La Source.
Institut et Haute
Ecole de la Santé

Bachelor of Science HES-SO en Soins infirmiers

HAUTE ÉCOLE SPÉCIALISÉE DE SUISSE OCCIDENTALE

Domaine santé

CORPS EN PRÉPARATION, ESPRIT SOUS TENSION, LIEN SOCIAL EN TRANSITION : ACCOMPAGNER L'INCERTITUDE DE LA TRANSPLANTATION RENALE SOUS LA PERSPECTIVE BIOPSYCHOSOCIALE

Da Cruz Nogueira Inês

Gobiet Annabelle

Travail de Bachelor

Haute École de la Santé la Source

Lausanne, le 14 juillet 2025

Sous la direction de Monsieur Zulauf Bernard

Hes·so

TABLE DES MATIERES

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Nous déclarons que ce travail de Bachelor dans le cadre d'une formation en soins infirmiers à l'Institut et Haute École de la Santé La Source (HEdS La Source) a été réalisé seul et sans aide extérieure non autorisée.

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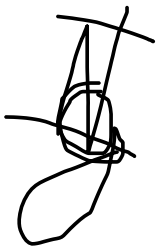

REMERCIEMENTS

Nous remercions sincèrement :

M. Zulauf Bernard, maître d'enseignement à la Haute École de Santé la Source, pour son accompagnement, sa disponibilité et ses précieux conseils tout au long de l'élaboration de ce travail de Bachelor.

Mme Pilon Nathalie, infirmière référente pour l'activité don vivant au Centre Hospitalier Universitaire Vaudois (CHUV), pour avoir accepté d'être notre experte de terrain et avoir contribué à l'évaluation de notre travail.

Swisstransplant, Fondation nationale suisse pour le don et la transplantation d'organes, pour avoir répondu à nos mails et pour nous avoir fourni les brochures nécessaires à l'élaboration de notre travail.

Enfin, nous remercions chaleureusement nos familles et nos proches pour leur soutien tout au long de la conception de ce travail exigeant, ainsi que leur aide pour la relecture de ce dernier.

RESUME

Introduction

Ce travail de Bachelor en soins infirmiers est réalisé à l'Institut et Haute École de la Santé la Source. Il explore l'expérience des patients atteints d'insuffisance rénale chronique inscrits sur liste d'attente pour une transplantation rénale. La période d'attente, marquée par une incertitude multidimensionnelle affecte la qualité de vie des patients sur les plans biologique, psychologique et social. À travers une revue de la littérature, ce travail s'appuie sur la théorie de l'incertitude de Mishel (1988, 1990) et sur le concept de l'espoir de Dufault et Martocchio (1985), afin d'analyser leurs vécus et d'identifier le rôle de l'infirmier dans leur accompagnement.

But

L'objectif est d'identifier les déterminants biopsychosociaux qui affectent ces patients durant le processus de transplantation rénale. De plus, ce travail explore comment la pratique infirmière peut proposer un accompagnement adapté, apportant un soutien émotionnel, éducatif et social.

Méthode

Cette revue de littérature qualitative a été réalisée avec les bases de données Pubmed/Medline et CINAHL, en utilisant des descripteurs combinés. Au total, six articles principaux ont été retenus et analysés de manière critique afin de comparer leurs résultats et de dégager des implications cliniques.

Principaux résultats

Les résultats montrent que l'incertitude est omniprésente et affecte les patients dans leur globalité. Biologiquement, ils vivent une détérioration progressive avec une vulnérabilité corporelle, ce qui renforce leur dépendance aux soins. Psychologiquement, ils oscillent entre espoir et désespoir avec des angoisses concernant le temps d'attente, le rejet de la greffe et les difficultés à se projeter dans l'avenir. Socialement, la vie est souvent « mise en pause » avec des ruptures professionnelles, des ajustements sociaux ou une perte d'identité.

Conclusion

Dans ce parcours marqué par l'incertitude, l'infirmier doit proposer une prise en charge holistique intégrant les ressources internes et externes du patient. La compréhension de l'incertitude comme une expérience inévitable ainsi que la valorisation de l'espoir en tant que pilier d'adaptation sont des axes essentiels pour renforcer la résilience et la qualité de vie.

AVIS AUX LECTEURS

L'utilisation des termes tels qu'*infirmier, patient, soignant, donneur, coordinateur* etc. au masculin inclut automatiquement la forme féminine.

LISTE DES ABREVIATIONS

- **CINHAL** : Cumulative Index to Nursing and Allied Health Literature
- **CHUV** : Centre Hospitalier Universitaire Vaudois
- **HeTOP** : Health Terminology / Ontology Portal
- **HUG** : Hôpitaux Universitaires de Genève
- **IRC** : Insuffisance rénale chronique
- **IRCT** : Insuffisance rénale chronique terminale
- **OFSP** : Office fédéral de la santé publique
- **OMS** : Organisation mondiale de la santé
- **RL** : Revue de littérature
- **RTS** : Radiotélévision Suisse
- **TB** : Travail de Bachelor

1. INTRODUCTION

Ce travail de Bachelor (TB), sous forme de revue de littérature (RL), est conçu dans le cadre de notre formation en soins infirmiers. Il a pour objectif d'explorer l'influence de l'attente d'une greffe rénale sur le vécu des patients atteints d'insuffisance rénale chronique terminale (IRCT), en se concentrant sur les déterminants biopsychosociaux ainsi que sur les possibilités d'accompagnement adaptées que la pratique infirmière peut offrir.

L'IRCT est une pathologie lourde qui engage le pronostic vital et impose des traitements de suppléance tels que la dialyse ou la transplantation. Pour un grand nombre de patients atteints d'IRCT, la greffe rénale représente une étape essentielle pour améliorer leur qualité de vie. Cependant, l'attente de ce traitement peut se prolonger sur plusieurs années engendrant une profonde expérience d'incertitude qui affecte les dimensions biopsychosociales du patient.

Selon la théorie de Merle Mishel (1988, 1990), l'incertitude vécue par ces patients provient souvent d'un manque d'informations, de l'imprévisibilité et de la complexité de leur situation. Dans cette période de grande vulnérabilité, l'espoir, décrit par Dufault et Martocchio (1985) comme un processus multidimensionnel (cognitif, affectif, temporel, contextuel et social), aide les patients à maintenir une vision positive de l'avenir et à s'adapter face à l'incertitude, malgré la souffrance et les difficultés qu'ils traversent.

Alors qu'un grand nombre de personnes endurent cette attente, nous avons rencontré très peu de patients greffés ou en attente de greffe au cours de notre formation. Peut-être étaient-ils présents, mais sans que cela ne soit clairement exprimé. Cette forme d'invisibilité a retenu notre attention. Elle nous a amenées à nous interroger sur la manière dont ces personnes vivent et ressentent cette expérience d'incertitude, et quel serait le rôle infirmier auprès d'elles alors même que leur vécu reste souvent intime.

Dans un premier temps, nous présentons l'intérêt de notre questionnement pour la discipline infirmière. Ensuite, nous détaillons la méthodologie employée pour sélectionner les six articles dont nous avons réalisé l'analyse critique. Enfin, nous mettons en avant les résultats et leurs implications pour la pratique infirmière, afin de répondre à notre question de recherche. Pour finir, nous évoquerons les apprentissages tirés de ce travail.

2. PROBLÉMATIQUE

La transplantation d'organes représente une option thérapeutique vitale. Elle permet une amélioration significative de la qualité de vie des patients atteints de maladies graves en phase terminale, en particulier pour l'IRCT (HUG, 2025).

Cependant, en Suisse, le don d'organes rencontre plusieurs défis majeurs. Bien que le nombre de dons soit en hausse ces dernières années, il demeure toujours insuffisant pour couvrir les besoins des patients en attente de greffe (Swisstransplant, 2024). Pour souligner l'ampleur de cette réalité, il s'avère que la probabilité d'avoir besoin d'un organe un jour est cinq à six fois plus élevée que celle de devenir un jour donneur d'organes (Swisstransplant, 2022). De plus, au 31 décembre 2024, 1283 personnes étaient inscrites sur liste d'attente pour une transplantation d'organe, pour seulement 539 organes transplantés durant l'année. Enfin, chaque semaine, un à deux patients décèdent faute de greffon disponible (Swisstransplant, 2024).

L'insuffisance rénale chronique (IRC), représente une part importante des maladies non transmissibles en Suisse. Un adulte sur dix est atteint d'IRC, tous stades confondus, ce qui correspond à environ 10% de la population adulte suisse (Société Suisse de Néphrologie, 2022). À l'échelle mondiale, 674 millions de personnes vivent avec l'IRC, soit 9% de la population mondiale (Organisation mondiale de la santé [OMS], 2025). Cela signifie qu'il existe un risque élevé de progression vers l'IRCT, nécessitant alors une transplantation ou une dialyse. Cette prévalence augmente avec le vieillissement de la population, atteignant environ 25% chez les plus de 60 ans (Wyss et al., 2017). De plus, l'IRC fait partie des maladies non transmissibles qui, selon l'OMS (2023), sont la principale cause de morbidité et de mortalité à l'échelle mondiale, étant responsable de 74% des décès. En Suisse, près de 329 patients par million d'habitants sont pris en charge pour une insuffisance rénale chronique terminale, nécessitant un traitement de suppléance tel que la dialyse ou la transplantation (ERA-EDTA, 2020).

Toujours en Suisse, la répartition des greffons rénaux est assurée par Swisstransplant, qui attribue les organes selon des critères légaux définis par la loi fédérale sur la transplantation. Ces derniers incluent l'urgence médicale, l'utilité, le temps d'attente afin de garantir une distribution équitable des organes disponibles.

Swisstransplant est la Fondation nationale suisse pour le don et la transplantation d'organes. Ce service, mandaté par l'Office fédérale de la santé publique (OFSP), est situé à Berne, où

une équipe de 40 personnes collabore avec diverses institutions telles que les cantons (Conférence suisse des directrices et directeurs cantonaux de la santé), les hôpitaux (Association H+ Les Hôpitaux de Suisse) ainsi que les assureurs (Fédération suisse pour tâches communes des assureurs-maladie) (Swisstransplant, 2024).

La période d'attente débute dès l'inscription officielle du patient sur la liste nationale de transplantation. Bien que ce processus soit strictement encadré, des facteurs d'incertitude tels que la compatibilité et la disponibilité des greffons persistent (Swisstransplant, 2024). En Suisse, la durée moyenne d'attente pour une transplantation rénale est d'environ 1000 jours, soit près de trois ans (Swisstransplant, 2022).

Le mot patient provient du latin « patiens », qui signifie étymologiquement « celui qui supporte avec patience les malheurs » (Ortolang, 2012). L'attente constitue un élément inévitable du parcours de soins : les patients patientent constamment, que ce soit pour un diagnostic, des rendez-vous programmés, en urgence ou encore pour obtenir des résultats d'examens. De plus, l'attente est une expérience vécue par tous et au quotidien. Ces situations causent souvent du stress, de l'impatience et de l'inquiétude. Cependant, pour les patients inscrits sur une liste d'attente de transplantation, elle devient une attente existentielle : il s'agit d'attendre un organe qui peut non seulement leur sauver la vie, mais aussi en améliorer considérablement la qualité.

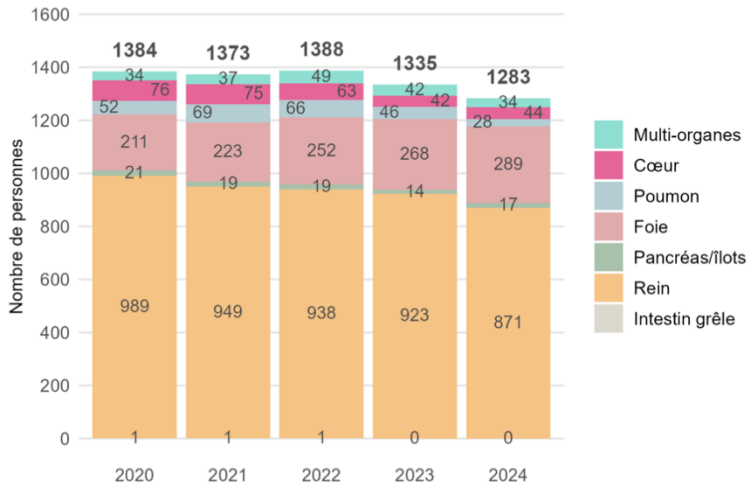

***Figure 1**. Personnes en liste d'attente par organe en Suisse, fin 2024*

Tiré de : Swisstransplant (2025)

Comme le montre le graphique de la figure 1, la majorité des personnes sur liste d'attente le sont pour une greffe de rein. Sur ce graphique, cette catégorie est représentée par la couleur orange, qui illustre de manière frappante l'ampleur du phénomène. Cette proportion élevée,

bien qu'en légère diminution ces dernières années, met en évidence un besoin constant en greffons rénaux. De ce constat, nous avons choisi d'axer notre travail sur la greffe rénale, puisqu'elle concerne la majorité des patients en attente.

Les principales étiologies pouvant conduire à une transplantation rénale sont les suivantes : la néphropathie diabétique, la glomérulonéphrite, la néphropathie hypertensive, certaines maladies rénales d'origine génétique comme la polykystose rénale, ainsi que des infections rénales chroniques comme la pyélonéphrite (Swisstransplant, 2019).

Au niveau économique, selon Chams (2019), en Suisse, un traitement par hémodialyse coûte environ 100'000 CHF par an, et environ 80'000 CHF pour la dialyse péritonéale. Une transplantation rénale, quant à elle, représente un coût d'environ 60'000 CHF la première année, puis les coûts annuels diminuent considérablement. Dans une interview, Swisstransplant explique que la durée de fonctionnalité d'un rein greffé est comprise entre 18 et 20 ans (RTS, 2024). Ainsi, bien que le coût initial soit élevé, la transplantation devient rapidement plus économique que la dialyse. La greffe rénale constitue donc une solution rentable pour notre système de santé, tout en améliorant significativement la qualité de vie des patients.

Une transplantation rénale est un processus complexe, structuré et coordonné par Swisstransplant ainsi que par les centres hospitaliers universitaires tels que Bâle, Berne, Genève, Lausanne, Zurich ou encore Saint-Gall (OFSP, 2023). Ce processus débute par un bilan médical et psychologique complet du receveur, afin d'exclure toute contre-indication à la greffe rénale (CHUV, 2019). Une fois cette étape achevée, le patient est inscrit sur une liste nationale d'attente. L'attribution de l'organe repose sur la compatibilité immunologique, le degré d'urgence et la durée d'attente. Lors du prélèvement, l'organe est récupéré dans des conditions stériles, conservé au froid, puis transporté rapidement vers le centre receveur (OFSP, 2023).

En général, la greffe chirurgicale dure entre deux à trois heures (CHUV, 2019 ; HUG, 2025). En phase post-opératoire, le patient est admis aux soins intensifs pendant environ 48 heures afin de bénéficier d'une surveillance rapprochée, avant de séjourner une dizaine de jours en service de transplantation. Par la suite, son quotidien est rythmé par un suivi à long terme, l'ajustement du traitement immunosuppresseur, la surveillance des complications, ainsi que l'accompagnement psychosocial assuré par l'équipe infirmière.

Durant la période d'attente, les patients doivent bénéficier d'un suivi médical rapproché ainsi que de contrôles réguliers, tels que des bilans sanguins, des échocardiogrammes et des rappels de vaccinations obligatoires, qui doivent être effectués périodiquement afin de garantir leur aptitude à recevoir une greffe dans les meilleures conditions. Comme ils doivent rester joignables en permanence, ils sont équipés d'un téléavertisseur (bipeur) fourni par le coordinateur de transplantation. Il est essentiel que les patients adoptent un mode de vie sain pour maintenir une bonne condition physique, pratiquer un maximum d'activités, poursuivre leur travail et leurs loisirs. Il est également primordial d'exclure la consommation d'alcool et de nicotine, tout en veillant à adopter une alimentation équilibrée. Cependant, les contraintes liées à la dialyse, à la maladie chronique et à l'attente de greffe affectent fortement leur quotidien, générant une tension et une incertitude constantes. Les coordinateurs de transplantation assurent un lien régulier, soutenu et restent disponibles pour répondre à toute question ou intervenir en cas de besoin (HUG, 2025 ; Swisstransplant, 2024).

L'attente prolongée d'une greffe rénale constitue une étape particulièrement éprouvante, générant de multiples souffrances d'ordre physique, psychologique et social. C'est précisément sur cette phase d'attente marquée par l'incertitude que nous souhaitons nous interroger. Celle-ci, liée aux délais, aux risques de complications cliniques et à la disponibilité d'un rein, impacte considérablement la qualité de vie des patients (HUG, 2025 ; Swisstransplant, 2024). Elle soulève également des réflexions existentielles et éthiques. Certains patients expriment des sentiments de dette ou de gratitude envers leur donneur. Comme en témoigne Valérie B. (2021) une patiente doublement greffée rein-pancréas : « Je pense tous les jours à mon donneur ou ma donneuse ! Je le ou la remercie tous les soirs avant de m'endormir. Nous sommes désormais un binôme, il ou elle vit à travers moi » (Blog de l'Hôpital du Valais).

La prise en charge de ces patients nécessite un accompagnement global, intégrant les dimensions biologiques, psychologiques et sociales. Les infirmiers jouent un rôle central grâce à leur proximité et à leur expertise relationnelle et éducative. Pourtant, les interventions infirmières spécifiques visant à accompagner l'incertitude des patients en attente de greffe restent encore peu documentées. Ainsi, cette problématique s'inscrit pleinement dans le champ infirmier qui se doit d'intégrer un accompagnement individualisé et holistique répondant aux besoins multiples des patients en attente de transplantation.

3. CADRE THÉORIQUE

Dans le contexte de la transplantation rénale, comprendre les concepts ci-dessous est essentiel.

3.1. CONCEPT DE L'ESPOIR

L'espoir est défini comme une force dynamique et multidimensionnelle, caractérisée par une attente confiante, bien qu'incertaine, d'un futur perçu comme positif pour la personne. Plus qu'une simple émotion, il s'agit d'un processus actif qui structure l'expérience humaine, notamment en situation de maladie ou de crise. De plus, il permet à la personne de donner un sens à sa vie (Dufault & Martocchio, 1985, cité dans A. Maire, communication personnelle, le 10 novembre 2022).

On distingue deux formes principales d'espoir. La première est l'espoir particularisé, centré sur des objets ou événements spécifiques, comme la réussite d'une greffe ou une rémission, ce qui soutient la motivation et protège du désespoir. La seconde est l'espoir généralisé, qui reflète une croyance fondamentale selon laquelle la vie vaut la peine d'être vécue malgré les difficultés (Dufault & Martocchio, 1985, cité dans A. Maire, communication personnelle, le 10 novembre 2022).

Selon Dufault & Martocchio (1985), l'espoir se décline en six dimensions. La dimension cognitive consiste en la capacité à identifier des buts réalistes ainsi qu'à mobiliser des pensées favorables au futur souhaité. L'espoir temporel articule le passé, le présent et le futur dans la construction de l'espoir, influencé par les expériences antérieures. La dimension affective regroupe les émotions qui accompagnent ce processus telles que la joie, la motivation et l'incertitude. L'espoir d'affiliation traduit le sentiment d'être en lien avec les autres, la famille et la spiritualité. La dimension comportementale se manifeste par des actions concrètes orientées vers le but espéré. Enfin, la dimension contextuelle rappelle que la reconnaissance de l'environnement peut stimuler ou freiner l'espoir.

Ainsi, l'espoir apparaît comme une ressource essentielle dans l'adaptation au cours du parcours de soins. Il favorise l'adhésion thérapeutique, renforce la résilience et encourage l'implication active du patient, même dans les moments d'incertitude et de vulnérabilité.

3.2. THEORIE DE L'INCERTITUDE

La théorie de l'incertitude développée par Merle Mishel (1988), intitulée « Uncertainty in Illness Theory », décrit la manière dont les individus perçoivent, interprètent et donnent un sens à leur expérience de la maladie. L'incertitude y est définie comme « un état cognitif où la personne est incapable de donner une signification et une valeur aux évènements et objets entourant la maladie, lorsque ceux-ci sont ambigus, hautement complexes, que l'information reçue est insuffisante et que les résultats ne peuvent être prédits » (Lazure, 1998, p.25).

Cette théorie montre que l'incertitude est présente tout au long du parcours de soins dès le diagnostic initial, lors de la gestion des traitements, et ceci jusqu'au rétablissement ou lors de récidives. Elle peut être perçue comme une menace, générant anxiété et détresse. Mais elle peut également représenter une opportunité de croissance personnelle, selon les ressources internes et le soutien disponible.

En 1990, Mishel présente une version révisée de son modèle, nommé « Reconceptualized Uncertainty in Illness Theory », qui introduit des dimensions sociales et des facteurs cognitifs supplémentaires. Ce modèle permet d'analyser les mécanismes d'adaptation développés et mobilisés face à l'incertitude persistante. L'incertitude est conceptualisée comme un phénomène dynamique et évolutif. Ceci est particulièrement pertinent dans un contexte de maladie chronique telle que l'insuffisance rénale.

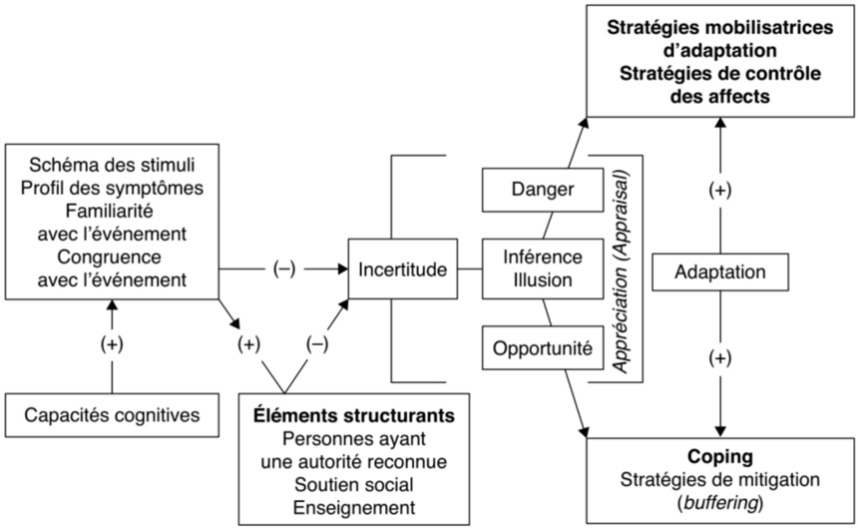

***Figure 2**. Modèle de l'incertitude dans la maladie de Mishel M.*

Source : Celis-Geradin Marie-Thérèse et al., *Initiation À La Discipline Infirmière : une sélection de concepts et théories en science infirmières* (p.33) ,2024, Elsevier Health Sciences.

Cette théorie repose sur trois concepts clés. Le premier correspond aux antécédents de l'incertitude, c'est-à-dire aux facteurs déclencheurs tels que les symptômes ambigus, le

manque d'information ou la complexité de la situation vécue. Le deuxième est l'appréciation cognitive, soit le processus par lequel l'individu évalue l'incertitude selon son vécu, ses ressources personnelles et son environnement. Enfin, le dernier concept est la gestion de l'incertitude, également appelée coping. Il s'agit de la stratégie adaptative mise en place pour réduire l'impact émotionnel et fonctionnel de l'incertitude. Cela inclut la recherche d'informations, les échanges avec les professionnels de santé ou la quête de sens face à la situation traversée. Le schéma du modèle de l'incertitude dans la maladie (cf. Figure 2) illustre visuellement ces interactions et met en évidence le rôle des éléments structurants dans l'adaptation.

4. BUT ET QUESTION DE RECHERCHE

Dans un contexte où la liste d'attente de transplantation rénale s'allonge et où la souffrance psychologique des patients devient un véritable enjeu de santé, il est essentiel de s'interroger sur les conditions d'accompagnement afin qu'elles puissent être adaptées aux besoins.

Ce travail de Bachelor a pour objectif d'explorer comment les patients adultes en attente de transplantation rénale peuvent être accompagnés dans leurs dimensions biopsychosociales par la pratique infirmière, au travers des concepts de la théorie de Mishel (1988, 1990) et du concept de l'espoir de Dufault et Martocchio (1985).
L'attente prolongée ainsi que le traitement par dialyse mêlent espoir et inquiétude, rendant le patient impuissant dans cette période d'attente difficile.

Notre réflexion rejoint une volonté de renforcer les interventions infirmières autour de l'accompagnement des patients en attente de transplantation rénale, en plaçant leurs besoins spécifiques au centre de la démarche. Cela soulève plusieurs questionnements : « Que vivent les patients dialysés lorsqu'ils sont inscrits sur liste d'attente pour une transplantation ? », « Quel est le rôle de l'infirmier dans ce contexte de soins ? », « Quelles actions peuvent être mises en place pour les accompagner au mieux durant cette attente ? ». Ces réflexions ont débouché sur la question de problématique suivante :

« Quels sont les déterminants biopsychosociaux des patients adultes en processus de transplantation rénale pour lesquels la pratique infirmière peut offrir un accompagnement ? »

La présentation de la question de recherche à l'aide de la méthode PICo se trouve dans l'annexe 2.

5. MÉTHODOLOGIE

Dans ce chapitre, nous détaillons les démarches méthodologiques entreprises tout au long de notre travail, notamment en ce qui concerne la recherche d'informations.

5.1. BASES DE DONNEES

Pour débuter notre démarche, nous avons consulté le catalogue électronique Renouvaud. Cette étape nous a été suggérée par notre professeur de TB, afin de vérifier s'il existait déjà des travaux de Bachelor portant sur une thématique similaire. Nous avons effectivement trouvé quelques études comparables, bien que la plupart datent de cinq à dix ans. Malgré cela, nous avons choisi de nous concentrer sur cette problématique. La lecture d'articles récents ainsi que l'actualité liée à l'application de la loi sur le consentement présumé confirment qu'elle demeure pleinement d'actualité dans notre société.

Dans un deuxième temps, nous avons visionné les deux vidéos didactiques mises à disposition par le CEDOC. Celles-ci portaient sur l'utilisation des bases de données Pubmed/Medline et CINAHL (Cumulative Index to Nursing and Allied Health Literature). Elles nous ont permis de comprendre leur fonctionnement et de sélectionner des descripteurs pertinents.

Parallèlement, nous avons consulté le site de l'Office Fédéral de la Santé Publique (OFSP, 2025) ainsi que celui de Swisstransplant (2025) afin de recueillir des statistiques liées à la transplantation rénale. Nous avons également pris contact directement avec Swisstransplant pour obtenir des informations complémentaires et renforcer la validité de nos données.

Une fois ces premières étapes achevées, nous avons débuté nos recherches exploratoires. Nous avons notamment utilisé Google Scholar pour identifier des articles traitant de notre thématique et mieux saisir les enjeux actuels.

Nous avons ensuite poursuivi nos recherches scientifiques sur Pubmed/Medline et CINAHL. Pour ce faire, nous avons traduit nos mots-clés en anglais grâce à l'outil HeTOP, ce qui nous a permis d'identifier les descripteurs utilisés dans les thésaurus respectifs. Sur Pubmed/Medline, nous avons utilisé les termes issus du thésaurus MeSHTermes (Medical Subject Headings) et les avons combinés à l'aide d'opérateurs booléens tels que AND*, OR* et *NOT* afin d'affiner ou d'élargir nos résultats. Nous avons procédé de manière similaire sur CINAHL, en nous référant cette fois au thésaurus CINAHL Headings. A l'aide de cette

stratégie, les résultats obtenus sont plus pertinents et mieux ciblés. Cependant, nous avons relevé que la contribution de la pratique infirmière dans l'accompagnement de l'incertitude vécue par les patients en attente d'une transplantation rénale demeure un sujet encore peu exploré dans la littérature scientifique. Cela souligne ainsi la nécessité d'approfondir cette thématique et justifie pleinement notre question de recherche.

5.2. DESCRIPTEURS ET LEURS COMBINAISONS

Lors de la recherche d'articles scientifiques, plusieurs équations de recherche ont été mobilisées en raison du nombre limité d'articles disponibles sur cette thématique, en particulier au cours des dix dernières années. Les descripteurs ont été choisis pour refléter les concepts principaux de notre question de recherche : la transplantation rénale, l'attente, l'incertitude ainsi que le rôle infirmier. Les descripteurs utilisés pour la recherche des articles sont présentés dans le tableau suivant :

5.2.1. TABLEAU DE SYNTHESE DES EQUATIONS DE RECHERCHE

Bases de données	Descripteurs	Filtres	Articles obtenus	Articles retenus
PubMed	humans AND kidney transplantation AND nursing care	✶ Date de publication : dès 2015	31	✶ Life in standby : hemodialysis patients' experiences of waiting for kidney transplantation
	kidney transplantation OR renal transplant AND nursing OR nurse AND everyday life	✶ Date de publication : dès 2015	6	✶ Balancing everyday life-Patients' experiences before, during and four months after kidney transplantation
	Adult AND kidney transplantation/psychology OR kidney transplantation AND waiting lists AND	✶ Date de publication : dès 2015	9	✶ "The experience of waiting for a kidney transplant: A qualitative study. Journal of Renal care

	qualitative research			
	Kidney transplantation/psychology AND waiting lists	✶ Date de publication : dès 2015	7	✶ Waiting for kidney transplantation from deceased donors: Experiences and support needs during the waiting time -A qualitative study
CINAHL	dialysis patients AND hemodialysis AND kidney transplantation AND anxiety	✶ Date de publication : dès 2015 ✶ Langue : anglais	5	✶ Experiences of Patients on Outpatient Hemodialysis Therapy Who Are Anticipating a Transplant.
	kidney transplantation AND nursing role	✶ Date de publication : dès 2020	11	✶ « I can't imagine it without my nurse » : Experiences of people with chronic kidney disease in the evaluation process as kidney transplant candidates

6. RÉSULTATS

6.1. NOMBRE D'ARTICLES TROUVES ET RETENUS

Les critères de sélection des articles, minutieusement définis afin d'assurer la qualité des sources retenues, sont présentés sous forme de tableau :

Critères	Inclusions / exclusions
Population ciblée	Nous ciblons une population adulte atteinte d'insuffisance rénale chronique sous hémodialyse et en attente de transplantation rénale. Les enfants et adolescents ont donc été exclus.
Articles	Les articles doivent avoir été publiés de préférence entre 2015 et 2025. Ils doivent être disponibles en version intégrale et de préférence en accès libre.

Recherches	Les articles doivent être scientifiques et utiliser une méthodologie qualitative. Nous avons exclu les articles de revue de littérature ainsi que les études quantitatives.
Langues	Les articles retenus devaient être rédigés ou traduits en anglais ou en français. Les autres langues ont donc été exclues.

Sur la base de ces critères de sélection, nous avons répertorié une dizaine d'articles. Cependant, après une lecture plus approfondie et une évaluation de leur pertinence, nous en avons gardé six pour l'analyse finale. Cette sélection garantit ainsi la validité des résultats présentés dans cette RL.

6.1. REFERENCES DES ARTICLES

Après avoir pris en compte les différents critères de sélection, les articles retenus sont exposés ci-dessous, dans l'ordre dans lequel nous les avons analysés :

Moran, A. (2016). Experiences of Patients on Outpatient Hemodialysis Therapy Who Are Anticipating a Transplant. *Nephrology Nursing Journal*, 43(3), 241–250

Yngman-Uhlin, P., Fogelberg, A., & Uhlin, F. (2016). Life in standby: hemodialysis patients' experiences of waiting for kidney transplantation. *Journal of clinical nursing*, *25*(1-2), 92–98. https://doi.org/10.1111/jocn.12994

Nielsen, C., Clemensen, J., Bistrup, C., & Agerskov, H. (2018). Balancing everyday life-Patients' experiences before, during and four months after kidney transplantation. *Nursing open*, *6*(2), 443–452. https://doi.org/10.1002/nop2.225

Burns, T., Fernandez, R., & Stephens, M. (2017). The experience of waiting for a kidney transplant: A qualitative study. *Journal of renal care*, *43*(4), 247–255. https://doi.org/10.1111/jorc.12209

Nilsson, K., Westas, M., Andersson, G., Johansson, P., & Lundgren, J. (2022). Waiting for kidney transplantation from deceased donors: Experiences and support needs during the waiting time -A qualitative study. *Patient education and counseling*, *105*(7), 2422–2428. https://doi.org/10.1016/j.pec.2022.02.016

Pedreira, R. G., Morín, F. V., Bach, P. A., Graells, S. A., & Garcimartín, P. (2024). «I can't imagine it without my nurse»: Experiences of people with chronic kidney disease in the evaluation process as kidney transplant candidates. *Research in Nursing & Health*, 47(6), 635–647. https://doi.org/10.1002/nur.22414

Pour l'analyse de nos articles, nous avons eu recours à la grille d'analyse inspirée de Fortin & Gagnon (2022) et Letts et al. (2007). Il s'agit d'un outil que nous avions déjà mobilisé dans le

cadre du travail de validation du module Recherche 2.1 (REC 2.1). Cette grille nous a permis d'évaluer la qualité, la fiabilité et la pertinence de chaque article.

6.2. ANALYSE CRITIQUE

Ce chapitre expose les arguments qui justifient la pertinence des articles sélectionnés. L'analyse critique vise à mettre en évidence leur contribution à la pratique clinique ainsi que leur lien direct avec notre question de recherche.

Les études retenues ont été majoritairement menées en Europe, et une en Australie. Nous n'avons malheureusement trouvé aucune étude conduite en Suisse. Étant donné que notre système de santé diffère des pays dans lesquels les études ont été menées, nous considérons cela comme une limite globale des articles. De ce fait, nous interprétons les résultats avec réserve.

Nos recherches portent essentiellement sur la période de pré-transplantation rénale, c'est-à-dire la phase sur liste d'attente.

Article n°1 : « Experiences of patients on outpatient hemodialysis therapy who are anticipating a transplant »

Cet article a été publié dans la revue scientifique américaine « Nephrology Nursing Journal », spécialisée dans le domaine des soins infirmiers en néphrologie, reconnue par l'American Nephrology Nurses Association (ANNA), ce qui renforce sa validité scientifique. L'auteure Aoife Moran, est infirmière diplômée, spécialisée en néphrologie, exerçant dans un hôpital à Dublin, en Irlande.

Cette étude qualitative a pour but d'explorer et d'analyser les vécus de chacun en s'appuyant sur la théorie des humeurs existentielles d'Heidegger (1962, 1995). L'étude a été menée dans deux grands hôpitaux universitaires en Irlande, où 32 participants hémodialysés et en attente de greffe ont été sélectionnés sur base de critères de pertinence en regard de leur vécu de l'insuffisance rénale et de l'hémodialyse. Chacun a reçu les informations nécessaires avant l'étude et a signé un consentement éclairé. Les données ont été recueillies lors d'entretiens sous forme de conversation, réalisés en deux étapes espacées d'environ un an. Elles ont ensuite été analysées selon une approche herméneutique proposée par Diekelmann, Allen et Tanner (1989). Par la suite, trois grands thèmes ont émergé : être anxieux, vivre dans l'incertitude, surmonter les humeurs pénibles (cf. 6.3.1 synthèse des résultats).

Une des forces de cet article réside dans la richesse des verbatims présentés, qui valorisent la parole des participants et permettent de faire émerger leurs motivations, leurs émotions et leurs comportements. Parmi les limites, on peut souligner que l'ensemble des patients était de nationalité irlandaise. De plus, tous les participants étaient sous hémodialyse en ambulatoire

dans un centre hospitalier, ce qui laisse envisager des différences possibles avec les patients traités en hémodialyse hors hospitalier.
Nous avons retenu cet article pour notre thématique car il permet de comprendre ce que peuvent ressentir les patients vivant sous hémodialyse en attente d'une greffe rénale. Selon Moran (2016), cette étude contribue à enrichir notre compréhension de la détresse vécue par ces patients. Cela permettra aux infirmiers de mieux reconnaître et répondre à la détresse des patients, tout en améliorant la qualité et l'efficacité des soins, ceci en proposant des pistes de recommandations pour la pratique infirmière.

