Positive and negative aspects of mental health after unspecified living kidney donation: A cohort study

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Objectives. Unspecified donors give a kidney to a stranger with end-stage kidney failure. There has been little research on the long-term impact of unspecified donation on mental health outcomes. The aim of this study was to assess the positive and negative aspects of mental health among unspecified donors.

Design. We invited all unspecified donors who donated a kidney between 2000 and 2016 at our centre to participate in an interview and to complete validated questionnaires.

Methods. We measured positive mental health using the Dutch Mental Health Continuum-Short Form (MHC-SF), psychological complaints using the Symptoms Checklist-90 (SCL-90) and psychiatric diagnoses using the Mini-International Neuropsychiatric Interview (M.I.N.I.) Screen for all donors and the M.I.N.I. Plus on indication.

Results. Of the 134 eligible donors, 114 participated (54% female; median age 66 years), a median of 6 years post-donation. Scores on emotional and social well-being subscales of the MHC-SF were significantly higher than in the general population. Psychological symptoms were comparable to the general population. Thirty-two per cent of donors had a current or lifetime psychiatric diagnosis. Psychological symptoms did not significantly change between the pre-donation screening and the post-donation study.

Conclusions. We concluded that, with the appropriate screening, unspecified donation is a safe procedure from a psychological perspective.

Statement of contribution

What is already known on this subject?

- Among the majority of living related (non-anonymous) donors, mental health returns to baseline within 3 to 12 months after donation.

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- There are few studies that investigate (long-term) mental health specifically in this group of unspecified (anonymous) donors.

What does this study add?

- The level of psychological symptoms reported on average 6 years after donation was comparable to the pre-donation level among unspecified donors.
- Mental health among unspecified donors was on average comparable to norm scores in the general population.
- Emotional and social well-being was significantly higher among donors than the norms scores among the Dutch general population.

Background

Living kidney donors make a significant contribution to reducing the shortage of organs for transplantation. Initially, living donors were genetically related family members; however, with increasing knowledge on blood and tissue typing, the number of genetically unrelated donors increased. In the early 2000s, a new type of living donor emerged: unspecified kidney donors (UKDs) also referred to as anonymous or non-directed donors (Dor et al., 2011; Morrissey et al., 2005). These individuals do not have a genetic or emotional relationship with a specific recipient and donate anonymously. Unspecified donation can be either to the patient at the top of the deceased donor waiting list or to a recipient with a incompatible living donor in a domino-paired kidney exchange programme (Roodnat et al., 2010). Despite this lack of direct relationship UKDs often describe being intrinsically motivated to donate. For example, having had a kidney patient in their close social network (Massey et al., 2010), wanting to help others in need (Jacobs et al., 2019) and wanting to give someone the chance of a normal life (Tong, Craig, et al., 2012). They often have an altruistic lifestyle (Balliet et al., 2019) and are independent thinkers (Massey et al., 2011).

In general, unspecified donation has met scepticism and has been the topic of much (ethical) debate (e.g., Adams et al., 2002; Henderson et al., 2003; Hilhorst et al., 2005; Mamode et al., 2013; Neuberger, 2011). One of the questions that has been raised is whether or not unspecified donors are psychologically (un)stable or vulnerable?

Systematic reviews have shown that there is return to baseline of health-related quality of life among all living kidney donors (Clemens et al., 2006; Dew, Myaskovsky, Steel, & DiMartini, 2014; Wirken et al., 2015). Most studies show that while psychological outcomes are positive among the majority of donors, there is a small group who struggle psychosocially after donation (Jacobs et al., 2015). Examples of psychosocial issues include worry about the recipient, financial burden and physical consequences for themselves (Jacobs et al., 2019). Two prospective studies on living donors demonstrated no significant increase in psychological complaints up to 1 year post-donation compared to their own pre-donation level (Maple, Chilcot, Weinman, & Mamode, 2017; Timmerman et al., 2015). Similarly, there was no evidence that donors experienced psychological benefits in terms of increased well-being. One of the few studies that has included a comparator group found no significant difference between donors and matched controls from the general public on psychological symptoms and well-being (Timmerman et al., 2015). However, a limitation of these studies was that they grouped all types of donors together and did not focus specifically on UKDs. Moreover, the proportion of UKDs in these cohorts was limited (5% in the UK; 11% in the Netherlands). One prospective study that did focus exclusively on UKDs ($N = 49$)

