



**MEDICATION ADHERENCE FOLLOWING  
KIDNEY TRANSPLANTATION:  
A GROUNDED THEORY STUDY OF  
TRANSPLANT RECIPIENTS'  
PERSPECTIVES**

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**Medication Adherence Following  
Kidney Transplantation:  
A Grounded Theory Study of  
Transplant Recipients' Perspectives**

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**Thesis Submitted in February 2016  
for the Degree of  
Doctor of Advanced Healthcare Practice**

**School of Healthcare Sciences  
Cardiff University**

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## Summary

**Background:** Medication adherence has shown to be problematic for many renal transplant recipients. While factors promoting or inhibiting medication adherence have been extensively researched, little is known about the processes leading to this behaviour as perceived by kidney transplant recipients. Also, no research on the perspectives of German kidney transplant recipients has yet been carried out.

**Research Question:** The question underpinning this research was: “How do German renal transplant recipients perceive the processes leading to medication adherence or non-adherence?”

**Methods:** Following informed consent, telephone interviews with 17 German renal transplant recipients were conducted, transcribed verbatim, and analysed according to the tenets of constructive Grounded Theory, until theoretical saturation was reached. The research has been approved by the research ethics committees of the School of Healthcare Sciences and the German Society of Nursing Science.

**Results:** This research established the theory of *medication-taking as a symbol of living with a chronic condition*. This theory is underpinned by two categories: in the category *reflecting on one's own position*, the participants discussed their role regarding the intake of medication, which was perceived very ambivalently and as just one component of self-management following transplantation. In the category *experiencing facilitators and challenges*, participants reported factors supporting or impeding medication-taking. Crucially, these are perceived very individually: what one finds helpful or challenging may be perceived in a fundamentally different way by someone else.



**Conclusions:** This research has similar findings to other research in this field, such as the fact that renal transplantation is not a cure for a chronic condition. However, in contrast to other research, it has found a strong connection between medication-taking and participants' self-reflection of being chronically ill. In this regard, it has emphasised the need for individualised care, preferably in the form of a team approach that includes patients and families as well as the different healthcare professions.

## Zusammenfassung

**Hintergrund:** Es ist bekannt, dass Medikamentenadhärenz für viele Nierentransplantierte problematisch ist. Während Faktoren, die Medikamentenadhärenz fördern oder erschweren, stark beforscht wurden ist über die Prozesse, die aus Sicht der Nierentransplantierten zu diesem Verhalten führen, wenig bekannt. Zudem wurde bislang noch keine Forschung zur Sichtweise deutscher Nierentransplantierten durchgeführt.

**Forschungsfrage:** Die Frage, die dieser Arbeit zugrunde lag, war folgende: "Wie nehmen deutsche Nierentransplantierte die Prozesse wahr, die zu Medikamentenadhärenz oder Non-Adhärenz führen?"

**Methode:** Nach der Einverständniserklärung wurden insgesamt 17 deutsche Nierentransplantierte telefonisch interviewt, die Interviews wörtlich transkribiert und nach den Vorgaben der konstruktivistischen Grounded Theory ausgewertet, bis Datensättigung erreicht wurde. Diese Studie wurde von den Ethikkomitees der School of Healthcare Sciences der Universität Cardiff und der Deutschen Gesellschaft für Pflegewissenschaft freigegeben.

**Ergebnisse:** Diese Arbeit begründet die Theorie *Medikamenteneinnahme als Symbol mit einer chronischen Krankheit zu leben*. Diese Theorie ist von zwei Kategorien untermauert: in der Kategorie *die eigene Rolle reflektieren* diskutierten die Teilnehmer ihre eigene Rolle bezüglich der Medikamenteneinnahme, welche als sehr ambivalent und als nur eine Komponente des Selbstmanagements nach der Transplantation wahrgenommen wurde. In der Kategorie unterstützende Faktoren und Herausforderungen erlebten berichteten die Teilnehmer von Faktoren, die die Medikamenteneinnahme erleichtern oder erschweren. Diese wurden extrem unterschiedlich wahrgenommen: was jemand als hilfreich oder herausfordernd wahrnimmt, kann von jemand anderem grundlegend anders wahrgenommen werden.

**Schlussfolgerungen:** Diese Studie erzielte ähnliche Ergebnisse wie andere Arbeiten in diesem Bereich, wie z.B. die Tatsache, dass die Nierentransplantation keine Heilung einer chronischen Krankheit darstellt. Im Gegensatz zu anderer Forschung hat sie jedoch einen starken Zusammenhang zwischen der Medikamenteneinnahme und der Selbstreflexion der Teilnehmer chronisch krank zu sein gefunden. In diesem Zusammenhang wurde die Notwendigkeit individualisierter Betreuung betont, bei der vorzugsweise ein Teamansatz gewählt werden sollte. Dabei sollten die Patienten und ihre Familien und die verschiedenen Berufe im Gesundheitswesen eng zusammenarbeiten.

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## Abbreviations

CKD	Chronic Kidney Disease
CsA	Cyclosporine A
EPS	Everyday Problem Solving
ESRD	End-Stage Renal Disease
GFR	Glomerular Filtration Rate
GT	Grounded Theory
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
ICD	International Classification of Diseases
IM	Immunosuppressive Medication
KTx	Kidney Transplantation
KTx/PTx	Kidney-Pancreas Transplantation
MMF	Mycophenolat Mofetil
mTOR	mechanistic Target of Rapamycin
NA	Non-Adherence
NTI	Narrow Therapeutic Index
OED	Oxford English Dictionary
QoL	Quality of Life
SI	Symbolic Interactionism
Tx	Transplantation
WHO	World Health Organization

# CHAPTER ONE: INTRODUCTION TO THE STUDY

This thesis examines the beliefs and perspectives of German patients who have received a renal transplant, regarding their intake of immunosuppressive medication (IM) and the impact of these drugs on their lives. It also examines the facilitators and barriers to medication adherence in these patients. This establishes a basis from which healthcare professionals can adapt their care, and possibly the setting they act in, to meet the needs of their patients and ameliorate their care.

This work is divided into eight chapters: this chapter, Chapter One, will provide an introduction to the study, outlining the context and background of the research question, aims, and intended outcomes. This will include the operational concept definitions forming the framework of this research. Chapter Two will be dedicated to an in-depth introduction and discussion of the terms of reference of this research; that is, the terms related to medication-taking behaviour, namely *compliance*, *adherence*, *concordance*, and *persistence*. This will conclude with a rationale for the use of the term *adherence* in this work. In this chapter, the statutory and medical state of renal transplantation in Germany will also be outlined to provide the reader with the necessary understanding of the situation of German renal transplant recipients. Additionally, the special circumstances of renal transplant recipients in regard to medication adherence will be discussed.

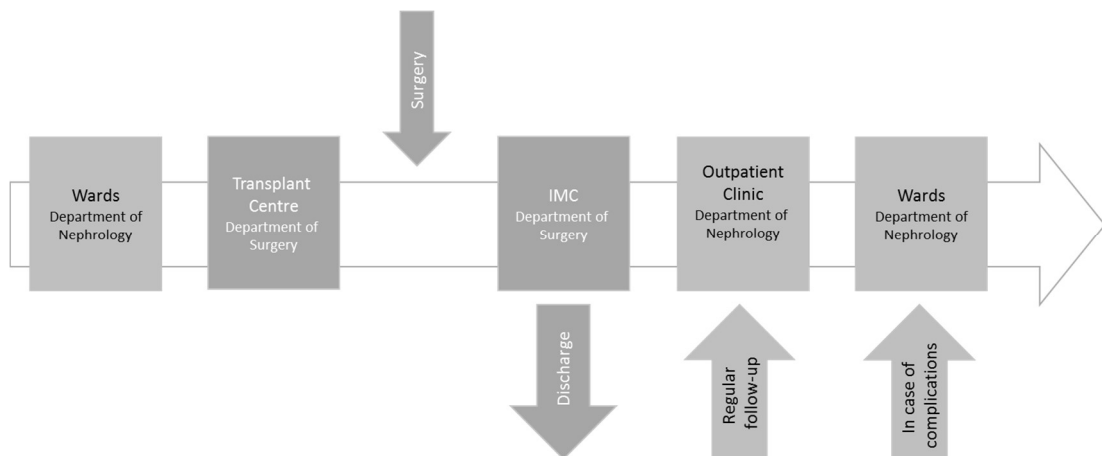
Chapter Three provides an appraisal of the literature and discusses the available evidence for factors facilitating or hindering medication adherence in renal transplant recipients. This chapter will also outline and discuss the gaps in evidence that have contributed to the research questions guiding this study. Chapter Four will establish and justify my own ontological position as a researcher that has led to the choice of methodology. It will also introduce and discuss methodological aspects of this study, focusing on Grounded Theory (GT) and its philosophical roots in Symbolic Interactionism (SI), and will discuss the development of GT over the past years. Finally, Chapter Four will discuss GT in relation to this research.

Chapter Five presents this study's research design and will discuss issues related to the realisation of the research, including sampling and data management, which is the strategy of data collection and analysis. It will also discuss ethical considerations and issues related to rigour. Subsequently, Chapter Six will present the findings of this study and a secondary literature review will be carried out. Chapter Seven will discuss the findings in detail in relation to the available evidence. Chapter Eight will offer recommendations for future research, as well as considerations on the clinical application of the findings. This chapter will also discuss the strengths and weaknesses of this research and contain a final conclusion.

## **1.1 Setting the Scene**

My area of practice is the Centre for Internal Medicine of a major German university hospital. As an advanced practice nurse in the Department of Nephrology and Primary Care and the Department of Pneumology, I often care for patients who have received kidney or lung transplants. The lung transplant programme at my hospital is small, and thus my work focuses primarily on the care of renal transplant recipients. My work involves direct care for these patients, and additionally, I regard it as crucial to equip the nurses on the wards with the necessary knowledge and with both communication and practical skills to provide the best possible care for our patients.

In my institution, as Figure 1 illustrates, the typical treatment path of someone undergoing renal transplantation spans two departments and involves several wards and outpatient clinics, each equipped with staff nurses, physicians, and surgeons as appropriate. The preparation for kidney transplantation, as well as the actual transplantation surgery, occurs in the Department of General and Visceral Surgery, where direct post-operative care also takes place. Patients who have undergone kidney transplantation typically receive treatment and care for about two weeks on an intermediate care unit (IMC), until they are discharged home or transferred to a rehabilitation centre. Long-term follow-up is then continued in my area of practice, the Department of Nephrology and Primary Care, where patients are cared for in the outpatient clinic and admitted to the ward for routine biopsies or if complications occur. This department is equipped with 43 beds on two wards, one-third to one-half of which are typically occupied with renal transplant recipients suffering from diverse complications, with organ rejection being the leading admission diagnosis.



**Figure 1: Typical kidney transplantation treatment path in my institution**

Abbreviations: IMC = Intermediate Care Unit



## 1.2 The Research Problem

One reason, among many, for graft deteriorations or rejection episodes in renal transplant recipients may be poor adherence to the immunosuppressive medication (Howard et al. 2002; Sellarés et al. 2012) that they must take on a daily basis to prevent rejection of the transplant (Achille et al. 2006). These drugs are potent but come with a variety of debilitating side effects (Kley & Sasse 2003; Fiebiger et al. 2004; International Transplant Nurses Society 2007a; International Transplant Nurses Society 2007b; Rote Liste® Service GmbH 2014) and must be taken accurately for establishment and maintenance of appropriate levels in the blood (Krämer et al. 2012; Johnston 2013). A broad evidence base shows that internationally, many renal transplant recipients experience problems with taking their IM as prescribed by their healthcare professional (Denhaerynck et al. 2005; Dew et al. 2007).

My own work on the wards, as well as communication with staff nurses, indicates that renal transplant recipients are predominantly perceived as 'uncomplicated' patients due to their relative capability for self-care. The perception of renal transplant recipients as being 'easy to handle' causes several problems, of which one is a view that these patients do not need much nursing care. This perception arises not from a lack of interest, but rather from nurses making difficult prioritisations under heavy workloads. The patient-to-nurse ratio in Germany is 13, the highest in Europe and much higher than the ratio of seven in England (Aiken et al. 2012). It is therefore comprehensible that possible problems experienced by renal transplant recipients, including medication-taking behaviour, are not addressed by nurses. Moreover, all issues related to medication are regarded as the domain of physicians rather than nurses.

On the other hand, my frequent visits to the outpatient clinic and ward rounds have indicated that physicians rarely address the issue of medication-taking, despite claims of adherence to guidelines (KDIGO 2009), a problem confirmed by an internal audit (Steffl 2009). Physicians do not regard non-adherence as problematic, or, as one put it in direct conversation, “we don’t have an issue with adherence here.”

These observations led to my decision to engage with this issue in my Master’s thesis, where I reviewed the literature on medication adherence in renal transplant recipients. This review revealed that internationally, medication adherence is regarded one of the major issues following kidney transplantation. Two issues emerged from the review. First, I was surprised by the marginal attention that the topic, predominantly regarded a behavioural phenomenon (Leventhal & Cameron 1987; Sabaté 2003; Munro et al. 2007), had attracted from qualitative researchers. Secondly, I found no sources that considered perceptions of medication adherence in German renal transplant recipients. Both issues will be discussed in more depth in Chapter Three of this thesis.

### **1.2.1 The Research Question**

The discrepancy between the knowledge gained from my Master’s thesis and my experiences in my daily practice led to the development of the main question guiding this research, which is: “How do German renal transplant recipients perceive the processes leading to medication adherence or non-adherence?”

This question is underpinned by several more specific questions:

- How do German renal transplant recipients perceive the need to take medication on a daily basis?
- Does the daily intake of medication impact the lives of patients? If yes, to what extent?
- Which underlying processes promote or hinder medication adherence?
- How do patients perceive the role of healthcare professionals in their medication-taking behaviour?

### **1.2.2 Aims and Outcomes**

This research aims to understand the processes leading to medication adherence or non-adherence in German renal transplant recipients, by

- exploring the beliefs and perspectives of German renal transplant recipients regarding the intake of immunosuppressive medication;
- learning how IM impacts participants' lives;
- determining the role of adherence or non-adherence from the patients' perspective;
- gaining insight into barriers to, or facilitators of, medication adherence; and
- determining the role of healthcare professionals in medication adherence.

