Title: Living in one's own world, while life goes on: patients' experiences prior to a kidney transplantation with a living donor

Key words: end-stage renal disease, Patient experience, Ricoeur, existential experiences, qualitative research

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Author contributions

IVK, RB, JH, HA and AN all contributed to the study design and contributed to the manuscript preparation.

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Living in one’s own world, while life goes on: patients’ experiences prior to a kidney transplantation with a living donor

Abstract

Aims and objectives

To investigate patients’ existential experiences in everyday life prior to a kidney transplantation with a living donor.

Background

Kidney transplantation is a well-established treatment for patients with end-stage kidney disease. The prevalence of patients living with end-stage renal disease is increasing. Simultaneously, kidney transplantations with a living donor are increasing. However, patients experience challenging existential aspects concerning kidney transplantation.

Design

A qualitative study with a hermeneutic-phenomenological approach inspired by Ricoeur was chosen.

Methods

Fourteen interviews with patients living with end-stage kidney disease were conducted 7-14 days before a planned kidney transplantation with a living donor. Analysis and interpretation were based on Ricoeur’s theory of interpretation. We applied the Criteria for Reporting Qualitative Research (COREQ) (see supplementary file).
Results

Four themes were identified: Living with subjective feelings of illness while objectifying the body; Living in one’s own world while the world outside goes on; Feeling grateful while being concerned for the donor; and Hoping for the best, while preparing for the worst.

Conclusion

Patients’ existential challenges are multifaceted. Patients articulate their kidney function in numeric terms, trying to make the invisible visible for themselves and others. Sustaining normality becomes important for patients, and the waiting time from donor evaluation to transplantation triggers excitement, hope and frustration.

Relevance to clinical practice

The results increase insights into individuals’ existential experiences in their everyday lives. Hereby, the results articulate the need for support from health professionals prior to a kidney transplantation.

What does this paper contribute to the wider global clinical community?

This paper provides insights into and deeper knowledge about living with end-stage kidney disease prior to a kidney transplantation with a living donor.

This study shows that patients experience multifaceted existential challenges in their everyday lives prior to a kidney transplantation with a living donor.

The results articulate the need for support from health professionals prior to a kidney transplantation, and hereby enhance the need to focus on developing a programme to support recipients undergoing a kidney transplantation.
Introduction

This article presents patients’ existential experiences prior to a kidney transplantation with a living donor. Research shows that kidney transplantation is the treatment of choice when living with end-stage renal disease (ESRD) (Knoll, 2008; Ummel, Achille, & Mekkelholt, 2011). Because it is the most effective form of renal replacement therapy and offers longer life expectancy (Oniscu, Brown, & Forsythe, 2005), when possible, kidney transplantation is the treatment of choice for patients living with ESRD. Compared to dialysis, kidney transplantation furthermore offers higher quality of life, less need of medication and fewer restrictions in everyday life – such as fluid and nutrition restrictions (Landreneau, Lee, & Landreneau, 2010; Martin, 2014; Oniscu et al., 2005).

Background

Currently, the number of living donor kidney transplantations is increasing in Western countries (Horvat, Shariff, & Garg, 2009; Martin, 2014). In 2018, a total of 536 patients with ESRD in Denmark were enlisted for kidney transplantation (Scandiatransplant, 2019). Of these, 77 were transplanted in the same year with a kidney from a living donor (Danish Centre for Organ Donation, 2019; Danish Nephrology Registry, 2017). For both clinical and ethical reasons, living kidney donors’ experiences have received much research attention; nevertheless, there is a lack of research on the experience of receiving a kidney from a living donor (Ummel et al., 2011). A literature review of patients’ experiences of living kidney donor transplantation shows that decision-making and relationship with the donor are important issues (Croft & Maddison, 2017). Concomitantly, concerns regarding the donor’s financial situation and health appear amongst patients prior to a kidney transplantation (Croft & Maddison, 2017; Martin, 2014). However, the literature review also reveals that patients need to maintain hope and positive expectations of life after transplantation (Croft & Maddison, 2017). Furthermore, patients receiving a kidney from a living donor declare a greater sense of happiness compared to patients receiving a kidney from a deceased donor (Gozdowska et al., 2016).

