



University of Southern Denmark

Living in limbo while one's identity is changing

Patients' existential experiences 6 months after a kidney transplantation with a living donor

Kristensen, Ingrid Villadsen; Birkelund, Regner; Henriksen, Jette; Norlyk, Annelise

Published in:

Journal of Advanced Nursing

DOI:

10.1111/jan.14683

Publication date:

2021

Document version:

Accepted manuscript

Citation for pulished version (APA):

Kristensen, I. V., Birkelund, R., Henriksen, J., & Norlyk, A. (2021). Living in limbo while one's identity is changing: Patients' existential experiences 6 months after a kidney transplantation with a living donor. *Journal of Advanced Nursing*, 77(3), 1403-1410. <https://doi.org/10.1111/jan.14683>

Go to publication entry in University of Southern Denmark's Research Portal

Terms of use

This work is brought to you by the University of Southern Denmark.

Unless otherwise specified it has been shared according to the terms for self-archiving.

If no other license is stated, these terms apply:

- You may download this work for personal use only.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying this open access version

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim. Please direct all enquiries to puresupport@bib.sdu.dk

Title page

Title: Living in limbo while one's identity is changing: patients' existential experiences six months after a kidney transplantation with a living donor

Running head: Living in limbo while identity is changing

Corresponding and first author:

Ingrid Villadsen KRISTENSEN, Senior lecturer, Section for Nursing, Department of Public Health, Aarhus University, Research Centre for Health and Welfare Technology, Programme for Rehabilitation, VIA University College, Gl. Struervej 1, 7500 Holstebro. Denmark. Mail: invk@via.dk

Co-authors:

Regner BIRKELUND, Professor, Lillebaelt Hospital, Vejle & Institute of Regional Health Research, University of Southern Denmark. Mail: Regner.Birkelund@rsyd.dk

Jette HENRIKSEN, Senior lecturer, VIA Nursing, VIA University College. Mail: jhen@via.dk

Annelise NORLYK, Professor, Study Director, Section for Nursing, Department of Public Health, Aarhus University. Mail: an@ph.au.dk

Author contributions

Criteria	Author Initials
Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data;	IVK, RB, JH and AN

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/JAN.14683](https://doi.org/10.1111/JAN.14683)

This article is protected by copyright. All rights reserved

Involvement in drafting the manuscript or revising it critically for important intellectual content;	IVK, RB, JH and AN
Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content;	IVK, RB, JH and AN
Agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.	IVK, RB, JH and AN

This article has not been published and is not under consideration for publication anywhere else. Therefore, we declare that there is no breach of copyright.

The authors declare that they have no conflict of interests.

Acknowledgements

We would like to acknowledge the patients participating in this study. Furthermore, we would like to acknowledge Odense University Hospital and Department of Medicine, Holstebro Hospital for their collaboration as well as VIA Health Promotion & Rehabilitation, Center for research for support and inspiration during the study.

Funding

This work was supported by VIA Faculty of Health Sciences, Via University College; Department of Public Health, Aarhus University and the Kidney Organization in Denmark.

Article type : Original Research: Empirical research - qualitative

Living in limbo while one's identity is changing: patients' existential experiences six months after a kidney transplantation with a living donor

Abstract

Aim: to investigate patients' existential experiences in everyday life after a kidney transplantation with a living donor.

Design: A qualitative study anchored in a hermeneutic-phenomenological approach inspired by Ricoeur's theory of narrative and interpretation.

Method: Eleven patient interviews were conducted approximately six months after a kidney transplantation with a living donor. The interviews were conducted between August 2017 - May 2019. Analysis and interpretation are based on Ricoeur's theory of interpretation.

Results: Four themes were identified: Experiencing bodily vulnerability while getting back to life; Feeling guilt while experiencing gratitude; Living in limbo while one's identity is changing; and Facing the future with hope while having reservations.

Conclusion: This study reveals that patients experience multifaceted existential challenges in their everyday lives during the transition of the kidney transplantation process. Post-surgery complications for donors lead to feelings of guilt in patients; plus, they must adapt to a new existence, including a new identity. The patients feel they are in limbo, as they experience their existence as uncertain and their identity as unknown.

Impact: The study highlights a need for developing a rehabilitation programme to address the individual and various existential challenges faced by patients who need to undergo a kidney transplantation.