Consequently, the outcome is two-fold: first, an understanding of participants' points of view regarding medication adherence, and secondly, a theory explaining the processes leading to medication adherence and non-adherence, respectively. This will be achieved by

- understanding how German adult renal transplant recipients perceive medication-taking;
- establishing how IM impacts the participants' lives;
- determining whether renal transplant recipients perceive non-adherence as relevant for themselves, and if yes, to what extent;
- being aware of factors promoting or inhibiting medication adherence from the participants' perspective; and
- establishing a basis from which healthcare professional can adapt their care, and possibly the setting in which they act, to meet the needs of their patients.

### **1.2.3 Benefits, Justification and Costs**

This study will contribute evidence of German renal transplant recipients' perspectives on medication adherence. Knowledge of patients' perspectives is important as it will provide a basis from which healthcare professionals in Germany, especially nurses, can plan and implement patient education programmes. In particular, cultural aspects specific to experiences with German health systems may contribute to a better understanding of my patients and provide starting points to ameliorate their care. It is also hoped that findings from this study will help to address possible non-adherence in a non-threatening way that embraces and respects patients' beliefs and wishes and meets their needs in relation to their medication-taking behaviour.

Failure to uncover the full facts may make change more challenging in several respects. Leaving some research questions unanswered would limit the knowledge base and make it more difficult to design education programmes to foster medication adherence among renal transplant recipients. Also, means of effective communication could not be used if the wishes and perspectives of German renal transplant recipients were to remain unknown. The same applies to possible cultural or country-specific barriers to adherence that may be in place in Germany.

### **1.3 Context and Background of the Focus of the Study**

This study engages with medication adherence in the context of kidney transplantation in Germany. The central concept of this work is medication adherence, particularly adherence to immunosuppressive medication after kidney transplantation. The subsequent sections introduce the concept of medication adherence following renal transplantation, as well as the German context of kidney transplantation. These issues will be discussed in more depth in Chapter Two.

### **1.3.1 Immunosuppressive Medication Following Kidney Transplantation**

Following renal transplantation, kidney transplant recipients are required to follow a strict medication regimen that suppresses their immune system in order to prevent rejection of the transplanted graft (Achille et al. 2006). This therapy is usually accompanied by a variety of drugs for co-morbidities and side effects, such that renal transplant recipients often need to take more tablets than they did prior to transplantation. Moreover, IM in particular must be taken accurately, usually at twelve-hour intervals, to achieve and maintain stable blood levels within narrow therapeutic margins (Krämer et al. 2012; Johnston 2013). If IM is not taken on a strictly regular basis, the risks of complications and rejection of the transplanted kidney are significantly elevated and lead to re-hospitalisations, placing a rising financial burden on the healthcare system (Sabaté 2003; Nevins & Matas 2004; Sokol et al. 2005; Chisholm et al. 2007; Gordon et al. 2009).

Nevertheless, both research and clinical practice have shown that correct intake of IM is a major problem for renal transplant recipients (Denhaerynck et al. 2005; Dew et al. 2007) and many transplant failures result, at least partly, from non-adherent behaviour (Butler et al. 2004c; Morrissey et al. 2005; Chisholm et al. 2007). In comparison to recipients of other solid organs, kidney recipients tend to display earlier (Sabaté 2003; Nevins & Matas 2004; Osterberg & Blaschke 2005; Hansen et al. 2007) and more pronounced (Hansen et al. 2007) non-adherent behaviour. The reasons for this are diverse and are not restricted to patient 'failure' (Sabaté 2003), but rather include potential obstacles in all stages of the medication-taking process. Possible causes of non-adherence will be discussed in Chapter Three.

Despite the magnitude and impact of the problem, it is rarely addressed by healthcare professionals or patients. This silence leads to an atmosphere of concealment that hinders engagement with the issue, preventing identification of possible barriers and encouragement of patients in overcoming them, as will be discussed in Chapter Two.

### 1.3.2 Operational Concept Definition

Whether or not patients follow the advice given by their healthcare professional is commonly referred to using one of the terms: *compliance*, *adherence*, *concordance*, or *persistence* (Vrijens et al. 2012). The application of these terms in clinical practice has developed considerably since the term *compliance* was introduced in the 1970's (Lehane & McCarthy 2009). However, *compliance* is being replaced by *adherence* or *concordance* in the international literature for several reasons. Among these, the term *compliance* is regarded as representing a hierarchical, and perhaps even paternalistic, relationship between patient and healthcare provider (Kyngäs et al. 2000; Bissell et al. 2004; Ingram 2009), putting the patient in an obedient role rather than granting him or her responsibility in the medication-taking process. From my own perception, this is the case in the German healthcare system, where the term *compliance*, or rather *Incompliance*<sup>1</sup>, as it is referred to in German, is still predominantly used in clinical practice. *Incompliance* carries a negative connotation, implying that patients not only ignore medical advice but also are 'difficult.'

The term *adherence* was introduced to provide a more neutral point of view and avoid an assignment of guilt (Bissell et al. 2004). *Adherence* also takes into account that the actual intake of medication is just one step in the complex process of medication-taking (Sabaté 2003). Furthermore, the term represents patients and healthcare providers as equals and emphasises the patients' responsibility in the process of medication-taking (Vermeire et al. 2001; Tilson 2004).

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<sup>1</sup> Nouns are generally capitalised in German

*Concordance*, a term recommended by the Royal Pharmaceutical Society of Great Britain (RPSGB), is predominantly used in the United Kingdom (UK). This term was introduced to remove some of the ideological issues associated with *compliance* and *adherence* (Bissell et al. 2004) and instead place emphasis on the crucial process in regard to medication-taking: the process of negotiation between patient and healthcare provider leading to shared decision-making. In this respect, however, *concordance* cannot be regarded as a synonym for the preceding terms (Horne et al. 2005), but rather suggests a new way of communicating. Similarly, *persistence* describes the duration of the intake of medication (Vrijens et al. 2012) rather than the many steps comprising the whole process of medication-taking.

Following these and other considerations, discussed in more depth in Chapter Two, this work will consequently utilise the terms *adherence* and *non-adherence*.

### **1.3.3 Kidney Transplantation in Germany**

As in many other countries, kidney transplantation is well-established in Germany and is the preferred treatment option for end-stage renal disease (ESRD) (Wolfe et al. 1999; Ogutmen et al. 2006) for both medical and financial reasons. Survival time is higher (Wolfe et al. 1999), and quality of life (QoL) better (Dew et al. 1997; Neipp et al. 2006), for patients post-transplant than for their peers on dialysis treatment. Moreover, the financial costs of dialysis treatment exceed those of kidney transplantation within two years (Lattrell & Abendroth 2007).



As a result, approximately 76,000 kidneys have been transplanted since 1963 in Germany (Deutsche Stiftung Organtransplantation 2014), in 40 transplant centres that typically are integrated into university hospitals (Deutsche Stiftung Organspende 2015). However, Germany faces a severe lack of donor organs and associated challenges regarding its renal transplant programmes. The number of patients on the waiting list is rising, and the average waiting time for a deceased donor kidney donation is six to seven years (Deutsche Stiftung Organspende 2016). In the federal state in which I live and work, waiting times of ten or more years are not uncommon.

The waiting time for a kidney in Germany is longer than in other European countries (Stel et al. 2012), perhaps partly due to comparatively strict legislation regarding allocation of donor organs. In contrast to other European countries, for example, a diagnosis of brain death of a potential donor is required before organ procurement can occur, which means that non-heart-beating donations are illegal. Moreover, the German transplant act requires an expanded consent procedure whereby organ donation requires explicit consent from either the deceased persons or their relatives. Living donation is limited to close relatives or other persons with an evident close relationship to the recipient (Bundesministerium der Justiz und für Verbraucherschutz 2007). The German legislation on organ donation and procurement will be discussed further in Chapter Two.

Germany has recently been shaken by a series of scandals in solid organ transplantation (Spiegel Online International 2012; Connolly 2013). The first scandal concerned manipulations of the waiting list, especially in the case of liver transplantation. In some instances, certain patients ascended on the waiting list even if they were not qualified, displacing patients in worse states of health. This was not limited to a single transplant centre, suggesting general abuse of the system. The second scandal concerned misconduct in one hospital with regard to diagnosis of brain death. In this case, organ retrieval may have been initiated before the diagnosis of brain death was correctly established. The hospital denied this misconduct, but the public reaction was huge. These scandals have shattered public trust in the system and the numbers of donor organs available for transplantation has since declined considerably (Deutsche Stiftung Organspende 2014).

#### **1.3.4 The Role of the Transplant Nurse in Germany**

As in other countries (ITNS 2007a), nurses care for transplant candidates and recipients through all phases of the transplant process, from the treatment of ESRD and workup for waitlisting through to post-operative care and long-term follow-up. Nursing care in the different stages of the transplant process includes diverse tasks such as personal hygiene, infection prevention, wound assessment and management, drug administration, and patient education, just to mention some.

Nurses, however, are predominantly found in hospital settings, as in Germany they rarely work outside hospitals. In terms of the transplant process, this means that both before transplantation and in the long-term follow-up phase nurses see patients infrequently, as the treatment of ESRD and the long-term follow-up after transplantation typically take place in nephrology practices outside hospitals.

In contrast to other nursing specialisations such as psychiatric care, oncology care or intensive care, there is no state-approved course for transplant nursing in Germany. However, in order to close this gap, the first transplant nursing curriculum based on the International Transplant Nurses' core curriculum (ITNS 2007a) and the scope and standards of transplant nursing as approved by the American Nurses Association (International Transplant Nurses Society & American Nurses Association 2009) was established in 2011 (Rebafka et al. 2013).

## **1.4 Summary of Chapter One**

In giving an overview on the background of kidney transplantation, this chapter has put the research problem and corresponding research questions into the context of the legal and clinical situation in Germany. In this respect, it has also briefly reviewed some of the problems associated with medication-taking by renal transplant recipients and introduced terminology associated with the medication-taking process. Finally, it has introduced the reader to the role of the German transplant nurse. The next chapter will introduce the terms of reference for the study and provide a comprehensive discussion of the terms surrounding medication-taking. It will conclude with a comprehensive definition of adherence.

## CHAPTER TWO: TERMS OF REFERENCE

This chapter provides a systematic and comprehensive discussion regarding the concept of adherence and how it is operationalised within the study. First, a conceptual definition of adherence will be provided, then the concept positioned within the field of study. This will be achieved by discussing terminology in the healthcare literature, as well as providing an account of the historical development of the terminology. Following this, the predominantly used terms, *compliance*, *adherence*, *concordance*, and *persistence*, will be compared and contrasted to provide a comprehensive rationale for the utilisation of the term *adherence* in this study. This will be followed by background information regarding adherence in renal transplant recipients to clarify the importance of adherence and non-adherence among a special and vulnerable group of people.

### 2.1 Operational Concept Definition of Adherence

Whether or not patients take their medication as prescribed by a healthcare provider, who in Germany must be a licensed physician, has been a subject of discussion since the beginnings of modern medicine. The first observation of patients not taking their medication is accredited to the ancient Greek physician Hippocrates (540 – 370 BC) who reportedly stated that patients might have not taken their medication even if they asserted they had (Sackett 1979). However, an in-depth discussion around this issue did not take place until the 1970's (Lehane & McCarthy 2009). Since then, the behaviour of taking or not taking medication as prescribed or advised has been discussed using different terms, of which *compliance*, *adherence*, *concordance*, and *persistence* are most commonly used (Vrijens et al. 2012). These terms encompass a variety of health-related behaviours, such as exercising, following a diet, attending regular follow-up, avoiding smoking or substance abuse, and more (Sabaté 2003). While this work focuses on medication adherence, this does not imply that other health-related behaviours are not equally important or deserving of attention.

The discussion of terminology for medication-taking behaviour is based on the assumption that the terms presented above have different definitions and are connected with different underlying concepts. However, in the literature, they are often used interchangeably (Bissonnette 2008). Table 1 provides an overview on the most commonly used definitions of these terms, which will be discussed in the following section as the conceptual framework for this research. This section will outline the development of the terminology, examine the meaning of and concepts underpinning each term, and conclude with the rationale behind the use of *adherence* in this work.

Term	Definition	Origin
Compliance	“the extent to which the patients’ behaviour [...] coincides with medical or healthcare advice”	Landmark concept on medication compliance (Sackett & Haynes 1976, p. 2)
Adherence	“the extent to which a person’s behaviour [...] corresponds with agreed recommendations from a health care provider”	World Health Organization (Sabaté 2003, p. 3)
	“the extent to which patients follow the instructions they are given for prescribed treatment”	Cochrane Review (Haynes et al. 2008, p. 3)
Non-adherence	“deviation from the prescribed medication regimen sufficient to influence adversely the regimen’s intended effect”	Non-adherence Consensus Conference (Fine et al. 2009, p. 36)
Concordance	“agreement between the patient and healthcare professional, reached after negotiation that respects the beliefs and wishes of the patient in determining whether, when and how their medicine is taken, and [in which] the primacy of the patient’s decision [is recognised]”	Royal Pharmaceutical Society of Great Britain (RPSGB) (Marinker et al. 1997, p. 1049)
Persistence	“persistence is the length of time between initiation and the last dose, which immediately precedes discontinuation”	(Vrijens et al. 2012, p. 696)

**Table 1: Most commonly used definitions of compliance, adherence, concordance and persistence**

## 2.2 Compliance, Adherence, Concordance and Persistence in the Literature

In order to identify the predominantly used terms in the medical and nursing literature, a broad search of Medline via PubMed and the Cumulative Index of Nursing and Allied Literature (CINAHL) via EBSCO was carried out in January 2015. As search terms, in PubMed, the MeSH-terms *patient compliance* and *medication adherence* were used, together with the terms *medication concordance* and *medication persistence*, for which no MeSH-terms exist. In CINAHL, only *compliance* is indexed as *patient compliance* as a Subject Term Heading, the analogue to MeSH terms, and therefore all other terms were searched as indicated in Table 2. The numbers of hits provided by this search are also shown in Table 2.