However, kidney transplant recipients must adhere to various changes in everyday life when being transplanted, as they may experience lifestyle changes, including altered body image, hygiene practices, self-monitoring, blood tests, clinic appointments and side effects of medication, among other complications (Luk, 2004; Murphy, 2007; Rosaasen et al., 2017).
Patients undergoing a kidney transplantation therefore need education to adapt to life changes thereafter. Furthermore, a mismatch between expected and actual quality of life outcomes (Schulz et al., 2014; Smith et al., 2008) manifests the need to address preparation and education of patients undergoing a kidney transplantation (Rosaasen et al., 2017).

Research concerning patients’ experiences before transplantation are often aimed at patients waiting for a kidney from a deceased donor (Nielsen, Clemensen, Bistrup, & Agerskov, 2019). Besides, patients facing a kidney transplant are in a challenging situation regarding existential issues, given that kidney transplantation gives the prospect of a new life (Schulz & Kroencke, 2015; Schulz et al., 2014). Furthermore, research indicates that the psychosocial burden is usually less severe after transplantation, than during the preoperative period (Schulz & Kroencke, 2015). Therefore, research concerning the patient’s perspective prior to a kidney transplantation with a living donor is of significant interest and importance.

Aim

The aim of this study was to investigate patients’ existential experiences in everyday life prior to a kidney transplantation with a living donor.

Methods

Design

This study was qualitative and explorative. According to Ricoeur, we tell stories because human life ultimately needs and deserves to be told (Ricoeur, 1984). narration furthermore entails reflection and leads to new perspectives (Ricoeur, 1976). Therefore, we used a hermeneutic-phenomenological approach inspired by Ricoeur’s theory of narrative and interpretation to reach a new understanding (Ricoeur, 1976, 1991b, 1991a). To gain insight into patients’ existential experiences in everyday life prior to a kidney transplantation with a living donor, we chose to conduct in-depth interviews (Kvale & Brinkmann, 2014). We applied the Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007) (See supplementary file 1).

Participants and data collection
We included potential kidney recipients who had a living accepted donor from February 2017 to October 2018. Participants were recruited from one of three Danish kidney transplant centres situated at a university hospital and a regional hospital. The inclusion criteria were Danish-speaking recipients over the age of 18 who were due to undergo a kidney transplantation with a living donor. At the time of inclusion, the participants had obtained approval and a date for the transplantation. A research nurse called potential participants, and if they were interested in participating, written information about the study was sent to them. The first author thereafter called the patients, gave oral information about the study, and planned a date for the interviews. In total, we included 14 patients: six women and eight men. Table 1 presents some of the characteristics of the included patients.

Please insert table 1

To gain insight into the existential experiences of living with ESRD, the interview questions were open-ended (Kvale & Brinkmann, 2014), such as “please, tell me about your experiences of living with chronic kidney disease in your everyday life?” The first author conducted the interviews 7-14 days before a planned kidney transplantation. Twelve interviews took place in the patients’ homes and two in a quiet room at the hospital, in accordance with the patients’ wishes. Under consideration of ethical and methodological dilemmas (Norlyk, Haahr, & Hall, 2016), we preferred that the patient participated alone in the interview, in line with the aim of the study that focuses on patients’ experiences, as opposed to, e.g., those of close relatives. All interviews were audio recorded and transcribed verbatim.

**Ethical Considerations**

In accordance with the Helsinki Declaration (World Medical Association, 2013), all patients received written and oral information about the study before giving written informed consent. The patients were advised of the voluntary nature of the study and their right to withdraw at any time. The study was approved by the Danish Data Protection Agency, journal number: 2015-57-0002-62908/274. Furthermore, the Danish Patient Safety Authority gave approval for the study, journal number: 3-3013-2033/1. In accordance with Danish law (National Committee on Health Research Ethics, 2019), approval from the National Committee on Health Research Ethics was not required.

