

Supplemental Table 1. Characteristics of studies included in quantitative synthesis by year

Authors	Year	Country	Article Type	Purpose	No. of Participants	Average Age at Enrolment, yr±SD	Modality at Enrolment	Average Age at RRT Start, yr±SD	Design <sup>a</sup>	Sampling Method	Recruitment / Response Rate / Key Variable Completeness	Funding	Control Data Source
Cross-sectional studies with control data													
Ehrich <i>et al.</i> (20)	1992	Europe	Journal article	Survey to establish schooling, employment and social status in young adult patients on RRT	617	21-35	RRT	Not reported	Descriptive	Registry (international)	617 / 864 Surviving and not lost to follow-up (survey)	Grants (government, national societies, and industry)	Age-matched general population in France, Germany, the United Kingdom, Italy, and Spain; <i>n</i> not reported
Prather (21)	1992	United States	Thesis	Investigate whether medication adherence is related to psychosocial and family factors	41	16±2	Transplant	4±2 yr Post-transplant	Descriptive	Convenience, single center	Not reported	Not reported	Age- and sex-matched United States high school students, <i>n</i> not reported
Ayonayon (22)	1997	United States	Thesis	Examine personal and family coping style, self-image, and general life adjustment in those transplanted in childhood	45	30	Transplant	11	Descriptive	Convenience, single center	46 / 108 (Survey)	Research grant	Age-matched United States census data, <i>n</i> not reported
Querfeld <i>et al.</i> (23)	1997	Germany	Journal article	Long-term observation of pediatric RRT recipients	30	25±4	RRT	Duration 13 yrs	Descriptive	Convenience, single center	30 / 33 Surviving and not lost to follow-up (interview)	Not reported	Age-matched German regional statistics, <i>n</i> not reported
Offner <i>et al.</i> (24)	1999	Germany	Journal article	Long-term observation of pediatric kidney transplant recipients	124	25	Transplant	12±3	Descriptive	Convenience, single center	120 / 120 Surviving and not lost to follow-up	Not reported	Age-matched German regional statistics (25-35 yr old), <i>n</i> not reported
Wingen and Feldhoff (25)	1999	Germany	Journal article	Long-term follow-up of pediatric patients with kidney transplants	117	22	Transplant	12±3	Descriptive	Convenience, single center	123 / 123 Surviving and not lost to follow-up	Not reported	Age-matched German general population, <i>n</i> not reported
Olausson <i>et al.</i> (26)	2001	Sweden	Journal article	Long-term follow-up of pediatric patients with kidney transplants	28	23	Transplant	12	Descriptive	Convenience, single center	28 / 32 (Interview)	Research grant and charity grant	Young adults with ulcerative colitis, <i>n</i> =33
Rosenkranz <i>et al.</i> (27)	2005	Germany	Journal article	Assess vocational rehabilitation and quality of life in adult patients with early onset of ESRD	39	26±6	RRT	Not reported	Descriptive	Convenience, single center	39 / 192 (Participated in survey/eligible)	Not reported	Age-matched German regional statistics, <i>n</i> not reported
de Castro <i>et al.</i> (28)	2007	Spain	Journal article	To examine psychologic adaptation in young adults transplanted in childhood	13	19	Transplant	Not reported	Descriptive	Convenience, three centers	Not reported	Not reported	Other solid organ transplants, <i>n</i> =11
Kärrfelt and Berg (29)	2008	Sweden	Journal article	To describe long-term psychosocial outcome after kidney transplantation during childhood	42	25	Transplant	Not reported	Descriptive	Convenience, single center	42 / 68 (Interview)	Not reported	Age-matched Statistics Sweden data, <i>n</i> not reported
Aasebø <i>et al.</i> (30)	2009	Norway	Journal article	Describe the life situation, lifestyle and quality of life of young adult kidney transplant recipients	131	29±4	Transplant	24	Descriptive	Registry (national)	131 / 280 (Survey)	Not reported	Age-matched regional Norwegian health survey data, <i>n</i> =2360
Riaño-Galán <i>et al.</i> (31)	2009	Spain	Journal article	Investigate health-related quality of life in a group of children and adolescents with ESRD	81	16±3	RRT	10±4	Descriptive	Multicenter; five of ten pediatric nephrology centers	81 / 82 (Survey)	Research grant	Age-matched Spanish schoolchildren, <i>n</i> =901
Rafie (32)	2011	United States	Thesis	To identify psychosocial issues	46	24±4	Transplant	19±5 (Age at transplant)	Descriptive	National recruitment <i>via</i> internet	Not reported	Not reported	Healthy high school children, <i>n</i> =458; chronically ill study participants, <i>n</i> =2987
