

BMJ Open Older kidney transplantation candidates' expectations of improvement in life and health following kidney transplantation: semistructured interviews with enlisted dialysis patients aged 65 years and older

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ABSTRACT

Objective The aim was to study the expectations of improvement in life and health following kidney transplantation (KTx) in a population of wait-listed patients ≥65 years with end-stage kidney disease.

Design Qualitative research with individual in-depth interviews.

Setting Patients on dialysis enlisted for a KTx from a deceased donor were included from an ongoing study of older patients' perspectives on KTx. Qualitative face-to-face interviews were conducted in a safe and familiar setting, and were analysed thematically using the theoretical framework of lifespan.

Informants Fifteen patients (median age 70 years, range 65–82) from all parts of Norway were interviewed. Informants were included consecutively until no new information was gained.

Results Two main themes were evident: receiving a kidney is getting life back and grasp the chance. In addition, the themes 'hard to loose capacity and strength', 'reduced freedom' and 'life on hold' described the actual situation and thereby illuminated the informants' expectations. The informants tried to balance positive expectations and realism towards KTx, and they were hoping to become free from dialysis and to live a normal life.

Conclusion This study shows that older KTx candidates comprise a heterogeneous group of patients who take individual approaches that allow them to maintain autonomy and control while waiting for a transplant. This study provides new knowledge about the older KTx candidates relevant for clinicians, patients and researchers.

INTRODUCTION

Successful kidney transplantation (KTx) is the optimal treatment for patients with end-stage kidney disease (ESKD).^{1–3} Throughout the world, an increasing number of patients ≥65 years are enlisted for KTx, despite the long waiting time.^{4–6}

Strengths and limitations of this study

- Included patients were selected by their local nephrologist, had passed necessary medical investigations and had been enlisted to receive a deceased donor kidney transplant. The initial contact with the informants was not made by the researchers.
- Data richness was established by including 15 informants and interviews, with a mean duration of 52 min.
- Marital status may affect expectations of life after kidney transplantation (KTx). One limitation may be that all informants were married.
- All informants were Caucasian. Informants with another ethnicity might have introduced variations or nuances into the results.
- No patients scheduled to receive a living donor kidney transplant were included. Therefore, their negative attitude towards living donors may not be typical for all older KTx candidates.

Health-related quality of life improves after a successful KTx.^{7 8} Knowledge of health-related quality of life in older kidney transplant recipients is limited,^{9 10} even though a few recent studies have focused on older candidates and recipients.^{11 12} Older patients' thoughts about their situation awaiting a kidney transplant should be investigated.¹³

The life experience of candidates for KTx ≥65 years is broad and helps these patients cope with their situation. In lifespan theory, research on self-esteem and perceived control in relation to the ageing population in general are comprehensive.^{14 15} We used a lifespan perspective as the framework for this study.¹⁶ Self-esteem is defined as the subjective evaluation of one's worth; self-esteem increases through adult life until the

60s, then starts to decline.¹⁷ The decline in older life may be influenced by health impairment, loneliness and less perceived control,¹⁴ the latter of which is considered to be defined as a learnt expectation that can change.¹⁸ In a Dutch study, Jansen *et al* found that a relatively high self-esteem in dialysis patients was associated with low concern about the illness and low negative impact of dialysis treatment on life.¹⁹ The situation of patients ≥ 65 years with ESKD awaiting KTx is complex. To our knowledge, no previous study has focused on older ESKD patients' expectations of life and health following KTx. We studied the expectations of KTx in a population of wait-listed patients ≥ 65 years with ESKD.

METHODS

Informants and setting

In Norway, all KTx are performed at one national hospital and dialysis treatment including pretransplant work-up is spread throughout the country. Informants were included consecutively from an ongoing multimethod study that explores health-related quality of life in KTx candidates ≥ 65 years.¹¹ Patients who did not understand the Norwegian language or had cognitive dysfunction were excluded. Cognitive dysfunction was investigated as part of the pre-enlisting evaluation. Information regarding the pre-enlisting evaluation of KTx candidates have been described previously.¹¹ Patients receiving dialysis (ie, no predialytic patients were included) from all Norwegian regions were invited to participate in this qualitative study. Invitations were sent when the patient had completed the first questionnaire in the quantitative study. Semistructured interviews were performed within the first 6 months following enlisting and aimed to identify the informants' initial expectations after being accepted for the waiting list. According to the principle of data saturation within depth interviews,²⁰ inclusion of informants continued until no new information was gained.

Eighteen patients were invited to participate; three of them declined to participate for unknown reasons.