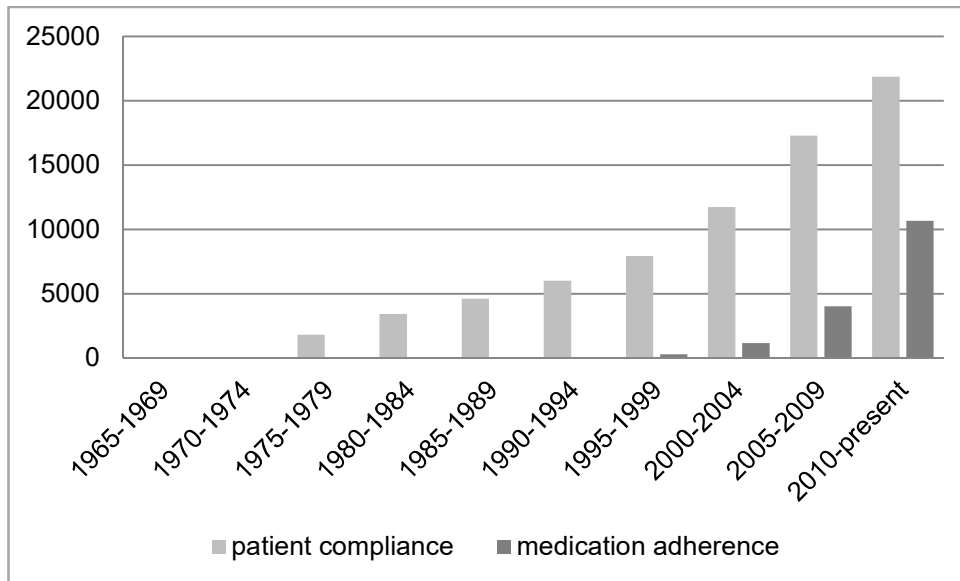
Search Terms	Number of Hits	
	PubMed	CINAHL
Patient compliance	74,276	21,881
Medication adherence	16,199	3,204
Medication concordance	780	50
Medication persistence	16,828	159

**Table 2: Predominantly used terms in medical and nursing literature**

This search reveals that *compliance* is by far the most commonly used term in this context. The high number of hits in the search for *medication persistence* in Pub Med is most likely due to the PubMed indexing policy, which integrates articles on *persistence* under *compliance* and *adherence*, as the screening of hits indicates.

## 2.3 Development of Terminology

Insights into the development of *compliance* and *adherence* over the past 50 years were gained when the PubMed search described above was limited to a period of five years. This search showed a continuing increase in the use of *compliance*, but also a strong increase in *adherence*, which currently represents nearly half of the hits in this context (Figure 2).



**Figure 2: Comparison of the development of compliance vs. adherence**

Both searches reveal existing interest in the issue, but also illustrate a shift in terminology from *compliance* to *adherence* for the description of patient behaviour. Despite past and current discussions, *compliance* still dominates; however, according to the results of the second search, *adherence* has slowly gained importance, as Vrijens et al. (2012) also observe. These results, however, are not to be overestimated, as it is likely that these results include multiple duplicates, with many references including both *compliance* and *adherence* as key words. A similar search in the future may generate different results as terminology continues to change.

## 2.4 Comparison of Terms

As was illustrated in Table 1, terms referring to taking or not taking medication as prescribed have somewhat general definitions. This section discusses each term, including commonalities and differences with others.

### 2.4.1 Compliance

The term first introduced in the 1970s to describe patients' behaviour in regard to medication-taking was *compliance* (Lehane & McCarthy 2009). The most-cited, and landmark, definition of compliance is by Sackett & Haynes (1976): "the extent to which the patients' behaviour [...] coincides with medical or healthcare advice" (p.2). The etymological roots of *compliance* derive from the Latin verb *complere* (to fulfil) that is used in the sense of obedience but may also connote surrender (OED 2015a).

Both the classic Latin meaning of *compliance* and the above definition render the patient a follower of instructions rather than a responsible part of the treatment process. It also incorporates a paternalistic relationship between the healthcare professional and the patient, with the former giving advice and the latter obliged to follow. From this perspective, the responsibility of medication lies exclusively with the patient, and potential other barriers to medication-taking need not be taken into account. Consequently, *compliance* applies primarily to negative aspects of patients' behaviour (Hobden 2006) in both English and German, where *Compliance* and *Incompliance* (non-compliance) have been introduced as loan words.

Judging a patient as being *incompliant* in German has extremely negative connotations, similar to labelling the respective patient 'difficult' or even 'bad'. Moreover, non-compliance or "personal history of noncompliance with medical treatment and regimen" (World Health Organization 2012a, no page) represents a medical diagnosis in the current version of the International Classification of Diseases (ICD) as a subgroup of "personal history of risk-factors, not elsewhere classified" (World Health Organization 2012b). Even a single diagnosis as non-compliant may cause serious problems for a patient, as this is likely to remain in the medical record for a long time. Consequently, the concept has been redefined to reflect a more patient-centred approach (Kyngäs et al. 2000; Ingram 2009), leading to the emergence of *adherence* around the year 2000.



### 2.4.2 Adherence

The replacement of *compliance* with *adherence* was driven by three main considerations that paralleled a shift in the relationship between healthcare provider and patient. First, a more neutral and less judgmental term than *compliance* was needed (Fraser 2010). Secondly, reflection of a patient-oriented approach, rather than a paternalistic relationship, was proposed (Vermeire et al. 2001). Lastly, a new term would emphasise the responsibility of the patient in the medication-taking process (Tilson 2004).

Like *compliance*, *adherence* has Latin roots, with *adhaerere* (to stick to) meaning “to believe in and follow the practices of” something (OED 2015b). This supports an autonomous patient who must believe in the necessity of the medication before following the prescribed regimen. Although the use of *adherence* has risen considerably in the international literature in recent years (Figure 2) and a direct German translation (*Adhärenz*) is available, the term is not yet integrated into the medical discourse in Germany.

Despite a frequent emphasis on the fundamental advancement of the concept, definitions of *adherence* differ considerably (Bissonnette 2008). This is visible in the two most commonly cited definitions. The best-known definition has been shaped by the World Health Organization (WHO) and defines *adherence* as: “the extent to which a person’s behaviour [...] corresponds with agreed recommendations from a health care provider” (Sabaté 2003, p. 3). In contrast, in a Cochrane review on interventions for enhancing medication adherence, Haynes et al. (2008) use the following definition: “adherence can be defined as the extent to which patients follow the instructions they are given for prescribed treatments” (p. 3).

Both definitions intend to represent a non-judgemental, less paternalistic relationship between prescriber and patient, and to value the patient's role in medication-taking and decision-making processes. However, the Haynes et al. (2008) definition retains similarities with the Sacket and Haynes (1976) definition of *compliance*, even sharpening the tone by replacing the verb 'to coincide' with 'to follow'. While 'to coincide' means "to be in agreement" (OED 2015c), 'to follow' can be defined as "to accept the authority or example of" (OED 2015d). This is also reflected in the shift from 'advice' to 'instruction.' In contrast, the WHO (2003) definition adds the term 'agreed', emphasising the patient's active role and thus changing the underlying concept.

A different approach was taken by Fine et al. (2009), who defined *non-adherence* as "deviation from the prescribed medication regimen sufficient to influence adversely the regimen's intended effect" (Fine et al. 2009, p. 36). This definition differs from previously on two points. First, by defining the problem, rather than the goal, it avoids distributing responsibility, and the use of 'deviation' employs a relatively neutral point of view. Secondly, this definition incorporates a previously neglected issue, which is the possible adverse consequences of the behaviour.

### **2.4.3 Concordance**

A further development of the terminology was suggested in the 1990s by the RPSGB, who introduced the term *concordance* to emphasise the need for patient-centred communication (Marinker et al. 1997; cited in Cushing & Metcalfe 2007). *Concordance* can be defined as:

*agreement between the patient and healthcare professional, reached after negotiation that respects the beliefs and wishes of the patient in determining whether, when and how their medicine is taken, and [in which] the primacy of the patient's decision [is recognised] (p. 1049).*

This definition, however, illustrates that the term is not synonymous with *adherence* or *compliance* (Horne et al. 2005), as it does not describe the process of medication-taking but rather aims to represent a “new way of consulting” (Hobden 2006, p. 257) between the parties involved. Literally meaning “being one of heart or mind” (OED 2015e), *concordance* can be traced back to its Latin etymological roots: the word *concordantia* consists of two parts, *con*, together, and *cor*, heart (Kluge & Seebold 2001). The awareness *concordance* differs from *compliance* and *adherence* may be why the term is predominantly used in the UK (Horne et al. 2005). In the UK, however, *concordance* is often misleadingly used as a replacement for adherence.

#### **2.4.4 Persistence**

The last term describing medication-taking behaviour is *persistence*, defined as “the length of time between initiation and the last dose, which immediately precedes discontinuation [of a medication]” (Vrijens et al. 2012, p. 696). *Persistence* is derived from the French verb *persister* (OED 2015f), to continue, emphasising its time aspect. *Persistence*, therefore, cannot be used synonymously with *compliance* or *adherence*, but rather describes the time-period over which medication is continued, regardless of what causes the medication-taking (Vrijens et al. 2012).

### **2.5 Rationale for Using the Term *Adherence***

The differences between *compliance* and *adherence* are marginal. In contrast, both *concordance* and *persistence* are, in fact, closely related to *compliance* and *adherence* but deal with two distinct features of the medication-taking process: *concordance* is concerned with the relationship and mode of communication between healthcare provider and patient, and *persistence* describes the duration of medication-taking.

Following the work of Fine et al. (2009), this thesis will use the terms *adherence* and *non-adherence*, as defined above, to describe patients' medication-taking behaviour. This decision is based on the following considerations:

- *Compliance* holds such negative implications that an impartial approach toward patients having problems taking their medication seems impossible. In contrast, *adherence* and *non-adherence* facilitate a neutral view that leads to a shared approach in tackling the problem.
- *Adherence* describes medication-taking as a fact, not a diagnosis. This enables both healthcare professionals and patients to take into account factors aside from the patient that may lead to *non-adherent* behaviour. These factors will be highlighted in the next chapter.
- *Adherence* and *non-adherence* enable a solution-driven approach to patients' behaviour, which can form the basis for the joint work of healthcare professionals and patients.

Any indications of a patient being *non-adherent* should be followed by a detailed description of the individual circumstances, including the characteristics and extent of the non-adherent behaviour.

## **2.6 Dimensions of and Approaches to Medication Adherence**

A variety of approaches can be taken to classifying medication adherence with reference to its different aspects. The most popular approaches include dimensions identified by the WHO (Sabaté 2003), and person-related and medication-related approaches to medication adherence.

### 2.6.1 Dimensions of Medication Adherence

Responsibility for regular medication intake has traditionally been assigned to the patient. However, in a landmark paper (Sabaté 2003), the WHO identified five factors influencing medication-taking behaviour. The dimensions comprise social and economic factors, therapy-related factors, patient-related factors, condition-related factors, and healthcare team and system-related factors (Sabaté 2003, p. 27). Table 3 presents an overview of the aspects incorporated in each factor.

Factors Influencing Adherence	Included Aspects
Social and economic factors	<ul style="list-style-type: none"> <li>• gender</li> <li>• age</li> <li>• race</li> <li>• financial issues</li> <li>• education level</li> <li>• employment status</li> <li>• social support</li> </ul>
Therapy-related factors	<ul style="list-style-type: none"> <li>• complexity, stability, and duration of treatment</li> <li>• perception of medication effects and side effects</li> </ul>
Patient-related factors	<ul style="list-style-type: none"> <li>• beliefs and attitudes regarding medication</li> <li>• patient knowledge of treatment and medication</li> <li>• expectations regarding treatment</li> </ul>
Condition-related factors	<ul style="list-style-type: none"> <li>• diseases-related symptoms</li> <li>• co-morbidities</li> </ul>
Health-system and healthcare-team-related factors	<ul style="list-style-type: none"> <li>• relationship between patient and healthcare professionals</li> <li>• organisation of the local healthcare system</li> </ul>

**Table 3: Aspects included in the factors influencing adherence**

The idea of the patient not being the solely party responsible for taking or not taking medication as prescribed has triggered a paradigm change in both the clinical approach to the issue of medication-taking and research on the topic.

## 2.6.2 Approaches to Medication Adherence

There is no consensus on either the definition or classification of *adherence*. This leads to uncertainty about what is meant by *non-adherence*. As Gordon et al. (2007) observe, research on non-adherence often focuses on total omission of medication, to the exclusion of less extreme and more variable presentations. Additionally, identifying non-adherent persons as early as possible in order to offer individualised adherence-enhancing interventions (Russell et al. 2006) demands a profound knowledge of types of non-adherence and a framework that unambiguously classifies these and their extent. These considerations have led to the development of two main approaches toward classification of non-adherence: a medication-related and a person-related approach.

### 2.6.2.1 Medication-Related

Medication-related approaches to non-adherence aim to describe and quantify the extent of the issue. One medication-related perspective classifies adherence according to the proportion of medication taken. Examples include defining *non-adherence* as “missing at least 20% of days medication” (Butler et al. 2004b), or percentage conceptualisations such as

$$\text{Adherence rate} = 1 - \left( \frac{\text{days between refills} - \text{total days' supply}}{\text{days between refills}} \right) \times 100\%,$$

as used by Chisholm-Burns et al. (2010). This classification is known as “taking adherence” (Denhaerynck et al. 2007, p. 111) and is supplemented by “drug holidays”, defined as the omission of medication for 24 hours in once-daily regimens or 48 hours in twice-daily regimens (Denhaerynck et al. 2007, p. 111). Other medication-related approaches include dosing adherence, which is a change in the medication’s dose, or timing adherence, a change in the medication intake times (Denhaerynck et al. 2007; Gordon et al. 2007) exceeding a certain time-frame that may vary depending on the type of medication.

### **2.6.2.2 Person-Related**

In contrast to medication-related classification, person-related approaches classify patients according to their adherence behaviour. This approach includes factors related to self-care and emphasises the patient and his/her beliefs about the necessity of medication. Its aim is not to describe the extent of adherence, but rather to evaluate the reasons behind non-adherent behaviour.

The best-known classification was published by Siegal & Greenstein (1999), who sorted non-adherent patients into three groups. Nearly half of non-adherent patients were “accidental noncompliers” (Siegal & Greenstein 1999, p. 1362) who sometimes failed to take their medication as prescribed due to forgetfulness. The next group of non-adherers comprised “invulnerables” (Siegal & Greenstein 1999, p. 1362), patients who did not believe in the efficacy of the medication or doubted the need for it, regardless of the condition of their kidneys. The third group were “decisive noncompliers” (Siegal & Greenstein 1999, p. 1362), who had distinct beliefs about their medication and opted to change their regimen without consulting a healthcare professional (Gordon et al. 2009).

A similar approach was taken by Wroe (2002), who distinguished between intentional and unintentional non-adherence. Intentional non-adherence resulted from weighing the pros and cons of medication-taking (Wroe 2002) and involved deliberate omission or alteration of medication doses for a purpose, such as positively influencing side effects or saving costs.