Article n°2 : « Life in standby: hemodialysis patients' experiences of waiting for kidney transplantation »

Les auteurs de cet article sont des infirmiers diplômés travaillant à l'université de Linköping en Suède et dans une université technologique en Estonie. Cette étude est issue du « Journal of Clinical Nursing », une revue de référence majeure pour les professionnels et chercheurs en soins infirmiers, reconnue pour sa rigueur et son engagement dans le développement continu de la pratique infirmière.
Cette étude qualitative avait pour objectif d'explorer l'expérience vécue de huit patients hémodialysés, âgés de 33 à 53 ans, inscrits sur liste d'attente pour une transplantation rénale afin de mieux comprendre leurs besoins psychologiques et pratiques durant cette période. Le devis de recherche est basé sur des entretiens semi-structurés qui ont été analysés par la méthode descriptive selon Burnard (1991). Cela inclut un système de catégorisation et de codage détaillé. Ces participants ont été interrogés, lors d'entretiens, avec des questions ouvertes puis avec des questions d'approfondissement.
L'analyse des résultats a permis de faire ressortir quatre catégories principales et huit sous-catégories identifiées comme aides à la gestion du processus d'attente. Les quatre catégories sont les suivantes : le processus d'attente, la conscience que le temps est compté, le besoin de communication et le soulagement ainsi que l'espoir pour l'avenir (cf. 6.3.1 synthèse des résultats).
La principale force de cet article est liée à l'application rigoureuse de cette méthode d'analyse de contenu (Burnard, 1991) et dans la collaboration étroite des auteurs tout au long du processus analytique. Cependant, l'étude est limitée par la faible représentation féminine, avec une seule participante.
Nous avons retenu cet article car il illustre bien le besoin de soutien des patients durant la période d'attente pour une transplantation. Il met également en lumière le rôle essentiel des soignants dans la préparation des patients dialysés inscrits sur liste d'attente, face aux changements à venir. Cette recherche est pertinente car elle nous fournit des pistes concrètes pour orienter la pratique infirmière.

Article n°3 : « Balancing everyday life - Patients' experiences before, during and four months after kidney transplantation »

Cet article a été publié dans la revue scientifique « Nursing Open », qui est une revue internationale en soins infirmiers. Cette revue est reconnue dans le domaine des sciences infirmières, ce qui garantit la fiabilité des données. Les auteurs sont affiliés à l'hôpital universitaire d'Odense et à l'Université du Danemark du Sud. Ils travaillent dans le domaine de la néphrologie et de la recherche clinique, ce qui leur confère une expertise solide sur la transplantation rénale.

Cette étude qualitative avait pour objectif d'explorer l'expérience vécue des patients avant, pendant et jusqu'à quatre mois après une transplantation rénale. Elle est basée sur une approche phénoménologique-herméneutique inspirée de Ricoeur afin de décrire en profondeur le vécu subjectif des patients tout au long de leur parcours de transplantation. Cette méthode combine la description de leurs expériences et l'interprétation du sens qu'ils leur attribuent. L'étude se concentre sur les ajustements que les patients doivent effectuer dans leur quotidien ainsi que sur les défis émotionnels auxquels ils font face tout au long du parcours de la transplantation. L'enquête a été réalisée dans un centre hospitalier universitaire au Danemark, auprès de 18 patients adultes atteints d'insuffisance rénale terminale, âgés de 33 à 73 ans, dont 6 femmes et 12 hommes. Ils ont été répartis sur trois étapes du processus de greffe : 6 patients en pré-greffe, 6 patients en période post-opératoire et 6 patients quatre mois après la greffe. Deux patients ont participé à deux étapes mais aucun n'a suivi les trois. Les données ont été recueillies par 150 heures d'observations participantes et des entretiens semi-structurés. Les données ont été analysées en trois niveaux d'interprétation selon Ricoeur, ce qui renforce la crédibilité.

Les résultats montrent que la transplantation est vécue comme un parcours global nécessitant des ajustements constants, décrit en trois phases et cinq thèmes principaux (cf. 6.3.1 synthèse des résultats).

Parmi les forces, on note la richesse des données et le recours à deux méthodes complémentaires ainsi qu'une analyse rigoureuse selon Ricoeur. Les limites sont que les patients n'ont pas été suivis de manière longitudinale, c'est-à-dire que chaque étape a été représentée dans la majorité des cas par des patients différents. Bien que ce soit un article qualitatif, l'échantillon en pré-transplantation reste limité avec un déséquilibre marqué entre hommes et femmes.

Nous avons choisi cet article car il met en évidence les incertitudes vécues par les patients tout au long du processus de transplantation, y compris pendant l'attente, mais aussi sur l'importance de l'accompagnement infirmier pendant les phases de transition. L'étude permet

d'identifier des besoins liés à la gestion de l'attente, aux émotions, à l'autonomie et à la reconstruction du quotidien.

Article n° 4: « The experience of waiting for a kidney transplant: A qualitative study »

Cet article a été publié dans la revue scientifique « Journal of Renal Care », une revue professionnelle reconnue dans le domaine des soins infirmiers spécialisés en néphrologie et reliée à la British Renal Society. Les auteurs se trouvent à Sydney, en Australie. Ils travaillent au St George Hospital et à l'Université de Wollongong, avec une expertise en transplantation rénale et en néphrologie.

Cette étude descriptive a pour objectif d'explorer le vécu de patients sous dialyse en attente d'une transplantation rénale à partir de donneurs décédés. Elle est établie dans le but de comprendre comment ils vivent cette période marquée par les incertitudes, les bouleversements émotionnels, les ajustements personnels, les relations sociales altérées et le rapport complexe au donneur. Il s'agit d'une étude qualitative descriptive menée selon une approche inductive. L'analyse des données repose sur l'approche de Thorne (2008) et Hsieh & Shannon (2005). Les données ont été recueillies par deux focus groups, enregistrées, retranscrites et analysées selon une procédure de codage thématique. La saturation des données a été atteinte, ce qui permet d'approfondir le vécu subjectif.

L'analyse a permis de faire ressortir quatre thèmes et neuf sous-thèmes. L'étude a été réalisée dans un hôpital métropolitain à Sydney, en Australie. L'échantillon est composé de six patients adultes (3 hommes, 3 femmes), âgés de 29 à 63 ans, hémodialysés depuis 10 à 72 mois, inscrits sur la liste d'attente. Ils ont été recrutés par convenance.

L'étude révèle une expérience marquée par la lourdeur physique et psychologique de la dialyse, une forte incertitude et des relations sociales perturbées. Elle souligne également l'ambivalence émotionnelle vis-à-vis du donneur (cf. 6.3.1 synthèse des résultats).

Parmi les forces, on trouve la richesse des verbatims et des résultats clairs qui permettent d'ouvrir des pistes d'implications pratiques pour les soignants. Les limites sont la taille de l'échantillon, jugée restreinte, ainsi que le manque de détails méthodologiques sur l'analyse des données, par exemple l'absence de codage explicite ou de logiciel précisé.

Nous avons retenu cette étude car elle met en lumière l'importance d'un accompagnement infirmier individualisé pendant cette phase d'attente. Elle montre que les patients expriment des besoins de communication, soutien émotionnel et gestion de l'incertitude. Ces points peuvent être placés au cœur de la pratique infirmière.

Article n° 5 : « Waiting for kidney transplantation from deceased donors : Experiences and support needs during the waiting time - A qualitative study »

Cet article a été publié en 2022 dans la revue « Patient Education and Counseling », une revue internationale reconnue dans les domaines de l'éducation thérapeutique et des soins infirmiers. Les auteurs sont affiliés à l'Université de Linköping et à l'Institut Karolinska en Suède. Leur expertise en néphrologie et sciences infirmières confirme, la solidité de l'étude.

Cette étude qualitative vise à explorer et à décrire les expériences vécues par les patients adultes en attente de transplantation rénale à partir de donneurs décédés, ainsi que le soutien qu'ils ont reçu pendant cette période. Le devis de recherche est une étude qualitative par des entretiens semi-structurés, avec une analyse inductive thématique selon Braun et Clarke. L'enquête a été réalisée dans deux unités de néphrologie du sud de la Suède. L'étude se concentre sur quatorze patients (10 hommes et 4 femmes), âgés de 39 à 72 ans dont sept étaient en attente de greffe et sept avaient récemment été transplantés. Les entretiens ont été réalisés par téléphone entre novembre 2018 et janvier 2019, puis analysés à l'aide du logiciel NVivo.

Les résultats décrivent une oscillation entre espoir et désespoir, une charge psychologique importante et l'utilisation de stratégies d'adaptation diverses (6.3.1 synthèse des résultats).

Parmi les forces de l'étude, nous trouvons sa rigueur méthodologique avec une analyse thématique structurée, un codage croisé et une validation par plusieurs chercheurs. De plus, il y a une transparence dans la présentation des résultats et une pertinence clinique élevée. Les limites sont la petite taille de l'échantillon, l'absence de cadre théorique explicite et le fait que l'étude se déroule en Suède.

Cet article a été sélectionné car il éclaire directement notre problématique. Il apporte des données concrètes sur l'incertitude liée à l'attente de transplantation et les besoins de soutien des patients adultes. Il met aussi en avant le rôle des professionnels de la santé notamment des infirmiers dans l'éducation, le soutien émotionnel et l'ajustement des attentes du patient.

Article n°6 : « I can't imagine it without my nurse »: Experiences of people with chronic kidney disease in the evaluation process as kidney transplant candidates

Cet article, daté de 2024, a été publié dans une revue scientifique internationale « Research in Nursing & Health », spécialisée dans la recherche en soins infirmiers et en science de la santé. Les auteurs sont affiliés à l'hôpital Del Mar et à l'université de Barcelone. De plus, ils sont spécialistes en néphrologie et en recherche infirmière. L'étude est réalisée dans une clinique de transplantation située dans un hôpital en Espagne.

L'échantillonnage repose sur 11 adultes atteints d'IRC. Les critères étaient que les patients devaient être stables cliniquement, sans difficultés de communication, ayant au moins trois rendez-vous avec l'infirmier coordinateur de transplantation ainsi qu'une indication à la

transplantation égale ou supérieure à trois mois. Les entretiens semi-structurés réalisés entre octobre 2022 et juillet 2023 à l'aide d'un guide préétabli, ont fait ressortir un thème central. Ce thème est « le candidat à la transplantation et sa réalité », incluant les dimensions biologiques, psychologiques, sociales et culturelles ainsi que le rôle de l'infirmier dans ce processus de transplantation (cf. 6.3.1 synthèse des résultats).

L'article se différencie par la richesse des verbatims et une collaboration interdisciplinaire, permettant de bénéficier de diverses expertises pour la conception de cet article. Cette étude dévoile des limites liées à sa réalisation dans une seule zone géographique, ce qui freine sa portée quant à une généralisation pour d'autres populations et pays. Il y a également une limite dépendante au fait d'avoir exclu dans l'échantillon les patients qui n'avaient pas été suivis par un infirmier coordinateur, pouvant conduire à une compréhension incomplète du processus global.

La pertinence de cet article repose sur sa capacité à illustrer concrètement les besoins multidimensionnels des patients en attente de transplantation rénale, tout en mettant en évidence la contribution infirmière dans ce contexte.

6.2.1. SYNTHESE DES RESULTATS

Articles	Principaux résultats	Impact sur la pratique infirmière
N°1 **« Experiences of Patients on Outpatient Hemodialysis Therapy Who Are Anticipating a Transplant »** ✶ Aoife Moran, PhD, BNS (Hons), Dip HE Nursing, RN, CNN, 2016 Nephrology Nursing Journal	Cet article met en évidence que l'expérience des personnes atteintes d'insuffisance rénale sous hémodialyse peut être marquée profondément par des humeurs existentielles pénibles lors de cette attente. Trois thèmes principaux ressortant de cette étude : 1) **être anxieux** : Les patients en attente de greffe rénale expérimentent une anxiété croissante liée à l'incertitude du délai, ce qui bouleverse leur rapport au temps et à l'avenir. 2) **vivre dans l'incertitude** : Ils racontent un sentiment de vie suspendue où le temps semble figé, marquée par l'incapacité à se projeter dans l'avenir et la perte d'activités quotidiennes en raison de la dialyse. 3) **surmonter les humeurs pénibles** : Certains d'entre eux ont surmonté leurs humeurs pénibles liées à l'ennui en réactivant leurs désirs pour l'avenir et en reprenant des activités quotidiennes. Cette reconnexion à la temporalité perme de redonner du sens à leur existence malgré l'attente.	Dans la conclusion, l'étude offre une nouvelle interprétation de la détresse vécue chez ces patients ce qui peut renforcer l'accompagnement et la compréhension. Plusieurs recommandations pour la pratique infirmière en ont découlé. Parmi celles-ci figurent la formation des infirmiers à la prise en charge et à la gestion des états émotionnels, une plus grande implication des familles et les proches dans le processus de soins et encore intégrer des techniques de méditation dans la pratique afin d'offrir aux patients des outils de relaxation pour se recentrer dans le moment présent.
N°2 **« Life in standby : hemodialysis patients' experiences of waiting for kidney transplantation »** ✶ Yngman-Uhlin, P., Fogelberg, A., & Uhlin, F. 2016 Journal of Clinical Nursing	Cet article démontre que les participants ont adopté différentes manières de gérer l'attente. Les quatre catégories ressorties sont les suivantes : 1) **le processus de l'attente** : est décrit comme une période éprouvante définie par la fatigue, l'incertitude et des émotions conflictuelles. Pour gérer ces humeurs, ils optent pour différentes stratégies d'adaptation. 2) **la conscience que le temps est compté** : un sentiment d'urgence face au temps limité est exprimé, ponctué par l'épuisement physique, le manque de liberté et l'angoisse liée aux complications de santé. Cette conscience de leur vulnérabilité renforce les humeurs comme l'anxiété, la frustration et le stress face à un avenir incertain. 3) **le besoin de communication** : le soutien familial et l'écoute du personnel soignant sont essentiels pour aider les patients dans	Cet article recommande que le personnel soignant spécialisé communique aux patients le temps d'attente, la procédure, les risques et de leur offrir un soutien psychologique également. Il est également indiqué de mieux préparer les patients aux changements importants que va impliquer la transplantation même si ce jour est perçu comme positif.

	la gestion de leurs inquiétudes. Le manque d'informations sur la transplantation génère une frustration les poussant à rechercher par eux-mêmes des données afin de se rassurer. 4) **le soulagement et l'espoir pour l'avenir** : le succès des autres et leur acceptation sur la liste d'attente maintiennent la volonté de ne pas perdre l'espoir. Le désir de retrouver une vie normale est un élément important durant cette attente.	
N°3 **«Balancing everyday life—Patients' experiences before, during and four months after kidney transplantation »** ✶ Nielsen, C., Clemensen, J., Bistrup, C., & Agerskov, H. 2018 Nursing Open	Les patients vivent la transplantation rénale comme un processus continu qui nécessitant une adaptation constante avec une réorganisation complète de leur quotidien. Cinq thèmes principaux : 1) **Vivre en attente entre espoir et incertitude** 2) **L'expérience de la greffe** avec la dépendance et les apprentissages 3) **Le retour à domicile** avec l'adaptation aux nouvelles routines et la vulnérabilité 4) **Faire face aux incertitudes :** peur du rejet, anxiété 5) **Se reconstruire :** reprise progressive d'une vie « normale » et redéfinition de l'identité L'équilibre est constamment menacé et cela se décline en trois grandes étapes : l'attente avant la greffe, la phase hospitalière et le retour à domicile	Cet article recommande au personnel soignant de ne pas limiter la transplantation rénale à l'opération. Il s'agit d'un processus longitudinal qui commence bien avant la greffe et se prolonge après. Cela comprend un soutien émotionnel, éducatif et relationnel. La transplantation doit être pensée comme une étape d'un parcours plus large avec un suivi adapté aux besoins spécifiques de chaque patient.
N°4 **« The experience of waiting for a kidney transplant: A qualitative study. Journal of Renal care »** ✶ Burns, T., Fernandez, R., & Stephens, M. 2017	Il en découle quatre thèmes principaux identifiés : 1) **Vivre sous dialyse est physiquement et mentalement exigeant**, avec une perte de liberté et de spontanéité 2) **L'attente est vécue comme une incertitude permanente** qui est difficile à supporter émotionnellement, accompagnée d'un sentiment de vie « en suspens » et d'une peur de la déception 3) **Un changement dans les relations sociales et familiale** avec parfois de la protection envers les proches et le soutien de la communauté dialysé 4) **Sentiments vis-à-vis du donneur** : ambivalence avec un mélange de gratitude, de culpabilité et de confrontation à la mort, concernant la perte subie par le donneur et sa famille.	Cet article met en évidence l'importance du rôle infirmier dans la communication, le soutien émotionnel et l'accompagnement des patients qui font face à l'incertitude liée à l'attente de greffe. Cela nécessite une prise en charge centrée sur l'écoute active, la clarification du parcours de soins et la préparation psychologique continue tout au long du processus de transplantation.

Journal of Renal Care	Ces résultats montrent bien la complexité émotionnelle, physique et sociale vécue par les patients pendant la phase d'attente.	
N°5 **«Waiting for kidney transplantation from deceased donors: Experiences and support needs during the waiting time -A qualitative study. »** ✶ Nilsson, K., Westas, M., Andersson, G., Johansson, P., & Lundgren, J. 2022 Patient Education and counseling	Il en découle deux thèmes principaux identifiés : 1) **Oscillation entre espoir et désespoir :** marquée par des difficultés émotionnelles, sociales et physique tout au long de l'attente. Il y a une charge psychologique forte lié à la perte de contrôle, aux incertitudes et aux contraintes imposées par la dialyse. Il y a une difficulté à maintenir l'espoir face à l'incertitude ainsi que les déceptions après greffe. 2) **Face à la période d'attente :** qui identifie les stratégies d'adaptation mise en place par les patients. Nous y trouvons la recherche ou l'évitement d'informations, le soutien social, le maintien d'activités valorisant et la gestion des relations avec leurs proches. Les interactions avec les soignants jouent aussi un rôle central qui apporte un soutien pratique et émotionnel. Les patients expriment un besoin clair d'accompagnement supplémentaire pour réduire l'isolement, renforcer leurs ressources psychologiques et se préparer de manière réaliste aux différentes étapes de la transplantation.	L'étude montre l'importance d'un accompagnement infirmier global, éducatif, émotionnel et pratique pendant l'attente et après la greffe. L'infirmier doit informer de façon claire et personnalisée pour réduire l'incertitude et préparer le patient. Il peut soutenir l'autonomie, renforcer les stratégies de coping et favoriser un maintien des liens sociaux. La préparation psychologique, la promotion d'une activité physique adaptée et la surveillance des complications complètent cet accompagnement. Un suivi individualisé permet d'améliorer la qualité de vie et l'adaptation globale à la transplantation.
N°6 **« I can't imagine it without my nurse » : Experiences of people with chronic kidney disease in the evaluation process as kidney transplant candidates** ✶ Pedreira, R. G., Morín, F. V., Bach, P. A., Graells, S. A., & Garcimartín, P.	Cet article met au **centre l'individu candidat à la transplantation rénale et sa réalité**. Cet individu et sa réalité sont des éléments complexes et multi-dimensionnalisés (biologique, psychologique, social et culturel). Cette étude démontre que les expériences psychologiques et sociales liées au parcours de soins de ces personnes font émerger des états émotionnels et d'adaptations face à la maladie, l'attente de greffe mais montre aussi les obstacles que les processus de transplantation peuvent avoir. Cette recherche fait également ressortir trois rôles principaux que l'infirmier peut endosser comme les soins, l'organisation et l'accompagnement dans le parcours du patient puis également le rôle d'informateur et d'éducateur sur la situation de santé de ces personnes.	L'étude souligne l'importance d'améliorer l'éducation des patients en élaborant des documents complets sur les soins et le processus de la transplantation afin de leur transmettre des informations pour que ces personnes puissent acquérir des connaissances sur leur situation de santé et se sentir en confiance. Dans cet article, il est également recommandé d'adapter les services de soins aux besoins spécifiques identifiés chez les candidats à la transplantation rénale notamment en ce qui concerne les conseils, le soutien à la santé mentale voire l'aide financière. Il est aussi recommandé d'intégrer les résultats obtenus lors de l'étude dans notre

2024 Research in Nursing & Health		pratique. Cela peut conduire à des initiatives d'amélioration continue de la qualité des soins, donc affiner les modèles de soins et ainsi obtenir de meilleurs résultats pour les patients. De manière globale, il est nécessaire d'avoir une approche centrée sur la personne, ainsi qu'une vision holistique et respectueuse.

7. DISCUSSION ET PERSPECTIVES

L'objectif principal de notre recherche est de répondre à notre question de problématique : **« Quels sont les déterminants biopsychosociaux des patients adultes en processus de transplantation rénale pour lesquels la pratique infirmière peut offrir un accompagnement ? »**

Dans ce chapitre, nous articulons nos résultats avec la théorie de l'incertitude (Mishel, 1988, 1990) et le concept de l'espoir de Dufault & Martocchio (1985) afin de mieux comprendre l'impact multidimensionnel de l'attente de transplantation rénale ainsi que les possibilités d'accompagnement.

7.1. DIMENSION BIOLOGIQUE

Sur le plan biologique, la transplantation représente une étape majeure pour les patients atteints d'IRCT. Le passage de la dialyse à la greffe provoque une transformation profonde des contraintes physiologiques et métaboliques. Cette période s'accompagne d'une incertitude constante liée à l'évolution de la maladie, à la disponibilité des organes et aux risques opératoires (Moran, 2016 ; Yngman-Uhlin et al., 2016 ; Burns et al., 2017 ; Nielsen et al., 2018 ; Nilsson et al., 2022 ; Pedreira-Robles et al., 2024). Cette incertitude n'est pas un simple inconfort psychologique : elle altère la capacité du patient à se projeter dans un avenir meilleur et renforce le sentiment de vulnérabilité corporelle.

L'ensemble des études (Moran, 2016 ; Yngman-Uhlin et al., 2016 ; Burns et al., 2017 ; Nielsen et al., 2018 ; Nilsson et al., 2022 ; Pedreira-Robles et al., 2024) confirme que la période d'attente est associée à une détérioration progressive de l'état biologique en lien avec la maladie chronique, la dialyse et son corollaire : une fatigue chronique, des troubles du sommeil, des altérations immunitaires ainsi qu'à une perte de masse musculaire (Burns, 2017 ; Nilsson et al., 2022). Elle est aggravée par des comorbidités telles que l'hypertension, l'anémie ou les troubles du métabolisme phosphocalcique. Ce ne sont pas des symptômes à banaliser car ils participent à la fragilité de l'identité corporelle et alimentent la peur d'une détérioration irréversible de l'état de santé. Cela met en lumière la nécessité d'un accompagnement pour soutenir non seulement la préparation physique mais également la perception du corps (Burns, 2017 ; Nilsson et al., 2022).

En Suisse, l'attente moyenne de trois ans (Swisstransplant, 2022), accentue ces vulnérabilités en exposant le patient au risque d'inéligibilité temporaire à la greffe. En effet plus l'attente est

longue, plus la vulnérabilité biologique s'accentue, fragilisant ainsi leur capacité à entretenir l'espoir d'une vie meilleure post-greffe (Nilsson al., 2022).

La préparation pré-greffe exige un suivi rigoureux (Nielsen et al., 2018 ; Nilsson et al., 2022). De plus, après la transplantation, le contrôle des paramètres tels que la créatininémie et les marqueurs immunologiques reste essentiel afin de prévenir les rejets et les complications (CHUV, 2019 ; HUG 2023). Ces étapes renforcent la perception de dépendance vis-à-vis de l'état biologique et créent une oscillation constante entre espoir et désespoir. Le patient dépend des résultats biologiques et n'a pas de contrôle sur le processus. D'autre part, certains patients rapportent un manque d'information sur les conséquences métaboliques et biologiques, si bien que cela contribue à augmenter l'incertitude et le sentiment d'impuissance sur son état de santé (Nilsson et al., 2022 ; Pedreira-Robles et al., 2024).

Selon Mishel (1988, 1990) cette incertitude est une réalité inévitable du parcours qui est marquée par la complexité biologique, les répercussions psychologiques et les ajustements sociaux. Ces résultats montrent la nécessité d'un accompagnement sur la réappropriation du corps et la valorisation des capacités résiduelles (Moran, 2016 ; Yngman-Uhlin et al., 2016 ; Burns et al., 2017 ; Nielsen et al., 2018 ; Nilsson et al., 2022 ; Pedreira-Robles et al., 2024).
Dans ce contexte, l'espoir tel que décrit par Dufault & Martocchio (1985) n'est pas une simple émotion mais un processus dynamique qui aide le patient à structurer son expérience en réintroduisant un sens à son corps et en envisageant la transplantation comme une étape vers une vie perçue comme meilleure. C'est un véritable moteur d'adhérence aux soins biologiques et d'adaptation à l'incertitude, car son parcours de transplantation peut renforcer les sentiments d'espoir et favoriser sa résilience.

7.2. DIMENSION PSYCHOLOGIQUE

Une convergence apparaît sur le fait que la période d'attente d'une transplantation est marquée par une incertitude constante, présente tout au long du processus de transplantation. Cette incertitude façonne l'expérience des patients et influence leur équilibre émotionnel (Moran, 2016 ; Yngman-Uhlin et al., 2016 ; Burns et al., 2017 ; Nielsen et al., 2018 ; Nilsson et al., 2022 ; Pedreira-Robles et al., 2024). Cette dernière est multidimensionnelle, longitudinale et interconnectée. En effet, cette incertitude provient également des vulnérabilités biologiques mais aussi des ruptures sociales et de la diminution des activités quotidiennes. Il en découle que certains patients rapportent une fatigue émotionnelle avec parfois des symptômes dépressifs ce qui renforce la sensation de « ne plus être soi-même » (Burns et al., 2017 ; Pedreira-Robles et al., 2024).

Si l'incertitude peut souvent être perçue comme une menace, elle peut devenir une opportunité d'apprentissage et de croissance. Apprendre à vivre avec cette imprévisibilité, c'est la percevoir comme une composante naturelle du processus, ce qui améliorera la capacité du patient à structurer et organiser son quotidien, mais aussi à s'adapter aux imprévus (auto-organisation). Accepter l'incertitude comme un opportunité de redéfinir ses priorités et ses valeurs, en valorisant l'espoir comme une ressource adaptative, permet au patient de préserver une continuité psychique et de renforcer sa qualité de vie tout au long de l'attente (Mishel, 1988, 1990).

Parallèlement, des divergences apparaissent dans les stratégies d'adaptation. Certains patients choisissent de « mettre sur pause » l'attente de greffe pour se protéger émotionnellement (Yngman-Uhlin et al., 2016). Cela peut amener à un sentiment d'isolement (Yngman-Uhlin et al., 2016 ; Burns et al., 2017). Au contraire, d'autres adoptent une posture proactive en cherchant activement des informations afin de se préparer au mieux, ce qui peut générer une surcharge émotionnelle ou une anxiété accrue. (Nilsson et al., 2022). Ces différences traduisent la variabilité interindividuelle dans la façon de vivre l'attente, qu'il est essentiel de prendre en compte dans l'accompagnement infirmier.

En mobilisant ces dimensions, l'espoir (Dufault & Martocchio, 1985, cité dans A.Maire, communication personnelle, le 10 novembre 2022) n'apparaît pas seulement comme un concept théorique mais comme un outil actif d'adaptation psychologique chez les patients en attente de transplantation rénale. La dimension cognitive aide le patient à envisager la transplantation non seulement comme un acte médical mais aussi comme une étape vers un retour à la « normalité » avec un avenir meilleur (Nielsen et al., 2018 ; Burns et al., 2017). La dimension temporelle de l'espoir renforce la capacité à se projeter et à maintenir un engagement actif (Yngman-Uhlin et al., 2016). Enfin, la dimension affective permet d'apaiser les tensions émotionnelles et de prévenir l'épuisement psychique (Nilsson et al., 2022).

La dimension psychologique des patients met en lumière la tension permanente entre perte et reconstruction de sens. Cette tension est à la fois un déterminant majeur du vécu et un levier possible d'accompagnement infirmier afin de maintenir une qualité de vie renforcée jusqu'à la greffe.

7.3. DIMENSION SOCIALE

La transplantation rénale peut être perçue comme une « renaissance » par de nombreux patients après un parcours long, exigeant et socialement difficile (Blog de l'Hôpital du Valais, 2021). La synthèse des six articles retenus (Moran, 2016 ; Yngman-Uhlin et al., 2016 ; Burns et al., 2017 ; Nielsen et al., 2018 ; Nilsson et al., 2022 ; Pedreira-Robles et al., 2024) met en évidence une vie sociale « mise en pause ». Elle est impactée par l'arrêt du travail, la réduction des activités sociales due à la dialyse, la maladie chronique mais également l'attente de la transplantation rénale. Cette planification continue entraîne une perte de spontanéité, une diminution de l'autonomie financière, ainsi qu'un affaiblissement de l'identité sociale, fragilisant le sentiment d'appartenance des patients.

L'importance du soutien social est confirmée dans toutes les études (Moran, 2016 ; Yngman-Uhlin et al., 2016 ; Burns et al., 2017 ; Nielsen et al., 2018 ; Nilsson et al., 2022 ; Pedreira-Robles et al., 2024). Cependant, des divergences apparaissent dans les stratégies adoptées par les patients. Par exemple, Burns et al. (2017) et Moran (2016) montrent que certains patients préfèrent s'isoler temporairement afin de préserver leur état émotionnel et éviter d'inquiéter leurs proches. Cela peut renforcer la solitude et illustre la théorie de l'incertitude de Mishel (1988,1990) selon laquelle la qualité du contexte social influence directement la manière dont la maladie est vécue. D'autres cherchent à maintenir une vie sociale active comme source d'espoir et de continuité identitaire (Moran, 2016 ; Nilsson et al., 2022). Ces différences montrent que la qualité du réseau social est déterminante. Selon la théorie de Mishel (1988, 1990), le soutien social contribue à réduire la perception de l'incertitude et à donner du sens aux étapes de la maladie, renforçant ainsi l'adaptation sociale.

Le sentiment d'appartenance à une communauté de dialyse est identifié comme une ressource majeure qui permet de valider les émotions, renforcer le sentiment de compréhension mutuelle et de diminuer la perception d'isolement (Burns et al., 2017 ; Nilsson et al., 2022). Toutefois, cet équilibre est fragilisé en post-greffe par une rupture sociale souvent inattendue et peu anticipée (Nilsson et al., 2022). Cette reconfiguration des liens sociaux peut entraîner une perte de repères sociaux qui compromet la réinsertion et accentue la vulnérabilité du patient en post-transplantation.

Ainsi, la dimension sociale dans l'attente de transplantation est profondément marquée par un paradoxe qui est à la fois l'isolement et le besoin d'appartenance. La qualité du soutien social, tout comme la capacité du patient à l'intégrer, semblent être des facteurs importants pour l'adaptation et la conservation identitaire tout au long du processus. Cette dynamique

complexe souligne l'importance d'un accompagnement qui prend en compte l'imprévisibilité et l'ambiguïté de l'expérience (Moran, 2016).

7.4. RECOMMANDATIONS POUR LA PRATIQUE INFIRMIERE

Les articles analysés mettent en évidence des axes prioritaires pour renforcer la pratique infirmière dans le processus de la transplantation. Ces recommandations soulignent l'importance d'une approche globale qui intègre les déterminants biologiques, psychologiques et sociaux du patient (HUG, 2023 ; Swisstransplant, 2021 ; KDIGO, 2020 ; ISN, 2023 ; Moran, 2016 ; Yngman-Uhlin et al., 2016 ; Burns et al., 2017 ; Nielsen et al., 2018 ; Nilsson et al., 2022 ; Pedreira-Robles et al., 2024).

Sur le plan biologique, l'infirmier doit avoir pour objectif de soutenir le patient dans la préparation pré-greffe ainsi que dans la gestion de la phase post-greffe. Un suivi clinique rigoureux avec évaluations cliniques systématiques et personnalisées, permet d'anticiper les vulnérabilités liées à la maladie chronique et aux traitements. L'éducation thérapeutique individualisée est essentielle, elle doit inclure la compréhension de la maladie rénale terminale, des étapes de la greffe et des mesures préventives (hygiène, nutrition, activité physique). Cet apport en information permet de renforcer la capacité d'auto-gestion, d'améliorer l'adhérence thérapeutique et de favoriser l'adaptation à l'incertitude. Par ailleurs, il est essentiel d'intégrer un accompagnement psychocorporel qui favorise la réappropriation du corps et la valorisation des capacités résiduelles. Cela peut inclure des entretiens infirmiers ciblés sur l'image corporelle, la mise en place d'un plan d'activité physique progressif ou encore des interventions de relaxation. En mobilisant l'espoir, l'infirmier contribue au maintien d'un sentiment de contrôle sur le parcours de soins biologique. Enfin, l'infirmier développe son leadership professionnel par des propositions d'actions de soins centrés sur les besoins spécifiques dans une perspective holistique qui place la dimension biologique en interaction constante avec les dimensions psychologiques et sociales.

Sur le plan psychologique, l'accompagnement émotionnel est fondamental. Le rôle infirmier aide à identifier et verbaliser les peurs mais aussi à diminuer les attentes irréalistes et les émotions ambivalentes, le tout contribuant à renforcer la résilience. Les entretiens infirmiers réguliers, en présentiel ou par téléphone, peuvent être structurés afin de fixer des objectifs adaptés et individuels, dans le but de soutenir l'espoir cognitif conformément à la définition de Dufault & Martocchio (1985), et de favoriser le maintien d'un engagement dans le traitement. La mise en place de groupes de paroles avec les pairs est un excellent moyen de faciliter l'expression des émotions, de réduire l'isolement et de soutenir l'espoir d'affiliation (HUG,

2021). Enfin, s'il y a présence de signaux de vulnérabilité importante telle que des symptômes dépressifs, il est souhaitable de procéder à une évaluation psychosociale approfondie, dans le but de réorienter le patient vers des spécialistes en santé mentale si nécessaire. (KDIGO, 2020).

Sur le plan social, l'accompagnement infirmier doit être axé sur la reconnaissance et la valorisation du réseau social du patient. L'infirmier peut identifier les signes d'isolement lié à la dépendance à la dialyse ou à la perte d'identité induite par la maladie chronique (Moran, 2016 ; Burns et al., 2017). L'outil AERES (Centre Ressources Réhabilitation psychosociale, 2020) et le génogramme (Epsilon Melia, s.d.) sont des moyens permettant d'évaluer et renforcer le réseau social du patient. Le soutien au maintien de la participation sociale et des liens avec la communauté est crucial. Pour cela, l'infirmier peut valoriser la communauté de dialysés afin de renforcer le sentiment d'appartenance. L'infirmier peut aussi envisager une collaboration avec les assistants sociaux pour inclure un soutien matériel ou logistique si nécessaire.

Ces recommandations rejoignent les constats de Nilsson et al. (2022) qui décrivent un écart entre les recommandations et la réalité, notamment en ce qui concerne la personnalisation du soutien émotionnel. De plus, la variabilité des stratégies d'adaptation montre la nécessité de tenir compte de leurs vécus et de leurs ressources mais aussi des contextes sociaux afin de garantir un accompagnement centré sur la personne.

Dans le modèle de l'incertitude de Mishel (1988, 1990), le rôle de l'infirmier est d'accompagner l'incertitude en mettant en place un environnement interne et externe qui soutient le développement du patient et l'aide à trouver un équilibre ainsi qu'un sens à sa vie (Lazure, 1998). Les actions infirmières d'une manière globale doivent donc être orientées vers un apport en informations claires et individualisées qui permettra au patient de donner du sens à son parcours. Accepter l'incertitude comme une opportunité de redéfinir ses priorités et ses valeurs en valorisant l'espoir comme une ressource adaptative, renforce la qualité de vie du patient tout au long de l'attente et du processus de transplantation.

7.5. RECOMMANDATIONS POUR LA FORMATION ET LA RECHERCHE

Les résultats de cette RL soulignent la nécessité d'intégrer plus largement, dans la formation initiale et continue des infirmiers, une compréhension approfondie des déterminants biopsychosociaux dans l'accompagnement des patients en attente de transplantation rénale.

