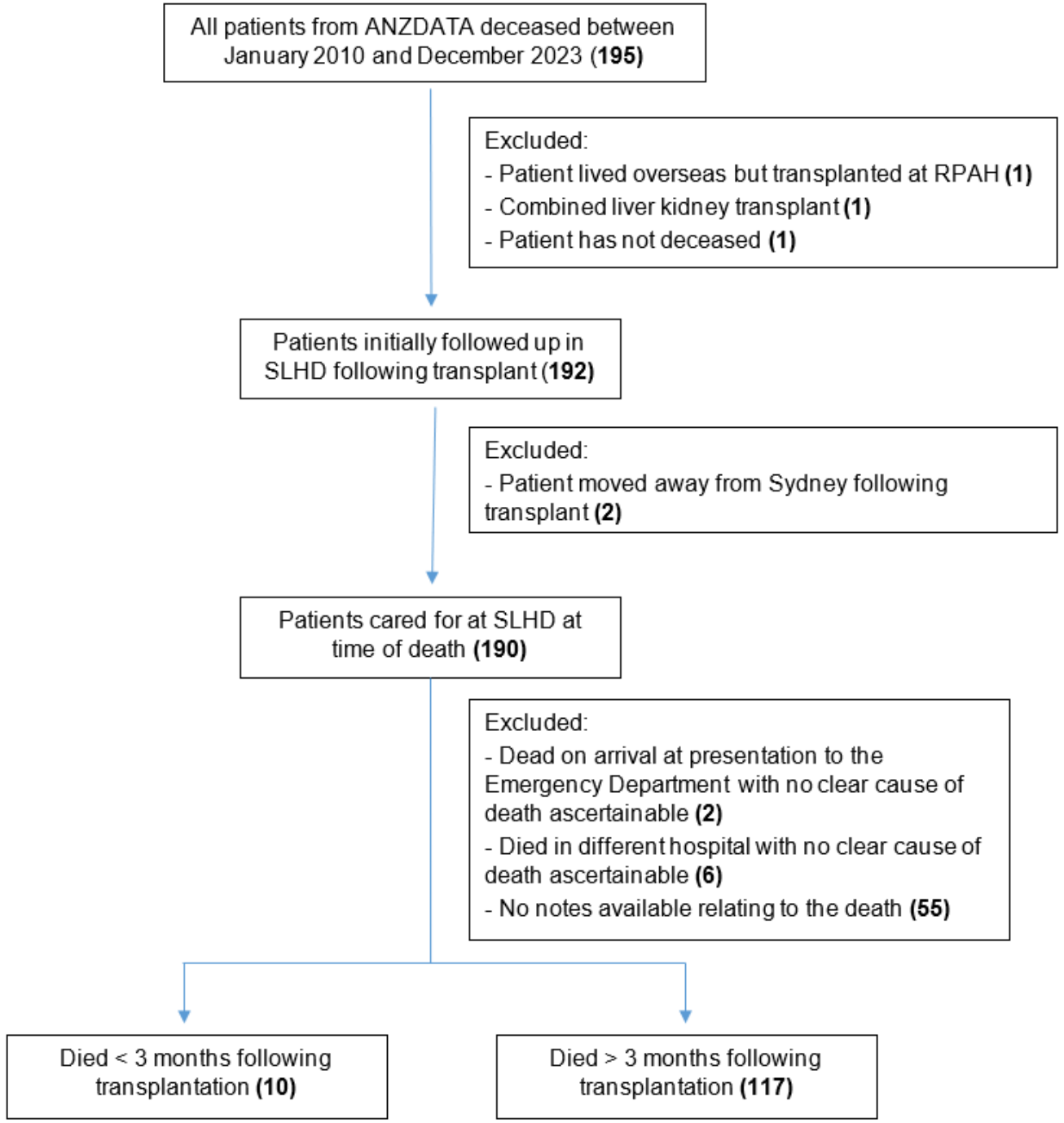
- Retrospective observational study including all kidney transplant recipients transplanted at and managed by SLHD (Sydney Local Health District) who died between January 2010 and December 2023.
- Excluded:
  - Multi-organ transplants.
  - Receiving ongoing nephrology care outside of the SLHD.
- Pre-death clinical data was extracted from paper and electronic district medical records.