suggested that there was no significant increase in psychological complaints up to on average one and a half years post-donation (Timmerman et al., 2013). A large cross-sectional study comparing UKDs with specified kidney donors showed no significant difference between groups in current or past psychiatric symptoms and well-being (Maple et al., 2014). Conversely, a retrospective study among thirteen UKDs, 10 years after donation, showed that health-related quality of life among donors was significantly superior to that of the general population (Bramstedt, 2018). Given the paucity in research in this target group, greater understanding of the (long-term) impact of anonymous donation on mental health is needed.

Finally, many studies have focussed mainly on the negative aspects of mental health (symptoms or illness), which is understandable from a donor safety perspective. However, it is also of interest to explore the impact of donation on the positive aspects of mental health (well-being) such as personal growth, satisfaction or fulfilment (e.g., Menjivar et al., 2018; Tong, Chapman, et al., 2012). The World Health Organization asserted that health is more than just the absence of disease but also the presence of well-being (Basic documents - forty-ninth edition, 2020). Following this, Keyes stated that mental illness (i.e., the presence of psychological complaints) and mental health (i.e., emotional, psychological and social well-being) are two distinct, but correlated axes, rather than opposite ends of a single continuum (Keyes, 2005). Examples of positive mental health indicators include a purpose in life, autonomy, self-acceptance, environ-mental mastery, positive relationships and personal growth (Ryff, 2014). Including these aspects may give insights into potential benefits of living organ donation.

The main aim of this retrospective study was therefore to investigate the positive and negative aspects of mental health among unspecified living kidney donors. This was translated into the following research questions: (1) To what extent do UKDs report positive mental health after donation and is this comparable to the general population? (2) To what extent do UKDs report psychological symptoms after donation and are they comparable to the general population? (3) Is there a change in psychological symptoms over time (between pre-donation screening and the post-donation study) and are socio-demographic factors and time since donation related to this change? (4) How many UKDs have a psychiatric diagnosis at the time of the post-donation study and do these UKDs with a diagnosis differ on symptoms and well-being from those without a diagnosis? (5) What were the diagnoses and were they receiving any form of therapy?

Materials and methods

Participants

All eligible UKDs who donated a kidney at the Erasmus Medical Centre between 2000 and 2016 were invited to participate. All donors were above the age of 18 years. Donors were included if they had donated anonymously to the waiting list or through a domino-paired exchange programme. Exclusion criteria were death or donation anonymously through the paired exchange programme (donors from a incompatible donor–recipient couple). There was no upper age limit set for unspecified donation nor for inclusion in the study. We note that we included in this analysis 'therapeutic donors' who had medical reasons for nephrectomy (such as loin pain [Ceuppens et al., 2020]). All donors underwent psychological screening, with the exception of therapeutic donors.

Procedure

Ethical approval for the study was obtained from the institutional review board (METC-2017-1180). All procedures complied with the ethical standards outlined in the Helsinki Declaration of 1975, as revised in 2008. Written information and an informed consent form was sent by post. Donors were contacted by telephone 2 weeks later to discuss participation. Among those willing to participate an appointment was made to obtain written consent and to administer the measures (between February 2018 and August 2019). The majority of the data collection took place in the out-patient clinic (combined with the yearly check-up). In some cases, data were collected at the donors' home, depending on participants' preference, mobility and health. Regardless of setting, data were collected individually to ensure privacy.

In this article, we present quantitative data from a mixed-methods study. Data were collected (in this order) by means of questionnaires, a structured mental health screening interview and a semi-structured interview about their donation experiences. On indication, a structured clinical diagnostic interview was conducted. Questionnaires were completed independently by the participants, in the presence of the study coordinator (WZ). Data collection took between 45 and 90 min.

