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Expectations towards kidney transplantation

Semi-structured interview with enlisted kidney candidates over 65 years

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ABBREVIATIONS PAGE

ESKD, end stage renal disease

HRQoL, health related quality of life

KTx, kidney transplantation

ABSTRACT

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

Setting: Patients in dialysis enlisted for a deceased KTx were included from an ongoing, single center, prospective, nationwide study investigating Health Related Quality of Life (HRQoL). Qualitative face-to-face interviews were conducted. The interviews were performed in a safe and familiar setting and analyzed thematically using the theoretical framework of life span.

Participants: Fifteen patients (70 years, range 65-82) from all part of Norway were interviewed. Participants were included consecutively until no new information was gained.

Results: Five main themes were revealed: 1) Receiving a kidney is getting life back, 2) When getting the chance – grab it, 3) Losing capacity and strength is hard to accept, 4) Freedom is reduced, 5) Life on hold. The themes reflected life expectancies and the patient's wishes to add more active years. At the same time they expressed realism towards the risks of KTx. Life in dialysis was a hurdle to active life and a threat to maintaining self-esteem and perceived control.

Conclusion: The informants balanced positive expectations and realism towards KTx and were hoping to gain freedom from dialysis and continue a normal life. The study reveals useful information for health professionals to use in the pre KTx evaluation process.

Strengths and Limitations

- Included patients were selected by their local nephrologist, had passed necessary medical investigations and had been enlisted for deceased donor KTx.
- All informants were married. Having a partner may affect quality of life positively and may also influence on the expectations post-transplant.
- Since no patients scheduled for living donor KTx were included, their negative attitude towards living donor may not be typical for all older KTx candidates.
- Gender distribution was comparable to the general age-matched Norwegian ESKD population.
- Data richness was established with 15 informants and interviews with a mean duration of 52 minutes.

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 long waiting-time (4-6).

Health related quality of life (HRQoL) improves after a successful KTx (7, 8). In older kidney transplant recipients HRQoL knowledge is limited (9, 10), even though a few recent studies have focused on older KTx candidates and recipients (11, 12). Older patients' thoughts about their situation while waiting for a kidney and expectations towards KTx need to be investigated (13).

In KTx candidates ≥65 years life experience is broad and helps the patients cope with their situation. A life span perspective has been used as framework in the study of this population (14). In life span theory research, self-esteem and perceived control in relation to the aging population in general is comprehensive (15, 16). Self-esteem defined as the subjective evaluation of one's worth, increases through adult life until 65 years, then start to decline. The decline in older life may be influenced by reduced health, loneliness and lower perceived control (15). Perceived control is defined as a learnt expectation that can undergo changes (17). In a Dutch study a relatively high state of self-esteem in dialysis patients was connected to low concern about the illness and low negative impact of dialysis-treatment on life (18).

The aim was to study expectations towards improvement of life and health following kidney transplantation in a population of wait-listed ESKD patients ≥65 year.

METHODS

Participants

Participants were included from an ongoing study investigating HRQoL in wait-listed first KTx candidates ≥65 years (11). Patients not understanding the Norwegian language or with cognitive dysfunction were excluded. Cognitive dysfunction was investigated as part of the pre-enlisting evaluation. Information regarding pre-enlisting evaluation of KTx candidates and distribution of HRQoL questionnaires prior to KTx have been described previously (11). Patients in dialysis (i.e. no pre-dialytic patients were included) from all Norwegian regions were invited to participate in the qualitative study. Invitations were sent when the patient had completed the first HRQoL-questionnaire in the main study. Semi-structured interviews were performed within the first six months aiming to reveal the initial expectations after being accepted for the waiting-list. Inclusion of informants continued until no new information was gained according to the principle of data saturation within depth interviews (19).

Eighteen patients were invited to participate, three of them denied participating from unknown reasons.

Comorbidity was evaluated according to the comorbidity index developed by Liu (20). Clinical data were retrieved from the Norwegian renal registry and from patient records at our center.