Comorbidity was evaluated according to the comorbidity index developed by Liu.²¹ Clinical data were retrieved from the Norwegian Renal Registry and from patient records at the National Transplant centre.

Interviews

A semistructured interview guide (box 1) was used for all interviews. The guide was developed based on clinical experience and previous research. The interviews lasted between 32 and 68 min, mean duration 52 min. The interviews were recorded. Each informant decided where the interview would be performed: four during dialysis treatment, six at the hospital before or after dialysis and five in the informant's home. All interviews were conducted in a separate room and started with information about the aim of the study. Two researchers conducted the interviews (KL, MHA). Towards the end

Box 1 Semistructured interview guide

1. How is life on dialysis?
2. How is your physical condition right now? Do you experience any physical symptoms from your kidney disease?
3. How are you coping mentally? How is your everyday mood?
4. Currently, how is this situation influencing your social life (family, friends and hobbies)?
5. In the current situation, what thoughts do you have about the rest of your life?
6. To what extent does the kidney disease occupy your time? Can you describe how the illness is 'controlling' your time?
7. What do you hope to gain from receiving a kidney transplant?
8. Do you have any thoughts on what you yourself can do to contribute to improve the result/outcome?
9. How do you experience the follow-up by the health professionals?
10. Are there any other themes/aspects you would like to discuss with us?

of the interview, the informants were asked if they had anything to add and were given the opportunity to ask questions.

Data analysis and trustworthiness

All interviews were transcribed verbatim by an assistant.

An inductive thematic analysis strategy was chosen using Kvale and Brinkmann's five steps for meaning condensation.²⁰ In the first step, the texts were read several times to obtain an overall impression. During step 2, the transcribed text was perused in more detail by looking for meaning units (a meaning unit corresponds to one or more sentences being marked in the coded process from the raw data). In step 3, the theme that dominated each natural meaning unit was stated as simply as possible. In step 4, the condensed meanings were grouped into categories and themes, and discussed in light of the study purpose. Finally, the main themes were placed together in a descriptive text²⁰ (example shown in table 1).

To ensure strict interpretation throughout the process, we switched back and forth between the transcript and the preliminary themes to ensure that all of the initial meaning units were included. In the beginning of the analysis process, KL and MHA coded the text into meaning units, and each step of analysis was thoroughly discussed. Thereafter, the categories were discussed with clinical experts (KM and KH), and consensus was gained.

Patient and public involvement

Patients have not been involved in design, recruitment or conduct of this study, but the researchers have long clinical experience with the actual study population including direct contact with patients with ESKD who are waiting for a kidney. The Norwegian Association for Kidney Patients and Organ Transplanted have been involved in the funding process and a simplified abbreviated publication is planned in their journal. The study informants will receive a copy of the published papers.

Table 1 Examples from the data analysis process

Meaning units (meaning of the expectations)	Subcategories	Themes (theoretical reflections)
Take a small drive with coffee and some food. Find a nice place to stop for a picnic. I might put together a band, which was the original plan for my retirement.	The informants had several expectations of a better life after receiving a kidney transplant	Receiving a kidney is getting life back
I think I will be very healthy, but to be realistic I am not so sure everything will be changed.	Life experiences were used to be realistic about kidney transplantation.	
I suppose my expectations are a bit high. But I have a relative who received a transplant and he had a good 10 years.		

Ethical considerations

The study was approved and was performed according to the Helsinki Declaration.

RESULTS

The informants' experiences could be grouped in two main themes: 'receiving a kidney is getting life back' and 'grasp the chance'. In addition, the themes 'hard to loose capacity and strength', 'reduced freedom' and 'life on hold' describe the actual situation and thereby illuminate the informants' expectations. The informants' demographic characteristics are presented in table 2. None of the informants received haemodialysis at home, and three of six informants on peritoneal dialysis received automated dialysis. The analysis revealed no special patterns related to background variables. In the following presentation, the informant's number is indicated at the end of each quotation.

