Donors’ health status and experiences ten years after kidney donation

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Summary

Background: Throughout the world, end-stage renal disease is an escalating health problem. Live kidney donation is increasingly performed to reduce the gap between the number of patients waiting for transplantations and the availability of organs from deceased donors and can account for nearly half of all transplantations in kidney transplantation programs. Live kidney donors are healthy individuals undergoing major surgery for the benefit of others. Even though live kidney donation is considered a safe procedure, live kidney donors may experience long-term physical and/or psychosocial effects. Various factors may influence live kidney donors’ perceptions and experiences of the donation process and its long-term consequences.

Aim: The overall aim of this research was to obtain new understanding of long-term outcomes for live kidney donation, both from live kidney donors’ own perspectives and a clinical perspective. Comprehensive knowledge of live kidney donors’ long-term health status and experiences were sought with the intention of creating a foundation for the safe expansion of donor selection criteria, ensuring donors’ qualified informed consent and the creation of guidelines for long-term follow-up.

Methods: A partially sequential mixed-methods design was used, including both quantitative and qualitative methods. The research comprised three studies, all with equal status. The first study was a cross-sectional survey used to investigate live kidney donors’ self-reported health outcomes (quality of life and fatigue), including factors associated with long-term self-reported health outcomes, with particular reference to age groups in a nationwide cohort approximately ten years post-donation (Paper 1). The second study was based on qualitative in-depth interviews with the aim to explore live kidney donors’ long-term experiences approximately 10-14 years post-donation (Paper 2). The third study was a prospective study used to investigate links between clinical, self-reported and donation-specific outcomes in a nationwide cohort approximately ten years post-donation (Paper 3). All individuals undergoing live kidney donation at Oslo University Hospital between 2001 and 2004 were invited to participate in these studies.

Statistical analysis included a Wilcoxon Mann-Whitney U-test, the analysis of variance (ANOVA), generalized linear models and linear regression. The interviews were analyzed using a hermeneutic interpretative approach.

Results: A sample of 217 donors was included in the cross-sectional survey, of which data were available on 202 of the total sample. A purposeful sample of 16 donors participated in the qualitative
study. The mean age of the donors was 60 years; a minority was older than 70 years and the majority was females. The most common relationship to the recipient was sibling followed by parent.

Of those participating in the studies, the majority was associated with high scores on quality of life: mean scores between 63.9 and 91.4 (scale 1-100), highest for role emotional and lowest for vitality. Recognition for being a donor from family and/or friends was associated with higher quality of life scores in four domains: role physical, bodily pain, vitality and role emotional. Fatigue scores were generally low with mean scores between 7.3 and 8.8 (scale 4-20), with the lowest score for reduced motivation and highest for general fatigue. Females scored significantly higher than males on four out of five dimensions of fatigue. Surviving recipients were associated with lower scores for mental fatigue. Live kidney donors who regretted their decision to donate scored higher than average on all dimensions of fatigue.Recipient death, worries about own health and worsened relationship with the recipient retrospectively influenced live kidney donors’ willingness to donate. Donor age did not affect long-term health outcomes.

The interpretative analysis resulted in four main themes: 1) The recipient outcome justified long-term experiences; recipients’ improved health and positive impact on recipients’ family were important aspects. 2) Family dynamics – tension still under the surface; while donation was an obvious choice for some, implicit or explicit pressure could cause prolonged tension within families. 3) Ambivalence – healthy versus the need for regular follow-up; long-term follow-up safeguarded donors’ need to monitor their own health and be valued for their “good deed”. 4) Life must go on; in the long-term the significance of the donation faded and life went on.

The majority of the donors were normotensive: mean systolic BP was 129.2 mmHg (SD=14.7) and mean diastolic BP was 78.5 mmHg (SD=7.8). One third had hypertension (n=67) and 52 used statins. Mean age of hypertensive donors was 63.7 years (SD 10.5). A minority (n=54) had low eGFR (<60 ml/min/1.73m2): mean age was 67.1 (SD=10.2). Those with hypertension perceived a significantly higher degree of recognition for being a donor from health personnel than those without hypertension. While nearly all indicated that they would donate again if possible, those with hypertension seemed more reluctant than those who were normotensive. Less than 20 percent perceived the donation to be harmful for own health. None of the clinical parameters were significant predictors for self-reported health.
Conclusions: Live kidney donation was mainly a positive experience and live kidney donors’ health status post-donation was in general reported as good. Adverse effects on donors’ health status and life were counterbalanced by recipients’ improved health and life.

Still, live kidney donation is a complex issue. As seen in this research, donors’ self-reported quality of life improved with recognition from family and friends. Those who regretted donation and those who had experienced recipient death reported a higher level of fatigue. Donors justified donation by focusing on the positive impact it made on others’ lives, despite complicated family dynamics. While no relationship between clinical and self-reported outcomes were seen, hypertension appeared to be associated with donation specific factors.

These results suggest the need for realistic and consistent information to ensure that potential donors give a qualified informed consent. The systematic education of health professionals, with an emphasis on information, acknowledgement and individual support might be beneficial for the pre- and post-donation donor care. A plan for long-term donor follow-up is highly recommended, including monitoring of blood pressure and kidney function. Such follow-up may also assist in identifying donors who are at risk.
List of papers

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Paper 2

Paper 3
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<td>BMI</td>
<td>body mass index</td>
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<td>BP</td>
<td>blood pressure</td>
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<td>ESRD</td>
<td>end stage renal disease</td>
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<td>HRQL</td>
<td>health-related quality of life</td>
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<td>LDN</td>
<td>laparoscopic donor nephrectomy</td>
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<td>LKD</td>
<td>live kidney donor</td>
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<td>MCS</td>
<td>mental component score</td>
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<td>ODN</td>
<td>open donor nephrectomy</td>
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<td>OUS</td>
<td>Oslo University Hospital</td>
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<td>PCS</td>
<td>physical component score</td>
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<td>PRO</td>
<td>patient-reported outcome</td>
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<td>PTH</td>
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<td>QoL</td>
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1. Introduction

Through my work as a nurse and transplant coordinator at Oslo University hospital (OUS), I have experienced that live kidney donation may be a sensitive matter for live kidney donors (LKDs), recipients and/or their families. When making the decision whether to donate a kidney or not, LKDs may experience varying degrees of pressure. Additionally, how prepared LKDs are prior to donation varies. Some know that they are potential donors for years and, as such, are well-prepared, while others are less well-prepared and lack knowledge about the donation process. I have always been curious about LKDs’ experiences, including what is important to them from a long-term perspective.

Since the 1950s, kidney transplantation has been regarded as the best treatment for end-stage renal disease (ESRD). The increased use of LKDs stems from a limited source of deceased-donor organs and superior results from live kidney donation. Norway has been a “pioneer country” in regard to live donation, and LKDs have been used in approximately 40% of all transplantations in Norway (1). Nevertheless, a significant decline in live kidney transplantations has occurred during the last few years, and in 2016 the proportion of such was less than 20% (Figure 1).

Figure 1: Kidney transplantations in Norway and the source of donors 1969-2016. Source: OUS.
While a similar decline has also been noted in other countries (2, 3), as yet there are no clear indications as to why this is occurring. The decline in live donations may reflect ethical views and/or a societal ambiguity toward healthy individuals “unnecessarily” undergoing major surgery (4). From an ethical viewpoint, the realization of non-coerced, informed decision-making should be an essential element of live kidney donation (5, 6). For such to occur, LKDs must be able to access comprehensive and up-to-date information on the benefits and disadvantages of the donation process. Ever since a live kidney donation was first attempted, health professionals have concentrated on what the benefits of the procedure are, or its outcome: primarily defined as the medical or surgical outcomes for recipients. Research into outcomes for LKDs, especially LKDs’ own perspectives over the long-term, is lacking.

Various factors influence LKDs’ perceptions and experiences of the donation process and its long-term consequences. Even though live kidney donation has traditionally been considered a safe procedure with minor medical risks (7-11), LKDs may experience long-term physical and/or psychosocial effects. Previous research has found that LKDs’ experiences vary both pre- and post-donation (12-15) and that live kidney donation may affect LKDs’ physical and psychosocial health outcomes (16-21). Furthermore, the medical risks associated with live kidney donation have recently been reconsidered. Researchers have found that an increased medical risk and a relative risk for increased mortality for LKDs over the long-term exists (22-27). Follow-up studies are needed to ensure that the long-term outcomes for LKDs are fully understood and to ensure that qualified informed consent from potential LKDs (6, 28, 29) is realizable. A foundation for the safe expansion of donor selection criteria (7, 30, 31) and the creation of guidelines for long-term follow-up are also needed (32). Previous research indicates that live kidney donation is a complex phenomenon. Therefore, to facilitate evidence-based practice, research that includes both LKDs’ own perspectives and a clinical perspective is needed.

A mixed-methods design was used to investigate LKDs’ health status and experiences in a long-term perspective. A cross-sectional survey was performed to investigate kidney donors’ self-reported health outcomes (quality of life and fatigue), and factors associated with self-reported health ten years post-donation. The outcome scores on self-reported health were used to select candidates for in-depth interviews. Concurrently, a prospective study was performed to investigate the donors’ kidney function and clinical outcomes and the relationship between clinical, self-reported outcomes and donor specific factors ten years post-donation.
2. Aims
The overall aim of this research was to obtain new understanding of long-term consequences of live kidney donation both from donors’ own perspectives and from a clinical perspective.

There were three specific aims addressed in three papers.

In paper 1, the aim was to investigate donors’ self-reported health outcomes and factors associated with donors’ long-term self-reported quality of life (QoL) and fatigue with particular reference to age groups in a nationwide cohort approximately ten years after donation.

In paper 2, the aim was to provide insight into the donors’ experiences approximately ten years after donation.

In paper 3, the aim was to investigate relationships between clinical, self-reported and donation specific outcomes in a nationwide cohort approximately ten years after donation.
3. **Background of the study**

In the first part of this chapter, I present the background information on the increasing need for kidney transplantation and live kidney donation. I then define and outline the concepts and definitions included in the overarching concept of health status as relevant to live kidney donation. I thereafter explore the existing body of research on live kidney donation.

### 3.1 Live kidney donation

Used as a supplement to deceased donation, live kidney donation is increasingly performed to reduce the gap between the number of patients waiting for transplantations and the availability of organs from deceased donors. Patients with ESRD scheduled for live kidney transplantation are excluded from the deceased donor waiting list. Consequently, transplantation programs that include live kidney transplantation can shorten their waiting lists and also save lives. Figure 2 illustrates the differences seen between the annual rates of all (deceased and live) kidney transplantations undertaken in the European countries in 2015.

Figure 2: Annual rate of kidney transplantation in 2015. Rated in per million populations (pmp). Source: Newsletter Transplant of the Council of Europe, edition 2016. (Copyright) Used with permission.
Worldwide, a large number of patients with ESRD are waiting for deceased donor kidney transplantations (33). However, given that deceased donor resources are limited, inevitably some patients will die while waiting (34). Other than the reduction in time that patients may spend on waiting lists, there are several other advantages to live kidney transplantation. A live kidney transplantation is planned and scheduled and reduces time in dialysis. Also, the transplantation outcome is better than with deceased kidney transplantation (35-37), all of which provides socio-economic benefits. To meet the increasing need for kidney transplantations, new ways to expand the rate of live donation have been introduced and the selection criteria for LKDs have been broadened (2, 35, 38-46). As a result, there are more elderly, obese or hypertensive LKDs and a reduced estimated glomerular filtration rate (eGFR) for LKDs has been deemed acceptable. Figure 3 shows the distribution of live kidney transplantations in Europe in 2015.

Figure 3: annual rate of kidney transplantation from LKD in 2015. Rated in per million populations (pmp). Source: Newsletter Transplant of the Council of Europe, edition 2016. (Copyright). Used with permission.

Internationally, the number of LKDs has increased the last decades. However, while live kidney donations can represent nearly half of all transplantations in some programs (35), evidence
nonetheless exists that in some programs live kidney transplantations are decreasing (2, 47). In the Nordic countries, the numbers of live kidney transplantations have varied between 318 and 352 the last five years. Of the 240 kidney transplantations taking place in Norway in 2016, 47 were from LKDs (48).

3.1.1 Ethical considerations in live kidney donation

Live kidney donation entails ethical considerations (49-52), in that LKDs are essentially healthy individuals who undergo major surgery for the benefit of others. To protect poor and vulnerable people and prevent organ trafficking, transplant professionals have drawn up a declaration on organ trafficking and transplant tourism (53) and developed international standards on care for live organ donors (54). National and international authorities have also established guidelines with the aim to ensure high-quality organs and safety for both live organ donors and recipients (55-58). Such guidelines include recommendations for the extensive assessment of the potential donor’s physical and psychosocial health pre-donation and a plan for post-donation follow-up. Furthermore, some transplant professionals advocate long-time or even life-long follow-up after donation (59-61).

Non-coerced informed consent is an important ethical aspect of live donation. Potential donors may experience implicit or explicit pressure from others, depending on cultural, social, moral, familial or financial aspects (15, 49, 62). To ensure that non-coerced informed consent is realized, potential donors must be provided with information about the short- and long-term consequences of donation, including recipients’ prospects for a successful transplantation and recovery (6, 62, 63).

3.1.2 Surgical procedures

Live kidney donation involves major surgery, performed either as laparoscopic or open donor nephrectomy (64-69). Originally, donor nephrectomy included a flank incision and rib resection, and as such the postoperative period was often painful and required a long period of hospitalization and convalescence.

To meet the increasing need for kidney transplantation and recruit more LKDs, new and less invasive techniques have been developed. In 1995, the first laparoscopic donor nephrectomy (LDN) was performed in Baltimore, USA (70). Subsequent studies have verified that LKDs undergoing LDN experience less pain and require shorter hospital stays and convalescence than those undergoing open donor nephrectomy (ODN) (16, 71-73). Nonetheless, no significant difference in regard to LKDs’ long-term QoL is seen between the techniques.
Even though there are numerous advantages to LDN, one significant disadvantage remained; more complications, including an increased risk for intraoperative bleeding. Given this, less invasive techniques have been sought: mini incisions, hand-assisted LDN with or without hand-port, retroperitoneal techniques or robotic-assisted techniques (8, 65). LDN was gradually introduced in Norway in 1998, and a randomized study in which LDN and ODN were compared was undertaken from 2001 to 2004 (16, 64, 73, 74). In this study, the researchers concluded that a higher risk for surgical complications existed when LDN was used versus ODN. They noted, however, that there were advantages when an LDN was deemed “uncomplicated”, including less pain, better self-reported health status and shorter convalescence. They also noted that, when measured at the one-year follow-up, LDN yielded more favorable outcomes than ODN. During the time that this particular study was ongoing, changes were made to the surgical method or technique that LDN is based on, in order to improve LKD safety. Since 2009, hand-assisted LDN (HALDN) is used at OUS. Even though donor nephrectomy is considered to be safe and minimally-invasive, it nonetheless constitutes major surgery and as such a risk for complications exists (8, 64, 65, 67, 75).

3.1.3 The Norwegian context
Organ transplantation and donation are core fields for OUS, and it is one of the largest transplant centers in Europe. All live donations in Norway are performed at OUS, while local nephrologists at 26 nephrology centers throughout Norway have an active role in promoting live donation and approaching potential LKDs (5, 56). In contrast to many other countries, anonymous altruistic donation is not recommended in Norway; instead blood- or emotionally related donors are promoted. Potential LKDs are invited by their local nephrologist to a consultation, either by telephone or letter. This initial consultation primarily serves as an informational meeting and as such is a non-committal introduction to live donation and transplantation. What happens during this consultation is crucial; it is essential that potential donors are seen as the unique human beings that they are and that their different needs, e.g., for information, are met. If potential donors decide to continue with the process, the next consultation includes the recording of medical history and determination of health status. Afterwards, a further consultation includes a more detailed physical assessment and medical work-up and psychosocial evaluation. There may be more than one potential donor in some families. When such occurs, the challenge is to choose the most suitable donor based on biological, physical and psychosocial evaluations. During this entire process, it is essential that the health personnel involved in the process ensure that the potential LKDs have understood the information being presented to them. It is moreover the health personnel’s professional duty to determine whether any
hindrances exist as to the suitability of certain individuals in regard to acting as LKDs, including any hesitation about the donation process or any other contraindications, physical or otherwise.

In 2012, the Norwegian Directorate of health updated their guidelines on donations from live donors and in 2015 the Transplantation Act (Law on the Donation and Transplantation of Organ, Cell and Tissue) was updated; in both, post-donation follow-up for LKDs is recommend (56, 76). Recommendations now include LKD follow-ups at three, six and twelve months during the first post-donation year and a minimum of five-year-interval follow-ups after this first year. Nevertheless, actual practice in Norway varies. Some nephrologists offer LKDs follow-ups annually or bi-annually, while others offer follow-ups every five years or at even longer intervals. One reason given for not following the recommended guidelines is that LKDs are healthy individuals who do not require healthcare; as such valuable (and limited) resources need not be allocated to them.

3.2 Health status - concepts and definitions

As a concept “health status” is quite broad and includes a variety of different perspectives. In this thesis, health status is defined as an overarching concept that includes several domains: health-related QoL (HRQL), fatigue, donor specific factors and clinical outcomes. These were chosen because they encompass both LKDs’ own perspectives and a clinical perspective.

When determining the research parameters of a study, the creation of a model can help a researcher clarify the relationship between the concepts being investigated in the study. The research presented in this thesis is inspired by Wilson and Cleary’s conceptual model of patient outcomes (77-79). In the research, a modified version of Wilson and Cleary’s model was used with the aim to elucidate the different aspects of health status and how they are related (Figure 4). The modified model served several purposes. First, it encompassed a broad understanding of health status. Second, it provided direction for the various variables included in the research. Third, it provided a guideline for a statistical analysis strategy (80). In the modified model, the category biological and physiological variables includes clinical outcomes and parameters associated with kidney disease; the categories symptoms, functional status and general health include self-reported outcomes (QoL, fatigue and donor specific factors), and the category overall QoL includes self-reported outcomes and satisfaction with life. Researchers have previously found that such models are complex and that reciprocity between the causal relationships seen in such models may exist (81). For example, in the modified model used in this research satisfaction with life can be both an input and an outcome; as
an input it can influence an individual’s perception of symptoms, functional status or clinical outcomes while as an outcome it can influence the individual’s perception of satisfaction in relation to symptoms, functional status or clinical outcomes.

Figure 4: Overarching definition of health status and concept domains in relation to LKDs’ health status on a continuum. A modified version of Wilson and Cleary’s conceptual model of patient outcomes.

3.2.1 Health

Health can be seen as a subjective concept, given that many different definitions of the concept exist. In 1946, the World Health Organization (WHO) was established. In its constitution, health is defined as, “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (57). This definition, while considered groundbreaking at first, has since come to be seen as too absolutist and limited. Huber et al (82) argue that WHO’s definition is no longer viable; chronic disease is widespread and the world population is growing older. They instead suggest that it is unnecessary to include a focus on “complete” wellbeing in any future definition of health: human
beings possess the ability to adapt and self-manage when faced with challenges. They maintain that, if human beings’ capacity for adaptability is taken into account and health is deemed as something other than complete wellbeing, the instruments whereby health can be measured already exist, including methods for measuring functional status, QoL and sense of wellbeing.

**Health-related quality of life**

As yet, no uniform definition of QoL exists (83, 84). As a concept, HRQL is subjective and multidimensional and specifically related to the impact that health aspects have on QoL. It includes biological, physiological, psychological, social and spiritual functions (78, 79, 83, 84). The concept HRQL is dynamic and changeable and may vary according to context and the meaning one attaches to experiences (84, 85). According to Ferrans (78), HRQL is influenced by both individual and environmental characteristics. The individual characteristics are intrapersonal and include demographic, developmental, psychological and biological factors. The environmental characteristics include physical and/or social factors. In both Wilson and Cleary’s (79) and Ferrans’ (78) conceptual HRQL models, subjective perceptions of health outcomes are defined as symptoms. Furthermore, the subjective general health perceptions in their models are influenced by the categories biological function, symptoms and functional status. Poradzisz and Florczak (84), however, maintain that shifting the perspective that HRQL is an outcome to it being an input could be beneficial. They argue that a patient’s perspective must first be understood if one is to understand what is important to the patient.

**Fatigue**

Fatigue is also a subjective and multidimensional concept. While no universal definition exists (86-88), most researchers agree that fatigue includes both physical and mental aspects (87-90). Fatigue is defined in the Oxford English dictionary as, “extreme tiredness resulting from mental or physical exertion or illness” (91). While fatigue as a normal response to exercise or lack of rest can be addressed through adequate rest, chronic fatigue persists over time and is not easily remedied. Persistent fatigue can affect an individual’s level of activity, daily life and/or QoL. Aaronson et al. (86) define fatigue as, “the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization and/or restoration of resources needed to perform activity” (p.46).

**Donor specific factors**

In existing literature on live organ donation, researchers have found that pre-donation expectations and donation-related experiences may be linked to LKDs’ post-donation perceptions of own health.
LKDs may experience physical and/or psychosocial impairment post-donation if an adverse recipient outcome occurs or if the overall outcome is unanticipated (20, 31, 96, 97). Furthermore, there is evidence that a link might exist between becoming an LKD and a sense of responsibility for the recipient’s health or expectations regarding the recipient’s future health or behavior (14, 15, 31, 98). Regular follow-up and support from health personnel, family and/or friends also appears to be important to LKDs’ long-term experiences of donation (13, 99, 100). These aspects are linked to donation and are defined in this thesis as donor specific factors.

3.2.2 Donors’ perspective and experiences

In an attempt to transform or improve current healthcare, health professionals, health authorities and patients are increasingly placing a focus on patient-centered care and involving patients in their actual care (83, 101-104). Consequently, in the field of health research, researchers are focusing on patients’ perspectives and experiences. A patient- or self-reported outcome (PRO) is a health outcome reported by a patient and which is un-interpreted by healthcare professionals (101). Patient-reported outcome measures (PROMs) and/or patient-reported experience measures (PREMs) can be used when assessing patient outcomes. PROMs were developed to quantify measurements of patient-reported outcomes, including how patients perceive own health in relation to physical, psychological or social aspects, HRQL, fatigue or satisfaction with care and/or life. PROMs can be generic or disease specific (101, 105). The advantage of a generic PROM measurement instrument is that it can also be used to measure healthy populations or a wide range of patient populations or treatments. Research on PROMs has increased during the last few decades and PROMs are now commonly used. The widespread use of PROMs has had an impact on the quality of patient treatment and care (102, 105-107). In clinical trials, PROMs are now commonly used as a supplementary measurement instrument whereby to evaluate the risks or benefits of a treatment are evaluated and are also used as a singular component to evaluate health status in patient groups.

Researchers have found that live organ donation is a life event that can have a lasting impact on LKDs’ lives (7, 31, 95, 97, 108). Not only does each individual human being perceive and experience life events in his/her own unique way but differing circumstances, such as relationship to recipient, expectations or perceptions of support and care, can also influence LKDs’ experiences of the donation process (14, 15, 31, 109). Moreover, the actual outcome of the donation process can differ from what an LKD has anticipated. The motivations underlying LKDs’ consent to the donation process may also affect their long-term perceptions.
Consequently, a need exists to investigate LKDs’ perspectives on the outcomes of live kidney donation over the long-term. This will facilitate patient-centered care by adding the LKD perspective to the existing body of research on the subject and help improve the realization of evidence-based practice. LKDs possess unique knowledge and experiences about what it means to undergo major surgery as healthy individuals. What their values, needs and/or preferences are, the subsequent expected or unexpected consequences of the procedure/donation process over the long-term; all are of great value and should be explored (83, 84). Note that since kidney donors are healthy individuals prior to donation and it is expected that they will return to and maintain a normal health status post-donation, their unique perspectives are that of healthy individuals, not patients. Therefore, in this thesis the term “self-reported outcomes” is used.

