

Palliative Care in Paediatric Nephrology

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How common is ESRF and death in children?

- 70s
- 80s
- 90s
- 2000s



ORIGINAL ARTICLE

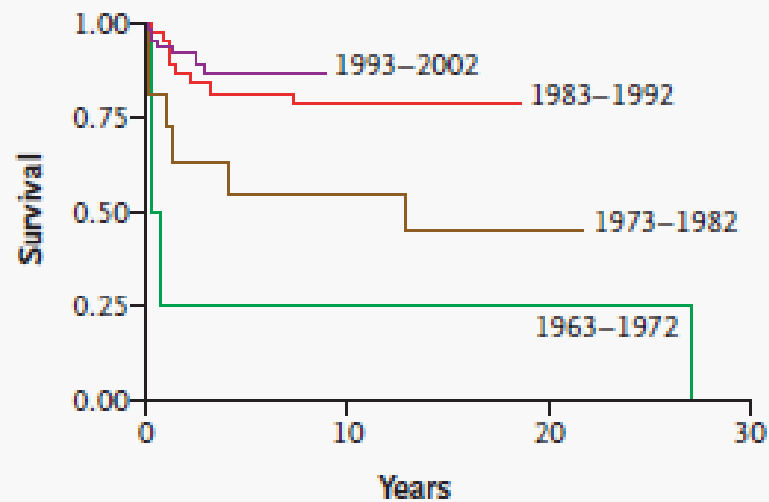
Long-Term Survival of Children with End-Stage Renal Disease

Stephen P. McDonald, Ph.D., and Jonathan C. Craig, Ph.D.,
for the Australian and New Zealand Paediatric Nephrology Association



