

ANZDATA SPECIAL REPORT



Parenthood survey 2020

Summarising the findings from the annual ANZDATA parenthood survey data collection in December 2020.

CONTENTS

SUGGESTED CITATION	2
INTRODUCTION	3
PURPOSE OF THE PARENTHOOD SURVEY	3
METHODS	3
DESCRIPTIVE DATA – PARENTHOOD EVENTS IN WOMEN RECEIVING KRT	4
1. TOTAL NUMBER OF PARENTHOOD EVENTS IN WOMEN REPORTED TO ANZDATA DURING 1968-2020	4
2. TOTAL NUMBER OF PARENTHOOD EVENTS FOR WOMEN BY TREATMENT MODALITY AT PARENTHOOD EVENT DURING 2018-2020	4
3. MATERNAL CHARACTERISTICS	5
4. CONCEPTION TYPE.....	5
5. FETAL OUTCOMES FOR BABIES BORN TO MOTHERS RECEIVING KRT.....	5
DESCRIPTIVE DATA – PARENTHOOD EVENTS IN MEN RECEIVING KRT	6
1. TOTAL NUMBER OF PARENTHOOD EVENTS FOR MEN REPORTED TO ANZDATA DURING 1968-2020	6
2. TOTAL NUMBER OF PARENTHOOD EVENTS FOR MEN BY TREATMENT MODALITY AT CONCEPTION	6
3. PATERNAL CHARACTERISTICS.....	6
4. CONCEPTION TYPE.....	7
5. FETAL OUTCOMES FOR BABIES BORN TO FATHERS RECEIVING KRT.....	7
CONCLUSIONS	7
ADDITIONAL RESOURCES	7
WEBSITES AND VIDEO RESOURCES:	7
PREVIOUS PUBLICATIONS USING THE ANZDATA PARENTHOOD DATASET.....	8

SUGGESTED CITATION

Hewawasam E, Davies C, McDonald S, Jesudason S. ANZDATA Special Reports 2: Parenthood Survey 2020. Australia and New Zealand Dialysis and Transplant Registry, Adelaide, Australia. 2021. ISBN: 978-0-6453621-1-4 Available at: <http://www.anzdata.org.au>

INTRODUCTION

This is the second of the ANZDATA “Special reports” series. These reports aim to complement existing output (such as the Annual Report) and provide an opportunity to release material that is of relevance to contributors but does not fit readily within an annual reporting structure, or suitable for publication in a peer-reviewed research journal. These reports are prepared and reviewed internally. We hope to allow publication of material that is of interest and relevance outside of the existing formats.

This report provides summary information about key parenthood survey responses, to inform contributing units in Australia and New Zealand and others about parenthood outcomes in women and men receiving kidney replacement therapy (KRT; chronic dialysis or kidney transplantation) for kidney failure. Further substantial work is underway in this area using ANZDATA and links to additional resources are provided at the end of this report.

We encourage all units to report parenthood events. If you need help with completing the ANZDATA parenthood data collection please contact anzdata@anzdata.org.au or +61 8 8128 4758.

PURPOSE OF THE PARENTHOOD SURVEY

Pregnancies in women receiving KRT are relatively uncommon¹ but remain an important goal for women². These pregnancies are complex and remain at high-risk of adverse outcomes such as early pregnancy loss, pre-eclampsia, hypertension, prematurity and low birthweight, affecting both the mother and the baby^{3,4,5,6,7,8,9}.

Men receiving KRT are subjected to impaired fertility, although fertility is largely restored post-transplantation¹⁰. The long-term use of immunosuppressive medications may have an impact on sperm production and the potential fetotoxic effects of these medications are a key concern in individuals' post-transplantation¹¹.

The parenthood data collection within the ANZDATA registry has laid the foundation for our understanding of parenthood in women³⁻⁹ and men¹¹ with kidney failure in Australia, substantially informing evidence-based clinical practice. This report provides the latest findings of this data collection informing data contributors, clinicians, and patients on what to expect in these pregnancies.