### 2.6.2.3 Combining Different Approaches

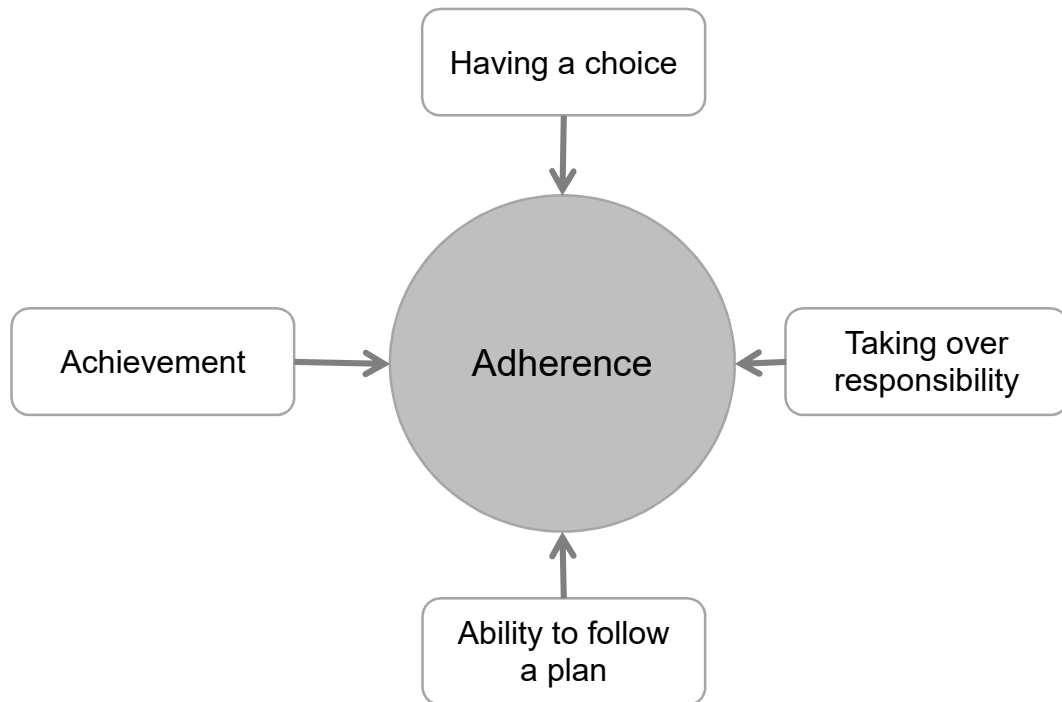
In an attempt to diagnose “noncompliance syndrome” (Chapman 2004, p. 782), four aspects of non-adherence were identified that represented a combination of medication- and person-related approaches to medication non-adherence. These aspects are timing, frequency, origin and diagnostic certainty, and are needed to diagnose non-adherence. Timing describes the point in time of the onset of non-adherence (see the section on *persistence* in this chapter), frequency specifies the extent of the issue, origin is concerned with the causes of non-adherence, and diagnostic certainty describes the likeliness of the behaviour (Chapman 2004). This combination offers the chance to identify non-adherent behaviour, quantify its extent, and evaluate possible causes.

## 2.7 Defining Attributes of Adherence

In one of the assignments that formed the taught phase of this doctorate, I carried out a concept analysis of adherence as proposed by Walker & Avant (1998). This approach includes the determination and discussion of attributes defining adherence, to differentiate the phenomenon from other similar or related phenomena. Defining attributes also illustrate terms connected with the concept of interest and enable a comprehensive insight into it by building a framework (Walker & Avant 1995). Although this approach has been criticised as “arbitrary and vacuous” (Paley 1996, p. 578), in the context of this work, defining attributes can be helpful for a better understanding of the concept, serving as the framework for this research.

The concept of adherence (Figure 3), comprises four defining attributes: having a choice, taking over responsibility, ability to follow a plan, and achievement. Following the seminal work by the WHO (Sabaté 2003) as outlined above, the five dimensions of adherence and its defining attributes are closely connected. While the defining attributes may be attributed to either the patient or the healthcare professional at first glance, closer consideration reveals that all dimensions interact with the defining attributes.





**Figure 3: Defining attributes of adherence**

The most common definitions of adherence and non-adherence (Sabaté 2003; Haynes et al. 2008; Fine et al. 2009) emphasise that having a choice is vital for adherence. This approach is also reflected in the word's etymology, as outlined previously. Choice may occur predominantly on the patient side, but healthcare providers are also entitled to considerable choice in the medication-taking process. Responsibility also applies to all parties involved in the process; whilst healthcare professionals are responsible for providing the best possible care, their patients are responsible for taking the medication as negotiated. Both parties are also responsible for the intended effect of medication. However, other dimensions of adherence, such as the healthcare system, may interfere with the taking of responsibility.

The attribute primarily connected with patient-related factors is his or her ability to follow a plan. However, if an individual patient cannot follow a plan, this attribute needs to be supported by someone else, and thus the issue returns to responsibility. Still, ability to follow a plan is not exclusively patient-related, as the patient may experience barriers that may be out of his or her control, again connecting this attribute to the other dimension of adherence as outlined by Sabaté (2003).

Finally, achievement, the last attribute of adherence, is reflected in the definition of non-adherence by Fine et al. (2009), taking into account the possibility of not achieving adherence and the possible consequences, namely to “adversely [influence] the regimen’s intended effect” (Fine et al. 2009, p. 36). However, non-achievement, or failure, of adherence may occur despite all efforts across all dimension of adherence, again emphasising that the patient is not the only responsible party in the medication-taking process.

## **2.8 Non-Adherence in Renal Transplant Recipients**

This section will outline basic topics regarding the issue of medication adherence in kidney transplant recipients. A broad overview of chronic kidney disease, including treatment options, will be followed by a discussion of IM. An introduction to medication adherence will be given and facts on non-adherence in renal transplant recipients will be provided.

### **2.8.1 Chronic Kidney Disease and its Treatment**

CKD is one of the most common chronic diseases worldwide. Around 10% of the world’s population suffer from this condition in various stages (Jha et al. 2013; The Lancet 2013). CKD comes in five stages (Table 4) and is defined as a decline in renal function; that is, a reduced glomerular filtration rate (GFR) and/or increased urinary albumin excretion (Jha et al. 2013), exceeding a duration of three months (Stevens & Levin 2013). The major criterion for the classification of CKD is GFR, the amount of glomerular filtrate formed per minute, which is about 125 mL/min in healthy persons (Chalmers 2008). In this classification system, stage V is defined as kidney failure, or end-stage renal disease (ESRD), with the patient requiring dialysis treatment.

	GFR (mL/min)	Descriptor
Stage 1	≥ 90	Normal or high
Stage 2	60-89	Mildly decreased
Stage 3a	45-59	Mildly to moderately decreased
Stage 3b	30-44	Moderately to severely decreased
Stage 4	15-29	Severely decreased
Stage 5	<15	Kidney failure

**Table 4: Stages of CKD (Stevens & Levin 2013)**

Treatment options for ESRD are either peritoneal, haemodialysis, or kidney (or renal) transplantation. In Germany, most patients with ESRD undergo haemodialysis treatment, with only 5% treated using peritoneal dialysis (Frei & Schober-Halstenberg 2008). In Germany, undergoing dialysis treatment typically means three four- to five-hour dialysis sessions per week in dialysis centres that may or may not be affiliated with hospitals. However, while dialysis treatment is a lifesaving procedure, patients with ESRD undergoing dialysis treatment suffer from a variety of symptoms. These may include fatigue/tiredness, pruritus, constipation, anorexia, pain, sleep disturbance, anxiety, dyspnoea, nausea, restless legs, and depression (Murtagh et al. 2007).

Of the three treatment options for ESRD, kidney transplantation is the preferred method for suitable patients (The European Renal Best Practice Transplantation Guideline Development Group 2013). Despite obstacles regarding kidney transplantation, this treatment method is regarded as the preferred option, as it offers better outcomes than haemodialysis or peritoneal dialysis from both medical and financial perspectives. However, from the patients' perspective, the decision regarding their treatment modality is not easy (Morton et al. 2010), especially if no living donation is possible.

The graft survival time in European kidney transplant recipients is high; 91% of grafts survive the first year, 77% survive for five years, and 57% of transplanted kidneys remain functional ten years post-transplantation (Gondos et al. 2013). However, in Germany, the probability of having a functioning kidney five years after transplantation is 74%, slightly lower than the international level (Deutsche Stiftung Organtransplantation 2014). Generally, the survival time of patients with a kidney transplant exceeds the survival time of patients on dialysis (Wolfe et al. 1999). Post-transplant patients benefit from better quality of life (QoL) than patients on dialysis (Dew et al. 1997). There are hints that QoL following kidney transplantation is comparable to that of the general population (Neipp et al. 2006), while both types of dialysis treatment are associated with reduced QoL (Maglakelidze et al. 2011).

Regarding financial aspects, health economic research has shown that kidney transplantation is the more cost-effective treatment of ESRD in many countries, including Germany (Lattrell & Abendroth 2007; Howard et al. 2009; Blotière et al. 2010; Jensen et al. 2014). In Germany, kidney transplantation costs between 50,000 € and 65,000 €, while one year of dialysis costs between 25,000 € and 50,000 €, meaning that a kidney transplantation is paid off within two years of dialysis (Lattrell & Abendroth 2007).

According to the European Renal Best Practice guideline (The European Renal Best Practice Transplantation Guideline Development Group 2013), all patients on dialysis or shortly requiring dialysis are regarded as suitable for kidney transplantation. Individual decisions regarding kidney transplantation must be made (The European Renal Best Practice Transplantation Guideline Development Group 2013) if one of the following is present:

- Current oncological disease or a history of cancer
- Unstable HIV infection or non-adherence to medical treatment in HIV-positive patients
- Alcohol dependence
- A high-risk cardiovascular profile

In 2013 alone, 2,272 kidneys from either living or deceased donors were transplanted in Germany (Deutsche Stiftung Organtransplantation 2014), and nearly 76,000 kidney transplantations have been performed in Germany since 1963 (Deutsche Stiftung Organtransplantation 2014). However, solid organ transplantation, and particularly renal transplantation, faces several challenges in Germany. In contrast to other countries, for example, the German transplant act makes strict prescriptions for the use of grafts from non-heart-beating donors, consent for transplantation, and living kidney donation (Bundesministerium der Justiz und für Verbraucherschutz 2007).

In many countries, kidney grafts from non-heart-beating donors – that is, persons “dying from cardiorespiratory arrest” (Bos 2005, p. 574), who have not been diagnosed as brain-dead – are routinely used for transplantation. This practice is illegal in Germany, where the diagnosis of brain death is the first prerequisite for organ procurement in deceased donors. The removal of a kidney from a brain-dead donor also requires the consent of the deceased donor or close relatives, who must follow the presumed will of the deceased person. The national transplantation act (Bundesministerium der Justiz und für Verbraucherschutz 2007) also requires that

*the removal of a kidney [...] is only permitted for the purpose of transfer to first or second degree relatives, spouses, registered partners, fiancées or other persons who have an obvious and particularly close relationship<sup>2</sup>*  
(§8)

which eliminates anonymous or non-directed kidney donations.

For these and other reasons, there is a severe shortage of donor organs in Germany, which has increased patients’ time on the waiting list to six to seven years on average (Deutsche Stiftung Organspende 2016); but, in my personal experience, waiting times of ten years are common.

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<sup>2</sup> Own translation

Despite the undoubted benefits of kidney transplantation, it is not a 'cure' for ESRD (Tong et al. 2009), and renal transplant recipients are therefore not 'healthy' as is often misleadingly assumed by the public and the recipients themselves. This is despite the fact that the surgical techniques are well established (Koch et al. 2015) and less than 20% of patients experience postoperative complications requiring surgical, endoscopic or radiological interventions (Kantas 2014), and the long-term survival rates of the graft and patient are high. Hence, emphasis in the care of renal transplant recipients has shifted from short-term to long-term follow-up (Luk 2004; Schäfer-Keller et al. 2006; Dobbels 2009; Drent 2009), leading to a view of renal transplant recipients as chronically ill patients. This long-term care aims to prevent complications, such as rejection or infections, to enable the patient to keep the transplanted kidney as long as possible.

### **2.8.2 Adherence to Immunosuppressive Medication**

The development of emphasis on long-term care following kidney transplantation is connected with the development of powerful IM. Following kidney transplantation, renal transplant recipients, like all recipients of solid organs, must take IM on a regular basis to prevent rejection of the transplanted organ (Achille et al. 2006). After pre- or intra-operative induction therapy, the medication regimen in Germany typically consists of a triple therapy of two types of IM, a calcineurin inhibitor and an anti-proliferative agent, along with cortisone. This regimen must be taken accurately at specific times at least once, but more commonly twice, daily (Krämer et al. 2012). Also, IM must be monitored very closely, as the dosing is delicate and must be carefully balanced between overdose and under-dose. Often, this medication is accompanied by other drugs that treat underlying diseases or co-morbidities, as well as side effects of the IM. It is therefore common that a renal transplant recipient takes more tablets than before transplantation. Although patients are informed about this prior to surgery, my impression is that freshly-transplanted persons are frequently overwhelmed by the amount of medication they need to take.

The need for regular medication to prevent complications or aggravations of a disease is not exclusive to solid organ transplant recipients, but rather a feature shared with many other chronically ill patient groups. In most chronic conditions relying on medication-taking, from mental illnesses to HIV infections, regular intake of medication is a difficult issue for many patients (Sabaté 2003; Haynes et al. 2008). The consequences of non-adherence are severe, in terms of both medical and financial concerns.

Medical consequences of non-adherence may include sub-optimal clinical benefits, re-hospitalisations, deterioration of the disease, medical or psychosocial complications, and reductions in the patient's QoL (Sabaté 2003; Sokol et al. 2005). In renal transplant recipients, poor adherence can induce rejection, which may lead eventually to loss of the transplant (Nevins & Matas 2004; Chisholm et al. 2007; Gordon et al. 2009). Non-adherent renal transplant recipients face a seven- to eight-fold risk of graft loss compared to their adherent peers (Chisholm et al. 2007; Takemoto et al. 2007).

In financial terms, the consequences of not taking medication as prescribed place an estimated annual financial burden of €13 billion on the German healthcare system (Laschet 2013), a sum exceeding the total cost of the treatment of coronary heart disease (Gorenoi et al. 2007). The German Federal Statistical Office (2014) has recently estimated that a minimum of 3% of the total healthcare spending in Germany goes to the consequences of medication non-adherence, and with growing numbers of chronically ill patients, this number is likely to rise. No data could be found regarding the financial consequences of medication non-adherence following renal transplantation in Germany. However, older data from 2004 suggests that in the USA alone, between 14 and 16 million US\$ were spent to treat non-adherence-related episodes of rejection (Hansen et al. 2007).