The study coordinator was known to all participants through her previous role as unspecified living donation coordinator; however, during the study, she was not involved in the clinical care pathway. If medical issues arose, these were communicated to the nephrologist with permission of the donor. If mental health issues arose, these were discussed with the donor, and, if desired, communicated in writing to the donors' general practitioner (GP) for further follow-up.

Measures

Socio-demographic and medical characteristics of donors can be found in Table 1. All socio-demographic and medical characteristics were obtained from patients records or donor database and those which are subject to change were checked for accuracy at the beginning of the interview.

Positive mental health

Positive mental health was measured using the Dutch Mental Health Continuum-Short Form (D-MCH-SF; Lamers, Westerhof, Bohlmeijer, ten Klooster, & Keyes, 2011). Participants indicated the extent to which they experienced positive aspects of mental health over the past month on a scale from 0 (never) to 5 (every day). Mean scores were calculated. This questionnaire consists of 14 items which can be divided into three subscales: psychological well-being (includes items on autonomy and personal growth), social well-being (includes items on social acceptance, integration and a feeling of contribution to society) and emotional well-being (includes items on positive emotions and life satisfaction). Lamers and colleagues demonstrated high internal and moderate test–retest reliability, as well as convergent and discriminant validity.

Psychological symptoms

Psychological symptoms were measured using the Symptoms Checklist (SCL-90; Derogatis, Lipman, & Covi, 1973). Participants indicated the extent to which they had experienced symptoms over the past week on a scale from 1 (not at all) to 5 (a lot) and

Table 1. Socio-demographic and medical characteristics, and use of mental health services (N = 114)

Socio-demographic characteristics	
Female gender: N (%)	62 (54.4)
Age (years) at donation: median (range)	58 (21–89)
Age (years) at study: median (range)	66 (25–94)
Ethnicity; N (%)	
European	113 (99.2)
Asian	1 (1)
Born in the Netherlands: n (%)	109 (95.6)
In paid employment: n (%)	62 (54.4)
Highest level of education	
Primary school	6 (5.3)
Secondary/high school	54 (47.4)
Further/higher education	54 (47.4)
Marital status: n (%)	
Married/living together/partnership	61 (53.5)
Single/divorced/widowed	53 (46.5)
Has children: n (%)	73 (64.0)
Has religious affiliation: n (%)	49 (43.0)
Medical characteristics	
Time (months) since donation: median (range)	76.50 (23–178)
Registered in deceased donor register: N (%)	96 (84.2)
Registered to donate body to science: N (%)	2 (1.8)
Use of mental health services	
Psychological/psychiatric treatment currently/recently: N (%)	17 (14.9)
Psychological/psychiatric treatment prior to donation: N (%)	45 (39.5)
Psychiatric admission currently/recently: N (%)	1 (0.9)
Psychiatric admission prior to donation: N (%)	19 (16.7)
Psychotropic medication use currently/recently: N (%)	31 (27.2)
Psychotropic medication use prior to donation: N (%)	38 (33.3)

scores were summed. The questionnaire contained 90 items and can be divided into eight subscales: Anxiety, Agoraphobia, Depression, Somatization, Inadequacy in thought and action, Interpersonal Sensitivity, Hostility and Sleep problems. A total Psychoneuroticism score can also be calculated as an indication of general psychological (dys)functioning. The SCL-90 was also administered to UKDs prior to donation as part of the routine screening procedure; these data were retrieved from the medical records and compared to the data collected as part of this study. Scores were also compared to the Dutch norm scores (Arrindell & Ettema, 2003). The internal consistency of the subscales and total score of the SCL-90, as well as the concurrent and discriminant validity, were found to be good (Derogatis, Rickels, & Rock, 1976; Holi, Marttunen, & Aalberg, 2003; Koeter, Ormel, & van den Brink, 1988).