METHODS

ANZDATA has collected parenthood data since 1968, with over 2500 events reported thus far. Parenthood outcome data is collected for female patients who have conceived while receiving KRT, or have commenced dialysis during their pregnancy. Initially, data collection was limited to pregnancy outcome (live or still birth, spontaneous abortion or surgical termination), date of fetal birth or loss, and gestational age. A specific parenthood survey was introduced in 2001 to formalise this data collection, and capture information on estimated date of conception, date of outcomes, pregnancy outcome, medical complications during pregnancy (i.e., pre-eclampsia or gestational diabetes), fetal outcome, neonatal survival, graft outcome (creatinine prior to conception and 3 months post-partum) and birthweight. In 2017, the survey was further expanded to enhance the depth of data on gestational age, congenital abnormalities, fetal gender, renal function at delivery, immunosuppression at conception, labour and

¹ (Hewawasam, et al., 2021)

² (Jesudason, et al., 2020)

³ (Hewawasam, et al., 2020)

⁴ (Tang, et al., 2020)

⁵ (Wyld, Clayton, Kennedy, Alexander, & Chadban, 2015)

⁶ (Jesudason, Grace, & McDonald, 2014)

⁷ (Shahir, Briggs, Katsoulis, & Levidiotis, 2013)

⁸ (Wyld, Clayton, Jesudason, Chadban, & Alexander, 2013)

⁹ (Levidiotis, Chang, & McDonald, 2009)

¹⁰ (Mallett, et al., 2014)

¹¹ (Jesudason, et al., 2020)

delivery, medical complications including diabetes, hypertension, and pre-eclampsia as well as specific data on transplant and dialysis treatments in pregnancy. This data will be reported in future analyses.

In addition to maternal parenthood events, data is collected for men who have a parenthood event while receiving KRT. Prior to 2017, this was limited to estimated date of conception, date of outcomes, pregnancy outcome, fetal outcome, neonatal survival, and birthweight. Since 2018, ANZDATA also collects gestational age, congenital abnormalities, foetal gender, renal function at conception and immunosuppression at conception.

A national consumer advisory group helped shape what data should be presented in this report, based on their priorities.

ANZDATA parenthood dataset has been recently validated against the births captured in mandated state-based perinatal datasets, with 75% concordance in completeness and accuracy¹, which is sufficient to justify the ongoing parenthood data collection within ANZDATA.

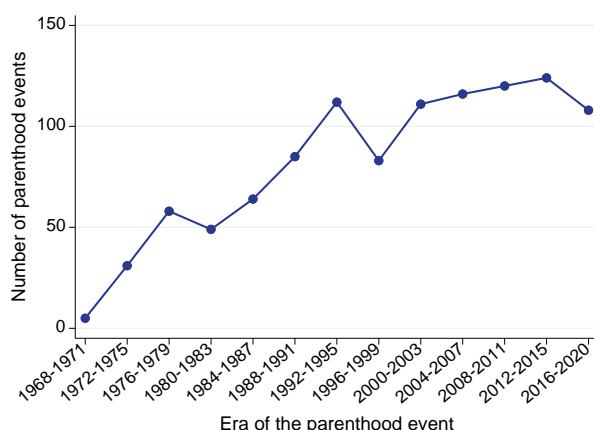
DESCRIPTIVE DATA – PARENTHOOD EVENTS IN WOMEN RECEIVING KRT

In this report, basic descriptive data are presented for key survey items.

1. Total number of Parenthood events in Women reported to ANZDATA during 1968-2020

Overall, maternal parenthood events are increasing over the years with more than 100 events reported for each era since 2000 (Figure 1).

Figure 1. Total number of Parenthood events in Women reported to ANZDATA during 1968-2020



2. Total number of Parenthood events for Women by treatment modality at parenthood event during 2018-2020

The vast majority of women receiving KRT had a parenthood event with a kidney transplant (Table 1). Pregnancy whilst receiving haemodialysis is a much rarer event. No pregnancies were reported for women receiving peritoneal dialysis since 2018.