**Data Analysis**

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Interpretation of the data involved a spiral process involving three levels: naïve reading, structural analysis and comprehensive understanding. In the first phase of the analysis, we read the data repeatedly with an open approach, in accordance with Ricoeur’s ‘ naïve reading’, to obtain an understanding of the text as a whole (Ricoeur, 1976). Ricoeur writes about the ‘intersection of the world of text with the world of the reader’ (Ricoeur, 1991b). Therefore, the reading itself becomes a critical step for the entire analysis. The interviews were transcribed verbatim in order to translate speech into text. According to Ricoeur, the naïve reading gives an initial impression and understanding of what the text is about (Ricoeur, 1976). At this level of the analysis, an interconnected understanding of the patients’ existential experiences in everyday life prior to a kidney transplantation with a living donor emerged.

Next, we carried out the structural analysis to adjust and validate the naïve reading and to reach a deeper understanding of the patients’ experiences. Hereby, we examined the text for meaningful units and identification of themes through the structural analysis (Ricoeur, 1976). This involved dividing the text into units of meaning (what is said) and units of significance (what the text talks about). We identified units of meaning by identifying quotations in the data material that illuminated the meaning. Hence, the analysis took place in a process of moving back and forth from units of meaning to units of significance to illuminate patterns of meanings, which were then structured into themes and subthemes. See Table 2.

Finally, at the last level, comprehensive understanding, we conducted a critical interpretation based on the themes extracted through the structural analysis. To nuance the understanding of the themes and reach a deeper interpretation, the themes were elucidated and discussed with theory and other research (Ricoeur, 1976).

**Results**

The naïve reading revealed that patients seemed to experience multifaceted challenges before the kidney transplantation. Through the structural analysis, we identified four themes: Living with subjective feelings of illness while objectifying the body, Living in one’s own world while the world outside goes on, Feeling grateful while being concerned for the donor and Hoping for the best, while preparing for the worst.

*Living with subjective feelings of illness while objectifying their body*
The findings show that patients with ESRD experience living with an invisible condition with no outward signs of their illness. Still, patients have subjective feelings regarding their feelings of illness. They feel tired and frustrated that they are not able to live their everyday lives as before the imminent kidney transplantation. At the same time, the patients objectify the body in numbers regarding their kidney function. “You can’t see you’re sick. I think that is strange. I thought you had to suffer from something visible to undergo surgery. I think that is hard. However, my kidney function is down to eight (percent) now. In fact, the most challenging, is that you cannot see nor feel it. But blood samples and tests show that I am sick” (P5). Although living with ESRD challenges patients’ everyday lives, the consequences of living with this invisible illness can also be difficult for others to recognize or acknowledge. “Well, I stand on my legs, I can walk myself, and I can think for myself, I can do everything. That is, I think it is hard when I do not feel sick, and it must be just as hard for people around me to relate to when they can’t see that I’m sick” (P6). Patients feel that others may not understand the cause of the problem, if they cannot see evidence of it in a visible way. This could be the reason why they articulate their kidney function in numbers, hereby trying to make the invisible visible for themselves and others.

Living in one’s own world while the world outside goes on

The patients experience living in their own world while the world outside goes on without them. Feelings of loneliness and changed identity due to the progression of illness trigger existential worries: “Before (the progression of ESRD), I could participate in everything I wanted. Now, I feel like I live alone in my own world and I am cut off” (P12). The patients’ identities are strongly connected to their social lives, having a job and feeling useful in society. Patients feel cut off and out of reality, as they cannot participate anymore in social activities and work in the same way as before. These existential experiences in the patients’ everyday lives have a tremendous impact, and make them feel like they are living in their own world. The feeling of loneliness is elaborated: “I feel it is tremendously lonesome to be sick because I am by myself in it.” (P8).