Settings

The interviews, using a semi-structured interview guide (table 1), lasted for about 50 minutes and were recorded. The informants decided where the interviews should be performed (4 during dialysis treatment, 6 at the hospital before/ after dialysis and 5 in the informant’s home). All interviews were done in a separate room, starting with information regarding the aim of the study. Two researchers conducted the interviews (KL, MHA). Towards the end of the interview, the informants were asked if they had anything to add and were given the opportunity to ask questions of their own.

Data analysis and trustworthiness

All interviews were transcribed verbatim by an assistant. Data analyses were performed by KL and MHA according to the five steps described by Kvale and Brinkmann (21). In the first step the texts were read several times to get an overall impression. Thereafter the natural meaning units expressed by the informants were highlighted and formulated into condensed meanings in the third step. A meaning unit corresponds to one or more sentences being marked in the coded process directly from the raw data. In the fourth step, the condensed meanings were grouped into categories and discussed in light of the study purpose. Finally the main themes revealed were connected into descriptive statements (table 2).

To ensure strict interpretation throughout the process we switched back and forth between the transcript and the preliminary themes to ensure that the initial meanings were taken care of. 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.

Ethical considerations

The Study was approved by the Regional Committee for Medical and Health Research Ethics, South East (#2012/527) and was carried out according to the Helsinki Declaration.

RESULTS

The results of the interviews were grouped into five themes: “Receiving a kidney is getting life back”, “When getting the chance – grab it”, “Losing capacity and strength is hard to accept”, “Freedom is reduced” and “Life on hold.” Demographic characteristics are presented in table 3.

Receiving a kidney is getting life back

The informants separated their lives into a life before and after KTx with 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 it will become even better.”* *(3)* Get life normalized again was important: *“Not going in dialysis is a benefit from being transplanted. Then I can be a regular retiree again, as I was supposed to.*” *(4)* The expectations towards life after KTx included plans of different sizes: *“Take a small drive with coffee and some food. Find a nice place to stop for a picnic.”* *(2)* Or: *“I might put together a band, which was the original plan for my retirement.”* *(11)* All informants had travel plans. Being able to perform travels 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 portion of realism in the expectations: *“I think I will be very healthy, but to be realistic I am not so sure everything will be changed.”* *(15)* The informants also rested on others’ experiences: *“I suppose my expectations are a bit high. But I have a relative who got a transplant and he got 10 good years.”* *(11)* An informant with experience from 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)* Anyway KTx was worth a try. *"I don't want to live like this the rest of my life if I don't have to. I'm so tied up."* *(12)*

When getting the chance, grab it!

The informants experienced the approach towards KTx in different ways. For some it was expected, others were sure they would not get it. Neither of them 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, because it was an opportunity. I knew the alternative, so…"* *(10)* For one informant it turned the situation totally: *"I had to start planning the future. Transplantation was a solution to my problems. It was a chance to live a little longer."* *(11)* To remain in dialysis was not considered as an alternative: *"I knew that if I stayed here (in dialysis) I would become moss-grown, I would soon disappear so it is worth the chance."* *(13)* There was however, a respectable portion 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, age is coming."* *(7)*

Losing capacity and strength is hard to accept

An important subject for the informants was to describe life in dialysis: *"I am getting more tired now. Previously I moved the lawn within 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: *“Day to day condition is like an elevator; up and down.”* *(1)* Those recently started dialysis experienced a better physical condition than before. A woman said: *“I am feeling better now after starting dialysis, I have more energy.”* *(9)* There were nuances in the data, an informant being in 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 having a little less energy than I used to have.”* *(3)* One informant felt he was put on the sideline. *“I am struggling a bit with depression. You are placed on the sideline.”* *(11)* Another presented his coping strategy: *“What helps on my mental health is making my own way to dialysis. I am using public transport like other workers.”* *(4)*

Freedom is reduced

The informants were all retired or about to be when they developed ESKD. To terminate work gave 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 anywhere.”* *(4)* Furthermore, it was difficult to make autonomous decisions: *“The illness is deciding what I can do; I cannot just jump into the car and go away anymore.”* *(14)*