3.2.3 Clinical perspective

To evaluate LKDs’ health status from a long-term perspective, not only are LKDs’ own perspectives and experiences needed but also objective clinical parameters. Potential LKDs need evidence-based information about clinical outcomes in order to be able to make informed and qualified decisions about donation. In addition to information about surgical risks, they even need knowledge of the long-term medical risks and clinical outcomes associated with live kidney donation (9, 10, 22, 23). Furthermore, to meet the growing demand for LKDs, a need exists for more knowledge of LKDs’ long-term clinical health outcomes so that donor selection criteria can be expanded and guidelines for long-term follow-up can be established (53, 57, 58, 110, 111).

3.3 Current knowledge

Earlier research has shown that live donation is safe (66) and that most donors report a high level of QoL in comparison to the general population (7). Still, the suggestion has been put forth that donors’ lives may be not merely be positively influenced but even negatively influenced by donation (2, 31, 95). A disparity is seen in the design and body of research on live kidney donation in relation to LKDs, in that there is a wide variation in the time-spans investigated in such; the concepts of short-term and long-term follow-up are rarely defined. In this thesis, short-term follow-up is defined as one-year post-donation, mid-term as one-to five-years post-donation and long-term as longer than five-years post-donation.
3.3.1 Donors’ perspectives

When LDN was first introduced as a surgical option, several studies were undertaken in order to investigate the safety of the method and whether any change was seen in LKDs’ self-reported outcomes. In studies comparing LDN versus ODN, researchers found that LKDs’ QoL reached baseline scores in most domains for both groups within one-year post-donation (16, 72, 112). Nevertheless, the researchers also found that both techniques affected LKDs’ QoL and fatigue. In another short-term study, which did not focus on the outcome of the different surgical methods, Kroencke et al. (92) followed 79 LKDs and found that their physical function and vitality (measured as QoL domains) was significantly reduced compared to baseline when measured at three months and at one-year post-donation. Kroencke et al also found a correlation between the LKDs’ mental health and their perceptions of recipients’ health. Kroencke et al therefore suggested that those factors that might possibly affect LKDs’ post-donation QoL should be further studied in future research.

The mean age of LKDs has increased in recent years as older individuals are more commonly accepted in an attempt to meet the increased need for kidneys. Researchers have determined that differences do exist between older and younger LKDs in relation to QoL and fatigue post-donation (113-115). Klop et al (114) defines older as more than 60 years old at the time of donation. In Klop’s study, older LKDs recovered more quickly and reported better QoL than younger LKDs across several QoL domains when measured during the first three months post-donation. In a study by Minnee where older was defined as more than 55 years old at the time of donation (115), older LKDs initially experienced slower physical recovery than younger donors but one-year post-donation no significant differences were seen between the groups.

In a retrospective study with a median follow-up time of 5.5 years where LKDs’ self-reported QoL was investigated (17), the authors did not find any significant differences between LKDs and healthy non-donor controls. Similar results have been seen in a Norwegian study (116) with a median follow-up time of 12.7 years (range 1 - 43 years) and an American retrospective study (19) with a mean follow-up time of 17 years (range 5 - 48 years). Still, in the American study factors such as obesity and/or a history of psychiatric problems were associated with impaired physical and mental health: protective factors were older age at donation and a close familial (first-degree) relationship with the recipient (19). Another study in which Messersmith et al (93) investigated satisfaction with life on the same American donor population as in the aforementioned study, significant associations between post-donation satisfaction with life and donation-related experiences were found. They also
determined that social support and improved relationship with the recipient had a positive effect while recipient outcome had no effect. In a study by de Groot (18), where mean time since donation was 5 years, decreased QoL was associated with fatigue, societal participation and changes in the relationship between donor and recipient. Moreover, similar to the results seen in Messersmith et al’s article (93), pre-donation expectations were associated with post-donation HRQL.

A long-term perspective study was undertaken by Janki et al (21), who found that LKDs’ QoL had decreased and fatigue had increased when measured at a ten-year post-donation follow-up. Janki et al noted, however, that such findings could be attributed to natural ageing. In another long-term follow-up study, significant gender differences were seen (117). Sommerer et al found that the HRQL mental component summary score was lower and the prevalence of fatigue higher for female LKDs.

In various other qualitative studies, LKDs have explained that their own concern and feeling of responsibility for the recipient’s health influenced their decision to donate (14, 94, 118-121). Andersen et al (120) found that one week post-donation LKDs experienced feelings of responsibility and obligation toward recipients. Some also experienced a dual role during the course of their hospital stay: acting both as a patient and the recipient’s relative could be difficult to balance. Lagenbach et al (122) found that two- to three-years post-donation LKDs’ were concerned about disturbed family hierarchies and organ rejection and that some were ambivalent toward recipients. Gill et al interviewed both donors and recipients and found that both groups were concerned for the other’s health pre-donation (100). Gill et al found that ten months post-donation both donors and recipients were healthy. Still, the donors were disappointed with their follow-up care and concerned about the apparent lack of interest in their health while the recipients were concerned about the possibility of organ rejection. In another study investigating the same sample, Gill et al (14) found that for most LKDs the decision to become a donor had been instantaneous and easy to make. Post-donation, the LKDs emphasized the positive impact that recipients’ improved health status had on their own (LKDs’’) lives. Andersen et al (15) and Williams et al (123) found that adverse recipient outcomes could affect LKDs’ physical and emotional health. Williams moreover found that in the event of an adverse recipient outcome, LKDs’ rehabilitation could take longer than expected and they could experience physical or emotional discomfort, such as sadness, depression or fatigue, up to one-year post-donation. LKDs’ experiences of the donation process were also influenced by their perception of health professional’s support and care (13, 15, 100); a lack of follow-up care could be
disappointing and lead to concern, while humanistic care and emotional support were seen as comforting and could make it easier to tolerate hospitalization issues.

3.3.2 Post-donation clinical outcomes

Previous research findings on long-term, post-donation clinical outcomes have been inconclusive, and recent research has found that LKDs experience a higher incidence of ESRD and risk for cardiovascular disease than healthy non-donors (23-25). Garg et al (27) also found that female LKDs experience a higher incidence of gestational hypertension and preeclampsia when compared to non-donors. In a Norwegian study (124) that assessed post-donation pregnancy outcomes, preeclampsia was more common post- rather than pre-donation. Still, no significant differences were seen between LKDs and the general population in this study in relation to adverse pregnancy outcomes.

Kasiske et al (125) performed a prospective controlled study following 203 LKDs and 201 controls. When observed at six-months follow-up, Kasiske et al found that kidney donation affected some clinical parameters related to reduced kidney function and that at three-years follow-up the reduced kidney function was still evident (22). However, when comparing results from six-months and three-years follow-ups, they also found that clinical parameters improved. The indication is that the kidney function may recover over the long-term and therefore longer follow-up studies are motivated.

In a study of long-term donor outcomes, Fehrman-Ekholm et al (10) found that after years of increased and stable kidney function, a phase of progressive decline occurs, especially among older LKDs. Conversely, in a long-term study of 310 LKDs Fournier et al (9) found that live kidney donation did not affect kidney function over the very long-term. In another long-term study in Korea with a follow-up rate of 11% and a mean follow-up time of 2.5 years (126), researchers found incidence of hypertension, proteinuria and reduced kidney function and that age was significantly associated with the post-donation development of ESRD. In another study in which the impact of age on the long-term safety of live kidney donation was investigated (127), researchers found that when comparing age groups, no significant change in renal function or rise in blood pressure was seen for older LKDs (≥ 60 years). Still, in a Norwegian study Mjøen et al (128) found an increase in blood pressure post-donation when LKDs were observed at one-year and five-year follow-ups, though no evidence of further decline in renal function. In two other studies, age, gender and body mass index have been associated with impaired renal recovery after live kidney donation (129, 130). Additionally, in two recent studies in which self-reported and clinical outcomes over the long-term were investigated (21, 117), hypertension, reduced kidney function and a decrease in self-reported outcome were seen.
While all of the studies mentioned above contribute valuable information to the body of knowledge on LKDs, none investigated whether a relationship between clinical and self-reported outcomes existed or whether clinical and self-reported were associated with donor specific factors. Existing research on clinical and self-reported outcomes in live kidney donation varies greatly in design: retrospective, prospective, or matched control group studies are seen. Furthermore, in the existing research time-spans vary greatly (from less than 5 years to nearly 50-years post-donation) and sample sizes vary tremendously (from less than 100 LKDs up to several thousand) (9, 10, 19, 21, 23, 25, 128, 129, 131, 132). Such variations not only make comparisons of the research findings seen in these studies difficult but can also lead to uncertainty in regard to what the actual long-term consequences of live kidney donation for LKDs are. Moreover, LKDs’ own perceptions and experiences of the donation process and its long-term consequences are not well understood. It is understood that qualitative research can supplement quantitative research, by providing in-depth understanding on experiences and perspectives that surveys cannot capture (133). Yet, as previously mentioned, the existing qualitative research on LKDs is fragmented and the methods of data collection, sampling and time-spans employed vary greatly (14, 15, 94, 120).

In sum, very few broad evaluation studies using mixed-methods design with the purpose of investigating LKDs’ long-term perceptions of live kidney donation exist. More research is therefore needed whereby more comprehensive knowledge of LKDs long-term health status and experiences are sought, which can enable the safe expansion of donor selection criteria, the assurance of LKDs’ qualified informed consent and the creation of clear guidelines for long-term follow-up.
4. Specific aims and research questions

In Paper 1, the aim was to investigate donors’ self-reported health outcomes and factors associated with donors’ long-term self-reported QoL and fatigue with particular reference to age groups in a nationwide cohort approximately ten years after donation.

The research questions were:

What are LKDs’ self-reported health outcomes 10 years post-donation?
Which donor specific factors are associated with QoL and fatigue?

In Paper 2, the aim was to provide insight into donors’ experiences approximately ten years after donation.

The research question was:

What characterizes LKDs’ experiences over the long-term post-donation?

In Paper 3, the aim was to investigate relationships between clinical, self-reported and donation specific outcomes in a nationwide cohort approximately ten years after donation.

The research questions were:

What are the links between clinical and self-reported outcomes and donation-specific factors ten years post-donation?
5. Methods

A mixed-methods design was chosen for the research presented here, because different methodological approaches provide new knowledge and therefore supplement the perspectives seen in the existing body of research. In sub-chapter 5.1, I present an overview of the overall mixed-methods research design and then the different methodological approaches used in the three separate studies included in the research. In 5.2, I present the study population for the overall research and the inclusion criteria, recruitment and sampling strategy for the three studies. In 5.3, I present the various data collection methods used in the three studies, in 5.4 ethical considerations for the overall research project and in 5.5. analysis used in the three studies.

5.1 Mixed methods design

As their use in research has increased, so has the variety of mixed-methods designs being developed and used (134-137). For the purposes of this research, a partially mixed sequential equal status design was chosen (135, 136), illustrated in Figure 5. The research design can be deemed sequential in that the results from the cross-sectional survey guided the selection of participants for the qualitative study and inspired the development of the interview guide used in the qualitative study. The design is partially mixed in that while each study had equal status they were nonetheless published in different journals. The sequential design allowed for the three studies to complement and strengthen each other. Quantitative and qualitative methods were employed to comprehensively and thoroughly investigate LKDs’ own perspectives. The main reason for using a combination of methodological approaches was that it allowed the profiling of the complexity of the donors’ situations. The quantitative research, comprised of a cross-sectional survey, was conducted first (Study 1). After an analysis of the survey results, the self-reported health outcomes were explored in a qualitative study, which was comprised of in-depth interviews (Study 2). The quantitative data were collected before the qualitative data so that the latter could provide new information and deeper understanding of donors’ self-reported outcomes. Concurrently, a prospective study was conducted to investigate the relationship between clinical, self-reported and donor specific outcomes (Study 3). As the three studies had equal status, data from each study were analyzed separately. The results from the cross-sectional survey were essential to the interpretation of the results in the qualitative and prospective studies.
Figure 5: The diagram illustrates the three studies included in the mixed-methods design and how they are connected.

5.1.1 Cross-sectional survey (Study 1)
A cross-sectional survey was conducted to investigate the association between self-reported health outcomes (QoL and fatigue) and donor specific factors ten years after donation (138). The donors’ perspectives included measurement of QoL, fatigue and donor specific factors that comprised the donors’ perceptions, experiences and expectations of the donation and transplantation outcome. All donors who donated a kidney at OUS during 2001-2004 and who resided in Norway and could speak, read and write Norwegian were eligible to participate in the study (N=351). An invitation letter including information about the project was sent by mail. Those who accepted the invitation to participate in the study received the questionnaire by mail.

5.1.2 Qualitative study (Study 2)
Explorative in-depth interviews were performed to provide insight into the donors’ subjective meaning and interpretation of their experiences in a long-term perspective (136, 139). In this study, qualitative research provided in-depth understanding of experiences and first-person perspectives that the survey could not encompass (133, 140, 141).
The in-depth interviews were conducted between spring 2014 and spring 2015. Donors who participated in the cross-sectional survey were eligible for participation in this study.

5.1.3 Prospective follow-up study (Study 3)
A prospective follow-up study was performed to study potential relevant clinical outcomes, and investigate their relationship with self-reported outcomes and donor specific factors at ten years post-donation. This study included pre-donation baseline data and ten-year’s follow-up data (138) and provided information about clinical outcomes from a long-term perspective. Donors who participated in the cross-sectional survey and had attended a post-donation follow-up consultation more than five years after donation were eligible for participation in this study.

5.2 Study population

5.2.1 Inclusion criteria and recruitment
A total number of 365 LKDs donated a kidney at OUS during the period 2001-2004. Kidney donors residing in Norway who could speak, read and write Norwegian were eligible to participate (N=351). Of these 5 were excluded because there was no contact information available for them. At an expected standard deviation (SD) of 15, a sample size of 200 LKDs would give 80% power if a 5 unit difference was seen (142). As Mjøen et al (116) had a dropout rate of 24%, a comparable dropout rate here was expected. Inclusion of the total number of eligible and contactable LKDs (N=346) was expected to reveal even small differences.

An invitation letter including information about the project was sent by mail to the remaining 346 LKDs. In order to be as close to ten years post-donation as possible, donors meeting the inclusion criteria were invited by mail to participate in the study between November 2012 and May 2013. At this point another 2 were excluded because they were not able to answer questionnaires due to old age and dementia.

One reminder was sent to the 123 LKDs who did not respond to the invitation letter. All in all, 262 donors consented to participate by returning the consent form included in the invitation letter. The donors who consented to participate and accepted the invitation received the questionnaire booklet by mail; of these 217 completed and returned the questionnaire, forming the actual participant group for the study.
Clinical data were available for 202 LKDs and these donors were included in the prospective study. A purposeful sample of 16 donors was included in the qualitative study. Figure 6 show the flow diagram of the inclusion.

Figure 6: Inclusion process flow diagram.
Purposeful sampling

A purposeful sample of LKDs was invited to participate in the qualitative study. For selecting donors to participate in the in-depth interviews, maximum variation sampling was conducted from the larger sample based on self-reported health outcomes, relationship to recipient, age and gender. A purposeful sample strategy was chosen to include information-rich participants, providing both insight and depth. In addition, the maximum variation sampling strategy provided an opportunity to compile central themes across various experiences (139).

5.3 Data collection

5.3.1 Study 1

Demographics

The participants’ demographic variables included age, gender, marital status, educational level, vocational status and relationship to the recipient.

Self-reported outcomes

Quality of life

QoL was measured in Study 1 using the second version of the generic 36-item Short Form (SF-36v2®) constructed by Ware (143). There are several reasons why SF-36 v2 was used here; i) the instrument has previously been used in live organ donor studies (16, 17, 19, 21), ii) the SF-36v2 has been translated into Norwegian and widely tested in a Norwegian context (144), iii) it evaluates both a physical (PCS) and mental (MCS) component score in addition to its eight different domains: physical functioning, role physical, vitality, mental health, role emotional, social functioning, general health, and bodily pain. Consequently, it yields detailed data of the different dimensions of QoL.

Each of the instrument’s eight subscales has a theoretical range of 0-100, and lower scores indicate reduced QoL. Each domain has a theoretical range of 0-100. The component scores PCS and MCS are transformed to have a mean value of 50 and a standard deviation of 10.

Fatigue

The multidimensional fatigue inventory (MFI) instrument developed by Smets (87) was chosen to measure fatigue in Study 1 because; i) the instrument has been previously used to measure fatigue in
several studies on LKDs (18, 21, 92), ii) it has been translated into Norwegian and validated in a Norwegian context (145), iii) it is multidimensional and compatible with Aaronson’s definition of fatigue (86). The MFI includes the five domains general fatigue, physical fatigue, reduced activity, reduced motivation and mental fatigue. Thus, it yields detailed data of the different dimensions of both physical and mental fatigue. Each of the instrument’s five subscales has a theoretical range of 4-20. Higher scores indicate more fatigue.

Donor specific questions
In order to better understand what it means to be a kidney donor and what is important from a long-term perspective, donor specific factors were measured. The participants responded to donor specific questions measuring psychosocial and clinical factors, such as regret donation (yes/no/do not know), recipient outcome (from much better than expected to much worse than expected), economic problems (from to a great extent to not at all), regular follow-up (from annually to never), recognition for being a donor from family and/or friends, and recognition for being a donor from health professionals (from to a great extent to not at all), use of analgesics or tranquilizers/hypnotics (from daily to never) and satisfaction with life pre- and post-donation (from very satisfied to very dissatisfied) (16).

Open-ended questions
In the last part of the questionnaire, participants were given the opportunity to respond to four open-ended questions. These were: 1) How has your life been affected by the donation? 2) Why in hindsight would you choose not to donate? 3) What has been important for your experience of health and QoL as it relates to being a kidney donor? 4) What would your recommendations be for potential donors?

Through the open-ended questions, the participants could give an account of what was important to them and what they considered relevant to their HRQL (146).

**Invitation to participate**
An invitation letter including information about the purpose of Study 1 and ensuring confidentiality was sent to the eligible donors. To be as close as possible to 10 years follow-up for all participants, LKDs who donated in 2001 and 2002 received an invitation in November 2012 and donors who donated in 2003 and 2004 received an invitation in May 2013. A total of 262 donors returned the
consent form and agreed to participate in the survey. Of these, 217 donors who returned the questionnaire were included in the study.

5.3.2 Study 2

Interview guide

Prior to the in-depth interviews, a semi-structured interview guide (Table 1) was prepared to ensure that relevant themes were discussed (136, 139). The themes used here were based on clinical experiences, previous research and donors’ responses to the open-ended questions in the cross-sectional survey (Study 1). The themes included the importance of donation with regard to possible changes in the donor’s life, donor’s relationship with the recipient, donor’s contact with the health care system post-donation, the recipient outcome, and the donor’s expectations of the donation.

Table 1: Semi-structured interview guide.

<table>
<thead>
<tr>
<th>Themes</th>
<th>Open-ended questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Present situation</td>
<td>How is your life today?</td>
</tr>
<tr>
<td>The effect of donation</td>
<td>In what way do you think the donation has influenced your life?</td>
</tr>
<tr>
<td></td>
<td>What kind of significance has the donation on your relationship with the recipient?</td>
</tr>
<tr>
<td></td>
<td>Can you describe reactions from family and friends on your decision to be a donor?</td>
</tr>
<tr>
<td>Expectations and outcomes</td>
<td>What kind of expectations did you have before the donation?</td>
</tr>
<tr>
<td>Follow-up</td>
<td>What is the recipient’s situation today?</td>
</tr>
<tr>
<td></td>
<td>How would you describe the follow-up after donation?</td>
</tr>
<tr>
<td>Contentment</td>
<td>All in all, are you content with being a donor?</td>
</tr>
<tr>
<td></td>
<td>Do you have any advice for future donors?</td>
</tr>
</tbody>
</table>
In-depth interviews
During the interviews, the participants’ long-term experiences were emphasized. Open-ended questions elicited narratives in the donor’s own words. The question “could you describe how your life is today” opened the interview. Other questions included, “could you describe in what way the donation has had an impact on your life” and “what significance has the donation had on your relationship to the recipient”. Probing was used to further explore the donors’ meanings (139). The interviews were performed by the candidate and the main supervisor. Both have clinical experience with LKDs, but neither had an existing health care relationship with any of the participants. The interviews were conducted in the period between spring 2014 and spring 2015.

Invitation to participate
An invitation letter was sent to 22 eligible donors, and 16 donors accepted to participate. The reason why some donors chose not to accept the invitation is unknown. The demographics and characteristics for the six non-participating donors did not differ from the participating donors. Those who returned the consent form included in the invitation were contacted by telephone so that an interview could be arranged and a suitable place and time agreed upon.

5.3.3 Study 3
Demographics
Demographic characteristics included donors’ age, gender, relationship to recipient and follow-up time since donation.

Clinical outcomes
Clinical parameters such as body mass index (BMI), BP, parathyroid hormone (PTH), hemoglobin and creatinine may be of importance in the long-term after donation. The clinical parameters included in this study were weight, systolic and diastolic BP, use of antihypertensive drugs and statins, and smoking status. Blood tests included hemoglobin, plasma creatinine and parathyroid hormone (PTH). Estimated glomeruli filtration rate (eGFR) was calculated according to CKD-EPI equations. Urinary albumin/creatinine ratio was also measured. Changes in creatinine and BMI were estimated by comparing follow-up measures with baseline measures. PTH levels in the donors was assessed at ten years and compared to reference values for the normal background population. Hypertension was defined as BP >140/90 or use of antihypertensive drugs.
Self-reported outcomes

QoL were assessed by the two component score PCS and MCS that evaluate physical and mental health, respectively, as measured by the generic instrument SF-36v2® (143, 147). Fatigue was assessed using the five domains of fatigue as measured by MFI (87).

Donation specific factors

Donation specific factors were assessed using five of the donor specific questions (Study 1). Recognition for being a donor from family members and/or friends and recognition for being a donor from health professionals: range 1-5 (to a great extent - not at all). Expected recipient’s health outcome (worse than expected=1; as expected or better than expected=0). Donor’s assessment of donation’s effect on own health: range 1-5 (to a great extent to not at all). Would donor in hindsight donate again (yes/no/unsure).

The baseline data were available in the Scandiatransplant Living Donor Registry database. The clinical variables were collected by local nephrologists, who performed the medical follow-up 10 years after donation. Donors’ self-reported outcomes and donation specific factors were collected in the cross-sectional survey 2012-2013.

5.4 Ethical considerations in this research

The Declaration of Helsinki (DOH) Ethical Principles for Medical Research Involving Human Subjects (148) and the Norwegian laws on health research (149), health register (150) and data protection (151) were followed throughout this research project. Such considerations are important and intended to not only protect participants but also ensure that no harm comes to any human beings involved in the research. Before the start of the research an application along with the research protocol was sent to the Regional Medical Research Committee for the South-East Norway Regional Health Authority. The studies were approved both by the committee (2011/2595 D) and OUS’s data protection officer.