Intake of IM may be challenging. Most IM is associated with severe side effects (Table 5) (Kley & Sasse 2003; Fiebiger et al. 2004; International Transplant Nurses Society 2007a; International Transplant Nurses Society 2007b; Rote Liste® Service GmbH 2014). In a review, Kugler et al. (2009) showed that many recipients of solid organ transplants experience a variety of distressing symptoms related to IM.

Steroids	Calcineurin Inhibitors (CsA, Tacrolimus)	Anti-Proliferative Agents (Azathioprine, MMF)	mTOR-Inhibitors (Sirolimus, Everolimus)
<ul style="list-style-type: none"> <li>• Infections</li> <li>• Diabetes</li> <li>• Hypertension</li> <li>• Hyperlipidaemia</li> <li>• Osteoporosis</li> <li>• Delayed wound healing</li> <li>• Stomach irritation/ulcers</li> <li>• Oedema</li> <li>• Candidosis</li> <li>• Cataracts</li> <li>• Glaucoma</li> <li>• Increased appetite</li> <li>• Weight gain</li> <li>• Alopecia</li> <li>• Acne</li> <li>• Mood changes</li> <li>• Cushingoid appearance</li> </ul>	<ul style="list-style-type: none"> <li>• Infections</li> <li>• Renal failure</li> <li>• Diabetes</li> <li>• Arterial hypertension</li> <li>• Malignancies</li> <li>• Hand tremors</li> <li>• Gingival hypertrophy</li> <li>• Thrombotic thrombocytopenic purpura/haemolytic uraemic syndrome</li> <li>• Nausea</li> <li>• Diarrhoea</li> <li>• Cephalalgia</li> <li>• Insomnia</li> <li>• Numbness</li> <li>• Tingling of hands and feet</li> <li>• Hirsutism</li> <li>• Acne</li> <li>• Alopecia</li> <li>• Depression</li> </ul>	<ul style="list-style-type: none"> <li>• Infections</li> <li>• Diarrhoea</li> <li>• Bone marrow suppression</li> <li>• Stomach irritation</li> <li>• Mouth sores</li> <li>• Nausea, emesis</li> <li>• Fatigue</li> <li>• Thrombotic thrombocytopenic purpura/haemolytic uraemic syndrome</li> <li>• Cephalalgia</li> <li>• Alopecia</li> <li>• Arthritis</li> <li>• Muscle cramps</li> </ul>	<ul style="list-style-type: none"> <li>• Infections</li> <li>• Hyperlipidaemia</li> <li>• Pancreatitis</li> <li>• Delayed wound healing</li> <li>• Thrombotic thrombocytopenic purpura/haemolytic uraemic syndrome</li> <li>• Acne</li> <li>• Alveolitis</li> </ul>

**Table 5: Side effects of IM.**

Abbreviations: CsA = Cyclosporine A, MMF = Mycophenolat Mofetil, mToR = mechanistic Target of Rapamycin

Due to the immune system suppression, patients taking IM are at higher risk of acquiring infections than the general population. Patients thus need to consider food safety, general hygiene, and contact with others (International Transplant Nurses Society 2007b). Moreover, many IMs are nephrotoxic agents (Table 5), meaning that regular intake of the medications may slowly destroy the transplanted kidney.



Research has shown that non-adherence is a major international problem among renal transplant recipients. About one-third of recipients display some extent of non-adherence at some time (Denhaerynck et al. 2005; Dew et al. 2007); exact numbers for German kidney transplant recipients are not known. Around one-third of kidney graft losses are caused by medication non-adherence (Butler et al. 2004c; Morrissey et al. 2005; Chisholm et al. 2007).

In renal transplant recipients, non-adherence may occur in different forms. These include timing adherence, or taking medication correctly at specific times of day, and dosing adherence, or taking the correct dose (Osterberg & Blaschke 2005). In renal transplant recipients, both forms of adherence deserve attention, as IMs are narrow therapeutic index (NTI) drugs; that is, the patient's blood levels must be monitored closely in order to avoid reduced immunosuppression and its associated risk of rejection, as well as possible toxicity and severe side effects (Johnston 2013).

Two features of non-adherence in renal transplant recipients warrant closer attention. First, kidney transplant recipients are significantly less adherent than recipients of other solid organs. In a meta-analysis, Dew et al. (2007) showed that 35.6% of renal transplant recipients displayed some extent of medication non-adherence, compared to only 6.7% of liver recipients and 14.5% of heart recipients. Similar results were found by Hansen et al. (2007). Reasons for this are largely unknown, but causes of non-adherence in renal transplant recipients will be discussed in detail in Chapter Three. The second feature unique to renal transplant recipients' adherence is that non-adherence occurs relatively early after transplantation (Sabaté 2003; Nevins & Matas 2004; Osterberg & Blaschke 2005; Hansen et al. 2007), although no satisfactory explanations for this have been advanced to date.

It is thus unsurprising that graft rejection is a leading admission diagnosis in renal transplant recipients to my area of practice, the Department of Nephrology and General Medicine at a major German university hospital. Although graft rejection may have diverse aetiologies (Howard et al. 2002; Sellarés et al. 2012), a likely explanation is non-adherence, given its prevalence among renal transplant recipients. Therefore, this issue must be actively addressed when caring for these patients, as the appropriate international guideline (KDIGO 2009) recommends.

However, in my area of practice, this crucial issue is rarely addressed. This lack of communication applies to all parties involved in treatment, in this case nurses, physicians, and patients. The issue of medication-taking is rarely addressed by nurses in my area of practice. The reasons for this are diverse. Many nurses lack knowledge of IM, as this is regarded as the physician's domain. Moreover, renal transplant recipients often face the 'problem' of being relatively independent in terms of nursing care. In my area of practice, the normal patient-to-nurse ratio during day shifts is about ten-to-one. However, in hospitals not affiliated with Schools of Medicine, a nurse has to care for about 13 patients (Aiken et al. 2012). This is the highest patient-nurse ratio in Europe, burdening nurses in German hospitals with extremely high workloads. Additionally, patients with low self-care capability are common in my area, and nurses tend to prioritise and dedicate their scarce working time to patients requiring more direct care. This, however, neglects the fact that a high extent of self-care does not necessarily imply a low illness burden.

In my experience, physicians do not discuss the issue of adherence, despite claiming to follow the relevant guideline (KDIGO 2009). This applies during any contact the patient may have with the university hospital, either on the ward or in the outpatient clinic. This gap in medical care was detected in an internal quality review several years ago (Steffl 2009), but, from my perspective, not much has changed since. This may be due to a lack of awareness that patients may experience adherence as problematic, or, as a consultant responsible for the care of renal transplant recipients once put it, “we don’t have an issue with adherence here.” Another reason for this gap may be the system of physician education, which involves bi-annual rotations of young physicians between different departments in the hospital. These frequent changes of medical contact persons may impede the familiarity necessary for an appropriate discussion of such a sensitive issue.

The issue of adherence is also rarely addressed by patients. Patients may be reluctant to address possible issues for fear of being blamed as ‘incompliant,’ as non-adherence is referred to in Germany. Indeed, they may be correct in this, as any actual or potential episodes of non-adherence are reported in the patient charts and are likely to remain there forever. Moreover, as physicians and nurses are reluctant to address adherence (Steffl 2009), the patient may assume that perfect adherence is simply expected by carers and that any problems will evoke negative responses. However, research clearly indicates that addressing adherence and connected issues in a non-judgemental way is one of the most important facilitators of adherence (Sabaté 2003).

## 2.9 Summary of Chapter Two

This chapter has introduced the terms of reference of this study. First, terms related to medication-taking after renal transplantation were discussed and compared, leading to the choice of the term *adherence* for the remainder of this thesis. Secondly, dimensions of and approaches to medication adherence have been outlined. Lastly, medication adherence was set in the special context of ESRD and its treatment, including kidney transplantation. Additionally, the current situation in Germany was outlined, revealing a lack of knowledge regarding medication non-adherence among German renal transplant recipients, a specific and highly vulnerable group. Chapter Three will provide a literature review of medication adherence in renal transplant recipients and pinpoint knowledge gaps.

## CHAPTER THREE: LITERATURE REVIEW

As outlined in Chapter One, adherence to long-term medication poses a serious problem in many chronically ill patients, particularly renal transplant recipients, for a variety of reasons. To gain insight into factors contributing to or preventing medication non-adherence in kidney transplant recipients, the literature was searched and available evidence critically appraised.

Through a literature review, this critical appraisal of evidence aimed

- to gain an insight into factors contributing to adherence and non-adherence in renal transplant recipients, and
- to explore the patients' perceptions regarding adherence to IM.

The outcomes of this critical appraisal of the literature were

- to reveal factors promoting or hindering medication adherence in renal transplant recipients,
- to understand how these factors influence adherence, and
- to understand renal transplant recipients' perceptions of medication adherence.

### 3.1 Literature Search

The literature search was performed using a three-step process, as recommended by the Joanna Briggs Institute (2011). In the first step, relevant keywords were identified. This was carried out using the SPICE mnemonic (*setting, perspective, intervention of interest, context, and evaluation*) which enables the reviewer to identify relevant search terms for all parts of the aims of the review and can be used in quantitative as well as in qualitative reviews (Joanna Briggs Institute 2011). The parts of this review, following SPICE, are outlined in Table 6.

Setting	Perspective	Intervention of Interest	Context	Evaluation
n/a	renal transplant recipients kidney/pancreas recipients	medication adherence	any	influencing factors

**Table 6:** *Parts of the review aims according to SPICE*

### 3.1.1 Inclusion and Exclusion Criteria

Studies included in the review needed to meet all criteria stated below.

Papers meeting any exclusion criterion were omitted.

This review considered evidence on adult kidney or kidney/pancreas transplant recipients. Children or adolescent renal transplant recipients were not considered. Also excluded were papers dealing with recipients of other solid organ transplants or following stem cell transplantation.

The phenomenon of interest for this literature review was medication adherence or non-adherence. This included the five factors influencing medication adherence, as outlined by the WHO (Sabaté 2003), but also any other relevant factors. Renal transplant recipients' experiences regarding medication-taking, including challenges and the meaning they attributed to it, were also taken into account.

This review included primary research or reviews of primary research independent of their research paradigms, which means that qualitative, quantitative, and mixed-methods research was included. Excluded were editorials, medication studies, or comments. Only studies in English or German were considered, as I do not understand any other language to a point that would allow in-depth engagement with the respective paper, and no time-frame for studies considered in this review was applied.

### 3.1.2 Search Strategy

A preliminary search was conducted in PubMed and CINAHL to identify relevant key words. This broad search revealed that due to the multidimensionality of medication adherence, a search using limited or specialised search terms was not feasible. Therefore, the search was conducted using broad search terms to include as many relevant papers as possible. To ensure the appropriateness of this approach, the search strategy was discussed with three colleagues independently and the search terms determined subsequently (Table 7).

	Perspective	Intervention of Interest	Evaluation
Search Question	renal transplant recipient	medication adherence	influencing factors
Relevant Search Terms	renal transplantation	<ul style="list-style-type: none"> <li>• adherence</li> <li>• compliance</li> <li>• concordance</li> </ul>	

**Table 7:** Search terms used in the review

Where possible, all relevant keywords were classified in the “controlled vocabulary” (Saimbert 2011, p. 90) or thesaurus of each database such as MeSH terms in Medline. Also, synonyms were taken into account, such as 'renal' for 'kidney.'

In a second step, this comprehensive search was carried out in relevant databases successively. All terms were searched separately and subsequently combined. As databases may use different thesauri and search methods, the terms were adapted to each database and included both thesauri and keywords, as the limitation to subject terms may not cover all relevant material in each database (Higgins & Green 2011).

Literature for appraisal of the current knowledge must be retrieved from multiple databases (Parahoo 2006; Polit & Beck 2006; Higgins & Green 2011; Saimbert 2011), as no single database covers all relevant journals. Searching at least four different databases is recommended (Saimbert 2011). As many professional perspectives in addition to nursing were of interest here, databases covering psychology, social sciences, medicine, pharmacy, and education were required. The following databases were searched:

- Medline via OvidSP<sup>3</sup>
- PsycInfo via OvidSP
- The Joanna Briggs Institute EBP Database via OvidSP
- CINAHL via EBSCO<sup>4</sup>
- The Cochrane Library

In the third phase of the literature search, the reference lists of included studies were searched by hand to capture all relevant published evidence and to identify unpublished work or any other work that were missed by the comprehensive search in the second step. Additionally, grey literature was searched. Grey literature is information “not readily available through regular market channels because it was never commercially published/listed or was not widely distributed” (Reitz 2012, no page), and may include conference proceedings, dissertations, and ongoing research (Saimbert et al. 2011). Hence, OpenGrey, a European database of grey literature (OpenGrey 2014), was also searched. The full search strategy is outlined in Appendix 1.

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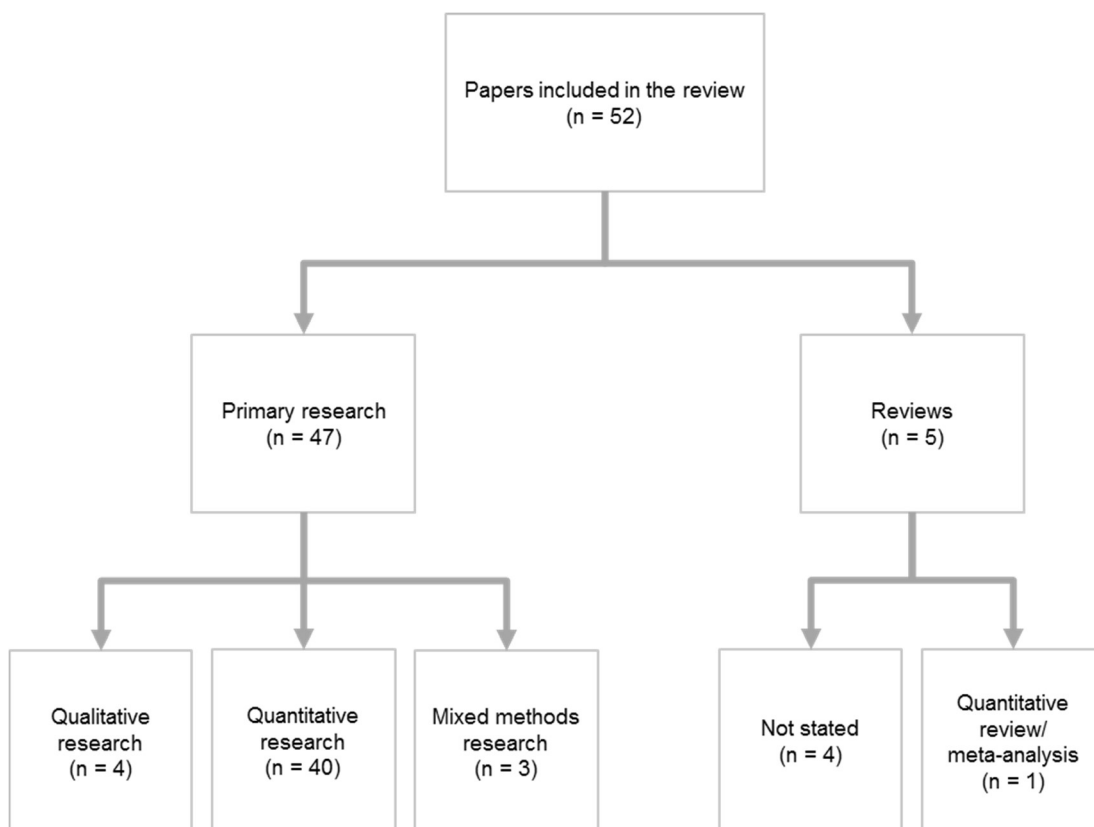
<sup>3</sup> OvidSP: database search interface of Ovid Technologies, Inc.