ESKD and dialysis also had impact on social life: *“There has always been lot of people at our place, but now it is reduced since I’m so tied up. Some nights it is not possible for me to be social at all.”* *(6)* Reduced social life was not only about energy and vitality, dietary restrictions and appetite also mattered: *“When I’m visiting people and I’m offered food, I hardly have any appetite at all, some food I’m not able to eat at all. So it is easier* *to stay at home."* (8) Two of the informants did however not experience that the ESKD was affecting the social life: *"I am bringing the peritoneal-dialysis solution in the car when I go to a soccer match."* (5) and *"I love to have visitors. Sometimes I actually invite people over just for a regular everyday-day dinner."* (15) This informant made some further reflections: *"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 in dialysis put future plans in life on hold. *"I have told the doctor I will continue living as today and then get starting again. I have lots of things on hold."* (13) There was no quick fix, the informants were fully aware of the fact that waiting-time for KTx could be long. *"You have to be patient. It doesn't help to yell and scream."* (10) Simultaneously there were thoughts about how to handle the waiting-time: *"You can't think about when or if you will receive a transplant. You just have to go. You can't make things difficult."* (5)

Even if the informants were 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 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)

Some informants have had a living donor evaluated. When the donor was turned down it was somehow a relief: *"Donor safety is important, I could not live with the fact that something went wrong with the donor."* (8)

DISCUSSION

The main themes “receiving a kidney is getting life back” and “when getting the chance – grab it” summarize the most important messages from the informants in this study. Dependency of dialysis is the outermost negative consequence of ESKD, having the greatest impact on life. Selecting dialysis patients waiting for their first transplantation as informants gave us a unique insight in their expectations towards KTx. The informants had clear perspectives on the process of enlisting showing that a high level of self-esteem leads to active participation in decision making regarding one’s own life (22).

The informants’ expectations regarding getting life back are not surprising; it is the obvious way to reestablish perceived control (17). Previous studies have revealed improved vitality and youth after KTx, and recipients, regardless of age, are able to enjoy life and freedom again despite the challenge also posed to transplanted recipients (12, 23). One informant dreamed about buying a boat after transplantation, just as one in Schipper’s study (23), – i.e. it is possible to reach a dream.

Reaching 65 years of age indicates moving towards the last part of life. However our informants still had plans to realize and when offered, they grabbed the chance to get a new kidney i.e. taking their life back. Previous studies have shown that patients on the waiting-list overestimate the outcome of transplantation (24, 25), but the positive expectations lead to a positive attitude; optimism and hope rather than distress (24). Despite this, in a recent publication we have described that HRQoL is worsened during the waiting time for KTx (11). Although the informants had great expectations they also reflected over the fact that a KTx does not reverse aging. The fact that “healthy” friends in their social network also have struggles was highlighted as a reason for reduced social life. A stable self-esteem in older years sustains the hope of getting life back. Dialysis treatment is not equivalent with a “full life”. If getting the chance to a better life, grab it (26).

Despite low comorbidity, the burden of ESKD and dialysis treatment had made the informants loose physical capacity and strength. All talked about the consequences of the disease, also demonstrated by Burns et al (27). These findings may reflect how changed health condition and self-esteem affect each other (22). Some days were hard to get through, even for those characterizing themselves as optimistic and positive. Especially the male informants were struggling. Traditionally they were used to perform out-door work (gardening/snow-plowing etc.) which was hard or even impossible to manage in their present situation. They had to admit that their role in life was changed leading to a changed self (28) and reduced perceived control (29). The ESKD symptoms were bothersome and lifelong dialysis was not considered an alternative even if the health professionals did their best to optimize treatment. Some of the informants considered dialysis treatment as a job where they had their tasks and the nurses and doctors had theirs. Nevertheless their aim was to quit dialysis and start retirement for real, which can be interpreted as the expectation to restore life and perceived autonomy (12).

Retirement is freedom from work and freedom to engage in new activities. The retiree has full sovereignty of time (30). Many retirees have a very active life. The informants talked about how plans were changed when starting dialysis treatment. This might explain the feeling of reduced perceived control (15) and is in accordance with results from the study by Pinter et al where the informants appreciated the freedom they regained after KTx (12).

All informants had a partner and the reduced freedom also affected them, as another burden to bear. On the other hand, having a partner prevents loneliness, which in turn is known to reduce self-esteem (31). Lack of chance to travel was a main issue in the interviews even though possible while in dialysis. The planning ahead and risks associated with having dialysis abroad, made it become a “no-alternative”. Additionally the risk of being off the transplant list when a suitable kidney was offered also stopped them from travelling.