Keywords: end-stage renal disease, existential experiences, kidney transplantation, nursing, qualitative research, Ricoeur

Introduction

Due to technological developments, organ transplantation has become an established treatment in end-stage organ failure (Schulz & Kroencke, 2015). However, research shows that patients face challenges in their everyday lives after transplantation, especially concerning existential aspects (Orr, Willis, Holmes, Britton, & Orr, 2007). Hence, the focus of this article is patients' existential experiences in everyday life after a kidney transplantation with a living donor.

Background

Kidney transplantation offers longer life expectancy, fewer restrictions in everyday life, higher quality of life and less need of medication – compared to dialysis (Landreneau, Lee, & Landreneau, 2010; Martin, 2014; Oniscu, Brown, & Forsythe, 2005). Thus, when possible, kidney transplantation is the usual treatment of choice for most patients living with end-stage renal disease (ESRD) (Knoll, 2008; Ummel, Achille, & Mekkelholt, 2011).

Despite the increasing number of living-donor kidney transplantations in Western countries (Horvat, Shariff, & Garg, 2009; Martin, 2014) research reveals that patients experience challenges after transplantation. These challenges relate to lifestyle changes, including additional hygiene practices, altered body image, side effects of medication and clinic appointments (Luk, 2004; Murphy, 2007; Rosaasen et al., 2017). Furthermore, a study about the intensity and impacts of fatigue in kidney transplant patients shows that some patients still face fatigue in their everyday lives after undergoing kidney transplantation (Procópio et al., 2014).

In addition, research shows that transplantation leads to a variety of stressors for recipients. Despite feeling positive about the transplant, patients may be concerned about the possibility of graft rejection (Gill, 2012). Fear of graft failure has a major influence on the lives of kidney transplant patients (Harrington & Morgan, 2016). Moreover, transplant survival seems to be more important than life itself to kidney transplant recipients, and patients rank side effects as having very low importance, compared with transplant survival (Howell, Tong, Wong, Craig, & Howard, 2012).

An exploratory study investigating patients' experiences of living with a transplanted kidney shows that the transplanted kidney is central to the lives of the recipients and that living with a transplanted kidney entails long-term psychosocial impacts (Orr et al., 2007). Thus, studies indicate that transplantation resembles a new chronic condition and can be associated with various uncertainties (Gill, 2012; Orr et al., 2007). According to Rees, the psychosocial impact of end-stage kidney disease (ESRD) is still often overlooked (Rees, Chilcot, Donnellan, & Soulsby, 2018). However, psychosocial issues play an important role in the management of kidney disease, due to its impact on well-being and clinical outcomes (Cukor, Cohen, Peterson, & Kimmel, 2007). A phenomenological study has shown that the experiences of patients after kidney transplantation are complex and contradictory in the early post-surgery phase, as patients report feelings of ambivalence (Wiederhold, Langer, & Landenberger, 2011). In addition, patients experience existential concerns related to the fact that the viability of the transplanted kidney is time-limited, while also feeling gratitude towards the donor (Orr et al., 2007). Accordingly, qualified support and care for patients after kidney transplantation are especially needed. Consequently, research that takes its departure in the patient's perspective after a kidney transplantation with a living donor is important.

Research indicate that living with end-stage renal disease entails complex challenges related to the meaning of existence, striving for normality, and accepting changing roles (Kristensen, Henriksen, Birkelund, & Norlyk, 2020). As kidney transplantation gives the prospect of new life (Schulz & Kroencke, 2015; Schulz et al., 2014), patients undergoing a kidney transplantation are standing midstream regarding existential issues. Therefore, research concerning patients' existential experiences after a kidney transplantation with a living donor is of importance. However, knowledge is sparse concerning the existential aspects faced by patients after transplantation.

Aim

The aim of this study was to investigate patients' existential experiences in everyday life 6 months after a kidney transplantation with a living donor.

Method

Design

To reach a new understanding of patients' existential experiences, the study is anchored in a hermeneutic-phenomenological approach inspired by Ricoeur's theory of narrative and interpretation (Ricoeur, 1976, 1991a, 1991b). As stated by Ricoeur, human life needs and deserves

to be told and this substantiates why we tell stories (Ricoeur, 1984). Furthermore, narration involves reflection and hereby allows new perspectives to emerge (Ricoeur, 1976). Thus, to gain in-depth insight into the patients' stories of their existential experiences in everyday life after a kidney transplantation with a living donor we chose to conduct in-depth interviews (Kvale & Brinkmann, 2014).