Il paraît essentiel de renforcer la formation des infirmiers sur la gestion de l'incertitude (Mishel, 1988, 1990) mais aussi sur le développement de l'espoir (Dufault & Martocchio, 1985) comme une ressource adaptative, dans le but de préparer les futurs professionnels à soutenir les patients dans des parcours de soins complexes.

Dans le cursus de formation, il est important d'insister sur l'éducation thérapeutique, l'évaluation des vulnérabilités psychosociales, la gestion des émotions mais aussi sur une communication centrée sur la personne. L'utilisation d'outils pédagogiques tels que la mise en situations cliniques avec des jeux de rôles favorise l'acquisition de compétences réflexives et relationnelles essentielles à la qualité des soins.

Certaines formations continues comme le CAS et/ou DAS (Université de Genève, s. d.) en éducation thérapeutique proposent un contenu global qui peut être mobilisé pour l'accompagnement des patients transplantés. À ce jour, il n'existe pas de CAS ou DAS spécifiquement dédié à l'accompagnement de la transplantation. Swisstransplant propose une plateforme d'offres d'informations et de formations dans le domaine du don d'organes (Swisstransplant, s.d).

En ce qui concerne la recherche, nous estimons nécessaire de développer des études centrées sur les expériences des patients en Suisse, en particulier sur les aspects psychosociaux et leur perception de l'accompagnement infirmier. Actuellement, peu d'études qualitatives suisses explorent ces thématiques. Nous jugeons pertinent d'encourager des recherches longitudinales afin de mieux comprendre les besoins au cours du parcours de transplantation. De plus, le développement d'outils d'évaluation tels que des échelles d'incertitude ou d'espoir ou des questionnaires sur le vécu psychosocial permettrait de standardiser la collecte des données et d'améliorer la comparabilité entre les études.

7.6. FORCES ET LIMITES DE LA REVUE DE LITTERATURE

Cette RL présente plusieurs forces qui démontrent sa pertinence pour la pratique infirmière. Premièrement, le choix de la problématique est particulièrement ancré dans une réalité clinique actuelle en Suisse, notamment en lien avec la modification de l'ordonnance sur la transplantation du 1er mai 2024 sur le consentement présumé et la persistance de pénurie d'organes. De plus, ce sujet est encore peu exploré dans la littérature. L'approche biopsychosociale apporte une vision holistique centrée sur le patient, permettant une meilleure compréhension du vécu complexe des patients en attente de transplantation rénale. Cette RL offre une richesse analytique essentielle pour saisir les mécanismes d'adaptation et les

besoins de soutien. La RL bénéficie également d'une analyse critique détaillée des articles retenus, ce qui renforce la crédibilité des conclusions. En outre, la discussion présente les résultats en les appuyant sur la théorie de l'incertitude de Mishel (1988, 1990) ainsi que le concept d'espoir de Dulfault et Martocchio (1985), ce qui met en évidence des implications concrètes pour la pratique.

Cependant, certaines limites doivent être relevées. L'absence d'étude menée en Suisse limite la transférabilité des résultats. De même, la taille des échantillons de plusieurs études est restreinte, avec parfois un déséquilibre hommes-femmes, ce qui limite la généralisation des données. Enfin, plusieurs études ne s'appuient pas sur un cadre théorique explicite et ne valident pas les résultats auprès de leurs patients, ce qui peut réduire leur fiabilité.

8. CONCLUSION

Au travers de ce travail, nous avons exploré les déterminants biopsychosociaux des patients atteints d'insuffisance rénale chronique dans le processus de transplantation, pour lesquels la pratique infirmière peut offrir un accompagnement. La RL incluant six études qualitatives a permis non seulement d'éclairer la complexité mais aussi la profondeur du vécu des patients. Par ailleurs, nous avons pu mettre en évidence les différents rôles essentiels des infirmiers dans ce contexte.

Les résultats mettent en lumière l'impact global de l'attente d'une transplantation rénale sur les dimensions biologique, psychologique et sociale. L'omniprésence de l'incertitude affecte la qualité de vie des patients dans cette attente durant tout le parcours de soins. Cette incertitude impose une tension entre espoir et désespoir pouvant rendre la préparation à la vie post-greffe plus difficile.

L'infirmier joue un rôle fondamental en soutenant les patients à travers l'éducation thérapeutique, la gestion émotionnelle et l'accompagnement social. Ce rôle est crucial puisque la relation infirmier-patient est identifiée comme un pilier pour renforcer la résilience et l'adaptation aux événements imprévisibles. Ainsi cela permet la construction d'un espoir réaliste et une meilleure préparation à la vie post-greffe.

Ce travail de bachelor est aligné avec notre vision du rôle infirmier centré sur la personne et sur la co-construction d'un parcours de soins porteur de sens. Par ailleurs, cette recherche souligne l'importance d'une approche individualisée et interdisciplinaire afin de répondre de

façon optimale aux besoins variés de chaque patient et de réduire les inégalités potentielles en lien avec le contexte social et culturel.

Les limites relevées dans les études sélectionnées, notamment l'absence d'études menées en Suisse, soulignent la nécessité de faire preuve de prudence dans la généralisation des résultats et démontrent un besoin de recherches locales supplémentaires.

Au-delà des recommandations concrètes destinées à la pratique infirmière, telles que le développement d'interventions axées sur l'espoir, l'adaptation à l'incertitude, la formation à l'accompagnement ou encore l'élaboration de protocoles spécifiques, ce travail invite à poursuivre une réflexion approfondie sur le rôle infirmier en tant que partenaire de soin engagé dans le parcours de la transplantation.

Nous concluons ce travail par une paraphrase inspirée de la philosophie de Florence Nightingale (1860) : ***« Il ne s'agit pas seulement d'aider le malade à guérir, mais de l'aider à vivre »***.

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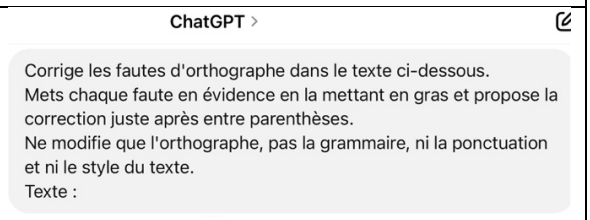
10. ANNEXES

ANNEXE 1

Tableau détaillé pour l'annonce d'utilisation des outils IA

Outil IA	Utilisé pour	Chapitre du travail	Liens ou copies (Screenshot) des prompts
ChatGPT	Corrections	Tous les chapitres	

ANNEXE 2

Présentation de la question de recherche à l'aide de la méthode PICo :

Population ciblée :	les infirmiers les patients adultes en attente de transplantation rénale.
Intervention / phénomène d'intérêt :	l'accompagnement de la part des infirmiers l'incertitude vécue par les patients les dimensions biopsychosociales l'attente d'une transplantation la confrontation à la mort les maladies chroniques.
Contexte :	en établissement de soins aigus le parcours de santé du patient les soins en ambulatoire et à domicile.

Dans notre questionnement, la population ciblée (P) fait référence aux infirmiers et le soutien qu'ils peuvent apporter aux patients atteints d'insuffisance rénale sous dialyse et en attente de transplantation.
Pour les interventions et phénomènes d'intérêt (I) ils consistent en l'accompagnement par les infirmiers dans les dimensions biopsychosociales du patient atteint d'une maladie chronique sur liste d'attente d'une transplantation spécifiquement dans son incertitude vécue. Le contexte (Co) est large impliquant les établissements de soins aigus mais aussi les soins ambulatoires lors des dialyses, par exemple, ou à domicile.

ANNEXE 3

Article 1 : Moran, A. (2016). Experiences of Patients on Outpatient Hemodialysis Therapy Who Are Anticipating a Transplant. *Nephrology Nursing Journal*, 43(3), 241–250.	
Eléments d'évaluation	**Questions à se poser pour faire la critique de l'article**
Titre et abstract	**Donnent-ils une vision globale de la recherche ? / Le titre précise-t-il clairement les concepts clés et la population à l'étude ? / L'abstract synthétise-t-il clairement les grandes lignes de la recherche : problème, méthode, résultats et discussion ?** Dès la lecture du titre de cet article nous avons su qu'il nous serait pertinent et c'est pourquoi nous l'avons gardé. Il montre bien qu'il y a un recueil d'expériences venant des patients sous hémodialyse en ambulatoire en attente d'une transplantation.
Introduction	
Problème de recherche	**Le phénomène à l'étude est-il clairement défini et placé en contexte ?** L'auteur commence par expliquer ce qu'est l'insuffisance rénale (IR), puis exprime que les personnes atteinte d'IR peuvent ressentir plusieurs émotions telle que la dépression ou l'anxiété. Mais l'auteur cherche à démontrer, au travers d'une étude phénoménologique en se basant sur les expériences de patients sous hémodialyse en ambulatoire, que d'autres réactions peuvent apparaître face à l'attente d'une transplantation. **Le problème a-t-il une signification particulière pour la discipline concernée ?** A la fin de l'article, il est proposé, dans la pratique infirmière, de prendre en compte les différentes humeurs, de soutenir les patients dans la redéfinition de leurs projets de vie ainsi que l'implication des proches. On y trouve également les notions d'adaptation des soins, d'intégration d'un accompagnement psychologique et le recours à la pleine conscience. Ceux sont des leviers proposés pour renforcer l'autonomie et la qualité de vie des patients.
But de l'étude:	**Le but de l'étude est-il énoncé de façon claire et concise ?** Oui on retrouve le but de cette étude assez rapidement dans le texte. Elle vise à montrer qu'en plus de la dépression et de l'anxiété, d'autres réactions psychologiques fréquentes peuvent survenir chez les personnes atteintes d'IR sous hémodialyse dont certains sur liste d'attente de transplantation. **Les questions de recherche sont-elles clairement énoncées ?** Aucune question de recherche est clairement explicité. **Traitent-elles de l'expérience des participants, des croyances, des valeurs ou des perceptions ?** Elles traitent des perceptions des patients.
Méthode	

Devis de l'étude:	**Le devis de recherche est-il clairement énoncé ? De quel type de devis s'agit-il ? / Y'a-t-il suffisamment de temps passé sur le terrain et auprès des participants ?** Il y a eu 2 étapes : la première avec un premier entretien puis la deuxième étape un an plus tard pour obtenir des informations plus approfondies abordées lors du premier entretien. Les entretiens qualitatifs sont réalisés sous forme de conversation basées sur des questions ouvertes. Dans cette étude, l'utilisation d'une méthodologie de recherche phénoménologique herméneutique est mentionnée qui veut dire que c'est une méthode de recherche qualitative utilisée pour explorer et interpréter les expériences personnes dans leur vie quotidienne (Diekelmann & Ironside, 1998).
Population et échantillon :	**La population à l'étude est-elle décrite de façon suffisamment détaillée?** Un échantillon constitué de 32 participants dans deux unités d'hémodialyse différentes (16 femmes et 16 hommes au total). Les participants inclus dans l'étude devaient remplir les critères suivants : être âgés de plus de 18 ans, être capables de converser en anglais et suivre un traitement d'hémodialyse en ambulatoire pour une insuffisance rénale. **Comment les participants ont-ils été recrutés ?** L'échantillonnage raisonné consiste pour le chercheur à choisir des patients qui sont les plus susceptibles de fournir des informations pertinentes sur leur expérience de l'insuffisance rénale et de l'hémodialyse.
Méthodes de collecte des données	**Les questions de recherche ont-elles été bien posées ou les observations du phénomène, bien ciblées ?** 47 entretiens réalisés durant l'étude : utilisation d'entretiens qualitatifs ressemblant à une conversation. Avec une question d'ouverture telle que : « Que signifie pour vous vivre sous traitement par hémodialyse ? ». Après cette question initiale, des questions de relance ont été utilisées, telles que : « Qu'est-ce que cela signifiait pour vous ? », « Comment avez-vous vécu cela ? », ou encore « Pouvez-vous me décrire cela ou m'en dire plus ? ». **Les méthodes et les outils de collecte des données, ainsi que les procédés d'enregistrement, sont-ils bien décrits et appropriés ?** Les données ont été enregistrées et transcrites intégralement.
Analyse de données:	**L'organisation et le processus d'analyse des données sont-ils décrits de façon suffisamment détaillée?** Tous les entretiens enregistrés et ensuite retranscrits. Les transcriptions de chaque entretien ont été lues plusieurs fois et de là en a découlé une liste de catégories/thématiques. Il y a eu un processus continu de lecture, d'écriture, de réflexion et de dialogue, tout au long de l'analyse. Un dialogue critique a permis de mettre à l'épreuve et d'affiner les interprétations, renforçant ainsi la rigueur de l'analyse. **Les thèmes font-ils ressortir adéquatement la signification des données?** Oui, il y a 3 grands thèmes qui ont émergé de l'analyse : être anxieux, vivre dans l'incertitude et surmonter les humeurs pénibles.
Résultats	

Présentation des résultats	**Les thèmes ou les modèles sont-ils logiquement associés entre eux afin de bien représenter le phénomène ?** Oui, il est bien expliqué que les participants décrivaient ressentir de l'anxiété durant l'attente d'une greffe rénale. Ils exprimaient également que cette attente pouvait souvent être longue et donc les empêchaient de se projeter dans l'avenir, les plongeant ainsi dans un état de flottement.
Discussion, Conclusion et Implications	
Interprétation des résultats	**Quelles sont les conclusions de l'étude ? Découlent-elles logiquement des résultats ?** Cet article met en évidence que les humeurs existentielles pénibles peuvent constituer un aspect important de l'expérience des personnes atteintes d'insuffisance rénale sous traitement d'hémodialyse en ambulatoire. À la conclusion, il est dit que cette étude offre une nouvelle interprétation de la détresse vécue chez ces patients et espère que ça contribuera à un meilleur accompagnement et compréhension. **Quelles sont les conséquences des résultats pour la pratique ou pour l'enseignement ?** Plusieurs recommandations pour la pratique infirmière en ont découlé comme par exemple former les infirmières à la gestion des états émotionnels, apporter une plus grande implication des familles et les proches ou encore introduire des techniques de méditation lors des soins afin que les patients puissent avoir une technique de relaxation pour se détendre dans le moment présent. **Quelles étaient les principales limites de l'étude ?** La méthodologie qualitative et la méthode d'échantillonnage raisonné ne permettent pas de généraliser les résultats à l'ensemble de la population des patients sous hémodialyse. De plus tous les participants étaient de nationalité irlandaise, leurs expériences pourraient donc être spécifiques et différentes de celles de patients vivant dans d'autres pays.

Article 2 : Yngman-Uhlin, P., Fogelberg, A., & Uhlin, F. (2016). Life in standby: hemodialysis patients' experiences of waiting for kidney transplantation. *Journal of clinical nursing*, *25*(1-2), 92–98. https://doi.org/10.1111/jocn.12994	
Éléments d'évaluation	**Questions à se poser pour faire la critique de l'article**
Titre et abstract	**Donnent-ils une vision globale de la recherche ? / Le titre précise-t-il clairement les concepts clés et la population à l'étude ? / L'abstract synthétise-t-il clairement les grandes lignes de la recherche : problème, méthode, résultats et discussion ?** Le titre et l'abstract donne directement une vision globale de la recherche. Dès le début, nous avons l'objectif et le but de cet étude qui est celui d'explorer les expériences des patients sous hémodialyse en attente de greffe.
Introduction	
Problème de recherche	**Le phénomène à l'étude est-il clairement défini et placé en contexte ?** Au début de l'article, il y a une exposition du contexte vis-à-vis du nombre de personne sur liste d'attente de transplantation rénale aux Etats-Unis ainsi qu'en Suède. **Le problème a-t-il une signification particulière pour la discipline concernée ?** Cette étude met en évidence le besoin d'une attention particulière pour les patients en attente de greffe de rein. Ils présentent un besoin accru de préparation pour la transition et pour la vie après la greffe également.
But de l'étude:	**Le but de l'étude est-il énoncé de façon claire et concise ?** Oui, le but de l'étude est déterminé dès les premières phrases. **Les questions de recherche sont-elles clairement énoncées ?** Aucune question de recherche est clairement explicitée. **Traitent-elles de l'expérience des participants, des croyances, des valeurs ou des perceptions ?** Elles souhaitent explorer les expériences des patients sous hémodialyse en attente d'une greffe de rein.
Méthode	
Devis de l'étude:	**Le devis de recherche est-il clairement énoncé ? De quel type de devis s'agit-il ? / Y'a-t-il suffisamment de temps passé sur le terrain et auprès des participants ?** Les patients ont été interrogés et par la suite il y a eu la réalisation d'une analyse descriptive des contenus.

Population et échantillon :	**La population à l'étude est-elle décrite de façon suffisamment détaillée?** La sélection de l'échantillon de patients adultes en traitement d'hémodialyse s'est fait sous les critères d'inclusions suivant : une hémodialyse pendant au moins 6 mois avec des expériences d'attente pour une transplantation rénale pendant cette période, cela incluait autant bien les patients sur liste d'attente que les patients ayant eu un refus suite à une transplantation. Les critères d'exclusion étaient les suivants : patient transplanté depuis plus de 10 ans et patient incapable de communiquer en suédois. Au total, huit patients : 7 hommes et 1 femmes. **Comment les participants ont-ils été recrutés ?** Dix patients d'un hôpital universitaire ont été invités par l'infirmière responsable.
Méthodes de collecte des données	**Les questions de recherche ont-elles été bien posées ou les observations du phénomène, bien ciblées ?** Entrevues d'une durée de 25 à 40 min. Les données ont été recueillies entre janvier et mars 2013. L'entretien a débuté avec une question ouverte telle que « Pouvez-vous décrire ce que c'est que d'attendre une greffe de rein ? », puis ça a été suivi de questions d'approfondissement et de clarification **Les méthodes et les outils de collecte des données, ainsi que les procédés d'enregistrement, sont-ils bien décrits et appropriés ?** Les entretiens ont été enregistrés sur des bandes et ont ensuite été retranscrits.
Analyse de données:	**L'organisation et le processus d'analyse des données sont-ils décrits de façon suffisamment détaillée?** Tous les entretiens ont été retranscrits et ont été analysés avec une méthode d'analyse descriptive par système de catégorisation et de codage de données. Les données ont amené à des sous-catégories et des catégories, toutes décrivaient l'expérience d'attendre une greffe de rein. **Les thèmes font-ils ressortir adéquatement la signification des données?** Oui, l'analyse a fait ressortir 4 catégories et 8 sous-catégories (illustrées dans le texte par des citations de patients).
Résultats	
Présentation des résultats	**Les thèmes ou les modèles sont-ils logiquement associés entre eux afin de bien représenter le phénomène ?** Oui, les participants ont décrit différentes manières de gérer l'attente. Les 4 catégories ressorties sont les suivantes : le processus de l'attente, la conscience que le temps est compté, le besoin de communication, et le soulagement et l'espoir pour l'avenir.
Discussion, Conclusion et Implications	

Interprétation des résultats Les auteurs répondent-ils à leur(s) questionnement(s) ?	**Quelles sont les conclusions de l'étude ? Découlent-elles logiquement des résultats ?** Cette étude montre que les patients hémodialysés en attente d'une greffe rénale vivent dans l'incertitude et sont affectés à la fois physiquement et psychologiquement. Les résultats de l'étude montre qu'il y a des patients qui ont besoin de plus de soutien durant la période précédant la transplantation afin de se sentir prêts. Cet article démontre également que les patients en dialyse ressentent un manque de liberté par le fait d'être reliés à une machine pour vivre, ils expriment également la peur de mourir lors de l'attente de leur greffe. **Quelles sont les conséquences des résultats pour la pratique ou pour l'enseignement ?** Il en découle que de manière générale, les directives sur la transplantation rénale se focalisent sur les aspects médicaux. Cet article recommande que le personnel soignant spécialisé informe les patients sur le temps d'attente, la procédure, les risques et de leur offrir un soutien psychologique également. Il est également indiqué de mieux préparer les patients aux changements importants ce qui va impliquer la transplantation même si ce jour est perçu comme positif. **Quelles étaient les principales limites de l'étude ?** Le fait qu'il y ait qu'une seule femme participant à cette étude est déjà une limite.

Article 3 : Nielsen, C., Clemensen, J., Bistrup, C., & Agerskov, H. (2018). Balancing everyday life-Patients' experiences before, during and four months after kidney transplantation. Nursing open, 6(2), 443–452. https://doi.org/10.1002/nop2.225	
Eléments d'évaluation	**Questions à se poser pour faire la critique de l'article**
Titre et abstract	**Donnent-ils une vision globale de la recherche ? / Le titre précise-t-il clairement les concepts clés et la population à l'étude ? / L'abstract synthétise-t-il clairement les grandes lignes de la recherche : problème, méthode, résultats et discussion ?** Le titre est clair et reflète bien le contenu. L'abstract présente la méthode qualitative, la population, les principaux résultats et les implications cliniques. Cependant l'incertitude et le cadre théorique n'y sont pas mentionné.
Introduction	
Problème de recherche	**Le phénomène à l'étude est-il clairement défini et placé en contexte ?** Oui, les auteurs décrivent la transplantation rénale comme une trajectoire complexe marquée par des changements majeurs et une forte incertitude. Ils mettent l'accent sur le vécu subjectif des patients, peu exploré dans la littérature. **Le problème a-t-il une signification particulière pour la discipline concernée ?** Oui, comprendre ce que vivent les patients dans ce parcours complexe, est essentiel. Pour les soignants et en particulier les infirmiers cela permet d'ajuster l'accompagnement : au quotidien, face à la maladie, et surtout face à l'incertitude.
But de l'étude:	**Le but de l'étude est-il énoncé de façon claire et concise ?** Oui : comprendre comment les patients atteints d'insuffisance rénale terminale vivent leur quotidien autour de la greffe avant, pendant et après la transplantation rénale. **Les questions de recherche sont-elles clairement énoncées ?** Non, il n'y a pas de question de recherche formulée mais l'objectif joue un rôle de fil conducteur. **Traitent-elles de l'expérience des participants, des croyances, des valeurs ou des perceptions ?** Oui, l'étude explore le vécu subjectif, les perceptions, et les ajustements émotionnels des patients dans la trajectoire de greffe.
Méthode	
Devis de l'étude:	**Le devis de recherche est-il clairement énoncé ? De quel type de devis s'agit-il ? / Y'a-t-il suffisamment de temps passé sur le terrain et auprès des participants ?** Oui. Les auteurs précisent avoir utilisé une approche qualitative descriptive basée sur la phénoménologie herméneutique de Ricoeur qui combine une lecture naïve, une analyse structurelle et une interprétation critique. Les données ont été recueillies à trois étapes clés du parcours : avant, pendant et après la greffe.

Population et échantillon :	**La population à l'étude est-elle décrite de façon suffisamment détaillée ?** Oui, ils précisent l'âge, le sexe, la situation professionnelle et familiale. Il s'agit de patients adultes, tous inscrits pour une première greffe rénale. **Comment les participants ont-ils été recrutés ?** Le recrutement a été réalisé par une infirmière de coordination dans un centre hospitalier universitaire au Danemark. Les critères d'inclusions sont clairs et la temporalité du recueil est bien définie
Méthodes de collecte des données	**Les questions de recherche ont-elles été bien posées ou les observations du phénomène, bien ciblées ?** Oui. L'intention de comprendre l'expérience vécue tout au long du parcours est claire et cohérente avec la phénoménologie descriptive. **Les méthodes et les outils de collecte des données, ainsi que les procédés d'enregistrement, sont-ils bien décrits et appropriés ?** Partiellement, Les données ont été recueillies par des entretiens semi-structurés, enregistrés et retranscrits. La grille d'entretien n'est pas jointe, ce qui limite l'accès aux questions. Mais globalement cela est adapté aux objectifs.
Analyse de données:	**L'organisation et le processus d'analyse des données sont-ils décrits de façon suffisamment détaillée ?** Partiellement. Les auteurs décrivent les grandes étapes selon Ricoeur mais sans détail précis sur le codage, l'outil utilisé, ni la validation entre chercheur. **Les thèmes font-ils ressortir adéquatement la signification des données ?** Oui. Les thèmes sont clairs et illustrés par des citations. Ils reflètent l'expérience vécu des patients ce qui met en valeur la richesse des données.
Résultats	
Présentation des résultats	**Les thèmes ou les modèles sont-ils logiquement associés entre eux afin de bien représenter le phénomène ?** Oui. Les résultats sont organisés en quatre thèmes qui reflètent le vécu des patients avant, pendant et après la greffe. Chaque thème est illustré par des verbatims.
Discussion, Conclusion et Implications	

Interprétation des résultats	**Quelles sont les conclusions de l'étude ? Découlent-elles logiquement des résultats ?** Oui. Ils concluent que la transplantation rénale est un processus long et complexe. Les patients ont une tension continue entre ce qu'ils attendent, ce qu'ils vivent et ce à quoi ils doivent s'adapter. Les conclusions sont cohérentes avec les résultats. **Quelles sont les conséquences des résultats pour la pratique ou pour l'enseignement ?** Les auteurs recommandent de considérer la greffe comme un parcours global qui nécessite un accompagnement individualisé et continue, avant, pendant et après la greffe. Une attention au vécu subjectif est essentielle. **Quelles étaient les principales limites de l'étude ?** Les principales limites sont la taille réduite de l'échantillon, le recrutement dans un seul centre hospitalier au Danemark mais aussi l'absence de validation des résultats par les participants.

Article 4 : Burns, T., Fernandez, R., & Stephens, M. (2017). The experience of waiting for a kidney transplant : A qualitative study. Journal of renal care, 43(4), 247–255. https://doi.org/10.1111/jorc.12209	
Eléments d'évaluation	**Questions à se poser pour faire la critique de l'article**
Titre et abstract	**Donnent-ils une vision globale de la recherche ? / Le titre précise-t-il clairement les concepts clés et la population à l'étude ? / L'abstract synthétise-t-il clairement les grandes lignes de la recherche : problème, méthode, résultats et discussion ?** Oui. Le titre précision la population et indique la méthodologie qualitative. L'abstract résume de manière synthétique le problème, la méthode, les résultats et les implications clinique. Cela permet de comprendre rapidement le contenu.
Introduction	
Problème de recherche	**Le phénomène à l'étude est-il clairement défini et placé en contexte ?** Oui, le phénomène de l'étude est clair. Il concerne le vécu des patients dialysés en attente de greffe rénale. Les auteurs expliquent le contexte de pénurie d'organes, d'allongement des délais d'attente et les impacts psychologiques associés **Le problème a-t-il une signification particulière pour la discipline concernée ?** Oui. Les infirmiers accompagnent les patients dans la gestion de l'incertitude, le soutien émotionnel et la communication. Des éléments essentiels en dialyse et en transplantation.

But de l'étude:	**Le but de l'étude est-il énoncé de façon claire et concise ?** Oui, dès l'introduction le but de l'étude est énoncé c'est-à-dire explorer l'expérience vécue des patients sous dialyse en attente de transplantation rénale. C'est annoncé de manière simple et précise. **Les questions de recherche sont-elles clairement énoncées ?** Non, il n'y a pas de question de recherche formulée de manière explicite mais un but général qui guide la recherche. **Traitent-elles de l'expérience des participants, des croyances, des valeurs ou des perceptions ?** Oui, l'étude explore le vécu subjectif des patients en attente de greffe tout en incluant leurs émotions, leurs perceptions de l'incertitude, les changements sociaux et leurs sentiments vis-à-vis du donneur.
Méthode	
Devis de l'étude:	**Le devis de recherche est-il clairement énoncé ? De quel type de devis s'agit-il ? / Y'a-t-il suffisamment de temps passé sur le terrain et auprès des participants ?** Oui il s'agit d'une étude qualitative descriptive qui est adaptée pour explorer le vécu des patients en attente de transplantation rénale. Les données ont été recueillies avec deux focus groups de six participants. Mais la durée des échanges n'est pas précisée, ce qui limite la profondeur.
Population et échantillon :	**La population à l'étude est-elle décrite de façon suffisamment détaillée?** Oui, les critères d'inclusions (18 ans et plus, sous dialyse et inscrits sur liste d'attente pour transplantation rénale) et d'exclusions (patients qui ne peuvent pas communiquer en anglais) sont bien précisés. Cependant les caractéristiques individuelles des participants c'est-à-dire âge, sexe… sont peu détaillées. **Comment les participants ont-ils été recrutés ?** Via une liste d'attente d'un service de néphrologie d'un hôpital de Sydney, selon les critères définis.
Méthodes de collecte des données	**Les questions de recherche ont-elles été bien posées ou les observations du phénomène, bien ciblées ?** Oui, malgré que la question de recherche ne soit pas formulée de manière formelle, l'objectif que l'étude est claire c'est à dire explorer l'expérience vécue de l'attente d'une greffe rénale. Les thèmes abordés en focus groups ont permis d'explorer cet objectif en abordant les perceptions subjectives et les échanges entre patients sur le vécu de l'attente. **Les méthodes et les outils de collecte des données, ainsi que les procédés d'enregistrement, sont-ils bien décrits et appropriés ?** Partiellement. Les auteurs précisent que les données ont été recueillies par deux focus groups, enregistrés et retranscrits. Leur rôles est expliqué mais les questions exactes et la durée des discussions ne sont pas détaillées.

Analyse de données:	**L'organisation et le processus d'analyse des données sont-ils décrits de façon suffisamment détaillée?** Partiellement. Les auteurs précisent avoir utilisé une analyse qualitative descriptive avec un codage inductif des focus groups qui a été relu plusieurs fois. Mais ils ne donnent pas d'exemple sur le codage et ne disent pas le logiciel utilisé. **Les thèmes font-ils ressortir adéquatement la signification des données?** Oui les thèmes identifiés : fatigue, incertitude, relations sociales, relation au donneur reflètent bien le vécu des patients. Ils sont illustrés par des citations ce qui renforce la crédibilité.
Résultats	
Présentation des résultats	**Les thèmes ou les modèles sont-ils logiquement associés entre eux afin de bien représenter le phénomène ?** Oui, les résultats de l'étude sont présentés sous forme de quatre thèmes principaux : la difficulté de la dialyse, l'incertitude permanente, le changement dans les relations sociales et le rapport au donneur. Ces thèmes sont logiquement associés entre eux et reflètent bien le phénomène.
Discussion, Conclusion et Implications	
Interprétation des résultats	**Quelles sont les conclusions de l'étude ? Découlent-elles logiquement des résultats ?** Oui, les auteurs concluent que les patients vivent une attente marquée par des difficultés physique et psychologique, un sentiment d'incertitude, des changements dans les relations sociales et un lien émotionnel au donneur. Cette période de vulnérabilité nécessite un accompagnement renforcé. Les conclusions sont cohérentes avec les thèmes présenter. **Quelles sont les conséquences des résultats pour la pratique ou pour l'enseignement ?** Les auteurs insistent sur l'importance d'une meilleure communication ainsi qu'un soutien émotionnel et informationnel constant afin de mieux gérer cette attente. **Quelles étaient les principales limites de l'étude ?** Les limites sont la taille de l'échantillon réduite, qui est seulement de 6 participants et des données issues d'un seul centre hospitalier.

Article 5 : Nilsson, K., Westas, M., Andersson, G., Johansson, P., & Lundgren, J. (2022). Waiting for kidney transplantation from deceased donors: Experiences and support needs during the waiting time -A qualitative study. Patient education and counseling, 105(7), 2422–2428. https://doi.org/10.1016/j.pec.2022.02.016	
Eléments d'évaluation	**Questions à se poser pour faire la critique de l'article**
Titre et abstract	**Donnent-ils une vision globale de la recherche ? / Le titre précise-t-il clairement les concepts clés et la population à l'étude ? / L'abstract synthétise-t-il clairement les grandes lignes de la recherche : problème, méthode, résultats et discussion ?** Oui, le titre est clair et informatif. Il précise la population, les expérience et les besoins de soutien. L'abstract présent bien la problématique, l'objectif, la méthode qualitative, les résultats et les implications pratiques.
Introduction	
Problème de recherche	**Le phénomène à l'étude est-il clairement défini et placé en contexte ?** Oui. L'étude décrit précisément l'expérience et les besoins de soutien des patients en attente de greffe rénale avec donneur décédé en soulignant les impacts physiques, psychologiques et sociaux. L'absence de cadre théorique réduit toutefois la profondeur. **Le problème a-t-il une signification particulière pour la discipline concernée ?** Oui. Les infirmiers accompagne ces patients sur le plans éducatif, psychologique et pratique.
But de l'étude:	**Le but de l'étude est-il énoncé de façon claire et concise ?** Oui. L'objectif est d'explorer et de décrire l'expérience des patients en attente de greffe rénale et le soutien reçu pendant cette période. **Les questions de recherche sont-elles clairement énoncées ?** Non. Il n'y a pas de questions de recherche mais le but décrit bien l'objet de l'étude. **Traitent-elles de l'expérience des participants, des croyances, des valeurs ou des perceptions ?** Oui. L'étude explore en profondeur les expériences vécus, les représentations et les perceptions des patients sur l'attente et le soutien.
Méthode	
Devis de l'étude:	**Le devis de recherche est-il clairement énoncé ? De quel type de devis s'agit-il ? / Y'a-t-il suffisamment de temps passé sur le terrain et auprès des participants ?** Oui. Il s'agit d'une étude qualitative descriptive basée sur des entretiens semi-structurés. Les entretiens (réalisés entre novembre 2018 et janvier 2019) duraient en moyenne 30 minutes, bien que les entretiens téléphoniques puissent limiter la profondeur de la collecte.

Population et échantillon :	**La population à l'étude est-elle décrite de façon suffisamment détaillée?** Oui avec quelques limites. L'étude inclut 14 patients (7 en attente, 7 transplantés), âgés de 39 à 72 ans, dont 10 hommes et 4 femmes avec une durée d'attente moyenne de 29 mois. Il y a peu d'informations sur les aspects culturels et psychosociaux. **Comment les participants ont-ils été recrutés ?** Par échantillonnage intentionnel (purposive sampling) qui vise la diversité des perspective. Les critères : patients adultes, suédophones, suivis en néphrologie ayant accepté par consentement écrit après un envoie à 31 personnes
Méthodes de collecte des données	**Les questions de recherche ont-elles été bien posées ou les observations du phénomène, bien ciblées ?** Oui, globalement. Les entretiens semi-structurés et les questions ouvertes ont permis d'explorer en profondeur les expériences et les besoins de soutien. Le guide d'entretien n'est cependant pas détaillé. **Les méthodes et les outils de collecte des données, ainsi que les procédés d'enregistrement, sont-ils bien décrits et appropriés ?** Oui. Les entretiens semi-structurés par téléphones sont cohérents et adaptés (fatigue, dispersion géographique). Les entretiens duraient entre 18 à 55 minutes et étaient enregistrés.
Analyse de données:	**L'organisation et le processus d'analyse des données sont-ils décrits de façon suffisamment détaillée?** Oui. L'analyse inductive de Braun et Clarke est décrite avec un codage réalisé par deux chercheurs et des d'équipe. L'usage de Nvivo est mentionné. Cependant, il manque des détails sur la grille de codage et aucun validation par les participants n'as été faite. **Les thèmes font-ils ressortir adéquatement la signification des données?** Oui. Les thèmes reflètent bien la signification des données et décrivent l'expérience des patients. Les deux thèmes principaux couvrent les aspects émotionnels et les stratégies d'adaptation.
Résultats	
Présentation des résultats	**Les thèmes ou les modèles sont-ils logiquement associés entre eux afin de bien représenter le phénomène ?** Oui. Les thèmes sont logiquement associés. Le premier (espoir et désespoir) décrit le vécu émotionnel et le second les stratégies pour gérer l'attente. Ils représentent bien l'expérience globale du patient.
Discussion, Conclusion et Implications	

Interprétation des résultats	**Quelles sont les conclusions de l'étude ? Découlent-elles logiquement des résultats ?** Oui. L'étude conclut que l'attente de greffe est une période difficile, marquée par l'incertitude, des attente élevées et un besoin important de soutien. Cela est cohérent avec les deux thèmes principaux et les témoignages recueillis. **Quelles sont les conséquences des résultats pour la pratique ou pour l'enseignement ?** Les résultats montrent la nécessité d'un accompagnement infirmier prolongé, personnalisé et global pendant l'attente et après la transplantation. Ils soulignent aussi l'importance de former les soignants à la prise en charge de l'incertitude et des besoins éducatifs spécifiques. **Quelles étaient les principales limites de l'étude ?** Un petit échantillon suédois, le mélange de patients en attente et transplantés, pas de cadre théorique explicite et peu de détails sur la grille de codage

Article 6 : Pedreira, R. G., Morín, F. V., Bach, P. A., Graells, S. A., & Garcimartín, P. (2024). «I can't imagine it without my nurse»: Experiences of people with chronic kidney disease in the evaluation process as kidney transplant candidates. *Research in Nursing & Health*, 47(6), 635–647. https://doi.org/10.1002/nur.22414	
Eléments d'évaluation	**Questions à se poser pour faire la critique de l'article**
Titre et abstract	**Donnent-ils une vision globale de la recherche ? / Le titre précise-t-il clairement les concepts clés et la population à l'étude ? / L'abstract synthétise-t-il clairement les grandes lignes de la recherche : problème, méthode, résultats et discussion ?** Le titre et l'abstract expose directement le sujet qui est abordé dans cet article. Dès le début, nous avons l'objectif et le but de cette étude, qui est d'explorer les expériences de 11 adultes atteint IRC ainsi que d'examiner le rôle de l'infirmière dans ce processus de transplantation rénale.
Introduction	
Problème de recherche	**Le phénomène à l'étude est-il clairement défini et placé en contexte ?** Au début de l'article, il y a une mise en contexte vis-à-vis de l'augmentation du nombre de personnes atteint d'IR. Il survole aussi le processus d'accès à une transplantation rénale. **Le problème a-t-il une signification particulière pour la discipline concernée ?** En plus des expériences des personnes atteintes d'IRC subissant une évaluation pour la transplantation, cette étude cherche également à adapter les activités infirmière aux besoins émergents.