Furthermore, patients experience restrictions in their everyday lives, some of which relate to practical issues, such as restrictions connected to fluid and diet. Other restrictions concern existential aspects, such as lack of freedom, as patients cannot travel as they usually could. “When I get transplanted I will be free. I do not feel freedom right now. After all, I depend on dialysis; I depend on my medication and so on. Once I have been kidney transplanted, I will
be free. I will be a free human being” (P14). Existential worries, such as the experience of restrictions and loss of freedom, threaten the patients’ feelings of normality. Still, they have hope for new perspectives and the feeling of freedom in their lives at all levels. Furthermore, they are excited about the upcoming transplantation and about how their lives will be after transplantation. They strive for normality and “hope to be a part of life again” (P7).

Feeling grateful while being concerned for the donor

The patients perceive receiving a kidney from a living donor as the greatest gift in life, but they simultaneously worry about consequences for the donor during and after the donation. “He (the donor) was totally cool. Right from the start, he said, you will get mine. It has gone without a hitch, and all this time I have kept it a little open and thought, fair enough, if you get cold feet. It is a big thing to give an organ” (P1). The patients pay great attention to acknowledging the donors. Still, they are also reluctant to receiving what they quote as: “the most precious gift you can receive – worth more than a diamond” (P4). Some patients question if it would be acceptable that they had received an organ, if something were to happen to their donor. Feelings of gratitude and concern are coexistent. Furthermore, their worries also concern the family of the donor. Most of all, the patients are worried that their donors will have complications during and after the donation. “The worst thing is if something happens to her (the donor). We also talked about gratitude. Well, it is very difficult for me, because I cannot say thank you enough” (P10). This quotation furthermore shows that the patients may have a feeling of inadequacy in expressing their gratitude toward the donor. Additionally, the patients express that they are very grateful that someone will donate a kidney. In this way, they can avoid an unknown waiting period before receiving a kidney from a deceased donor.

Hoping for the best, while preparing for the worst

The patients experience an oscillation between positive expectations of life after transplantation and feelings of uncertainty. Accordingly, patients take one day at a time, while still maintaining hope of having “their life back” (P11). They hope for the best, while preparing for the worst. The feeling of uncertainty is pervasive, and expressed as: “The uncertainty before surgery really affects me” (P13). Patients are affected by the uncertainty and feel insecure before the transplantation. Still, they are excited and have hope for the future. “The only thing I am nervous about is that something will happen, so I will not be operated (transplanted). That something is coming up so it (the transplantation) is postponed” (P9). Furthermore, they are in a waiting position and facing the unknown prior to
a kidney transplantation. The waiting time from the evaluation of the donor to the transplantation triggers excitement and hope but also frustration, as patients feel this period is protracted. “Of course, I have heard many bad things about having to have a kidney transplant. Conversely, I also know someone where everything went well” (P3). The patients look forward and keep hoping to have a normal life again and to feel free again. However, they have concerns related to the unknown in the time after the transplantation. Another said, “I hope, but do not expect it (that the transplantation will proceed as planned)” (P2).

Furthermore, the unknown raises questions such as: what will my everyday life be like? How much medicine will I need? Will I be able to work full-time again? Will our sexual relationship be as before I got sick, etc.?

Discussion

This study reveals patients’ existential experiences in their everyday lives prior to a kidney transplantation with a living donor. In the following, the results above will be discussed with theory and other research, to nuance the understanding of the themes and reach a deeper interpretation (Ricoeur, 1976).