Participants

We recruited patients from one of three kidney transplant centres situated at a university hospital in Denmark. The inclusion criteria were Danish-speaking recipients over the age of 18 who had received a kidney from a living donor.

The included participants had been interviewed prior to their transplantation in a previous study investigating the existential experiences of patients prior to a kidney transplantation with a living donor (Kristensen, Birkelund, Henriksen, Agerskov, & Norlyk, 2019). The first author contacted patients who were interested in participating in an interview after transplantation, provided the patients with oral information about the study, and planned a date for the interview. In total, we included 11 patients: five women and six men. Some of the characteristics of the included patients are presented in Table 1.

Data collection

Participants were interviewed approximately six months after their transplant. Nine interviews took place in the patients' homes and two in a quiet room at the hospital in accordance with the patients' wishes. The first author conducted the interviews. The interviews were based on open-ended questions (Kvale & Brinkmann, 2014), such as "please, tell me about your everyday life after being kidney transplanted?". The participants were interviewed between August 2017 - May 2019. All interviews were audio recorded and transcribed verbatim. The interviews were conducted in Danish. To find the right expression, a native English speaker translated the quotes included in the findings.

Ethical Considerations

All patients received written and oral information about the study before giving written informed consent, in accordance with the Helsinki Declaration (World Medical Association, 2013). The study was approved by the Danish Data Protection Agency, journal number: 2015-57-0002-62908/274. Moreover, the Danish Patient Safety Authority gave approval for the study, journal number: 3-

3013-2033/1. Approval from the National Committee on Health Research Ethics was not required in accordance with Danish law (National Committee on Health Research Ethics, 2019).

Data analysis and interpretation

Interpretation of the data consisted of a spiral process on three levels: naïve reading, structural analysis and comprehensive understanding. In accordance with Ricoeur's 'naïve reading' (Ricoeur, 1976) we read the data repeatedly with an open approach to obtain an understanding of the text as a whole. The naïve reading gives an initial impression and understanding of what the text is about (Ricoeur, 1976). At this first level of the analysis, a coherent understanding of the patients' existential experiences in everyday life after a kidney transplantation with a living donor emerged. Then, we carried out the structural analysis, to reach a deeper understanding of the patients' experiences. This involved dividing the text into units of meaning. Quotations that illuminated aspects related to patients' existential experiences were identified. They served as units of meaning in the structural analysis and covered 'what is said'. This was followed by a process of moving from what is said to units of significance, i.e. 'what the text talks about' (Ricoeur, 1976). Accordingly, the analysis process consisted of a movement back and forth from units of meaning to units of significance, to illuminate patterns of meanings, which we then structured into themes (Table 2). At the final level of the analysis, the comprehensive understanding, we conducted a critical interpretation based on the themes extracted through the structural analysis. The identified themes were illuminated and discussed with theory and other research to nuance our understandings and finally reach a deeper interpretation (Ricoeur, 1976).

Rigour

As this study is anchored in a hermeneutic-phenomenological approach (Ricoeur, 1991a), it is argued that the philosophical underpinnings of phenomenology becomes paramount (Norlyk & Harder, 2010). Therefore, the clarification of phenomenological research criteria entails being true to principles of phenomenological inquiry (Giorgi, 2000; Norlyk & Harder, 2010). Thus, we strove to establish transparency in the study by clearly setting out and stringently following Ricoeur's steps in the analytical process (Ricoeur, 1991a). The first author collected the data, and during the analysis, the findings were continually discussed with the co-authors. Hereby, an ongoing discussion of the analysis among the authors lead to in a refinement of themes. Furthermore, we applied Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury and Craig, 2007) during the study.

Findings

The naïve reading revealed that patients seemed to experience complex existential challenges after a kidney transplantation with a living donor. Through the structural analysis, we identified four themes: Experiencing bodily vulnerability while getting back to life, Feeling guilt while experiencing gratitude, Living in limbo while one's identity is changing, Facing the future with hope while having reservations.