Psychiatric diagnoses

Two versions of the Mini-International Neuropsychiatric Interview (M.I.N.I.; Sheehan et al., 1998) were used to diagnose Axis I psychiatric syndromes according to the Diagnostic and Statistical Manual of Mental Disorders-IV classification. The M.I.N.I. was found to have a good interrater, and retest reliability, a satisfactory concurrent validity, and

Table 2. Positive mental health among UKDs

(Dutch) Mental Health Continuum	Mean score UKD	Average score general population[†]	Correlation with psychological symptoms; r
Emotional well-being	3.91	3.67*	−.57***
Social well-being	2.73	2.33***	−.40***
Psychological well-being	3.31	3.18	−.44***
Total positive well-being	3.24	2.98*	−.50***

Note. [†]Data taken from Lamers et al. (2011).
[‡]Significance level *$p < .02$, **$p < .01$, ***$p < .001$ due to a Bonferroni correction.

specificity and sensitivity for most diagnoses (Lecrubier et al., 1997; Sheehan et al., 1998; Zandee & de Jong, 2018). The M.I.N.I. Screen (Sheehan et al., 1998), consisting of 14 screening questions that can be answered with yes or no, was administered to all participants by the study coordinator who had been trained in use of this instrument. Subsequently, the M.I.N.I. Plus was conducted among all donors who reported a potential diagnosis on the M.I.N.I. Screen. This was carried out by a psychologist (SI or EM). The M.I.N.I. Plus (Sheehan et al., 1998) is a 26-item structured interview that assesses (subtypes and chronology of) 23 Axis I diagnoses, as well as the risk of suicidality.

Use of mental health services was measured using standardized interview questions (see Table 1). Answers were scored dichotomously (yes/no). If answered affirmatively, further questions were asked on the date, type and duration of treatment.

Statistical analysis

All data were analysed using SPSS version 25. One-sample *t* tests were used to compare donor data to norm scores. Paired *t* tests were used to assess the relationship between pre-donation and post-donation psychological symptoms (SCL-90). A Bonferroni correction was applied when there were multiple subscales. Independent *t* tests were used to assess differences in continuous outcomes between two groups. Pearson's correlations were used to test associations between the continuous outcomes on the one hand and continuous socio-demographic variables and time since donation on the other hand. Independent *t* tests were used to explore the difference in positive mental health and psychological symptoms between donors with and without a psychiatric diagnosis.

Results

Participants

During the study period, 142 unspecified donors had donated a kidney, either to a patient on the deceased donor waiting list or in an exchange procedure. At the moment of inclusion, eight donors in this cohort had died. Cause of death was unrelated to living donation and occurred after a median of 52 months (range 31-164) after donation. Of the 134 remaining eligible donors, 114 gave consent to participate (85%). Reasons for not wishing to participate are outlined in the Supplementary Material. Both positive reasons, such as closure, and negative reasons, such as dissatisfaction, were reported.

Eight participants had their kidney removed for medical reasons and chose to donate it (therapeutic donation). Socio-demographic, medical and psychiatric characteristics can

be seen in Table 1. Median age at donation was 58 (range 21–89 years). Time since donation was a median of 76.5 months (range 23–178 months). In sixteen cases, data collection took place in the donor's home or alternative private location.

Positive mental health

UKDs reported on average a significantly higher positive mental health score than the Dutch general population on emotional and social well-being. Similarly, the average total score was significantly higher than the general population (see Table 2). There was no significant difference between these groups on the subscale psychological well-being.

Regarding factors associated with this outcome, participants with a religious affiliation reported significantly higher scores on the positive mental health total scale ($t = -2.7$, $p < .01$), as well as on the psychological ($t = -2.6$, $p < .01$), social ($t = -2.1$, $p < .05$) and emotional well-being subscales ($t = -2.3$, $p < .05$). No other associations were found with socio-demographic variables or time since donation (in months). Psychological symptoms were negatively correlated with the total score as well as the subscales psychological, social and emotional well-being (see Table 2).