But de l'étude:	**Le but de l'étude est-il énoncé de façon claire et concise ?** Oui, le but de cette étude qualitative est déterminée au début de l'abstract. **Les questions de recherche sont-elles clairement énoncées ?** Aucune question de recherche est clairement explicitée. **Traitent-elles de l'expérience des participants, des croyances, des valeurs ou des perceptions ?** Elles souhaitent explorer les expériences des patients atteints d'IRC qui sont en évaluation pour une transplantation rénale.
Méthode	
Devis de l'étude:	**Le devis de recherche est-il clairement énoncé ? De quel type de devis s'agit-il ? / Y'a-t-il suffisamment de temps passé sur le terrain et auprès des participants ?** Les patients ont été interrogés lors d'entretien semi-structuré afin de n'oublier aucun sujet important. Les entretiens étaient d'une durée d'environ 45 min.
Population et échantillon :	**La population à l'étude est-elle décrite de façon suffisamment détaillée?** Patients adultes atteints d'IRC et soumis à une évaluation pour la transplantation rénale. Le profil des participants était constitué de personnes pour lesquelles la transplantation rénale était envisagée depuis une période égale ou supérieure à trois mois et qui avaient au moins trois visites en personne avec l'infirmière du service de transplantation. **Comment les participants ont-ils été recrutés ?** 11 patients venant d'une clinique de transplantation se situant dans un hôpital en Espagne.
Méthodes de collecte des données	**Les questions de recherche ont-elles été bien posées ou les observations du phénomène, bien ciblées ?** Les entretiens étaient d'une durée d'environ 45 min. Les données ont été recueillies entre octobre 2022 et juillet 2023. Les entretiens étaient semi-structurés afin de ne pas oublier des sujets importants tels que la signification de la maladie, la transplantation rénale, les besoins émergents au cours du processus de transplantation et du rôle des infirmiers, c'était donc des questions ouvertes et ciblée sur des thèmes clés. **Les méthodes et les outils de collecte des données, ainsi que les procédés d'enregistrement, sont-ils bien décrits et appropriés ?** Les entretiens ont été enregistrés, à la connaissance des participants et il y a eu également des notes de terrain qui ont été réalisées. .

Analyse de données:	**L'organisation et le processus d'analyse des données sont-ils décrits de façon suffisamment détaillée?** Tous les entretiens ont été retranscrits et ont été analysés. Puis il y a eu la réalisation d'un codage et une identification des thèmes principaux. Suite à cette analyse, une carte thématiques a été réalisée afin d'établir des relations entre les thèmes. **Les thèmes font-ils ressortir adéquatement la signification des données?** Oui, il y a 3 catégories : le candidat en attente de transplantation et sa réalité, le processus de l'insuffisance rénale chronique et la transplantation rénale et le rôle de l'infirmier. Ces catégories sont accompagnées de sous-catégories alimentées par des verbatims pertinents.
Résultats	
Présentation des résultats	**Les thèmes ou les modèles sont-ils logiquement associés entre eux afin de bien représenter le phénomène ?** Oui, les participants ont décrit leurs expériences et leurs besoins en lien avec le processus de la transplantation rénale.
Discussion, Conclusion et Implications	
Interprétation des résultats	**Quelles sont les conclusions de l'étude ? Découlent-elles logiquement des résultats ?** Cette étude montre que les patients, qui sont des êtres entiers, sont surpris d'apprendre leur IRC, ce qui crée un choc entre leur état de santé passé et leur état de santé actuel. Cela perturbe également leur routine de la vie quotidienne. Mais il également dit que cet impact va au-delà de l'individu, sa famille est également affectée à cause des émotions émergeantes de cette situations. **Quelles sont les conséquences des résultats pour la pratique ou pour l'enseignement ?** Il en ressort que la pratique infirmière, dans la prise en charge de patient atteints d'IRC sur liste de transplantation, va au-delà des gestes techniques comme par exemple le soutien émotionnel ou encore l'éducation thérapeutique. **Quelles étaient les principales limites de l'étude ?** Le fait que les patients viennent d'une même clinique, c'est un marqueur de limitation pour faire une généralisation. Le fait qu'ils aient exclu les personnes qui réalisent moins, voire pas de suivi par des infirmiers lors de leur processus de transplantation. Il y a également une possibilité d'un biais de désirabilité social (patients répondent d'une manière socialement acceptable).

Experiences of Patients on Outpatient Hemodialysis Therapy Who Are Anticipating a Transplant

CNE Continuing Nursing Education

Aoife Moran

Moran, A. (2016). Experiences of patients on outpatient hemodialysis therapy who are anticipating a transplant. *Nephrology Nursing Journal, 43*(3), 241-249.

The person with kidney failure may experience many lifestyle disruptions that initiate distressing responses. This article reports on the results of a phenomenological study that explored the experiences of patients with kidney failure who were receiving outpatient hemodialysis therapy and who were either on the transplant list or in the process of being assessed to get on the transplant list. The participants described the existential distress they endured as a result of living with this disease and treatment; however, the participants' descriptions of distress were different than the psychological perspective of emotional distress depicted in the existing research. The information provided in this article can enhance nurses' ability to recognize and respond more appropriately to the distressing moods experienced by patients with kidney failure on outpatient hemodialysis.

Key Words: **Kidney failure, hemodialysis, phenomenology, patients' experiences, existential moods.**

Chronic kidney disease (CKD) has reached an epidemic proportion worldwide (Bikbov, Perico, & Remuzzi, 2014; Couser, Remuzzi, Mendis, & Tonelli, 2011). When CKD progresses to end stage renal disease (ESRD), the kidneys are permanently damaged, and the person can no longer survive independently without renal replacement therapy.

The person with kidney failure on outpatient hemodialysis or peritoneal dialysis may experience many losses and lifestyle disruptions, culminating in emotional distress. For instance, kidney failure and hemodialysis or peritoneal dialysis may affect the person's ability to perform normal, everyday activities, such as working, socializing, and travelling (Harwood, Wilson, Sondrup, & Clark, 2012; Moran, Scott, & Darbyshire, 2009, 2011). As a result of these lifestyle disruptions, the existing international research cites depression as a common psychological reaction to kidney failure (Abdel-Kader, Unruh, & Weisbord, 2009; Bhatti, Farhan, & Satti, 2014; Gottdiener, 2011; Khalil, Frazier, Lennie, & Sawaya, 2011; Kimmel & Peterson, 2006; Kop et al., 2011; Palmer et al., 2013).

In particular, various lifestyle modifications are required by the patient on outpatient hemodialysis, which may contribute to psychological distress. For instance, these patients have to be present in the hemodialysis unit approximately three times a week for sessions lasting an average of four hours. They must also adhere to a strict regimen of dietary and fluid restrictions, and medications (Kim & Evangelista, 2010; Krueger, 2009). These patients are also dependent for survival on the technology of the hemodialysis machine and on the healthcare team (Danquah, Zimmerman, Diamond, Meininger, & Bergstrom, 2010; Richard & Engebretson, 2010).

For many patients, the hope of a kidney transplant enables them to cope with kidney failure and hemodialysis therapy (Krueger, 2009; Mitchell, Farrand, James, Luke, & Wyatt, 2009; Moran et al., 2011). However, the patient's experience of hope is often undermined by feelings of anxiety as they endure the increasing uncertainty of life with a debilitating disease (Curtin, Mapes, Petillo, & Oberley, 2002; Moran et al., 2011, Pradel, Suwannaprom, Mullins, Sadler, & Bartlett, 2009). Indeed, there is growing recognition in the existing literature that the life-limiting complications associated with kidney failure may force the person to confront his or her own mortality, culminating in psychological distress (Johnston & Noble, 2012; Molzahn et al., 2012; Morton, Tong, Howard, Snelling, & Webster, 2010; Schick-Makaroff, Shields, & Molzahn, 2013).

The analysis of the existing international research indicates that depression and anxiety are among the most prevalent psychological responses in patients with kidney failure. However, it is important to emphasize that the majority of research predominantly describes the experience of depression and anxiety as emotional or psychological responses.

This article reports on a phenomenological study that explored the experiences of patients with kidney failure on outpatient hemodialysis therapy. In contrast to the existing research,

Aoife Moran, PhD, BNS (Hons), Dip HE Nursing, RN, CNN, *is a Renal Nurse, Trinity Kidney Health Centre, St. James's Hospital, Dublin, Ireland, and is an International Member of ANNA.*

Statement of Disclosure: *The author reported no actual or potential conflict of interest in relation to this continuing nursing education activity.*

Note: *The Learning Outcome, additional statements of disclosure, and instructions for CNE evaluation can be found on page 250.*

the findings of the study indicated that patients experienced a form of existential distress in response to kidney failure and hemodialysis. Moreover, the existential distress illustrated by participants in the study mirrored the existential moods of anxiety and boredom, as depicted by the German philosopher Martin Heidegger (1962, 1995).

Heidegger's Account of Existential Mood

According to Heidegger (1962), our moods arise from our existence or being in the world. Although Heidegger (1962) sometimes uses the term "state-of-mind" to describe mood, his notion of mood does not refer to a subjective, private mental state. Thus, he rejected the idea that moods should be understood purely from a psychological perspective as feelings, emotions, or consciousness. It is important to note that Heidegger (1962, 1995) was not trying to dispute the psychological characterization of feelings and experiences. Rather, by linking mood to existence, Heidegger offers an alternative way of understanding these everyday feelings and experiences, which contributes to the existing psychological interpretation.

According to Heidegger (1962, 1995), anxiety and boredom are fundamental existential moods. These moods are described as fundamental because all the other moods experienced by the person originate from them. Moreover, they are described as existential because they uncover the finitude of existence to the person. In order to understand Heidegger's (1962, 1995) depiction of existential mood, it is necessary to understand his description of time or originary temporality.

Originary Temporality

For Heidegger (1962), time is not merely the seconds, minutes, and hours we associate with clock time. Instead, time is originary temporality and is a basic structure of our existence or being. Heidegger (1962) uses the term *originary temporality* to indicate that his description of time or temporality evolves or "originates" out of the person's existence or being. Table 1 provides a list of terms Heidegger (1962) uses to describe originary temporality.

Table 1
List of Terms

Dasein – The human being.
Temporality – Time.
Originary temporality – Time or temporality is defined as originary because it originates or develops out of the person's existence or being.
Threefold structure of originary temporality – The past, present, and future are connected in originary temporality. Thus, originary temporality is described as a unified or threefold structure.
Originary past – The originary past is not merely the past tense. The originary past is made up of the important set of relationships, practices, values, and language the person has developed since birth.
Originary future – People move forward into goals, possibilities and aspirations in the future. Thus, the originary future provides the threefold structure of originary temporality with projective or future-directed features.
Originary present – This dimension of time consists of the tasks and activities the person performs on a daily basis. The originary present also provides the connection between the originary past and future. Thus, individuals act in the originary present, based on the contextual features of the originary past, to move forward into life goals and aspirations in the originary future.
Ordinary time – Clock time. Individuals normally use clock time to structure the everyday activities they perform in the originary present. Thus, ordinary time or clock time is connected to originary temporality through the originary present.

In originary temporality, the past, present, and future are not three separate units of time. Rather the present incorporates the past and future as a unified or threefold structure (Dostal, 1993). The originary future refers to the way the person is always pressing ahead or projecting him/herself into some way of life or some aspiration in the future (Mulhall, 1996). The projective or future-directed character of the originary future provides the projection for the entire threefold structure of originary temporality (Blattner, 1999).

The originary past is composed of the significant set of relationships, practices, and language that we have by virtue of being born into a particular world (Heidegger, 1962). These background or contextual features set up the life goals and ambitions for the individual's future existence.

The originary present is the time that contains the tasks and activities we perform on an everyday basis. The person acts in the originary present based on the contextual features from the past to project forward into possibilities and aspirations in the originary future (Blattner, 1992). Consequently, the originary present provides the connection in the threefold structure of originary temporality (Blattner, 1992).

From Heidegger's (1962) perspective, we do not normally understand clock or ordinary time as an abstract entity consisting of isolated units (i.e., seconds, minutes, hours). Instead, we understand clock time in relation to the everyday activities we perform in the originary present (Blattner, 1999; 2005). Therefore, the human being, which Heidegger calls Dasein, uses clock time so he or she can fit a number of tasks into the originary present each day (Blattner, 1999, 2005). However, Heidegger emphasizes that when the person focuses primarily on the endless sequence of ordinary time, the features of the originary

present and the larger unified structure of originary temporality, which form its basis, remain covered over. Based on Heidegger's account, time ultimately depends upon human beings (Blattner, 1999, 2005). Without Dasein (the human being), there would be no time (Blattner, 1999).

This article proposes that the experiences of participants in the study who were on outpatient hemodialysis and who were either on the transplant list or in the process of being assessed to get on the transplant list, mirrors the perspective of the existential moods of anxiety and boredom depicted by Heidegger (1962, 1995). Thus, this article provides a detailed discussion of the study participants' experiences in relation to Heidegger's analysis of existential mood. It is anticipated that the perspective of existential mood provided in this article will serve to complement and expand our current understandings of the experiences of distress in this patient group. This information can enhance the ability of nurses to recognize and respond more appropriately to the distress experienced by their patients. As a result, quality and effectiveness of care may be enhanced. Finally, this article also proposes recommendations for practice that would potentially assist patients to overcome distressing existential moods associated with kidney failure.

Study Methodology

The overall aim of the study was to provide an accurate and detailed description of the experiences of patients with kidney failure undergoing outpatient hemodialysis therapy. Therefore, a hermeneutical phenomenological research methodology was deemed appropriate to achieve the aim of the study. Hermeneutical phenomenology is a qualitative research methodology used to explore and interpret the experiences of people in their everyday lives (Diekelmann & Ironside, 1998). It provides a way to create an understanding of people's experiences within the context of their whole lives, incorporating their past, present, and future (Diekelmann & Ironside 1998). The approach to hermeneutical phenomenology utilized in the study was based on the philosophy of Martin Heidegger (1962, 1995).

Participants

The study was carried out in two large teaching hospitals in the Republic of Ireland. A purposive sample of 32 participants was selected for inclusion in the study. Purposive sampling involves the researcher selecting patients who would be most likely to contribute information on their experiences of kidney failure and hemodialysis. Participants were included in the study if they were over 18 years of age, able to converse in English, and on outpatient hemodialysis for kidney failure.

Ethical Issues

Formal written ethics approval to conduct the study was given by the Research Ethics Committee at both study hospitals. Participants were given verbal and written information regarding the study, and full written consent was obtained. Participants were assured that their privacy and confidentiality would be maintained throughout the study. Each participant was assigned a pseudonym to protect his or her identity. Participants were informed that they had the right to refuse to participate or withdraw from the study at any time.

Data Collection

Data collection took place in two stages:

- Stage 1: One qualitative in-depth interview was conducted with 16 participants (7 female, 9 male) at one outpatient hemodialysis facility.
- Stage 2: Two qualitative in-depth interviews were conducted with 16 participants (7 female, 9 male) at another outpatient hemodialysis facility. The second interview took place approximately one year after the first. A second interview was conducted with participants with the aim of collecting more in-depth descriptions of the themes developed in the initial interviews. One participant died before the second interview took place.

A total of 47 interviews were conducted during the study. The approach to qualitative interviewing resembled a conversation. For instance, one opening question was used in which the participants were asked: "What is it like to live on hemodialysis therapy?" After the initial question, probing questions were used, such as: "What did that mean to you? What was that like?" and "Can you describe or tell me more about that?" Data were recorded and transcribed verbatim.

Data Analysis

Data were analyzed using an approach to hermeneutical analysis, proposed by Diekelmann, Allen, and Tanner (1989). Transcripts from each interview were read several times, and a list of categories was created. The categories were compared and contrasted between the interview texts from all participants. This allowed the shared or similar categories to be identified and developed into themes.

A continuous process of reading, writing, thinking, and dialogue occurred throughout the analysis process. For instance, research supervisors read the interview transcripts and discussed and debated the categories and themes created. This dialogue ensured that interpretations were challenged and questioned, which subsequently enhanced the rigor of the analysis. It is proposed that the participants' accounts of living with kidney failure mirrored the depiction of existential mood advanced by Heidegger (1962, 1995).

Results and Discussion

The findings discussed in this article include a subset of data from 12 participants who were on outpatient hemodialysis and who were either on

Table 2
Sample Demographics

Patient #	Age (Years)	Sex	Time on Hemodialysis
1	60	Female	2 years
2	32	Male	1 year, 8 months
3	46	Female	1 year, 9 months
4	54	Male	4 years, 1 month
5	33	Male	2 years
6	45	Female	4 years
7	34	Male	3 years, 2 months
8	27	Male	2 years, 1 month
9	48	Female	5 years
10	29	Female	1 year, 1 month
11	44	Male	2 years, 6 months
12	51	Male	3 year, 4 months

the transplant list or in the process of being assessed to get on the transplant list. Participant demographics are reported in Table 2. The 5 female and 7 male participants ranged in age from 27 to 60 years. All participants were of Irish nationality. Participants had been on hemodialysis from 20 months to 5 years.

Three main themes were constructed: 1) Being Anxious, 2) Living in Limbo, and 3) Overcoming Distressing Moods. Participants described their experience of anxiety while they waited for a kidney transplant. The anxiety of waiting on a long-term basis prevented participants from planning their futures. Thus, they described their experience of living in limbo while they waited for a transplant. Distressing moods were threaded throughout the participants' accounts of living in limbo. Despite the complexities of living on hemodialysis, some participants described their experience of overcoming distressing moods and getting on with life while on hemodialysis.

It is proposed that the experiences of the participants in this study mirror the fundamental existential moods of anxiety and boredom described by Heidegger (1962, 1995). Thus, Heidegger's depiction of these existential moods will be interwoven throughout the participants' accounts. This holistic approach of interweaving data (results) with discussion is fitting and appropriate for the hermeneutical phenomenological philosophy embedded in this study. This article suggests that the existential perspective of the participants' experiences of distress provides an alternative perspective to the predominantly psychological interpretation of the individual's experience described in existing literature (Abdel-Kader et al., 2009; Bhatti et al., 2014; Gottdiener, 2011; Kimmel & Peterson, 2006; Palmer et al., 2013).

Theme 1: Being Anxious

Several participants in the study thought they would receive a kidney transplant within a specific duration of time, and this would enable them to return to a normal life. This understanding encouraged them to remain hopeful and focus on clock time while they waited for a kidney transplant. However, when they went beyond the estimated waiting time for a transplant, they experienced uncertainty and anxiety. They began to realize that the timeline to recovery was uncertain, and there was potentially no endpoint to the illness trajectory of kidney failure. Consequently, they were no longer able to focus on clock time and became increasingly anxious about their aspirations and possibilities for the future.

For instance, a female participant described her anxiety about the future while she waited for a kidney transplant. This participant had previously received a kidney transplant from a family member, which had functioned well for many years. She had now returned to dialysis and was waiting for her second kidney transplant.

> *I'm so long waiting now [for a transplant]. It just seems to get harder the longer you are on the transplant list… I feel I'm so long waiting; will I ever get another transplant? Will I get another transplant? It's just the waiting… I know I need dialysis, but I find it very difficult to come to terms with it.*

Similarly, a male participant highlighted his anxiety about the future as he waited for a kidney transplant.

> *Well, in the beginning, I was told that the average waiting list [for a transplant] was around 12 to 18 months, so when I started on dialysis, I had two years left out in my head for it all [dialysis] to be over…but I'm nearly two years on dialysis now, so you just don't know…it's waiting all the time…I was told that I wouldn't have to wait that long [for a transplant] because I was young, and I'm waiting nearly 19 months now.*

Heidegger (1962) claims that when the person predominantly concentrates on the seconds, minutes, and hours of clock time, the threefold structure of originary temporality, which forms its base, remains concealed. However, if for some reason the person is no longer able to focus on clock time, the threefold structure of originary temporality is revealed to him or her (Heidegger, 1962). When the threefold structure of originary temporality is revealed to the person, this creates the existential mood of anxiety (Heidegger, 1962, 1995).

According to Heidegger (1962, 1995), anxiety and boredom are fundamental existential moods because all the other moods the person experiences on a daily basis originate from them (Hoffman, 2005). Moreover, these two moods confront the person with the finitude of existence (Hoffman, 2005). The projection or forward movement of the originary future provides the projection for the entire threefold structure of originary temporality. However, because of the projective character of the originary future, death lies ahead of the person throughout existence (Mulhall, 2005). Indeed, as a result of our finite existence, Heidegger (1962) declared, "Dasein is dying as long as it exists" (p. 295). By uncovering the threefold structure of originary temporality, anxiety confronts the person with the finitude of existence. Thus, the experience of uncertainty or anxiety paradoxically illuminates the certainty of death to the person. This unpleasant awareness of death also culminates in the distressing moods the person experiences on a daily basis, such as sadness, depression, despair, frustration, and anger (Hoffman, 2005). It is suggested that participants' experiences correspond to Heidegger's (1962) description of anxiety. For example, the following female participant's account illustrated how living on hemodialysis caused her to feel anxious about her hopes and aspirations in the future.

> *I just worry a lot because you don't know how long you're going to be on it [dialysis]… I don't see any end to being on dialysis… I think I'm going to be on it for the future... I don't want to be on dialysis for the rest of my life… If I got a transplant, at least I'd have a break… There doesn't seem to be any break… You don't know whether there's any light at the end of the tunnel.*

The distressing moods that arise from experience of existential anxiety are also highlighted in participants' accounts. A male participant succinctly described these distressing moods. He had recently received a kidney transplant, which unfortunately failed within a few days. Consequently, he remained very anxious about his future life plans. Moreover, the distressing moods of frustration, anger, and despair were palpable throughout his account.

> *You get a transplant; it doesn't mean it's going to work… It may work for a while… They [healthcare team] tell you that there's no problems, you've got a 95% chance (of success)… It's not! I've seen people die on two occasions…a man got a transplant three days before me, and he kicked the bucket…a woman got a transplant the same day as me, and she wasn't very well. I don't know whether she survived it.*

From Heidegger's (1962) perspective, the person can overcome anxiety in two ways. First, by creating possibilities and aspirations for the future, the person can maintain the projective characteristics of the originary future. Second, by engaging in everyday activities, individuals are able to maintain the functional characteristics of the originary present. Either approach can serve to maintain the connection in the unified structure of originary temporality, and subsequently, enable the person to overcome existential anxiety. However, if the person is unable to overcome the experience of existential anxiety, the threefold structure of originary temporality will be suspended or disrupted. The suspension or disruption of originary temporality culminates in existential boredom.

Theme 2: Living in Limbo

Participants described how they were unable to focus on future goals and aspirations in life, while they waited on a long-term basis for a kidney transplant. Moreover, restrictions caused by the treatment regimen of dialysis meant they were unable to participate in the everyday activities they took for granted in the past. Thus, their narratives illustrated they were merely living in limbo while they endured life on hemodialysis. The experience of living in limbo was described as being held back from a normal life and forced to endure the repetitive regimen of hemodialysis.

For instance, the following male participant's account exemplifies how his inability to work contributed to this experience of living in limbo.

> *I think my life is on hold because I worked until just before I started dialysis, and there's days when I feel I could work now, and there's days when I know that I couldn't…so if I got a job, I know I wouldn't be able to keep it, and I'd be off all the time… If I was in work, my performance would be pretty poor, like falling asleep at your desk and that kind of thing. That's how I was before I gave up work.*

It is proposed that the participants' experiences of living in limbo mirrors Heidegger's (1995) depiction of existential boredom. Heidegger (1995) presents boredom as a fundamental existential mood. Like anxiety, boredom discloses the finitude of existence to the individual. In anxiety, the threefold structure of originary temporality is highlighted to the person, creating an uneasy awareness of death. However, in boredom, the threefold structure of originary temporality is suspended or disrupted, and the person is held in limbo by the suspension of originary temporality (Haar, 1999).

According to Heidegger, when we are held in limbo by the suspension of originary temporality, we are held back from our own possibilities in life, and subsequently, held back from our past and future (Haar, 1999). We are also held back from the normal, everyday activities we perform in the originary present (Haar, 1999). It is proposed that the experience of being held in limbo by the suspension of originary temporality was expressed in the participants' descriptions of "living in limbo." This is illustrated vividly in the following female participant's account.

You're always constantly aware of dialysis… You'd love to just pick up a brochure and go on holiday, but you can't... And you say to yourself, "Well, when I get the transplant, I'll be back to normal." You look at life as if it's on hold until you get a transplant…Your life is on hold because you're not doing what you want to do… I know I have to follow these rules, but it gets in the way of work; it gets in the way of a normal routine…it's like I'm bonded to it [dialysis]…I'm always walking around with it, and when you do get the transplant, it's like the shackles are gone.

When the person is held in limbo by the suspension of originary temporality, the originary present is characterized by inactivity. This empty present is the empty time of existential boredom, and it merely culminates in a repetition of the same empty present over and over (Haar, 1999). Participants emphasized how their lives were dominated by the continuous demands of kidney failure and hemodialysis. These features of their accounts seemed to symbolize the empty time of existential boredom, advanced by Heidegger (1995). The following excerpt from a female participant succinctly describes how her life revolves around the repetitive treatment regimen of hemodialysis.

Every Tuesday, Thursday, Sunday for the past 23 months…I'm just planning to go to dialysis… I watch everything I eat, everything I drink… After getting the [kidney] transplant, I think I'd get my life back… I feel as if my life is on hold…it [life] wouldn't be on hold then. I could go out and have a drink; eat whatever I wanted. I'd go back to a normal life again.

Heidegger (1995) indicates that the suspension or disruption of originary temporality associated with existential boredom, confronts the person with the finitude of existence. This prompts the person to reconnect the threefold structure of originary temporality. However, if the person is unable to reconnect the unified structure of originary temporality in response to boredom, he or she will experience all the other distressing moods we are familiar with on a daily basis (e.g., sadness, low mood, frustration, and irritability). Moreover, if the person is unable to reconnect the threefold structure of originary temporality for a prolonged duration, these moods will intensify to a level of sheer hopelessness, depression, and despair. These distressing moods were interwoven throughout the participants' accounts of living in limbo. For instance, the anecdote from the following male participant illustrates the depression he experiences when he feels he is unable to cope with work.

It's [dialysis] just holding me back… At the moment, I don't feel able for it [work]… I start getting depressed when I'm trying to work, and at the end of it all, I have to come into hospital [for dialysis]…then I wake up the next day feeling worse. It's [dialysis] the only thing that can get me down; it wears me out and wears me out. I'm actually a bit depressed at the moment because the job I am working on went wrong yesterday.

Theme 3: Overcoming Distressing Moods

Some participants' accounts illustrated they had overcome the experience of living in limbo (i.e., existential boredom). These participants exemplified how the importance of having future life goals and aspirations was essential in this process. For instance, the following female participant emphasized how the hope of receiving a kidney transplant in the future enabled her to maintain a positive perspective, despite living on hemodialysis. This participant had previously received a kidney transplant, which eventually failed. However, she still looked forward to returning to the freedom of a normal life with a transplant in the future.

Well, I'm hoping that when I get a transplant, I'll be able to go out and work full time…because when I had the [first] transplant, I was working full time, and I could go on a holiday each year. You can just plan a holiday, so I'm hoping now that when I get another transplant that I'll get a full-time job, and I'll be able to go on holiday abroad whenever I want to, instead of having to work my life around dialysis.

Similarly, another female participant described how the prospect of receiving a kidney transplant in the future enabled her to maintain a positive outlook on life.

I'm on the transplant list, and I think that's what is keeping me positive. Otherwise, I think I would be very down. If I hadn't been told about a transplant I would feel there was no outlook for me... I think that's what keeping me going, I know there's light at the end of the road for me.

For other participants, the ability to re-engage in normal everyday activities, such as working and socializing, was extremely important in their ability to overcome the experience of living in limbo. For example, the following participant's narrative illustrates the lifestyle changes he made to increase his potential of returning to work in the future. This enabled him to overcome the experience of being held in limbo.

It's [life] not so much on hold now… I'm waiting for a transplant, but I'm thinking if I get a transplant, I might not be able to work in construction, so I'm looking to the future…maybe construction is not the best thing to be doing… I know something about computers, and I decided to do some exams and try and get a job at that… It's interesting…I like working with them… So now, I just want to do some more exams… If I'm looking for a job, I guess the more certificates you have, the better.

Correspondingly, another participant described his ability to overcome the experience of living in

limbo by planning goals in the future and re-engaging in work.

> *I had to get back into my life, get on with life, and get on with earning, and do as many normal things as I can… I plan ahead now, like I've planned Christmas. I'm going to take off at the weekend and just go shopping. I'm pretty much trying to get on with it [life] as best I can.*

It is proposed that by having life goals, possibilities, and aspirations for the future, participants were able to resume the projective and future-directed characteristics of the originary future. Moreover, by re-engaging in normal everyday activities, the functional capacity of the originary present was resumed. Consequently, this enabled the threefold structure of originary temporality to be reconnected for the participants. The reconnection of the threefold structure of originary temporality enabled the participants to overcome the experience of existential boredom (living in limbo) and anxiety. It subsequently allowed them to overcome the additional distressing moods culminating from these two fundamental existential moods.

Limitations

There are various limitations in this study. The qualitative methodology and purposive sampling strategy preclude generalization of the findings to the larger population of patients on hemodialysis. All participants in the study were of Irish nationality. Thus, their experiences may be uniquely different compared to patients from other countries. All participants in this study were attending outpatient hemodialysis in a hospital-based setting. There may be differences in the experiences of patients attending outpatient hemodialysis in the hospital setting as opposed to patients in outpatient hemodialysis centers located away from the hospital setting. Finally, data discussed in this article relate specifically to participants who were either on the transplant list or in the process of being assessed to get on the transplant list. Their experiences may be different to patients on outpatient hemodialysis who are unable to receive a transplant due to additional medical complications.

Conclusions

This article highlighted that distressing existential moods may be an important feature of the person's experience of kidney failure and outpatient hemodialysis therapy. The perspective of existential moods, illustrated in participants' accounts, mirrored the description of existential moods depicted by Heidegger (1962, 1995). The international research describes anxiety and depression as the most prevalent psychological responses in patients with kidney failure on hemodialysis and peritoneal dialysis. The majority of this research tends to describe anxiety and depression as emotional or psychological responses (Abdel-Kader et al., 2009; Bhatti et al., 2014; Palmer et al., 2013). It is proposed that the description of existential moods exemplified in this article provides a new interpretation of the distress experienced by patients with kidney failure on outpatient hemodialysis therapy.

It is anticipated that this interpretation will contribute to the predominantly psychological perspective of emotional distress advanced in the existing research. Further, findings of this study support the existing research, which suggests that the complications of kidney failure and hemodialysis may confront the person with their own mortality, culminating in distress (Johnston & Noble, 2012; Molzahn et al., 2012; Schick-Makaroff et al., 2013). This article contributes to this research by specifically identifying two fundamental existential moods experienced by patients on outpatient hemodialysis therapy.

Implications for Nursing Practice

There are various recommendations for nephrology nursing practice based on the perspective of existential mood provided in this article. It is important that these recommendations would enable patients to maintain the connection in the threefold structure of originary temporality and overcome the experience of existential moods.

For instance, there is a need to educate nurses on existential moods and their distressing impact on patients. There is also an emphasis on nurses assisting and encouraging patients to create new realistic and achievable life goals despite the restrictions of kidney failure. It is essential that nurses incorporate patients' families and significant others to be active participants in the patient's care. This would ensure the patient receives the necessary support to formulate and achieve these new life goals.

There is a need to encourage and facilitate patients on outpatient hemodialysis to continue to engage in their everyday activities, such as working, socializing, travelling, and hobbies. In particular, there is a need to facilitate treatment times that suit their life schedules. This would ensure these individuals are able to integrate dialysis therapy around their normal daily routine.

There is also a need to offer patients other modalities of dialysis that fit more appropriately around their life schedules. There is current focus on home dialysis therapies due to favorable economic outcomes and patient benefits, yet the use of these therapies remains underused (Harwood et al., 2012; Jiwakanon, Chiu, Kalantar-Zadeh, & Mehrotra, 2010). It is proposed that there is a need for improvements in patient education, specifically at the advanced stages of chronic kidney disease in relation to home dialysis therapies. This would empower more patients to select these treatment modalities and enhance their ability to fit their dialysis treatments more seamlessly around their life schedules.

Many outpatient hemodialysis centers in Ireland do not have designated healthcare personnel to attend to the psychological and existential

distress experienced by patients. There is an urgent need to incorporate specialist counselors to attend to the distress experienced by patients on outpatient hemodialysis therapy in all settings. These counselors might assist patients to develop strategies to cope with the distressing moods outlined in this article. Further, they would facilitate patients to create future life goals while living with kidney failure.

Mindfulness-based meditation techniques might enable patients with kidney failure to become more comfortable and relaxed while living in the present moment. According to Kabat-Zinn (1991), we spend much of our time absorbed in doing, striving, planning, reacting, and busyness. However, the practice of mindfulness-based meditation enables us to stop and feel where we are right now (Kabat-Zinn, 1991). It is further proposed that by enabling the person to focus on the "now" or present dimension of clock time, mindfulness would assist patients to overcome the distressing existential moods depicted in this article.

Heidegger (1962) asserts that it is the suspension or disruption of originary temporality that culminates in the distressing moods experienced by the person. However, he emphasizes that when we focus on the "now" of clock or ordinary time, the threefold structure of originary temporality, which forms its basis, remains concealed or covered up. Hence, it is proposed that by encouraging patients to focus on the "now" or the present tense of ordinary time, mindfulness-based meditation may indeed be an effective way to relieve the distressing existential moods, as illustrated in this article.

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Nephrology Nursing Journal

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ORIGINAL ARTICLE

Life in standby: hemodialysis patients' experiences of waiting for kidney transplantation

Pia Yngman-Uhlin, Annika Fogelberg and Fredrik Uhlin

Aim and objectives. Our aim was to explore the experiences of hemodialysis patients who are waiting for a kidney transplant.

Background. Currently, more than 100,000 persons are waiting for kidney transplantation in the United States. In Sweden, the number is exceeding 600. The waiting period for a deceased donor can be one to three years or even longer in Sweden. This can be challenging, since the patients' situation, with chronic treatment and illness, is burdensome and requires advanced self-care.

Design. This study included a purposeful sample of eight patients (33–53 years old) who had been undergoing hemodialysis treatment for at least six months and were waiting for kidney transplantation.

Methods. The patients were interviewed, and descriptive content analysis was performed.