Experiencing bodily vulnerability while getting back to life

The findings show that patients experience vulnerability related to the body. They feel that their bodies are changing due to the medication and they are constantly reminded of their situation. Clinical appointments and blood tests serve to reassure the patients that the new kidney is functioning, but they are also a continual reminder: "Side effects from the medication cause hair loss. You can see it on my skin and I have more appetite. I have gained weight; not that it matters, but I am constantly reminded of that (the transplant). Then there are all the blood tests and clinical appointments (P6)." Furthermore, patients still experience fatigue six months after kidney transplantation. Patients experience vulnerability when reminded of the kidney transplantation by bodily expressions: "I did not even realize how ill I was. Then one day, it turned around and got *much better* (P7)".

Additionally, patients articulate the feeling of freedom as encouraging and the feeling of getting back to daily life as promising: "I feel free now. That is positive, after all. I can still feel the scar, especially when sitting in the car or in my chair. Then I feel it (P5)." However, the feeling of freedom is enhanced by existential experiences of being in the present: "It feels like I am much more present. I no longer feel that I am a spectator of my own and others' lives. I do not feel cut off anymore. The layer that surrounded me and kept me in my own world has been removed. Now I feel present. But when I get tired, I get really tired. (P5)." The feeling of having been a spectator of one's own and others' lives before transplantation causes a new and encouraging feeling of being present and getting back to life.

Feeling guilt while experiencing gratitude

Patients are standing midstream; they are oscillating between feelings of guilt and gratitude towards to their donor. The donor's complications after surgery trigger existential feelings of guilt and mental distress: "*I was really affected mentally, when he (the donor) got so ill after the transplantation* (P3)". Furthermore, the fear of rejection of the donated kidney triggers anxiety and

feelings of guilt related to the donor's health: "Somehow, I felt a sense of guilt. I gave most of my attention to him (the donor), because I felt guilty that the kidney did not seem to work at first.

Somehow, I had such a strange feeling of guilt. Imagine if I just wasted his kidney (P1)".

Simultaneously, the patients articulate gratitude for the chance to receive a kidney from a living donor, and the fact that someone would donate a kidney. Patients feel gratitude towards their donor and pay great attention to acknowledging their donor while also being concerned about the donor's health. However, unexpected complications maintain the patients' experience of oscillation between guilt and gratitude; thus feelings of gratitude and guilt are coexistent: "She (the donor) has given me a very precious gift. It was very hard for me that she felt this way and had so many complications after the donation. I did not expect that. (P4).

Living in limbo while *one's* identity is changing

Patients experience living in limbo while their identity is changing, as two of the multifaceted existential challenges they face in their everyday lives after kidney transplantation. They experience people around them articulating that they must be happy in their new lives, suggesting that the patients have a completely new life to embrace. Additionally, expectations and statements from others reinforce uncertainty about their own identity: "I do not feel a big difference from before until now. Somehow, I think people around me expect me to feel better now (P4).

For patients, being employed and getting back to work is crucial, as working is presumed to be a sign of normality. However, getting back to work does not mean that everything feels normal, as work life may not be the same as before. Simultaneously, patients experience a changing identity: "It is a huge part of my identity. All of a sudden, you are just another person. You just have to find a balance in life (P5). The feeling of living in limbo while their identity is changing is illustrated by the struggle to find a balance in their everyday lives; by trying to establish normality and stability in their new existence. Balancing one's everyday life involves adapting levels of activity and adjusting to fatigue. Furthermore, patients face the other side of the coin with long-lasting restrictions, described as: "*I still have to take into account that I have a chronic disease, in the things I do, and I prioritize not participating in some activities (P2)*".

Patients struggle to adapt to a changed life and to cope with their existential challenges in everyday life. Related to the changing identity and balancing everyday life, some patients need to share their experiences and, in particular, their existential challenges with those who have also been kidney transplanted: "*I would really like to talk to someone who is in the same situation as me (P9).*"

The uncertainty of living in limbo and having a changed identity due to the kidney transplantation trigger existential concerns: *“I have become a symbiosis with my illness. My illness is my identity. Now I have a new kidney and my body is functioning. Well, then I think, what should I do? If it is a completely new life, what am I going to do with it? Does it mean that I am obliged to do something?”* (P6). This means that patients must adapt to a new existence, including a changed identity. However, gratitude for a newfound freedom, which the kidney transplantation entails, is coexistent with the feeling of living in limbo.