<sup>4</sup> EBSCO: EBSO information services provide access to databases



### 3.1.3 Literature Included in the Review

A total of 52 papers were selected for inclusion in the review. The selection process is described in detail in Appendix 2. The retrieved literature consists of quantitative and qualitative work, including reviews. Of the 52 selected papers, 47 reported primary research and five were reviews (Figure 4). Of the articles reporting primary research, four followed a qualitative design, 40 used quantitative methods and three applied mixed-method designs. In the review group, one paper contained a meta-analysis of qualitative research and four did not explicitly report their research method. A detailed table of included papers can be found in Appendix 3.



**Figure 4: Types of literature included in the review**

Regardless of article type, of the 52 included articles in this review, only 24 (46%) provided a definition of *adherence* or *compliance* (see Appendix 3), a gap that has been noted by Butler et al. (2004c). Only Nevins & Matas (2004) and Wainwright & Gould (1997) discussed the challenges associated with the terminology. However, their articles offer no definition of what is researched. Most other authors refer to the WHO definition of *adherence* (Sabaté 2003), although the Sackett & Haynes (1976) definition of compliance is also used.

Some studies (Kiley et al. 1993; De Geest et al. 1995; Hilbrands et al. 1995; Evans 2003; Butler et al. 2004a; Butler et al. 2004b; Chisholm et al. 2005; Rosenberger et al. 2005; Takemoto et al. 2007; Chisholm-Burns et al. 2008a; Chisholm-Burns et al. 2010; Lennerling & Forsberg 2012) conceptualise adherence according to their research aims and methods. Given the ambiguities surrounding the concept of medication-taking behaviour, this approach seems necessary to enable thorough assessment of the research outcomes and conclusions. Failure to define the concept, and with it the primary outcome, raises the risk of misinterpretation of the results from the given study.

Additionally, only six of 52 papers (11%) specifically deal with patients in German-speaking countries (Austria, Switzerland), and not a single paper specifically addressed the issue in Germany.

### **3.2 Factors Contributing to Adherence or Non-Adherence in Renal Transplant Recipients**

The WHO has identified five factors contributing to medication adherence in chronically ill patients; these are social/economic, therapy-related, patient-related, condition-related, and health system or healthcare team-related factors (Sabaté 2003, p. 27). These factors are used to organise the review thematically here.

### 3.3 Social and Economic Factors

Socioeconomic factors are mainly education level, occupation, and income (Lampert & Kroll 2009); however, regarding medication adherence, the WHO (Sabaté 2003) also includes gender, age, ethnicity, and social support.

Regarding gender, some studies suggest that male kidney transplant recipients are more likely to be non-adherent (Kiley et al. 1993; Chisholm et al. 2005; Rosenberger et al. 2005; Chisholm et al. 2007; Denhaerynck et al. 2007; Griva et al. 2012), while others place the higher risk of non-adherence with female recipients (Hilbrands et al. 1995; Gheith et al. 2008). However, most research studies found no association between gender and degree of medication adherence in international settings (Vasquez et al. 2003; Butler et al. 2004b; Chisholm et al. 2005; Russell et al. 2010) or European settings (Bunzel & Laederach-Hofmann 2000; Vlaminck et al. 2004; Gremigni et al. 2007; Germani et al. 2011; Lennerling & Forsberg 2012; Massey et al. 2013). A systematic review (Denhaerynck et al. 2005) supports the conclusion of no association between gender and medication adherence.

Much research has also been conducted on the association between age and medication adherence. Studies have shown that younger age is often associated with non-adherence (Raiz et al. 1999; Rudman et al. 1999; Bunzel & Laederach-Hofmann 2000; Butler et al. 2004b; Denhaerynck et al. 2007; Gremigni et al. 2007; Takemoto et al. 2007; Gelb et al. 2010; Griva et al. 2012), and that adherence increases with age (Chisholm et al. 2007; Lin et al. 2011; Massey et al. 2013). This findings were also confirmed by the systematic review (Denhaerynck et al. 2005). Although this finding applies to children and especially adolescents, an age group that has been excluded from the present review, it also holds for young adults, with evidence suggesting that kidney transplant recipients in their twenties may be at higher risk of non-adherence.

Conflicting studies have found that older kidney transplant recipients may display a greater extent of non-adherence to medication than their younger peers (Chisholm et al. 2005; Chisholm-Burns et al. 2008a). This phenomenon may be attributed to general cognitive and physical declines over the age of 60 years (Chisholm-Burns et al. 2008a). However, the issue is inconclusive, as many studies have found no association between adherence and age in kidney transplant recipients (Vasquez et al. 2003; Vlamincx et al. 2004; Russell et al. 2010; Germani et al. 2011; Lennerling & Forsberg 2012; Tielen et al. 2014).

Some research has been conducted on the relationship between ethnicity and medication adherence. While most studies found no association (Vasquez et al. 2003; Vlamincx et al. 2004; Chisholm et al. 2005; Russell et al. 2010; Massey et al. 2013; Tielen et al. 2014), some found that African Americans may be less adherent than white Americans (Schweizer et al. 1990; Kiley et al. 1993; Chisholm et al. 2007). These findings, however, can be attributed to the lower average socioeconomic status of African Americans compared with white Americans, rather than to ethnicity.

No conclusive association could be established between education level and non-adherence following renal transplantation. While some studies suggest that higher levels of education are associated with better adherence or vice versa (Rudman et al. 1999; Chisholm et al. 2007; Griva et al. 2012), other research found no significant association (Vasquez et al. 2003; Denhaerynck et al. 2005; Germani et al. 2011; Massey et al. 2013; Tielen et al. 2014).

Employment status and household income, as two of the three major factors contributing to socioeconomic status, have been studied extensively, but no conclusions could be drawn. Some research has found better socioeconomic status to be associated with better adherence (Schweizer et al. 1990; Lin et al. 2011) and unemployment to be more common in non-adherent persons (Kiley et al. 1993). However, it is unclear whether this may be explained by a financial inability to afford IM (Schweizer et al. 1990; Gordon et al. 2009) or a general low income of non-adherent kidney transplant recipients (Chisholm et al. 2005), as some research from the USA suggests. In contrast, other studies have found no association between adherence and socioeconomic status (Vasquez et al. 2003; Denhaerynck et al. 2005; Russell et al. 2010; Germani et al. 2011; Massey et al. 2013; Tielen et al. 2014), or have found that employment may lead to less adherent behaviour (Griva et al. 2012).

Much research has been conducted on social support and medication adherence. In research settings, social support is often conceptualised as being provided by a spouse or partner, but may also come from other family members, friends, acquaintances, colleagues, or neighbours (Taylor 2011). Research on this topic concludes that marriage or living as a couple is a protecting factor for non-adherence (De Geest et al. 1995; Bunzel & Laederach-Hofmann 2000; Butler et al. 2004b; Lin et al. 2011; Lennerling & Forsberg 2012). This conclusion is supported by studies, including a systematic review, that stress the importance of subjective feelings of being socially supported as a crucial factor for adherent behaviour (Denhaerynck et al. 2005; Scholz et al. 2012), and by other qualitative studies (Gordon et al. 2009; Tong et al. 2011). Rosenberger et al. (2005) have also found that more non-adherers complain about a lack of social support than adherers, and Vlamincx et al. (2004) use low social support as predictor for non-adherence. Household and emotional support seems to play a particularly large role (Chisholm-Burns et al. 2010). This may be why a study suggests that wives provide better social support than husbands (Scholz et al. 2012).

In contrast to these findings, other research found no association between social support and medication adherence (Russell et al. 2010; Germani et al. 2011; Massey et al. 2013), with some even suggesting that people living in relationships may be more likely to be non-adherent (Griva et al. 2012) or that participants with perceived social support display a larger extent of non-adherence than other persons (Kiley et al. 1993).

### **3.4 Therapy-Related Factors**

According to the WHO (Sabaté 2003), therapy-related factors refer to all factors that may influence adherence that are directly related to therapy. In the case of medication adherence in renal transplant recipients, these factors comprise not only the complex medication regimen but also pre-transplant treatment, which may have included dialysis.

While there is a shortage of research on the connection between having undergone dialysis and medication adherence following transplantation, qualitative studies have consistently found that fear of having to return to dialysis is a major driver of adherence (Russell et al. 2003; Orr et al. 2007a; Tong et al. 2009). However, the only quantitative study found (Lin et al. 2011) concluded that dialysis was not associated with adherence.

The intake of IM may be, and in many cases is, associated with a variety of side effects (Table 5) that may cause considerable symptom distress (Kugler et al. 2007). However, this has not been clearly established as a cause or predictor of medication adherence. According to some findings (Butler et al. 2004b; Russell et al. 2006; Lennerling & Forsberg 2012), side effects are not associated with medication adherence, a conclusion also drawn by a systematic review of the literature (Denhaerynck et al. 2005).

However, other findings suggest that the perception of side effects may be associated with medication-taking behaviour in some kidney transplant recipients. Without indicating specific side effects, two studies (Schweizer et al. 1990; Rudman et al. 1999) found that self-reported reasons for non-adherence included the presence and experience of side effects. This finding was also confirmed by a more recent, though small, Egyptian study (Gheith et al. 2008). Other research has found evidence that specific side effects may be associated with non-adherence; these include gastrointestinal problems (Takemoto et al. 2007), spots on the face (Denhaerynck et al. 2007) and CsA toxicity (Rudman et al. 1999). Also, Rosenberger et al. (2005) found that non-adherent patients complain significantly more about weight gain, gingival hyperplasia and depression and Raiz et al. (1999) suggest that less pain experience is associated with a less degree of forgetfulness.

In contrast to the conflicting evidence of quantitative research, qualitative research has found that many kidney transplant recipients experience bothersome side effects (Russell et al. 2003; Gordon et al. 2009). Additionally, Orr et al. (2007a) found that participants in their study experienced side effects but perceived these to be less debilitating than dialysis. These findings are also highlighted in a systematic review of qualitative studies (Tong et al. 2011).

Although the WHO has not specifically classified QoL as a therapy-related factor, especially health-related QoL, “the functional effect of a medical condition and/or its consequent therapy upon a patient” (International Society for Quality of Life Research (ISOQOL) 2014) can be regarded as a direct consequence of therapy-related issues. In this context, QoL is therefore considered a therapy-related factor. Rosenberger et al. (2005) found that non-adherent kidney transplant recipients experience poorer health than adherent patients. The direction of this association remains unclear: does non-adherence trigger poorer health or does a self-rated poor health status lead to poor adherence? A vast amount of evidence supports the first direction, while the latter is supported by findings that poor QoL leads to poor adherence (Hilbrands et al. 1995) and that a higher impact of medication on daily living results in poorer adherence (Gremigni et al. 2007); however, Griva et al. (2012) found no association between QoL and adherence.

Many studies have examined the association between donor characteristics, particularly the donation type (living or deceased), and adherence. While some studies (Chisholm et al. 2005; Griva et al. 2012; Massey et al. 2013; Tielen et al. 2014) found no difference between live and deceased donor kidney transplantation, others (Butler et al. 2004b; Denhaerynck et al. 2007; Takemoto et al. 2007) concluded that recipients of live donations are more likely to be non-adherent. Conversely, a qualitative study (Orr et al. 2007a) found that loyalty to the donor was a driver of recipient adherence, regardless of whether the donation was from a living or a deceased donor. This was confirmed by Achille et al. (2006), who found that a feeling of indebtedness toward the donor improved adherence. The work of Vlaminck et al. (2004) suggests that donor age is not a good predictor of recipient adherence. There are hints that discontent with any part of the transplant process is associated with poorer adherence (Raiz et al. 1999).



The type of IM taken does not seem to play a major role in non-adherence. Only two, contradictory, studies dealing with this issue could be found. While Chisholm et al. (2005) found better adherence among patients treated with cyclosporine than among those taking tacrolimus (Chisholm et al. 2005), Griva et al. (2012) established no association between these two factors.

In contrast, frequency of medication intake seems to play a role in adherence. Research has shown that once-daily medication formulations enhance adherence relative to twice-daily intake (Kuypers et al. 2013; Van Boekel et al. 2013), although for regimens comprising multiple medications, Russell et al. (2007) found that at the time one medication is taken, others are usually taken simultaneously. Non-adherence seems to be associated more with changes in the treatment (Gordon et al. 2009). Denhaerynck et al. (2007) also noted an increase in non-adherence over the week, from Monday to Sunday. However, others have suggested that the most doses are missed on Saturday, with non-adherence lower on Sunday than on other days (Kuypers et al. 2013), and additionally that more doses are missed in the evenings than in the mornings.

The WHO has established the duration of treatment as a therapy-related factor that may influence adherence. For kidney transplant recipients, this period is usually regarded as the time since transplantation. Prior treatment is rarely taken into account, yet a Swiss cohort study (De Geest et al. 2014) found that adherence decreased from the pre-transplant phase to six month post-transplant, then increased until the end of the study period three years post-transplant. In this study, pre-transplant adherence was a predictor of post-transplant adherence. The same findings were reported by Nevins & Matas (2004) who concluded that early patterns of adherence predict patients' later behaviour.