Psychological symptoms

Mean scores on each of the SCL-90 subscales and total score of Psychoneuroticism were compared to the average norm scores for the general population (see Table 3). Using one-sample t tests, there were no significant differences between the average scores of the UKDs and the Dutch norm scores. We note that the range of individual scores is wider, indicating that some donors had scores higher than average. The subscales of depression, inadequacy in thought and action, and sleep problems had the highest proportion of donors who scored above average compared to the norm scores.

Table 3. Psychological symptoms in the past week among UKDs ($N = 114$)

Symptoms checklist-90	Range for average scores of Dutch general population	Post-donation score range	Post-donation mean (SD)	Category according to norm scores
Anxiety	12–14	9–27	11.45 (2.64)	Below average
Agoraphobia	7–8	6–18	7.53 (1.43)	Average
Depression	20–23	15–56	21.34 (6.93)	Average
Somatization	15–18	11–37	15.54 (4.37)	Average
Inadequacy in thought and action	11–14	8–24	12.77 (3.76)	Average
Interpersonal sensitivity	22–26	17–47	22.30 (6.06)	Average
Hostility	7–8	6–17	6.67 (1.46)	Average
Sleep problems	4–5	3–13	4.99 (2.57)	Average
Psychoneuroticism (total score)	113–123	89–210	112.7 (24.3)	Average

Table 4. Psychological symptoms at pre-donation (during screening) versus post-donation (during the interview; *N* = 98)

Symptoms checklist-90	Range for average scores of Dutch general population	Pre-donation mean (SD)	Post-donation mean (SD)	Pre/post-donation mean difference	Paired *t* tests	
					t	*p* value[†]
Anxiety	12–14	11.11	11.26	−.14	−.599	.550 (NS)
Agoraphobia	7–8	7.47	7.45	.02	.162	.871 (NS)
Depression	20–23	19.59	20.91	−1.31	−1.763	.081 (NS)
Somatization	15–18	14.48	15.23	−.76	−2.066	.042 (NS)
Inadequacy in thought and action	11–14	11.81	12.51	−.70	−2.031	.045 (NS)
Interpersonal sensitivity	22–26	21.78	22.27	−.49	−.916	.362 (NS)
Hostility	7–8	6.71	6.62	.09	.488	.626 (NS)
Sleep problems	4–5	4.37	4.66	−.30	−1.225	.223 (NS)
Psychoneuroticism	113–123	107.53	111.17	−3.64	−1.817	.072 (NS)

[†]Significant level was $p < .005$ due to the application of a Bonferroni correction.

Table 5. Self-reported present and past psychiatric diagnoses among UKDs

Diagnosis Dutch M.I.N.I. plus	Past prevalence (%)	Current prevalence (%)	Lifetime prevalence (%)
Major depressive disorder	13 (11.4)	6 (5.3)	
Dysthymic disorder	11 (9.6)	11 (9.6)	
Mood disorder due to physical illness		1 (0.9)	
Suicidality		11 (9.6)	
Current risk low		6 (5.3)	
Current risk medium		5 (4.4)	
Current risk high		0 (0.0)	
Generalized Anxiety Disorder		7 (6.1)	
Post-traumatic Stress Disorder	5 (4.4)	7 (6.1)	
Attention deficit hyperactivity disorder		8 (7.0)	
Mania	3 (2.6)		
Agoraphobia	2 (1.8)	3 (2.6)	
Adaptation disorder (emotions and behaviour)		2 (1.8)	
Panic disorder		1 (0.9)	2 (1.8)
Social phobia		1 (0.9)	
Alcohol abuse/dependence		1 (0.9)	3 (2.7)
Substance abuse			1 (0.9)
Psychotic Disorder – NOS			1 (0.9)
Bulimia nervosa	1 (0.9)		
Panic attacks with limited symptoms		1 (0.9)	
Pain disorder associated with psychological and somatic factors		1 (0.9)	

For 98 donors, psychological symptoms data were available from the pre-donation screening. There was no significant change in the SCL-90 subscales and total score between pre-donation and post-donation means (see Table 4).

There was no significant correlation between time since donation (in months) and the psychological symptoms total score. None of the socio-demographic variables were related to the post-donation psychological symptoms total score nor to the change in symptoms over time.