Throughout the entire research project, all collected data were coded and de-identified to protect the participants. The code book was stored in a locked storage unit to which only the head researcher had the key. The de-identified data were stored on the hospital’s secure server for research to maintain data security (148, 150, 151).
To ensure that all participants received and understood the information provided them about their participation in the project, the eligible candidates received written information about the studies in the invitation letter sent by mail. Additional information was given by phone as needed. The invitation letter included information about the possibility to withdraw from the research project at any time. The candidates were also ensured confidentiality and anonymity. To secure voluntarily participation, only one reminder was sent to those eligible for inclusion in the research project who did not respond to the first invitation. The questionnaire booklet was sent to those candidates who returned a signed consent form. To avoid distress, no reminder was sent to those who did not return the questionnaires; they were thereafter considered non-responders.

Those donors eligible for participation in Study 2 received information about that qualitative study in a separate letter inviting them to participate in interviews. As a precaution against distress, in Study 2, no reminder was sent to those who did not return a signed consent form. The information about the study was repeated before the start of the interview and participants were informed that they could terminate the interview at any time.

A combined questionnaire- and interview-based approach was considered necessary in that donors who have had adverse experiences may find it easier to respond to a questionnaire than being interviewed. Adverse experiences can awaken a sense of vulnerability, especially if the donation experience did not go as anticipated.

In order to maintain anonymity and confidentiality, the overall research results are presented so that no participants can be recognized. In that those participating in the qualitative study were especially vulnerable to identification, as the number of participants was limited, special care was taken to protect their identities. There was limited description of donor characteristics in Study 2, to ensure anonymity and confidentiality in the presentation of the results.

5.5 Analysis

In this chapter I describe the statistical analyses performed in Studies 1 and 3 and the interpretative analysis conducted in Study 2.

5.5.1 Statistical analysis (Studies 1 and 3)

All statistical analyses in Study 1 and Study 3 were performed using the Statistical Package for the Social Sciences, version 21 (SPSS Inc. Chicago, IL, USA). Testing for appropriate link function and
family for generalized linear regression was done with linktest in STATA 13.1 (StataCorp, College Station, Texas, USA). A two-tailed p-value less than 0.05 was regarded as statistically significant.

Data on demographics, the self-reported outcome scales, donor specific questions and clinical data were explored with descriptive analysis. The data were presented with frequencies, measures of centrality and variance.

**Statistical analysis of difference**

Due to skewed data distribution on both SF-36 and MFI, the nonparametric independent samples Wilcoxon Mann-Whitney U-test was performed to test for differences between donor groups. Nonparametric tests provide the opportunity to test for differences when data has a skewed distribution because such tests are not rigorous about distribution (142). Hence, the Wilcoxon Mann-Whitney U-test was used to examine potential gender or age differences in QoL and fatigue in Study 1. The same procedure was performed to investigate differences in donation specific factors between donors with eGFR <or > 60 ml/min/1.73m2 and donors with or without hypertension in Study 3.

In Study 1, analysis of variance (ANOVA) was used to examine the relationship between donors’ expectations and feelings of responsibility. When a variable outcome has more than two categories, ANOVA enables the examination of how much of the variation in outcome is caused by differences between or within groups (142). In Study 1, the two variables “feeling responsible for the recipient’s health” and “expectations for the recipient’s health” had five categories each.

**Statistical analysis of association**

In Study 1, a generalized linear model with gamma family and log link as default was used to examine factors that may be associated with QoL and fatigue. For regressions where the default gamma family and log link was not appropriate, Poisson with log link or gamma with identity link was used. The generalized linear model with Poisson family was used to investigate potential associations between donor specific factors and overall satisfaction with life 10 years after donation. Generalized linear models are regression models that through transformation of the outcome variable allow for a series of outcome distributions (142).

In Study 3, linear regression analysis was conducted to investigate potential associations between clinical and self-reported outcomes. A logarithmic transformation on the domains general fatigue, physical fatigue and reduced activity was performed to compensate for skewness in three of five domains of fatigue (142).
**Missing data**

Missing data on SF-36 were managed in accordance with the instructions given in the SF-36v2® manual (147). Missing data on fatigue and donor specific questions were treated as missing.

5.5.2 **Interpretative analysis (Study 2)**

The interviews were transcribed verbatim. The text was analyzed through a hermeneutical approach using Kvale and Brinkmann’s three analysis contexts of qualitative data (140). In the analysis, focus lay on the condensation and interpretation of meaning. The study’s hermeneutical approach provided an opportunity to understand live donation in the context of donors’ lives from a long-term perspective (139, 152). Examples from the analysis are shown in Table 2.

The transcripts and reflection notes from each interview were read several times to provide an overall impression of the participants’ long-term experiences. The initial context of the analysis comprised a rephrased condensation of each participant’s own views. In the following context, the elucidated meanings were interpreted by continuously comparing the data and the researchers’ perspectives. The meanings were thereafter merged into broader categories. First, the categories were discussed by the researcher in charge of the interpretation and two of the study supervisors. Second, in an effort to make the interpretations clear, credible, transferable and confirmable all co-authors discussed and agreed on the formation of categories. This was done to make the study as trustworthy as possible. The findings were furthermore illustrated with quotations from the interviews to show how the participants’ experiences were interpreted. Finally, the categories were investigated from a theoretical perspective in order to position the results in a broader context, i.e., previous research and theoretical framework (140).
Table 2: Examples from the analysis.

<table>
<thead>
<tr>
<th>Natural meaning unit, statements</th>
<th>Sub themes</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>It was not intentionally, I understand that, but my stomach is damaged for life. I had a much better life before this, but my sister is fine, the kidney works well. I think I had given her the kidney again</td>
<td>Experiencing that the recipient had a good life compensated the donor’s own adverse experiences</td>
<td>The recipient outcome justified long-term experiences</td>
</tr>
<tr>
<td>She considers I have given a huge gift, I would say. Thus I believe she felt I was intimate and yes, we have had good relations. I have felt she was very grateful. Even if the kidney doesn’t work anymore, you may say it was many years she had a better life, by receiving a kidney.</td>
<td>The donation triggers gratefulness from the recipient and his/her family</td>
<td></td>
</tr>
</tbody>
</table>
6. Results

In this chapter, I present the results of the three studies included in this research. In sub-chapter 6.1 the donor characteristics are described while in 6.2-6.4 the results from the three studies are presented, study by study.

6.1 Donor characteristics

Overall, the mean age of LKDs at follow-up was 59.5 years (range 31-91) in Study 1 and 60.6 (range 34 – 89) in Study 3. The percentage of older donors, defined as 70 years of age or older at follow-up time, was 16%. The majority (63%) were females, and the most common relationship to the recipient was sibling (33%) followed by parent (25%). As shown in Table 3, there are small variations in participants’ relationship to recipient, age and gender when the participant groups included in Study 1 and Study 3 are compared. In both studies, parents were more represented in the older LKD group and more older donors were widowed or retired compared to younger donors. Median follow-up time was 10 years (range 8.5-12 years) in Study 1 and 11 years (range 6-15 years) in Study 3.

Table 3: Donor demographics and relation to recipient for study 1 and 3.

<table>
<thead>
<tr>
<th></th>
<th>Study 1</th>
<th>Study 3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%) Mean (SD)</td>
<td>N (%) Mean (SD)</td>
</tr>
<tr>
<td><strong>All donors</strong></td>
<td>217 (100%)</td>
<td>202 (93%)</td>
</tr>
<tr>
<td><strong>Age at follow-up</strong></td>
<td>59.5 (10.6)</td>
<td>60.6 (10.6)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>138 (63.6%)</td>
<td>127 (62.9%)</td>
</tr>
<tr>
<td>Male</td>
<td>79 (36.4%)</td>
<td>75 (37.1%)</td>
</tr>
<tr>
<td><strong>Age groups</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;70 years</td>
<td>183 (84.3%)</td>
<td>170 (84.2%)</td>
</tr>
<tr>
<td>&gt;70 years</td>
<td>34 (15.7%)</td>
<td>32 (15.8%)</td>
</tr>
<tr>
<td><strong>Donor’s relation to recipient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>73 (33.6%)</td>
<td>67 (33.2%)</td>
</tr>
<tr>
<td>Parents</td>
<td>53 (24.4%)</td>
<td>52 (25.7%)</td>
</tr>
<tr>
<td>Spouse</td>
<td>37 (17.1%)</td>
<td>36 (17.8%)</td>
</tr>
<tr>
<td>Offspring</td>
<td>23 (10.6%)</td>
<td>21 (10.4%)</td>
</tr>
<tr>
<td>Other</td>
<td>31 (14.3%)</td>
<td>26 (12.9%)</td>
</tr>
</tbody>
</table>
Sixteen donors participated in Study 2 and were interviewed between 10 and 14 years after donation. The youngest participant was 42 years of age at the time of the interview and the oldest was 66. As in Study 1 and Study 3, there were more women (n=10) than men (n=6) participating in the study. All four health regions in Norway were represented.

6.2 Long-term self-reported health outcomes (Study 1)

The aim in Study 1 was to describe LKDs’ self-reported health outcomes and investigate associations between self-reported health outcomes and donor specific factors. Participants scored high on QoL with mean scores between 63.9 and 91.4 for the eight subscales, with highest for role emotional and lowest for vitality. The mean scores on the five subscales of fatigue were low and varied between 7.3 and 8.8: lowest on reduced motivation and highest on general fatigue. A gender difference was seen in self-reported health outcomes; female donors scored lower than male donors on two of eight domains in QoL and higher on four of five domains in fatigue. There was no difference between donors older or younger than 70 of age years at follow-up.

Few donors perceived that donation had negatively influenced their health, vocational status or economic situation. In retrospect, nearly all LKDs (94%) stated that they would donate again if possible. Among those who would not donate again were donors who indicated that their own health had been harmed, they had an impaired relationship with the recipient, or that they had experienced recipient graft failure or death occurred. Those who indicated that they would not donate again scored higher on fatigue than the participant mean. Higher scores on fatigue were also significantly associated with recipient death. The majority perceived that the recipient’s health was better than expected and more than half felt responsible for the recipient’s health. There was a positive association between feeling responsible for the recipient and perception of recipient’s health; donors who perceived that the recipient’s health was much better than expected felt more responsible for the recipient than those who perceived that the recipient’s health was worse than expected. The feeling of responsibility for the recipient’s health was not associated with donors’ self-reported health outcomes. Recognition for being a donor from family and/or friends was significantly associated with higher scores on four of eight domains in QoL but no association was seen with fatigue. Overall satisfaction with life ten years after donation was positively associated with recognition for being a donor from health professionals.
6.3 Long-term experiences of live kidney donors (Study 2)

The aim in Study 2 was to provide insight into donors’ experiences over the long-term after donation. The donors’ experiences were categorized into four main themes.

1) The recipient outcome justified long-term experiences; recipients’ improved health and positive impact on recipients’ family was an important aspect. Even if the benefits from the transplantation were not as anticipated, donors were still confident about their decision. Their delight in seeing recipients to live an active and normal life compensated for their own adverse experiences. The donation gave a feeling of pride and privilege over being able to help. Even if no participants in this study claimed to feel responsible for recipients’ current health, an underlying anxiety was expressed regarding recipient well-being and survival of the graft. After donation, donors elected to forget adversities, such as losing contact with the recipient, tension within the family or reduced health, and instead focused on positive experiences.

2) Family dynamics – tension still under the surface; while donation was an obvious choice for some, implicit or explicit pressure could cause prolonged tension within families. Implicit pressure was related to the donor taking responsibility for the whole family. Explicit pressure was related to the donation becoming a difficult process and continuing to affect interpersonal and interfamilial relationships. Donors stated that any duplicity or sense of betrayal arising during the donation process could cause a permanent breach in familial relationships.

3) Ambivalence – healthy versus the need for regular follow-up; long-term follow-up safeguarded donors’ need to monitor their own health and be valued for their “good deed”. Inconsistent statements from health professionals caused donors uncertainty about the importance of follow-up, while regular follow-up provided them a sense of being taken care of and valued. Despite assurances about the safety of donation, an underlying insecurity about own health was seen. Actual follow-up practices differed. A comprehensive follow-up where donors could discuss own health or recipient’s health worries was valued.

4) Life must go on; in the long-term the significance of the donation faded and life went on. To move forward in life, donors refrained from focusing on any donation-related changes or negative aspects post-donation. Even though an attachment still existed between donors and recipients, in the long-term they did not see each other as often as they had in the beginning. Some donors appreciated when recipients “honored” their donation annually, while others maintained that the donation was in the past and should no longer be paid attention.
6.4 Relationships between clinical, self-reported and donor specific outcomes (Study 3)

The aim in Study 3 was to investigate associations between clinical, self-reported and donation specific factors. The results in this study show that donors were generally in good health ten years after donation and that few perceived the donation as being harmful to own health. Measurements of the participants’ clinical outcomes were mostly within the normal range (Table 4). The majority of donors were normotensive with mean systolic BP 129.2 mmHg (SD=14.7) and diastolic BP 78.5 mmHg (SD=7.8). One third had hypertension (n=67) and 52 used statins. Mean eGFR was 68.1 ml/min/1.73m² (SD=14.0) and 54 had low eGFR (<60 ml/min/1.73m²). Those with hypertension and low eGFR had higher mean age than the average, 63.7 years (SD 10.5) and 67.1 years (SD=10.2), respectively.

Table 4: Kidney donors; characteristics by clinical data at follow-up (N=202)

<table>
<thead>
<tr>
<th>n</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systolic BP (mmHg)</td>
<td>185 129.2 (14.7)</td>
</tr>
<tr>
<td>Diastolic BP (mmHg)</td>
<td>185 78.5 (7.8)</td>
</tr>
<tr>
<td>BMI</td>
<td>163 26.5 (3.7)</td>
</tr>
<tr>
<td>Creatinine (µmol/L)</td>
<td>202 91.6 (18.4)</td>
</tr>
<tr>
<td>eGFR (ml/min/1.73m²)</td>
<td>201 68.1 (14.0)</td>
</tr>
<tr>
<td>Hemoglobin (g/dl)</td>
<td>197 14.3 (1.1)</td>
</tr>
<tr>
<td>PTH (pmol/l)</td>
<td>98 7.1 (4.2)</td>
</tr>
<tr>
<td>Cholesterol (mmol/L)</td>
<td>195 5.4 (1.0)</td>
</tr>
<tr>
<td>Triglycerides (mmol/L)</td>
<td>159 1.4 (0.7)</td>
</tr>
<tr>
<td>HDL (mmol/L)</td>
<td>181 1.6 (0.5)</td>
</tr>
<tr>
<td>LDL (mmol/L)</td>
<td>148 3.4 (0.9)</td>
</tr>
</tbody>
</table>

The donors mainly scored high on PCS (mean=53.52, SD=8.74) and MCS (mean=53.32, SD=8.64) and low on all the domains of fatigue, mean scores between 7.3 and 8.8. No significant association was seen between clinical variables and the physical and mental components of QoL. In fatigue, there was a significant association between BMI and the domain reduced activity, and between the domain general fatigue and gender. The majority (87%) of donors experienced recognition for being
a donor from family and/or friends, and approximately two-thirds to a great or some extent experienced recognition for being a donor from health professionals. A significantly higher share of hypertensive donors experienced recognition for being a donor from health professionals than normotensive donors. While nearly all would be a donor again if possible, hypertensive donors were more reluctant to donate retrospectively. The recipients’ health was perceived as better than expected or as expected by the majority (70.8%) of donors.
7. Discussion

The increased need for organs as treatment for patients with life-threatening organ failure combined with limited access to deceased organs for transplantation has resulted in the expanded use of live organ donors. While to a certain extent restrictive attitudes toward live liver or lung transplantation are seen, attitudes have not been so restrictive in regard to live kidney donation. Awareness is needed of the current situation that is both extensive use and the decrease in LKDs. A variety of studies have been performed to investigate outcomes after live kidney donation. However, the parameters of these have varied and there is a lack of comprehensive knowledge about health status and experiences after live kidney donation in the long-term.

In this chapter, I discuss the main findings of the three studies included in my research and position the findings into the existing knowledge base within this area of research. Next, I present the methodological considerations, implications for clinical practice and scientific contribution. Finally, I discuss possible areas for future research.

7.1 Discussion of main findings

Due to its design, the research presented in this thesis adds new knowledge of LKDs to the existing body of knowledge. Used to investigate different aspects of live kidney donation, the three studies were complementary in design and had equal status. The design provided an opportunity not only to integrate donors’ perspectives and clinical data but also allowed “the donor’s voice” to be heard, yielding profound knowledge about LKDs’ experiences. Such extended knowledge can be used in evaluating and developing the information and knowledge LKDs need during the donor decision-making process and in adapting post-donation follow-up care (6, 61, 153-155).

A condensation of the three studies included in this research, shows that the LKDs were generally in good health. This is similar to the results seen in other long-term follow-up studies (10, 19, 20, 99, 156). Still, because this research employed broad ten-year follow-up and robust methods, it contributes new and important knowledge to the existing body of knowledge. Furthermore, nuances were revealed through the use of a mixed-methods design.

For example, donation has previously been considered harmless in relation to donors’ health, yet here the presence of underlying insecurity of own health was revealed. Regular medical follow-ups were seen to compensate for this insecurity: safeguarding donors’ need to monitor own health and be valued by health professionals and society for their donation. Other findings revealed in this research
include that fatigue was more pronounced in female donors than male donors and in donors who regretted donation, yet fatigue was not associated with recognition for being a donor from family and/or friends. Recognition for being a donor, however, was significantly associated with better self-reported QoL, confirmed by the study participants during interviews. Furthermore, recognition for being a donor from health professionals appeared to be a factor associated with hypertension in donors when relationships between clinical and self-reported outcomes were investigated.

Recipient health was seen as a factor in the self-reported outcomes and interviews. For donors, the possibility to improve the recipient’s health emerged as a strong motivation to donate and recipient outcome justified long-term experiences. This again might be related to the association between donors’ underlying anxiety regarding the recipient’s well-being and the recipient’s improved health found here.

These novel findings present deeper and broader knowledge about kidney donors in the long-term. Still, as the studies took place approximately ten years after donation the actual contributing factors may be difficult to determine. The donors’ ages, life situations or personal characteristics, the outcome of the donation or all of these altogether may be factors that affect donors’ health status and experiences.

Other researchers have demonstrated that QoL, satisfaction with life and expectations may vary throughout life (157-160). In a longitudinal study by Hopman et al (159), QoL improved over time in younger age groups, especially in the mentally orientated domains. In their study, Hopman et al followed a Canadian cohort over five years. They found that the female group showed an increase in mean change in the domains role emotional and mental health all the way up until 75 years of age: in the male group a decrease started at 65 years of age (159). Most of the donors in this research scored higher than the general Norwegian population on QoL (144), which is similar to results seen in other, previous studies (17, 19, 21, 116). The majority of the donors here were middle-aged, which may explain the excellent self-reported outcomes. There is limited evidence on the course of self-reported outcomes in the long-term after kidney donation. Most long-term follow-up studies have a cross-sectional design. Few studies have both followed LKDs for longer than a five-year period and investigated self-reported outcomes. In a prospective study by Janki et al, a decrease in QoL and an increase in fatigue ten years post-donation were seen, even though the donors in their study scored better than the general Dutch population (21). Janki et al argue that the decrease in self-reported outcomes among donors might be an effect of aging; their donor cohort mean age was 59. Yet in another study, Hopman et al (159) found that this age group should still be showing an increase in
QoL, not a decrease. The design of this research project did not allow for a prospective investigation on self-reported outcomes, so whether the course of self-reported outcomes in the donor cohort was increasing, decreasing or stable cannot be determined. More research is therefore needed in which collecting longitudinal data is investigated.

In this research, a gender difference was seen both in QoL and fatigue which cannot be easily explained. However, such results are comparable to the results shown by da Rocha et al (161), who found a gender difference in QoL and depressive symptoms in adults with a chronic health condition and therefore suggest that depression is more related to QoL than being ill. Still, there is a lack of evidence supporting gender differences in fatigue after donation. None of the short-term studies found during this research project investigated gender differences, with the exception of one. In a retrospective study, Sommerer found that a gender difference in fatigue and QoL was present with a median follow-up time of 77 months (117). Results from research on fatigue in the general population show inconsistencies in relation to gender differences (162-164), and as a consequence it is difficult to understand the pronounced fatigue in female donors seen here. One explanation for fatigue among female LKDs may be an imbalance in life roles (role responsibilities, multiple roles or interpersonal relationships), which have been described as aspects of fatigue in studies among healthy working adults and may be related to females more than males (165, 166).

In several studies, researchers have found that LKDs can be surprised by unexpected health consequences post-donation such as protracted pain or physical or emotional discomfort and that physical and emotional discomfort could last longer than expected (15, 109, 123). Donors may find it difficult to live up to own expectations about recovery and maintain their role as “healthy”. Expectations, such as being able to resume their “normal life” within a few weeks may not be possible due to pain or fatigue: when such expectations are not met donors’ awareness of e.g., reduced capacity may turn into persistent fatigue (86).

In their studies, Andersen et al (15, 120) explored the burden, dual role and expectations that donors can experience. Many donors experience their loved ones’ suffering for years and are aware that kidney donation may at some point in time be necessary. Such awareness can cause explicit or implicit pressure to donate. Even increased public awareness about organ donation can cause lead to pressure on potential donors. Worldwide, discussions are ongoing about the benefit of organ replacement and the limited access to organs (50, 167-170). In the media, organ donation is promoted both as a “gift for life” or even a “moral obligation”. When interpreted thus, such expectations can be perceived as pressure from family, recipients or health professionals or even
society at large and may contribute to a feeling of obligation or duty to help. In this research, the use of in-depth interviews revealed that some donors had felt an obligation or duty to donate. Such findings are supported in other studies (108, 120, 171-173). Beggley and Piggott (174) explored the relationship between moral distress and siblings among potential stem cell donors and found that sibling guilt about not donating or perceived lack of support from fellow siblings may create tension within a family. In this research, family negotiations could cause disturbance and/or tension, which could still be present approximately ten years after donation. Expectations, perceived pressure or familial tension may cause stress and donors can experience an “overload”, which may be manifested as fatigue (165). Even though such may be difficult to uncover, health professionals should nonetheless be aware of these factors so that donors can be fully supported.

In the research findings, a variation is seen in associations between fatigue and QoL over the long-term post-donation and different factors. In the cross-sectional study, recognition for being a donor from family and/or friends was significantly associated with several domains in QoL but not with fatigue. As both live and deceased donation are generally acknowledged as constituting a “good deed”, such associations is not surprising. Donors’ perception of appreciation and recognition for being a donor was found in this research to generate improved self-esteem and personal growth. Yet, again, improved self-esteem and personal growth may be associated with QoL and/or satisfaction with life. Findings in previous studies (31, 175, 176), which indicate that changed roles, improved self-esteem and personal growth are positive outcomes linked to donation, support this conclusion. Revealed in the in-depth interviews, donors’ sense of pride, as a result of perceived respect and gratitude, strengthen the demonstrated association between recognition for being a donor from family and/or friends and QoL. Moreover, Rudow et al (177) found a correlation between extroversion and post-donation growth and therefore advocate that social support may be important in positive coping and growth after donation.