Facing the future with hope while having reservations

Patients experience an oscillation between facing the future with hope while also having reservations about what lies ahead. They hope that the kidney will last for many years. Conversely, they also experience existential challenges concerning having faith for the future. They have doubts about what lies ahead and feel a need to work or embark on new activity. I do not actually know why I feel unresolved, but I think I need something to fill my calendar. Some work. I also think about the future. I feel a bit like being on benefits having trouble getting started (P8)”.

Moreover, patients experience hope connected to their newfound freedom, such as travelling, studying and starting a family. Nevertheless, this feeling of hope is coexistent with an underlying uncertainty and doubt: *“I am thinking about starting a family in the near future. What if the kidney stops functioning in 5 years and I have to be on dialysis?”* (P10). Additionally, patients are realistic about the chances that the function of their new kidney may decrease. Clinical appointments can be helpful for patients to maintain optimism about the future: *“After all, something can happen. That is why you are under continuous observation, so they (health professionals) can react quickly”* (P7). Furthermore, patients look to the future with a mix of hope, relief and gratitude: *“I think a lot about the future. I am really grateful that I have been kidney transplanted”* (P11)”.

Discussion

This study contributes with new knowledge about patients’ multifaceted existential experiences in everyday life six months after a kidney transplantation with a living donor. The findings show that patients experience bodily vulnerability after undergoing a kidney transplantation, in that they experience vulnerability due to bodily changes. Their body constantly reminds them of the kidney transplantation, and they experience fatigue as a bodily expression. Another study found that patients substantially overestimated the benefits of a successful kidney transplant (Smith et al., 2008). However, our findings show that patients experience a new feeling of being present and

getting back to life. In line with our findings, another study emphasized how patients worked hard to reestablish normality and were prepared to accept a new form of normality that aligned with their capacities post-transplant (Boaz & Morgan, 2014).

Our study reveals that patients experience vulnerability connected to their body while striving towards the feeling of getting back to life. These existential challenges align with key findings in another study, which indicate patients live with paradoxes and conflicts after a kidney transplant (Amerena, Wallace, & Wallace, 2009). This study unfolds paradoxes such as that society sees them as well, yet they feel physically vulnerable (Amerena et al., 2009). These findings are supported in our current study, as patients' experience an expectation from others that they must be happy in their new lives as having to embrace a whole new life; yet they still feel vulnerable and ill. Additionally, our findings concerning the fear of rejection and the fact that the feeling of hope coexists with an underlying uncertainty and doubt, are underpinned by another study's finding on increased anxiety about actual viability of the graft and fear of losing the transplanted organ (Amerena et al., 2009).

In relation to the donor, we found that patients experienced coexistent existential emotions, such as guilt and gratitude. A qualitative study concerning the positive and negative consequences of renal transplantation showed that patients experienced a wide range of positive and negative emotions, such as guilt, gratefulness and fear (Schipper et al., 2014). However, the feeling of guilt in the study is related to receiving a kidney from a deceased donor (Schipper et al., 2014), whereas our study focuses on existential experiences after living related donation. There may be differences in the feeling of guilt, depending on whether the donor is living or deceased; recipients of a kidney from a living donor may be confronted with guilt on meeting their donor.

Our findings show that patients face the future with hope while having reservations. Taking these findings into account, a recent survey shows common themes related to changes following transplantation, such as a return to normality, more energy, better health and quality of life (Tucker et al., 2019). Conversely, patients have concerns regarding duration of graft survival, fears about one day returning to dialysis or needing to undergo another kidney transplant, along with comorbidities (Tucker et al., 2019). Hereby, this study supports our findings regarding the fact that patients experience an oscillation between hope and reservations that are complex, as patients simultaneously face the challenges of living with a changing identity.

We found that patients have feelings of living in limbo while their identity is changing. They have concomitant existential experiences, such as uncertainty and changed identity, and they also struggle for normality. These findings can be understood in the context of transition. According to Meleis, all transitions can be characterized as movement and flow over time (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). Before patients can enter a new beginning, they seem to go through phases of uncertainty, confusion and anxiety during the transition (Meleis et al., 2000). Furthermore, patients in transition tend to be more vulnerable (Meleis et al., 2000). The process of transplantation, which involves existential concerns, illustrates this transition. Hereby, our study adds to the theory of transition by illustrating existential dimensions related to the transition, as experienced by patients after a living kidney transplantation. However, patients who have undergone kidney transplantation have to endure uncertainty related to living with a transplanted organ, as long as the kidney is functioning. The experience of transition substantiates the need for focusing on existential experiences in rehabilitation, as patients undergoing a kidney transplantation during transition experience existential challenges. To address the existential experiences, an individualized interdisciplinary collaborative approach is essential to create meaningful communication between health professionals and patients undergoing kidney transplantation.