To keep focus on the future goal, the level of personal mastery is important (32). Even if the informants had decided to put life on hold, they made efforts to continue or find new activities adapted to the situation to sustain self-esteem (18, 28). Their main focus was to get a kidney within reasonable time, although not at any price.

Regarding kidney from a living donor, the informants focused on how to minimize the risk for the donor and when turned down it was often a relief. At present, in Norway, the waiting time for a first deceased donor KTx is approximately 15 months (11). In countries where the expected waiting time is much longer, the “pressure” to use a kidney from living donor is stronger. Kaufmann et al described that recipients either “lined up” potential donors as soon as they knew they needed a kidney or they refused to use living donor even knowing the long waiting time (26). As in our study, the informants demonstrated willingness to stand up against both health professionals and family by choosing to wait for a kidney from deceased donor. This indicates high level of self-esteem and autonomy. Patient's view must be an important part of the decision basis when health professionals evaluate and select patients for KTx.

Clinical implications

This study provides new knowledge about older ESKD patient's heterogeneity and their expectations towards KTx. Adapted and realistic information during the entire pre KTx process is crucial. Experienced health professionals knowledge about health status after KTx may be more realistic than the patients' expectations (25). The challenge is to meet the patients' expectations with a realistic view without removing hope (1, 7, 12).

CONCLUSION

This selected population of older KTx candidates has positive expectations towards KTx - to get back the freedom in life. Simultaneously there is a great portion of realism towards the effect of a KTx. Life in dialysis is a hurdle to the life they want to live. The study reveals the challenge for the health professionals to balance old patients' expectations and health condition in the evaluation process for KTx.

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Contribution of the authors:

Conception or design, or analysis and interpretation of data or both: KH, KM, KL, MHA

Drafting the article: KL, MHA

Providing intellectual content/ critical evaluation: KH, KM, MHA

Final approval of the submitted version: KL, KH, KM, MHA

The authors declare no conflict of interests.

Data Sharing Statement

Data supporting our findings are included in the manuscript. According to the Norwegian Personal Data regulations and the Regional Committee for Medical and Health Research Ethics, South East the dataset cannot be published or shared outside the hospital responsible for the study/ data.

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Table 1 Interview questions

1. How is life in 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 being kidney transplanted?
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 from the health professionals?
10. Are there any other themes/aspects you would like to discuss with us?

Table 2 Examples from the data analysis process

Meaning units (meaning of the expectations)	**Sub categories**	**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 informant had several expectations regarding a better life after a kidney transplantation	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. I suppose my expectations are a bit high. But I have a relative who got a transplant and he got good 10 years.	Life experiences were used to be realistic towards kidney transplantation	

Table 3 Patient Characteristics

N	15
Age (years)	
65-72	11
72-82	4
Mean	71
Median	70
Gender	
Male	10
Female	5
Dialysis	
HD	9
PD	6
Marital Status	
Married	15
Comorbidity	
≤ 3	10
4-6	4
7-9	1
≥ 10	0
Time in dialysis (months)	
< 6	2
6-12	4
12-24	5
24-36	2
>36	2

Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

No	Item	Guide questions/description	Answers
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	KL and MHA
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	RnMsm and RnPhD
3.	Occupation	What was their occupation at the time of the study?	PhD student and Senior researcher
4.	Gender	Was the researcher male or female?	Females
5.	Experience and training	What experience or training did the researcher have?	Both experienced within qualitative and quantitative research
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Participants got oral and written information prior to study commencement
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? *e.g. personal goals, reasons for doing the research*	Participants knew the rationale for doing the study and that the researchers were experienced
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Participants knew that the interviewers were clinical experts within the field of renal transplantation
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse*	We captured a realistic research approach based on thematic data analysis, and in