Survival with ESRF

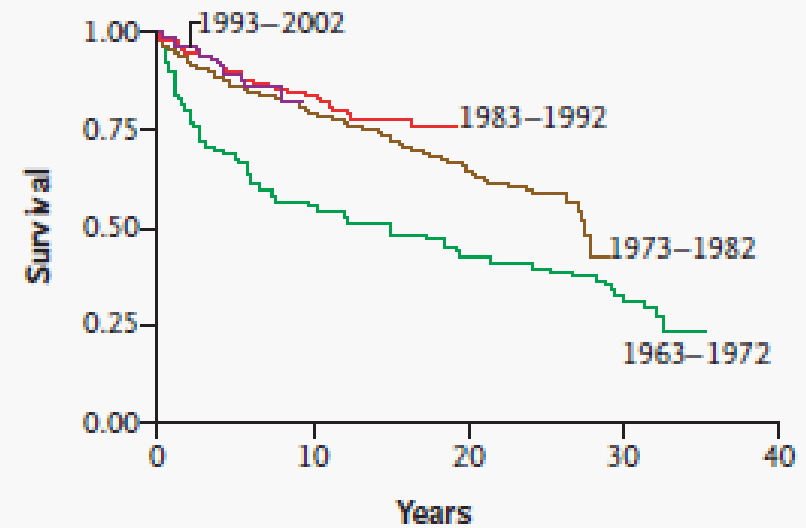
A Age, 1 to 4 Years



Beginning of Treatment

1993-2002	64	—	—	—
1983-1992	38	24	—	—
1973-1982	12	6	4	—
1963-1972	4	1	1	0

D Age, 15 to 19 Years



Beginning of Treatment

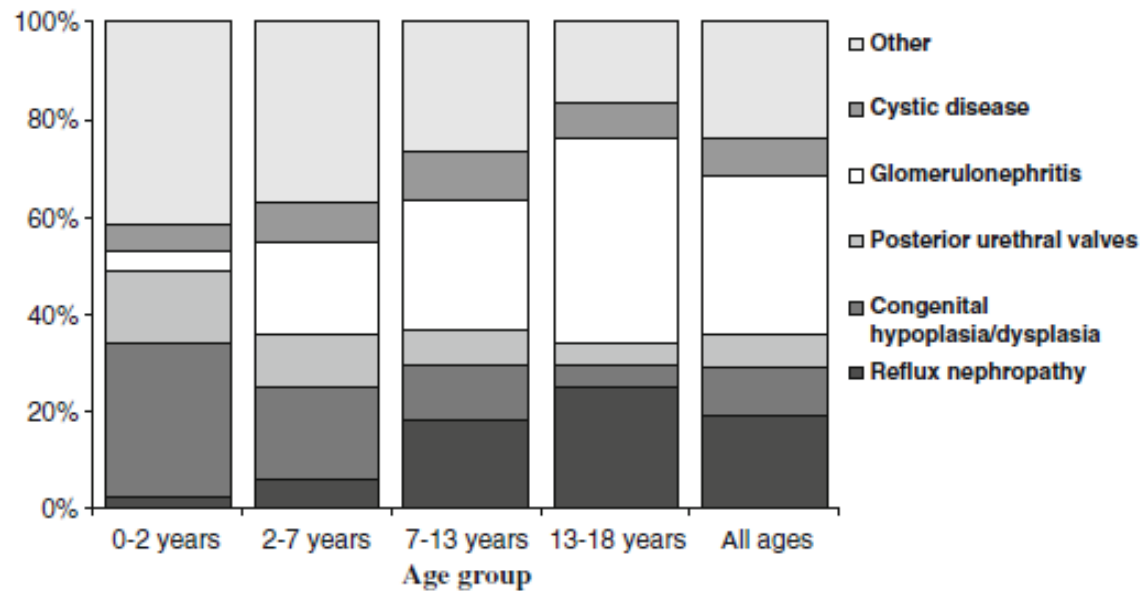
1993-2002	215	—	—	—
1983-1992	267	192	—	—
1973-1982	262	205	149	—
1963-1972	86	47	35	24

Who

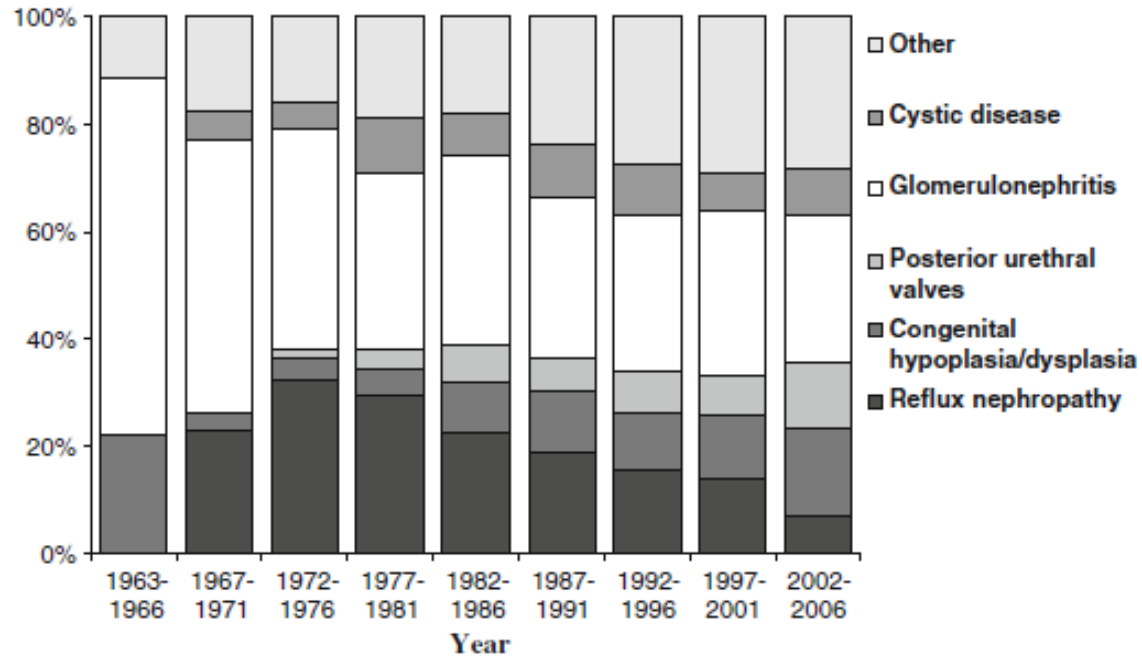
- Advance warning: Prenatal Testing
- Predictions
- Anuric neonate
- Neonate with multiple disabilities
- Syndromic but can go home
- Other Causes
 - Cancer
 - Infection
 - Accident

Causes of ESRF in Children (ANZ)