Living with ESRD involves an invisible condition with no outward signs of illness. However, there are a number of subjective experiences regarding feelings of illness. There are feelings of tiredness and frustration related to restrictions in everyday life. Additionally, the study shows that patients try to make the invisible condition visible and explain the imperceptible processes in the body by articulating their kidney function in numbers. In line with our findings, another study emphasized how bone scans created new illness experiences and dependency on the technology and doctors’ explanations among a group of women (Reventlow, Hvas, & Malterud, 2006). They found that the participants articulated a change in their bodily experience after their encounter with the medical technology of the bone scan. The study reveals issues like patients’ consciousness of their body and bodily signs, bodily identity and bodily integrity (Reventlow et al., 2006). This aligns with the findings of this study, where patients pay great attention to their body because of blood samples and other test results. According to Carel & Macnaughton (2012), reconciling objective images with a subjective feeling of the body may, especially when repeated, lead to a sense of alienation from one’s body. This positions the body as an aberrant object over which one has little control (Havi & Macnaughton, 2012). Additionally, a major challenge for rehabilitation is to make the invisible visible, and to make the imperceptible perceptible (Møller, 2013).
We found that patients have feelings of living in their own world while the world outside goes on without them. They have concomitant existential worries, such as loss of freedom, changed identity and the struggle for normality prior to the kidney transplantation. These findings can be perceived in the context of transition from health to illness. During transition, patients seem to go through a period of instability, confusion and distress (Meleis et al., 2000), before they can enter a new beginning. Flow and movement over time characterize all transitions (Meleis et al., 2000). In our study, the process of transplantation, which involves existential worries, illustrates this transition. This study adds to the theory of transition by illustrating existential dimensions related to the transition as experienced by patients planned for kidney transplantation with a living donor. Consequently, patients in transition tend to be more vulnerable (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). Thus, this study shows that the waiting time from the evaluation and approval of the donor to the transplantation is the beginning of a transition that triggers not only excitement and hope but also frustration.

Our study shows that patients cautiously hope for the best even though they face the unknown and experience uncertainty in their everyday lives. According to Penrod (2007), uncertainty is pervasive in human existence. Sustaining normality becomes important for patients. Living as normally as possible during the transition is important, for example being active participants in the workforce represents an important aspect of achieving a sense of autonomy and living a normal adult life (Penrod, 2007).

Based on the findings of the patients’ feelings of gratitude towards and concern for the donor, we found that some patients find it challenging to put their gratitude and concern into words. The patients oscillate between gratitude and concern for the donor, and hereby they experience a paradox. Research shows that patients prefer directed living kidney donation instead of non-directed altruistic donation (Bailey, Ben-Shlomo, de Salis, Tomson, & Owen-Smith, 2016). A thematic synthesis of qualitative studies about the expectations and attitudes of patients towards living kidney donation (Hanson et al., 2015) embraces the idea that enhanced education and psychosocial support may help clarify and address patients’ worries regarding donor outcomes and their relationship with the donor.

Taking the findings of our study into account, support from health professionals becomes paramount. According to Carel & Macnauhton (2012), both objective and subjective points of view are present when patients are in need of support from health professionals. By
recognizing the constant oscillation from the one to the other point of view, we may also bridge the gap between the view of illness as a pathology and illness as a way of being, and so reduce the distance between these two contrasting perspectives present in the clinic (Havi & Macnaughton, 2012). Taking into account that patients have individual perceptions of illness, and of their needs in the kidney transplantation process, we therefore recommend developing tailored support and education. This is with the purpose of meeting patients’ existential experiences in their everyday lives prior to a kidney transplantation with a living donor.

Methodological considerations

We strove to establish confirmability by clearly setting out and stringently following Ricoeur’s steps in the analytical process (Ricoeur, 1991a). Furthermore, we included quotes from participant interviews to illustrate examples of how meanings were expressed by patients. Only Danish-speaking participants were included in the study, which could be a limitation. The disparity in the participants’ treatment modality are reflected due to the hermeneutic-phenomenological approach as we strove for variation in the experiences of the participants. The literature on phenomenological research does not offer much on sampling procedures. However, it is argued that the aim in a phenomenological study is to understand a phenomenon more deeply and that variation within the phenomenological framework is variation of the experiences (Norlyk & Harder, 2010).