Results. Four categories emerged: (1) 'The waiting process,' what thoughts and expectations occur and what to do and how to be prepared for the transplant. (2) 'Awareness that time is running out,' patients felt tied up by treatment and by needing to be available for transplantation, and they had concerns about health. (3) 'Need for communication,' patients described needing support from others and continuous information from the staff. (4) 'Having relief and hope for the future,' patients described how to preserve the hope of being able to participate fully in life once again.

Conclusions. This study reveals the need for extra attention paid to patients waiting for kidney transplantation. Patients' experiences during the waiting period indicate that pretransplant patients have an increased need to be prepared for the transition and for life post-transplantation.

Relevance to clinical practice. Dialysis patients on waiting lists must be prepared for the upcoming life change. This includes preserving hope during the waiting period and being mentally prepared for transplantation and a dialysis-free life. A pretransplant education program to prevent medical and psychosocial issues is highly recommended.

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

- This study demonstrates that dialysis patients have increased need for supportive care while waiting for a kidney transplant.
- The study emphasises the role of caregivers to prepare dialysis patients on the waiting lists for the upcoming life change.

Authors: *Pia Yngman-Uhlin*, PhD, RN, Senior Lecturer, Research and Development Unit in Local Health, Linköping University and Department of Medicine and Health Sciences, Linköping University, Linköping; *Annika Fogelberg*, BSc, RN, Department of Nephrology, Linköping University and Department of Medicine and Health Sciences, Linköping University, Linköping; *Fredrik Uhlin*, PhD, RN, University Nurse, Senior Researcher, Department of Nephrology, Department of Medicine and Health Sciences, Linköping University, Linköping, Sweden and Department of Biomedical Engineering, Technomedicum, Tallinn University of Technology, Tallinn, Estonia

Correspondence: Pia Yngman-Uhlin, Senior Lecturer, Department of R&D Unit in local Health Care, Region Östergötland, S:t Larsgatan 9D, 58185 Linköping, Sweden. Telephone: +46 101038503.
E-mail: pia.yngman.uhlin@regionostergotland.se

Key words: content analysis, end-stage renal disease, hemodialysis, kidney transplantation, nursing care

Accepted for publication: 18 July 2015

Introduction

Since the breakthrough of immunosuppressive therapy in 1962, renal transplantation has been dramatically successful over the past 40 years. More than, 100,000 individuals are waiting for a renal transplant in the United States (Organ Procurement and Transplantation Network 2015). In Sweden, approximately 608 patients are listed (The Council for Organ and Tissue Donation 2014). There is a disparity between the number of patients listed for renal transplantation and the access to organs. Nevertheless, the number of transplants has increased in Sweden during the last decade, from 345 in 2003 to 421 in 2013 (The Council for Organ and Tissue Donation 2014).

Background

For patients in end-stage renal disease (ESRD), dialysis treatment is often the only option during the waiting time for a deceased donor, a period that can last one to three years or even longer in Sweden (SNR). The waiting period can be excessive, since the circumstances, with dialysis treatment and general uremic symptoms of ESRD, are often burdensome (Donciu *et al.* 2013) and require advanced self-care skills from the patients. Despite dialysis, some uremic intoxication can remain, and it entails all organ systems, causing a multitude of uremic symptoms (Murtagh *et al.* 2007), such as fatigue, sleeping problems (Yngman-Uhlin & Edell-Gustafsson 2006), pruritus, nausea and restless legs (Murtagh *et al.* 2007). In addition, dialysis patients have to adhere to food and fluid restrictions and often must cope with extensive drug lists. Several symptoms may be experienced simultaneously by the patient, and the experiences are multiplicative rather than additive (Lenz *et al.* 1997). An increase in anxiety and depression before the kidney transplant, followed by a marked decrease afterwards, has been described previously (Corruble *et al.* 2010).

The change experienced by hemodialysis patients during the time spent waiting for transplantation has been described as feelings of living in hope. The waiting time was also described as a period of uncertainty, during which patients are unable to consider opportunities in the future. The restrictions that occur during dialysis treatment are experienced by patients as feelings of 'being on hold' (Moran *et al.* 2011). Other studies have described decreased Health-Related Quality of Life (HRQoL) scores in dialysis patients during the waiting period (Donciu *et al.* 2013), while transplanted patients were shown to have increased HRQoL (Landreneau *et al.* 2010). Although transplantation is generally a positive treatment, the effects of the waiting period prior to transplantation require further investigation. Few studies have described the experience of waiting for a kidney, both from the health care perspective, but especially from the patient's perspective. To provide patients with the appropriate level of support necessitates greater knowledge of patients' experiences and needs during the waiting process. Therefore, this study aimed to further explore hemodialysis patients' experiences during the waiting period before kidney transplantation.

Methods

Participants

A purposeful sample of adult patients in hemodialysis treatment was chosen. Inclusion criteria were hemodialysis for at least six months with experiences of waiting for kidney transplantation during that time. These criteria included both patients on the waiting list and patients with rejected organs (Table 1). Exclusion criteria were patients transplanted for more than 10 years and patients unable to communicate in Swedish. Ten patients from a university hospital in southeast Sweden were invited by the nurse in charge to participate. These patients received written information about the study and contact information for the first author. Two patients declined participation; in total, eight patients, seven men and one woman, were included in the study.

Data collection

All interviews were performed by the second author in a quiet room at the clinic and lasted between 25 and 40 minutes. Data were collected between January and March 2013. The interview started with one opened-ended question: 'Can you describe what it is like to wait for a kidney transplant?' To make the interview more in depth and to

Table 1 Characteristics of the informants

No.	Gender	Age (years)	Months in dialysis	Months on waiting list	Transplantation status	Employment
1	Male	33	12	7	Waiting	Part time
2	Male	38	132	36	Waiting	Sick leave
3	Male	46	32	25	Transplanted	Full time
4	Male	53	16	12	Transplanted/Waiting	Sick leave
5	Male	37	60	36	Waiting	Sick leave
6	Male	52	48	48	Waiting	Full time
7	Female	47	24	72	Transplanted/Waiting	Sick leave
8	Male	35	32	42	Transplanted	Sick leave

solicit more data, follow-up and clarification questions were asked, such as 'Could you tell me more about?' At the end of the interview, additional questions were asked about patient characteristics. The audiotaped interviews were verbally transcribed by the second author.

Data analysis

Transcripts were analysed by means of the descriptive content analysis method described by Burnard (1991); this method comprises a system of categorisation and coding of data. Data were read and reread by the authors to ensure that they were understood. The authors meet several times until agreement about the findings was reached. During the discussions, subcategories and categories appeared that described the experience of waiting for a kidney transplant. Throughout the process, the authors avoided theoretical influences, maintained openness to the data, and allowed new aspects of the experience of waiting for a kidney transplant to emerge.

Ethical considerations

Written informed consent was obtained from all participants, and the ethical principles of the Helsinki Declaration (WMA 2013) were followed. The study was approved by the regional ethical review board (no. M153-07).

Results

From the analysis, four categories and eight subcategories emerged (Table 2). The subcategories are exemplified by quotes from the patients.

The waiting process

The informants described different ways of handling the waiting.

Table 2 Characteristics of the informants

Subcategories	Categories
Finding an approach to waiting	The waiting process
Being prepared	
Feeling tied up	Awareness that time is running out
Concerns about health	
Support from others	Need for communication
Being continuously informed	
Preserving hope	Having relief and hope for the future
Being able to work again	

Finding an approach to waiting

The informants described the waiting time as stressful and tiring; they lived with uncertainty about the future, which meant that they lost patience. They also described the dialysis treatment as tiring. Trying to focus on when dialysis treatment might end could make the waiting less tiring. Informants who had been informed about an approximate waiting time were disappointed when the time became longer, sometimes as long as one to two more years of waiting:

> I'm pretty tired of it, you know. They said right at the start of course—they said between 3 and 4 years. So that's what I've been expecting, but now it's getting to be longer than that, and now when I call they say 4–5 years. (Informant 6)

Dialysis treatment during the waiting period became a routine and was considered to be a task that facilitated the waiting. Another way of waiting was to 'stop' waiting. The informants tried to turn off their feelings and not think about the long waiting time; they took one day at a time, since they could not force the process.

The informants also described the process of waiting as becoming harder after a while. To see other patients undergoing transplantation was stressful, and suspicious thoughts arose as to how the transplantation selections were made.

They also described their conflicted emotions when they read about accidents in the newspaper. They felt a little bit of hope, while at the same time they felt sorry for the victims.

Being in a constant state of preparedness

Those informants who had undergone transplantation previously and had had side effects from the medical treatment for the graft found the waiting time to a helpful intermission in which to get ready for the next transplantation. Other informants prepared by packing a bag to be ready when the day of transplantation came. They also described that they were exercising regularly to be in good physical shape for the surgery. The informants also expressed they were in a 24-hour state of preparedness, and that they were aware of the possibility of a phone call. Their hope was awakened when there was an unknown number on the display. They described that they always had a charged cellphone at hand. If they involuntarily left the cellphone at home, they were under stress and worried about the waiting time being extended:

> You have to remember to always have your cell with you and keep it fully charged—that's how I think. (Informant 4)

Awareness that time is running out

Health problems during the period of waiting tied up the informants, and they described how they faced practical problems and adversities.

Feeling tied up

Informant described feeling tied up by dialysis treatment, especially if they had earlier had peritoneal dialysis or a renal graft. The machine tied them up, and they felt immobilised during the treatment. The also expressed difficulties with travel, and it was time consuming to plan for a vacation a long time ahead. This was also a hindrance for the family. Even weekends with friends were hard to plan. Those who had experience with home dialysis treatment expressed that they preferred this option:

> Going for dialysis isn't the most fun thing to do by any means. It takes a lot of time, and it's a real pain to always have to budget your time—"Can we do something tomorrow?" "When am I going to go to dialysis then?" It's that kind of thing, plus that I can't just take off and be away for a couple of nights—can't do that. (Informant 5)

Concerns about health

Some patients described concerns about complications that could arise and temporarily remove them from the waiting list; this was described as very stressful. On the other hand, other patients just accepted it since there was a clear reason. Other concerns they described were complications that could delay their transplantation, such as increased antibodies. The informants also expressed a feeling of being passed over when other patients were transplanted before themselves, especially if they were from further down the waiting list. There were also patients who described no fear regarding transplantation surgery; they trusted the physicians and did not worry at all:

> I know I was in some kind of machine at the hospital to get rid of all of these antibodies, but they'd never seen a case like me before, and the antibodies are supposed to all disappear, but I just kept producing more and more, and got even more antibodies while I was in that machine. (Informant 7)

Anxiety and worries about kidney function after transplantation were described by the informants. Those who had been transplanted earlier worried about a rejection and being forced into dialysis treatment again. They were also anxious about side effects from the medical treatment, such as increased susceptibility to infections and malignancies. The informants mentioned worries about health during the waiting period, as dialysis treatment was wearying. They had anxiety about whether they would live long enough to undergo transplantation. Their health was also affected by dialysis treatment; for example, they had to restrict fluid intake and had decreased sleep quality and increased tiredness. In addition, they experienced problems with pain related to the dialysis needles. Another problem that was described was a difficult economic situation caused by sick leave or unemployment. The limited economic resources were limiting their life and their activities:

> It was made clear to you when you started that for the body, undergoing dialysis treatment is like running a marathon. (Informant 3)

Need for communication

During the waiting period, support and information were important.

Support from others

The informants described that support came mainly from family members and friends; it came mostly from their partner, but also from parents, siblings and workmates. The support comprised listening to patients' concerns and worries about transplantation and the difficulties they experienced during the waiting time. Informants who had not

used support from others felt confident in knowing that they would be able to get support from others if needed:

Yeah, well I have my family of course, I didn't really need them for this. (Informant 4)

The support patients received from health care personnel was mostly related to practical concerns and dialysis issues, such as organising transport and taking blood specimens for the transplantation unit. However, health care personnel could also obtain information from the transplantation unit for the patients. The patients described that it was difficult to talk about emotional issues, since there were always other patients in the same room. The informants emphasised the importance of health care personnel being available and being good listeners. They also stated that they did not want to burden personnel with their worries. If the informants lived alone, the personnel might be closer and meet the patient more often than family and were therefore an important source of support:

So you never feel alone I never did—but I mean it was...you felt...when you arrived you were made to feel welcome, and that is extremely important, because this stuff is pretty traumatic. (Informant 8)

Being continuously informed

Informants described that being continually informed by the physician and surgeon reduced their anxiety about transplantation. They expressed frustration about silence from the transplantation unit and the lack of information regarding how long they had to wait and how patients were given priority. The patients also searched for information about national transplantation outcomes on the Internet by themselves, and this made them feel secure about the success rate:

Yes, but if you know why it's being done, you don't worry. I get information from my doctor all the time about all kinds of things. (Informant 4)

Having relief and hope for the future

Thinking of the future could preserve patients' hope of having a normal life and working again.

Preserving hope

At the same time that informants described a feeling of hopefulness, they also expressed an extinguishment of hope. The hope for a kidney transplant diminished the longer they had been waiting. They doubted that it would ever be their turn. On the other hand, they felt happy for patients at the dialysis unit who had been transplanted, which gave them hope. A common blood type gave them hope, as well as having been accepted for transplantation. They also expressed that they said to themselves to never lose hope. A long waiting time was exhausting, and hope failed and hope disappeared. They described it as though the bag they had prepared was now unpacked:

Yes, if you see what I mean when I say you mustn't give up hope. (Informant 8)

Being able to work again

The informants expressed that when it was not possible to work due to the dialysis treatment, the desire to work became stronger. They explained that it was valuable to preserve the hope of being able to work again. They longed for the transplant and for a time when they could feel normal again. Transplantation was seen as the ticket to a normal life:

Yes, I want to go back to work after the transplant. I had a job before I got sick and put on furlough. (Informant 5)

Discussion

This study shows that patients in hemodialysis treatment who are waiting for a renal transplant experience uncertainty and are affected both physically and psychologically. This was illuminated in the following four categories: the waiting process, awareness that time is running out, need for communication, and having relief and hope for the future. Our findings indicate that these patients need more support during the pretransplantation period to feel prepared.

One way of waiting was to take each day as it came and to live for the day. This has previously been stated by patients in dialysis treatment, who also tried to have positive thinking (Polaschek 2003). In our study, the informants described the waiting process as a period of uncertainty and a period of shifting from readiness to sometimes resignation; the waiting became more difficult as time passed. The waiting time and the uncertainty regarding how long one needs to wait have been presented as the toughest parts of the waiting process, especially in younger patients aged 30–45 years (Herlin & Wann-Hansson 2010). Another study also found increased anxiety during the waiting time (Corruble *et al.* 2010). In this study, the patients were urgently aware of the need to always be available by phone. This availability has previously been described as

'being on hold' (Moran *et al.* 2011). It entails restrictions and limitations on the patients' lives caused by the dialysis treatment and the need to be available. In this study, the patients further described limited freedom and difficulty traveling even on shorter trips; this finding is supported by earlier studies (Moran *et al.* 2011).

Our findings further show that patients in dialysis treatment felt tied up and immobilised. This lack of freedom has previously been described as a dependency that patients try to adapt to without having any other choice (Schipper *et al.* 2013). Furthermore, the patients in our study described the worry of diminished health status or even the risk of dying during the waiting period. This is a significant stress, and it has been described by patients waiting for a liver transplant (Bjork & Naden 2008). In this study, the process of waiting was described as becoming more tiring and difficult after a while, and patients became impatient and stressed. Hope also weakened over time. This could lead to a vicious circle when patients' health status adopted downward trends. This has previously been described as a transformation from hope to a feeling of uncertainty (Moran *et al.* 2011). This knowledge is of importance with respect to meeting patients' needs during the sometimes long process of waiting.

The patients further described that support from others was expected to be from someone who could listen to worries and concerns about the forthcoming transplant, but patients stated that they had difficulty bringing up emotional issues when there was no privacy at the dialysis unit. This is a serious problem, since results from a previous study show that pretransplant patients experience various emotions like hope, anger, jealousy and doubt (Schipper *et al.* 2013). Some patients in this study described no need for information from professionals. Based on these findings, we recommend that healthcare professionals be more proactive; that is, they should pay attention even to those patients who do not express concerns or need for support. The necessity of informing patients about their transplantation issues is evident; nevertheless, a recent publication stated that patients sometimes did not know that they were on the transplantation list or that they had been removed from it (Hinton *et al.* 2011).

In this study, the informants described how they tried to preserve hope. Hope for a normal life with a graft can turn into profound despair if a rejection occurs. In a longitudinal case study, the author concluded that recipients felt inadequately prepared for graft failure (Gill & Lowes 2009). The present study indicates that patients need to be carefully prepared for an eventual rejection or for other complications during the pretransplant period.

To describe human experiences, qualitative methods are required. Strengths of this study are the faithful application of Bernard's content analysis method (Burnard 1991) and the authors' cooperation during the analysis process. A limitation is that only one woman participated. Nevertheless, the number of participants is not the priority in qualitative studies, and in this study both men and women was represented. Despite the low number of participants, the amount of data was satisfactory and qualitatively rich.

Relevance to clinical practice

Guidelines for renal transplantation mostly focus on medical concerns (Transplant working group 2009, Guideline development group 2013). This also applies to the guidelines from the Swedish Kidney Association (Swedish Kidney Association 2006). The guidelines state that all pretransplant patients must receive detailed information about estimated waiting time, the transplantation procedure, and complications due to immunosuppressive treatment. They also state that in case of a graft loss, patients should be offered psychological support. For several years, it has been known that patients on dialysis before transplantation are more physically and psychologically affected compared to patients preempted to transplantation (Starzomski & Hilton 2000). The health care system should take extended responsibility for pretransplant patients in dialysis who need to be prepared for the life changes that renal transplantations entail (King *et al.* 2006). This includes being mentally prepared for a dialysis-free life and for returning to a more normal life without dialysis treatment and with reduced self-care responsibilities. It also means that patients need to be prepared for the ups and downs and complications that can arise. Even though renal transplantation has a markedly positive outcome with respect to physical conditions and patients have decreased self-care demands compared to patients in dialysis treatment, a renal transplant is a life-altering experience. The expectations of patients have been described as being too high and one sided; this is attributed to positive messages from the media and also from health care personnel (Schipper *et al.* 2013). Support in the transition from being a waiting pretransplant patient in dialysis to being a post-transplant patient is lacking. This area requires more attention, particularly since a recently published longitudinal study showed associations between early post-transplant HRQoL plus kidney function and long-term patient outcome. Future research should address outcomes associated with pretransplant education. A pretransplant education program to prevent medical and psychosocial issues that could affect patients' post-transplant status is highly recommended.

Conclusion

This study reveals the need for increased attention to patients waiting for kidney transplantation while receiving hemodialysis treatment. The experiences of waiting, which were described as a waiting process, awareness that time is running out, need for a conversation partner, and finding relief and hope for the future, indicate that pretransplant patients have an increased need to be prepared for the transition and for life post-transplantation.

Contributions

Study design: AF, PY-U; data collection: AF; data analysis: AF, FU, PY-U and manuscript preparation: AF, FU, PY-U.

Conflicts of interest

We hereby declare that no financial or other conflicts of interest exist.

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Received: 24 August 2018 | Revised: 11 October 2018 | Accepted: 9 November 2018

DOI: 10.1002/nop2.225

RESEARCH ARTICLE

WILEY NursingOpen Open Access

Balancing everyday life—Patients' experiences before, during and four months after kidney transplantation

Charlotte Nielsen[1,2,3] | Jane Clemensen[2,3,4] | Claus Bistrup[1,2] | Hanne Agerskov[1,2]

[1]Department of Nephrology, Odense University Hospital, Odense, Denmark

[2]Department of Clinical Research, University of Southern Denmark, Odense, Denmark

[3]Centre for Innovative Medical Technology, Odense University Hospital, Odense, Denmark

[4]HCA Research, Hans Christian Andersen Children's Hospital, Odense University Hospital, Odense, Denmark

Correspondence
Charlotte Nielsen, Department of Nephrology, Odense University Hospital, Odense, Denmark.
Email: charlotte.nielsen@rsyd.dk

Funding information
EWII, The Danish Kidney Association, Region of Southern Denmark and Danish Council of Nurses, Odense University Hospital

Abstract

Aim: To explore patients' experiences before, during and four months after kidney transplantation as a coherent process.

Design: A qualitative explorative study with a phenomenological-hermeneutic approach.

Methods: Participant observations and semi-structured interviews were used complementary. In total, 18 kidney recipients were included. Data were analysed in accordance with Ricoeur's theory of interpretation, on three levels: naïve reading, structural analysis and critical interpretation and discussion.

Results: Three themes emerged: waiting time and hope during everyday life, transformation during the kidney transplantation process and towards a new everyday life with positive prospects. Going through the kidney transplantation process was challenging for the patients. Everyday life was affected through the process, and the patients had to balance the associated challenges like hope, positive prospects and health-related issues.

KEYWORDS
kidney, nurses, nursing, renal, transplantation

1 | INTRODUCTION

This paper presents patients' experiences during the period from approval for kidney transplantation to four months after transplantation. The knowledge gained provides a deeper understanding of transplantation as a coherent process from a patient perspective, which is significant to the improvement of treatment and nursing care during the process.

Kidney transplantation is, when possible, the treatment of choice for patients with end-stage renal disease because of its survival benefit, higher quality of life, less medication and fewer restrictions in everyday life—compared with dialysis (Landreneau, Lee, & Landreneau, 2010; Oniscu, Brown, & Forsythe, 2005). Kidney transplantation is a significant milestone; however, everyday life may be affected, because transplantation involves continuous close contact with the healthcare system. Furthermore, being a kidney recipient implies daily routines, such as self-monitoring, medical adherence, careful hygiene and sufficient fluid intake. A total of 543 individuals were enlisted for kidney transplantation and 257 were transplanted among these 165 with a kidney from a deceased donor in Denmark in 2017 (Scandiatransplant, 2018).

2 | BACKGROUND

Patients hoped for a normal life after transplantation and had only positive expectations despite of not knowing what a kidney transplantation implied; however, the focus was specifically on recipients' experiences of a challenging decision-making and the relationship to the living donor in a literature review of patient experiences in the

period before living donor kidney transplantation (Croft & Maddison, 2017). Studies of the time before transplantation are often aimed at patients waiting for a kidney from a deceased donor. Experiences during this period were characterized as an uncertain and confusing time with thoughts of the deceased donor. Furthermore, hope and expectations of a future free from dialysis treatment were present (Burns, Fernandez, & Stephens, 2017; Chong et al., 2016; Croft & Maddison, 2017; Spiers & Smith, 2016; Tong et al., 2015). Another perspective was how waiting time was used to prepare patients for the upcoming transplantation (Jones et al., 2016; Rodrigue, Mandelbrot, & Pavlakis, 2011; Sieverdes et al., 2015).

Postoperative discomfort such as pain and nausea was showed in a study of the first postoperative days among patients with a living donor; however, the main theme related to the relationship with the living donor (Bertelsen et al., 2015). Barriers towards learning caused by emotional reaction, side effects from medication and the physical changes were identified among kidney recipients in the period from the transplantation until six weeks after. An individual approach was desirable, to tailor information and develop individual everyday competences (Urstad et al., 2012; Wiederhold, Langer, & Landenberger, 2011).

Patients' experiences after transplantation are well described, with a time range from six months until many years after. A need to improve self-management and patient education has been identified to support stability in everyday life with the obligations of being a kidney recipient. One area of focus is the patient perspective on self-management and education, to improve transplantation outcome and stability in everyday life. (Grijpma et al., 2016; Jaieson et al., 2016; Rosaasen et al., 2017; Schmid-Mohler et al., 2014).

In summary, the systematic literature search identified patients' perspective of kidney transplantation on specific stages of the transplantation process and selected topics, such as education or adherence have been covered. There is a lack of studies investigating patients' experiences of going through transplantation as a coherent process. Therefore, to close the knowledge gap, patients' experiences of what is significant during the process could provide valuable new knowledge for improving quality of treatment and nursing care to meet the patients' specific needs.

2.1 | Research question

How do the patients experience the process before, during and four months after kidney transplantation?

3 | METHODS

The study was a qualitative explorative study of the patients' experiences during the transplantation process. The approach applied was phenomenological-hermeneutic inspired by Ricoeur's theory of narrative and interpretation. Ricoeur combines phenomenology with a critical hermeneutic philosophy, which makes it possible to reach a new understanding through critical interpretation (Pedersen, 1999/2005; Ricœur, 1976). Semi-structured interviews (Kvale & Brinkmann, 2014) and participant observations (Spradley, 1980) were performed. Interviews are reflected experiences told by the participants to the researcher (Kvale & Brinkmann, 2014). Participant observations are data collected by researchers participation in practice where observations reveal specific information that the participants might not express in words, including informal interviews which contribute with the patients' perspectives to the observations (Spradley, 1980). The combination of the two methods provides a rich and valid data material to gain in-depth knowledge of the transplantation process.

3.1 | Setting

The study took place in one of three Danish kidney transplant centres, situated at a university hospital. The study included patients with living or deceased donors to achieve a rich data material. However, it was not the intention to compare the two groups. Approval for kidney transplantation included a consultation with a nephrologist after several clinical examinations and physical tests. Subsequently, patients were waiting for the approval of the donor or were referred to the waiting list. The patients were admitted acute or the day before the transplantation and hospitalized for approximately one week postoperatively. Afterwards, they came to the outpatient clinic for evaluation of their clinical condition and renal status. In the first four weeks, the patients attended the outpatient clinic twice a week. After the first month, the consultations became less frequent.

3.2 | Participants

Participants represented patients from three different stages of the kidney transplant process: Those accepted for transplantation, patients undergoing transplantation and at four months after transplantation. The participants were screened using purposeful sampling according to gender, type of donor and age. Inclusion criteria were as follows: patients waiting for or undergoing a kidney transplantation, patients who speak Danish. Exclusion criteria were as follows: patients under the age of 18 or lack of mental acuity. In total, 18 patients were included: six women and 12 men, with a mean age of 53 years (Range: 33–73). The participants characteristics are presented in Table 1.

Participants were included in participant observation or interviews. Among 15 patients invited, 12 accepted participation in participant observations. Three pre-transplant patients declined participation, because they found it difficult to talk about their situation. Among 21 patients invited, 11 participated in individual interviews. Due to lack of mental and physical resources, five patients waiting for a kidney and four patients from the early postoperative stage declined participation. Furthermore, one interview with a posttransplant patient was not completed due to patient withdraw. Five patients participated in both participant observations and interviews. The inclusion of participants is illustrated in Figure 1.

TABLE 1 Participants characteristics

Participant	Sex M: Male F: Female	Age Years	TX type L: Living D: Deceased	Participation O: Observation I: Interview	Stage B: Before D: During A: After
P1	M	57	L	O	B
P2	M	55	L	O	B
P3	M	33	L	O	B
P4	F	42	D	O	B
P5	M	49	D	I	B
P6	M	51	D	I	B
P7	F	67	D	I	B
				O	D
P8	M	42	L	O	D
P9	F	43	L	O	D
				I	A
				O	A
P10	M	68	D	O	D
P11	M	68	L	I	D
P12	M	61	D	I	D
P13	M	43	L	I	D
P14	F	39	L	I	D
P15	F	66	D	O	A
				I	A
P16	F	37	L	O	A
				I	A
P17	M	73	D	I	A
P18	M	57	D	O	A

3.3 | Data collection

Data were collected by the first author from April to November 2016. The first author is experienced in qualitative research and renal care, however, not involved in clinical work.

3.4 | Before transplantation

Participant observation was performed by following four participants, during a three-day clinical examination programme of evaluation for transplantation at the hospital. In addition, interviews were performed with three participants, allowing them to tell about their experiences of being on the waiting list. The interviews were planned to take place before their transplants; however, two participants received their transplant before the interview took place at the hospital.

3.5 | During the time close to transplantation

Four participants were followed with participant observation on the ward before and after the transplant operation and during the first outpatient consultations. In addition, four participants were interviewed about their experiences. The interviews took place in the homes of the participants or at the hospital, approximately five weeks posttransplantation.

3.6 | After transplantation

Finally, participant observation was conducted at the outpatient clinic with four participants approximately four months after the kidney transplantation. Subsequently, three of them were interviewed in their homes about the experiences they had following the transplantation. Because of patients' restitution and time limitations, data were collected four months posttransplantation.

Participant observation was conducted with inspiration from Spradley's nine domains, as a support to the structure and to help keep an open mind during the observations (Spradley, 1980). Field notes were taken during observations and transcribed immediately afterwards. Field notes contained the researcher's description of the observations and short quotations from informal interviews. In total, 150 hr of participant observation were conducted. All interviews were performed using a semi-structured interview guide with open-ended questions that provided the opportunity to let the participants narrate about their experiences, such as: "Please,

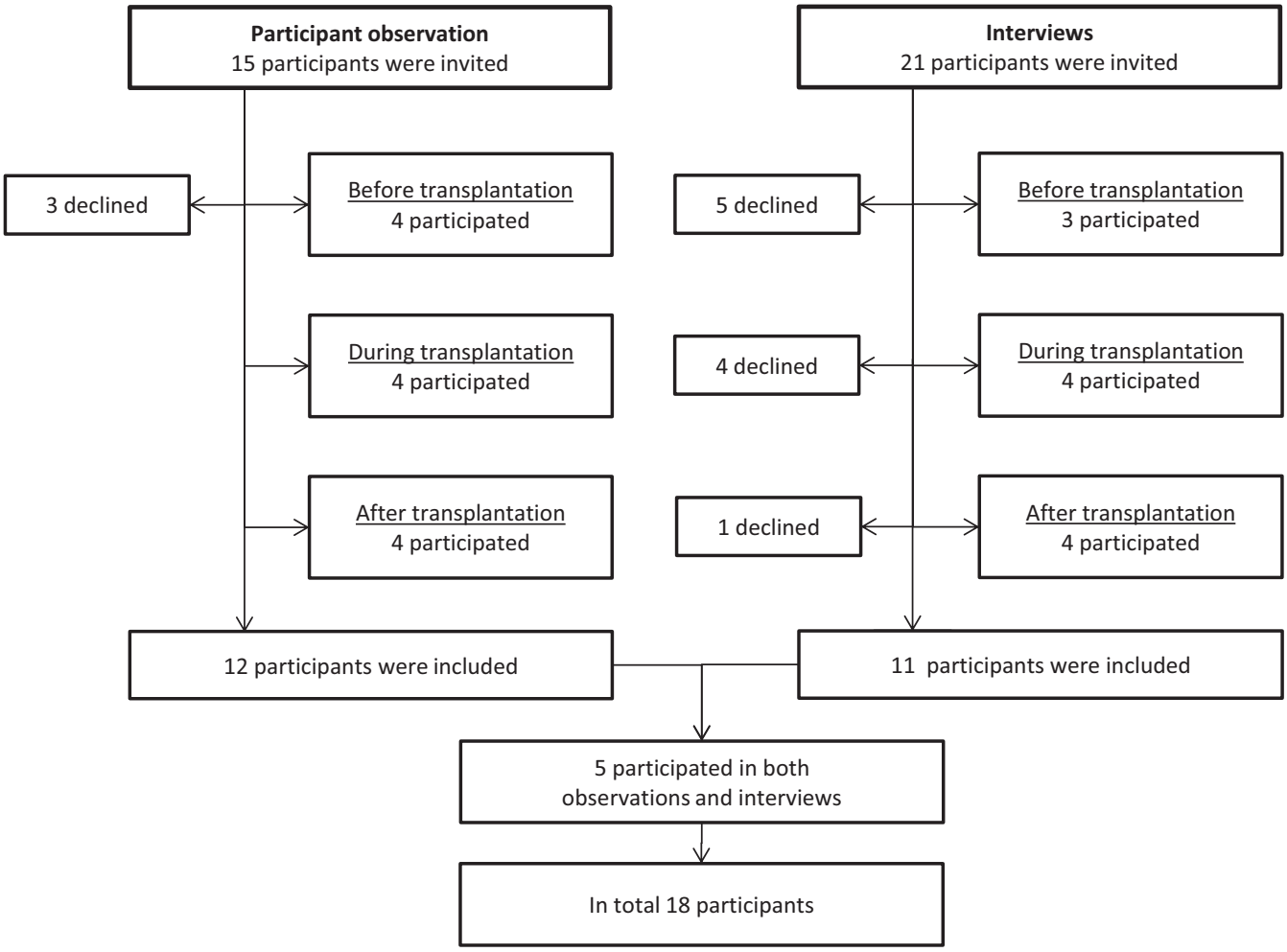

FIGURE 1 Inclusion of participants for participant observations and interviews

tell me about your experiences of the time close to your kidney transplantation." Literature and data from the participant observations were used to develop the interview guide. The interviews lasted 18–83 min and were recorded and transcribed verbatim by the first author. The findings were discussed by the entire research team.

3.7 | Data analysis

The field notes and the transcribed interview data were analysed as one coherent text. Inspired by Ricoeur's thoughts about narrative and interpretation, the analysis was conducted on three levels: naïve reading, structural analysis and critical interpretation and discussion (Pedersen, 1999/2005; Ricœur, 1976). The naïve reading is the first impression of the text, where the researcher reads the text with an open mind to "let the text speak" and the first impressions are obtained. In the structural analysis, there is a movement from the participants' quotations, that is, "what is said" to a first interpretation of "what the text is talking about." It is a dialectical process, in which themes will emerge and continuously be compared to the text and the impressions in the naïve reading to fulfil a deeper understanding and interpretation argued with the text itself (Pedersen, 1999/2005; Ricœur, 1976), as illustrated in Figure 2.

It is the beginning of a movement from an individual to a general level, which will further unfold in the final critical interpretation and discussion of the emerged themes. A significant approach is the distance to the text, which makes it possible for the researcher to work thoroughly with the text to get in-depth knowledge and achieve a new understanding of the investigated field (Dreyer & Pedersen, 2009). The approach inspired by Ricoeur does not include patient evaluation to validate the interpretation. According to Ricoeur, narration implies a process of reflection in the participants and leads to new perspectives into their lives, which make validation among the participants inappropriate (Ricœur, 1976).

3.8 | Ethical considerations

The participants were informed orally and in writing about the study, in accordance with applicable ethical rules (Helsinki, 2018). Participants gave written informed consent. The study was approved

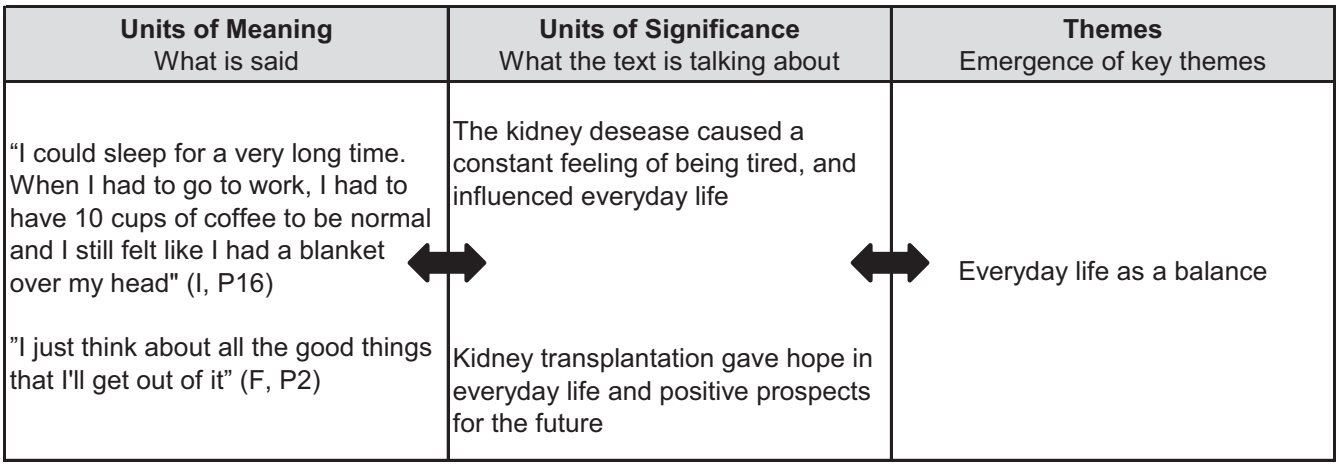

FIGURE 2 Illustration of structural analysis

by the Danish Data Protection Agency, journal number: 15/48886. Approval from The National Committee on Health Research Ethics was not required, in accordance with Danish law.