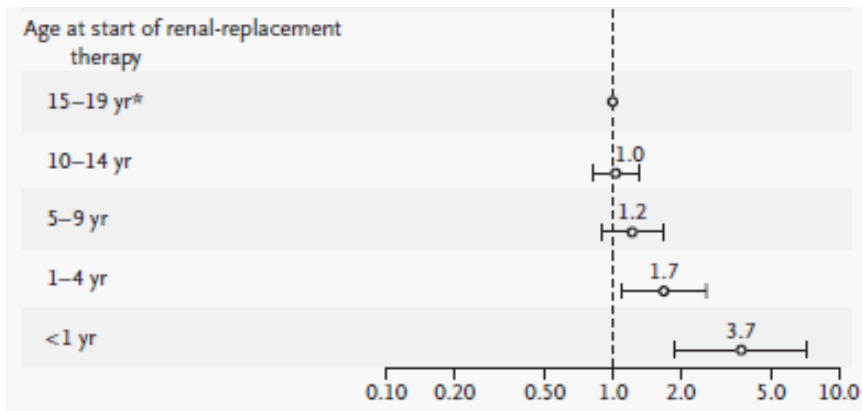
By Age



Causes of ESRF in Children (ANZ) By Decade



Relative Risk of Death with ESRF



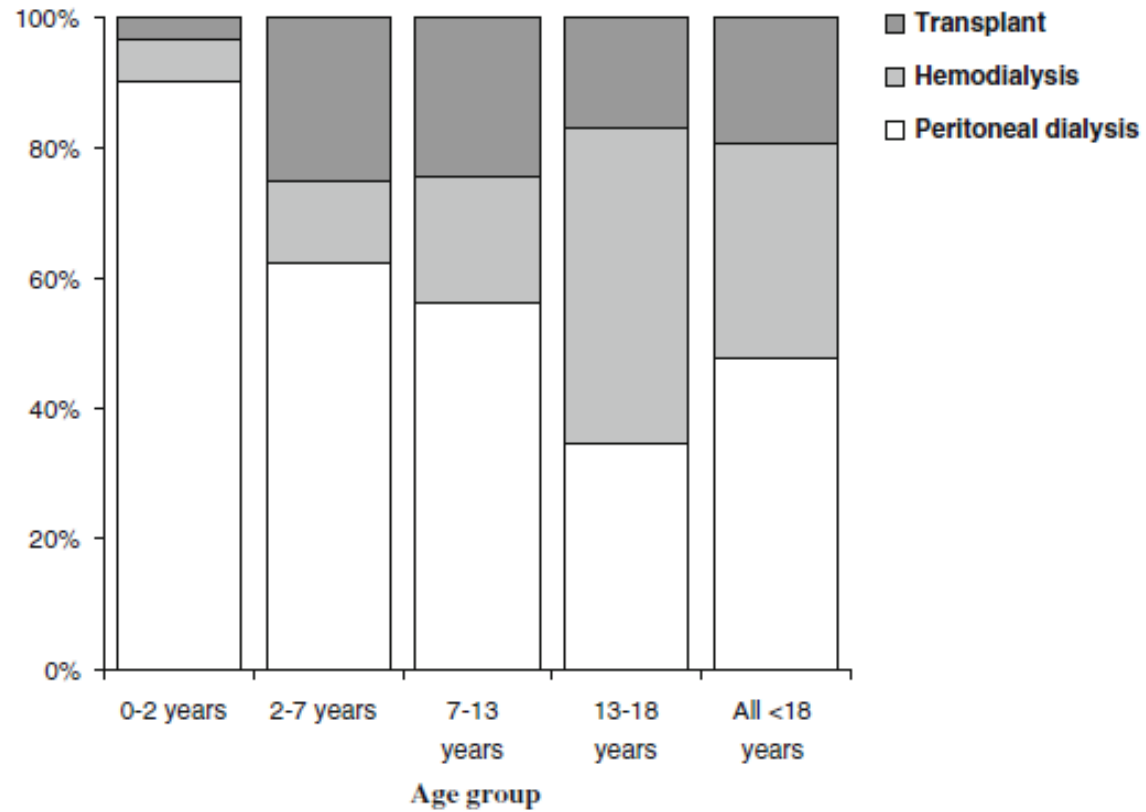


Absolute Risk of Death With RF

Table 3. Age-Specific Rate Ratios for Death within 10 Years among Children Who Started Renal-Replacement Therapy in Australia in the Period from 1963 to 2002, as Compared with Age-Specific Mortality among the General Australian Population.*