Conclusion

The aim of this study was to investigate patients’ existential experiences in everyday life prior to a kidney transplantation with a living donor. This study reveals that patients experience various existential challenges in their everyday lives. Patients articulate their kidney function in numbers, thereby trying to make the invisible visible for themselves and others around them. The process of transplantation illustrates a transition, where sustaining normality becomes important for patients. Furthermore, the waiting time from the evaluation and approval of the donor to the transplantation triggers not only excitement and hope but also frustration.

Relevance to clinical practice

We conducted this study to increase knowledge of the experiences of individuals living with ESRD prior to a kidney transplantation with a living donor. The results show that patients are
in need of support from health professionals prior to a kidney transplantation. The findings of this study may help health professionals to recognize the various forms of existential challenges faced by patients living with end-stage renal disease and receiving a kidney from a living donor. Psychosocial support from health professionals may help to clarify and address patients’ existential worries, together with worries regarding donor outcomes and the relationship to the donor. However, there is a need to developing a programme for rehabilitation that would provide strategies to support patients prior to a kidney transplantation.

References


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Table 1: Characteristics of the included patients

<table>
<thead>
<tr>
<th>Patient</th>
<th>Gender</th>
<th>Age</th>
<th>Dialysis modality before transplantation</th>
<th>Relationship to the donor:</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>Male</td>
<td>40</td>
<td>None</td>
<td>Father</td>
</tr>
<tr>
<td>P2</td>
<td>Male</td>
<td>58</td>
<td>None</td>
<td>Acquaintance</td>
</tr>
<tr>
<td>P3</td>
<td>Female</td>
<td>63</td>
<td>None</td>
<td>Spouse</td>
</tr>
<tr>
<td>P4</td>
<td>Male</td>
<td>20</td>
<td>Haemodialysis</td>
<td>Father</td>
</tr>
<tr>
<td>P5</td>
<td>Female</td>
<td>59</td>
<td>None</td>
<td>Brother</td>
</tr>
<tr>
<td>P6</td>
<td>Female</td>
<td>42</td>
<td>Haemodialysis</td>
<td>Mother</td>
</tr>
<tr>
<td>P7</td>
<td>Male</td>
<td>43</td>
<td>Home Haemodialysis</td>
<td>Mother</td>
</tr>
<tr>
<td>P8</td>
<td>Female</td>
<td>43</td>
<td>None</td>
<td>Sister</td>
</tr>
<tr>
<td>P9</td>
<td>Male</td>
<td>45</td>
<td>Peritoneal dialysis at home</td>
<td>Brother</td>
</tr>
<tr>
<td>P10</td>
<td>Female</td>
<td>59</td>
<td>Home haemodialysis</td>
<td>Sister</td>
</tr>
<tr>
<td>P11</td>
<td>Male</td>
<td>49</td>
<td>None</td>
<td>Brother</td>
</tr>
<tr>
<td>P12</td>
<td>Male</td>
<td>72</td>
<td>None</td>
<td>Spouse</td>
</tr>
<tr>
<td>P13</td>
<td>Male</td>
<td>26</td>
<td>Haemodialysis</td>
<td>Father</td>
</tr>
<tr>
<td>P14</td>
<td>Female</td>
<td>45</td>
<td>Haemodialysis</td>
<td>Spouse</td>
</tr>
</tbody>
</table>
Table 2: Example of the structural analysis

<table>
<thead>
<tr>
<th>Units of meaning</th>
<th>Units of significance</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What is said</strong></td>
<td><strong>What the text talks about</strong></td>
<td><strong>Emergence of key themes</strong></td>
</tr>
<tr>
<td>“You actually feel like you live in your own world. The world it just goes on. It goes on outside you. You are just inside your own world all the time and you do not feel healthy at any time. I feel cut off” (P7).</td>
<td>Reflections on how living with end-stage renal disease is experienced as living in one’s own world prior to a kidney transplantation</td>
<td>Living in one’s own world while having existential worries</td>
</tr>
</tbody>
</table>