Some studies have suggested that a longer time since transplant is associated with deteriorating adherence (Vasquez et al. 2003; Chisholm et al. 2005; Denhaerynck et al. 2005; Chisholm et al. 2007; Chisholm-Burns et al. 2008a; Gelb et al. 2010; Germani et al. 2011; Lin et al. 2011; Massey et al. 2013). However, others have found no association between the two (Vlaminck et al. 2004; Russell et al. 2006; Russell et al. 2010; Griva et al. 2012). This has also been investigated using qualitative methods; Ruppap & Russell (2009) reported that participants get used to medication-taking over time and eventually no longer consider it problematic.

### **3.5 Patient-Related Factors**

Together with social and economic factors, patient-related factors as drivers for or barriers to adherence have been studied extensively. According to the WHO (Sabaté 2003), patient-related factors comprise “resources, knowledge, attitudes, beliefs, perceptions, and expectations of the patient” (p. 30). The review presented here, shows that many other patient-related factors, based on a variety of behavioural and psychological concepts, are also relevant.

Vasquez et al. (2003) reported a lack of medication-related knowledge to be associated with poor medication adherence. This finding agrees with other studies suggesting that health literacy, or the ability to access, understand, and implement health-related information (Fraser et al. 2013), is necessary for adherence (Williams et al. 2014). These findings, however, are contradicted by a literature review that found inconclusive evidence of this association (Denhaerynck et al. 2005).

*Intention* can be defined as the “aim or plan” (OED 2015g) to take medication as negotiated. Intention to adhere has not been studied to a great extent, although Scholz et al. (2012) found that intentions are positively associated with adherence, and Da Silveira Maissiat et al. (2013) found that non-adherence can be traced back to non-intentional behaviour.

De Geest et al. (1995) concluded that adherent transplant recipients display better self-care than non-adherers. More recent work by Gelb et al. (2010) assessed everyday problem solving (EPS) with regard to medication adherence following renal transplantation. EPS, “the ability of individuals to solve specific problematic situations that are representative of what individuals might face in their daily lives” (Gelb et al. 2010, p. 515), was found to be a predictor of adherence. This is supported by qualitative evidence (Orr et al. 2007a) that study participants took their self-care seriously.

A sense of autonomy regarding medication intake has been subject to study, with most research finding a positive association between a sense of autonomy and adherence (Rudman et al. 1999; Gremigni et al. 2007; Massey et al. 2013). This agrees with the qualitative finding that control of medication intake is important (Russell et al. 2003), and a systematic review added that kidney recipients were aware of their responsibility (Tong et al. 2009). However, one study hinted that active coping styles may be associated with less adherent behaviour (Gremigni et al. 2007).

While one study included in the present review concluded that belief in the necessity and importance of IM did not impact adherence (Lennerling & Forsberg 2012), other research has shown an association. Only two studies found a positive association; that is, that the belief that medication is needed contributes to better adherence (Butler et al. 2004b; Massey et al. 2013). Additionally, Massey et al. (2013) reported that patients who thought their graft would last longer reported higher overall adherence. Other research suggests that the converse also holds; that is, perceptions of IM as unimportant (Gheith et al. 2008) and scepticism (Goetzmann et al. 2006) are predictors of non-adherence. Griva et al. (2012) also found that minor beliefs in medication necessity, little worry about the viability of the graft, and medication-related concerns could trigger non-adherence. Participants who think they are less susceptible for negative outcomes might display poorer adherence, as might participants who do not believe in the effectiveness of their treatment (Rudman et al. 1999). Additionally, Tielen et al. (2014) found that anxiety regarding the treatment regimen may lead to non-adherence.

Another potential factor in medication adherence following kidney transplantation is the 'locus of control'. This is internal if one believes in self-control over one's life, or external if control is attributed to external forces, such as luck or fate (Neill 2006). Studies agree that an external locus of control is negatively associated with adherence; that is, people who believe that chance controls their health are more likely to be non-adherent (Raiz et al. 1999; Rudman et al. 1999; Denhaerynck et al. 2005). Self-efficacy, a concept related to locus of control (Judge et al. 2002), stems from social cognitive theory and refers to the perceived ability to succeed in specific situations (Bandura 1993). Some research, including a review (Denhaerynck et al. 2005), suggested a positive association between self-efficacy and adherence (De Geest et al. 1995; Rudman et al. 1999; Denhaerynck et al. 2007; Massey et al. 2013), while others found no association (Russell et al. 2006; Gordon et al. 2009; Scholz et al. 2012). Moreover, Massey et al. (2013) noted that self-efficacy decreases with time after transplantation.

Forgetfulness (Sabaté 2003) has been examined qualitatively and established as a main reason for intermittent non-adherence (Gordon et al. 2007; Orr et al. 2007a; Gordon et al. 2009; Tong et al. 2011). According to Weng et al. (2013), forgetfulness is most likely when routines are disrupted.

While post-transplant distress has not been studied extensively, most sources included in this review agree that stress, caused for example by a busy lifestyle, may lead to poor adherence (Achille et al. 2006; Denhaerynck et al. 2007; Gordon et al. 2009). However, Russell et al. (2006) found no significant association between emotional burden and adherence.

### **3.6 Condition-Related Factors**

For renal transplant recipients, condition-related factors refer to both illness-related issues induced by the kidney transplantation itself and to new or pre-existing co-morbidities. Co-morbidities include somatic and psychological disorders, such as anxiety and/or depression or alcohol and substance abuse (Sabaté 2003).

Somatic co-morbidities have received little attention in the literature, with the notable exception of a study by Griva et al. (2012), which found no relationship between adherence and the ESRD severity index, a measure which incorporates serum concentrations of IMs, estimated glomerular filtration rate, haemoglobin, current drugs, primary kidney disease diagnosis, time since transplantation, and co-morbidities (Craven et al. 1991).

In contrast, the relationship between adherence and mental health has been studied more widely, with particular focus on depression and sometimes anxiety. Most studies found depression to be associated with non-adherence (Kiley et al. 1993; Cukor et al. 2008; Cukor et al. 2009; Gelb et al. 2010) and intentional non-adherence to be more common in patients with depression than those without (Griva et al. 2012). Also, evidence suggests that non-adherers experience more depression-related distress than adherers (Rosenberger et al. 2005). These findings are supported by a review, which concluded that anxiety and depression are related to adherence (Denhaerynck et al. 2005). Other research, however, found that depression was not strongly associated with non-adherence (Butler et al. 2004b), that depression and anxiety did not impact medication adherence (Bunzel & Laederach-Hofmann 2000; Russell et al. 2006) and even that people with depression had better adherence scores (Hilbrands et al. 1995). With regard to other mental health disorders, alcohol and substance abuse were found to be predictors of non-adherence (Schweizer et al. 1990; Bunzel & Laederach-Hofmann 2000; Denhaerynck et al. 2005). A review also concluded that kidney transplant recipients with personality disorders are more likely to be non-adherent (Bunzel & Laederach-Hofmann 2000).

### **3.7 Healthcare Team and System-Related Factors**

Of the five factors associated with the development of non-adherence in chronic illness, healthcare team and system-related factors have been received significantly less attention than the four other factors (Denhaerynck et al. 2005). However, there are some hints of the role that the healthcare system might play.

Some studies, particularly from the USA, emphasise that the lack of financial coverage of IM by health insurance systems may be a severe threat to post-transplant adherence (Rudman et al. 1999; Chisholm et al. 2007; Ruppert & Russell 2009; Evans et al. 2010). Structural issues, such as lack of access to a pharmacy, may promote non-adherence even in industrialised countries (Gordon et al. 2009). Problems with organisation of the healthcare system may lead to patients taking their medication considerably later than prescribed; for example, patients needing testing of IM levels in the blood usually must adapt to the structure of their local healthcare provider, rather than their own schedules (Gordon et al. 2007).

Another issue is the relationship between the kidney transplant recipient and his or her healthcare team. Qualitative research (Orr et al. 2007a), including one systematic review (Tong et al. 2009), has found that loyalty to the healthcare team was a major driver of participant adherence. In these studies, participants reported embarrassment when medication was forgotten. These feelings of indebtedness towards healthcare providers, however, may result in “white coat adherence” (Butler et al. 2004a, p. 789), which is when medication is taken with particular precision immediately before contact with healthcare providers.

### **3.8 Summary of Chapter Three**

This appraisal of the literature demonstrates the multitude of potential reasons for medication non-adherence in renal transplant recipients. All possible causes can be classified according to the five factors leading to non-adherence in chronic illness proposed by the WHO (Sabaté 2003). However, gaps remain in our knowledge of medication adherence after renal transplantation specifically. To date, research has focused primarily on patient-related factors, whether from socioeconomic or other patient-related perspectives (Sabaté 2003; Fine et al. 2009; Aslani & Schneider 2014), and work on factors related to the healthcare system remains scarce.

This review raises the point that in kidney transplant recipients, non-modifiable factors, such as gender, age, race or education level, play a minor role in the development of non-adherence, compared with factors that are potentially modifiable. These include such diverse aspects as perceived social support, experiences with dialysis, experiences of side effects, features of the treatment regimen, intentions to adhere, beliefs regarding medication, forgetfulness, and state of mental health.

It must be noted that a statistically significant association between adherence and a factor does not imply causation. Additionally, a higher likelihood of non-adherence in a group of people does not mean that the whole group can be regarded as non-adherent. Such conclusions may lead to stereotyping of the group and subsequent neglect, and opportunities to help members of other groups who are experiencing problems with adherence may be missed.

The study of non-adherence following kidney transplantation has been dominated by quantitative methods, but these are insufficient for exploring most potentially modifiable factors. Meanings, perceptions, and interpretations of phenomena are best explored using qualitative methods (Holloway & Wheeler 2002; LoBiondo-Wood & Haber 2002; Polit & Beck 2006), but a surprisingly small body of literature applies qualitative methods (see Appendix 3), suggesting that knowledge of the processes leading to medication non-adherence is meagre. This review found only four qualitative studies (Russell et al. 2003; Orr et al. 2007a; Ruppap & Russell 2009; Tong et al. 2009) and one qualitative meta-synthesis (Tong et al. 2011), while three studies used mixed-methods designs (Gordon et al. 2007; Gordon et al. 2009; Tielen et al. 2014).

Most findings are derived from non-German settings. Of the qualitative or mixed-method studies included in this review, most (N = 4) were conducted in the USA (Russell et al. 2003; Gordon et al. 2007; Gordon et al. 2009; Ruppert & Russell 2009), and two, including the meta-synthesis, were from Australia (Tong et al. 2009; Tong et al. 2011). Only two studies on European renal transplant recipients could be found, one from the UK (Orr et al. 2007a) and the other from The Netherlands (Tielen et al. 2014). No Germany-specific research could be found; thus, there is a need for the study presented in this thesis.

Chapter Four will introduce methodological aspects of this thesis, which include both my own ontological position as a researcher and the method I have chosen, GT based on the premises of SI.



## CHAPTER FOUR: PHILOSOPHICAL CONSIDERATIONS

Medication adherence is crucial for solid organ transplant recipients to prevent rejection of the transplanted organ. However, non-adherence is a major issue in these patients. As Chapter Three has shown, there is a shortage of research on this topic in general and of qualitative research in particular. Additionally, and crucially, no research on this topic has been conducted in Germany. This thesis, therefore, is the first to explore German kidney transplant recipients' perspectives on medication adherence.

This chapter introduces the philosophical framework of the research. First, I will elaborate on the importance of some philosophical considerations prior to any research. Then, I will outline my own philosophical position as a researcher in the context of research philosophy and paradigms. Finally, my chosen research methodology, constructive GT, and its philosophical roots in SI, will be introduced and justified.

### 4.1 Positioning Myself as Researcher

Before conducting any research, the researcher must consider how his or her worldview impact the choice of research paradigm. The first step in conducting research is providing answers to some basic questions, such as *'What exists?'*, *'How do I know?'* and *'What is valuable?'* (Chrucky 2015). The researcher must be clear on his or her own philosophical perspectives or beliefs, as the outcome depends on clarity in these beliefs and positioning within research paradigms. The next section will briefly introduce the basics of research philosophy, and will then continue to my own philosophical stance, on which both the paradigm and methodology depends.

### 4.1.1 The Philosophical Trinity

The disciplines concerned with answering the fundamental questions of *'What exists?'*, *'How do I know?'* and *'What is valuable?'* are ontology, epistemology, and axiology, respectively. These are known as the "philosophical trinity" (Durant-Law 2015, no page).

Ontology, also known as metaphysics (Schwandt 2007), is the occupation with questions like *'What exists?'* or *'Is there a "real" world out there that is independent of our knowledge of it?'* (Durant-Law 2005, p. 5). Thus, ontology questions the nature of reality and how it is perceived by humans (Durant-Law 2005; Denzin & Lincoln 2011b). In other words, ontology describes a person's worldview, including beliefs regarding the nature of reality.

*'How do I know?'* or *'What is the relationship between the inquirer and the known?'* (Denzin & Lincoln 2011b) are epistemological questions.

Epistemology is the theory of knowledge. A researcher's epistemological stance depends at least partly on her ontological point of view. Answers to epistemological questions lead to methodological questions and directly influence the methodology chosen for the research. In choosing a research methodology, one must be aware of one's own epistemological position; hence, there is considerable overlap between epistemology and methodological considerations (Durant-Law 2005).

Axiology is "the branch of philosophy dealing with ethics, aesthetics, and religion" (Lincoln et al. 2011, p. 116). In the context of research, this concerns not only ethical issues but also whether something is worth knowing (Durant-Law 2015); or, in other words, whether the research has a purpose or is done for the sake of knowing.

## 4.1.2 My Philosophical Stance and Alignment

I describe my personal philosophical stance as follows.

### 4.1.2.1 Ontology

Realities may or may not exist, depending on the nature of the research question. For example, I believe that rejection following kidney transplantation can be traced back to distinct physiological and immunological causes in most cases. The diagnosis is thus an objective reality that can be verified beyond personal doubts. While believing at least partly in the existence of objective realities, I reject absolute beliefs, as I doubt that we can fully understand nature and reality.

However, it is also my view that behaviours and reality can be perceived differently depending on cultural, emotional, psychological, and other circumstances. That is, I believe that realities are, to a large extent, constructed by individuals, and therefore that multiple realities exist. Consequently, human perceptions, attitudes, and beliefs can change via social interactions, cultural changes, or other circumstances. Also, I strongly believe in the ability of the human mind to adapt, progress, and develop.