Rocha <i>et al.</i> (33)	2011	Portugal	Journal article	Assess the sociodemographic situation of adult-aged kidney-transplanted children	91	26±5	Transplant	13±2 (Age at transplant)	Descriptive	Convenience, single center	91 / 91 Surviving and not lost to follow-up	Not reported	Age-matched Portuguese census data, <i>n</i> not reported
Ritchie <i>et al.</i> (34)	2012	Australia	Journal article	Description of demographic characteristics of a cohort of young adults on RRT	495	22	RRT	16	Analytic, observational	Registry (national)	489 / 495 on Remoteness variable	Not reported	Australian official statistics, <i>n</i> not reported
Mekahli <i>et al.</i> (35)	2014	United Kingdom	Journal article	To assess the long-term quality of life of young adults treated with dialysis or transplantation since childhood	41	19±2	RRT	4	Descriptive	Convenience, single center	41 / 41 Surviving and not lost to follow-up	Not reported	Age-matched United Kingdom health survey data and official statistics (16–24 yr old), <i>n</i> not reported
Mellerio <i>et al.</i> (36)	2014	France	Journal article	Assess the socioprofessional situation of adult-aged kidney-transplanted children	374	27	Transplant	Not reported	Descriptive	Registry (national)	374 / 624 (Survey)	Industry grant	Age- and sex-matched French national statistics, <i>n</i> not reported
Cohort studies with control data													
Reynolds <i>et al.</i> (37)	1993	United Kingdom	Journal article	Assess social adjustment in survivors of a pediatric RRT program	45	24±3	RRT	14	Analytic, observational	Convenience, single center	45 / 50 (Interview)	Not reported	Age- and sex- matched United Kingdom control group, <i>n</i> =48
Morton <i>et al.</i> (38)	1994	United Kingdom	Journal article	Assess lifetime psychiatric adjustment in survivors of a pediatric RRT program	45	24±3	RRT	14	Analytic, observational	Convenience, single center	45 / 50 (Interview)	Not reported	Age- and sex-matched United Kingdom control group, <i>n</i> =48
Groothoff <i>et al.</i> (39)	2003	The Netherlands	Journal article	To determine quality of life in young adults with ESRD since childhood	135	29	RRT	10	Analytic, observational	Registry (national)	135 / 187 (Survey)	Funded by the Dutch Kidney Foundation	Age-matched healthy Dutch control group (18–44 yr old), <i>n</i> =551
Longitudinal studies with control data													
Haavisto <i>et al.</i> (40)	2011	Finland	Journal article	Long-term follow-up of pediatric patients with kidney transplants	21	21	Transplant	2 years (age at transplant)	Observational	Convenience, single center	21 / 30 (Interview)	Research grant	Age-matched Finnish health survey, <i>n</i> =427
Studies without control data													
Fine <i>et al.</i> (41)	1978	United States	Journal article	Long-term follow-up of pediatric patients with kidney transplants	69	Not reported	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	54 / 54 Surviving and not lost to follow-up	Not reported	
Poznanski <i>et al.</i> (42)	1978	United States	Journal article	Long-term follow-up of pediatric patients with kidney transplants	18	16	Transplant	12	Descriptive, cross sectional	Convenience, single center	Not reported	Not reported	
Velasco de Parra <i>et al.</i> (43)	1980	Mexico	Journal article	Evaluate social and psychologic status in patients with childhood RRT	8	20	Transplant	8	Descriptive, cross sectional	Convenience, single center	15 / 15 Surviving and not lost to follow-up	Not reported	
Simmons <i>et al.</i> (44)	1987	United States	Book chapter	Long-term follow-up of pediatric patients with kidney transplants	33	19-24	Transplant	Childhood	Observational, longitudinal	Convenience, single center	100 / 100 Surviving and not lost to follow-up	Not reported	
Lee <i>et al.</i> (45)	1989	United States	Journal article	Long-term follow-up of pediatric patients with kidney transplants	30	10-yr Follow-up	Transplant	5-18 (age at transplant)	Descriptive, cross sectional	Convenience, single center	30 / 30 Surviving and not lost to follow-up	Not reported	
Sato <i>et al.</i> (46)	1990	Japan	Journal article	Long-term follow-up of pediatric patients with kidney transplants	32	20	RRT	11 (age at transplant)	Observational, longitudinal	Convenience, single center	Unknown	Not reported	