Another donor specific factor that showed variation in association within self-reported outcomes was recipient status. In this research, recipient death but not recipient graft failure influenced donors’ self-reported outcomes. This finding is in direct contrast to other findings in the existing body of knowledge. While in the existing body of knowledge there is a lack of supporting evidence on the relationship between fatigue and recipient health status, the absence of significant association with QoL is supported by some studies (17, 18, 93). Other studies have found that recipient graft failure or death could affect donors’ physical and mental health (15, 96, 123, 170). In this study, the results from the in-depth interviews strengthened the findings in the cross-sectional survey; even if the
result of donation was unanticipated, donors felt satisfied knowing they had taken action to improve the recipient’s health status. Moreover, recipient death was associated with fatigue ten years post-donation. Watson et al (96), however, suggest that any decreases linked to recipient death seen in the domains vitality and/or mental health could possibly improve over time. The increased fatigue experienced by the donors seen in this research may be a symptom of normal grief (178, 179), but it is nonetheless unclear whether the impact shown is linked to donation or the grief that follows recipient death. Grief can be seen as a continuum of normal to prolonged grief disorder (179). Still, Watson et al demonstrated that recipient graft failure had a persistent impact on donors’ QoL (96). Then again, the difference might be explained by the difference in follow-up time. Here data were collected approximately ten years post-donation while, for example, Watson et al (96) followed donors for an average of four years. A connection is seen between recipient graft failure and donors who sought help for psychological problems (97) in other long-term follow-up studies, even though the majority of donors do not experience an increase in depressive symptoms (19). The inconsistency seen in the findings on recipient graft failure in different studies may be due to the variability in follow-up times used. It would seem however, that graft failure does affect donors’ QoL but that its impact waxes and wanes over time. The diversity between fatigue and QoL revealed in this research supports the need for deeper and broader understanding of the factors associated with self-reported outcomes.

In the findings seen in this research, an underlying insecurity about own health was seen among donors, despite little reported concern about own health and overall good donor health outcomes. There is scant research or evidence available on donors’ understanding and/or knowledge of the long-term consequences of donation, and therefore little previous research at hand to help interpret the underlying insecurity seen in this research. In one quantitative study, researchers indicated that donors were less concerned about kidney damage than non-donors (180). Furthermore, research on pre-donation information has demonstrated a variety in the information provided (6, 181-183). Moreover, previous knowledge on long-term health outcomes indicates minimal long-term risks (9, 10, 17) and that kidney donors tend to live longer than general population (184). Also, donors’ QoL scores tend to be better than those of the general population. This might be used as an argument when recruiting live donors and promoting live donation. According to some of the donors participating in the in-depth interviews, the prospect of good health outcomes was highlighted in the pre-donation information.
Furthermore, several of the donors participating in the qualitative study expressed ambivalence toward the need for long-term follow-up. Such ambivalence was stemmed from the inconsistency with which pre- and post-donation information was given to them; on the one hand they were told healthy and on the other hand they were told that they needed long-term follow-up. Despite that long-term follow-up for LKDs is delineated in international and national guidelines (56-58), in this research the donors experienced that the health professionals they encountered held varying views on follow-up. The findings seen in here reveal that a lack of planning and inconsistency in post-donation follow-up exists. Subsequently, there is an oblivious need to support the development of evidence-based research on the long-term consequences of live kidney donation and the further investigation of the long-term benefits of donor follow-up plans.

In this research, adverse effects on donors’ health status and life were counterbalanced by recipients’ improved health and life, and the overwhelming majority of donors did not regret their decision to donate. Live donation has been described as a significant life event that requires negotiations of identity and role (31). In two recent studies (177, 185) where resilience in relation to live donation was investigated, researchers drew attention to resilient qualities that LKDs may demonstrate. The concept of resilience can be seen as a dynamic process that enables an individual to confront or recover from adversities (186, 187). Individual qualities such as sense of self-esteem and self-efficacy seem to be protective factors involved in resilience (187). An individual’s resilient qualities are the results of their experiences and may vary according to circumstances. Consequently, life events must be seen in relation to context and meaning, and an individual’s capacity to appreciate and process the experiences gained must be taken into consideration. In several studies, increased self-esteem and personal growth have been observed as being positive outcomes of live donation (176, 177, 188, 189). Additionally, attributes such as self-esteem, self-efficacy and personal growth have been understood to constitute motivating factors for donors (40, 172, 188, 190). When faced with adversity, an individual’s personal growth, knowledge, and self-understanding may be enabled through the use of different coping strategies.

Different coping strategies in turn may strengthen the resilient qualities and thereby reduce stress, while chronic stress may appear if an individual have no resilient qualities or growth (186, 191). In this research LKDs seem to use coping strategies that strengthen resilient qualities and reduce negative outcomes. Similar results have been demonstrated among patients with cardiac disease (192). In that study, the researchers recommended that psychosocial variables such as dispositional optimism should be assessed, because such variables may be linked to patients’ treatment.
satisfaction. None of the donors in this research perceived that they were (still) responsible for the recipient’s health ten years after donation. From a long-term perspective, donors understood that recipient outcomes were no longer their responsibility. Thus, by using a coping strategy or cognitive restructuring, donors may minimize own distress (170, 191, 193).

Richardson found that resilient qualities can be strengthened when individuals experience that it is possible to find meaning in and control the outcome of life events (186). One can extrapolate and say that donors who take a positive view of the donation process and choose to look forward may strengthen their resilient qualities. In Richardson’s metatheory on resilience, “resilient reintegration” can be seen as a return to “biopsychospiritual homeostasis”, a physical, mental and spiritual adaptation. Such reintegration can lead to growth, loss or dysfunction (186). The reciprocal action between the donation and donors’ resilient qualities determines disruption, and both negative and positive outcomes are possibilities for growth. Thus, the positive self-reported outcomes seen in this research may stem from donors’ perceiving that their adverse experiences were beyond their control or choosing to disregard these adverse experiences and instead focus on positive experiences. In this research, no relationship between self-reported outcomes and clinical variables or between hypertension and the perception of donation being harmful to own health was seen. Donors’ employment of coping strategies may explain such results (191, 194).

Uncertainty nevertheless remains in regard to what (if any) role resilience plays or coping strategies have in live kidney donation. Consequently, to further develop knowledge of the factors that may influence the donors’ long-term health status and experiences, more research on resilience, coping strategies and self-reported outcomes is needed.

### 7.2 Methodological considerations

One benefit of using a combination of methodological approaches is that one can address different research questions. By combining approaches, it is possible to gain a deeper and broader understanding of the phenomena under investigation (136, 195-198). In mixed-methods studies, the various components are connected while in multiple-method studies they are not. The use of a mixed-methods design, therefore, requires that researchers are rigorous when using and reporting their findings. Recommendations on how to perform and report mixed-methods studies (135, 137, 139, 196, 197) include reporting the connections between the methods, data collection, analysis and generalizability or transferability used in each study/component in the same way as in single
methods. The three studies included in this research were connected to each other by: 1) use of the SF-36 and MFI scores from the cross-sectional survey to select participants for the qualitative study through purposeful sampling and 2) use of the same sample in the cross-sectional survey and the prospective study (137).

The extensive use of LKD and expanded selection criteria required evidence-based information about long-term consequences after donation. Different factors might influence donors’ health status, when viewed from a long-term context versus a short-term context. Hence, there was a need for a more comprehensive understanding of long-term outcomes. In this research, a modified version of Wilson & Cleary’s conceptual model of patient outcomes was used to provide an overview of the different aspects of donors’ health status and how they might be linked, thus garnering better understanding of donors’ health status over the long-term (77-79). As understood from other studies, from a short-term perspective pain and regaining physical strength can be considered dominant aspects in self-reported outcomes. Over the long-term, however, psychosocial aspects such as social support or favorable recipient outcomes might be more important for QoL and fatigue and therefore, consequently, overall QoL. The modified model used in this research also guided the analysis used both in Study 1 and Study 3. The individual and environmental factors and continuum of outcomes delineated in the model revealed both dependent and independent variables in the different regression models. From the analysis in Study 2, the concept of resilience (186, 187) emerged as one possible interpretation of donors’ experiences and motivations. In their revised model of health outcomes (77), Valderas and Alonso included resilience in the category “other health related constructs”. They suggested that resilience might be an important aspect in overall health outcome. Therefore, one can surmise that if an instrument on resilience had been included in the questionnaire booklet in Study 1, knowledge of the factors associated with long-term self-reported outcomes after donation could have been expanded. If such had occurred, scores on resilience could have been one criterion in the purposeful sampling to expand the understanding about of resilient factors and organ donation. Then, scores on resilience could have been one criterion in the purposeful sampling to expand the understanding about of resilient factors and organ donation.

7.2.1 Criteria for evaluating inference, generalizability and transferability

Validity and reliability are criteria for evaluating the inference and generalizability of quantitative research. The validity of a study refers to the accuracy and foundation of the inferences made in a study, while the reliability refers to the degree of consistency a concept is measured when using an instrument (138, 142). The generic instruments SF-36v2 and MFI had previously been used in LKD
populations (16, 19, 21). Furthermore, they had been translated into Norwegian and validated in Norwegian study populations (144, 145). When selecting which instruments should be used to measure the concepts of self-reported outcomes QoL and fatigue in this research, one criterion was that the instruments had previously been used in donor populations. Another was that the instruments actually measured what they were meant to measure. The analysis methods used in Study 1 and Study 3 are recognized as being robust (142). In Study 3, clinical variables known to be associated with kidney function were used (10, 22, 24). Moreover, the results were positioned in the context of existing research.

A central question when evaluating qualitative research is whether the results are trustworthy and transferable, relevant also to a study’s credibility and confirmability (139). Small sample sizes and the absence of standardized instruments characterize qualitative research designs. In these the researcher is the instrument, and as such the researcher’s pre-understanding might influence both an interview and subsequent analysis (140, 199). To resolve such concerns in this research, the interviews in Study 2 were performed by two researchers with extensive clinical experience in live kidney donation. First, the results were discussed by the researcher in charge of the interpretation and two of the study supervisors and then by all the co-authors. Second, the results were positioned within the literature and existing research in the field to ensure credibility and confirmability.

### 7.2.2 Strengths and limitations

One of the strengths of this research was that three studies were used to address three different research questions, which allowed the investigation of different perspectives (134, 200, 201). Other strengths were the delineated time-span and that a nationwide cohort was used. Previous research on LKDs in which a long-term perspective is employed varies greatly in regard to sample size, design and/or follow-up time (9, 10, 18, 21, 97, 100, 132, 202). Consequently, the current body of knowledge is built upon somewhat contradictory results.

Yet another strength of the research presented here was the development of a semi-structured interview guide in Study 2. To make certain that relevant topics were included in the interview guide, an expert group consisting of four experienced nurses in the field of live organ donation was consulted. As such, the interview guide was developed from clinical experience, donors’ responses to the open-ended questions in the cross-sectional survey and existing knowledge from previous research. Use of an interview guide ensured the discussion of relevant themes and also allowed participants to give voice to their own stories (139, 199).
When investigating factors associated with self-reported health post-donation, a prospective study rather than a cross-sectional survey could have been used. Also, longitudinal data could have been used to determine which factors influence self-reported data and could also allow for the investigation of a possible response shift in self-reported health (203). Response shift is defined as changes in one’s self-evaluation of QoL, resulting from change in internal standards, values and/or conceptualization (204). Seeking a response shift might have given a broader understanding of the influencing factors and self-reported outcomes, specifically those factors associated with fatigue, which in turn could strengthen the evaluation of potential donors and delineation of follow-up guidelines.

In the hierarchy of research evidence, research that compares a study population with a control group is considered robust. The lack of such control groups in Study 1 and Study 3 could be considered a limitation. However, it is difficult to find an appropriate control group for donors: LKDs are a healthy selected group and therefore comparisons between LKDs and the general population might be biased (205). Another limitation might be the lack of power analysis for evaluating potential associations between clinical parameters and self-reported outcome measures (142).

To reach information-rich participants, maximum variation was sought in Study 2, and accordingly one criterion in the study’s purposeful sampling was scoring on self-reported outcomes. However, no donors younger than 30 years or older than 70 years of age at time of donation were included, which might reduce the variation in the sample. Additionally, an imbalance exists between the local nephrologist centers in the use of live kidney donation, which might explain the inclusion of more donors from certain health-regions than others. Moreover, the population covered by the South-East Norway Regional Health Authority is larger than in other regions. Even though fatigue was more pronounced in donors who had experienced recipient death, none of the donors participating in the qualitative interviews had experienced such: their recipients were still alive. This might also be a limitation in that donors’ experiences after recipient death were not explored in this research.

### 7.3 Implications for clinical practice

This research has contributed unique knowledge of live kidney donors’ self-reported outcomes and experiences to the existing body of knowledge. The use of patient-reported outcomes can improve the quality of healthcare (101, 206). Previous research projects have demonstrated that patient-reported outcomes can be used as web-based support for patients with chronic diseases such as cancer or juvenile rheumatoid arthritis (207-210). In this research, recognition for being a donor from family and/or friends was associated with improved QoL, while recognition for being a donor
from health professionals showed no association with self-reported outcomes. Furthermore, significantly more donors perceived a higher degree of recognition for being a donor from family and/or friends than from health professionals. Still, hypertensive donors perceived a significantly higher degree of recognition for being a donor from health professionals, which may indicate closer follow-up. It is possible that web-based support that includes measurement of self-reported outcomes could have an impact on LKDs’ outcomes over the long-term. Previous research has shown that donors may experience physical and/or psychological impairment as long as one year after donation. Such impairment could be diminished or even prevented if donors were given the opportunity to communicate with health professionals in between follow-ups. Also, health professionals should be made more aware of this issue, so that the importance of both physical and/or psychological issues after donation can be properly addressed. In the research here, some donors noted that a need existed for opportunities where donors could voice their concerns about own health and the recipient’s health. One solution to this could be the inclusion of self-reported outcomes in donor follow-up. If donors were given the opportunity to, for example, respond to a questionnaire prior to a follow-up consultation, this information could be used by health professionals to more fully examine the donor’s situation. This in turn would yield more comprehensive emotional support and care, and even more importantly, care that is related to each unique donor’s needs. The inclusion of self-reported outcomes, e.g., allowing “the donor’s voice” to be heard, could promote coping through an emotional approach, and seems to be more beneficial when transpiring in receptive environments (193). Furthermore, a recent study indicates that because adverse donor or recipient medical outcomes can constitute a risk factor for donors’ mental health, psychological support should be offered as needed (211). Health professionals should engage donors in active discussions about donors’ post-donation expectations. Such discussions may not only improve the overall quality of care being provided donors but can also alleviate any negative psychological outcomes post-donation, such as donors’ disappointment that expectations are not being met (188).

As seen in earlier research, kidney donors are healthy individuals prior to donation and for the most part their health status is also preserved after donation. This may result in professional healthcare not being allocated to them. In this research, some donors stated that if their clinical parameters such as BP or creatinine were considered normal, the actual consultation with a physician could be quite brief. For health professionals, time is often limited and organizational priorities may hinder the realization of quality patient-practitioner relationships. A structured and individualized consultation could be one measure whereby the quality of follow-up can be improved (200). In spite of the perception that donors remain healthy post-donation, a potential for negative outcomes and reduced
health status exists. Health professionals are responsible for not only preserving donors’ health status but also preventing adverse outcomes, whether physical or psychosocial. As seen in this research, medical follow-up could compensate for donors’ insecurity of own health. The establishment of regular follow-up for LKDs, in which not only BP or kidney function is measured but also psychosocial variables are explored, could provide donors with both a sense of security and acknowledgement. Such regular follow-up could also assist in identifying and monitoring donors who are at risk for regretting donation. Moreover, consistent and accurate information from health professionals on all levels is an important aspect in the care of live donors (189). The systematic education of health professionals should emphasize the importance of providing LKDs with information, acknowledgement and individual support both pre- and post-donation, because this might be beneficial in creating supportive care for donors. Moreover, the development of a diagnostic pathway for both donors and recipients that allows for an efficient and streamlined evaluation process could be used to increase the donor pool (212). Several of the local nephrology centers in Norway have outpatient clinics nurses who are specialized in kidney disease and care. Both pre-donation work-up and post-donation follow-up could be shared between these nurse specialists and the nephrologists. The realization of such shared responsibility could provide more holistic care.

The Norwegian organization for patients with kidney disease and transplanted patients (Landsforeningen for Nyrepasienter og Transplanterte, LNT) includes LKDs among its members. LNT is therefore uniquely placed to create peer-led support groups where fellow donors could provide one another with support and supplement to professional care. Furthermore, as peers, LKDs could be used to help inform and educate potential donors (103, 213, 214). An additional benefit of such a measure would be that this would allow LKDs to share their experiences and maintain a relationship with health professionals, which may provide or reinforce a sense of recognition for being a donor.

A more visible symbol of appreciation from health professionals and/or society could be the development of a pin or diploma to be given to donors. For example, prior to initial discharge from hospital following nephrectomy, the surgeon who performed the procedure could deliver the pin and signed diploma to the donor. This might be considered be an acceptable way for society to show gratitude for the “gift” the donor has given. Wearing such a pin also allows other individuals or even other donors to identify and acknowledge donors; it may even facilitate peer-to-peer contact among fellow LKDs.
7.4 Scientific contribution

Through this research, which is the first in which different methodological approaches to research on LKDs are combined, important information has been added to the existing body of knowledge. Knowledge that emerges from research performed with a mixed-methods design is needed in the field of live donation. The study design seen in this research allowed for the investigation of different perspectives in live kidney donation. Each methodological approach has its own strength; when combined, the one strengthens the other and thus yields a more complex picture than each approach alone. Consequently, the research presented here contributes to a more comprehensive understanding of the significance of being a live donor in a long-term context. A combination of quantitative and qualitative approaches facilitated the exploration of donors’ multifaceted health status and their experiences. The new, comprehensive knowledge presented here in this thesis may contribute to a change of view among researchers and transplant professionals and may additionally generate further understanding of the unique and specific needs that live donors have. Moreover, and perhaps most importantly, the application of this new knowledge may help support potential donors during the donation decision-making process and even help encourage others to consider live donation.

7.5 Future research

A need exists for more research on self-reported outcomes in relation to live donation. The creation of a health register could be a valuable contribution in prospective studies on LKDs. Health registers comprising a coherent battery of outcomes could facilitate the systematic collection of clinical and self-reported data. A better understanding of gender differences in relation to fatigue and the role of resilience, resilient qualities and coping strategies in regard to health-related outcomes is also needed. These categories could be measured using self-reported outcomes, hereby also providing a broader understanding of the factors associated with self-reported outcomes. The inclusion of self-reported outcomes in a health register could even be beneficial in the evaluation of potential donors and in improving the information provided to potential donors about the long-term outcomes for LKDs. A health register could also help in the creation of guidelines for LKDs’ long-term follow-up care. Likewise, in that a health register allows for longitudinal data collection, donors’ response shift after donation can be investigated. Response shift is explained by an individual’s appraisal characteristics such as symptom amplification, motivation and value preferences.

Little research exits on the information given to donors pre-donation. It is currently unknown what information donors actually receive, what their perceptions are of the information given and, not
least, whether they receive the information they need. An intervention study, employing a combination of approaches to investigate the different aspects of the information given donors, could allow researchers to obtain more knowledge about this topic.

Furthermore, organ donation does not only involve the donor. The donor’s family, the recipient and the recipient’s family are also involved. Researchers should therefore investigate the different perspectives of all of the different individual groups affected by donation. In-depth or focus group interviews, mixed-methods designs or a combination thereof could be used to reveal the perspectives of those groups not previously investigated but nonetheless affected by donation. Donors’ dependents, especially, may have special needs for information, etc., that are not currently being met. A retrospective study may reveal more knowledge about the factors influencing dependents’ perceptions and the needs that they might have. Another area where little knowledge exists is when spouses decide to donate to one another. Not only should the influencing factors in such circumstances be investigated, but also the perspectives of the (eventual) children of such couples should be investigated.

Lastly, recognition for being a donor emerged in this research as an aspect that seemed to affect donors’ experiences and self-reported outcomes. More understanding about recognition as a concept is needed, and in-depth interviews could be used to explore donors’ perceptions of recognition for being a donor: from health professionals, society and/or recipients.
8. Conclusions

The present thesis provides novel and comprehensive understanding of long-term consequences of live kidney donation.

The main conclusions of this thesis are as follows:

- Live kidney donation was reported as a positive experience. Adverse effects on the donors’ health status and life were counterbalanced by the recipients’ improved health and life.
- The cross-sectional survey provided evidence of the good long-term QoL both in younger and older donors. The self-reported QoL improved with recognition from family and friends.
- Fatigue was more pronounced in female donors than in male donors. Donors who regretted donation and those who experienced recipient death reported a high level of fatigue.
- The qualitative in-depth interviews provided insight in donors’ long-term experiences and indicated that kidney donors possess resilient qualities that enable them to address both expected and unexpected long-term consequences.
- The prospective study provided new information about donors’ long-term clinical outcomes and revealed that hypertension and reduced kidney function were evident in a minority of the donors.
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Paper 1-3

Appendix
Long-term, self-reported health outcomes in kidney donors

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Abstract

Background: The wide use of healthy persons as kidney donors calls for awareness of risks associated with donation. Live kidney donation may impair quality of life (QOL) and result in fatigue. Long-term data on these issues are generally lacking in the donor population. Thus we aimed to investigate long-term self-reported health outcomes in a nationwide donor cohort.

Methods: We assessed self-reported QOL, fatigue and psychosocial issues after donation in 217 donors representing 63% of those who donated 8–12 years ago. QOL was measured using the generic Short Form-36 Health Survey (SF-36), fatigue using the Multidimensional Fatigue Inventory (MFI) and psychosocial issues using donor specific questions. For each of the 8 domains of SF-36 and the 5 domains of MFI, we performed generalized linear regression.

Results: Donors scored high on QOL with mean scores between 63.9 and 91.4 (scale 1–100) for the 8 subscales. Recognition from family and friends was associated with higher QOL scores in four domains. There were no significant gender differences. Fatigue scores were generally low. Females generally scored higher than males on all five dimensions of fatigue, although significantly only on two. Recipient still alive was associated with lower scores on mental fatigue. Regretting donors scored higher than average on all domains of fatigue. Recipient death, worries about own health and worsened relationship with the recipient influenced willingness to donate in retrospect. Donor age did not affect long-term health outcomes.

Conclusions: Eight till 12 years after donation QOL scores were generally high and improved with recognition from family and friends. Fatigue was independent of donor age and more pronounced in females and in those who regretted donation.

Keywords: Kidney donation, Quality of life, Fatigue, Questionnaires, Long term, Health outcomes

Background

End stage renal disease is an escalating health problem worldwide, with kidney transplantation being the gold standard treatment. Due to the increasing shortage of organs from deceased donors, transplantation with live kidney donor (LKD) has increased by 50% [1], and in some countries, more than half of kidney transplants are live donor kidneys. The introduction of laparoscopic donor nephrectomy with a less traumatic surgery has boosted the use of LKD and also allowed for more extensive use of elderly donors. The wide use of healthy persons as kidney donors for the benefit of others calls for awareness to the risks associated with donation. Beyond the surgical and medical risks, there is evidence suggesting that live donation is associated with a decreased donor quality of life (QOL) and increased fatigue [2–4].