4 | RESULTS

The naïve reading revealed that the patients' everyday lives were affected in different ways through the transplantation process. It emerged that there were experiences of challenges, hope and gratitude during the process. Through the structural analysis, three themes emerged: waiting time and hope during everyday life, transformation during the kidney transplantation process and towards a new everyday life with positive prospects. Table 2 gives a presentation of themes and subthemes. The themes will be interpreted in the following section. (I) refers to interview, (F) refers to field note and (P) refers to the participant number.

TABLE 2 Themes and subthemes derived through the structural analysis

Theme	Subthemes
Before	
Waiting time and hope during everyday life	Everyday life as a balance Opposing reflections before transplantation
During	
Transformation during the kidney transplantation process	Dealing with being a patient at the hospital Balancing between recovery and ensuring that the kidney graft functions
After	
Towards a new everyday life with positive prospects	

4.1 | Waiting time and hope during everyday life

Before the kidney transplantation, the patients focused on everyday life, but there were also reflections on the future transplantation.

4.1.1 | Everyday life as a balance

Living with end-stage renal disease caused symptoms that affected everyday life, as one expressed:

> "I could sleep for a very long time. When I had to go to work, I had to have 10 cups of coffee to be normal and I still felt like I had a blanket over my head" (I, P16).

The experience was a constant feeling of being tired. It also had a mental influence. Hence, the kidney disease caused difficulty concentrating and need for rest during the day. The limited resources influenced the way roles and tasks could be managed in everyday life. Often, the patients' limited resources meant that they could not fulfil their own expectations. This could challenge family and working life, because resources had to be balanced. Nutrition, fluid and dialysis treatment could also cause restrictions to everyday life.

Restrictions in everyday life gave strength to the hope for kidney transplantation, as illustrated in this field note, with a quotation:

> The patient relates about what he considers he will get out of the transplantation; first and foremost, freedom to travel but also in his everyday life [...] "I just think about all the good things that I'll get out of it" (F, P2).

This expresses hopeful thoughts about having a kidney transplant. There was a focus on positive prospects and this could be a way to maintain hope in everyday life. The thoughts of transplantation were positive and optimistic and possible disadvantages

and complications were not addressed as an issue. Hence, everyday life implied balancing the kidney disease and the hope for transplantation.

4.1.2 | Opposing reflections before transplantation

The time before the transplantation was perceived variously, depending on the prospects of having to wait for a deceased or living donor. One patient with a living donor expressed:

> "I had known for a long time that I was going to have a transplant [...] from May [one year ago] I started to train really hard to be ready" (I, P13).

This illustrates how the time before transplantation was used as preparation, in the knowledge that there was a living donor. The prospect of a limited timeframe before transplantation resulted in self-preparation. This could be physical, that is, improving one's health; however, there was also mental preparation, alone or together with the donor, by sharing thoughts about the future transplantation.

In contrast, the situation seemed different when waiting for a deceased donor, as illustrated in this quotation:

> "You can't go round wondering about it every day, or else you can't live your life" (I, P17).

The waiting time for a kidney from a deceased donor was of unknown duration and it could last for years. The focus was on everyday life. Thus, the transplantation was placed in the background. Nevertheless, there was still a belief that the transplant would succeed one day:

> "Of course, it's going to be my turn at some point [...] I'm delighted every time someone gets a transplant" (I, P5).

Knowing about other patients' transplantations generated hope and there was a complete understanding of how the waiting list worked, that is, that it was based on finding the best match, rather than being operated on a first come first served principle. The time before the transplant revealed significant opposing experiences due to the type of donor and time perspective for transplantation. It involved either a focus on preparation or on maintaining everyday life. Nevertheless, this period was the only time when the patients' experiences were connected to the donor type.

4.2 | Transformation during the kidney transplantation process

The patients underwent a transformative process—from being in need of a kidney transplantation to managing everyday life as a kidney recipient.

4.2.1 | Dealing with being a patient at the hospital

The days after the transplant were challenged by postoperative symptoms, such as tiredness, pain and immobilization:

> "You lie in bed and sleep in the morning and wake up and eat something and then you sleep again and try to force yourself out of bed, but it's almost impossible to get up on your own, because it tightens up the wound" (I, P12).

Days merged together and there was only sufficient energy to fulfil one's most basic needs. Thus, physical challenges after transplantation dominated the early postoperative days.

It could be difficult to understand the expectations of patients at the hospital, as written in a field note with a quotation:

> The doctor asks if the patient has any questions: "No, if you're happy then I'm happy" (F, P9).

The postoperative circumstances and the fact that the daily routines and expectations were not made explicit created uncertainty about expectations of them which, meant that it was the healthcare professionals who had to take the initiative and assess the patient's situation. The non-transparent agenda and structure on the ward made it challenging to take part in daily routines.

During the course of admission, involvement in treatment and nursing care seemed to increase, as illustrated in a field note:

> The patient looks at his morning medicine and says: "I have to take a phosphate supplement" and picks up a copy of his blood test results and talks about his blood tests. The nurse looks at the observation notes and the patient says what his weight is, because he has weighed himself that morning (F, P8).

This shows how the daily routine on the ward was followed by observing the healthcare professionals' actions and behaviour. This facilitated motivation and initiative, as it became possible to take part in treatment and care. In contrast to the early postoperative days, the patients' energy and motivation increased and this allowed them to show more interest in education. New questions were raised, related to medicine, hygiene, nutrition, wound care etc. Thus, during the course of the admission, there was a transformation from a need for care and for expectations to be made explicit, to a need for support and patient education.

4.2.2 | Balancing between recovery and ensuring that the kidney graft functions

Going home was an opportunity to create a new everyday life after discharge and it also meant taking care of the kidney on one's own:

> "They all [the health professionals] say to ring, but I ring them only as a last resort" (F, P7).

Once home was followed by feelings of balancing increased responsibility for the kidney and the ability to assess one's own needs for support without troubling the healthcare professionals. The involvement in treatment and care had increased over the course of the admission; however, the responsibility was experienced as overwhelming once back at home on one's own. Being discharged was perceived as a milestone in the process:

> "You feel good to be at home and it helps me to be relaxed [...] to get my own structure and everyday life, I mean, you don't feel so good at the hospital" (I, P16).

Going home was experienced as a significant step, because recovery was best achieved at home. However, side effects after the kidney transplantation affected everyday life:

> The patient relates that she is very happy to be home, even though she is very tired and is in pain [...] she sleeps badly, because she has to get up to go to the toilet every two hours (F, P7).

Despite the fact that it was good to be at home, physical and psychological side effects challenged everyday life and the feeling of being vulnerable emerged. Practical and emotional support was needed to facilitate recovery. New ways had to be developed to structure everyday life, regarding medical adherence and self-monitoring. New habits were developed, for example, how to cope with nutrition, hygiene and medication. However, everyday life also involved positive changes:

> "I'm looking forward to running and riding and all those things that I love and of course there are also a lot of limitations, but it's really just about setting some conditions" (I, P14).

Everyday life was a balance between coping with health-related issues regarding being a kidney recipient and a new life with future possibilities. There was a need for being at home for recovery and adapting to new habits to be able to balance the everyday challenges and the new possibilities.

Conversely, there were also a need for contact to the healthcare system as the kidney graft functioning could fluctuate especially in the immediate posttransplant period. It affected everyday life, with worries about the new kidney and outpatient visits or admissions. Often, the need for kidney biopsy was discussed:

> "For five weeks I discussed it with them, I didn't want the biopsy, I was afraid because of the risk of bleeding [...] I was so scared" (I, P16).

The discussions about the kidney graft functioning and need for a kidney biopsy were stressful and resulted in vulnerability because of the possible complications and consequences. The intervention was described as a threat hanging over one's head. It involved being constantly on standby and ready to go to the hospital at any time, which compromised a relaxed recovery at home.

Consultations at the outpatient clinic were the connection between recovery at home and ensuring the kidney graft functioning. Appointments were taken seriously; however, patients perceived that it was the nephrologist who set the agenda. Various perspectives were expressed:

> "I think it's been great to find out about the blood test results and that they got better, that's been reassuring" (I, P11).

In contrast, another expressed:

> "If I'm required [to go in for a check-up], then I'll do it, [...] but when it's going as well as it is, then I think it's meaningless" (I, P11).

Thus, the outpatients visits provided confidence and ensured the kidney graft functioning. However, time spent on visits could be perceived as unnecessary if there were no health-related problems. There was a need to balance between monitor the function of the transplanted kidney in cooperation with the healthcare professional and at the same time a need to stay at home for recovery.

4.3 | Towards a new everyday life with positive prospects

Four months after discharge, everyday life began to be reestablished, as one expressed:

> "Now I have the structure, the times to take medicine, what I have to eat and I have to drink three litres, now I have structure over my things, so suddenly it has started to be a normal everyday life that, that's the way my life is" (I, P16).

A structure involving new routines, related to being a person with a kidney transplant, began to be a part of everyday life. However, tiredness was an ongoing issue, as one said:

> "I'm still trying to improve and I'm not finished with that, I still want it to be even better" (I, P9).

Everyday life improved after the transplantation; however, rehabilitation was not fully achieved. There continued to be an expectation of improved health. As the focus on everyday life increased, the need for frequent contact with the healthcare system decreased:

> "Sometimes they make adjustments to the pills and the doctor could do that here at the local hospital, if it came to that" (I, P17).

The participants' confidence and belief in their ability to take care of themselves increased, leading to outpatients consultations were of less significant to the participants.

Overall, looking back four months after the kidney transplantation process, it was experienced as positive and expressed as a metaphor:

> "Two months in hospital [because of complications] is nothing, because just think, I got my life back" (I, P16).

Going through the process was experienced as overwhelming and challenging; however, the outcome outweighed the challenges and provided the opportunity to live an everyday life with positive prospects due to improved health and new possibilities.

5 | DISCUSSION

The study showed how reestablishment of everyday life was significant and that a balance was achieved between hope, positive prospects and health-related challenges throughout the transplantation process. The challenges which the patients were balancing can according to Meleis et al. be explained as a multi-faceted and complex transition process (Meleis et al., 2000). Various types, patterns and properties of transition were represented during the transplantation process and in accordance with the theory the patients' challenges can be viewed as a balance between a healthy transition and vulnerability (Meleis et al., 2000).

Before transplantation, the kidney disease restricted everyday life; however, the prospect of a kidney transplant gave the patients hope. The patients with a living donor could prepare for the transplantation. Wait-listed patients focused on everyday life and maintaining belief that, the transplant would succeed at some point in the future. In accordance with Meleis et al., a transition is a movement over time, which can be experienced as an ongoing long-term transition similar to the patients' situation before transplantation (Meleis et al., 2000). Our findings are similar to others, where waiting for a kidney is described as becoming a normalized part of everyday life and how hope is generated when other patients in the dialysis community receive a transplant (Burns et al., 2017). Several studies exploring the period pre-transplantation focus on education whose aim is to help the patients to be prepared for their new situation (Jones et al., 2016; Rosaasen et al., 2017). Our study showed that wait-listed patients could not relate to ongoing education regarding the future transplant. They moved the possible future transplant into the background and focused on maintaining everyday life. Studies find that the challenge of being a wait-listed patient includes confusion, worries and constant uncertainty (Burns et al., 2017; Rosaasen et al., 2017; Spiers & Smith, 2016). In our study, wait-listed patients experienced the same challenges and were not in a mental condition to cope with education. Thus, it could be significant to support everyday life as wait-listed and facilitate hope, for example, knowing of others who received a transplant. In contrast, our study showed that patients with a living donor spent the time before the transplant on mental and practical preparation. It is mentioned how transplant from a living donor gives an opportunity for patient education (Crawford et al., 2017). We found how these patients were motivated for education related to the transplant process. To our knowledge, studies did not identify this specific need, however. This might be because the period before a transplant with a living donor is not defined as waiting time.

Going through a kidney transplantation represented a challenging time for the patients and they seemed unprepared on admission. However, during the course of the admission, they became more involved and began to take responsibility for their treatment and personal care. Only a few studies seem to explore the first days of the kidney transplant with a focus on patient experiences in this early postoperative period. The time is illuminated as challenging, with postoperative discomfort and a "feeling of being torn" between the positive prospects and worries related to the kidney transplantation (Bertelsen et al., 2015; Urstad et al., 2012; Wiederhold et al., 2011). This echoes the findings in our study, where patients balanced health-related challenges and hope for new possibilities after the transplantation. According to Meleis et al., in our study, transplantation was a transition and the challenges could be viewed as a balance between healthy transition and vulnerability. An inhibitor for healthy transition could be the patients' lack of knowledge at the time of admission; however, their involvement increased over time which could be viewed as a facilitator (Meleis et al., 2000). Transplantation requires a new learning process, similar to an apprenticeship, because of the changes experienced (Wiederhold et al., 2011). This supports the importance of the patients' increased involvement in treatment and care during admission to manage everyday life after discharge and to ensure the best conditions for long-term graft survival. The patients were admitted for up to 21 days (Wiederhold et al., 2011), while patients in our current study were discharged after approximately a week. Thus, short hospitalization stresses the importance of involvement of the patients during admission as quickly as possible.

Patients described that they looked forward to going home. However, the period after discharge was challenging, because it involved balancing between adapting to daily routines and worries about the functioning of the kidney graft. Meleis' theory of transitions explains how the patients were experiencing several transitions during the transplantation process and could move either in the direction of health or towards vulnerability (Meleis et al., 2000). In a study by Urstad et al., a gap between knowing and practice is identified. At home, the patients find it difficult to use the knowledge gained during admission; thus, the feeling of control is challenged (Urstad et al., 2012). Furthermore, kidney transplantation brings instability to most areas of the recipients' lives (Schmid-Mohler et al., 2014). This may explain the challenges the patients in our study

experienced in the early period after discharge and how it took time to re-establish everyday life and stability. Thus, being home for recovery seems significant in the early period after discharge.

Worries about rejection and loss of graft functioning have been identified in several studies (Crawford et al., 2017; Jamieson et al., 2016; Schmid-Mohler et al., 2014; Urstad et al., 2012; Wiederhold et al., 2011). Furthermore, frequent follow-ups and re-hospitalizations were challenging, frustrating and tiring and experiencing of complications were stressful (Crawford et al., 2017; Schmid-Mohler et al., 2014). Nevertheless, overcoming complications strengthens the kidney recipients' capacity to master health situations (Jamieson et al., 2016). Given that unstable kidney graft functioning and complications occur most frequently close to the time of the transplant, this is well-known to be a challenging time. Nonetheless, according to Jamieson et al., the experienced challenges will improve over time. Due to the design of our study, this was not a specific finding, as the patients were followed only up to four months posttransplantation. We found that the patients, at that time, were beginning to adapt to new routines in everyday life and the need for frequent contact with the health system was decreasing. This was also found by Jamieson et al. (2016). Furthermore, they found that, after kidney transplantation, the patients try to free themselves from the role of being a patient and that continuous contacts with the health system reinforce the identity as a patient and this can lead to non-adherent behaviour (Jamieson et al., 2016). However, that does not seem to be an issue in our study. Four months after discharge, the patients began to re-establish everyday life, still striving to improve their condition and were focusing on adherent behaviour. According to Meleis et al., the patients' situation could be explained as going towards a healthy transition as stability became a part of everyday life. A process indicator could be the patients' development of confidence with their situation (Meleis et al., 2000). Rosaasen et al. find that patients expect they should live a normal life after the kidney transplantation. However, the chronic disease is still a reality, just with a new set of things to deal with (Rosaasen et al., 2017). This could explain the patients' experiences of adapting to a new everyday life at this point in the process.

5.1 | Limitations

It can take up to a year or more before patients are completely familiar with their new everyday life situation (Crawford et al., 2017; Rosaasen et al., 2017; Schmid-Mohler et al., 2014). This might have influenced our findings; however, our study showed that patients experienced that everyday life was beginning to be established four months after transplantation. Another limitation could be that, we did not follow the same participants throughout the transplant process. Instead, the participants were recruited from different stages of the process, contributing with their perspectives of the transplant process. Between four and eight participants represented each of the stages—before, during and after the kidney transplant. However, they could often contribute with experiences from more than one stage, depending on how far they were in the process. Thus, the study is based on experiences from 18 participants in total.

6 | CONCLUSION

Exploring kidney transplantation as a coherent process provides a new understanding and insight into patients' experiences. The transition perspective explained the coherent process as multi-faceted and complex with various transitions, where patients are balancing hope, positive prospects and health-related challenges. This can guide nursing care to recognize and support the patients' individual needs in the kidney transplantation process.

ACKNOWLEDGEMENTS

The authors wish to thank the participants in the study.

CONFLICT OF INTEREST

No conflicts of interest have been declared by the authors.

ORCID

Charlotte Nielsen https://orcid.org/0000-0002-8920-7758

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How to cite this article: Nielsen C, Clemensen J, Bistrup C, Agerskov H. Balancing everyday life—Patients' experiences before, during and four months after kidney transplantation. *Nursing Open*. 2019;6:443–452. https://doi.org/10.1002/nop2.225

THE EXPERIENCE OF WAITING FOR A KIDNEY TRANSPLANT: A QUALITATIVE STUDY

Tania Burns [1], *Ritin Fernandez* [2,3], *Moira Stephens* [2]
[1] *St George Hospital, Sydney, Australia*
[2] *University of Wollongong Faculty of Science Medicine and Health, Wollongong, NSW, Australia*
[3] *Centre for Research in Nursing and Health, St George Hospital, Kogarah, NSW, Australia*

Burns T., Fernandez R., Stephens M. (2017). The experience of waiting for a kidney transplant: A qualitative study. *Journal of Renal Care* **43**(4), 247–255.

SUMMARY

Background: In Australia over 1100 people are living on dialysis while waiting for a kidney transplant from a deceased donor. Worldwide there are an estimated 170,000 people who wait an average of three years before an organ becomes available.
Objective: To provide an understanding of the lived experience of people waiting on dialysis for a kidney transplant from a deceased donor.
Approach: A qualitative descriptive research design was used. Participants were recruited from a large metropolitan hospital. Two focus groups were conducted with six participants ranging in age from 29–63 years, with dialysis experience of 10–72 months. Data saturation was achieved and thematic analysis was used to interpret the data providing a descriptive account of the experience of waiting for a kidney transplant.
Findings: Waiting for a kidney transplant takes place in the context of living on dialysis. Four main themes were identified: living on dialysis is physically and mentally demanding; living with uncertainty; altered relationship dynamics; and feelings towards the deceased donor.
Conclusions: This study provides a descriptive summary of what it is like to live on dialysis while waiting for a kidney transplant from a deceased donor from the perspective of the person waiting. People are burdened by; uncertainty; the experience of the dialysis therapy; and the thought of the human cost of transplantation. These findings suggest that this cohort may benefit from strategies to relieve uncertainty such as effective communication from the treating team and peer support from the dialysis community.

KEY WORDS Experience • Qualitative • Renal • Transplantation

BIODATA

Tania Burns *RN, GCert Acute Care Nursing (Renal), MPhil, is a clinical nurse consultant working as the renal transplant coordinator at St George Hospital in Sydney Australia. This study was conducted as part of a master's research degree with the concept for the question inspired by the experience of working with people waiting for a kidney transplant.*

CORRESPONDENCE
Tania Burns,
RN, GCert Acute Care Nursing (Renal), MPhil,
Renal Department, St George Hospital,
Kogarah, NSW, Australia
Tel: +1 (02) 9113 4205
Fax: +1 (02) 9113 3452
Email: tania.burns@health.nsw.gov.au

INTRODUCTION

Kidney transplantation has been recognised as the best renal replacement therapy option in terms of survival, cost and health-related quality of life (HRQOL) (Von Der Lippe *et al.* 2014; Van Holder *et al.* 2014). It is estimated that over 170,000 individuals worldwide are waiting for a kidney transplant (Council of Europe 2014). In Australia people cannot join the waiting list for a kidney from a deceased donor until they commence dialysis (Transplantation Society of Australia and New Zealand (TSANZ) 2014). Donated kidneys are allocated by a computer algorithm that calculates the compatibility of an organ with a recipient. This means that it is possible for a person to receive an organ after a short time if a perfect match comes up. However, it also means that some people wait a very long time. On average people wait 2.7–3.6 years for a kidney from a deceased donor (Australia and New Zealand Dialysis and Transplant Registry 2015; N.H.S. Blood and Transplant 2015; United States Renal Data System 2015). People on the waiting list must be ready to be called for a transplant at any time, while being prepared to continue to wait. There is a dearth of literature specifically exploring the experience of waiting for a kidney transplant from a deceased donor, thus,

the aim of this study was to explore and describe the experience of waiting for a kidney from a deceased donor.

LITERATURE REVIEW

Much of the information relevant to the experience of waiting for a kidney transplant is found in literature about living on dialysis and about waiting for other types of solid organ transplant.

The experience of living on dialysis has been called a 'lost life' (Monaro *et al.* 2014) and a 'restricted life' (Clarkson & Robinson 2010). Time on dialysis has been described as '... the strongest modifiable risk factor for renal transplant outcomes' in people waiting for a kidney transplant (Meier-Kriesche *et al.* 2000). Living on dialysis while waiting for a kidney transplant has been shown to impact physical health, psychological health and normal activities of life (Burns *et al.* 2015). The physical limitations of living with a chronic disease means that people are not able to invest time in the activities that previously defined their sense of self, such as independent living, employment, education and social relationships (Bennett *et al.* 2013; Pierce 2014). In people waiting for a kidney transplant, the thought of getting a transplant gives them hope of returning to a normal life one day, free from the constraints of end-stage kidney disease (ESKD) and dialysis therapy. The transplant is viewed as a 'light at the end of the tunnel' (Moran *et al.* 2011; Yngman-Uhlin *et al.* 2015) and finding 'freedom' despite ongoing uncertainty (Lonargáin *et al.* 2017). Even the act of being placed on the transplant waiting list has been linked to better HRQOL and less depression (Santos 2011; Osthus *et al.* 2012), possibly reflecting the transplant selection criteria (Transplantation Society of Australia and New Zealand (TSANZ) 2014) which picks out healthier candidates with less physical co-morbidities. While they wait people describe their life as being 'on hold' (Moran *et al.* 2011) and 'in standby' (Yngman-Uhlin *et al.* 2015). They live in a state of constant readiness and experience feelings of powerlessness and acceptance as they continue to wait (Pierce 2014; Yngman-Uhlin *et al.* 2015; Lonargáin *et al.* 2017).

Although the thought of getting a transplant gives people hope (Moran *et al.* 2011; Pierce 2014; Yngman-Uhlin *et al.* 2015) as time goes by hope changes to uncertainty (Moran *et al.* 2011; Pierce 2014). Waiting for a transplant has been described as an 'emotional rollercoaster' with uncertainty the 'only constant in this state of flux' (Pierce 2014, p. 104). Regular communication has been shown to help people cope with uncertainty while they wait for a transplant and make them feel cared-for and supported (Rodrigue *et al.* 2011; Yngman-Uhlin *et al.* 2015).

STUDY DESIGN

As there is currently little literature specifically relating to waiting for a kidney transplant, a qualitative descriptive research design was adopted to document the characteristics of the experience in broad terms.

DATA COLLECTION

Focus groups were used as the method of data collection. Focus groups are designed to 'foster a sense of collaboration between group members in order to explore a topic and achieve a deeper level of discussion than would be possible with individual interviews alone' (Kamberelis & Dimitriadis 2011, p.546). A focus group enables the participants to discuss and develop the topic, as experts in their lived experience, with the researcher in a facilitative role, whereas with group interviews, the researcher has a more prominent role in directing the questions. The social interaction within focus groups encourages people who may not be confident to take part on their own, and makes it easier to form opinions and create a shared perspective (Greenwood *et al.* 2014). The number of focus group participants recommended in the literature ranges from 4 to 12 (Halcomb *et al.* 2007), although groups with smaller numbers have also been reported to be effective (Côté-Arsenault & Morrison-Beedy 1999). Focus groups were used in this study to capitalise on the networks that exist within communities of dialysis patients.

PARTICIPANTS

Participants were recruited from the renal department at one metropolitan hospital in Sydney, Australia. Inclusion criteria for the study were people aged 18 years and over, undergoing dialysis therapy for CKD and on the waiting list for a kidney transplant. Exclusion criteria were people who could not communicate in English. Two focus groups were conducted with a total of six participants ranging in age from 29 to 63 years and with dialysis experience of 10 months–6 years. Three were married, three were single and they came from a variety of ethnic backgrounds. Sampling in qualitative research is less concerned with 'size' per se, but more concerned with 'richness' (Kuzel 1992). The actual number of participants required depends on the research question, design and context and the available resources (Gaskell 2000; O'Reilly & Parker 2013). The potential participants of this study were a time-poor group of people, maintaining dialysis therapy as well as work and family commitments. In order not to add to the burden of appointments, only those who responded were included and no further attempts were made to recruit more participants. In qualitative research it is important to show the adequacy of the sample by achieving data

saturation, where the existing findings are consistently repeated and where no new findings appear (Morse 2015). In this study, the data from both focus groups was remarkably consistent, with participants voicing the same concerns in both groups. Data saturation was reached with the six participants who took part.

PROCEDURE

A semi-structured question guide was developed as an initial prompt for the discussion that was informed by the literature and researchers' experience as clinicians. The focus groups took place at a meeting room on the hospital campus. The place and space used for data collection have been found to play an active role in the interactions between the participants, the facilitator and the data, and potentially has an effect on the sense of authority, security and confidentiality within the group (Gagnon *et al.* 2014). The two groups were held on different days of the week and at different times of day to maximise the number of people who would be able to attend. Each focus group was conducted by two facilitators.

DATA ANALYSIS

The trustworthiness of a qualitative study lies in the transparency of the data collection and analysis processes, and in establishing that the findings are credible (Polit & Beck 2014). In this study, the focus groups discussions were audio recorded and transcribed verbatim by a commercial transcription service to enhance the credibility and authenticity of the data. Clear documentation of the chosen study methods and the resulting findings are included for transparency (Altman & Moher 2013) with study findings resulting directly from the experiences of the participants as reported in the focus group transcripts and not from pre-conceived criteria dictated by the researcher (Shenton 2004). The data collection and data analysis methods adopted for this study have been used in similar studies relating to the experiences of a group of people with a shared clinical experience (Ravenscroft 2005; Gibson *et al.* 2013; Brewer *et al.* 2014). Adopting methods that have been used in other similar studies strengthens credibility (Shenton 2004).

Data were analysed using a qualitative descriptive approach (Thorne 2008). Immersion in the data through repeated listening to the recordings and reading of the transcripts was followed by coding. Concepts within the data were examined to see how they related to each other (Hsieh & Shannon 2005). Links and relationships between sub-categories were established and the data were organised to provide an account of what it is like and how it feels to wait for a kidney transplant from the participants' point of view. During this analytical process the researcher remained critical and reflective towards her own pre-knowledge, while attempting to hear what the participants were communicating at that moment.

ETHICAL APPROVAL

Ethical approval to conduct this study was obtained from the hospital and University Human Research Ethics Committees. The study was conducted with the support of the renal department at St George Public Hospital and with a scholarship from Kidney Health Australia. Pseudonyms have been used to protect the participants' privacy and participants were instructed at the start of the focus groups that information shared should remain confidential and not be shared outside the group.

FINDINGS

Four main themes were identified in the data: living on dialysis is physically and mentally demanding; living with uncertainty; altered relationship dynamics; and feelings towards the deceased donor. Within these four themes were nine subthemes. A summary of themes and subthemes is shown in Table 1.

LIVING ON DIALYSIS IS PHYSICALLY AND MENTALLY DEMANDING

The greatest challenge while waiting for a kidney transplant is living on dialysis. Living on dialysis is constraining and thus demanding in that it limits the activities and dreams of the participants. Dialysis affects people both physically and psychologically and impacts many areas of life.

> *Yeah, the waiting list pretty much doesn't—the dialysis is the one that affects you physically and mentally, but being on the waiting list? Not really (Mary).*

Theme	Subtheme
Living on dialysis is physically and mentally demanding	Transplant means freedom from dialysis
	Acceptance of the wait as a normal part of life
Living with uncertainty	Uncertain timing—an ongoing wait
	Uncertain outcome—fear of losing hope
Altered relationship dynamics	Valuing family support
	Protecting loved ones
	Supported from within the dialysis community
Feelings towards the deceased donor	Pragmatic appreciation
	Identifying with another's loss

Table 1: Waiting for a transplant themes and subthemes.

The data show that dialysis takes priority over everything else in life while waiting for a transplant. Hours set aside for dialysis limit the time available for other pursuits, while the level of activity between dialysis sessions is restricted. Dialysis is physically and mentally challenging, restricting a person's ability to have a career, travel overseas and be financially independent; leading to social isolation and disempowerment. Participants described the paradox of how they are subjugated by the thing that keeps them alive. Participants talked about the time when they would be free from the constraints of dialysis

TRANSPLANT MEANS FREEDOM FROM DIALYSIS

Set against the overwhelming burden of life on dialysis the thought of getting a transplant gives people hope of one day being free.

> *Kidney transplant I think is very good. I warm to it because I think first bring me the freedom. That's I really want. I want the freedom . . . I want lots of freedom—because this one [dialysis] definitely does affect my life (April).*

April's emphatic repetition of the word 'freedom' illustrates her sense of imprisonment. Dialysis is accepted as necessary to maintain life, but kidney transplant is viewed as a means of escape. Being active on the transplant waiting list gives hope that life on dialysis will not have to be endured for ever.

ACCEPTANCE OF THE WAIT AS A NORMAL PART OF LIFE

Participants described how the experience of waiting for a kidney transplant had become an accepted part of daily life; they normalised it. While the restrictions of dialysis loom large, the transplant waiting list does not feature highly. It becomes normalised, making it hard for participants to articulate any actual effect of waiting on their day-to-day lives. The participants' use of idiom illustrated their feelings of powerlessness and acceptance: 'It will happen when it happens', 'Go with the flow', 'It just is what it is' and 'Whatever is coming is coming'. One participant used the metaphor of a game to describe the wait

> *. . . if you're common that means that there's going to be a lot more common people on the list. It's just a percentage game (William).*

Another participant talked about luck:

> *I continue to wait if I'm lucky. If I'm not lucky, you can't do nothing else (Cathy).*

Chance and luck cannot be affected by any action and reflect the immutable nature of waiting for a kidney transplant which will occur at some unpredictable time in the future. The wait is accepted as something that exists but which does not affect life in any practical sense.

LIVING WITH UNCERTAINTY

Participants described the constant uncertainty. Uncertainty about how long they would have to wait, and uncertainty about the outcome of the transplant—the term of their constrained living and their long-term survival. The complete unknown that surrounds the timing of the transplant means that people are unable to plan for the future with confidence. Uncertainty surrounding the potential for complications after the surgery leads to fears that the restricted life on dialysis may continue indefinitely with no hope of escape, or death may ensue.

UNCERTAIN TIMING—AN ONGOING WAIT

People on the transplant waiting list live with uncertainty about when the transplant will come. The question 'How long will I wait?' caused considerable discussion in both focus groups with participants offering suggestions to help them tolerate the uncertainty better.

> *I don't know the system can inform you to say you are very close. I don't know is that how it works or not? (April).*

Participants debated whether it would be worse to be told they would get a kidney very soon and then be disappointed or to wait without any idea of when their name would come up. Despite understanding that it was not possible, and maybe not beneficial, to have that information, the question indicates a deep desire to reduce the level uncertainty in life and be able to plan for the future.

UNCERTAIN OUTCOME—FEAR OF LOSING HOPE

Participants also described concerns about the uncertain outcome of the transplant and whether it would really give them everything they hoped for. Whilst on dialysis there was always hope for a new kidney and freedom from dialysis but a failed transplant could take away that hope through a return to

dialysis or death. Participants were aware that a kidney transplant was not a guarantee of a problem-free future.

> *To be honest it's still a little bit scary in the transplant, but that's one way to get you back to normal life . . . so I like transplant, but only little bit scare me is things because some people tell me the story about you might be easy to get cancer or might be—but that's little bit scary things (April).*

As well as fear of the surgery and its unknown outcome, participants also feared a future without the hope of a transplant.

> *(April) . . . if you're not on the transplant list you feel, oh my god! You think about your rest of life; feel bad like this until you . . .*
>
> *(Cathy) . . . die.*

The thought of living on dialysis without the possibility of a transplant was overwhelming. They feared spending the rest of their lives feeling bad 'like this' on dialysis without any hope of an escape. People waiting for a kidney transplant live with the uncertainty of wanting something and yet not knowing when it will happen or what the outcome will be.

ALTERED RELATIONSHIP DYNAMICS

Waiting for a kidney transplant changes a person's relationships with their family and friends. Some relationships are strengthened by the experience of facing a serious illness together, while others are weakened by lack of common ground. Sometimes participants deliberately put up barriers to protect people they love from distress.

VALUING FAMILY SUPPORT

Although waiting for a transplant, some participants showed a heightened appreciation of the support they received from family members. Family support was a keystone in enabling some participants to live on dialysis. They acknowledged the burden that their disease placed on the family as a whole and contemplated the value of the family unit as a source of strength.

> *My wife's very supportive with me with it. Honestly, they're the ones that get the hard part . . . I think you need that support mechanism. I don't know how you'd cope (Barry).*

With the diagnosis of CKD and the need for dialysis, significant relationships became more highly valued as family members provided help and assistance.

PROTECTING LOVED ONES

Despite appreciating the help and support of family members, participants also admitted to shielding loved ones from the full impact of their illness and dialysis therapy. Five of the six participants described how they chose to withhold information from their loved ones in order to save them from worry.

> *I knew that I got a problem with my kidneys since 1996. . . . I didn't—even my family, my sisters I never tell them about that I have a problem. Just really no one knew . . . because I didn't want them to worry, especially my mum because she was very old already. I just keep it to myself (Vincent).*

This was also seen in participants who had family members come forward as potential living kidney donors. They described feeling burdened with gratitude and guilt at the prospect of their relative undergoing surgery for their benefit, and they hid their feelings of relief and disappointment when the donation could not proceed. Their hope of escaping from dialysis was suspended out of concern for their loved one.

SUPPORTED FROM WITHIN THE DIALYSIS COMMUNITY

People reported difficulty in relating to people in their non-dialysis social circle, but they formed new connections within the medical system and the dialysis community. The stories of these fellow dialysis patients provided participants with knowledge and information with which to compare their own experiences.

> *You finally realise, well I never thought about it that way. You hear other people's versions of things and it opens up your mind to that aspect of it as well (William).*

As well as providing perspective on their own experiences, stories from within the dialysis community also help people maintain hope while waiting for a transplant. Cathy happily recounted the time she heard that a person she knew from the dialysis unit had received a transplant:

> *. . . Maria told me . . . she say George has got a kidney. I'm like my cross and I was crying and I say, 'Good on you George', because you can say to yourself one day maybe going to be me too and somebody else might be happy (Cathy).*

This illustrates the peer support that exists between patients undergoing dialysis. Two patients talking joyfully about a third who

had got a transplant and Cathy recognising that when she too gets her kidney, other patients will hear about her and be given hope.

Living on dialysis while waiting for a kidney transplant, places pressures and expectations upon existing relationships and leads to the development of new friendships. Connections made through the dialysis experience can provide perspective and hope, while a renewed appreciation of significant relationships can lead to deceit and disconnection as loved ones are shielded from the true impact of the disease burden and the deep desire for a transplant.

FEELINGS TOWARDS THE DECEASED DONOR

The hoped-for return to normal life is ultimately enabled by the death of a stranger; the deceased donor. The data reveal a sense of the practicality of using organs from people who are deceased and an appreciation of the human cost of the donation.

PRAGMATIC APPRECIATION

Participants rationalised their need for a deceased donor as the logical employment of an organ that would otherwise have no use. For some it was culturally unacceptable to ask a living person for an organ, so a kidney from a deceased donor was the only option.

> *That's why donation I think is good, because I believe that when the people pass away, it's not useful anymore. What's that one used for? So, if not used for things you can reuse it, help other people live. That's good (April).*

The use of organs from people who are deceased is viewed as a sensible alternative to taking them from healthy living people.