Psychiatric diagnoses

Among the 114 UKDs, the M.I.N.I. Screen yielded a positive result for 54 (47%) of donors. Subsequently, among these individuals, a M.I.N.I. Plus was carried out. For 37 (32%) of these donors, a psychiatric diagnosis was diagnosed either current, past or lifetime. Twenty-four donors received two or more diagnoses (range 1–6). Nine donors (8%) had a lifetime diagnosis but no diagnosis at the time of the interview. The specific diagnoses can be found in Table 5. Among the 11 who reported some level of suicidality at the time of the interview, five were currently in treatment, five were taking psychotropic medication, and one had recently had an admission to a psychiatric clinic. All 11 reported having received psychological treatment prior to donation, and seven had had an admission to a psychiatric clinic prior to donation. Potential support was discussed, and, in two cases (with approval of the donor), findings were communicated with the GP for follow-up and/ or referral.

Table 6. Comparison of outcomes between UKDs with and without a psychiatric diagnosis

Outcome measure	UKD without M.I.N.I. Plus diagnosis (n = 77)	UKD with M.I.N.I. Plus diagnosis (n = 37)	p value
(Dutch) mental health continuum[†]			
Emotional well-being	4.23 (0.83)	3.28 (1.32)	.001*
Social well-being	2.97 (1.14)	2.24 (1.14)	.002*
Psychological well-being	3.63 (1.13)	2.65 (1.32)	.001*
Total positive well-being	3.53 (0.94)	2.64 (1.13)	.001*
Symptoms Checklist-90[‡]			
Anxiety	10.66 (1.188)	13.05 (3.79)	.001*
Agoraphobia	7.26 (0.86)	8.11 (2.04)	.02 (NS)
Depression	18.69 (3.10)	26.46 (9.23)	.001*
Somatization	14.44 (2.78)	17.84 (5.80)	.002*
Inadequacy in thought and action	11.43 (2.57)	15.40 (4.28)	.001*
Interpersonal sensitivity	20.65 (4.41)	25.65 (7.42)	.001*
Hostility	6.25 (0.54)	7.60 (2.22)	.001*
Sleep problems	4.49 (2.03)	6.03 (3.18)	.01 (NS)
Psychoneuroticism	103.58 (12.69)	131.92 (31.02)	.001*

[†]Significance level was *p < .02 due to the application of a Bonferroni correction.
[‡]Significance level was *p < .005 due to the application of a Bonferroni correction.

In an exploratory analysis, we compared positive mental health between donors with and without a psychiatric diagnosis. For all subscales and the total score of the D-MHC-SF, the positive mental health was significantly higher among the group without a psychiatric diagnosis (see Table 6). Similarly, we assessed the level of psychological symptoms between these two groups. For a number of subscales and the total score of the SCL-90, the group with psychiatric diagnoses scored significantly higher than the group without psychiatric diagnoses (see Table 6).

Use of mental health services

The number of UKDs currently (or recently) seeking mental health treatment at the time of the study was 17 (15%), while 45 (39.5%) reported having undergone psychiatric or psychological treatment at some point in their lives prior to donation (see Table 1). Thirteen of those currently undergoing current psychological treatment reported having undergone treatment prior to donation; four reported no prior history with mental health services. At the time of the study, one donor had recently been admitted to a psychiatric hospital/ward compared to 19 prior to donation. Thirty-eight donors reported taking psychotropic medication prior to donation; during the post-donation study, 31 donors reported taking these medications (mainly anti-depressive, sleep and antipsychotic medication).