		analysis, ethnography, phenomenology, content analysis	accordance with Kvale and Brinkmann's (2009) recommendations for content analysis.
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Participants were selected consecutively.
11.	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*	Participants were approached by mail.
12.	Sample size	How many participants were in the study?	15
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	3, reasons not asked.
Setting			
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*	Data were collected at hospital or at participants home
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Two participants had their partner present.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Kidney transplant candidates ≥65 years of age waiting for deceased donor kidney Dependent of dialysis treatment 10 Males/ 5 females
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The semi-structured interview guide were provided by the authors and pilot tested.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording was used in all interviews.
20.	Field notes	Were field notes made during	Field notes were made

		and/or after the interview or focus group?	after the interviews
21.	Duration	What was the duration of the interviews or focus group?	Mean duration was 52 minutes (range 32 -68)
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Data saturation was discussed. Transcripts were not returned to the participants.
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	2
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data.
27.	Software	What software, if applicable, was used to manage the data?	No software was used.
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*	Yes and each quotation was identified with participant number
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

Allison Tong, Peter Sainsbury, Jonathan Craig; Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *International Journal for Quality in Health Care*, Volume 19, Issue 6, 1 December 2007, Pages 349–357, https://doi.org/10.1093/intqhc/mzm042

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Older kidney transplantation candidates' expectations of improvement in life and health following kidney transplantation
Semi-structured interviews with enlisted dialysis patients aged 65 years and older

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Older kidney transplantation candidates' expectations of improvement in life and health following kidney transplantation

Semi-structured interviews with enlisted dialysis patients aged 65 years and older

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ABBREVIATIONS PAGE

ESKD, end-stage kidney disease

KTx, kidney transplantation

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 end-stage kidney disease patients ≥65 years.

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 patient's 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 (aged 70 years, range 65−82) from all parts of Norway were interviewed. Informants were included consecutively until no new information was gained.

Results: Five main themes were evident: 1) receiving a kidney is getting life back; 2) grasp the chance; 3) hard to lose capacity and strength; 4) reduced freedom; 5) life on hold. The informants tried to balance positive expectations and realism towards KTx, and they were hoping to become free from needing dialysis and to live a normal life.

Conclusion: This study shows that older KTx candidates are a heterogeneous group of patients who take individual approaches that allow them to maintain autonomy and control during both pre- and post-KTx phase. This study provides important new knowledge important for both clinicians and researchers.

Strengths and limitations

- 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 minutes.
- Marital status may affect expectations of life after kidney transplantation. 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.

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).

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 (16) as the framework for this study. 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), that latter of which is considered to be is defined as a learned expectation that can change (18). In a Dutch study 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 ESKD patients ≥65 years awaiting KTx is complex. To our knowledge no study has focused on older patient group's expectations of life and health following KTx. We studied the expectations of KTx in a population of wait-listed ESKD patients ≥65 years.

METHODS

Informants and setting

In Norway, all KTx is performed at one national hospital and dialysis treatment is spread throughout the country. Informants were included consecutively from an ongoing multi-method study that explored the perspective on KTx of candidate's ≥65 years. (11). Patients who did not understand the Norwegian language or with cognitive dysfunction were excluded; cognitive dysfunction was investigated as part of the pre-enlisting evaluation. Information regarding the pre-enlisting evaluation of KTx candidates has been described previously (11). Patients receiving dialysis (i.e. no pre-dialytic patients were included) from all Norwegian regions were invited to participate in this qualitative study. Invitations were sent when each patient had completed the first questionnaire in the quantitative study. Semi-structured interviews were performed within the first six months 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 our centre.

Interviews

A semi-structured interview guide (Table 1) was used for all interviews. The guide was developed based on clinical experience and previous research. The interviews lasted between 32 and 68 minutes, and the average was 52 minutes. The interviews were recorded. Each informant decided where the interview would be performed: four during dialysis treatment, six at the hospital before/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 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 text (20), example shown in Table 2.

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 ESKD patients while waiting for a kidney. The Norwegian Association for Kidney Patients and Organ Transplanted have been involved in the funding process and the result of the study is planned published in their journal. The study informants will get the published results.

Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics, South East (#2012/527), and was performed according to the Helsinki Declaration. The informants provided informed consent.