It seems to be a gender difference in who become live donors, and in several studies female donors outnumber male donors [3, 5–7]. Tumin and colleagues performed a comparison of QOL between donors and a control group [6]. They found a gender and age difference in scores among the donors and that male donors and...
donors older than 56 years had higher scores. A study comparing younger and elderly kidney donors showed that LKDs who were older than 60 years at the time of donation recovered faster in terms of QOL than younger donors who did not recover completely in all the domains within one year [8]. Importantly, long-term data on the associations between high donor age or gender differences are lacking.

Various factors other than age have also shown associations with QOL and fatigue post-donation, such as relationship to the recipient, pre-donation expectations, donation-related experience, transplant outcome and support from health professionals, family and friends [2, 3, 9, 10]. Furthermore, positive experiences and perceptions of support seem to be protective, while reduced QOL has been related to fatigue, pain, long recovery time and recipient graft-failure.

Altogether, the knowledge about long-term consequences of donor nephrectomy is sparse because most existing follow-up studies have a shorter time-span than 10 years [9, 11, 12], a variable time-span [3, 5, 13], and some have small samples [2, 6, 11, 14]. New data about long-term consequences after donation may provide a better basis for safe expansion of donor selection criteria [4, 15], informed consent [16, 17] and guidelines for long-term follow-up [18].

The present study is unique in the sense that this investigation uses a nationwide cohort that has been followed for 8–12 years. The aims were to investigate factors associated with long-term self-reported QOL and fatigue with particular reference to age groups.

**Methods**

The study was approved by the Regional Medical Research Committee for Health South East of Norway (2011/2595 D) and the hospital’s data protection officer. The results are presented in such a way that no individual can be recognized in any publication or presentation of the data. This study was designed to investigate QOL and fatigue in LKDs representing all parts of Norway.

**Study design and population**

A cross-sectional survey was performed using eligible Norwegian kidney donors (N = 351) who donated a kidney at Oslo University Hospital, the Norwegian transplant center, between 2001–2004. The eligible donors were invited by mail, including one reminder, to participate in the study. The invitation letter included information about the purpose of the study and ensured confidentiality. To be as close as possible to 10 years follow-up for all LKD, those who donated in 2001 and 2002 received the invitation in November 2012 and LKD who donated in 2003 and 2004 were invited in May 2013. Figure 1 shows a diagram of the inclusion criteria; 262 donors who agreed to participate were sent the questionnaire booklet, and informed consent to partake in the study was given by the 217 donors who returned the questionnaire.

**Questionnaires**

**QOL**

To measure QOL, we used the generic Short Form-36 Health Survey (SF-36v2®) [19]. The instrument includes 36 items and evaluates a physical (PCS) and mental (MCS)
component score in addition to eight different domains: physical functioning (PF), role physical (RP), vitality (VT), mental health (MH), role emotional (RE), social functioning (SF), general health (GH), and bodily pain (BP). Each of the eight subscales has a theoretical range of 0–100, and lower scores indicate reduced QOL. The instrument has been translated into and validated in Norwegian [20] and has been used in several studies among LKD [2, 3, 14, 21].

Fatigue
The Multidimensional Fatigue Inventory (MFI) (22) was used to measure fatigue, which includes 20 items covering the following five dimensions: general fatigue (GF), physical fatigue (PF), mental fatigue (MF), reduced motivation (RM) and reduced activity (RA). Each subscale has a theoretical range of 4–20, and a higher score indicates more fatigue. MFI has been translated into Norwegian and validated [22] and is used in other studies to measure fatigue after kidney donation [2, 11, 14, 23].

Donor specific questions
The participants also responded to donor specific questions, measuring psychosocial and clinical factors, such as regret of donation (yes/no/do not know), recipient outcome (from much better than expected to much worse than expected), economic problems (from to a great extent to not at all), regular follow-up (from annually to never), recognition from family, friends and health professionals (from to a great extent to not at all), use of analgesics or tranquilizers/ hypnotics (from daily to never) and satisfaction with life before and after donation (from very satisfied to very dissatisfied) [21].

Demographic variables
Demographic variables included age, gender, marital status, educational level, vocational status and relationship to the recipient.

Statistical analyses
The descriptive data are presented with frequencies and percentages. Due to the skewed distribution of QOL and fatigue, we used the non-parametric independent samples Wilcoxon Mann-Whitney U-test to test for differences in QOL and fatigue between males and females, and elderly and younger donors (<60 years or ≥ 60 years at donation time). To examine factors that may be associated with QOL and fatigue 10 years post-donation we used generalized linear model with gamma family and log link, as default. For regressions where gamma family and log link was not appropriate, we used Poisson with log link or gamma with identity link. Independent variables were recipient outcome, feeling responsibility for recipient’s health, recognition from family and friends, and health professionals’, use of analgesics and tranquilizers/hypnotics, and donor’s relationship to the recipient. Covariates were recognized demographics, such as age groups, gender, marital status and vocational status. The generalized linear model with Poisson family was used to investigate any association between the abovementioned factors and overall satisfaction with life 10 years after donation. One way ANOVA was used to examine the relationship between feeling responsible for the recipient’s health and expectations for the recipient’s health. Missing data were treated according to the manual for SF-36® [24] and for fatigue and donor specific questions treated as missing. A two-tailed p-value less than 0.05 was regarded as statistically significant. All analyses were performed using the statistical package for social sciences version 21 (SPSS Inc. Chicago, IL, USA). Testing for appropriate link function and family for generalized linear regression was done with linktest in STATA 13.1 (StataCorp, College Station, Texas, USA).

Results

Demographics and relationship to the recipient
The response rate was 63 % and median follow-up time was 10 years (range 8.5–12 years). Table 1 shows the characteristics of the donors by age group, older and younger than 70 years at the time of follow-up (60 years at donation). Overall, the mean age of the donors at follow-up was 59.5 years (range 31–91) and 34 (15.7 %) of the donors were 70 years or older. The majority (63.6 %) were females, and the most common relationship to the recipient was sibling (33.2 %) followed by parent (24.4 %). Parents were more represented in the elderly group, and more elderly donors were widowed and retired compared to younger donors. No new information was found about associations between self-reported QOL and fatigue, and the covariates marital status, educational level and vocational status

QOL
QOL scores evaluated by the SF-36 questionnaire are shown in Table 2. Females scored significantly lower in the domains RP and RE. There were no differences between donors <70 years or donors ≥70 years of age at follow up.

Fatigue
Results of measures of the different dimensions of fatigue tested with the MFI questionnaire are shown in Table 3. Females scored significantly higher than males on most scales. No differences in scores between donors <70 years and ≥ 70 years of age were found.

Donor specific questions
Nearly all LKDs (94 %) would have donated again; only seven (3.2 %) would not. Among those seven, there were donors who perceived that the donation had been
harmful to one's own health, the relationship with the recipient had worsened, or reported the recipient had lost the graft or died. Thirteen LKDs (6 %) believed the donation had been harmful to his or her own health. Sixteen LKDs (7.4 %) reported economic problems related to the donation, nine (4 %) claimed loss of income was the reason, and the donation had caused a change in vocation for 11 donors (5 %). Twenty three LKDs (10.7 %) used tranquilizers/hypnotics and 31 (14.4 %) used analgesics daily or every week. Female donors were more frequent users than male donors; 13.9 % vs. 5.2 % and 19.7 % vs. 5.1 % respectively. More than half of the LKDs (54.4 %) did not see a nephrologist for medical follow-up in the long-term after donation, while 55 (25.3 %) had regular visits every year or every other year. As illustrated in Fig. 2, LKDs perceived more recognition from family and friends than from healthcare personnel ($p < 0.001$).

The majority (71.5 %) reported to perceive that the recipient’s health was better than or as they had expected. Responsibility for the recipient’s health was perceived by nearly half of the donors, 35 % felt some responsibility and 12 % felt a great extent of responsibility for the

| Table 1 | Donor demographics and relationship to recipient by age groups |
|---|---|---|---|---|
|  | All donors  | <70 years  | >70 years  |  |
|  | n         | (100 %)  | (84.3 %)  | (15.7 %)  |  |
| Donors | 217       |          |          |          |  |
| Gender |           |          |          |          | 0.59 |
| Female | 138       | (63.6 %) | (62.8 %) | (67.6 %) |  |
| Male   | 79        | (36.4 %) | (37.2 %) | (32.4 %) |  |
| Marital status |           |          |          |          | 0.04* |
| Single/divorced/widowed | 52       | (24 %)  | (21.3 %) | (38.2 %) |  |
| Married/cohabitant | 164     | (75.6 %) | (78.1 %) | (61.8 %) |  |
| Educational level |             |          |          |          | 0.88 |
| High school or less | 120    | (55.3 %) | (55.2 %) | (55.9 %) |  |
| College or university | 93     | (42.9 %) | (43.2 %) | (41.2 %) |  |
| Vocational status |           |          |          |          | 0.00* |
| Employed | 147     | (67.7 %) | (76 %)   | (20.6 %) |  |
| Not employed | 70    | (32.3 %) | (23 %)   | (79.4 %) |  |
| Donor’s relation to recipient |           |          |          |          | 0.04* |
| Offspring | 23      | (10.6 %) | (12.0 %) | (2.9 %)  |  |
| Parents | 53       | (24.4 %) | (21.3 %) | (41.2 %) |  |
| Sibling | 73       | (33.6 %) | (35.0 %) | (23.5 %) |  |
| Spouse | 37       | (17.1 %) | (15.8 %) | (23.5 %) |  |
| Other | 31 | (14.3 %) | (14.8 %) | (8.8 %)  |  |

Pearson’s chi square: $P$-value is between age groups, asymp 2-tailed, *$p < 0.05$
Educational level comprise 213 donors, 4 unknown

| Table 2 | QOL scores by age and gender |
|---|---|---|---|---|
| SF-36 Subscales | Total sample | Age groups | Gender |  |
|  | Mean (SD) | <70y | ≥70y | $P$ |  |
| Physical function | 208 | 89.7 (15.7) | 90.1 (15.2) | 86.1 (19.2) | 0.29 |
| Role physical | 214 | 86.3 (24.2) | 85.8 (24.8) | 86.6 (25.1) | 0.36 |
| Bodily pain | 216 | 76.8 (26.0) | 76.8 (26.2) | 79.1 (25.7) | 0.76 |
| General health | 213 | 80.5 (21.0) | 81.6 (20.4) | 78.5 (22.2) | 0.16 |
| Vitality | 214 | 63.9 (22.9) | 64.3 (23.4) | 62.0 (23.3) | 0.38 |
| Social function | 214 | 88.9 (20.2) | 89.4 (19.7) | 86.1 (23.1) | 0.23 |
| Role emotional | 216 | 91.4 (17.0) | 91.6 (17.2) | 89.2 (19.3) | 0.13 |
| Mental health | 216 | 82.6 (16.1) | 82.7 (16.2) | 82.0 (15.9) | 0.43 |

Non-parametric independent samples, Wilcoxon, Mann-Whitney U- test: Values are given as mean (SD), $P$-value is asymp 2-tailed, *$p < 0.05$
recipient’s health. There was a relationship between the donor’s feeling of responsibility and the perceived health of the recipient at follow-up \((p = 0.002)\). The feeling of responsibility was highest when perceived health of the recipient was much better than expected.

As shown in Table 4, the donors’ perception of recognition from family and friends was associated with the SF-36 dimensions RP, BP, VT and RE. There was no association between recipient outcome or the donor feeling responsible for recipient’s health and QOL.

Table 5 shows the associations between the dimensions of fatigue and donor specific questions and demographics. There were no associations between donor’s self-reported fatigue and responsibility for recipient health, recognition from others, or relationship to recipient at follow-up. As illustrated in Fig. 3 recipient’s death was significantly associated with higher scores in the MFI dimensions GF, PF, RA and RM.

Overall satisfaction with life 10 years after donation was positively associated with perceived recognition from health personnel \((p < 0.01)\) and negatively associated with donors being younger than 70 years \((p < 0.001)\).

LKDs who would not have donated again had higher mean scores than the average on all domains of MFI; GF (12.9), PF (13.4), RA (11.4) RM (11.0) and MF (10.4).

**Discussion**

This study shows that the donors generally perceive their QOL as good, and also report a low degree of fatigue at 10 years after donation. The results are in line with studies reporting a good QOL in the short-term after transplantation [9, 11, 12]. However, in a follow-up study 10 years after donation Klop et al. reports both excellent health and a deviation from baseline values in several domains of QOL and fatigue [14]. The authors argue that the difference may be explained by an increase in age of 10 years. In the present survey representing a nationwide selection of donors followed according to European recommendations [18, 25] the research design did not allow for baseline data or a control group. However, approximately one third of the participants in this survey also participated in a Norwegian randomized study comparing laparoscopic and open donor nephrectomy [21]. The good health reported in the present study appears to be sustained long-term. Thus our study provides new knowledge about the long-term self-reported health outcomes that may have implications concerning information provided to future donors.

In the present study, a significant finding was the difference between males and females in the MFI for all domains except RA, and in the domains RP and RE in

### Table 3 Fatigue scores by age group and gender

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Age groups</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>&lt;70y</td>
<td>≥70y</td>
</tr>
<tr>
<td>General fatigue</td>
<td>8.8 (4.4)</td>
<td>8.4 (4.0)</td>
<td>0.89</td>
</tr>
<tr>
<td>Physical fatigue</td>
<td>8.2 (4.2)</td>
<td>8.7 (4.5)</td>
<td>0.28</td>
</tr>
<tr>
<td>Reduced activity</td>
<td>8.3 (4.1)</td>
<td>8.6 (4.3)</td>
<td>0.26</td>
</tr>
<tr>
<td>Reduced motivation</td>
<td>7.3 (3.1)</td>
<td>7.0 (2.6)</td>
<td>0.61</td>
</tr>
<tr>
<td>Mental fatigue</td>
<td>8.0 (3.5)</td>
<td>8.1 (2.9)</td>
<td>0.25</td>
</tr>
</tbody>
</table>

Non-parametric independent samples, Wilcoxon, Mann-Whitney U-test: Values are given as mean (SD), P-value is asym. 2-tailed, \(^* p < 0.05\)

**Fig. 2** Responses to donor specific questions according to levels of agreement (per cent)
### Table 4: Associations between QOL scores (SF-36) and donor specific questions

<table>
<thead>
<tr>
<th></th>
<th>Physical function</th>
<th>Role physical</th>
<th>Bodily pain</th>
<th>General health</th>
<th>Vitality</th>
<th>Social function</th>
<th>Role emotional</th>
<th>Mental health</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>n</strong></td>
<td>159</td>
<td>164</td>
<td>166</td>
<td>163</td>
<td>163</td>
<td>167</td>
<td>166</td>
<td>166</td>
</tr>
<tr>
<td><strong>Recognition</strong></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Family and friends</td>
<td>B (st.error)</td>
<td>3.242 (2.004)</td>
<td>7.984* (4.029)</td>
<td>7.490* (3.153)</td>
<td>0.063 (0.041)</td>
<td>6.778* (3.077)</td>
<td>0.048 (0.039)</td>
<td>0.055* (0.028)</td>
</tr>
<tr>
<td>Health personnel</td>
<td>B (st.error)</td>
<td>0.342 (1.322)</td>
<td>1.527 (2.830)</td>
<td>2.890 (2.496)</td>
<td>0.001 (0.027)</td>
<td>0.949 (2.266)</td>
<td>0.010 (0.025)</td>
<td>0.009 (0.017)</td>
</tr>
<tr>
<td><strong>Recipient’s outcome</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Still alive</td>
<td>B (st.error)</td>
<td>1.458 (4.705)</td>
<td>0.499 (9.913)</td>
<td>5.959 (8.205)</td>
<td>−0.027 (0.097)</td>
<td>0.363 (7.799)</td>
<td>0.036 (0.092)</td>
<td>0.034 (0.064)</td>
</tr>
<tr>
<td><strong>Responsibility</strong></td>
<td></td>
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</tr>
<tr>
<td>Feeling responsible for recipient’s health</td>
<td>B (st.error)</td>
<td>−0.612 (1.093)</td>
<td>3.277 (2.420)</td>
<td>1.271 (2.100)</td>
<td>0.008 (0.023)</td>
<td>0.754 (1.862)</td>
<td>0.020 (0.021)</td>
<td>0.021 (0.015)</td>
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<tr>
<td>Donor’s relationc</td>
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<tr>
<td>Offspring</td>
<td>B (st.error)</td>
<td>−0.126 (4.556)</td>
<td>2.923 (2.828)</td>
<td>1.725 (8.156)</td>
<td>0.054 (0.094)</td>
<td>−4.816 (7.850)</td>
<td>−0.149 (0.089)</td>
<td>−0.066 (0.062)</td>
</tr>
<tr>
<td>Parents</td>
<td>B (st.error)</td>
<td>0.021 (3.974)</td>
<td>8.459 (8.275)</td>
<td>8.052 (7.699)</td>
<td>0.068 (0.082)</td>
<td>−5.203 (7.059)</td>
<td>−0.104 (0.077)</td>
<td>−0.023 (0.054)</td>
</tr>
<tr>
<td>Sibling</td>
<td>B (st.error)</td>
<td>−0.777 (3.533)</td>
<td>3.039 (7.351)</td>
<td>3.450 (6.724)</td>
<td>0.040 (0.074)</td>
<td>−0.410 (6.417)</td>
<td>−0.097 (0.069)</td>
<td>−0.001 (0.048)</td>
</tr>
<tr>
<td>Spouse</td>
<td>B (st.error)</td>
<td>−1.627 (4.201)</td>
<td>4.645 (8.266)</td>
<td>3.094 (7.602)</td>
<td>0.031 (0.084)</td>
<td>−5.367 (7.041)</td>
<td>−0.121 (0.080)</td>
<td>−0.052 (0.056)</td>
</tr>
<tr>
<td><strong>Use of analgesicd</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Daily/every week</td>
<td>B (st.error)</td>
<td>−8.034* (4.001)</td>
<td>−15.978 (8.639)</td>
<td>−20.299** (7.117)</td>
<td>−0.057 (0.081)</td>
<td>−4.438 (6.827)</td>
<td>−0.042 (0.077)</td>
<td>−0.096 (0.054)</td>
</tr>
<tr>
<td>Use of relaxant/sleeping pills**</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Daily/every week</td>
<td>B (st.error)</td>
<td>−17.378** (4.817)</td>
<td>−11.263 (8.498)</td>
<td>−0.169 (6.831)</td>
<td>−0.116 (0.093)</td>
<td>−17.494** (6.437)</td>
<td>−0.095 (0.086)</td>
<td>−0.133* (0.060)</td>
</tr>
<tr>
<td><strong>Genderf</strong></td>
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<td></td>
</tr>
<tr>
<td>Male</td>
<td>B (st.error)</td>
<td>4.355 (2.532)</td>
<td>6.980 (5.889)</td>
<td>3.118 (5.011)</td>
<td>0.079 (0.053)</td>
<td>4.853 (4.832)</td>
<td>0.044 (0.050)</td>
<td>0.045 (0.035)</td>
</tr>
<tr>
<td>&lt;70 years</td>
<td>B (st.error)</td>
<td>4.419 (4.060)</td>
<td>3.637 (8.358)</td>
<td>7.450 (7.430)</td>
<td>0.070 (0.082)</td>
<td>5.565 (6.824)</td>
<td>0.079 (0.077)</td>
<td>0.076 (0.054)</td>
</tr>
<tr>
<td>Medical follow-uph</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>No regular controls</td>
<td>B (st.error)</td>
<td>−2.743 (2.360)</td>
<td>−2.947 (4.985)</td>
<td>−0.842 (4.419)</td>
<td>−0.062 (0.049)</td>
<td>0.016 (4.417)</td>
<td>0.018 (0.046)</td>
<td>−0.028 (0.032)</td>
</tr>
</tbody>
</table>

Generalized linear model: Each domain was analyzed separately; aGamma with log link, bGamma with identity; B, the regression coefficient; reference was: crelation category friends/others, dless than every week/never, eless than every week/never, ffemale, gage ≥ 70 years, hno controls; controlled for covariates marital status, educational level and vocational status; *p < 0.05, **p < 0.01
the SF-36. The gender difference in self-reported fatigue in our study differs from the results in a study on fatigue and physical function in mid-life [26]. Boter and colleagues found a strong association between physical function and the subscales in MFI but no gender difference. However, gender difference in fatigue is inconsistent in previous studies. While a study on the German population demonstrated a significant difference [27], the gender difference was present but not significant in a Swedish study [28], and a Danish study showed that while there

### Table 5 Associations between fatigue scores (MFI) and donor specific questions

<table>
<thead>
<tr>
<th></th>
<th>General fatigue&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Physical fatigue&lt;sup&gt;b&lt;/sup&gt;</th>
<th>Reduced activity&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Reduced motivation&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Mental fatigue&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>163</td>
<td>163</td>
<td>163</td>
<td>161</td>
</tr>
<tr>
<td><strong>Recognition</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family and friends</td>
<td>B (st.error) −0.021 (0.080)</td>
<td>0.066 (0.425)</td>
<td>−0.003 (0.058)</td>
<td>0.038 (0.049)</td>
<td>−0.016 (0.054)</td>
</tr>
<tr>
<td>Health personnel</td>
<td>B (st.error) −0.038 (0.038)</td>
<td>−0.130 (0.264)</td>
<td>0.010 (0.039)</td>
<td>−0.012 (0.030)</td>
<td>−0.038 (0.034)</td>
</tr>
<tr>
<td>Recipient’s outcome</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Still alive</td>
<td>B (st.error) 0.113 (0.141)</td>
<td>−0.172 (1.060)</td>
<td>0.011 (0.133)</td>
<td>0.086 (0.110)</td>
<td>0.363** (0.126)</td>
</tr>
<tr>
<td><strong>Responsibility</strong></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Feeling responsible for recipient’s health</td>
<td>B (st.error) 0.051 (0.033)</td>
<td>0.095 (0.238)</td>
<td>0.002 (0.032)</td>
<td>−0.008 (0.026)</td>
<td>−0.015 (0.030)</td>
</tr>
<tr>
<td>Donor’s relation&lt;sup&gt;d&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Offspring</td>
<td>B (st.error) −0.025 (0.135)</td>
<td>0.952 (0.895)</td>
<td>0.218 (0.130)</td>
<td>0.023 (0.107)</td>
<td>0.110 (0.122)</td>
</tr>
<tr>
<td>Parents</td>
<td>B (st.error) −0.005 (0.118)</td>
<td>0.660 (0.763)</td>
<td>0.103 (0.114)</td>
<td>−0.001 (0.092)</td>
<td>−0.047 (0.106)</td>
</tr>
<tr>
<td>Sibling</td>
<td>B (st.error) 0.064 (0.104)</td>
<td>0.832 (0.653)</td>
<td>0.140 (0.099)</td>
<td>0.094 (0.082)</td>
<td>0.040 (0.094)</td>
</tr>
<tr>
<td>Spouse</td>
<td>B (st.error) 0.135 (0.126)</td>
<td>0.366 (0.809)</td>
<td>0.208 (0.119)</td>
<td>0.067 (0.099)</td>
<td>0.091 (0.111)</td>
</tr>
<tr>
<td><strong>Use of analgesic&lt;sup&gt;d&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily/ every week</td>
<td>B (st.error) 0.356** (0.115)</td>
<td>3.599** (1.168)</td>
<td>0.258* (0.110)</td>
<td>0.071 (0.094)</td>
<td>0.158 (0.104)</td>
</tr>
<tr>
<td><strong>Use of relaxant/ sleeping pills&lt;sup&gt;e&lt;/sup&gt;</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily/ every week</td>
<td>B (st.error) 0.261* (0.128)</td>
<td>2.552* (1.277)</td>
<td>0.321* (0.125)</td>
<td>0.363*** (0.103)</td>
<td>0.161 (0.116)</td>
</tr>
<tr>
<td>Gender&lt;sup&gt;f&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>B (st.error) −0.196* (0.078)</td>
<td>−1.139* (0.489)</td>
<td>−0.037 (0.072)</td>
<td>−0.072 (0.060)</td>
<td>−0.068 (0.068)</td>
</tr>
<tr>
<td>Age group&lt;sup&gt;g&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;70 years</td>
<td>B (st.error) −0.088 (0.117)</td>
<td>−1.298 (0.889)</td>
<td>0.017 (0.114)</td>
<td>0.016 (0.092)</td>
<td>−0.093 (0.103)</td>
</tr>
<tr>
<td>Medical follow-up&lt;sup&gt;h&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No regular controls</td>
<td>B (st.error) −0.009 (0.071)</td>
<td>0.299 (0.476)</td>
<td>−0.006 (0.068)</td>
<td>−0.009 (0.055)</td>
<td>−0.078 (0.063)</td>
</tr>
</tbody>
</table>

*Generalized linear model; each domain was analyzed separately; <sup>a</sup>Gamma with log link, <sup>b</sup>Gamma with identity; B, the regression coefficient; reference was: *relation category friends/others, <sup>d</sup>less than every week/never, <sup>e</sup>less than every week/never, <sup>f</sup>female, <sup>g</sup>age ≥ 70 years, <sup>h</sup>no controls; controlled for covariates marital status, educational level and vocational status; *p < 0.05, **p < 0.01, ***p < 0.001

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**Fig. 3** Donors’ mean scores on dimensions of fatigue when recipient was still alive or dead ten years after donation.
was no general gender difference there seemed to be an excess of females with high scores [29]. Only few studies [2, 11, 14, 23] have specifically investigated fatigue after live donation, and as far as we know, none have examined the gender difference. Our results indicate that females may experience fatigue after donation. Since the majority of the donors are female it seems important to include information about fatigue in pre-donation information.