Decade Therapy Started	Rate Ratio for Death			
	0–4 Yr	5–9 Yr	10–14 Yr	15–19 Yr
1963–1972	116 (37–358)	236 (98–566)	111 (64–198)	52 (36–75)
1973–1982	63 (26–151)	122 (75–199)	71 (49–104)	20 (14–28)
1983–1992	30 (16–57)	30 (13–73)	37 (23–59)	19 (13–27)
1993–2002	32 (17–59)	94 (39–226)	35 (16–78)	30 (18–49)

Initial Treatment for RF

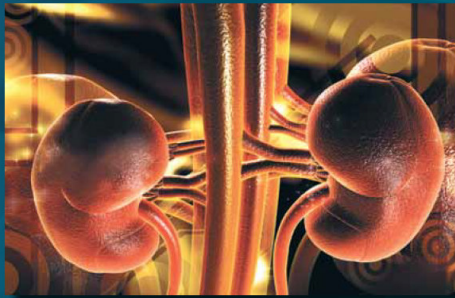




Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis

Clinical Practice Guideline

Second Edition



RPA
Renal Physicians Association

Rockville, Maryland
October 2010

Establishing Family-centered Shared Decision-Making

Recommendation No. 1

Develop a patient-physician relationship that promotes family-centered shared decision-making for all pediatric patients with AKI, CKD, and ESRD.

Informing Patients and Parents

Recommendation No. 2

Fully inform patients with AKI, stage 4 or stage 5 CKD, or ESRD and their parents about the diagnosis, prognosis, and all appropriate treatment options. Inform children and adolescents in a developmentally appropriate manner, and if feasible, seek their assent about treatment decisions.

Recommendation No. 3

Facilitate informed decisions about dialysis for pediatric patients with AKI, CKD or ESRD, discuss prognosis, potential complications, and quality of life with the patient, parents, and/or legal guardian.

Resolving Conflicts about What Dialysis Decisions to Make

Recommendation No. 4

Establish a systematic due process approach for conflict resolution if disagreements occur about dialysis decisions. Use conflict resolution interventions when family members disagree with one another, when children disagree with their parents, when families disagree with the health

Facilitating Advance Care Planning

Recommendation No. 5

Institute family-centered advance care planning for children and adolescents with AKI, CKD, and ESRD. The plan should establish treatment goals based on a child's medical condition and prognosis.

Making a Decision to Not Initiate or to Discontinue Dialysis

Recommendation No. 6

Forgo dialysis if initiating or continuing dialysis is deemed to be harmful, of no benefit, or merely prolongs a child's dying process. The decision to forgo dialysis must be made in consultation with the child's parents. Give children and adolescents the opportunity to participate in the decision to forgo dialysis to the extent that their developmental abilities and health status allow.

Recommendation No. 7

Consider forgoing dialysis in a patient with a terminal illness whose long-term prognosis is poor if the patient and the family are in agreement with the physician that dialysis would not be of benefit or the burdens would outweigh the benefit.

Recommendation No. 8

Consider the use of a time-limited trial of dialysis in neonates, infants, children, and adolescents with AKI or ESRD to allow for the assessment of extent of recovery from an underlying disorder.

Providing Effective Palliative Care

Recommendation No. 9

Develop a palliative care plan for all pediatric patients with ESRD from the time of diagnosis and for children with AKI who forgo dialysis. The development of a palliative care plan is a continuation of the process of advance care planning and should be family-centered.