Table 1. Total number of events Parenthood events for Women by treatment modality at parenthood event during 2018-2020, n (%).

Treatment	2018	2019	2020	Total
Haemodialysis	4 (21.05)	3 (17.65)	4 (16.67)	11 (18.33)
Kidney transplantation	15 (78.95)	14 (82.35)	20 (83.33)	49 (81.67)
Total	19 (31.67)	17 (28.33)	24 (40.0)	60 (100.00)

3. Maternal characteristics

Women who had a parenthood event during 2018-2020 had a median age of 33 years at the time of conception regardless of the treatment modality (Table 2).

Table 2. Maternal age at conception, 2018-2020, median (IQR).

Treatment	n	Age, years
Haemodialysis	10	33.5 (33-37)
Kidney transplantation	49	33 (29-36)
Total	59	33 (29-36)

4. Conception type

Since 2018, data on assisted reproduction has been collected. All women receiving haemodialysis and the vast majority of women with a kidney transplant conceived naturally (Table 3).

Table 3. Parenthood events for Women by Conception type in each parenthood event during 2018-2020, n (%).

Treatment	Haemodialysis	Kidney transplantation	Total
Assisted reproduction [#]	0 (0.0)	1 (2.94)	1 (2.56)
IVF	0 (0.0)	2 (5.88)	2 (5.13)
Natural	5 (100.0)	28 (82.35)	33 (84.62)
Unknown	0 (0.0)	3 (8.82)	3 (7.69)
Total	5 (12.82)	34 (87.18)	39 (100.00)

[#]Excluding IVF

5. Fetal outcomes for babies born to mothers receiving KRT

During 2018-2020, nearly 85% of babies of women receiving haemodialysis and 82% of babies of women with a kidney transplant had a live birth outcome (Table 4). Babies of women receiving haemodialysis were born earlier with a lower birthweight compared to babies of women with a kidney transplant (Table 5). The majority of these babies were born moderately preterm (33 to 36 weeks' gestation).

Table 4. Birth outcome, 2018-2020, n (%).

Treatment	Haemodialysis	Kidney transplantation	Total
Live birth	11 (84.62)	42 (82.35)	53 (82.8)
Spontaneous abortion	2 (15.38)	4 (7.84)	6 (9.38)
Surgical termination	0 (0.00)	5 (9.80)	5 (7.81)
Total	13 (20.31)	51 (79.69)	64 (100.0)

Table 5. Gestational age and birthweight, live born babies, 2018-2020, median (IQR).

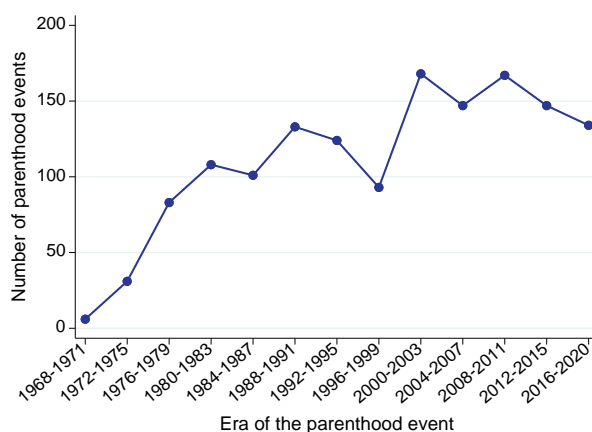
Treatment	n	Gestational age (weeks)	n	Birthweight (grams)
Haemodialysis	11	33 (30.2-35)	10	1900 (1455-2512)
Kidney transplantation	42	36 (32-37)	40	2642.5 (1880-3025)
Total	53	35 (31.7-37)	50	2500 (1700-2960)

DESCRIPTIVE DATA – PARENTHOOD EVENTS IN MEN RECEIVING KRT

1. Total number of parenthood events for men reported to ANZDATA during 1968-2020

Overall, paternal parenthood events are increasing over the years with around 150 events reported for each era since 2000 (Figure 2).