Another particular aspect of the present study was the effect of donation on the elderly population because elderly donors are frequently used. We defined an elderly donor as older than 60 years of age at the time of donation (70 years at follow-up) for comparison with previous studies on elderly donors [7, 30]. Even though there has been reported a linear relationship between dimensions of fatigue in MFI and age in a general population [27], we found no difference in self-reported fatigue between younger and older donors in the long-term. 

Nor did we find a difference in self-reported QOL. These results are in line with results from short-term observations [7, 30] and confirm the results from the long-term RELIVE study [3]. The elderly donors in our study also scored higher than the elderly participants (more than 70 years) in the Norwegian general population [20]. Although we have to have in mind that the normative data are nearly 20 years old, the long-term self-reported health seems not to be impaired in elderly donors. These results are reassuring for both clinicians and elderly persons considering being a kidney donor.

The large majority of the donors did not regret donation and would be willing to donate again as has been reported in many follow-up studies [11, 12, 31]. However, a small minority would say no if they were asked again, and the higher scores in fatigue in these donors call for attention. Fatigue among donors who regret donation has not been studied before and needs further investigation. We found that some of those who regretted donation had experienced recipient death. Our data also showed an association between fatigue and recipient death. This is in line with previous research which has demonstrated that recipient death can produce a feeling of guilt [32] and influence LKD’s well-being [10, 33]. In addition, there were donors who had experienced a negative change in the relationship with the recipient, which may be disappointing. Furthermore, three of those who regretted donation perceived that the donation had been harmful to his or her health. Worrying about own health may have provoked or contributed to the perception of fatigue. The real challenge would be to identify donors at risk for regret during donor work-up. Unfortunately, this aspect could not be addressed in the present study but paying attention to those who donate to a recipient at high-risk may be appropriate. Adverse outcomes for the recipient have also been found to be associated with adverse psychosocial outcomes for LKD in previous studies [10, 32, 33]. However, for the donor population as a whole, the donors in our study did not blame themselves if the result was poor. Nevertheless, recipient outcome better than expected and recipient still alive was associated with a positive emotional outcome and seemed to generate more responsibility among the donors.

Both live and deceased donation is generally acknowledged to be a good deed. Appreciation and recognition of the deed they have accomplished from the social environment in addition to improved recipient health may provide improved self-esteem and personal growth, which again may be associated with QOL and satisfaction with life. Findings from previous studies [32, 34, 35] such as changed roles, improved self-esteem, personal growth, and improved QOL among donors support this conclusion.

While Tong et al. [32] found that donors worry about potential kidney failure, physical well-being and ill health, a minority in our study considered the donation to be harmful to his or her health. The low number of donors who had regular visits to a nephrologist may both reflect that LKDs are healthy persons going through an extensive work-up ahead of the donation and that most recover within the first year post-donation. However, to obtain knowledge about the long-term consequences and ensure quality and safety, regular follow-up is essential [18, 36]. In Norway, which is a fairly small country and has limited mobility within the population, the possibility for medical follow-up for most donors may be better than in vast countries such as the USA [3, 36]. Still, less than half of the donors in the present study had medical follow-up 10 years after donation.

The strength of the present study is the sample size with a fairly high response rate 8–12 years after donation and representation from all parts of Norway [37]. The demographics and characteristics of the non-responders are similar to that of the responders. The data sets also had few missing data. We have used well-established methods previously validated in Norwegian populations. A limitation of cross-sectional follow-up studies is the lack of baseline data and a control group. Consequently, we do not know if there has been a change in self-reported outcomes 8–12 years after donation. Additionally, we do not have any information about the motivations to donate. There might be a recall bias in self-report up to 12 years later. Another limitation in this study is that we did not link our data to a recipient registry. However, we tried to restrict the weakness by questions about donors’ expectations and recipient outcome. We have contributed to new knowledge as seen from the donors’ perspective which recently was highlighted in the report from Thiessen et al (2015) as essential in the care of LKD.
Conclusions

The long-term QOL of donors was reported as good both in younger and older donors and improved with recognition from family and friends. Female donors had higher scores on fatigue than male donors. A few donors regretted donation and those donors reported a high level of fatigue. Identifying and following donors who are at risk for regretting donation is important. More research is needed on gender differences and factors that are associated with fatigue after live kidney donation in the long-term compared to baseline data.

Abbreviations

ANCOVA: Analysis of variance; BP: Bodily pain; GF: General fatigue; GH: General health; LKD: Live kidney donors; MCS: Mental component score; MF: Mental fatigue; MFI: Multidimensional Fatigue Inventory; MH: Mental health; PCS: Physical component score; PF: Physical functioning; PF: Physical fatigue; QOL: Quality of life; RA: Reduced activity; RE: Role emotional; RM: Reduced motivation; RP: Role physical; SF: Social functioning; SF-36: Short Form-36 Health Survey; VT: Vitality.

Competing interests

The authors of this manuscript have no conflicts of interest to disclose as described by the BMC Nephrology.

Authors’ contribution

KM, AKW, ITB, AH and MHA were responsible for the study design. KM drafted the article. MHA, AH, AKW, ITB, TR and TW revised the work critically. All authors approved the final version of the manuscript and agreed to be accountable for all aspects of the work.

Acknowledgement

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Received: 30 September 2015 Accepted: 8 January 2016

References

Abstract

Objective: Live kidney donation is generally viewed as a welcome treatment option for severe kidney disease. However, there is a disparity in the body of research on donor experiences and postdonation outcome, and lack of knowledge on long-term consequences described by the donors. This study was conducted to provide insight into donors’ subjective meanings and interpretation of their experiences ~10 years after donation.

Design: Qualitative explorative in-depth interviews.

Participants: 16 donors representing all parts of Norway who donated a kidney in 2001–2004 participated in the study. The interviews were analysed using an interpretative approach.

Results: The analysis resulted in 4 main themes; the recipient outcome justified long-term experiences, family dynamics—tension still under the surface, ambivalence—healthy versus the need for regular follow-up, and life must go on. These themes reflect the complexity of live kidney donation, which fluctuated from positive experiences such as pride and feeling privileged to adverse experiences such as altered family relationships or reduced health.

Conclusions: Live kidney donors seemed to possess resilient qualities that enabled them to address the long-term consequences of donation. The challenge is to provide more uniform information about long-term consequences. In future research, resilient qualities could be a topic to explore in live donation.

Background

Owing to the increasing need for kidney transplantation and the superior results of live transplantation, live kidney donors (LKDs) are frequently used. However, the increase in LKD use has slowed with no clear explanation in Norway and other countries.2

In previous research, the relationship to the recipient, expectations related to one’s own or recipient outcome, and perceived support have been associated with the donor’s health outcomes.3–12 Concern about the recipient’s health may influence the donor’s decision,13 14 and the outcome of the transplantation may have an impact on the donor’s life and health.7 8 15

Postdonation experiences vary from disturbed family hierarchies and failed relationships with the recipient to support from the recipient and other family members.11 Explaining the disparity in LKD experiences in the body of research is challenging, and resilience has recently been introduced in live donation as a possible protective factor.17 18 Resilience can be defined as a matter of coping or adapting to life events.19

Qualitative research can provide in-depth understanding of experiences and first-person perspectives that surveys cannot capture.20 However, qualitative research on LKDs varies in methods. Most of the qualitative research represents short-term follow-up,8 11 14 16 while other studies have shown variation in follow-up time ranging from <12 months to 29 years.12 15

Our
current knowledge indicates that live kidney donation is complex, and little is known about donors’ long-term experiences. To provide information and adapt follow-up care to future donors, a need exists for more knowledge of the donors’ unique experiences from a long-term perspective. The present study is part of a larger mixed-methods study in which a cross-sectional survey on self-reported health outcomes is the first component, and this explorative in-depth interview study is the second component. Hence, the aim of our paper is to provide insight into the donors’ experiences almost 10 years after donation.

METHODS

Design
Explorative in-depth interviews were performed to provide insight into the donors’ subjective meanings and interpretations of their experiences.²¹ ²²

Setting
Oslo University Hospital is the national centre for organ transplantation and donation in Norway. The donor work-up and follow-up is performed at 26 local nephrology centres situated in four health regions.

Participants
The purposeful sample consisted of 16 LKDs donating at Oslo University Hospital, who had participated in the cross-sectional survey. The donors’ postdonation follow-up was performed at local hospitals representing all parts of Norway. We conducted maximum variation sampling from the larger sample based on self-reported health outcome, age, gender and relationship to the recipients, to select donors to be invited to participate. However, it was not possible to reach every donor demographic, and none of the donors in the sampling were younger than 30 years or older than 60 years at donation time. Inclusion of participants was concluded when no new information was provided.²² A purposeful sample facilitates obtaining information-rich participants who can provide both insight and depth. Additionally, a maximum variation sampling strategy provides an opportunity to compile central themes across various experiences.²² Using this method we could obtain in-depth information about the experience of being a live donor in the long term.

Interviews
A semistructured interview guide was prepared to ensure that relevant topics were discussed. The topics were based on clinical experiences, previous research and responses on the cross-sectional survey.⁷ They included the importance of donation with regard to possible changes in the donor’s life, the relationship with the recipient, the donor’s contact with the healthcare system postdonation, the recipient outcome and the donor’s expectations of the donation. The informants’ long-term experiences were highlighted during the interview. Open-ended questions such as: ‘Could you please describe how your life is today?’ and ‘Could you please tell me what kind of significance the donation have had for your life?’, elicited narratives in the donor’s own words. The interviews were performed by the first and the last authors (KBM and MHA). Both have clinical experience with LKD, but neither have a present health-care relationship with any of the participants. The interviews were conducted in the period between spring 2014 and spring 2015. They took place in the participant’s home, workplace or in a hospital, and lasted between 25 and 65 min.

Data analysis
The narratives were transcribed verbatim either by KBM or by an assistant. The text was analysed through a hermeneutical approach using Kvale and Brinkmann’s²³ three contexts of analysis of qualitative data, and was focused on condensation and interpretation of the meaning. A hermeneutical approach provides an opportunity to understand live donation in the context of the donors’ lives in a long-term perspective. Examples from the analysis are shown in table 1.

KBM conducted the first steps of the analysis. To obtain an overall impression, the transcripts and reflection notes from each interview were read several times. The first context of the analysis comprised a rephrased condensation of the informant’s own views. In the next context the elucidated meanings were interpreted by moving back and forth between the data and the researchers’ perspectives, and the meanings were merged into broader categories. To make the study as trustworthy as possible the categories were first discussed by KBM, MHA and ITB. Second, all co-authors discussed and agreed on the categories. Additionally, the findings are illustrated with quotations from the interviews to show our interpretation of the persons’ experiences and make the interpretations clear, credible, transferable and confirmable. Finally the categories were investigated in a theoretical context as presented in the Discussion section.²⁵

Ethical considerations
An invitation letter was sent to eligible candidates that included information about the study, confidentiality and the possibility to withdraw from the study at any time. KBM contacted the donors who consented to participate and choose a suitable time and place for the interview.

RESULTS
Invitation to participate in the interviews was sent to 22 donors, and 16 donors accepted. Donor characteristics are shown in table 2. As the sample was small and the Norwegian living kidney donors are easily recognisable, the table displays merely gender, relationship with the
recipient and geographical area in order to maintain confidentiality and the donors’ anonymity. The youngest donor was 42 years old and the oldest was 66 years at the time of the interview. The time since donation varied between 10 and 14 years. The donors’ experiences were categorised into the following four main themes: the recipient outcome justified long-term experiences, family dynamics — tension still under the surface, ambivalence — healthy versus the need for regular follow-up, and life must go on.

**The recipient outcome justified long-term experiences**

A major theme was that the donation became meaningful because it was strongly motivated by the recipient’s prospect of living a good and active life with his/her family. Even if the benefit of the transplantation was less than anticipated, the donors were still confident about their decision. One of the donors reflected on having been the one to decide between life and death: “If I may be dramatic; I had the opportunity to give my sister a chance to live. She wasn’t going to die. Clearly, she had to receive a part of me” (F, 6). Even now the donors assumed that live donation was the recipients’ only possibility to avoid dialysis and live a better life due to the lack of deceased organs.

The delight in seeing the recipient living an active and normal life compensated for the donors’ own adverse experiences. Gratitude from the recipient and his/her family and the continued respect that they received from others contributed to a sense of pride and being privileged. However, an underlying anxiety existed regarding the recipient’s well-being and the graft survival even if none of the donors claimed to feel responsible for the recipient’s current health. A male informant said: “You are cautious when you know he is going to see the doctor. I wonder if it is the kidney, is the time running out? So I am on guard” (M, 9). The anxiety was associated with the assumption of limited graft survival time and the recipient’s possibility of receiving a new graft.

Being a donor was not merely a positive experience, and losing contact with the recipient was bothersome. One sibling tried to excuse a brother who had cut-off all contact:

> My brother and I have no connection after the donation. I figure this is quite rare. We lost touch completely. I believe he feels so grateful that he rejects me. We used to be very close, but after the donation it is the opposite. (F, 3)

Donors who experienced altered relationships or changes in their own health had decided to put the adverse experiences aside and continue onward. They wanted to focus on the positive experiences. Another donor explained how long-term complications associated with the donor nephrectomy had implications for family life:

> Fortunately, my husband is very understanding. Otherwise, I am not sure he would have been by my side today. My health has deteriorated in all respects. However, eventually it will go well, it will… (F, 13)

Although the donation had current physical and psychosocial consequences, a need existed to be optimistic and confident in regaining health. Others had experienced resistance in their own families or negative reactions to the decision to be a donor. However, they were determined to stand by their decision, and were certain that donation had been the appropriate choice.

<p>| <strong>Table 1</strong> Examples from the analysis |</p>
<table>
<thead>
<tr>
<th>Natural meaning unit, statements</th>
<th>Subthemes</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>It was not intentionally, I understand that, but my stomach is damaged for life. I had a much better life before this, but my sister is fine, the kidney works well. I think I had given her kidney again. Thus I believe she felt I was intimate and yes, we have had good relations. I have felt she was very grateful. Even if the kidney doesn’t work anymore, you may say it was many years she had a better life, by receiving a kidney.</td>
<td>Experiencing that the recipient had a good life compensated the donor’s own adverse experiences.</td>
<td>The recipient outcome justified long-term experiences.</td>
</tr>
</tbody>
</table>

| **Table 2** Donor characteristics |
|-------------|---------|
| Gender | N  |
| Male | 6  |
| Female | 10 |
| Relation to recipient |  |
| Parent | 6 |
| Sibling | 6 |
| Offspring | 3 |
| Spouse | 1 |
| Health-region affiliation |  |
| Northern Norway | 2 |
| Central Norway | 2 |
| Western Norway | 1 |
| South-Eastern Norway | 11 |
Family dynamics—tension still under the surface

For some, the donation was experienced as a watershed that did not concern only the donor and the recipient, but the whole family. “It was a tough time for me and my husband. Though, it might have been easier for me; I was allowed to do something. It was a hard-hitting marital event” (F, 10). In hindsight, the donor realised that it might have been easier to be the one who could actively be of help than being unable to take action.

While donation still was the obvious choice for some donors, others had felt an implicit or explicit pressure.

I decided to be the first one to be tested because I had the impression that my brother thought surgery and hospital was a bit scary. Afterwards we haven’t mentioned it. I do love my brother, you know. (F, 14)

When the pressure was implicit it seemed as if the donor had taken responsibility for the whole family and did not want to reconsider. Then again, explicit pressure appeared to have made the decision into a difficult process. One sibling explained the negotiation as follows: “I thought it was unfair, I was the youngest, the oldest brother could be the donor, but my older sister claimed; it was only you who offered to donate” (F, 11).

The process continued to affect interpersonal relationships within the families. Another sibling described how the process had altered family relations: “The dispute may still be there, in the back of my mind, it may never disappear 100%. There was a disappointment related to the way things were said” (M, 16). The siblings’ duplicity and the feeling of betrayal that emerged during the donation process caused a breach in their relationships that might never be fully mended.

Ambivalence—healthy versus the need for regular follow-up

Long-term follow-up safeguarded the donors’ need to monitor their own health and to be valued for the good deed. “The doctors monitor my health. I am at a medical follow-up every second year; the creatinine increases. I understand it’s nothing hazardous, I don’t worry” (M, 2). The donors relied on the physicians’ abilities to monitor their health and medical risks. The medical follow-up was appreciated and viewed as a warranty by those who had continued to visit the nephrologist. When the hospitals guaranteed follow-up on a regular basis they felt secure and valuable.

Looking back, donors deliberated about the predonation reassurances of the safety of the donation. Before donation, they avoided reflecting about the consequences and relied on the medical assessment. Afterwards, they took care of themselves, tried to avoid anything that might be harmful, and were protective of the remaining kidney. Although most of the donors denied that the nephrectomy had been harmful, an underlying insecurity was present.

Contradictory opinions among health professionals caused uncertainty about the value of the medical follow-up, as shown by a female informant:

I asked why, what is the point when I am healthy? That is how I feel, but then I think about what they said in the beginning; donors stay healthy because of the medical follow-up. They might uncover other things, so maybe it’s wise. I don’t worry about the kidney, but it could be high blood pressure or something. (F, 14)

Initially, the donors were guaranteed to be in good health; however, they were encouraged to continue their medical follow-up. The practice of follow-up consultation differed, and some of the donors perceived the consultations as shallow. The focus was on kidney parameters, and not on the donor’s well-being. “All is well, nevertheless, it feels good to have that chat; yes, your sister is doing well, of course I know that, but it is okay to receive that feedback, the follow-up is okay” (F, 6). A more comprehensive follow-up where the donor could discuss worries about their own health or the recipient’s health was valued.

Life must go on

When time had passed the donation was no longer the most important event in life. The focus on the donation waned and everyday life continued. Several claimed that being left with one kidney did not have any effect on their health or how they lived their lives. A male donor said:

My choice has been not to look for problems. I haven’t had any complications, and I never wanted to think I had any. It hasn’t had a negative effect on my everyday life. Have to have a positive view. I couldn’t do it any other way. (M, 16)

To move forward in life, it was important to look forward and not focus on changes or problems that followed the donation.

Quite a few donors underlined the sense of pride and the admiration that they still perceived from others. “I don’t know whether I am happier, but yes, I don’t mind the acknowledgement I sense once in a while” (F, 11).

Nevertheless, the improved quality of life predicted during the work-up before the donation seemed to be overrated. Although many of the donors still felt attached to the recipient, donors and recipients did not see each other as often as they did shortly after donation. One of the donors reflected on how the significance of the donation waned with time:

Looking back, we were never in doubt; when she received the kidney she would become well. Done! The first years we used to celebrate, one year, five years, but now, it’s kind of forgotten. (F, 14)

Several of the donors highlighted that their recipients showed their gratitude by honouring the day of the
donation by a phone call or a gift to the donor. Some of the donors appreciated the gesture while others argued that the significance of the donation was minor. It was something they had done more than 10 years ago and had left behind.

**DISCUSSION**

The results of our study illustrate how donors’ experiences fluctuated between pride and being privileged versus altered family relations and reduced health. However, the recipients’ potential for improved health seemed to supersede the donors’ own long-term consequences and justified donation even when the recipient outcome was not as good as anticipated. According to the metatheory of resilience and resiliency, live kidney donation can be seen as a life event. As we understand the model, a donor’s resilient qualities may be strengthened when the donor is able to choose the outcome of the life event. The donors made their own decision to donate and decided that no matter what happened they would live with the consequences. The risk and consequences of the donor nephrectomy became acceptable due to prospect of improvement of the recipient’s life. This may be understood as resilient reintegration; the donor adapted to the situation in mind, body and spirit. Consistent with previous research, the donors’ decision was motivated by a wish to help, altruism and personal benefit, which is part of the motivational force in resilience. The motivational force seems to persist and may elucidate how the recipient outcome of the donation compensated for the long-term consequences.

The sense of pride, as a result of perceived respect and gratefulness, corresponds with the results from our previous report on long-term self-reported health, perceived recognition from family and friends was significantly associated with quality of life. In another study, extroversion was correlated with postdonation growth, and the authors advocated that social support may be important in positive coping and growth after donation. This again can provide increased self-esteem and purpose in life which is part of resilience.

Donors with adverse experiences had chosen a positive view and they still had hopes to regain health or improve relationships. To cope with the disappointment when the recipient discontinued all contact, the recipient’s detachment was rationalised as unexpressed gratefulness. Hope, optimism and forgiveness have been identified as resilient qualities. The donors in our study seemed to employ these qualities. It looks as if the donation contributed to a lasting perception of purpose in life, self-esteem and personal growth that counterbalanced negative consequences.

The impaired relationships that were evident in some families and especially between siblings are consistent with the result in a Swedish cross-sectional study. Lennerling et al. found that spouses’ motivation was to improve the situation for the whole family, while siblings had a moral obligation to donate. The obligation may cause a moral incontinence, a combination between external and internal moral constraints. The persistent tension might be a result of inequality between the siblings; the sibling who took responsibility responded to the moral obligation while the siblings who did not donate might not be able to respond to internal and external constraints. The inequality may lead to a breach in the relationship between the donor, the non-donor siblings and the recipient.