IDENTIFYING WITH ANOTHER'S LOSS

As well as a pragmatic lack of concern for the donor, some participants demonstrated insight towards other people who might be affected.

> *Like you say if it is a donor kidney, I'm happy to—I won't feel the guilts in a way. In the back of my mind I think I will feel bad for the family, they've lost a family member (Mary).*

As the donor would have died whether or not they donated their organs, Mary did not feel responsible for causing them harm, but her comment shows recognition of the grief the donor's family would be experiencing. She identified with them as people who were suffering the loss of a loved one.

Cathy struggled with the idea that when her kidney came it meant that someone somewhere had passed away:

> *Myself, sometimes my husband tell me don't worry you know, you're going to be lucky. I said . . . I'm not make my cross to God somebody to die and I get the kidney. It's not good. If I'm lucky one will just come nicely (Cathy).*

Cathy said she could not pray to God for a transplant as it would be like praying for someone to die. She understood that there would not be a transplant unless someone died and knew that her lucky day would be a very bad day for the donor. She lived in hope for a kidney to 'come nicely'.

Participants recognised that when their transplant kidney became available, the donor's family would be grieving the loss of their loved one. While they did not express any feelings of personal guilt for the donor's death, wishing for the transplant to happen caused mixed emotions because it meant the death of another. They lived with the knowledge that when their longed-for transplant and escape from dialysis took place, it would be as a result of someone's death. When they finally received the call they had been waiting for, there would be a family of grieving relatives mourning the death of the donor.

DISCUSSION

People who are waiting for a kidney transplant are so immersed in the experience of living on dialysis that it is hard for them to separate their feelings about dialysis from their feelings about waiting for a transplant (Calvey & Mee 2011; Burns *et al.* 2015). The all-encompassing and overwhelming nature of living with kidney disease means that people accept dialysis as necessary to continue living, but with limited opportunities for travel, employment, financial independence and normal social interaction (Calvey & Mee 2011; Monaro *et al.* 2014). Living on dialysis is the context from which all their answers are made.

The possibility of a kidney transplant allows people to view their chronic disease more like an acute disorder, as something temporary that can be escaped from (Moran *et al.* 2011; Yngman-Uhlin *et al.* 2015). Study participants clearly articulated the hope they held that a kidney transplant would bring them freedom from dialysis. While living with the overwhelming

physical and psychological burdens of dialysis, the thought of getting a kidney transplant gave them hope that one day they would live a normal life again. This is congruent with the findings of other studies looking at people waiting for transplants. The hope of getting a transplant helps people to endure and gives them a more positive outlook on life while they wait (Pierce 2014).

People waiting for a kidney transplant develop a state of acceptance and acknowledge they have no influence over when a donor organ will become available (Sadala *et al.* 2012). They come to accept the wait for a transplant as a normal part of life, carrying on with their daily responsibilities without focusing on the transplant.

The wait for a kidney transplant is linked with feelings of uncertainty (Pelletier 2012). The experience of living with a chronic illness such as kidney disease has been described as unpredictable, with uncertainty 'a continuous companion' (Sheilds *et al.* 2015, p. 210). Participants were keen to suggest ways of being kept informed, to provide them with some certainty to prepare for the future. The unknown timing of the transplant means that people cannot plan for the future with any confidence (Tong *et al.* 2015). The literature has shown that sometimes the *mean* waiting time has been interpreted as the *actual* waiting time, resulting in people being disappointed when their wait exceeded that length of time (Moran *et al.* 2011; Yngman-Uhlin *et al.* 2015). People also experience fear about whether or not the transplant will be successful and free them from dialysis. They also experience fear about the surgery, the medications and the potential for the transplant to be lost (Burns *et al.* 2015). Uncertainty about the timing and the ultimate outcome is part of the experience of waiting for a kidney transplant.

The experience of waiting for a kidney transplant can alter the dynamics of a person's relationships. People appreciate being part of a community and place greater value on relationships with family and friends (Burns *et al.* 2015). They re-evaluate their priorities in life with families and relationships seen as a source of strength to help them endure the wait (Tong *et al.* 2009). As well as appreciating the support of their friends and family members, people make new connections within the dialysis community. Regular communication with the medical community has been shown to reduce anxiety while people wait, while people who have little interaction with their caring physicians report feeling frustrated and forgotten (Yngman-Uhlin *et al.* 2015). Information enables people to cope better with the experience of waiting for a kidney transplant and meeting with other people who are waiting or who have received kidney transplants can be beneficial (Calvey & Mee 2011). While the literature says a lot about the beneficial effect of contact with the healthcare team, this study found that participants spoke more about the other patients that they knew, rather than the staff they encountered. In the focus groups, the stories of others were reported along with those of the participants', and provided a reference framework with which the participants compared their own experiences.

The longed-for kidney transplant happens at the expense of another person's death and involves a series of events that cannot be predicted and can hardly be hoped for. Not only will someone have to die, but it will have to be in a specific set of circumstances; with a compatible blood group and tissue type; willing to donate their organs; and whose family allow the donation to take place. People on the waiting list for a kidney transplant from a deceased donor are powerless to make the transplant happen more quickly and so they just wait and wish for the unthinkable. They are aware of the paradox of needing someone else to die so that they can live (Calvey & Mee 2011; Tong *et al.* 2015). While it may be sensible to talk in abstract terms about using good organs from a donor who is deceased in order to benefit others, when people are faced with the thought of who that donor actually is, where they live, work and who their families are, it is more difficult to accept. Studies have described the 'moral guilt' experienced by people waiting for a kidney transplant (Tong *et al.* 2015) where transplant recipients feel responsible for the donor's death and worry that their survival is at the donor's expense (Sanner 2003).

The findings of this study captured both the practicality of using organs from people who are deceased, along with the sense of regret towards the donor and their family. Discussion about the deceased donor was limited and where comments were made the subject was not explored, seeming to confirm the literature which noted a culture of not discussing death within a dialysis setting (Sheilds *et al.* 2015). None of the participants specifically expressed gratitude or guilt towards the donor; instead there was a sense that if the donor did not need their organs anymore because they were dead, then it was logical to pass on those organs to people who needed them. Despite their pragmatism study participants identified with the donor family's loss. One participant could not pray for a kidney but hoped that if she was lucky one would 'come nicely'. It is a sad fact of transplantation that deceased donor organs do not come 'nicely' but always involve a death.

LIMITATIONS OF THE STUDY

The main limitation of this study is that it was a convenience sample made up of participants from one metropolitan hospital in Sydney, Australia. Although data saturation was considered to be reached, new data may have been revealed with longer or repeated focus group discussions or if the study were repeated with a different group of participants under the care of another hospital or in another state or country. The experience of waiting for a kidney transplant may vary depending on the resources that people have available to them. These findings of this qualitative study do not seek to be generalizable but transferable.

IMPLICATIONS FOR PRACTICE

The findings of this study suggest that people who are waiting for a kidney transplant may benefit from strategies to relieve uncertainty such as excellent communication with their caring team and harnessing the combined knowledge of the dialysis community to provide peer support and education. It highlights the need for a flexible approach towards providing care for people who struggle with the thought of the human cost of transplantation. By describing the experience of waiting for a kidney transplant this study has confirmed what has already been described in the literature, and provided further detail which may form a baseline for further research.

CONCLUSION

This study provides a descriptive summary of what it is like to live on dialysis while waiting for a kidney transplant from a deceased donor from the perspective of the person waiting. It has found that people are overwhelmingly burdened by the experience of the dialysis therapy, and that the thought of getting a kidney transplant offers hope that one day they will be free. While people are initially positive about getting a kidney, they experience uncertainty while they wait. Both the thought of how long they might wait and whether or not the kidney will really provide them with the freedom they desire generate uncertainty. Social connections are important while people wait. They value the support of loved ones and acquaintances made in the dialysis unit, developing a narrative from the experiences of others that helps them to cope with the wait day by day. People experience complex emotions towards the deceased donor, hoping that an organ will become available quickly, while appreciating the great cost to the donor and their family. Wishing for a transplant is like wishing for someone to die.

ACKNOWLEDGEMENTS

The study was conducted with the support of the renal department at St George Public Hospital and with a scholarship from Kidney Health Australia.

CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

AUTHOR CONTRIBUTIONS

TB: Responsible for conception and design of the study, recruitment, data collection, data analysis and wrote the manuscript as part of MPhil thesis. RF: Participated in conception and design of the study, and critically revised the manuscript as MPhil supervisor. MS: Participated in conception and design of the study and critically revised the manuscript as MPhil supervisor. All authors read and approved the final manuscript.

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Patient Education and Counseling 105 (2022) 2422–2428

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.journals.elsevier.com/patient-education-and-counseling

Waiting for kidney transplantation from deceased donors: Experiences and support needs during the waiting time -A qualitative study☆

Kristina Nilsson [a,*], Mats Westas [b], Gerhard Andersson [c], Peter Johansson [d], Johan Lundgren [b]

[a] Department of Internal Medicine in Norrköping, and Department of Health, Medicine and Caring Sciences, Linköping University, Norrköping, Sweden
[b] Department of Health, Medicine and Caring Sciences, Linköping University, Norrköping, Sweden
[c] Department of Behavioural Sciences and Learning, Department of Biomedical and Clinical Sciences, Linköping University, Linköping, Sweden. Department of Clinical Neuroscience, Karolinska Institute, Stockholm, Sweden
[d] Department of Health, Medicine and Caring Sciences, Linköping University, Norrköping, Department of Internal Medicine, Norrköping, Sweden

ARTICLE INFO

Keywords:
Kidney transplantation
Waiting list
Needs
Support
Education
Qualitative research

ABSTRACT

Objectives: The study aimed to explore and describe patients' experiences of the transplantation process and the support they had received during the waiting time.
Method: Semi-structured interviews were conducted with 14 patients currently waiting for kidney transplantation from deceased donors (n = 7) or recently having received kidney transplantation (n = 7). Interviews were transcribed, anonymized and analysed inductively using thematic analysis.
Results: Two themes and seven sub-themes were identified. The first theme, "Swaying between hope and despair" describes patients' perceptions of waiting for transplantation as a struggle, their expectations for life after the upcoming transplantation and experienced disappointments. The second theme, "Making your way through the waiting time", describes support, strategies and behaviours used to manage the waiting time.
Conclusion: Patients described life while waiting for kidney transplantation as challenging, involving unexpected events, not understanding the transplantation process and having unrealistic expectations on life after transplantation. They also described support, strategies and behaviours used, some of which led to unwanted consequences.
Practice implications: Patients waiting for kidney transplantation from deceased donors need continuous and easily available education, practical and emotional support to manage the waiting time. Transplantation specific education is also needed to facilitate preparation for transplantation and adjustment to life after transplantation.

1. Introduction

Around 95 000 kidney transplantations are performed annually worldwide and the number is steadily increasing [1]. While around one quarter of patients transplanted in Scandinavia receive a kidney from a living donor, the majority have to wait to receive kidneys from deceased donors [2]. Patients awaiting kidney transplantation from deceased donors have a higher risk of physical and psychosocial problems compared to those who have a living donor. As the waiting time is longer, dialysis treatment is often required. Patients treated with dialysis during the wait are profoundly affected by both the illness and the dialysis treatment [3–6]. They describe restrictions on freedom due to dialysis being physically and mentally tiring, time consuming and restraining. Patients also struggle to cope with the uncertainty of waiting and express mixed emotions, for example always having to be ready and at the same time sense that time is running out, as physical problems often increase during the wait. Many patients express high expectations and hope for a normal life situation once the kidney transplant is performed. However, physical problems and complications may further delay the transplantation and the longer the waiting time the greater the risk of patients losing hope [3,4]. While the wait for a kidney transplantation may bring hope, it also brings an experience of uncertainty in turn increasing stress and anxiety [5], symptoms which have previously been found to progressively increase during the wait [7].

Studies suggest that psychosocial distress not only affects quality of life, but also has a negative effect on self-care such as medication

☆ This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.
* Correspondence to: Department of Internal Medicine, Nephrology Clinic, Vrinnevi Hospital, SE-601 82 Norrköping, Sweden.
E-mail address: kristina.nilsson@liu.se (K. Nilsson).

https://doi.org/10.1016/j.pec.2022.02.016
Received 8 June 2021; Received in revised form 28 January 2022; Accepted 21 February 2022
Available online 22 February 2022

adherence [8,9], rejection episodes[9] and survival after transplantation [10,11]. Hence, patients awaiting kidney transplantation from deceased donors have emotional and educational needs that need to be better understood and addressed by clinicians. Knowledge may give these patients benefits through regaining a greater level of control of their lives [5]. Implementation of interventions including systematic education and psychosocial support have been requested to address these patients' complex challenges and self-care needs [3–5,12,13]. Importantly, Rosaasen et al. [14], found several pre-transplant misconceptions and unexpected post-transplant life changes. Furthermore, barriers towards learning in the early post-transplant phase have been described [15]. This suggests that education during the waiting time should address aspects of the transplant process as a whole, including both the waiting time, the transplantation, as well as life changes which may occur in the early post-transplant period.

Although psychosocial support including psychoeducation and interventions such as quality of life therapy or mindfulness may benefit patients awaiting kidney transplantation [16,17], a review reports that self-management interventions for patients with chronic kidney disease are often physiologically focused and 99% of interventions are designed without input from patients [18]. There is a lack of knowledge about what support patients awaiting kidney transplantation from deceased donors wish for or need. Such knowledge would be useful for designing and tailoring future education and psychosocial support programs addressing the whole transplantation process, which also may include the early post-transplant period. The aims of this study were therefore to explore and describe patients' experiences of the transplantation process and the support they had received during the waiting time.

2. Methods

2.1. Design

A descriptive qualitative interview study.

2.2. Sample and setting

Purposive sampling was used and a heterogenous sample was sought for diversity of perspectives. As previously described, pre-transplant education should address the entire transplantation process [14]. To capture experiences and support needs during the waiting time, also in preparation for the transplantation and the early post-transplant phase, we recruited patients currently on a waitlist for kidney transplantation from deceased donors, as well as patients having received kidney transplantation from a waitlist within the last 18 months. Participants were aged 18 years or above, Swedish speaking and recruited from two renal units in the south of Sweden. Information about the study was sent to 31 patients suiting the description. Those who wished to participate returned a written informed consent in a pre-stamped and addressed envelope. Fourteen patients accepted participation in the study, which we deemed adequate considering the prior knowledge of the topic, the narrow study aim and sample specificity and heterogeneity [19,20]. Coincidentally, seven of the participants were waiting for transplantation and seven had been transplanted. Participants were encouraged to choose date and time for interview that suited them.

Ethical approval was obtained by the regional ethics review board of Linköping (2018/313-31).

2.3. Data collection

Telephone interviews were conducted between November 2018 and January 2019 by KN and MW. Telephone interviews were used because the participants were geographically dispersed and often busy due to their illness and treatment. Telephone interviews is well accepted by respondents and allow them to share sensitive information more freely compared to face-to face interviews [21]. As KN had a clinical relationship with some of the participants MW was involved as a second interviewer, hence no study participant was interviewed by anyone previously known to them. KN had extensive experience working as a specialist nurse in the renal transplant field and MW had experience of specialist nursing and qualitative research but not renal or transplant nursing. A semi-structured interview guide was used to enable variation and width within the subject and to avoid missing information which is important. Open-ended questions were used, such as: "How did/do you experience the waiting time for kidney transplantation?", "What support have you received during the waiting time?", "What was your experience of that support?" and "What support would you wish/do you wish you had received during the waiting time?" Prompts and follow-up questions were used to get a richer description. Two pilot interviews were and minor alterations were made in the interview guide. This data was not included in the findings. During interviews, the interviewers checked continuously that they understood the participant correctly. Field notes were taken and used as support during the interviews only. Interviews lasted from 18 to 55 min, with a median of 30 min, not including time for preparatory information. The interviews were digitally recorded and transcribed verbatim by KN, and not returned to participants.

2.4. Data analysis

Thematic analysis according to Braun and Clarke [22] was used to inductively explore and report patterns in experiences, enabling discovery of new knowledge, not previously described in theories and therefore may provide a richer description. A semantic approach was used, i.e., themes were generated from the explicit meanings of the data, rather than underlying ideas of what was said, to give voice to the patients. However, also when staying close to the data, analysis should move beyond the data, rather than just paraphrasing data extracts [23]. Analysis was performed in the following phases: familiarizing with the data by the first author reading and rereading all transcripts, initial coding keeping code extracts to maintain the context [24]. Data were coded by KN and MW. NVIVO software was used to keep codes easily traceable to the context through the analysis process. In the next step analysis focused on broader themes, where the different codes were sorted into potential themes. As part of the analysis themes were reviewed and refined jointly by all authors to correctly represent the data. Any disagreements were resolved through discussion and revisiting initial data, to ensure codes were used correctly and themes and sub-themes were amended accordingly. Further reviewing and refining was conducted to produce a final description of the themes by KN with regular discussion and revision with JL, PJ and GA. Examples of data extracts, applied codes, subtheme and themes are given in Table 1. The consolidated criteria for reporting qualitative research (COREQ) checklist was used to report the study [25].

3. Results

Participant characteristics are displayed in Table 2. Two themes and seven sub-themes were identified and are outlined in Fig. 1. Illustrative quotations for themes and subthemes are given in Table 3. Main theme titles are described in bold below and sub-theme titles are underlined.

3.1. Swaying between hope and despair

This theme describes patients' perceptions of waiting for a transplant as a struggle, their expectations on life after the upcoming transplantation and disappointments that arise. Dialyzing patients appeared unable to separate the experience of waiting for transplantation from the experience of being dialysis dependent, but the two phenomena are entwined.

Table 1
Examples of data extracts, applied codes, subthemes and themes.

Data extract	Coded for	Subtheme	Theme
I think it is very positive, knowing about your illness. I think it is very important to know about different values and about diet, because diet can affect kidney failure// There is a lot that one can do. (P 6) I don't read up on side effects or the illness. // I feel somehow that I am wearing blinders. I don't dwell on what will come. It is a way to keep it at a distance, and to pretend… // I take the consequences as they come, that's how I feel. (P 2)	Important to engage Avoiding knowledge	Acquiring or avoiding knowledge	Making your way through the waiting time
I have lost my lust for things, so to speak. I am tired of everything, of this wait. Before, when it was new, I thought "It will soon be my turn, it will soon be time", but then other things continuously interfered, and now I have become so used to this swaying between hope and despair. Active and inactive [on the waiting list] and all this, so, I give up more for every day. (P 9)	Hope and despair	The struggle of waiting for transplantation	Swaying between hope and despair

Table 2
Participant characteristics.

Characteristic	
Gender	
Male, n	10
Female, n	4
Age **in years, range; median**	39–72; 58
Transplant status at the time of interview	
On waiting list, n	7
Transplanted, n	7
Waiting time at the time of transplant/ interview, **number of months; median**	9–44; 29
Dialysis treatment during waiting time	
In-hospital hemodialysis, n	7
Not in-hospital dialysis[a], n	7
Marital status	
Single or widowed, n	6
Married or co-habiting, n	6
Partner but not co-habiting, n	2
Educational level	
Elementary or upper secondary/high school, n	9
Postsecondary vocational education, n	2
College/ university, n	3
Employment	
Working full time, n	3
Working 50% of full time, n	2
Not working[b], n	9

[a] Not in-hospital dialysis = home hemodialysis, peritoneal dialysis or not yet started dialysis
[b] Not working = full sick leave, unemployed or retired.

3.1.1. The struggle of waiting for transplantation

Gratitude for having the chance of receiving a kidney transplant was expressed and being on the waiting list brought hope for a normalized life. However physical, psychological and social difficulties were perceived during the waiting time. There were experiences of always having to be ready for transplantation and putting life on hold while at the same time having to expect a very long wait, struggling to be hopeful while enduring negative effects by the illness and treatment.

While having the possibility for a transplant call at any time, having to be constantly available for transplantation prevented patients from making plans. Not being able to travel without finding out in advance how to get from the travel destination to the transplant center, should the call come, and being restricted by the dialysis treatment, regardless of dialysis treatment, led to lost spontaneity. Dialysis treatment was time consuming and was described as a part time job. Patients had difficulties making time for friends and social activities, leading to a sense of isolation.

The longer the patients had waited for transplantation, the more difficult they found the wait. Not only the wait itself that was difficult, but negative physical effects from the disease and dialysis treatment, such as hernias, peritonitis and vascular access problems caused a sense of an increasingly urgent need for transplantation. In turn, due to complications patients were repeatedly temporarily inactivated on the waiting list, causing frustration. Consequently, patients became aware that the more they felt that they needed the transplantation, the greater the probability of the transplantation being delayed or cancelled due to ill health. This complex situation caused psychological distress and was described as swaying between hope and despair.

Seeing co-patients receiving kidney transplants gave hope for the upcoming transplantation but was also a reminder of uncertainty. Seeing others receive a transplant after a shorter waiting time while oneself being left waiting was experienced as difficult and unfair.

3.1.2. Expectations for and disappointments with life after transplantation

During the wait for transplantation, patients expressed expectations for a new and normal life after transplantation, including returning to work, regaining a normal social life and a normal sex life and freedom from dialysis. However, those who were transplanted described that they felt unprepared at the time of the transplantation, despite the length of the wait, and experienced distress. The call for transplantation came unexpectedly and was described as a shock. The post-operative time in hospital was shorter than expected, leaving no room to mentally adapt to a new phase of life. Having waited for a long time, often supported by dialysis staff and co-patients, they had suddenly received a kidney and were to take care of themselves. There was an unexpected loss of close relationships with staff and co-patients which had developed over months or years. Although a well-functioning kidney transplant enabled patients to re-establish their social networks, the lost regular social interaction at the dialysis center was difficult to replace. Patients also expressed a new sense of uncertainty, fearing kidney rejection, and a sense of not being the same person as before transplantation.

3.2. Making your way through the waiting time

This theme describes support, strategies and behaviours, intentional or unintentional, which may be used during the waiting time, however often leading to unwanted consequences. For example, the waiting time was compared with a long journey. The patient described going into "travel-mode", not anticipating reaching the goal of the journey any sooner than the expected waiting time. This strategy was perceived to reduce stress during the wait, but when the transplant came sooner than expected the patient felt unprepared.

3.2.1. The need of being understood

In-hospital dialysis could be seen as a job, giving life structure and

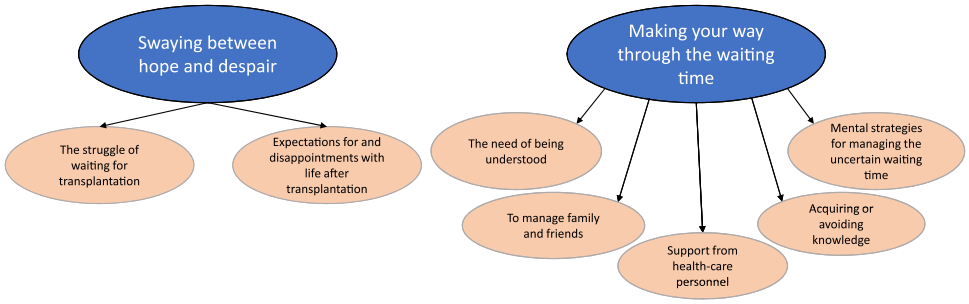

Fig. 1. Thematic map showing two main themes and seven subthemes. The first theme describes patients' experiences of waiting for kidney transplantation and expectations for and disappointments with life after transplantation and the second theme describes support, strategies and behaviours used while waiting for transplantation.

regular social interaction. The family-like relationships that developed with other patients and dialysis staff were supportive by being regular, continuous and with others who understood the situation. Patients not dialyzing and those dialyzing at home expressed a feeling of being forgotten.

Maintaining work life was described as important during the wait, both for the sense of feeling useful and for the regular social interaction. Through close contact with the employer, patients' specific needs as someone living on dialysis while waiting for transplantation were understood, and changes made enabling patients to perform peritoneal dialysis at the workplace, work part time or from home.

3.2.2. *To manage family and friends*

Kidney disease, dialysis and the wait for kidney transplantation affected not only the patients, but also family and friends. The patients chose either to involve their relatives or to not involve them, both with the intention to minimize concern. Regardless of which strategy the patients had chosen, they could lead to undesirable consequences.

While involving and informing friends or family in the illness was experienced as helpful by some patients leading to less concerns for both themselves and the relatives, others explained that relatives had difficulty understanding the tiredness that came with kidney disease. However, relatives who did understand could be helpful with practical issues when energy was poor.

For some patients involving relatives rather led to more concerns and some avoided talking about existential thoughts carried by relatives. Avoiding meeting friends or arranging dinners due to tiredness or food restrictions was common and led to friends no longer inviting them, resulting in a sense of isolation. A different strategy for managing family or friends was to keep up appearances in order to not concern them. By pretending all was well someone aimed to keep their relatives from worrying, which in turn made the patient feel treated as "normal", rather than as somebody who was ill.

The question of live kidney donation could cause stress. Relating to relatives who wished to donate a kidney but had been refused was described as stressful. Equally, relating to relatives who did not offer to get tested as potential kidney donors despite seeing the difficulties in waiting for a transplant, also caused stress.

3.2.3. *Support from health-care personnel*

When asked about received support patients mentioned practical support received from the health-care personnel. This support could be of clinical nature, such as managing vascular access or dialysis complications, ordering dialysis equipment or arranging appointments. Arranging holiday dialysis was found difficult and something that patients wanted more help with, to possibly make life less restricted while waiting for a transplant.

While patients with in-hospital dialysis felt supported, those with home dialysis experienced a lack of practical support. They described managing dialysis on your own, keeping track of stock and ordering dialysis equipment as stressful, adding to the strain of waiting for a transplant. Patients expressed that they sometimes remained without support which they thought would be beneficial, as they did not feel comfortable asking for it if it was not offered.

The hospital social worker was described as supportive and could offer a different angle on difficult issues. A few patients had previously tried cognitive behavioural therapy and found it helpful. They wished it were available via the renal units.

3.2.4. *Acquiring or avoiding knowledge*

Although patients expressed satisfaction with the information they had received, the education and information offered was described as sporadic, often provided too early in the transplantation process. Acquiring knowledge about kidney disease, treatment and the upcoming transplantation was described as a helpful strategy. Different ways of acquiring knowledge were described. However, avoiding knowledge was also described as a strategy.

Patients expressed that acquiring knowledge about the illness and how to manage the treatment could contribute to optimizing their treatment and help them control their life better. Some patients chose not to seek information about illness, symptoms or side-effects of medications, as they felt it caused them more concern and made them feel more restricted. However, finding out how to increase well-being in the moment, such as foods that reduce symptoms, was described as positive.

A need of transplant specific information was expressed, such as what could be expected from a transplant, the expected recovery time and how soon one could plan to return to work. This information could relieve stress during the waiting time. Many patients also wanted to be informed of their place on the waiting list, to be reassured that the waiting list progressed. However, patients who had been told an approximate waiting time experienced that the information repeatedly gave them false hope. They abstained from activities or trips believing that the transplant was close, leading to disappointment and lost hope.

Different strategies for acquiring knowledge were described. Some knew how to seek information regarding their illness, treatment or transplantation, while others relied on their doctor to inform them of anything they needed to know. Individual meetings with one's nurse or doctor was an important way to acquire knowledge, enabling a dialogue. Learning from co-patients was also considered important. Those who dialyzed in hospital had opportunity to meet others several times a week and described that regularly meeting others in a similar situation was educational. In contrast, patients who dialyzed at home or not at all explained that being able to discuss practical and emotional aspects with peers would be helpful.

Patients had suggestions for new ways of acquiring knowledge. Peer support could be arranged through health-care staff. Classes or book circles were suggested to enable patients to learn by reading facts and reflecting on them with peers. While some patients proposed that group meetings may be of great help, others thought it might be inhibitive. While meeting others was considered important, lack of energy made

Table 3
Illustrative quotations for themes and subthemes.

Theme/Subtheme	Illustrative quotation
Swaying between hope and despair/ The struggle of waiting for transplantation	I'm one of those who needs to be in control, and now I couldn't control when they would call [about the transplant]. That bothered me. I became worried when I wasn't in control -of anything, I thought. It was a huge psychological stress… Worst of all [during the wait for transplantation] was dialysis, I think. I found it horrible… (P 3) At times I am so sick of it (waiting), I just want to give up. Now there are weeks when I don't think about it at all. But then there are periods when I think about it a lot and I just want to give up. Like, I could just as well die. Why the hell am I waiting? (P 7)
Swaying between hope and despair/ Expectations for and disappointments with life after transplantation	So, I guess I was shocked somehow, it is starting to go away now. I am starting to find myself again. But I am not the same really, I have a spare part. It has been difficult, strenuous somehow. (P 3) You get so close up there [at the dialysis unit], it is almost like a family, you get so close and meet so often and talk quite a lot about both personal and private things, so you almost get the sense of being family when you are there. And that, in the other end, once you are transplanted and are not to go there and meet them. I like going there. (P 1) Once I had my surgery it occurred me, "Oh no, now I don't get to go for dialysis". I lost a lot of friends. (P 8)
Making your way through the waiting time/ The need of being understood	I always had people to talk to [at the dialysis unit] who understood me and all this. That is why I had a positive experience, I think. I don't know how you would otherwise get through things like this. (P 6)
Making your way through the waiting time/ To manage family and friends	I still believed that they would at least consider helping, but no, apparently not. And it has bothered me, and it still bothers me that they couldn't stop to think it through and not be so selfish. And sometimes I think about it more, and sometimes I just think that it is what it is, it is their decision, but I am very, very disappointed. (P 9)
Making your way through the waiting time/ Support from health-care personnel	There were so many things involved. Uhm, so much mentally and so much physically straining. Not just waiting, but it is all this hard work with the dialysis. And you are supposed to manage so much by yourself and ordering materials from the pharmacy and getting your equipment home and, No…it has been a difficult time. (P 3)
Making your way through the waiting time/ Acquiring or avoiding knowledge	It took two years from when she said that [the expected time for transplant is close], so I think, instead of saying "possibly in the autumn", "possibly next spring", "it is close"… Just shut up! They create expectations in those who are waiting, that are not fulfilled, and that is extremely difficult of course. I broke down every autumn and every spring when it didn't happen. (P 12)
Making your way through the waiting time/ Mental strategies for managing the uncertain waiting time	I exercised at a gym, which was good. I didn't want to go to physiotherapy at a hospital, because I didn't want to feel more ill than I was, if you see what I mean. I wanted to meet healthy, happy people as you do at a gym. So, they have been fantastic, and inspired me and, well it's been like therapy for me. I felt happy when I was there. It [the gym] cost some, but it was worth it. Mm. So, that's worth thinking of. And of course, nature has been good. Walking. And socializing with friends. (P 3) It's like when you are going for a long flight, you can think that the journey is tough and a long time to sit on a transfer or a plane, right, and you may think it is all tough. So instead, when I travel, I go into a kind of travel mode. You just have to accept it. So, you are prepared that this will take time, and it kind of takes the time it takes. And somehow I had gone into such a waiting-time mode: "Ok, this will be a long transfer." (P 5)

patients refrain from group meetings that were arranged.

The internet was thought potentially helpful for providing answers whenever needed. Development of a mobile application was suggested to facilitate good dietary choices in the moment, as information received from the dietitian often was not available or remembered when needed. Someone followed support groups in social media, but refrained from participation, explaining that participants often were irresponsible in the advice they gave one another. It was suggested that group discussions whether physical meetings or online may help broaden your views on your situation but should be aided by an expert.

3.2.5. Mental strategies for managing the uncertain waiting time

Different mental strategies were used to manage the waiting time. Some patients explained that their expected waiting time of 2–5 years was far too long to consider oneself as waiting. Their strategy was to accept and expect that the wait would be long and repressed thoughts of transplantation until they reached the expected time for transplantation. Those who were called for transplantation sooner than expected had not yet started thinking about transplantation or what it may involve. They believed that others may experience the wait as socially and psychologically difficult, and that they probably would too after reaching the minimum expected waiting time. One strategy to avoid disappointment was to stop expecting transplantation altogether and thereby emotionally switching off. Focusing on practical issues, such as performing dialysis, spending time with family and doing things you enjoy were other strategies. During the waiting time, declined physical and mental health was experienced, and physical activity was mentioned as a strategy to combat this, also giving the patient a sense of doing something good during the waiting time.

4. Discussion and conclusion

4.1. Discussion

In this study we explored and described patients' experiences of the transplantation process and the support they had received during the waiting time. We found new important information about patients' experiences of support during the waiting period. By including patients who were waiting for transplantation and transplanted patients, the study encompasses the entire transplantation process. This in contrast to earlier studies that focus only on the actual waiting time or only post-transplantation experiences [3–7,12,15–17,26].

Two themes were identified. The first theme, "Swaying between hope and despair", describes patients' perceptions of waiting for transplantation as a struggle, their expectations on life after the upcoming transplantation and experienced disappointments. The second theme, "Making your way through the waiting time", describes support, strategies and behaviours used to manage the waiting time. While patients mentioned certain support needs explicitly, they also mentioned difficulties and behaviours which may be interpreted as support needs. We

found that patients feared that their health would decline or be further complicated during the wait, a reasonable fear as patients with advanced kidney disease often have multiple chronic conditions associated with adverse outcomes [27]. Self-care, i.e., maintaining health through health promoting practices and managing illness [28], for these patients is often very complex and demanding especially for home-dialyzing patients. Our results indicate that self-care is an important aspect during the wait for transplantation. Patients therefore need support to manage their complex situation and guide their choice of strategies to maintain and improve physical, psychological and social well-being.

Patients described different strategies for managing the waiting time. Some acquired knowledge to improve their health, while others avoided information. We also found that transplanted patients felt unprepared for changes involved with the transplantation regardless of the waiting time, and experienced distress. These experiences may.

not only hinder self-care [29], but can also have significant negative effect on quality of life, medication adherence and survival after transplantation [8,10,11]. Unexpected posttransplant life changes have also been described earlier [14]. This suggests that patients need education as well as psychological tools for managing the uncertainty of waiting and potential complications during the waiting time as well as after transplantation.

Support from others and access to health-care affect the ability to perform self-care [29] and managing the waiting time. In our study patients treated with in-hospital dialysis described close supportive relationships with co-patients and health-care staff and felt supported and secure. However, transplanted patients in our study suffered unexpected loss of these dialysis-related relationships, indicating that patients may need guidance in maintaining or re-establishing social networks outside dialysis and health-care. Meanwhile, patients not dialyzing in hospital felt forgotten and lonely. Relatives could be supportive if they were involved by the patient, but some patients refrained from involving their relatives in order to minimize concern.

We and others [14] have argued that patients awaiting kidney transplantation need easily available support and education regarding life with kidney disease as well as information about the transplantation process and changes involved with transplantation. When designing future education and psychosocial support programs it is useful to note that our results show a contradiction regarding what form of support these patients want, i.e. group meetings, and what they are capable of, as they do not have energy to attend meetings despite finding them important. Moreover, as differences in attitudes towards self-care support demands different approaches [30], it is important to ensure that patients get sufficient and personalized support to manage important self-care during the wait for as well as after transplantation.

We included both patients who were waiting for transplantation and patients who had recently received a kidney transplantation, which could be considered a limitation. However, this choice enabled us to explore experiences and support needs during the whole transplantation process. As our study was performed in Sweden future research should focus on patients awaiting transplantation in countries where health-care and social welfare systems work differently.

4.2. Conclusion

In this study patients described their lives while waiting for kidney transplantation as challenging, involving unexpected events, complicated by not understanding the transplantation process and having unrealistic expectations. They also described support, strategies and behaviours used, some of which led to unwanted consequences such as unvoluntary isolation. These qualitative findings may form the basis for future development of education and support programs for patients awaiting kidney transplantation.

4.3. Practice implications

Patients who wait for kidney transplantation from deceased donors need continuous and easily available education, practical and emotional support to manage the waiting time. Transplantation specific education is also needed to facilitate preparation for transplantation and adjustment to life after transplantation.

CRediT authorship contribution statement

Kristina Nilsson: Conceptualization, Methodology, Project administration, Investigation, Data curation, Formal analysis, Writing – original draft, Writing – review & editing. **Mats Westas Klompstra:** Investigation, Data curation, Formal analysis, Writing – review & editing. **Gerhard Andersson:** Conceptualization, Methodology, Supervision, Writing – original draft, Writing – review & editing. **Peter Johansson:** Conceptualization, Methodology, Project administration, Data curation, Formal analysis, Writing – original draft, Writing – review & editing. **Johan Lundgren:** Conceptualization, Methodology, Supervision, Project administration, Data curation, Formal analysis, Writing – original draft, Writing – review & editing.