RESULTS

The results of the interviews were grouped into five themes: “receiving a kidney is getting life back”; “grasp the chance”, “hard to loose capacity and strength”; “reduced freedom”; and “Life on hold.” The informants’ demographic characteristics are presented in Table 3. None of the informants received home haemodialysis, 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 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 normalized life again 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 magnitude; for example, *“Take a small drive with coffee and some food. Find a nice place to stop for a picnic.”* *(2)* or *“I might put together a band, which was the original plan for 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…” (10)* For one informant, learning that [he] would receive 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 within 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 sidelines. *“I am struggling a bit with depression. You are placed on the sidelines.”* *(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 lot 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 perceived 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 of 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, and our study brings new important knowledge to both health professionals and patients. Information like this has not been reported before.

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

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 had plans to realize and, when offered, took the opportunity to be enlisted for a new kidney so that they could “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 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). However, our informants expressed no doubts about taking the opportunity to receive a KTx.

All informants had a partner, who was also affected by the informant's reduced freedom which 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 of how dialysis treatment affects patients with an active life and thereby the feeling of self-realization 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 performing out-door work (gardening/snowploughing etc.) and this 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 self (30) and reduced perceived control (14, 31). The descriptions of life on dialysis may reflect how the changed health condition and self-esteem affect each other (32) 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 KTx and the burden experienced because of chronic illness these informants seems to have a high level of self-esteem and autonomy, as shown in previous research (26). Further research is warranted within this area.

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's results reflects that older KTx candidates are a heterogeneous group with individual approaches to maintaining their autonomy and perceived control in both pre- and post-KTx phase. The study provides new knowledge that may be important for both clinicians and researchers.

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Contribution of the authors:

Conception or design, or analysis and interpretation of data or both: KH, KM, KL, MHA.

Drafting the article: KL, MHA.

Providing intellectual content/critical evaluation: KH, KM, MHA.

Final approval of the submitted version: KL, KH, KM, MHA.

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Table 1 Semi-structured 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?

Table 2 Examples from the data analysis process

Meaning units (meaning of the expectations)	**Sub-categories**	**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. I suppose my expectations are a bit high. But I have a relative who received a transplant and he had a good 10 years.	Life experiences were used to be realistic about kidney transplantation.	

Table 3 Patient characteristics

N	15
Age (years)	
Mean	71
Median	70
Range	65−80
Gender	
Male	10
Female	5
Dialysis	
HD	9
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

Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

No	Item	Guide questions/description	Answers
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	KL and MHA
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	RnMsm and RnPhD
3.	Occupation	What was their occupation at the time of the study?	PhD student and Senior researcher
4.	Gender	Was the researcher male or female?	Females
5.	Experience and training	What experience or training did the researcher have?	Both experienced within qualitative and quantitative research
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Participants got oral and written information prior to study commencement
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*	Participants knew the rationale for doing the study and that the researchers were experienced
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Participants knew that the interviewers were clinical experts within the field of renal transplantation
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse*	We captured a realistic research approach based on thematic data analysis, and in

		analysis, ethnography, phenomenology, content analysis	accordance with Kvale and Brinkmann's (2009) recommendations for content analysis.
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Participants were selected consecutively.
11.	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*	Participants were approached by mail.
12.	Sample size	How many participants were in the study?	15
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	3, reasons not asked.
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Data were collected at hospital or at participants home
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Two participants had their partner present.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Kidney transplant candidates ≥65 years of age waiting for deceased donor kidney Dependent of dialysis treatment 10 Males/ 5 females
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The semi-structured interview guide were provided by the authors and pilot tested.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording was used in all interviews.
20.	Field notes	Were field notes made during	Field notes were made

		and/or after the interview or focus group?	after the interviews
21.	Duration	What was the duration of the interviews or focus group?	Mean duration was 52 minutes (range 32 -68)
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Data saturation was discussed. Transcripts were not returned to the participants.
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	2
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data.
27.	Software	What software, if applicable, was used to manage the data?	No software was used.
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*	Yes and each quotation was identified with participant number
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

Allison Tong, Peter Sainsbury, Jonathan Craig; Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *International Journal for Quality in Health Care*, Volume 19, Issue 6, 1 December 2007, Pages 349–357, https://doi.org/10.1093/intqhc/mzm042

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Older kidney transplantation candidates’ expectations of improvement in life and health following kidney transplantation
Semi-structured interviews with enlisted dialysis patients aged 65 years and older

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Older kidney transplantation candidates' expectations of improvement in life and health following kidney transplantation

Semi-structured interviews with enlisted dialysis patients aged 65 years and older

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ABBREVIATIONS PAGE

ESKD, end-stage kidney disease

KTx, kidney transplantation

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 end-stage kidney disease patients' ≥65 years.