Another key finding was the ambivalence on medical follow-up. This may be a result of the predonation reassurances about the low medical risks and contradictory attitudes among health professionals regarding the need for follow-up. However, recent research on long-term risks indicates an increased medical risk after kidney donation and an increased risk during pregnancy. Garg and colleagues revealed a higher incidence of gestational hypertension and pre-eclampsia in female kidney donors compared with non-donors. Furthermore, we revealed an underlying anxiety regarding the remaining kidney. Conversely, Rodrigue et al. found non-donors to be more concerned about kidney damage than LKDs. They concluded that the donors were well informed about the risks. Nevertheless, a need to adjust predonation information might exist. In addition, it might be beneficial if long-term follow-up was a matter of discussion among transplant professionals to ensure a more consistent attitude. The donors in our study had different experiences and expectations of the medical consultations. The consultations could be an arena for the donors to discuss their own health and concerns for the recipient. However, according to the confidentiality oath, it may not be advisable to provide information about the recipient’s health.

In the long term, the significance of the donation waned and the donors continued with their lives. It is easy to comprehend this progression; the donors are healthy persons who for a period of time were affected by donating a kidney, and now the majority have returned to their daily life. Consistent with our qualitative data, several studies using a quantitative approach have documented similar findings.

We wanted to explore long-term experiences and used a maximum variation sampling strategy based on self-reported health outcomes, gender, age and relationship to the recipient. In our previous report, donors who regretted donation scored much higher than average on fatigue. A significant association was also present between fatigue and whether the recipient was alive or dead. None of the participants in this study regretted their decision, and all the recipients were still alive. This might be a limitation as we could not explore how the recipient’s status could influence long-term experience. However, for some of the donors in our study, the result of donation was not as anticipated; the recipient was back on dialysis or had other adverse outcomes. Another limitation might be that all our donors were related to the recipient as non-directed donation is not an option in Norway.
In conclusion, LKDs seem to possess resilient qualities that enable them to address both expected and unexpected long-term consequences. The challenge is to provide more uniform information about long-term consequences. The work done in this study has provided a scientific contribution to understanding how resilience might illuminate LKD experiences. In future research, resilience and resilient qualities could be one of several topics to explore regarding living donation.

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Contributors KBM and MHA participated in collecting and analysing the data, and writing and editing the manuscript. ITB, AKW and AL participated in analysing the data and editing the manuscript.

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Competing interests None declared.

Ethics approval The study was approved by the Regional Medical Research Committee for Health South-East of Norway (2011/2595 D) and the hospital’s data protection officer.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement No additional data are available.

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REFERENCES

Background: Long-term consequences of donor nephrectomy might be reduced kidney function, increased risk for cardiovascular disease, impaired quality of life, and fatigue. Few studies have investigated associations between clinical and self-reported outcomes in a long-term perspective. Thus, we aimed to investigate relationships between clinical, self-reported, and donation-specific outcomes in a nationwide cohort.

Material/Methods: We conducted a prospective follow-up study and assessed pre- and post-donation data from 202 donors who donated in 2001–2004. During 2012–2013, data on donors’ self-reported (quality of life and fatigue) and donation-specific outcomes were collected. We performed linear regression for each component score of the generic instrument Short-Form, SF36v2, measuring quality of life, and the 5 domains of fatigue. Clinical parameters tested as independent variables were medical treatment of hyperlipidemia or hypertension, current smoking status, BMI, hemoglobin, and eGFR. Data were adjusted for age and gender.

Results: Approximately 10 years after donation, 67 donors were hypertensive and 54 donors had eGFR <60 ml/min/1.73 m². Mean increase in plasma creatinine was 16.6 µmol/l (SD=16.3). None of the clinical parameters were significant predictors for QoL. Female gender was significantly associated with general fatigue. There was a significant difference in perception of recognition from health personnel between donors with hypertension and donors without hypertension.

Conclusions: Our results show no associations between clinical and self-reported outcomes. However, we found a significant relationship between hypertension and donation-specific outcomes. Hypertension or reduced kidney function was identified in a minority of the donors. The increased risk for fatigue among female donors needs more investigation.

MeSH Keywords: Kidney Transplantation • Patient Outcome Assessment • Quality of Life • Time • Tissue and Organ Procurement

Abbreviations: BMI – body mass index; BP – blood pressure; eGFR – estimated glomerular filtration rate; ESRD – end stage renal disease; GF – general fatigue; HB – hemoglobin; LKD – live kidney donor; MCS – mental component score; MF – mental fatigue; MFI – multidimensional fatigue inventory; PCS – physical component score; PF – physical fatigue; PTH – parathyroid hormone; QoL – quality of life; RA – reduced activity; RM – reduced motivation; SF-36v2 – Short-Form 36v2; SPSS – Statistical Package for the Social Sciences

Full-text PDF: http://www.annalsoftransplantation.com/abstract/index/idArt/902330
Background

Live donor kidney transplantation is considered to be the criterion standard treatment for patients with end-stage renal disease (ESRD). Globally, live kidney donation has increased by approximately 50% and is now an established treatment in most countries [1]. However, there has been stagnation and even a decline in some countries in Europe, Northern America, and Oceania [2,3]. This is also the case in Norway, where 40% of the kidney transplants were from live donors up to 2005 [4] but there has been a decline to 25% in 2015. This may reflect some ambiguity concerning the use of live donors. Obviously, there is a need for long-term follow-up to provide precise knowledge with regard to long-term health, as a basis for safe expansion of live kidney donor (LKD) selection criteria, and to ensure qualified informed consent from prospective donors [5–7], as well as guidelines for long-term follow-up [8].

Over the years, a variety of long-term follow-up studies have been conducted. Age, gender, body mass index (BMI), blood pressure (BP), and time since donation have been associated with renal function [9–15], and recent studies suggest an increased risk for cardiovascular mortality [16] and ESRD [17,18] in live donors compared to healthy non-donors. Furthermore, a recent prospective follow-up study assessed new-onset hypertension, finding a decrease in self-reported health outcomes and renal function 10 years after donation [19]. The authors suggest that the decrease was due to the donors’ increased age. Similarly, a study by Sommerer et al. [20] raised concerns about risk for fatigue and reduced mental health in female donors. They also found an expected decrease in renal function but no significant change in BP. However, none of these studies investigated if there was an association between self-reported health outcomes and renal function or other clinical parameters. To the best of our knowledge, no studies have actually investigated associations between long-term self-reported health and clinical variables. We therefore addressed a range of clinical parameters of potential relevance and their relationships with self-reported and donation-specific outcomes in a long-term prospective study.

Material and Methods

We invited 351 eligible Norwegian donors who donated a kidney at Oslo University Hospital, the Norwegian transplant center, in 2001–2004. The donors were invited by mail to participate in a 10-year follow-up study. Out of these, 217 were included. Data on self-reported health outcomes were presented in a previous report [21]. In the present study, long-term clinical data were also retrieved. Altogether, 202 out of 217 (93%) patients who gave informed consent had clinical data retrieved about 10 years after donation. Figure 1 shows a diagram of the inclusion process.

Data collection

Baseline data were available in the Scandiatransplant Living Donor Registry database. Clinical variables at 10-year follow-up were collected from the local nephrologists who performed the medical follow-up 10 years after donation. Donors’ self-reported outcomes and donation-specific outcomes were collected in 2012–2013.

Measurements

Demographic characteristics included donors’ age, gender, relationship to recipient, and years since donation.

Figure 1. Flow diagram for inclusion. Inclusion criteria flow diagram. The diagram describes how the sample of living kidney donors (LKD) who completed the questionnaires (N=217) was derived from the total donors at Oslo University Hospital in 2001–2004. Clinical data were available for 202 donors.
Clinical variables included weight, systolic and diastolic BP, use of antihypertensive drugs and statins, and smoking status. Blood tests included hemoglobin (HB), plasma creatinine, and parathyroid hormone (PTH). Estimated glomeruli filtration rate (eGFR) was calculated according to CKD-EPI equations. Urinary albumin/creatinine ratio was also measured. Changes in creatinine and BMI were estimated by comparing follow-up measures with baseline measures. PTH levels in the donors was assessed at 10 years and compared to reference values for the normal background population. Hypertension was defined as BP >140/90 or use of antihypertensive drugs.

Self-reported outcomes. The Short-Form (SF)-36v2 includes 36 items and evaluates 8 domains of functional health, which are summarized into physical (PCS) and mental health component scores (MCS). Each domain has a potential range of 0–100. The component scores PCS and MCS are transformed to have a mean value of 50 and a standard deviation of 10. Higher scores indicate better self-reported quality of life (QoL) [22]. Fatigue was assessed using the Multidimensional Fatigue Inventory (MFI), which includes 20 items covering 5 domains: general fatigue (GF), physical fatigue (PF), reduced activity (RA), reduced motivation (RM), and mental fatigue (MF). Each subscale has a potential range of 4–20; higher scores indicate more fatigue [23]. Both instruments were translated and validated into Norwegian [24,25].

Donor-specific factors. Donor-specific questions measured donation-specific factors; perceived recognition for going through the donation from family members and friends, and health care professionals; range 1–5 (from “not at all” to “a great extent”), expected recipient’s health outcome (worse=1; as good as or better than expected=0), donor’s assessment of the effect of donation on own health; range 1–5 (from “a great extent” to “not at all”), and if donor would have donated again (yes/no/unsure) [21].

Statistical analysis

Data were explored with descriptive analysis and are presented as frequencies, and measures of centrality and variance. The Wilcoxon Mann-Whitney U test was performed to investigate differences in donation-specific outcomes between donors with eGFR < or >60 ml/min/1.73 m², and donors with or without hypertension. Due to skewness in 3 of 5 domains in fatigue, we performed a logarithmic transformation on the domains GF, PF, and RA. To investigate potential associations between clinical and self-reported outcomes (SF36v2 and MFI), linear regression analysis was conducted. BMI, eGFR, medical treatment (antihypertensive drugs and statins), HB, and smoking status were independent variables, adjusted for age and gender. A 5% level of significance was considered statistically significant. All analyses were performed using the Statistical Package for the Social Sciences version 21 (SPSS Inc., Chicago, IL, USA).

Ethics

The study was approved by the Regional Medical Research Committee for Health of South-East Norway (2011/2595 D) and by the hospital’s data protection officer. An invitation letter, including information about the study, ensured confidentiality, and information about the possibility to withdraw from the study at any time was sent to eligible candidates. The candidates who returned the informed consent sheet were included in the study.

Results

Demographics and relation to the recipient

Median medical follow-up time was 11 years (range 6–15 years). Table 1 shows the characteristics of the donors. Mean age at medical follow-up was 60.6 years (range 34–89 years). The majority (62.9%) were females and the most common relationship to the recipient was sibling (33.2%), followed by parent (25.7%).

Clinical data

Clinical data at medical follow-up are shown in Table 2. At follow-up, donors’ mean systolic BP was 129.2 mmHg (SD=14.7) and diastolic BP was 78.5 mmHg (SD=7.8). One-third of the donors had hypertension (n=67) and 52 used statins. Mean age of hypertensive donors was 63.7 years (SD 10.5). Mean eGFR was 68.1 ml/min/1.73 m² (SD=14.0) and 54 donors had low eGFR (<60 ml/min/1.73 m²); their mean age was 67.1 (SD=10.2). Mean change in creatinine was 16.6 µmol/l (SD=16.3). The donors had a mean BMI of 26.5 kg/m² (SD=3.7) and the mean change in BMI was 0.7 (SD=2.2).

Self-reported outcomes

Scores on QoL (SF-36v2) and fatigue (MFI) are presented in Table 3. The donors mainly scored high on PCS and MCS and low on all the domains of fatigue. As shown in Table 4, we found no significant association between clinical variables and PCS and MCS. In fatigue, there was a significant association between BMI and the domain RA, and between the domain GF and gender.

Donation-specific factors

Recognition from family or friends for being a donor was perceived by the majority of the donors, and two-thirds perceived...
### Table 1. Demographics and relation to recipient.

<table>
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<tr>
<th></th>
<th>N</th>
<th>Mean (SD)</th>
<th>Range</th>
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<tbody>
<tr>
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<td>202</td>
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<td>Follow-up time after donation (years)</td>
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<table>
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<th>Relationship to recipient</th>
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<td>Parent</td>
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<td></td>
</tr>
</tbody>
</table>

Descriptive analysis: continuous variables presented by mean and standard deviation (SD); nominal variables presented by frequency and percent (%).

### Table 2. Kidney donors; characteristics by clinical data at follow-up (N=202).

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean (SD)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Systolic BP (mmHg)</td>
<td>185</td>
<td>129.2</td>
<td>(14.7)</td>
</tr>
<tr>
<td>Diastolic BP (mmHg)</td>
<td>185</td>
<td>78.5</td>
<td>(7.8)</td>
</tr>
<tr>
<td>BMI</td>
<td>163</td>
<td>26.5</td>
<td>(2.7)</td>
</tr>
<tr>
<td>Change in BMI</td>
<td>163</td>
<td>0.7</td>
<td>(2.2)</td>
</tr>
<tr>
<td>Creatinine (µmol/L)</td>
<td>202</td>
<td>91.6</td>
<td>(18.4)</td>
</tr>
<tr>
<td>Change in creatinine (µmol/L)</td>
<td>200</td>
<td></td>
<td></td>
</tr>
<tr>
<td>eGFR (ml/min/1.73 m²)</td>
<td>201</td>
<td>68.1</td>
<td>(14.0)</td>
</tr>
<tr>
<td>Hemoglobin (g/dl)</td>
<td>197</td>
<td>14.3</td>
<td>(1.1)</td>
</tr>
<tr>
<td>PTH (pmol/l)</td>
<td>98</td>
<td>7.1</td>
<td>(4.2)</td>
</tr>
<tr>
<td>Cholesterol (mmol/L)</td>
<td>195</td>
<td>5.4</td>
<td>(1.0)</td>
</tr>
<tr>
<td>Triglycerides (mmol/L)</td>
<td>159</td>
<td>1.4</td>
<td>(0.7)</td>
</tr>
<tr>
<td>HDL (mmol/L)</td>
<td>181</td>
<td>1.6</td>
<td>(0.5)</td>
</tr>
<tr>
<td>LDL (mmol/L)</td>
<td>148</td>
<td>3.4</td>
<td>(0.9)</td>
</tr>
</tbody>
</table>

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Low eGFR</td>
<td>54</td>
<td>(26.7)</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>67</td>
<td>(33.2)</td>
<td></td>
</tr>
<tr>
<td>Proteinuria</td>
<td>8</td>
<td>(41.7)</td>
<td></td>
</tr>
<tr>
<td>Microalbuminuria</td>
<td>17</td>
<td>(78.7)</td>
<td></td>
</tr>
<tr>
<td>Antihypertensive drugs</td>
<td>64</td>
<td>(29.5)</td>
<td></td>
</tr>
<tr>
<td>Statins</td>
<td>52</td>
<td>(25.7)</td>
<td></td>
</tr>
<tr>
<td>Current smoker</td>
<td>26</td>
<td>(12.9)</td>
<td></td>
</tr>
<tr>
<td>Intercurrent diseases</td>
<td>70</td>
<td>(34.7)</td>
<td></td>
</tr>
</tbody>
</table>

Descriptive analysis: continuous variables presented by mean and standard deviation (SD); nominal variables presented by frequency and percent (%). Hypertension was defined as BP>140/90 or antihypertensive drugs. Low eGFR was defined as <60 ml/min/1.73 m².
recognition to a great extent or to some extent from health personnel, as shown in Table 5. Donors with hypertension perceived significantly more recognition from health personnel than those without hypertension. Nearly all donors would donate again if possible, but significantly fewer donors with hypertension felt this way. Less than 20% perceived the donation to be harmful to their own health. The recipients’ health was described as expected or better than expected by the majority (70.8%) of the donors.

Discussion

This long-term follow-up study shows that the majority of the donors have good outcomes, both clinical and self-reported at approximately 10 years after donation. The results are in line with several follow-up studies performed over the years [5,11,14,19,20].

This is the first study to investigate the association between clinical outcomes and donors’ perception of their own health and donation-specific factors. One particular aspect of our study was the association between clinical outcomes and the donors’ perception of recognition for their donation. In our previous study [21], significantly fewer donors perceived recognition from health personnel than from family and friends. Thus, it is interesting that the hypertensive donors in the current study perceived significantly more recognition from health personnel than did normotensive LKD, while perception of recognition

<table>
<thead>
<tr>
<th>Physical Component Score (PCS)</th>
<th>N</th>
<th>Mean</th>
<th>(SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>182</td>
<td>53.52</td>
<td>8.74</td>
<td>21.98-65.51</td>
</tr>
<tr>
<td>Mental Component Score (MCS)</td>
<td>182</td>
<td>53.32</td>
<td>8.64</td>
<td>21.17-63.60</td>
</tr>
<tr>
<td>General fatigue (GF)</td>
<td>192</td>
<td>8.38</td>
<td>4.42</td>
<td>4-20</td>
</tr>
<tr>
<td>Physical fatigue (PF)</td>
<td>194</td>
<td>8.35</td>
<td>4.25</td>
<td>4-20</td>
</tr>
<tr>
<td>Reduced activity (RA)</td>
<td>196</td>
<td>8.38</td>
<td>4.11</td>
<td>4-20</td>
</tr>
<tr>
<td>Reduced motivation (RM)</td>
<td>193</td>
<td>7.31</td>
<td>3.14</td>
<td>4-19</td>
</tr>
<tr>
<td>Mental fatigue (MF)</td>
<td>197</td>
<td>8.03</td>
<td>3.57</td>
<td>4-19</td>
</tr>
</tbody>
</table>

Descriptive analysis: continuous variables presented by mean and standard deviation (SD); SF-36v2: each component score has a theoretical range of 0–100; MFI: each subscale has a theoretical range of 4–20; higher scores indicate more fatigue.

Table 3. Self-reported outcomes; Mean scores QoL (SF-36v2) and fatigue (MFI).

Table 4. Association between QoL and fatigue and clinical variables, gender and age.

Linear regression: each domain was analyzed separately; PCS – physical component score; MCS – mental component score; GF – general fatigue; PF – physical fatigue; RA – reduced activity; RM – reduced motivation; MF – mental fatigue; B – the regression coefficient.

**Table 4.** Association between QoL and fatigue and clinical variables, gender and age.
from family and friends did not differ. One explanation may be that LKD who develop hypertension might be followed more closely and therefore receive more attention from health professionals than did the normotensive donors. However, we do not know if the frequency of medical follow-up differs between the groups. Another noteworthy finding was that even though only a minority claimed that the donation had been harmful to own health, 4 of the 6 LKD who retrospectively were reluctant to donate were in the hypertensive group. This might be in line with our previous report [21], which found that 3 donors both regretted donation and perceived that the donation had harmed their health. None of our donors were in need of kidney replacement treatment; hence, it seems as if being dependent on antihypertensive agents might be more burdensome than symptom-free reduced kidney function. Being dependent of taking antihypertensive agents may give a feeling of reduced health as a consequence of the donation, which again can affect the retrospective willingness to donate. Still, in contrast to a previous study comparing QoL between kidney recipients and patients in dialysis [26], we did not find any association between hypertension and self-reported health QoL. The donors may be employing beneficial denial and avoidance strategies, because being hypertensive is a situation out of their control [27], and this might explain the incongruence

### Table 5. Perception of recognition and self-evaluation of health in donors with low GFR or hypertension.

<table>
<thead>
<tr>
<th>Perception of Recognition</th>
<th>All (N=202)</th>
<th>eGFR &lt;60 ml/min/1.73 m² (N=54)</th>
<th>Hypertension (N=67)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recognition from health personnel</td>
<td>0.71</td>
<td>0.02</td>
<td></td>
</tr>
<tr>
<td>To a great extent</td>
<td>74 (36.6)</td>
<td>20 (37.0)</td>
<td>29 (43.3)</td>
</tr>
<tr>
<td>To some extent</td>
<td>54 (26.7)</td>
<td>15 (27.8)</td>
<td>13 (19.4)</td>
</tr>
<tr>
<td>To a little extent</td>
<td>30 (14.9)</td>
<td>9 (16.7)</td>
<td>9 (13.4)</td>
</tr>
<tr>
<td>Not at all</td>
<td>25 (12.4)</td>
<td>4 (7.4)</td>
<td>6 (9.0)</td>
</tr>
<tr>
<td>Unsure</td>
<td>16 (7.9)</td>
<td>4 (7.4)</td>
<td>9 (13.4)</td>
</tr>
<tr>
<td>Recognition from family/friends</td>
<td>0.24</td>
<td>0.71</td>
<td></td>
</tr>
<tr>
<td>To a great extent</td>
<td>128 (63.4)</td>
<td>34 (63.0)</td>
<td>40 (59.7)</td>
</tr>
<tr>
<td>To some extent</td>
<td>47 (23.3)</td>
<td>13 (24.1)</td>
<td>18 (26.9)</td>
</tr>
<tr>
<td>To a little extent</td>
<td>15 (7.4)</td>
<td>2 (3.7)</td>
<td>3 (4.5)</td>
</tr>
<tr>
<td>Not at all</td>
<td>1 (0.5)</td>
<td>0 (0)</td>
<td>1 (1.5)</td>
</tr>
<tr>
<td>Unsure</td>
<td>7 (3.5)</td>
<td>4 (7.4)</td>
<td>4 (6.0)</td>
</tr>
<tr>
<td>Donation harmful to own health</td>
<td>0.21</td>
<td>0.38</td>
<td></td>
</tr>
<tr>
<td>To a great extent</td>
<td>1 (0.5)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>To some extent</td>
<td>11 (5.4)</td>
<td>2 (3.7)</td>
<td>3 (4.5)</td>
</tr>
<tr>
<td>To a little extent</td>
<td>27 (13.4)</td>
<td>6 (11.1)</td>
<td>7 (10.4)</td>
</tr>
<tr>
<td>Not at all</td>
<td>150 (74.3)</td>
<td>43 (79.6)</td>
<td>53 (79.1)</td>
</tr>
<tr>
<td>Unsure</td>
<td>11 (5.4)</td>
<td>2 (3.7)</td>
<td>4 (6.0)</td>
</tr>
<tr>
<td>Would have donated again</td>
<td>0.43</td>
<td>0.01</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>189 (94)</td>
<td>52 (96)</td>
<td>58 (86.6)</td>
</tr>
<tr>
<td>No</td>
<td>6 (3)</td>
<td>0 (0)</td>
<td>4 (6.0)</td>
</tr>
<tr>
<td>Unsure</td>
<td>6 (3)</td>
<td>2 (4)</td>
<td>4 (6.0)</td>
</tr>
</tbody>
</table>

Non-parametric independent samples Wilcoxon Mann-Whitney U Test; *p-value between donors with eGFR < or ≥60 ml/min/1.73 m²; ** p-value between donors with or without hypertension; low GFR: <60 ml/min/1.73 m²; hypertension: BP >140/90 or antihypertensive drugs.
in our findings. In the present study, one-third of the donors were treated by antihypertensive agents. Hypertension and use of antihypertensive drugs after donation has been shown in other studies; however, the incidence varies [9,14,19,28], and in 1 study nearly half of the donors were on antihypertensive agents or had undiagnosed hypertension at a mean follow-up time of 14 years [14]. Elderly donors might be more hypertensive than younger ones [19]; however, in our cohort the share of LKD at age 67 years or older who were treated for hypertension was lower than in the Norwegian population in the same age group [29], at 43.9% vs. 50%, respectively. The donors in the cohort studies by Kasiskie [28] and Janki [19] had a lower mean age than the donors in our cohort, which may explain the lower incident of hypertension. Most of our donors were younger than 67 years, and in the age group 45 to 66 years, 31% of the LKD were treated with antihypertensive drugs compared to 21% of the Norwegian general population in the same age group [29]. It appears that the incidence of hypertension is somewhat higher in the donors when compared to the background population. Although a higher incidence of hypertension in donors may possibly be explained by the donation per se, it may also be explained by the regular scheduled visits during long-term follow-up with a higher likelihood of detection of hypertension. These results indicate the importance of long-term follow-up in order to monitor BP and assure that hypertensive treatment will be initiated when needed.