Declaration of Competing Interest

The authors have no competing interests to declare.

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Received: 1 February 2024 | Accepted: 23 June 2024

DOI: 10.1002/nur.22414

RESEARCH ARTICLE

RESEARCH IN NURSING & HEALTH WILEY

«I can't imagine it without my nurse»: Experiences of people with chronic kidney disease in the evaluation process as kidney transplant candidates

Guillermo Pedreira-Robles[1,2,3,4] | Victoria Morín-Fraile[5] | Anna Bach-Pascual[1] | Ariadna Graells-Sans[2,3] | Paloma Garcimartín[6,7,8]

[1]Nephrology department, Hospital del Mar, Parc de Salut Mar, Barcelona, Spain

[2]ESIMar (Mar Nursing School). Parc de Salut Mar, Universitat Pompeu Fabra affiliated, Barcelona, Spain

[3]Social Determinants and Health Education Research Group (SDHEd), Hospital del Mar Institute for Medical Research (IMIM), Barcelona, Spain

[4]Nursing and Health PhD Program, University of Barcelona, Barcelona, Spain

[5]Department of Public Health, Mental Health, and Maternal and Child Health, Faculty of Nursing, University of Barcelona, Barcelona, Spain

[6]Nursing department, Hospital del Mar, Parc de Salut Mar, Barcelona, Spain

[7]Research Group in Nursing Care, IMIM (Hospital del Mar Medical Research Institute), Barcelona, Spain

[8]Biomedical Network Research Center for Cardiovascular Diseases, (CIBERCV, Carlos III Health Institute), Madrid, Spain

Correspondence
Victoria Morín-Fraile, C/de la Feixa Llarga, s/n, 08907 L'Hospitalet de Llobregat, Barcelona, Spain.
Email: victoriamorinf@ub.edu

Funding information
Generalitat de Catalunya, Grant/Award Number: SLT017/20/000001

Abstract

This qualitative study aimed to explore the experiences of 11 adults with chronic kidney disease (CKD) undergoing evaluation for kidney transplant (KT) and examine the role played by the nurse in the process. Employing a descriptive phenomenology approach, semi-structured interviews were conducted between October 2022 and July 2023. Thematic analysis, facilitated by Atlas. ti software, revealed a systemic management diagram with "The candidate for kidney transplant and their reality" at the center, followed by "The process of chronic kidney disease and kidney transplantation," and concluding with the most distal category centered on "The kidney transplant access nurse." This organizational framework provided insights into the layers of relationships between emerging themes. The findings underscored the complexity and multidimensionality of the CKD and KT process, emphasizing the nurse's pivotal role as a guide and protector throughout the evaluation process for accessing kidney transplantation. The convergence of results with existing literature highlighted the need to address challenges such as lack of time, resources, and emotional support to enhance the quality of care. Recognizing the nurse's crucial importance in this process, the study emphasizes the significance of addressing these challenges to improve patient care and calls for attention to the nurse's role in guiding individuals through the intricate journey of CKD and kidney transplantation.

KEYWORDS
advanced practice nurse, care, complexity, kidney transplant, management

1 | INTRODUCTION

A major challenge in healthcare is addressing the growing global prevalence of chronic kidney disease (CKD) due to factors such as increased life expectancy and the rise in non-communicable diseases (Bikbov et al., 2020; Jha et al., 2013; van Rijn et al., 2020). Kidney transplantation (KT) is considered the optimal renal replacement therapy for individuals with CKD, with decisions on its suitability involving collaborative evaluation by an interdisciplinary team of professionals, weighing risks and benefits (Chadban et al., 2020; Jones et al., 2023).

2 | BACKGROUND

The KT access process in our facility involves specialized consultations in nursing, nephrology, and urology, as per KDIGO guidelines, and complementary consultations may also be required (KDIGO, 2020). If deemed suitable and a living donor transplant is not possible, candidates are placed on the transplant waiting list and assessed annually, with an estimated average waiting time of 24 months from the start of dialysis (Organització Catalana de Trasplantaments OCATT, 2021). In considering the evolving protocols for evaluating KT candidates, it's notable that they've become less restrictive, benefiting individuals with more comorbidities, advanced age, or heightened risk factors (Axelrod et al., 2018; Kaballo et al., 2018). While maintaining safety and quality, these protocols now address a population with increasingly complex needs, implying greater investment in all respects (Pedreira-Robles et al., 2024).

The characteristics and benefits of interdisciplinary teams in KT access have not been thoroughly explored, with evidence either lacking quality (KDIGO, 2020) or being of low quality (Dudley & Harden, 2011). Equipping teams with nurses may not significantly increase healthcare costs and is associated with better clinical outcomes (Lasater et al., 2021; Mathy et al., 2021; McCrory et al., 2018; Zala et al., 2017). Despite the benefits, the role of the nurse in KT access is not widely established in Spain, and its competency remains to be defined (Pedreira-Robles et al., 2023).

Existing reports often focus on clinical outcomes rather than individuals' lived experiences, creating a research gap (Kloss et al., 2019). This study aims to explore the experiences of individuals with CKD undergoing KT evaluation, focusing on the process, their needs, and the nurse's role. By centering on individual experiences, the study seeks to adapt professional activities to reported emerging needs, aligning with the National Kidney Foundation's roadmap for improving access and outcomes in renal transplantation (Lentine et al., 2021).

3 | METHODS

3.1 | Design

This is a qualitative study, using Husserl's descriptive phenomenology (Al-Sheikh Hassan, 2023). The manuscript adheres to the Consolidated Criteria for Reporting Qualitative Research (Tong et al., 2007).

3.2 | Participants

Eleven adults with CKD undergoing KT evaluation participated in the study. Table 1 outlines their sociodemographic and clinical characteristics. The participant profile consisted of individuals being considered for KT for a period equal to or exceeding 3 months and with a minimum of 3 in-person visits with the KT access nurse

TABLE 1 Participants profile.

	Age	Gender	Country of birth	Educational level	RRT	Time in RRT	Study time for KT	Expected donor
P1	60	W	Spain	Primary	PD	6 months	6 months	Deceased
P2	68	M	Spain	Primary	HD	14 months	8 months	Deceased
P3	29	W	Ecuador	Secondary	HD	7 months	10 months	Deceased
P4	24	M	Venezuela	Primary	PD	18 months	10 months	Living
P5	52	W	Spain	Secondary	ACKD	–	3 months	Deceased
P6	80	W	Spain	Primary	ACKD	–	6 months	Deceased
P7	80	M	Spain	Primary	ACKD	–	3 months	Deceased
P8	78	M	Spain	Primary	ACKD	–	3 months	Living
P9	68	M	Spain	Primary	ACKD	–	4 months	Deceased
P10	26	M	Russia	Primary	HD	11 months	6 months	Deceased
P11	60	M	Spain	Secondary	PD	8 months	9 months	Deceased

Abbreviations: ACKD, advanced chronic kidney disease; HD, haemodialysis; KT, kidney transplant; M, man; P, participant; PD, peritoneal dialysis; RRT, renal replacement therapy; W, woman.

(average visits and time for the studied process). They had no communication difficulties, were clinically stable, and lacked acute processes limiting data collection. To ensure representation, diverse social groups and equitable gender distribution were maintained. Final participant selection followed pragmatic purposeful sampling until information saturation. Utilizing the purposive sampling technique for participant selection has allowed us to ensure ideal representatives of the target population, chosen based on their capacity to offer comprehensive insights into the phenomenon under study. In this manner, we followed the steps outlined in the data collection process.

3.3 | Data collection

We recruited participants from a KT access clinic located in a tertiary referral hospital in Spain. The lead nurse verbally informed all eligible patients about the study. Out of the 24 patients approached by the nurse, 11 agreed to participate. Subsequently, two members of the research team met with the eligible patients, provided further details about the study, and obtained their informed consent. This meticulous process ensured voluntary and altruistic participation in the study. It involved two members of the research team independently adhering to a pragmatic approach in selecting informants.

Data collection involved semi-structured interviews with a pre-planned guide to ensure that no important topics were left unaddressed (meaning of illness and KT; emerging needs during the evaluation process for KT; and the KT access nurse). This approach, endorsed by the research team, focused on key themes and open-ended questions, minimizing the risk of overlooking significant content (Mahat-Shamir et al., 2019; Zahavi & Martiny, 2019). Interviews occurred in person between October 2022 and July 2023, allowing participants to choose a comfortable location. Conducted in closed-door rooms, lasting around 45 min, the interviews were recorded with participants' knowledge, and field notes were compiled for analysis.

3.4 | Data analysis

The data analysis, following Braun and Clarke's (2006) framework, provided a rigorous examination closely tied to the data, offering a concise depiction of the studied phenomenon. Initially, we immersed ourselves in the data through transcription, repeatedly reviewing it and making initial annotations. Then, we systematically generated initial codes and identified themes, aided by Atlas. ti software version 22. After reviewing and refining the themes, we developed a thematic map and established relationships between them. Emerging themes were defined and named through consensus among the research team members, ensuring clarity. Finally, the analysis report selected extracts that best represented the participants' experiences, guided by the research question and existing literature (Braun & Clarke, 2006; Guba, 1981). This process adheres to credibility, transferability, dependability, and confirmability criteria in qualitative data collection and analysis, following literature guidelines (Guba, 1981). Investigator and theoretical triangulation criteria were established based on referenced contributions (Aguilar Gavira & Barroso Osuna, 2015).

3.5 | Theoretical framework and research team statements

Following Husserl's descriptive phenomenology approach (Al-Sheikh Hassan, 2023), this study recognizes research as a collective experience impacting both participants and researchers (Sorsa et al., 2015). Engaging in dialogues with interviewees, we aimed to explore lived experiences, ensuring new knowledge discovery while avoiding undue influence on participants' understanding of the phenomenon. Adhering to the four bracketing strategies proposed by Chan et al. (2013) – mental preparation, scope definition in the literature review, planning data collection, and planning data analysis—we prioritized rigor in our research. Notably, the principal investigator and interviewer had prior roles in the nephrology service and as a transplant nurse at the reference center, fostering intimacy and trust with participants. The presence of external researchers ensured a separation of personal ideas from the final analysis.

3.6 | Ethical considerations

This work is part of the principal investigator's doctoral thesis project, approved by the ethics committee of the reference institution (registration number 2020/9418/I).

4 | FINDINGS

After interpretively analyzing the data, it was discovered that these are intimately linked to the management theories currently used in the care of people with CKD. Accordingly, Figure 1 visually represents the emerged themes and subthemes from the interviews, organized in a systemic management diagram. The three main themes are interconnected concentrically, with «The candidate for kidney transplant and their reality» at the center, followed by «The process of chronic kidney disease and kidney transplantation», and concluding with the most distal category related to the professional network, centered on «The kidney transplant access nurse». The decision to arrange the findings under this diagram took into account the interconnection between them, and decisions were made to ensure that their representation flowed cohesively among them.

The following section describes and illustrates the identified themes and subthemes with excerpts from the interviews.

FIGURE 1 Systemic management diagram with the themes and subthemes found.

4.1 | The candidate for kidney transplant and their reality

4.1.1 | The person with a disease that is surprising, silent, and invisible

Most participants were astonished to find they had kidney disease because of its silent and imperceptible nature. Some had not experienced symptoms and learned of their disease during a primary care visit. Others learned of their disease when they were hospitalized following the onset of symptoms. Once the participants experienced symptoms, most had significant deterioration in renal function and were told they needed immediate renal replacement therapy. All participants lamented the confusion and dearth of information accompanying their diagnosis and grappled with the intricacies and emotional toll of treatment.

> *P8: The process started with the general practitioner, involving various tests and procedures. It was a prolonged sequence of instructions without a definitive diagnosis. During a vacation, I fell ill, leading to hospital admission. It was there that I was informed about kidney failure and related issues. Subsequently, I was referred to a specialist, marking the beginning of the ongoing journey.*

Participants who personally experienced CKD as surprising, silent, and invisible had also witnessed its impact on their personal and family environment. This has resulted in feelings of incomprehension and loneliness due to the lack of apparent physical justification.

> *P5: I lacked support from those around me. Despite experiencing fatigue due to work and the disease, I didn't receive understanding. Juggling work and family responsibilities, exhaustion took a toll, leading to misconceptions and a lack of support.*

Participants who had an inherited form of CKD had been monitored for the disease, sometimes since childhood, but nonetheless did not have a planned strategy or course of action for managing the disease as an adult.

> *P10: Since childhood, I underwent frequent blood tests. My doctor predicted I would undergo dialysis like my mother, and at the age of 25, it became a reality sooner than expected, catching me off guard in August.*

4.1.2 | The person with socioeconomic and cultural determinants

The participants revealed that the evaluation process as a KT candidate closely correlates with individual determinants and characteristics. Some interviewees, particularly migrants seeking better options than those available in their countries of origin, mentioned difficulties in accessing KT due to their personal characteristics.

> *P4: As an immigrant, I received unexpectedly good and fast care. I didn't anticipate such efficiency, considering my background. In other countries, the chances of receiving dialysis or a KT would have been slim, if not impossible – not in Ecuador, Venezuela, or even Aruba, where I had been.*

Some participants explored how religion serves as another personal characteristic limiting KT access in various contexts. Particularly among Jehovah's Witnesses, they recognized that care teams view these characteristics as constraints, sometimes leading to the denial of treatment options.

> *P3: The most challenging aspect is being alone, without family or financial support. Starting from scratch is tough, especially when your community doesn't provide solutions or support for your situation. Moving to a new place was the only option. Coming from a humble family, my parents couldn't provide substantial financial assistance, so I had to start working to navigate the challenges on my own.*

At this stage, the participants clearly showed that individual characteristics significantly influenced the progression of the KT evaluation process. They acknowledged that even those without apparent limitations would face greater challenges if they had encountered different socioeconomic and/or cultural determinants.

> *P9: If I had to travel from another city, it would be more challenging due to the longer distance. Commuting from another city to here involves covering a significant number of kilometers. However, now I find it more convenient to use the metro or bus, making the commute easier and cost-effective.*

4.1.3 | The informed, skilled, and trained person

Despite initially struggling to understand CKD and access KT, all the participants acknowledgeacknowledged gaining greater knowledge through various facilitators and experiences in the process. They recognized the strategy of providing all information in writing as particularly helpful, aiding in internalization for later understanding. Additionally, they appreciated having a direct contact telephone number for clarification in case of doubts.

> *P4: In case of doubt, it's crucial to address it during face-to-face consultations. Fortunately, my experience here has been positive, with all my needs promptly met. I cannot recall any instance where my requests were denied. Additionally, the nurse has been highly accessible, providing a direct phone line for immediate clarification of doubts.*

Furthermore, the participants acknowledged that they commonly seek information beyond the professional environment, such as through acquaintances, the internet, and books. This external information gathering helped them enhance their understanding and empowered them to navigate the complexities of the disease process.

> *P1: Initially, the diagnosis hit me hard as I struggled to comprehend what was happening. To cope, I delved into the internet, a double-edged sword, where I found a wealth of information about kidney failure, read diverse cases, and gained insights from others' experiences. This extensive reading became a significant part of my daily routine, providing valuable knowledge and understanding.*

Similarly, some participants also recognized the need for personal involvement in the process to achieve set objectives. Merely understanding the information was not sufficient; personal involvement was necessary to apply the agreed-upon changes.

> *P7: Upon a chance encounter with a doctor or nurse who expressed concern about my abdomen, I sought*

clarification. It turned out that my belly wasn't conducive to certain medical procedures. Urgently consulting a dietitian, I received personalized advice, including dietary restrictions and a daily walking regimen, which I promptly adopted. This lifestyle change resulted in a notable weight loss of 13 kilos. The positive outcomes included improved mobility, reduced insulin dosage, and adjustments to medications, contributing to an overall enhanced sense of well-being.

4.1.4 | The person with risks, fears, and uncertainties

The participants, receiving the diagnosis of CKD and undergoing the decision-making process, experienced fears intertwined with the misinformation discussed in previous points.

P1: Initially tough, the diagnosis was bewildering, and the entire experience has been highly challenging. Regrettably, I've lacked psychological support. It underscores the critical need for immediate psychological assistance upon detecting the illness.

Similarly, all the participants expressed excitement about the prospect of receiving a KT soon, anticipating a radical life change. Despite recognizing the associated risks and uncertainties, they perceived KT as necessary for improving their quality of life, personal time management, and overcoming restrictions in other treatments. They focused their uncertainties mainly on the timing of KT and its ultimate outcome.

P3: I hope everything goes well, that it happens soon and well. I also know there could be rejection and an adjustment period for the transplant to 'settle'… but I hope there's none and the opportunity comes soon.

Despite participants clearly identifying drawbacks of KT, there was a consensus to undergo it, primarily motivated by the desire to stop depending on a dialysis machine. It was acknowledged that KT won't last forever, and multiple transplants may be needed in the future.

P10: Despite the potential drawbacks, I am eager to proceed. The prospect of ending dialysis and living machine-free for a few years motivates me. I understand it might not be a lifelong solution, and multiple transplants may be necessary. I've carefully considered all the implications, as explained by the nurse.

Despite the possibility of experiencing side effects from certain medications observed in other transplant recipients, participants always reaffirmed their desire to proceed with KT, expressing concerns about the need for medication.

P8: I've observed acquaintances who underwent transplants, and I find it concerning. They often appear swollen, presumably due to the medication, including cortisone, taken to counterbalance the transplant. The last person I saw with a transplant complained of issues like high blood sugar and cholesterol.

Finally, the participants expressed major concern about being available when they receive the call for KT. They worried about the impossibility of scheduling a procedure dependent on a death, knowing when the organ will arrive, and whether they will be ready to answer the call at that time.

P11: My primary concern is whether I'll be available on the day they call me. That's the most anxious point for me.

4.1.5 | The indivisible person and not fragmented by processes

Some participants noted a simultaneous occurrence of processes in their CKD journey and candidacy for KT. Despite professionals separating these processes, the participants experienced them as interconnected. They observed that tests, visits, and involved professionals align with biomedical separations, which caused discomfort due to a mismatch between their individual needs and the provided care model.

P1: Two years ago, I frequently mentioned to doctors that I urinated a lot. During a skin checkup, the dermatologist conducted a blood test and informed me of a kidney problem. I continued informing my doctor, but I was repeatedly switched to different doctors. I didn't experience symptoms until later. They eventually said I needed nose surgery. When I consulted the anesthetist, she refused to operate due to my filtration rate of 20. Confused, I asked for an explanation, and she advised me to consult my primary care center for tests. This left me in tears, as I didn't comprehend the situation at that moment.

In this sense, the participants considered how the different parts, processes, diseases, and concurrences of the same person can affect the process of evaluating candidates for KT, as this evaluation is never isolated from the rest of the person's condition. They also considered external factors such as delays in care caused by the COVID-19 pandemic and the recognized slowdowns in hospitals during the summer vacation months.

P4: After the initial 3–4 months of tests and visits, the arrival of summer brought minimal progress. Despite having all the necessary information, there were significant delays during the summer months.

4.2 | The process of chronic kidney disease and kidney transplantation

4.2.1 | A process of patience and waiting

Most participants described the process of evaluation as a KT candidate as slow and challenging, involving visits to various specialists and undergoing multiple tests at different health centers. Despite the time and complexity involved, the participants acknowledged the necessity of this process and willingly underwent it to access the KT program. Consequently, the participants took on a complex, time-consuming role, always accompanied by the reference team.

P1: It is slow! The process involves numerous tests, from stool tests to blood tests for antibodies. I've been dealing with tests for a long time. I have two left, and I'm awaiting some requested reports. Today, I had a stool test, and tomorrow I get the vaccines, along with a gynecology test and other reports I've requested. Once this compilation is complete, I believe I'll be on the list soon. I'm praying for it to happen quickly. The nurse has been a tremendous help, solving many issues for me. For instance, when I had the stool test, I forgot how to do it, and she guided me through it, making the test possible. This modern approach is perfect!

Family members of the informants also recognized this wait, viewing KT as a potential solution to the diagnosed problems. No barriers in the personal environment hindering access to KT related to waiting have been reported.

P7: My family? They're great! They really want to see me, have me around, and I guess I solve a lot of problems for them [laughs]. Now, we just have to wait for the opportunity to come.

In this patient accompaniment, the professional team also identified the need to adapt and reorganize to offer their organizational capacity in the evaluation process, facilitate their progress, and avoid multiple trips.

P5: What's well-organized is that when I come, I do complete visits. That's good. I don't have to come for one thing 1 day and another thing another day. In that sense, it's quite good.

On the professional side, the wait was seen as an active preparation for the KT procedure. Most participants acknowledged the emphasis on maintaining healthy lifestyles to enhance the success of the procedure. Additionally, they recognized the disease itself has prompted healthier behaviors, and there was a clear motivation to access KT, driving a positive change in habits to approach the procedure in the best possible conditions.

P10: People often say, "five, six, 7 years…," and after those years, you have to go back to dialysis. I don't want this! Because, for example, the professional team explained many things: if you eat well throughout your life, you can extend the life of your kidney. I'm going to consider it this way: have a good diet, stay in shape… to make the transplant last longer. Yes, it's like having a competition with yourself!

4.2.2 | Neglect in the process with unmet needs

In the analyzed process, some participants identified limitations that result in neglecting individual needs due to perceived shortages of personnel and time constraints in healthcare teams. They acknowledged moments when healthcare providers cannot promptly convey information, and there was a lack of emotional support in dealing with a situation described as difficult and complex. While all questions have answers, information was provided in response to the questions they formulated, rather than being offered proactively by professionals within a pre-established timeframe.

P5: I have one thing clear: I know that if I had asked more, they would surely have given me the information. But initially, it's not done. There's no time!

P1: I complained because this has been very challenging, and I never received psychological support. I believe that such support is lacking in this illness, not only for me but for everyone. There should be psychological assistance at the moment of detection to help individuals understand and cope with it. Unfortunately, I had to navigate this journey alone, as there are insufficient professionals addressing these needs.

Additionally, in private institutions, the participants did not perceive the assistance to be better than in public ones, despite the assumed greater resources. They noted that while waiting times were shorter, the emphasis on care still lead to misinformation due to professionals having limited time and separating biomedical care from emotional and educational needs. Furthermore, the participants observed that follow-up in private care ceases as the disease progresses to severe stages, whereas public care continues to offer ongoing support and answers.

P7: The behavior and treatment by the nurse and another doctor left me astonished. I couldn't believe the level of care, even compared to the hospital where I pay a monthly fee. The external visits are not satisfactory; there are long waits and inadequate attention. Whether due to a shortage of doctors or insufficient allocated time, the situation hasn't improved.

Similarly, some participants acknowledged an economic impact associated with the hospital visits, which were their responsibility but were deemed necessary to fulfill the prescribed process and achieve the desired well-being.

P7: The challenges aren't just limited to the journey but extend to parking as well. Despite these inconveniences, the perspective on well-being makes it worthwhile. While there have been instances where multiple factors coincided favorably, navigating various hospitals and locations has been a part of the journey.

4.2.3 | A process of acceptance, resignation, and conformity

After grappling with the diagnosis and diligently striving to understand the situation, all participants eventually comecame to accept the disease and its treatments. This acceptance was described as natural, integrated into their lives, and accompanied by a sense of resignation. There was a consensus among the narratives indicating a preference to avoid dialysis treatment, but it was understood as an inherent part of their lives while awaiting KT, seen as the most natural future solution.

P5: I don't let kidney failure dominate my thoughts. While I take precautions, it doesn't scare me, and I believe there's a solution. I've worked hard to reach this point, and I choose not to be obsessed with it.

All participants recognized the prolonged duration of visits and tests across various hospitals and services, viewing it as a necessary journey to achieve the ultimate goal of KT. None of the participants expressed refusal to accept the process's time and travel demands, despite acknowledging difficulties and assuming familiarity with the healthcare system without anticipating any change.

P2: The testing and visiting phase spanned several months, with notifications for different tests scattered over time and locations. Despite the challenges, I approached it with the necessary commitment.

This resignation also influenced the possibility of living donation. Some narratives explained that their contentment with life has reached a point where they do not consider involving a third person in their process as a kidney donor, as long as there is the possibility of a deceased donor at some point.

P11: Initially, considering a donation from my wife was an option, but as I enjoy a good quality of life, I decided against making two individuals unwell. We explored the possibility, with the nurse's guidance, but seeing my positive response to treatment, I opted to remove myself from my wife's donor list. Now, I'm patiently awaiting a deceased donor, with an estimated wait of around a year due to my blood group and other factors.

4.3 | The kidney transplant access nurse

While exploring the nurse's role in the KT evaluation process, all the participants highlighted the challenge of imagining this step without the nurse's presence and engagement. They associated the nurse with three distinct functions, which they perceived as essential throughout the process, establishing a vital connection among stakeholders and activities. Simultaneously, the participants observed that through their role, the nurse operated within the spheres of the process and the individual, addressing specific needs and acting as a guardian in the healthcare domain.

P5: The nurse is indispensable. In my 23-year journey, I've realized their role goes beyond importance; it's necessary for the entire process. They provide crucial support, listening, caring, comforting, translating complex medical jargon, and guiding you through the journey. Without the nurse, it would be chaotic, a void of information and support that I cannot even fathom.

4.3.1 | The nurse coordinates (managerial role)

In the analyzed narratives, the participants acknowledged various professionals who facilitate access to KT through collaborative efforts in organizing required visits and tests, minimizing unnecessary travel, and ensuring efficient evaluation procedures. They specifically recognized the nurse as a central coordinating figure among different professionals and services, playing a crucial role. The participants highlighted the highly beneficial aspects of having the nurse provide support, guidance, warmth, and ensure the efficient completion of necessary procedures. They viewed the nurse as a facilitator of a positive experience, simplifying the process and making it less burdensome.

P6: The streamlined process here is magnificent for patients. With quick, one-trip management, it eliminates

the need for frequent visits, bringing immense positivity. It provides a sense of comfort, especially when facing uncertainties. Personally, I feel at home during my visits. The nurse, with her detailed explanations and organizational skills, ensures I know where to go and what to expect, creating a reassuring experience amidst the unknowns.

Participants acknowledged the experienced process as challenging in its coordination, and at times, they understood that it cannot be simplified as much as one would wish, but they accepted the difficulty. Similarly, they recognized that, in the face of any difficulty, there was always the nurse to provide support in this regard. In this way, the nurse's role emerged as the guardian of a process that facilitates and coordinates.

P7: The nurse efficiently combined tasks when possible, though there were limitations. I appreciate her efforts, and she has become my go-to person, my main point of contact. It's reassuring to know I can always reach out to her for anything.

4.3.2 | The nurse communicates with you (educational role)

Most participants described the nurse as pivotal in the information and support process for understanding the treatment and the disease. The nurse provided guidance and answers to all doubts, aiding in the comprehension of different professional appointments and offering personalized information in line with the expressed needs. Participants relied on the nurse to obtain clear and understandable information about their treatment, as they usually engaged in a more human dialogue and approach. The nurse played a vital role in the care process, providing invaluable support to the individuals they worked with.

P4: The nurse provided invaluable support, guiding us through the donation process. From initial discussions to addressing our doubts and helping with appointments, she played a crucial role, always attentive and helpful.

On the other hand, the lack of time and haste affected the explanations provided, meaning that the participants did not achieve a complete understanding of all the information given, necessitating the search for answers from other resources. This highlights an unmet need, acknowledged and denied by the system itself, in the words of the users.

P9: The nurse initially provided a detailed explanation of the transplant process, highlighting the advantages of living and deceased donors. However, as the process unfolded, I observed that they seemed rushed and had many tasks, leaving me with some uncertainties.

Most participants identified one of the most evident advantages in the communication process between themselves and the team as having a nurse with direct phone access. Additionally, they described the communicative style of this nurse as close, humane, understandable, and supportive throughout, whether in person or remotely. Despite this, they acknowledged that not having had this type of communication would not have been surprising because they recognized that this convenience was uncommon compared to other services within the healthcare system.

P6: If I hadn't had it, I would have found it normal too because it usually works like this. That's why I found it very close, like being at home, among acquaintances.

4.3.3 | The nurse performs (caregiving role)

On a more caregiving level, narratives acknowledged the nurse as crucial, not only for what they coordinate or explain but also for the direct actions they undertake. There are nursing activities that were clearly recognized and had a positive impact during the evaluation period, saving time and travel as well.

P9: She called recently, advising me to visit her before the blood test, providing tubes to save an extra needle prick or a trip to the hospital for additional blood draws.

5 | DISCUSSION

The study delved into the experiences of individuals undergoing evaluation as KT candidates, examining the process, their needs, and the role of nurses. Graphically represented through a systemic management diagram, this approach aids in understanding the intricate relationships among emerging themes, facilitating the analysis of the process based on the needs of the individuals and the services provided. The significance of this representation is validated by previous literature, demonstrating its effectiveness in portraying care models in complex processes of chronicity and multimorbidity (Grembowski et al., 2014). Similar models, like Buurtzorg's care model (Monsen & Blok, 2018), Bronfenbrenner's Ecological Systems Theory (Guy-Evans, 2023), and the Chronic Care Model (Wagner et al., 2001), position the individual at the center of a concentric network of relationships defining the process and stakeholders.

At the central level of the individual undergoing KT evaluation, findings regarding the surprise diagnosis of CKD resonate with previous research, emphasizing the abrupt and unexpected nature of this emergence, creating a clash between past and present

(Ramírez-Perdomo & Solano-Ruíz, 2018). This dissonance disrupts the routine of daily life, requiring physical evidence to reconcile the perception of illness with the onset of disease (Kleinman, 2020). The impact extends beyond the individual, affecting the family environment with emotional burden and misinformation (Ania-González et al., 2022; Hoang et al., 2018). Socioeconomic and cultural determinants further shape the experience, validated through the voices of those involved and supported by previous studies exploring access indicators to KT (Crews et al., 2019; Harding et al., 2021; Ng et al., 2020).

Despite efforts to provide information and empowerment, the lived experience involves a journey marked by a lack of information until individuals, through various strategies, overcome this barrier and become empowered (Farouk et al., 2020; Lentine et al., 2021). Emotional barriers, including risks, fears, and uncertainties, impact informed decision-making, expressing a lack of support (Hart et al., 2019). The emphasis on viewing individuals as a whole and centralizing their care to avoid duplication aligns with previous studies (Hastings et al., 2018; McKeaveney et al., 2022; Wlodarczyk et al., 2018), maintaining an understanding of the person beyond the disease process.

In exploring the sphere related to the CKD and KT process, participants described it as a patient process involving waiting, unmet needs, and recognition of a defined process requiring acceptance and resignation due to an inability to envision changes. Previous research on healthcare needs reveals an increase in clinical complexity, incidents during the evaluation process, and limitations in care related to time and human resources (Pedreira-Robles et al., 2024). This complex population experiences limitations impacting perceived quality, leading to resignation despite these challenges (Ramírez-Perdomo et al., 2020; Roberti et al., 2018). These findings conflict with the evolving healthcare paradigm that aims to provide sufficient support for self-management and empowerment (Been-Dahmen et al., 2018; Dwarswaard et al., 2016).

The third sphere of the results emphasizes the role of the nurse in the professional network, extending beyond technical aspects to encompass emotional, educational, and healthcare support. Recognizing the nurse as a guardian of the process aligns with prior research, emphasizing the need to acknowledge and strengthen the nurse's role in the KT access process for comprehensive care (Murabito & Hallmark, 2018; Xu et al., 2017; Zala et al., 2017). The absence of the nurse is considered chaotic, highlighting communication challenges due to a lack of time and emphasizing the need for adequate resources.

Protocols for caring for individuals with CKD are established theoretically, but the study suggests a mismatch between theoretical approaches and the lived experience, causing emotional distress, lack of information, fears, and insufficient time to address emerging needs (Ania-González et al., 2022; Hart et al., 2019; Muscat et al., 2021). Bridging this gap is crucial to align theoretical models with the practical realities faced by individuals undergoing the KT evaluation process.

5.1 | Strengths and limitations

The study's single-center design confined data collection to experiences within a specific geographical area, limiting its generalizability to broader populations. Additionally, the exclusion of individuals who did not have nurse involvement in kidney transplant evaluation might lead to an incomplete understanding of the overall process, thus posing a notable limitation. However, the study's findings can be contextualized and extrapolated to similar settings due to the extensive discussion of results found in international literature.

Moreover, the study's credibility is bolstered by robust qualitative analysis. A comprehensive literature review ensures that the study builds upon existing knowledge and incorporates relevant insights from previous research. Collaboration with a research team enabled diverse perspectives and expertise to inform the study's design, implementation, and interpretation. Additionally, adherence to ethical standards ensured the integrity and reliability of the study's findings.

An additional limitation is the possibility of recall bias, where participants may inaccurately remember or report past events, and social desirability bias, where participants may respond in a manner they perceive as socially acceptable, could influence the validity of the data.

5.2 | Implications for practice

The article highlights the practical implications of the findings through an examination of a care model for individuals undergoing KT consideration. It underscores the importance of integrating these findings into our activities to foster equitable and high-quality growth among the individuals we work for. By doing so, healthcare providers can enhance patient education by developing comprehensive materials on the care model and transplantation process, empowering individuals with knowledge and confidence. Moreover, the study highlights the value of interdisciplinary care coordination in meeting the diverse needs of KT candidates. Healthcare teams can leverage the findings to strengthen collaboration among specialties, ensuring a holistic approach to patient care. Additionally, the findings can inform the tailoring of support services to address the specific needs identified among KT candidates, including counselling, mental health support, and financial assistance. Furthermore, integrating the findings into practice can drive continuous quality improvement initiatives, leading to refinements in the care model and better patient outcomes. Lastly, by recognizing and addressing potential health disparities, healthcare organizations can use the findings to ensure equitable access to transplantation services for all individuals, regardless of socioeconomic status or background.

6 | CONCLUSIONS

The results align with existing literature, emphasizing the complexity of chronic kidney disease and transplantation. Participants stress the nurse's role as a guide and protector in the evaluation process. Improving care quality requires addressing issues of time, resources,

and emotional and educational support, acknowledging the nurse's crucial importance in the process.

AUTHOR CONTRIBUTIONS

All authors made substantial contributions to conception and design, and have been involved in drafting the manuscript or revising it critically for important intellectual content. All authors were involved in the data collection and analysis phases. All authors read and approved the final manuscript. Guillermo Pedreira-Robles take responsibility of the paper as a whole.

ACKNOWLEDGMENTS

The authors would like to thank the percipients involved in the data collection. Without them, it would have been impossible to reach the evidence published in this article. This work has been awarded in the XVIII edition of the National Research Contest 'José López Barneo' by the Illustrious Nursing College of Jaén, Spain. This work was supported by the "Strategic Plan for Research and Innovation in Health" of the Generalitat de Catalunya, grant number SLT017/20/000001, with a contribution of 57,239 euros. This funding source had no role in the design, execution, analyses, interpretation of the data, or decision to the submited results.

CONFLICT OF INTEREST STATEMENT

This study is part of the main researcher's doctoral thesis, within the doctoral program in Nursing and Health at the University of Barcelona. The remaining authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The phenomenon under investigation was examined through the perspectives of the people involved in this process. In this manner, the analysis arises directly from the users of the system and the process itself.

ORCID

Guillermo Pedreira-Robles http://orcid.org/0000-0002-6180-4059
Victoria Morín-Fraile http://orcid.org/0000-0002-7800-8091
Anna Bach-Pascual http://orcid.org/0000-0003-0571-6131
Ariadna Graells-Sans https://orcid.org/0000-0002-3881-083X
Paloma Garcimartín http://orcid.org/0000-0002-5758-6933

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How to cite this article: Pedreira-Robles, G., Morín-Fraile, V., Bach-Pascual, A., Graells-Sans, A., & Garcimartín, P. (2024). «I can't imagine it without my nurse»: Experiences of people with chronic kidney disease in the evaluation process as kidney transplant candidates. *Research in Nursing & Health*, *47*, 635–647. https://doi.org/10.1002/nur.22414