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 (aged 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.

Strengths and limitations

- 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 minutes.
- Marital status may affect expectations of life after 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.

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).

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), that latter of which is considered to be defined as a learned 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 ESKD patients' ≥65 years 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 ESKD patients' ≥65 years.

METHODS

Informants and setting

In Norway, all KTx are performed at one national hospital and dialysis treatment including pre-transplant work-up is spread throughout the country. Informants were included consecutively from an ongoing multi-method 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 (i.e. no pre-dialytic 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. Semi-structured interviews were performed within the first six 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 semi-structured interview guide (Table 1) was used for all interviews. The guide was developed based on clinical experience and previous research. The interviews lasted between 32 and 68 minutes, mean duration 52 minutes. 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 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 text (20), example shown in Table 2.

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 ESKD patients 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.

Ethical considerations

The study was approved by the Regional Committee for Medical and Health Research Ethics, South East (#2012/527), 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 3. 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 normalized 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 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…"* *(10)* 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 side-line. *"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 realize 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-realization 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 out-door 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 self (30) and reduced perceived control (14, 31). The descriptions of life on dialysis may reflect how the changed health condition and self-esteem affect each other (32) 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 i.e. the selection process, was performed by their local nephrologist and not the researchers. All informants had recently been enlisted i.e. 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 a 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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Drafting the article: KL, MHA.

Providing intellectual content/critical evaluation: KH, KM, MHA.

Final approval of the submitted version: KL, KH, KM, MHA.

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Table 1 Semi-structured 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?

Table 2 Examples from the data analysis process

Meaning units (meaning of the expectations)	**Sub-categories**	**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. I suppose my expectations are a bit high. But I have a relative who received a transplant and he had a good 10 years.	Life experiences were used to be realistic about kidney transplantation.	

Table 3 Patient characteristics

Variables	
N	15
Age (years)	
Mean	71
Median	70
Range	65−80
Gender	
Male	10
Female	5
Dialysis	
HD	9
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

Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

No	Item	Guide questions/description	Answers
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	KL and MHA
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	RnMsm and RnPhD
3.	Occupation	What was their occupation at the time of the study?	PhD student and Senior researcher
4.	Gender	Was the researcher male or female?	Females
5.	Experience and training	What experience or training did the researcher have?	Both experienced within qualitative and quantitative research
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Participants got oral and written information prior to study commencement Page 6
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*	Participants knew the rationale for doing the study and that the researchers were experienced Page 6 and 7
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Participants knew that the interviewers were clinical experts within the field of renal transplantation Page 7
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to	We captured a realistic research approach

		underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	based on thematic data analysis, and in accordance with Kvale and Brinkmann's (2009) recommendations for content analysis. Page 7
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Participants were selected consecutively. Page 6
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Participants were approached by mail. Page 6
12.	Sample size	How many participants were in the study?	15 (Page 6)
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	3, reasons not asked. Page 6
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Data were collected at hospital or at participants home. Page 7
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Two participants had their partner present.
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Kidney transplant candidates ≥65 years of age waiting for deceased donor kidney Dependent of dialysis treatment 10 Males/ 5 females
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	The semi-structured interview guide were provided by the authors and pilot tested. Page 7
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No

19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio recording was used in all interviews. Page 7
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made after the interviews
21.	Duration	What was the duration of the interviews or focus group?	Mean duration was 52 minutes (range 32 -68) page 7
22.	Data saturation	Was data saturation discussed?	
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Data saturation was discussed. Transcripts were not returned to the participants. Page 6
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	2
25.	Description of the coding tree	Did authors provide a description of the coding tree?	No
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data. Page 7
27.	Software	What software, if applicable, was used to manage the data?	No software was used.
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? *e.g. participant number*	Yes and each quotation was identified with participant number page 9-12
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes page 9-12
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes page 13-15

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