Another result that promotes long-term follow-up is that even though no donors were in treatment for reduced kidney function, a minority of the donors had low eGFR (<60 ml/min/1.73 m²) at 10 years after donation. This result corresponds with results from other studies [14,15,19,28,30]. However, previous studies indicate both an increase and a decrease in GFR after donation [14,15,28]. Fehrman-Ekholm et al. [14] suggested that GFR increases in the first years after donation, and then stabilizes before a decrease in GFR starts. If this is the case, the LKD in the current study might be in the stable phase at approximately 10 years post-donation, and we might see a decrease after 15 or 20 years after donation. In contrast, Fournier et al. [13] found no decrease in kidney function 30 years after donation. The uncertainty of the course of GFR after donation supports the need for long-term follow-up. However, even if the policy in Norway is to follow the donors at 5-year intervals, not all Norwegian donors have a medical follow-up at 10 years [21].

Another significant finding was the association between gender and general fatigue. Even though the evidence of gender differences in fatigue is inconsistent [31–34], female gender has previously been associated with fatigue in LKD [20,21]. In a previous report, we reported that female donors scored significantly higher than male donors on 3 out of 5 domains of fatigue [21]. Congruently, Sommerer et al. [20] found that female donors scored lower on MCS in QoL, and that middle-aged female donors scored higher on 2 out of 5 domains in fatigue compared to the German general population. The findings in the present study and in the previous studies seem to strengthen the notion that female donors might be more exposed to fatigue than male donors, and may need to be followed more closely after donation. The knowledge gap on gender differences in fatigue and live donation indicates a need for more research on this topic.

Even though we did not discover any association between gender and the 2 component scores PCS and MCS in this study, we did find a gender difference in 4 domains of QoL in our previous study [21]. This is similar to the results of Ay et al. [35], who compared QoL in recipients, donors, and a control group, and reported that male donors scored higher on PCS and MCS than female donors at 9 months after donation.

The body of long-term research on live kidney donation has a variation in design, including retrospective, prospective, or matched control groups. Additionally, time span varies from less than 5 years to nearly 50 years after donation, and there is a huge difference in sample sizes; from less than 100 LKD up to several thousand [9,10,13,17,18,36,37]. The dissimilarity makes it difficult to compare results. One of the strengths of our study was that median follow-up time was 11 years, with a limited time span. This may give more precise information about long-term health after donation. Other strengths were the sample size of 202 donors and that this was a nationwide study.

Our findings should be interpreted cautiously. This study was a follow-up of a previous study on quality of life in kidney donors. When planning the original study, we did not perform any power calculation for evaluating potential associations between blood pressure, renal function, and quality of life measures. Accordingly, our mainly negative findings could be explained by lack of statistical power. The design did not allow for comparison with healthy controls, which might be another limitation. However, studies using control groups have limitations as well, and it is difficult to find appropriate control groups [38].

Conclusions

Our results show no associations between clinical and self-reported outcomes. However, we found a significant relationship between hypertension and donor-specific factors. Hypertension and reduced kidney function were identified in a minority of the donors. Hypertension may affect the self-perception of health and retrospective willingness to donate.

Long-term follow-up appears to be mandatory for monitoring of blood pressure and kidney function. The increased risk for fatigue among female donors needs more investigation.
Competing interests

The authors of this manuscript have no conflicts of interest to disclose.

References:

24. We thank the local nephrologists who provided data on clinical parameters and, in particular, all the donors who participated in the cross-sectional study.
Forskningsprosjektet

10-års oppfølging av levende givere

Kreft-, kirurgi- og transplantasjonsklinikken
Oslo universitetssykehus HF, Rikshospitalet

Käthe Meyer
Marit Helen Andersen
Astrid Klopstad Wahl
Ida Torunn Bjørk
Anders Hartmann
Aksel Foss
Kjære levende giver av nyre.


Når du har svart på spørsmålene kan du sende skjema tilbake i vedlagte konvolutt som er frankert. Alle svar blir konffidensielt behandlet.

Først vil vi be deg om noen bakgrunnsopplysninger:

A. Fødselsdato

B. Er du kvinne eller mann?

C. Hva er din sivilstand?

<table>
<thead>
<tr>
<th>Enslig</th>
<th>Gift</th>
<th>Samboende</th>
<th>Skilt/separert</th>
<th>Enke/enkemann</th>
</tr>
</thead>
</table>

D. Hvilken utdanning er den høyeste du har fullført?

<table>
<thead>
<tr>
<th>Grunnskole 7-10 år</th>
</tr>
</thead>
<tbody>
<tr>
<td>Realskole, middelskole, yrkesskole, 1-2 årig videregående skole</td>
</tr>
<tr>
<td>Artium, økonomisk gymnas, allmennfaglig retning i videregående skole</td>
</tr>
<tr>
<td>Høgskole/universitet mindre enn 4 år</td>
</tr>
<tr>
<td>Høgskole/universitet 4 år eller mer</td>
</tr>
<tr>
<td>Annet, spesifiser, inkl. hvor mange år</td>
</tr>
</tbody>
</table>
Din Helse og Trivsel

Dette spørreskjemaet handler om hvordan du ser på din egen helse. Disse opplysningene vil hjelpe oss til å få vite hvordan du har det og hvordan du er i stand til å utføre dine daglige gjøremål. *Takk for at du fyller ut dette spørreskjemaet!*

For hvert av de følgende spørsmålene vennligst sett et ☐ i den ene luken som best beskriver ditt svar.

1. **Stort sett, vil du si at din helse er:**

<table>
<thead>
<tr>
<th>Utmerket</th>
<th>Meget god</th>
<th>God</th>
<th>Nokså god</th>
<th>Dårlig</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
<td>☐ 5</td>
</tr>
</tbody>
</table>

2. **Sammenlignet med for ett år siden, hvordan vil du si at din helse stort sett er nå?**

<table>
<thead>
<tr>
<th>Mye bedre nå enn for ett år siden</th>
<th>Litt bedre nå enn for ett år siden</th>
<th>Omtrent den samme som for ett år siden</th>
<th>Litt dårligere nå enn for ett år siden</th>
<th>Mye dårligere nå enn for ett år siden</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>☐ 1</td>
<td>☐ 2</td>
<td>☐ 3</td>
<td>☐ 4</td>
<td>☐ 5</td>
</tr>
</tbody>
</table>
3 De neste spørsmålene handler om aktiviteter som du kanskje utfører i løpet av en vanlig dag. Er din helse slik at den begrenser deg i utførelsen av disse aktivitetene nå? Hvis ja, hvor mye?

<table>
<thead>
<tr>
<th></th>
<th>Ja, begrenser meg mye</th>
<th>Ja, begrenser meg litt</th>
<th>Nei, begrenser meg ikke i det hele tatt</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>Anstrengende aktiviteter som å løpe, løfte tunge gjenstander, delta i anstrengende idrett</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>b</td>
<td>Moderate aktiviteter som å flytte et bord, støvsuge, gå en tur eller drive med hagearbeid</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>c</td>
<td>Løfte eller bære en handlekurv</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>d</td>
<td>Gå opp trappen flere etasjer</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>e</td>
<td>Gå opp trappen én etasje</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>f</td>
<td>Bøye deg eller sitte på huk</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>g</td>
<td>Gå mer enn to kilometer</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>h</td>
<td>Gå noen hundre meter</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>i</td>
<td>Gå hundre meter</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
<tr>
<td>j</td>
<td>Vaske eller kle på deg</td>
<td>▼ 1 .......... ▼ 2 .......... ▲ 3</td>
<td></td>
</tr>
</tbody>
</table>
4. **I løpet av de siste 4 ukene, hvor ofte har du hatt noen av de følgende problemer i ditt arbeid eller i andre av dine daglige gjøremål på grunn av din fysiske helse?**

<table>
<thead>
<tr>
<th></th>
<th>Hele tiden</th>
<th>Mye av tiden</th>
<th>En del av tiden</th>
<th>Litt av tiden</th>
<th>Ikke i det hele tatt</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Du har måttet redusere tiden du har brukt på arbeid eller på andre gjøremål</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>b Du har utrettet mindre enn du hadde ønsket</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>c Du har vært hindret i å utføre visse typer arbeid eller gjøremål</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>d Du har hatt problemer med å gjennomføre arbeidet eller andre gjøremål (f.eks. det krevde ekstra anstrengelser)</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

5. **I løpet av de siste 4 ukene, hvor ofte har du hatt noen av de følgende problemer i ditt arbeid eller i andre av dine daglige gjøremål på grunn av følelsesmessige problemer (som f.eks. å være deprimert eller engstelig)?**

<table>
<thead>
<tr>
<th></th>
<th>Hele tiden</th>
<th>Mye av tiden</th>
<th>En del av tiden</th>
<th>Litt av tiden</th>
<th>Ikke i det hele tatt</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Du har måttet redusere tiden du har brukt på arbeid eller på andre gjøremål</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>b Du har utrettet mindre enn du hadde ønsket</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>c Du har utførte arbeidet eller andre gjøremål mindre grundig enn vanlig</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>
6. I løpet av de siste 4 ukene, i hvilken grad har din fysiske helse eller følelsesmessige problemer hatt innvirkning på din vanlige sosiale omgang med familie, venner, naboer eller foreninger?

<table>
<thead>
<tr>
<th>Ikke i det hele tatt</th>
<th>Litt</th>
<th>En del</th>
<th>Mye</th>
<th>Svært mye</th>
</tr>
</thead>
<tbody>
<tr>
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<td>▼</td>
</tr>
</tbody>
</table>

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5

7. Hvor sterke kroppslige smerter har du hatt i løpet av de siste 4 ukene?

<table>
<thead>
<tr>
<th>Ingen</th>
<th>Meget svake</th>
<th>Svake</th>
<th>Moderate</th>
<th>Sterke</th>
<th>Meget sterke</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
<td>▼</td>
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</tr>
</tbody>
</table>

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5  ☐ 6

8. I løpet av de siste 4 ukene, hvor mye har smerter påvirket ditt vanlige arbeid (gjelder både arbeid utenfor hjemmet og husarbeid)?

<table>
<thead>
<tr>
<th>Ikke i det hele tatt</th>
<th>Litt</th>
<th>En del</th>
<th>Mye</th>
<th>Svært mye</th>
</tr>
</thead>
<tbody>
<tr>
<td>▼</td>
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<td>▼</td>
</tr>
</tbody>
</table>

☐ 1  ☐ 2  ☐ 3  ☐ 4  ☐ 5
9. Disse spørsmålene handler om hvordan du har følt deg og hvordan du har hatt det de siste 4 ukene. For hvert spørsmål, vennligst velg det svaralternativet som best beskriver hvordan du har hatt det. Hvor ofte i løpet av de siste 4 ukene har du...

<table>
<thead>
<tr>
<th>Spørsmål</th>
<th>Hele tiden</th>
<th>Mye av tiden</th>
<th>En del av tiden</th>
<th>Litt av tiden</th>
<th>Ikke i det hele tatt</th>
</tr>
</thead>
<tbody>
<tr>
<td>a Følt deg full av liv?</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>b Følt deg veldig nervøs?</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>c Vært så langt nede at ingenting har kunnnet munter deg opp?</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>d Følt deg rolig og harmonisk?</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>e Hatt mye overskudd?</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>f Følt deg nedfor og deprimert?</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>g Følt deg glad?</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
<tr>
<td>h Følt deg trett?</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>

10. I løpet av de siste 4 ukene, hvor ofte har din fysiske helse eller følelsesmessige problemer påvirket din sosiale omgang (som det å besøke venner, slektninger osv.)?

<table>
<thead>
<tr>
<th>Spørsmål</th>
<th>Hele tiden</th>
<th>Mye av tiden</th>
<th>En del av tiden</th>
<th>Litt av tiden</th>
<th>Ikke i det hele tatt</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<td>▼</td>
<td>▼</td>
<td>▼</td>
</tr>
</tbody>
</table>
11. Hvor RIKTIG eller GAL er hver av de følgende påstander for deg?

<table>
<thead>
<tr>
<th></th>
<th>Helt riktig</th>
<th>Delvis riktig</th>
<th>Vet ikke</th>
<th>Delvis gal</th>
<th>Helt gal</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>c</td>
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<td></td>
</tr>
<tr>
<td>d</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Det virker som om jeg blir syk litt lettere enn andre .................  
Jeg er like frisk som de fleste jeg kjenner ........................................  
Jeg tror at helsen min vil forverres ........................................  
Jeg har utmerket helse ........................................  

Takk for at du fylte ut dette spørreskjemaet!
Spørreskjema om helse

Norsk versjon, for Norge

(Norwegian version for Norway)
Vis hvilke utsagn som passer best på din helsetilstand i dag ved å sette et kryss i en av rutene utenfor hver av gruppenes nedenfor.

**Gange**
- Jeg har ingen problemer med å gå omkring.
- Jeg har litt problemer med å gå omkring.
- Jeg er sengeliggende.

**Personlig stell**
- Jeg har ingen problemer med personlig stell.
- Jeg har litt problemer med å vaske meg eller kle meg.
- Jeg er ute av stand til å vaske meg eller kle meg.

**Vanlige gjøremål** *(f.eks. arbeid, studier, husarbeid, familie- eller fritidsaktiviteter).*
- Jeg har ingen problemer med å utføre mine vanlige gjøremål.
- Jeg har litt problemer med å utføre mine vanlige gjøremål.
- Jeg er ute av stand til å utføre mine vanlige gjøremål.

**Smerthe/ubehag**
- Jeg har verken smerte eller ubehag.
- Jeg har moderat smerte eller ubehag.
- Jeg har sterk smerte eller ubehag.

**Angst/depresjon**
- Jeg er verken engstelig eller deprimert.
- Jeg er noe engstelig eller deprimert.
- Jeg er svært engstelig eller deprimert.
For å hjelpe folk til å si hvor god eller dårlig en helsetilstand er, har vi laget en skala (omtrent som et termometer) hvor den beste tilstanden du kan tenke deg er merket 100 og den verste tilstanden du kan tenke deg er merket 0.

Vi vil gjerne at du viser på denne skalaen hvor god eller dårlig helsetilstanden din er i dag, etter din oppfatning. Vær vennlig å gjøre dette ved å trekke en linje fra boksen nedenfor til det punktet på skalaen som viser hvor god eller dårlig din helsetilstand er i dag.

Din egen helsetilstand
Veiledning:
Ved hjelp av de følgende utsagnene vil vi gjerne danne oss et bilde av hvorledes du har hatt det i det siste. Ta for eksempel utsagnet:

"JEG FØLER MEG AVSLAPPET"

Dersom du synes at dette er **helt riktig**, at du faktisk har følt deg avslappet i det siste, setter du en X i ruta helt til venstre, slik:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>ja, det er riktig</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>nei, det er ikke riktig</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Jo mer du er uenig i utsagnet, desto mer setter du en X i retning av "nei, det er ikke riktig".

Vennligst ikke hopp over noe utsagn og sett en X i bare én rute for hvert utsagn.

<table>
<thead>
<tr>
<th>1</th>
<th>Jeg føler meg opplagt.</th>
<th>Ja, det er riktig</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Fysisk føler jeg meg bare i stand til å gjøre litt.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3</td>
<td>Jeg føler meg veldig aktiv.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4</td>
<td>Jeg har lyst til å gjøre alle slags hyggelige ting.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5</td>
<td>Jeg føler meg sliten og trett.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6</td>
<td>Jeg synes jeg gjør mye i løpet av en dag.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7</td>
<td>Når jeg driver med noe, kan jeg samle tankene om det jeg gjør.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8</td>
<td>Jeg klarer å gjøre mye fysisk.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9</td>
<td>Jeg gruer meg for å måtte gjøre ting.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>Jeg synes jeg gjør veldig lite i løpet av en dag.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11</td>
<td>Jeg kan konsentrere meg godt.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12</td>
<td>Jeg er uthvilt.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13</td>
<td>Det krever stor innsats å konsentrere seg om ting.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14</td>
<td>Jeg føler meg i dårlig fysisk form.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15</td>
<td>Jeg har masse planer.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16</td>
<td>Jeg blir lett sliten.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17</td>
<td>Jeg får gjort lite.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18</td>
<td>Jeg har ikke lyst til å gjøre noe som helst.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19</td>
<td>Tankene mine vandrer lett.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20</td>
<td>Jeg føler jeg er i utmerket fysisk form.</td>
<td>Ja, det er riktig</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
I den siste delen av spørreskjema ber vi deg om å svare på noen spørsmål knyttet til det å være giver av nyre.

**Forhold til mottager, familie og venner**

1. Den som mottok min nyre var:
   - Far
   - Mor
   - Bror
   - Ektefelle
   - Venn
   - Sønn
   - Datter
   - Søster
   - Samboer
   - Annen, spesifiser: 

2. I hvilken grad opplever du at du har fått anerkjennelse fra ditt nærmiljø for å være giver av nyre, det vil si fra de du omgås i arbeid, fritid, og i hjemmet?
   - I stor grad
   - I noen grad
   - I liten grad
   - Ikke i det hele tatt
   - Vet ikke

3. I hvilken grad har det å være giver påvirket ditt forhold til mottageren?
   - I stor grad
   - I noen grad
   - I liten grad
   - Ikke i det hele tatt
   - Vet ikke

4. Er helsen til den som fikk nyre nå så bra som du forventet før du ga nyren?
   - Mye bedre
   - Litt bedre
   - Omtrent
   - Litt dårligere
   - Mye dårligere
   - som forventet

5. I hvilken grad føler du deg som giver nå ansvarlig for helsen til mottager av nyren?
   - I stor grad
   - I noen grad
   - I liten grad
   - Ikke i det hele tatt
   - Vet ikke

6. Hvis dårligere enn forventet på spørsmål 4: vennligst angi mottakerens status:
   (sett bare ett kryss)
   - Er i dialyse – har ikke blitt transplantert igjen
   - Er i dialyse, men har blitt transplantert med en annens nyre
   - Har en annens nyre og klarer seg uten dialyse
   - Er død
   - Vet ikke
   - Annet, vennligst forklar:

7. I hvilken grad har det at du ga nyre ført til problemer i ditt nærmiljø, det vil si fra de du omgås i arbeid, fritid, og i hjemmet?
   - I stor grad
   - I noen grad
   - I liten grad
   - Ikke i det hele tatt
   - Vet ikke
Arbeidssituasjon

8. Var du i arbeid før du ga nyre?
   Ja, heltidsarbeid (utenom husarbeid)  Ja, deltidsarbeid (utenom husarbeid)
   Nei, ikke i arbeid

9. Dersom du har byttet arbeid etter donasjonen – har det sammenheng med at du ga nyre?
   I stor grad  I noen grad  I liten grad  Ikke i det hele tatt  Vet ikke

10. Er du i arbeid nå, 10 år etter donasjonen?
    Ja, heltidsarbeid (utenom husarbeid)  Ja, deltidsarbeid (utenom husarbeid)
    Nei, ikke i arbeid

11. Hvis du ikke er i arbeid, er det på grunn av:
    Arbeidsløshet, permittering
    Pensjon eller trygd
    Utdanning
    Sykemelding
    Annet, spesifiser:

12. Hvis du er i arbeid, i hvilken grad tror du at det at du har gitt nyre har påvirket din yrkeskarriere?
    I stor grad  I noen grad  I liten grad  Ikke i det hele tatt  Vet ikke

Helsetilstand/medisinske problemer etter donasjon

13. I hvilken grad opplever du at du har fått anerkjennelse fra helsepersonell for å være giver av nyre i årene som har gått siden donasjonen?
    I stor grad  I noen grad  I liten grad  Ikke i det hele tatt  Vet ikke

14. I hvilken grad opplever du at du har hatt anledning til å ta opp med helsepersonell eventuelle bekymringer du har hatt etter at du ga nyre?
    I stor grad  I noen grad  I liten grad  Ikke i det hele tatt  Vet ikke

15. I hvilken grad føler du det at du ga nyre har vært skadelig for din helse?
    I stor grad  I noen grad  I liten grad  Ikke i det hele tatt  Vet ikke

16. Hvor ofte går du til kontroll hos spesialist i nyresykdommer?
    Hvert år  Annet hvert år  Sjeldnere enn annethvert år  Aldri

13
17. Hvor ofte har du brukt smertestillende medisin den siste måneden? (sett bare ett kryss)
   
   Daglig   Hver uke, men ikke hver dag   Sjeldnere enn hver uke   Aldri

18. Hvor ofte har du brukt avslappende/beroligende medisin eller sovemedisin den siste måneden? (sett bare ett kryss)
   
   Daglig   Hver uke, men ikke hver dag   Sjeldnere enn hver uke   Aldri

19. For kvinnelige givere: har du hatt graviditet etter donasjonen?
   
   Ja   Nei
   Hvis JA: Hvor mange?

20. I hvilken grad har det å være giver av nyre medført økonomiske problemer for deg?
   
   I stor grad   I noen grad   I liten grad   Ikke i det hele tatt   Vet ikke

21. Dersom du har fått økonomiske problemer som følge av det å være giver av nyre, på hvilken måte?
   
   Tap av inntekt   Ikke fått dekket mine utgifter   Annet, vennligst spesifiser

De siste spørsmålene gjelder sammenlikning av din helsetilstand og tilværelse før donasjonen og situasjonen din nå.

22. Når du tenker på hvordan du hadde det før donasjonen, var du stort sett fornøyd med tilværelsen, eller var du stort sett misfornøyd?
   
   Svært fornøyd   Meget fornøyd   Nokså fornøyd   Nokså misfornøyd   Meget misfornøyd   Svært misfornøyd

23. Når du tenker på hvordan du har det nå ti år etter donasjonen, er du stort sett fornøyd med tilværelsen, eller er du stort sett misfornøyd?
   
   Svært fornøyd   Meget fornøyd   Nokså fornøyd   Nokså misfornøyd   Meget misfornøyd   Svært misfornøyd
24. Er det noen andre måter livet ditt er blitt påvirket av at du ga nyre?


25. Hvis du den gang du ga nyre hadde visst det du vet i dag, ville du da vært villig til å gi nyre?

Ja
Nei
Vet ikke

Hvis NEI, kan du si noe om hvorfor ikke?


26. De to siste spørsmålene skal gjøre det mulig for deg å beskrive opplevelser av det å være giver av nyre som ikke har kommet frem andre steder i spørreskjemaet. Det er ikke faste svaralternativer, men du kan bruke dine egne ord for å beskrive det som er viktig for deg.

a. Hva har vært viktig for deg i forhold til din opplevelse av helse og livskvalitet når det gjelder det å være giver av nyre?
Du er nå ferdig med spørreskjemaet.

Vennligst kontrollér at du har besvart alle spørsmålene.

Takk for at du har bidratt med din egen opplevelse av din situasjon, og har tatt deg tid til å besvare spørsmålene. Din innsats for å bidra til at vi vet mer om det å være giver av nyre, er høyt verdsatt.