Discussion

This study addressed an understudied group of 114 individuals who donated a kidney to a stranger. This is the largest cohort of unspecified donors reported to date. We did not find evidence of a change between pre-donation and post-donation psychological symptoms, and average level of symptoms was comparable to the Dutch general population. These findings are in line with those of the largest retrospective study to date and two prospective studies which also found no significant increase in psychological symptoms up to a year after donation (Maple et al., 2014, 2017; Timmerman et al., 2015). This study is of added value as the duration of the follow-up was considerably longer than the previous studies that followed donors up to 12 months post-donation. In contrast to our findings, however, Timmerman et al. and Maple et al. did not find evidence of psychological benefits after donation. The present study suggests that positive mental health is higher among this cohort of unspecified donors than in the Dutch general population. They reported experiencing positive emotions, a sense of being involved and having contributed to society. Placed in the context of Keyes' model of mental health, our findings suggest that UKDs are 'flourishing' after donation. However, we cannot draw any conclusions as to whether there was any change over time given the retrospective nature of this part of our study. The extent to which living donation contributes to this positive sense of well-being or indeed whether those with a higher sense of well-being are more likely to become anonymous living donors requires further (qualitative) investigation, preferably following donors over time.

With regard to the psychiatric diagnoses, in the present study we found that 32% had a lifetime diagnoses. This is considerably lower than the 42.7% reported for the Dutch population and lower than the 36.5% for the age group 55–64 years (de Graaf, ten Have, & van Dorsselaer, 2010), which is the average among this sample of donors. The lower prevalence in the donor cohort may be partly attributable to the withdrawal or exclusion

of some candidates based on current psychiatric illness detected during the psychological screening. Conversely, the use of mental health services at the time of the study appeared to be higher than the 12 month incidence rate in the general Dutch population, which is approximately 11% for the use of mental health services and 6% for psychotropic medication (de Graaf et al., 2010).

Almost 10% of UKDs were diagnosed with a low to medium suicide risk. This includes people who in the past 4 weeks imagined being dead or considered suicide, and/or attempted suicide in the past. In the general Dutch population, lifetime prevalence of suicidal ideation is 8.3% (Have, Van Dorsselaer, Tuithof, & de Graaf, 2011). In our sample, these were mostly cases of chronic depression whereby thoughts about death, dying and ending life are typical symptoms. Only two participants felt that action was desirable in the form of a letter relaying the suicidal thoughts to the GP. General practitioners are well placed to monitor (mental) health and should therefore be well-informed about living donation. UKDs in this cohort also reported a slightly higher current use of mental health care than the general Dutch population (11.4%, de Graaf et al., 2010). Use of psychotropic medication appears quite stable over time.

We note that we accepted donors with pre-existing conditions such as mood disorders, developmental disorders such as ADHD or autism, and personality disorders if these did not have a significant impact on psychosocial functioning. We always engage with both the GP and current psychologist/psychiatrist in such cases to assess resilience. As to whether or not donors attribute current psychological issues to the donation is a question that we cannot answer with this quantitative data. Further qualitative analysis will help shed light on this.

Comparison of prevalence with other studies is difficult due to the focus on different populations or use of alternative outcome measures. It would be interesting to compare these results with those from other centres with a large volume of UKDs as well as to outcomes among specified donors. The majority of transplant clinics that carry out unspecified donation apply stricter or more intensive psychological screening for unspecified donors than for 'living related' or specified donors (Kranenburg et al., 2008). Our findings show that unspecified donors have satisfactory or even a favourable mental health in the long term and suggest that the psychological screening was satisfactory. Hence, we agree with others in the field that unspecified donors should always be screened on mental health (Potts et al., 2018). In order to standardize psychosocial screening, promote equal access to living donation and ensure optimal outcomes, a number of psychosocial assessment tools have been developed. These tools should be implemented as standard (Iacoviello et al., 2015; Massey et al., 2018). An area for future research is exploring consensus on acceptance criteria for unspecified donation, that is whether to allow individuals with a psychiatric history to donate.

Regarding those donors who did not participate in the study, seven donors reported dissatisfaction with financial aspects of donation and with anonymity. Dissatisfaction has been reported as a cause of stress in a retrospective study among UKDs (Jacobs et al., 2019). Financial disincentives and burden for living donors have been well documented (Dew et al., 2014; Jacobs et al., 2015; Rodrigue et al., 2016), and many have made a plea for limitation of financial barriers (Jacobs et al., 2015; Rodrigue, Schold, & Mandelbrot, 2013). The extent to which financial burden is related to psychological outcomes is an area for further investigation.