Considering that patients have individual perceptions of illness and needs in the kidney transplantation process, patient-centred education becomes a key element in the care of such patients (Urstad, Wahl, Andersen, Øyen, & Fagermoen, 2012). A tailored, evidence-based education programme for the post-transplant phase consisting of three main areas: medication, rejection and lifestyle (Andersen, Wahl, Engebretsen, & Urstad, 2019) has been implemented in Norway. With the purpose of meeting patients' existential experiences in their everyday lives after a kidney transplantation with a living donor, we therefore recommend focusing on and further developing tailored support and education that encompasses the existential challenges faced by the individual patient.

Limitations

By clearly setting out and stringently following Ricoeur's steps in the analytical process (Ricoeur, 1991a), we strove to establish transparency in the study. Due to the hermeneutic-phenomenological approach, the disparity in the participants' treatment modality represents a variation in the experiences of the participants. The phenomenological literature does not offer much on sampling procedures. However, the aim in a phenomenological study is to understand a phenomenon more

deeply; besides which, variation in the phenomenological framework is variation of the experiences (Norlyk & Harder, 2010). Conversely, we did not study cultural views and beliefs, and the participants only reflected the Danish-speaking population; thus a multi-ethnic perspective is lacking.

Conclusion

The aim of this study was to investigate patients' existential experiences in everyday life after a kidney transplantation with a living donor. This study reveals that patients experience multifaceted existential challenges in their everyday lives during the transitional phase of undergoing kidney transplantation. Patients experience that people around them articulate that they must be happy in their new life, suggesting that the patients have a whole new life to embrace. Nevertheless, the donors' possible complications after surgery have an impact on patients' feelings of guilt, and patients have to adapt to a new existence – including a new identity. The patients live in limbo; they experience their existence as uncertain and their identity as unknown. They question the idea that they have a new life, while appreciating their newfound freedom. The process of transplantation hereby illustrates a transition that involves existential challenges. Based on our findings regarding existential experiences, support from health professionals becomes paramount. As patients undergoing a kidney transplantation need education to adapt to life changes thereafter, psychosocial support from health professionals may help to clarify and address patients' existential experiences. However, there is a need to develop a programme of rehabilitation that encompasses the existential challenges faced by the individual patient and provides strategies to support patients achieving meaningful lives.

References

- Amerena, P., Wallace, P. and Wallace, P. (2009) 'Psychological experiences of renal transplant patients: A qualitative analysis', *Counselling and Psychotherapy Research*, 9(4), pp. 273–279. doi: 10.1080/14733140902935195.
- Andersen, M. H. et al (2019) 'Implementing a tailored education programme: renal transplant recipients' experiences', *Journal of Renal Care*, 45(2), pp. 111–119. doi: 10.1111/jorc.12273.
- Boaz, A. and Morgan, M. (2014) 'Working to establish "normality" post-transplant: A qualitative study of kidney transplant patients', *Chronic illness*, 10(4), pp. 247–258. doi: 10.1177/1742395313504789.
- Cukor, D. et al. (2007) 'Psychosocial Aspects of Chronic Disease: ESRD as a Paradigmatic Illness', *Journal of the American Society of Nephrology*, 18(12), pp. 3042–55. doi: 10.1681/ASN.2007030345.
- Gill, P. (2012) 'Stressors and coping mechanisms in live-related renal transplantation.', *Journal of clinical nursing*, 21(11–12), pp. 1622–31. doi: 10.1111/j.1365-2702.2012.04085.x.
- Giorgi, A. (2000). Concerning the application of phenomenology to caring research. *Scandinavian Journal of Caring Sciences*, 14(1), 11–15. <https://doi.org/10.1111/j.1471-6712.2000.tb00555.x>
- Harrington, J. and Morgan, M. (2016) 'Understanding kidney transplant patients' treatment choices: The interaction of emotion with medical and social influences on risk preferences.', *Social science & medicine* (1982), 155, pp. 43–50. doi: 10.1016/j.socscimed.2016.02.027.
- Horvat, L. D., Shariff, S. Z. and Garg, A. X. (2009) 'Global trends in the rates of living kidney donation.', *Kidney International*, 75(10), pp. 1088–1098. doi: 10.1038/ki.2009.20.
- Howell, M. et al. (2012) 'Important Outcomes for Kidney Transplant Recipients: A Nominal Group and Qualitative Study', *American journal of kidney diseases*, 60(2), pp. 186–196. doi: 10.1053/j.ajkd.2012.02.339.
- Knoll, G. (2008) 'Trends in kidney transplantation over the past decade.', *Drugs*, 68 Suppl 1(SUPPL. 1), pp. 3–10. doi: 10.2165/00003495-200868001-00002.
- Kristensen, I. V., Henriksen, J., Birkelund, R., & Norlyk, A. (2020). Existential Contradictions in Living With End-Stage Renal Disease: A Qualitative Metasynthesis. *ANS. Advances in Nursing Science*, 43(2), 159–171. <https://doi.org/10.1097/ANS.0000000000000312>