Receiving a kidney is getting life back

The informants separated their lives into a life before and a life after KTx and they seemed to have clear expectations for the time after. 'I believe that after the transplantation I will be well again. My physical health will be much better. I am planning to buy a new boat. I am feeling ok now and will become even better.'³ Being able to live a more normalised life was important: 'Not going on dialysis is a benefit from being transplanted. Then I can be a regular retiree again, as I was supposed to.'⁴ The expectations of life after KTx included plans of various magnitudes; for example, 'Take a small drive with coffee and some food. Find a nice place to stop for a picnic'² and 'I might put together a band, which was the original plan for

Table 2 Patient characteristics

Variables	
N	15
Age (years)	
Mean	71
Median	70
Range	65–80
Gender	
Male	10
Female	5
Dialysis	
Hemodialysis (HD)	9
Peritoneal dialysis (PD)	6
Marital status	
Married	15
Comorbidity	
≤3	10
4–6	4
7–9	1
≥10	0
Time on dialysis (months)	
Mean	21
Median	18
Range	2–61

my retirement.'¹¹ All informants had travel plans. Being able to travel in the future was a main theme in several interviews: 'I do want to travel. I want to live abroad and stay there over longer periods. That's a goal for me. This is what I wish, and this is what I will do.'¹²

There was a great deal of realism in the expectations. Even though KTx was seen as the best treatment for their kidney disease, the informants did not expect improvements in other health issues: 'I think I will be very healthy but, to be realistic, I am not so sure everything will be changed.'¹⁵ The informants also related to others' experiences: 'I suppose my expectations are a bit high. But, I have a relative who received a transplant and he had a good 10 years.'¹¹ One informant with experience of long-term dialysis treatment balanced his expectations and realism: 'But of course, I am very well aware of the fact that it can be a bad outcome—I have to be. One cannot have too high expectations. But I trust it will go fine.'⁸

Grasp the chance!

The informants perceived the opportunity to receive KTx in different ways. For some, it was expected, but others were certain they would never receive it. Regardless of their view, none expressed doubt when the possibility of being listed for KTx was presented: 'I was a bit surprised that I could be enlisted at my age. But I never doubted it, because it was an opportunity. I knew the alternative,

so...’ For one informant, learning that (he) could receive a KTx completely changed the situation: ‘I had to start planning the future. Transplantation was a solution to my problems. It was a chance to live a little longer.’¹¹ Remaining on dialysis was not considered to be an alternative: ‘I knew that if I stayed here (on dialysis) I would become moss-grown, and I would soon disappear, so it is worth the chance.’¹³ However, there was a considerable amount of pragmatism: ‘I hope to live a little longer if I get a new kidney. There are a lot of things I want to see, grandchildren growing up and getting married. But it is ok, I am getting close to 80, I have to face that a new kidney won’t make me become 25 again. Be realistic, (old) age is coming.’⁷

Hard to loose capacity and strength

An important topic for the informants was describing life on dialysis: ‘I am getting more tired now. Previously I mowed the lawn in an hour, now it takes two. I’ve had heart surgery too.’¹⁰ One informant had noticed changes over time: ‘It wasn’t that bad before—I could join others and go for a walk. Now it is more or less gone.’² Everyday life was limited: ‘My day-to-day condition is like an elevator: up and down.’¹ Those who had recently started dialysis felt they were in better physical condition than before dialysis. One woman said: ‘I am feeling better now after starting dialysis; I have more energy.’⁹ There were nuances in their comments. For example, an informant who had been on dialysis for a long time tried to maintain the level of activity: ‘My physical function is good—exercising and cycling. Feeling the physical condition is quite good, but I have a little less energy than I used to have.’³ One informant felt he was being placed on the sideline. ‘I am struggling a bit with depression. You are placed on the side-line.’¹¹

Reduced freedom

The informants were all retired or about to retire when they developed ESKD. Leaving work offered opportunities to perform other activities, but dialysis treatment was a threat to this newly gained freedom: ‘The dialysis puts an end to the activities. The worst is not getting out and about.’⁴

ESKD and dialysis also affected their social life: ‘There has always been lots of people at our place, but now it has reduced since I’m so tied up. Some nights, it is not possible for me to be social at all.’⁶ However, two of the informants did not perceive that ESKD was affecting their social life: ‘I bring the peritoneal dialysis solution in the car when I go to a soccer match’⁵ or ‘I love to have visitors. Sometimes I actually invite people over just for a regular everyday dinner.’¹⁵ This informant reflected further: ‘I don’t know how much impact the kidney disease has on my social life. Things normally calm down when one gets older.’¹⁵

Life on hold

ESKD and especially starting dialysis made the informants put future life plans on hold: ‘I have told the doctor I will

continue living as today and then get started again. I have lots of things on hold.’¹³ There was no quick fix, and the informants were fully aware that the waiting time for KTx could be long: ‘You have to be patient. It doesn’t help to yell and scream.’¹⁰ Simultaneously, some informants also thought about how to handle the waiting time: ‘You can’t think about when or if you will receive a transplant. You just have to keep going. You can’t make things difficult.’⁵