Various strengths of the study are worth mentioning. This is the largest single-centre cohort of UKDs reported in the literature to date. The length of follow-up also exceeds that of previous prospective studies that have typically been up to 12 months post-donation.

Furthermore, as is common in research among living donors, the response rate was high. This speaks to the altruistic tendencies of this population. Involving an interviewer known to the donor could on the one hand have introduced bias, for example in an attempt to avoid disappointment or embarrassment. On the other hand, this may have boosted participation as well as honesty and disclosure during the interviews. Given high level of disclosure, we did not feel this relationship negatively influenced participation or responses. Finally, we employed a more holistic and balanced approach to the concept of mental health, investigating not only negative aspects but also positive ones.

There are also some limitations of the study. Firstly, this is a mainly retrospective analysis and as such only captures a snapshot of how a person is at that moment in time; however, we were able to incorporate some data from the pre-donation screening. We acknowledge that participants may have perceived and completed pre-donation questionnaires (being part of the screening procedure) differently than post-donation questionnaires (as part of research). In the future, there is a need for prospective studies to follow donors for longer than 12 months to assess the impact of living donation on both the positive and negative aspects of mental health on the long term. Retrospective studies can add insights into current mental health but lack the baseline measurement needed to assess change over time. In the present study, we only had pre-donation data for (negative) psychological symptoms but not for (positive) mental health.

Secondly, one could question whether the general population is a fair comparator group. Living donors must satisfy strict selection criteria whereas databases from the general population are likely to include individuals who would not satisfy these criteria. As such, these comparisons may show a more positive conclusion in favour of the donors. In the future, control groups, for example, from epidemiological studies in the general population, that can be matched on donor selection criteria are recommended.

Finally, while quantitative studies are useful in comparing levels of complaints and well-being to established benchmarks, these figures add little in the way of knowledge on the experience of the anonymous donation process by donors. For this, qualitative research is needed, either in the form of focus groups or interviews (Balliet et al., 2019; Bramstedt, 2018; Maghen et al., 2018). Pertinent questions include the impact of anonymity on mental health after donation as well as the extent to which any psychological problems may be attributed to the donation process and vice versa.

With regard to future directions, there is a need for (prospective) investigation into the factors predicting mental health among donors and whether there are differences between unspecified and specified donors. Additionally, a 'forgotten group' is those candidates who are not accepted for living donation either due to pre-existing conditions, the discovery of a medical issue or psychological reasons. The impact of being turned down as a living donor on mental health is an understudied area. This information is essential to help shape the psychosocial screening and make this more evidence based. The findings to come from the multi-centre 5-year BOUND study in the UK will make a significant contribution in this area (Gare et al., 2017).

In conclusion, psychosocial symptoms among this large cohort of unspecified living kidney donors are comparable to the general population and positive mental health is on average higher. Approximately, a third reported current or lifetime symptoms that satisfied the criteria for a psychiatric diagnosis. Psychological screening is important in order to estimate potential risks and to offer appropriate support during and after the process. Among this screened cohort, long-term mental health after unspecified donation appeared to be satisfactory.

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Conflicts of interest

All authors declare no conflict of interest.

Author contribution

Willem Weimar (Conceptualization; Methodology; Supervision; Writing – review & editing) Jacqueline van de Wetering (Conceptualization; Methodology; Supervision; Writing – review & editing) Sohal Y. Ismail (Conceptualization; Investigation; Methodology; Supervision; Writing – review & editing) Emma Kay Massey, Ph.D. (Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Supervision; Writing – original draft) Mathilde C. Pronk (Formal analysis; Project administration; Validation; Writing – review & editing) Willij C. Zuidema (Conceptualization; Data curation; Investigation; Methodology; Project administration; Writing – review & editing).

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

The following supporting information may be found in the online edition of the article:

Supinfo S1 Reasons for non-participation ($n = 20$).