Kristensen, I. V., Birkelund, R., Henriksen, J., Agerskov, H., & Norlyk, A. (2020). Living in one's own world, while life goes on: Patients' experiences prior to a kidney transplantation with a living donor. *Journal of Clinical Nursing*, 29(3–4), 638–644. <https://doi.org/10.1111/jocn.15117>

Kvale, S. and Brinkmann, S. (2014) *Interviews : learning the craft of qualitative research interviewing*. 3rd edn. Thousand Oaks, Calif.: Sage Publications.

Landreneau, K., Lee, K. and Landreneau, M. D. (2010) 'Quality of life in patients undergoing hemodialysis and renal transplantation--a meta-analytic review.', *Nephrology nursing journal : journal of the American Nephrology Nurses' Association*, 37(1), pp. 37–44.

Luk, W. S.-C. (2004) 'The HRQoL of renal transplant patients.', *Journal of clinical nursing*, 13(2), pp. 201–9. doi: 10.1046/j.1365-2702.2003.00867.x.

Martin, P. (2014) 'Living donor kidney transplantation: preferences and concerns amongst patients waiting for transplantation in New Zealand.', *Journal of health services research & policy*, 19(3), pp. 138–144. doi: 10.1177/1355819613514957.

Meleis, A. I. et al. (2000) 'Experiencing transitions: an emerging middle-range theory.', *ANS. Advances in nursing science*, 23(1), pp. 12–28. doi: 10.1097/00012272-200009000-00006.

Murphy, F. (2007) 'The role of the nurse post-renal transplantation.', *British journal of nursing (Mark Allen Publishing)*, 16(11), pp. 667–75. doi: 10.12968/bjon.2007.16.11.23689.

National Committee on Health Research Ethics (2019) *Act on Research Ethics Review of Health Research Projects*. Available at: <http://en.nvk.dk/>.

Norlyk, A. and Harder, I. (2010) 'What makes a phenomenological study phenomenological? An analysis of peer-reviewed empirical nursing studies.', *Qualitative health research*, 20(3), pp. 420–31. doi: 10.1177/1049732309357435.

Oniscu, G. C., Brown, H. and Forsythe, J. L. R. (2005) 'Impact of cadaveric renal transplantation on survival in patients listed for transplantation.', *Journal of the American Society of Nephrology : JASN*, 16(6), pp. 1859–65. doi: 10.1681/ASN.2004121092.

Orr, A. et al. (2007) 'Living with a kidney transplant: a qualitative investigation of quality of life.', *Journal of Health Psychology*, 12(4), pp. 653–62. doi: 10.1177/1359105307078172.