Burden of Disease

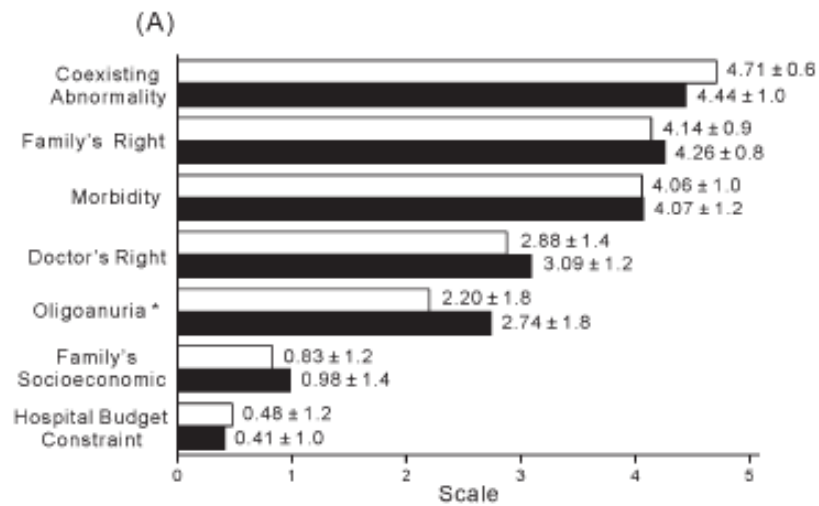


- Dialysis
- Transplantation

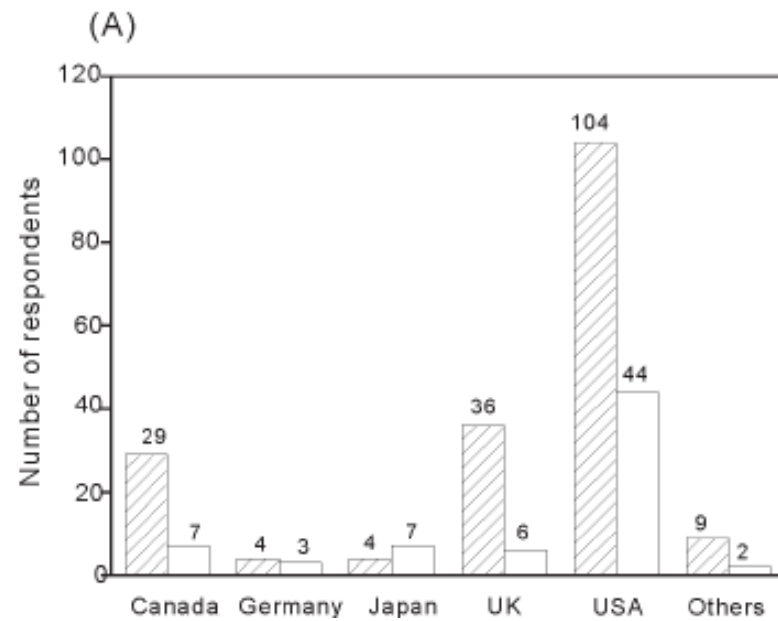




ATTITUDES OF CAREGIVERS TO MANAGEMENT OF END-STAGE RENAL DISEASE IN INFANTS

Jun Chuan Teh, Michelle L. Frieling, Julianna L. Sienna, and Denis F. Geary



(B)



 Usually Acceptable
 Never Acceptable

At Westmead

- Discussion about renal failure
- Therapies: information risk
- Role of the parent in representing the child
- Often second opinion
- Often a gradual decision making process
- Providing information
- Getting to know the family
- Helping parents to make a decision together
- Empowering the parents
- Aiming to be culturally aware
- Active decision not to proceed with care





Framework for Discussion

- Parents central
- Child is informed
- Etiquette for dying children
- Active Listening
- Areas of commonality
- Shared values of parents
- Strengths of the child



Team

- A variety of people who play a role:
- Religious
- Social Work
- Family
- Community
- Nursing
- Paediatrician/GP



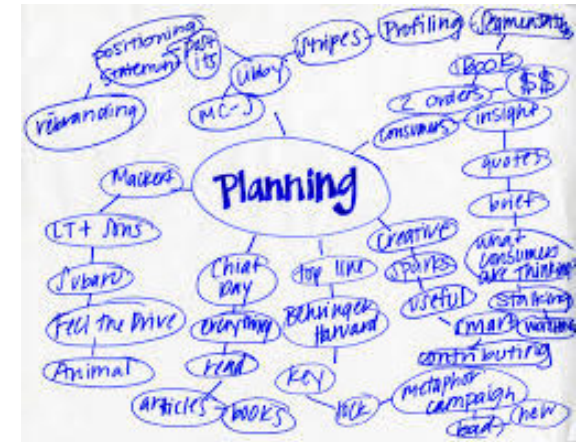
If Dialysis is not Taken Up

- In children receiving palliative treatment
- What does the family want.
- Home
- Hospital
- Bear Cottage
- Involvement of palliative care team.



How to plan

- Need for a plan (written)
- Death expected but sudden
- Death unexpected ICU
- Death outside the hospital
 - Transplants risk taking behaviour.
 - Malignancy
 - Infection



Follow up

- Family
 - PM
 - Genetic
 - ICU review
- Team



Never Fail to
Follow Up