Figure 2. Total number of parenthood events for men reported to ANZDATA during 1968-2020



2. Total number of parenthood events for men by treatment modality at conception

The vast majority of men receiving KRT had a parenthood event with a kidney transplant (Table 6). Parenthood whilst receiving haemodialysis is a much rarer event. Very few parenthood events were reported for men receiving peritoneal dialysis since 2018.

Table 6. Total number of parenthood events for men by treatment modality at conception, 2018-2020, n (%).

Treatment	2018	2019	2020	Total
Haemodialysis	4 (12.90)	3 (13.64)	3 (15.00)	10 (13.70)
Peritoneal dialysis	1 (3.23)	0 (0.00)	1 (5.00)	2 (2.74)
Kidney transplantation	26 (83.87)	19 (86.36)	16 (80.00)	61 (83.56)
Total	31 (42.46)	22 (30.14)	20 (27.40)	73 (100.00)

3. Paternal characteristics

Men who had a parenthood event during 2018-2020 had a median age of 35 years at the time of conception (Table 7). Men who fathered a baby whilst receiving peritoneal dialysis were younger.

Table 7. Paternal age at conception, 2018-2020, median (IQR).

Treatment	n	Age (years)
Haemodialysis	8	34 (30-37)
Peritoneal dialysis	2	30.5 (25-36)
Kidney transplantation	53	35 (31-39)
Total	63	35 (31-39)

4. Conception type

Since 2018, all men receiving dialysis and the vast majority of men with a kidney transplant reported a natural conception (Table 8).

Table 8. Conception type in each parenthood event, 2018-2020, n (%).

Treatment	Haemodialysis	Peritoneal dialysis	Kidney transplantation	Total
IVF	0 (0.00)	0 (0.00)	3 (9.68)	3 (7.89)
Natural	6 (100.00)	1 (100.00)	23 (74.19)	30 (78.95)
Unknown	0 (0.00)	0 (0.00)	5 (16.13)	5 (13.16)
Total	6 (15.79)	1 (2.63)	31 (81.58)	38 (100.00)

5. Fetal outcomes for babies born to fathers receiving KRT

During 2018-2020, all babies fathered by men receiving KRT reported a live birth outcome (Table 9). Babies of these men were born at term with a normal birthweight (Table 10).

Table 9. Birth outcome, 2018-2020, n (%).

Treatment	Haemodialysis	Peritoneal dialysis	Kidney transplantation	Total
Live birth	11 (100.00)	2 (100.00)	62 (100.00)	75 (100.00)
Total	11 (100.00)	2 (100.00)	62 (100.00)	75 (100.00)

Table 10. Gestational age and birthweight, 2018-2020, median (IQR).

Treatment	n	Gestational age (weeks)	n	Birthweight (grams)
Haemodialysis	8	39.5 (38.3-40)	8	3277 (2938.5-3773)
Peritoneal dialysis	2	40 (40-40)	2	3365 (2830-3900)
Kidney transplantation	54	39 (38-40)	49	3300 (2870-3620)
Total	64	39.4 (38-40)	59	3300 (2870-3690)

For live born babies

CONCLUSIONS

Overall, the number of parenthood events reported to ANZDATA have risen in the more recent eras. This may be attributable to increasing numbers of people of child-bearing age receiving KRT, changing clinicians' attitudes towards pregnancy in this cohort and/or increase in the reporting of parenthood events to ANZDATA. (A more detailed analysis of birth rates is presented in Reference 1). Live birth outcomes were $\geq 82\%$ in women receiving KRT, however babies of these women remain at high-risk due to prematurity and low birthweight. Babies of men receiving KRT had excellent fetal outcomes within the normal parameters. Ongoing capture of parenthood data in this cohort is essential for evidence-based pre-pregnancy planning and counselling.