- Procópio, F. O. et al. (2014) 'Fatigue Effects in Daily Life Activities of Kidney Transplant Recipients', *Transplantation proceedings*, 46(6), pp. 1745–1749. doi: 10.1016/j.transproceed.2014.05.024.
- Rees, J. et al. (2018) 'Exploring the nature of illness perceptions in people with end-stage kidney disease', *Journal of Renal Care*, 44(1), pp. 19–29. doi: 10.1111/jorc.12225.
- Ricoeur, P. (1976) *Interpretation theory: discourse and the surplus of meaning*. 6. print. Fort Worth, Tex.: Texas Christian University Press.
- Ricoeur, P. (1984) 'Time and Narrative. Volume 1', *Philosophical Studies*. Chicago: University of Chicago Press, pp. 356–358. doi: 10.5840/philstudies19883227.
- Ricoeur, P. (1991a) *From text to action*. Evanston, Ill.: Northwestern University Press (Essays in hermeneutics, 2).
- Ricoeur, P. (1991b) 'Life in quest of narrative', in *On Ricoeur. Narrative and interpretation*. London: Wood, D. edn, Routledge, pp. 20–33.
- Rosaasen, N. et al. (2017) 'Education Before Kidney Transplantation', *Progress in Transplantation*, 27(1), pp. 58–64. doi: 10.1177/1526924816685862.
- Schipper, K. et al. (2014) 'Sweet and sour after renal transplantation: a qualitative study about the positive and negative consequences of renal transplantation.', *British journal of health psychology*, 19(3), pp. 580–91. doi: 10.1111/bjhp.12057.
- Schulz, K.-H., & Kroencke, S. (2015). Psychosocial challenges before and after organ transplantation. *Transplant Research and Risk Management*, 7, 45.
<https://doi.org/10.2147/TRRM.S53107>
- Schulz, T., Niesing, J., Homan van der Heide, J. J., Westerhuis, R., Ploeg, R. J., & Ranchor, A. V. (2014). Great expectations? Pre-transplant quality of life expectations and distress after kidney transplantation: A prospective study. *British Journal of Health Psychology*, 19(4), 823–838.
<https://doi.org/10.1111/bjhp.12081>
- Smith, D. et al. (2008) 'Mispredicting and misremembering: patients with renal failure overestimate improvements in quality of life after a kidney transplant.', *Health psychology*, 27(5), pp. 653–658. doi: 10.1037/a0012647.

Tong, A., Sainsbury, P. and Craig, J. (2007) 'Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups.', *International journal for quality in health care*, 19(6), pp. 349–357. doi: 10.1093/intqhc/mzm042.

Tucker, E. L. et al. (2019) 'Life and expectations post-kidney transplant: a qualitative analysis of patient responses.', *BMC nephrology*, 20(1), p. 175. doi: 10.1186/s12882-019-1368-0.

Ummel, D., Achille, M. and Mekkelholt, J. (2011) 'Donors and Recipients of Living Kidney Donation: A Qualitative Metasummary of Their Experiences', *Journal of Transplantation*, 2011(2011), p. 11. doi: 10.1155/2011/626501.

Urstad, K. H. et al. (2012) 'Renal recipients' educational experiences in the early post-operative phase--a qualitative study.', *Scandinavian journal of caring sciences*, 26(4), pp. 635–42. doi: 10.1111/j.1471-6712.2012.00972.x.

Wiederhold, D., Langer, G. and Landenberger, M. (2011) 'Ambivalent lived experiences and instruction need of patients in the early period after kidney transplantation: a phenomenological study.', *Nephrology nursing journal: journal of the American Nephrology Nurses' Association*, 38(5), pp. 417–23; quiz 424.

Author Manuscript

Table 1: Characteristics of the included patients

Patient	Gender	Age	Dialysis modality before transplantation	Relationship to the donor
P1	Male	40	None	Father
P2	Male	20	Haemodialysis	Father
P3	Female	59	None	Brother
P4	Female	42	Haemodialysis	Mother
P5	Male	43	Home haemodialysis	Mother
P6	Female	43	None	Sister
P7	Male	45	Peritoneal dialysis at home	Brother
P8	Female	59	Home haemodialysis	Sister
P9	Male	49	None	Brother
P10	Male	26	Haemodialysis	Father
P11	Female	45	Haemodialysis	Spouse

Author Manuscript

Table 2: Example of the structural analysis

Units of meaning What is said	Units of significance What the text talks about	Themes Emergence of key themes
“I have become a symbiosis with my illness. My illness is my identity. Now I have a new kidney and my body is functioning. Well, then I think, what should I do? If it is a completely new life, what am I going to do with it? Does it mean that I am obliged to do something?”	Reflections on how living with ESRD has become an identity. Patient’s experience of identity is changing and experienced as uncertain and undefined after kidney transplantation.	Living in limbo while one’s identity is changing

Author Manuscript