Despite the informants being eager to go on with their lives, receiving a kidney at any price was not a solution: ‘I have decided to be on the waiting list. They say I’m stubborn, but I don’t mind. I have considered the pros and cons. My husband and I have discussed it a lot. I said he must accept that I don’t want to get a kidney at any price. I must do what’s right for me, and I’m doing just that.’⁹

DISCUSSION

The findings from our study reflect two overall perspectives: ‘receiving a kidney is getting life back’ and ‘grasp the chance!’ All informants clearly expressed their positive expectations towards KTx. Sometimes, these were embedded in their descriptions of problems experienced being on dialysis. Although the loss of physical capacity and strength was a major experience in the interviews, the informants revealed, as a driving force, their strong wish to return to a normal life after KTx. The interviews were performed while the informants were still on the KTx waiting list. The knowledge derived from this study affirms that attention should be paid to several aspects when addressing and evaluating an older KTx candidate awaiting transplantation. Information like this has not previously been reported.

Previous studies have shown that recipients report improved vitality and youth after a successful KTx and that, regardless of age, they are able to enjoy life and freedom again despite the challenges.^{12 22} The informants’ expectations of getting their life back are thus not surprising because KTx is an obvious way to re-establish perceived control.¹⁸

Reaching 65 years of age indicates the move towards the last part of life. The freedom from work provides the opportunity to engage in new activities, and the retiree has full sovereignty over time.²³ Our informants experienced that life on dialysis interfered with this. They had plans to realise and, when offered, they took the opportunity to be enlisted for a new kidney to be able to ‘take their life back’. Previous studies have shown that, although patients on a waiting-list may overestimate the outcome of transplantation,^{24 25} the positive expectations lead to a positive attitude of optimism and hope rather than distress.²⁴ Although the informants had high expectations, they also reflected on the fact that a KTx cannot reverse ageing. They highlighted the fact that ‘healthy’ friends also struggled as a reason for their limited social life. A stable self-esteem in older years may sustain the hope of getting one’s life back. For most patients, dialysis treatment is not equivalent to a ‘full life’.²⁶ Our

informants expressed no doubts about taking the opportunity to receive a KTx.

All informants had a partner, who also was affected by the informant's reduced freedom and this was perceived as an additional burden. Having a partner prevents loneliness, which is known to reduce self-esteem.²⁷ A main issue noted in the interviews was that travel plans had to be put on hold while on dialysis. These travel plans also included the partner, and the possibility of reactivating the plans after KTx was an important expectation. The missed opportunity for travel is a good example describing how dialysis treatment affects patients with an active life and thereby the feeling of self-realisation and autonomy, even at an advanced age.²³

A level of personal mastery is important for people to keep focusing on their future goals.²⁸ Despite the low comorbidity, these informants experienced loss of physical capacity and strength when on dialysis, and this affected their normal activities of living, as shown previously by Burns *et al.*²⁹ Gender differences in the loss of physical capacity were revealed; for example, the male informants were used to perform outdoor activities (gardening/snowploughing, etc), which became more difficult or even impossible in their present situation. Obviously, they had to admit that daily activities were not as easy to perform as before, which can lead to changes in self³⁰ and reduced perceived control.^{14 31} The descriptions of life on dialysis may reflect how the changed health condition and self-esteem affect each other³² and thereby provide an important backdrop for understanding the informants' expectations of KTx.

The informants demonstrated a willingness to make their own decisions independent of the views of health professionals and family by choosing to wait for a kidney from a deceased donor. In addition to the expectations of a future KTx and the burden experienced because of chronic illness, these informants seem to have a high level of self-esteem and autonomy, as shown in previous research.²⁶ Further research is warranted within this area.

A strength of this study was that the initial contact with the informants, that is, the selection process, was performed by their local nephrologist and not the researchers. All informants had recently been enlisted, that is, they were in a similar life situation. There are some limitations: all were Caucasian and all were married. Including patients with different ethnicity and not living in a relationship might have given different results.

No included patient was receiving an living donor (LD) kidney. The detected negative attitude towards LD does most likely not represent the typical attitude of elderly KTx candidates.

Clinical implications

For transplant professionals, it is important to balance hope and realistic information during the entire pre-KTx process. Our study shows the experience of the waiting phase from the patient's perspective. This might help

both health professionals and future patients to develop strategies while awaiting KTx.

CONCLUSION

This study shows that older KTx candidates comprise a heterogeneous group of patients who take individual approaches that allow them to maintain autonomy and control while waiting for a transplant. This study provides new knowledge about the older KTx candidates relevant for clinicians, patients and researchers.

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