ADDITIONAL RESOURCES

Websites and video resources:

<https://www.anzdata.org.au/anzdata/research/registry-projects/parenthood-with-kidney-disease/>
<https://www.anzdata.org.au/video-resources/>
<https://kidney.org.au/your-kidneys/living-with-kidney-disease/health-and-wellbeing/pregnancy>

Previous publications using the ANZDATA parenthood dataset`

- Hewawasam, E., Davies, C., Gulyani, A., Li, Z., Clayton, P., Sullivan, E., . . . Jesudason, S. (2021). *Factors influencing fertility rates in Australian women receiving kidney replacement therapy: analysis of linked ANZDATA registry and perinatal data over 22 years*. *Nephrol Dial Transplant*. doi:10.1093/ndt/gfab157
- Hewawasam, E., Gulyani, A., Davies, C., Sullivan, E., Wark, S., Clayton, P., . . . Jesudason, S. (2020). *Parenthood and pregnancy in Australians receiving treatment for end-stage kidney disease: protocol of a national study of perinatal and parental outcomes through population record linkage*. *BMJ open*. doi:10.1136/bmjopen-2019-036329
- Jesudason, S., Fitzpatrick, A., Gulyani, A., Davies, C., Hewawasam, E., Clayton, P., & McDonald, S. (2020). *Fatherhood and Kidney Replacement Therapy: Analysis of the Australian and New Zealand Dialysis and Transplant (ANZDATA) Registry*. *Am J Kidney Dis*. doi:10.1053/j.ajkd.2020.03.020
- Jesudason, S., Fitzpatrick, A., Gulyani, A., Davies, C., Hewawasam, E., Clayton, P., & McDonald, S. (2020). *Fatherhood and Kidney Replacement Therapy: Analysis of the Australian and New Zealand Dialysis and Transplant (ANZDATA) Registry*. *Am J Kidney Dis*. doi:10.1053/j.ajkd.2020.03.020
- Jesudason, S., Grace, B., & McDonald, S. (2014). *Pregnancy outcomes according to dialysis commencing before or after conception in women with ESRD*. *Clin J Am Soc Nephrol*. doi:10.2215/CJN.03560413
- Levidiotis, V., Chang, S., & McDonald, S. (2009). *Pregnancy and Maternal Outcomes Among Kidney Transplant Recipients*. *J Am Soc Nephrol*. doi:10.1681/ASN.2008121241
- Mallett, A., Tang, W., Clayton, P., Stevenson, S., McDonald, S., Hawley, C., . . . Johnson, D. (2014). *End-stage kidney disease due to Alport syndrome: outcomes in 296 consecutive Australia and New Zealand Dialysis and Transplant Registry cases*. *Nephrol Dial Transplant*. doi:10.1093/ndt/gfu254
- Shahir, A., Briggs, N., Katsoulis, J., & Levidiotis, V. (2013). *An observational outcomes study from 1966-2008, examining pregnancy and neonatal outcomes from dialysed women using data from the ANZDATA Registry*. *Nephrology*. doi:10.1111/nep.12044
- Tang, J., Gulyani, A., Hewawasam, E., McDonald, S., P, C., Webster, A., . . . Jesudason, S. (2020). *Pregnancy outcomes for simultaneous Pancreas–Kidney transplant recipients versus kidney transplant recipients*. *Clin Transplantation*. doi:10.1111/ctr.14151
- Wyld, M., Clayton, P., Jesudason, S., Chadban, S., & Alexander, S. (2013). *Pregnancy outcomes for kidney transplant recipients*. *Am J Transplant*. doi:10.1111/ajt.12452
- Wyld, M., Clayton, P., Kennedy, S., Alexander, S., & Chadban, S. (2015). *Pregnancy Outcomes for Kidney Transplant Recipients With Transplantation as a Child*. *JAMA Pediatr*. doi:10.1001/jamapediatrics.2014.3626