Morel <i>et al.</i> (15)	1991	United States	Journal article	Long-term follow-up of pediatric patients with kidney transplants	57	26±5	Transplant	10±5	Descriptive, cross sectional	Convenience, single center	57 / 57 Surviving and not lost to follow-up	Research grant	
Roscoe <i>et al.</i> (47)	1991	Canada	Journal article	Medical and social outcomes in adolescents with ESRD	90	22	RRT	14	Descriptive, cross sectional	Convenience, single center	90 / 96 (Information available for 90 survivors)	Not reported	

Supplemental Table 1. (Continued)

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Bocheńska <i>et al.</i> (48)	1992	Poland	Journal article	Assess emotional status in young adults on HD	5	18	HD	(duration 1 year)	Observational, longitudinal	Convenience, single center	Not reported	Not reported	
Gämperli <i>et al.</i> (49)	1996	Germany	Journal article	Long-term observation of pediatric kidney transplant recipients	37	28	Transplant	12	Observational, longitudinal	Convenience, single center	37 / 37 Surviving and not lost to follow-up	Not reported	
Park <i>et al.</i> (50)	1996	South Korea	Journal article	Long-term follow-up of pediatric patients with kidney transplants	20	18 (Approximation)	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	20 / 27 (Interview)	Not reported	
Krmar <i>et al.</i> (16)	1997	Argentina	Journal article	Assess long-term rehabilitation and quality of life after kidney transplantation	17	23 (Approximation)	Transplant	not reported	Descriptive, cross sectional	Convenience, single center	17 / 18 (Survey)	Not reported	
Haberal <i>et al.</i> (51)	2000	Turkey	Journal article	Long-term follow-up of pediatric patients with kidney transplants	12	5-yr Follow-up	Transplant	14±2 (age at transplant)	Descriptive, cross sectional	Convenience, single center	27 / 40 Surviving and not lost to follow-up	Not reported	
Fernández de Preliasco <i>et al.</i> (52)	2002	Argentina	Journal article	Analysis of associations with compliance	74	16±1	Transplant	4±2 years post-transplant	Descriptive, cross sectional	Convenience, single center	74 / 74 Surviving and not lost to follow-up	Not reported	
Kobayashi <i>et al.</i> (53)	2003	Japan	Journal article	Assess quality of life in pediatric patients on RRT	156	19	RRT	13	Descriptive, cross sectional	Registry (national)	Unknown	Research grant	
Penkower <i>et al.</i> (54)	2003	United States	Journal article	Describe the prevalence of psychologic distress in adolescent patients who were transplanted	22	16±1	Transplant	Not reported	Observational, longitudinal	Convenience, single center	22 / 24 (Interview)	Research grant	
Cetingok <i>et al.</i> (55)	2004	United States	Journal article	Assess quality of life by age group in patients with kidney transplants	51	18-29	Transplant	Not reported	Observational, longitudinal	Convenience, single center	Not reported	Research grant	
Feinstein <i>et al.</i> (56)	2005	Israel	Journal article	To evaluate factors influencing adherence in kidney transplant recipients	79	Median 4-yr follow-up	Transplant	11 (age at transplant)	Descriptive, cross sectional	Convenience, single center	Not reported	Not reported	
Wu <i>et al.</i> (57)	2007	China	Journal article	Long-term observation of pediatric kidney transplant recipients	20	24±5	Transplant	14±1 (age at transplant)	Descriptive, cross sectional	Convenience, single center	20 / 20 Surviving and not lost to follow-up	Research grant	
Ferraresso <i>et al.</i> (58)	2008	Italy	Journal article	Long-term observation of pediatric kidney transplant recipients	36	26±6	Transplant	12±5 (mean age at first transplant)	Observational, longitudinal	Convenience, single center	35 / 35 Surviving and not lost to follow-up	Research grant	
Tielen <i>et al.</i> (59)	2008	The Netherlands	Journal article	Identify health attitudes in young adult patients with kidney transplants	26	22.5	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	26 / 44 without Intellectual disability	Not reported	
El-Husseini <i>et al.</i> (17)	2010	Egypt	Journal article	To evaluate the effects of sex on health-related quality of life and health status in pediatric kidney transplants	77	19±3	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	77 / 77 Surviving and not lost to follow-up	Not reported	
Schiavelli <i>et al.</i> (60)	2010	Argentina	Journal article	Explore satisfaction with transition	20	27	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	20 / 20 Surviving and not lost to follow-up	Not reported	