Methods

- Cause of death (COD) was adjudicated by a panel of 3 blinded nephrologists and 2 cardiologists.
- Panel members could assign 1 *primary* COD, and multiple *secondary* COD
  - Primary COD: The major event or illness to which the death was directly attributed.
  - Secondary COD: An event or illness that was active at the time of death, or contributed to the development of the primary event but did not directly cause the death (AIHW, 2024)
- Cohen's κ was used to assess rates of overall agreement and agreement beyond chance between clinician-adjudicated and ANZDATA-recorded cause of death.

Study population

- 190 KTRs who died during the study period were cared for in SLHD at the time of death.
- Pre-death clinical information available for 127 (67%).



Baseline characteristics

- Mean age of transplant: 53 years
- Mean age at death: 63 years
- 66% male
- 17% diabetes as primary renal disease
- 80% deceased donor transplant
- 54% had a functioning graft at time of death
- 13% graft failure during terminal admission

Characteristic	Study population (n = 127)	All transplant recipients deceased over same period (n = 6752)
Age at transplant, mean (SD)	53 (14)	51 (13)
Age at death, mean (SD)	63 (13)	64.(11)
Male, n (%)	84 (66)	4371 (65)
Primary renal disease, n (%)		
Diabetes	21 (17)	1272 (19)
Glomerulonephritis	45 (35)	2631 (39)
Renovascular/Hypertension	10 (8)	400 (6)
Other	48 (38)	2155 (32)
Uncertain	3 (2)	279 (4)
Not reported	0 (0)	15 (1)
Duration of KRT prior to transplant (years), mean, SD	6.2 (7)	4.4 (5)
Transplant characteristic		
Number of transplants, n (%)		
1	114 (90)	5933 (88)
2	8 (6)	674 (10)
≥ 3	5 (4)	145 (2)
Transplant type, n (%)		
Deceased donor	102 (80)	5224 (77)
Living donor	24 (19)	1528 (22)
Living related donor	10 (8)	Not specified
Living unrelated donor	14 (11)	Not specified
Missing	1 (1)	
Acute rejection, n (%)	38 (30)	1779 (26)
Missing	18 (14)	-
Graft function at time of death		
Death with functioning graft	69 (54)	4582 (68)
Death following graft failure	58 (46)	2170 (32)
Graft failure during terminal admission	17 (13)	Not specified

Primary cause of death

COD category	Clinician-adjudicated (%)	ANZDATA-recorded (%)
Cardiovascular	43 (34)	33 (26)
Infection	41 (33)	31 (24)
Cancer	33 (26)	26 (20)
CKD	0 (0)	1 (1)
Other	6 (5)	16 (13)
Withdrawal	4 (3)	13 (10)
Unknown	0 (0)	7 (6)

Overall agreement 61%; Cohen's κ 0. 5

- Moderate agreement (Landis et al, Biometrics 1977)

Secondary cause of death

83% (n=105) of kidney transplant recipients had at least one secondary cause present

	Total deaths (%)	Present in (%) once primary cause excluded *
Cardiovascular	34 (27)	41%
Infection	41 (32)	48%
Cancer	8 (6)	9%
Graft dysfunction	72 (57)	57%
Other	21 (17)	17%

* Indicates the percentage of cases in which secondary COD is present after excluding cases where this cause is the primary COD

Infection – present as a primary or secondary cause in 82 cases (65%)

Discussion

- For kidney transplant recipients who die in hospital, death is often multifactorial and complex.
  - Majority of patients had one or more secondary causes of death.
  - Complexities are not captured with current reporting practices.
- Moderate agreement between clinician-adjudicated and ANZDATA-recorded cause of death.
- Infection present in 65% as either primary or secondary cause of death.
- Future research should focus on standardisation of coding practices and introduction of secondary causes of death in registry data.

Acknowledgements

- Professor Steve Chadban
- Dr Tracey Ying
- Ms Bree Shi
- Dr James Sindone
- Professor Rajesh Puranik
- Professor Mark Dennis
- ANZDATA registry, patients and clinicians