Feinstein <i>et al.</i> (61)	2011	Israel	Conference abstract	Service evaluation of continuing pediatric nephrology follow-up for young adults transplanted in childhood	64	23±5	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	Not reported	Not reported	
Tay <i>et al.</i> (62)	2011	Singapore	Journal article	Compare health-related quality of life in pediatric patients on RRT	29	17±2	RRT	Not reported	Descriptive, cross sectional	Convenience, single center	29 / 31 (Survey)	Not reported	
Haddiya <i>et al.</i> (63)	2012	Morocco	Journal article	Report experience of PD in young patients aged under 20 yr old	8	16±2	PD	Not reported	Descriptive, cross sectional	Convenience, single center	8 / 8 Surviving and not lost to follow-up	Not reported	
Tozzi <i>et al.</i> (64)	2012	Italy	Journal article	Assess quality of life in young adults with a transplant and childhood ESRD	66	23	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	66 / 86 (Interview)	Not reported	
Sattoe <i>et al.</i> (65)	2013	The Netherlands	Journal article	Effects of a peer support program on young adults with ESRD	24	20±3	RRT	Not reported	Analytic, observational, cross sectional	Convenience (camp for young people with ESRD)	24 / 52 (Survey)	Funded by the Dutch Kidney Foundation	
Tong <i>et al.</i> (66)	2013	Australia	Journal article	To elicit quality of life in adolescents and young adults with chronic kidney disease	14	17	RRT	Not reported	Descriptive, cross sectional	Multicenter; five pediatric nephrology centers and one adult center	27 / 30 (Interview)	Research grant	
Gralla <i>et al.</i> (67)	2014	United Kingdom and United States	Conference abstract	Assess education and career achievements in young adults with ESRD	31	25	Transplant	22	Descriptive, cross sectional	Not reported	Not reported	Not reported	
Johns <i>et al.</i> (68)	2014	United States	Journal article	To examine socioeconomic and racial differences in mortality in young adults receiving dialysis	11,027	25±3	Dialysis	Not reported	Analytic, observational, cross sectional	Registry (national)	10,986 / 11,027	Research grant	
Lewis <i>et al.</i> (69)	2014	United Kingdom	Journal article	Cross-sectional survey of young adult patients on RRT	296	25	RRT	17	Descriptive, cross sectional	Multicenter; 12 adult and two pediatric kidney units	296 / 931 (Survey)	Not reported	
Murray <i>et al.</i> (70)	2014	United Kingdom	Journal article	Assess education and career achievements in young adults with ESRD	55	23	RRT	Not reported	Descriptive, cross sectional	Convenience, single center	64 / 112 (Survey)	Charity grant	
Connelly <i>et al.</i> (71)	2015	United States	Journal article	Assess nonadherence in a cohort of pediatric patients with kidney transplants	175	23±6	Transplant	12±5	Observational, longitudinal	Convenience, single center	175 / 175 Not lost to follow-up	Not reported	
Gralla <i>et al.</i> (72)	2015	United Kingdom and United States	Conference abstract	Compare ESRD effect on education and employment between the United Kingdom and the United States	54	25	Transplant	23	Descriptive, cross sectional	Convenience, dual center	Not reported	Database supported by research grant	
Lewis and Arber (73)	2015	United Kingdom	Journal article	Explore effect of RRT on education and employment transitions in young adults	35	20-30	RRT	under 19	Descriptive, cross sectional	Multicenter: 14 hospitals	35 / 931 (Interview)	None	
Massey <i>et al.</i> (74)	2015	The Netherlands	Journal article	To investigate factors related to wellbeing and adherence among young adult kidney transplant recipients	62	25±2	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	62 / 84 (Interview)	None	
Patel <i>et al.</i> (75)	2015	Belarus	Conference abstract	Compare ESRD effect on education and employment between the United Kingdom and Belarus	20	23	Transplant	Not reported	Descriptive, cross sectional	Convenience, single center	Not reported	Not reported	
Rus <i>et al.</i> (76)	2015	Slovenia	Conference abstract	Long-term follow-up of pediatric patients with kidney transplants	25	Not reported	Transplant	16 years (age at transplant)	Descriptive, cross sectional	Convenience, single center	25 / 25 (Interview)	Not reported	

SD, standard deviation; RRT, renal replacement therapy; ESRD, end stage renal disease; HD, hemodialysis; PD, peritoneal dialysis

<sup>a</sup>According to The Centre for Evidence Based Medicine, University of Oxford, United Kingdom (77).