#### **4.1.2.2 Epistemology**

Based on my ontological perspective, I believe that knowledge can be gained through multiple means. One of these is the study of objective realities, but as humans, we can comprehend these only by approximation, not in their full scope. Regarding humans' perceptions and meanings attributed to certain things, persons, or behaviour, I believe that our understanding of this is necessarily shaped by individual experience, and that it is therefore subjective. As humans, we are what we know and what we have experienced, and this is shaped by our understanding of reality. Therefore, when striving for new knowledge, as it is the case in any research, we cannot strip away our worldview. In qualitative research, I therefore believe that findings depend on the researcher just as much as on the data. Knowledge can thus only be gained by an interaction between researcher and participants. In other words, findings are the researcher's understandings of the subjective perceptions of the persons studied and thus have an interpretive nature.

#### **4.1.2.3 Axiology**

I believe that knowledge should be utilised to serve a certain purpose, rather than purely for the sake of knowledge. As a nurse, my foremost interest lies in the care of my patients. In to my understanding, nursing or any other research should always aim to positively impact patients' care. I also believe that ethical considerations must be included in all aspects of research.

#### **4.1.2.4 Summary**

In summary, in my personal philosophical trinity, my ontological stance is partly post-positivist and partly relativist. However, as my epistemological position on the research of human behaviour is subjectivist, I lean toward a qualitative research paradigm, and more specifically a constructivist research paradigm (Denzin & Lincoln 2011a).

## **4.2 Research Paradigm**

A research paradigm can be defined as a “set of interrelated assumptions about the social world which provides a philosophical and conceptual framework for the organized study of that world” (Filstead 1979, p. 34). The paradigm used in research, therefore, results from the researcher’s “basic set of beliefs” (Denzin & Lincoln 2011b, p. 91), or, in other words, from her philosophical posture and alignment and thus her own ontological, epistemological, and axiological beliefs. Following this, the researcher must choose the methodology (Denzin & Lincoln 2011b). This section concerns research paradigms and issues surrounding research methodology in general. The particularly methodology I have chosen for this research will be discussed in the next section.

### **4.2.1 The Qualitative Research Paradigm**

As outlined above, this research explores a topic about which not much is currently known: the perceptions of German recipients of kidney transplants. The processes leading to medication adherence or non-adherence should be examined from their point of view. Meanings, perceptions, experiences, and interpretations of phenomena or behaviours are best explored using qualitative research methods (Holloway & Wheeler 2002; Polit & Beck 2006; Flick et al. 2010b). On the basis of my philosophical trinity, the research paradigm therefore needed to be located in the qualitative research tradition, rejecting both the positivist and post-positivist paradigm (Lincoln et al. 2011).

However, *qualitative research* is an umbrella term comprising a variety of philosophical underpinnings, ontological and epistemological assumptions, and methodologies (Silverman 2009; Flick et al. 2010b). The vast number of qualitative research approaches share some basic assumptions and characteristics (Flick et al. 2010b):

- The understanding of social reality can only be achieved by social interaction of the researcher and participant. This mutual interaction establishes meanings and connections.
- Qualitative research methodology utilises analyses of communications and interactions.
- Individual, as well as collective, attitudes and actions are shaped by the “Lebenswelt<sup>5</sup>” (Flick et al. 2010b, p. 21) of the respective persons. Thus, research requires hermeneutic interpretations of subjective meanings on the basis of preconceptions.
- Reality is shaped interactively and is subjectively meaningful; therefore, communication is crucial for qualitative research. Thus, data collection uses communicational and dialogic means.

In most qualitative research approaches, the researcher takes an emic perspective – that is, the perspective of those who are researched (Harris 1976) – whilst acknowledging that her own, etic, perspective enables her to abstract the data and theorise (Holloway & Wheeler 2002). Simultaneously, this approach demands a high extent of reflexivity from the researcher.

Reflexivity can be defined as

*an explicit, self-aware meta-analysis of the research process. Through the use of reflexivity, subjectivity in research can be transformed from a problem to an opportunity (Finlay 2002, p. 531).*

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<sup>5</sup> Lifeworld

By applying a high extent of reflexivity, the researcher's perceptions and interpretations become part of the findings, rather than attempting to eliminate any disturbing factors, as is the case in positivist research approaches (Cutcliffe 2000; Flick et al. 2010b).

Qualitative research includes various paradigms, such as constructivism, hermeneutics, feminism, and critical theory, leading to research methodologies that include ethnomethodology, phenomenology, action research, GT, and many more (Denzin & Lincoln 2011a).

### 4.2.2 The Constructivist-Interpretivist Approach

The constructivist-interpretivist approach is one of the oldest and best-established qualitative research paradigms. Its origin can be traced back to the philosopher Kant (1724-1804) and the first edition of his seminal work *Critik der reinen Vernunft*<sup>6</sup> (Filstead 1979), wherein he states the following:

*Die Ordnung und Regelmäßigkeit an den Erscheinungen, die wir Natur nennen, bringen wir selbst hinein, und würden sie auch nicht darin finden können, hätten wir sie nicht, oder die Natur unseres Gemüts ursprünglich hineingelegt (Kant 1781, p. 92)*<sup>7</sup>.

In other words, Kant assumes that our understanding of things has been shaped by how we perceive these things. This stance represents the main principle of constructivist thinking, namely a relativist ontology, a subjectivist epistemology, and a hermeneutic or interpretive methodology (Lincoln et al. 2011). In other words, constructivism is based on the assumption that there are multiple realities, and that understandings of these realities are constructed by individuals (Guba & Lincoln 1994).

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<sup>6</sup> Critique of Pure Reason

<sup>7</sup> "It is we therefore who carry into the phenomena which we call nature, order and regularity, nay, we should never find them in nature, if we ourselves, or the nature of our mind, had not originally placed them there" (Müller 1922).

The constructivist-interpretivist paradigm aims to understand phenomena, rather than explaining them as the positivist or post-positivist paradigms do. Understanding in the constructivist paradigm is reached through hermeneutics (Lincoln et al. 2011), which aim to understand, rather than describe, phenomena through interpretation (Holloway & Wheeler 2002). The quality criteria of the constructivist-interpretivist paradigm are trustworthiness, credibility, transferability, and confirmability (Denzin & Lincoln 2011a). These will be discussed in the context of this study in Chapter Five.

### **4.3 Research Methodology**

Methodology is “the best means for gaining knowledge about the world” (Denzin & Lincoln 2011b, p. 91) and is part of the researcher’s belief system; therefore, it can be regarded as a part of the research paradigm (Denzin & Lincoln 2011b). Thus, the choice of research methodology depends directly on the researcher’s philosophical trinity, particularly the epistemological aspect. In choosing a research methodology, the researcher must ensure that its underlying assumptions match her own worldview. As Durant-Law (2005) argues, methodology is the overlap between the three disciplines of the philosophical trinity (ontology, epistemology, and axiology) and represents the logical consequence of the researcher’s belief system (Ponterotto 2005).

However, methodology should not be confused with methods, as methodology is “a generic combination of methods that is commonly used as a whole” (Mingers 2003, p. 559). One methodology may use different methods, and in turn, the same method can be used in different methodologies. Methodology is composed from the researcher’s belief system and the application of specific methods, which in this context may include procedures, tools, and techniques of research (Durant-Law 2015).



Having provided my personal philosophical stance leading to a constructivist research paradigm, for this study, I have chosen a methodology matching both my philosophical assumptions and the aims of this research: GT on the premises of SI and the work of Corbin, Strauss, and Charmaz (Corbin & Strauss 2008; Charmaz 2014). This methodological approach strongly fits the research questions and aims, as stated in Chapter One, as well as my belief system as a researcher.

The perspectives of German renal transplant recipients may have been studied using other qualitative methods, such as phenomenology or ethnography. However, the literature demonstrates that medication adherence can be regarded as a behavioural phenomenon (Leventhal & Cameron 1987; Sabaté 2003; Munro et al. 2007). Therefore, the emphasis of this study is on the processes that facilitate or hinder medication adherence from the point of view of German kidney transplant recipients. This study does not aim to *describe* the participants' perspectives, or the meaning they attribute to medication adherence, as, for example a phenomenological approach would (Baker et al. 1992). Medication adherence also does not differ much between cultures, and hence an ethnographic approach would not be useful (Creswell 2013). Rather, this research develops an explanatory theory grounded in the concepts inherent in the data, based on the 'six Cs' of social processes outlined by Starks & Brown Trinidad (2007, p. 1374) which, as will be outlined below, is in line with GT based on the assumptions of SI. The use of GT follows a long tradition of exploring chronic illness that was shaped by Strauss (1984) and continued by many others (Charmaz 1990; Conrad 1990; Gerhardt 1990; Charmaz 1991; Charmaz 2008b).

In the subsequent sections, I will trace the philosophical foundation and development of GT, a turbulent and widely discussed methodology. Following this, I will examine GT in relation to this research.

### 4.3.1 Grounded Theory

GT was 'discovered' in the 1960s (Glaser & Strauss 1967) by Barney G. Glaser and Anselm L. Strauss. Despite being sociologists, the founders of GT had distinct professional backgrounds; while Glaser was trained in quantitative research methods, Strauss came from the 'Second Chicago School' (Jeon 2004; Bryant & Charmaz 2007a). The Chicago School is a strong contributor to post-war sociology and the development of sociology in the USA (Fine 1995), having produced an important theoretical qualitative tradition and with it some of the seminal qualitative research of the time (Becker 1999; Flick et al. 2010a). Strauss was, therefore, influenced by the work of thinkers such as George Herbert Mead and Herbert Blumer, and his background was in SI and ethnographic field research (Jeon 2004, Bryant & Charmaz 2007a).

One reason for the collaboration of these two scholars was to close the gap in social science research, wide at the time, between the positivist perspective of quantitative research and the research tradition of the Chicago School (Jeon 2004; Bryant & Charmaz 2007b), or, as Dey (1999) states,

*in the marriage of these two traditions, it was intended to harness the logic and rigor of quantitative methods to the rich, interpretive insights of the symbolic interactionist tradition (p. 25).*

This occurred at a time when the status of qualitative research was frequently (Annells 1997) challenged as "second rate" (Bryant & Charmaz 2007a, p. 35), which Glaser and Strauss rejected. Their original intent was to offer a systematic qualitative approach to make sense of data and thus bridge the gap between quantitative and qualitative research. Today, GT itself can be regarded as a "family of methods" (Bryant & Charmaz 2007b, p. 11), as it has undergone substantial development in many directions. Additionally, as one of the most widely applied qualitative research approaches (Bryant & Charmaz 2007b), GT has attracted harsh criticism.

The aim of GT is to create a theory deriving from the data (Bryant & Charmaz 2007b). Theory, in this respect, means

*identifying the relationship between and among concepts, and presenting a systematic view of the phenomena being examined, in order to explain what is going on” (Wiener & Wymans 1990, p. 12).*

GT thus explains human interaction in the context of the phenomenon under study. This interaction, expressed through behaviour, must be regarded in its natural environment, which requires the researcher to establish a relationship with the participants to gain an understanding of the interpretations and meanings behind their behaviour.

### **4.3.2 Philosophical Foundation of Grounded Theory**

Before the development of GT can be discussed, the philosophical foundation of the methodology must be outlined. The original GT developed by Glaser and Strauss was characterised by positivist influence and offered a qualitative approach that aimed to be as rigorous as quantitative research (Bryant & Charmaz 2007a) in terms of the criteria used to judge research, which are validity, reliability, and objectivity. However, GT was also strongly influenced by Strauss' background in the Second Chicago School and its research tradition in SI (Bryant & Charmaz 2007a).

SI is frequently regarded as the philosophical foundation of the GT proposed by Glaser and Strauss (Hutchinson & Wilson 2001; Milliken & Schreiber 2001; Jeon 2004; Aldiabat & Navenec 2011; Charmaz 2011). Although Glaser (2005) disagrees, SI and GT share various assumptions (Bryant & Charmaz 2007a; Aldiabat & Navenec 2011), and many researchers have used GT methodology underpinned by SI as their research paradigm (Jeon 2004; Mills et al. 2007; Newman 2008; Aldiabat & Navenec 2011). The basic assumptions of SI are mainly ascribed to George Herbert Mead, who, although not trained as a sociologist (Bulmer 1986), is regarded as a representative of the Chicago School of sociology (Bulmer 1986; Fine 1995). SI, however, was framed on the basis of Mead's preliminary work by his student, Herbert Blumer, who also refined the theory (Benzies & Allen 2001).

Central concepts of SI are the *self-concept*, the *object*, *role-taking*, *looking-glass self*, and *definition of the situation* (Aldiabat & Navenec 2011). The *self* or *self-concept* can be divided into the *Me* and *I* (Benzies & Allen 2001). The *I* is one's uncontrolled, impulsive component that acts and takes initiative. In contrast, the *Me* represents the social self that reacts upon our environment, trying to meet others' expectations. This ambiguous representation of one person leads to a constant debate within the self between *Me* and *I* that finally results in behaviour. This sustained interaction between one's outer and inner world may result in the presence of different *Me*'s depending on interactions and the diversity of others' expectations (Benzies & Allen 2001). When striving to understand behaviour, an understanding of the *self* is thus indispensable (Aldiabat & Navenec 2011).

The *object*, the second key concept in SI, refers to objects and the meaning attributed to them. According to Blumer (1986), there are three different types of objects: physical objects, such as things; social objects, such as other persons; and abstract objects, such as ideas. Human behaviour and interaction represents how a given person perceives the object and attributes meanings to it. Behaviour, however, is not static, as objects may change their meanings with the interaction between *I* and *Me* (Aldiabat & Navenec 2011).

*Role-taking* is the result of interactions between humans. It can be regarded as the process of becoming an object oneself or, in other words, the process of considering oneself through others' eyes, which again influences behaviour (Aldiabat & Navenec 2011). With the concept of role-taking, Blumer (1986) refined Cooley's (1902) concept of the *looking-glass self*, assuming that a person's identity or self is conceptualised by the perception of others (Appelrouth & Edles 2007).

The *definition of a situation* assumes that behaviour is shaped by individual perceptions. The *definition of a situation* is an elaboration of the work of Thomas (1978), and again clarifies the importance of the meaning attributed to a certain situation in understanding behaviour (Appelrouth & Edles 2007).

SI is based on three premises (Blumer 1986):

*The first premise is that human beings act towards things on the basis of the meanings that the things have for them. [...] The second premise is that the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows. The third premise is that these meanings are handled in, and modified through, an interpretive process used by the person in dealing with the things he encounters (p. 2).*

In other words, humans are only to be understood in relation to their behaviour and interaction with others. This especially concerns behaviour with regard to expressions of expectations, social roles, and acquired points of view (Hutchinson & Wilson 2001). To understand a phenomenon, the researcher must put herself in the position of the one researched (Blumer 1969), who is the real “knower” (Ponterotto 2005, p. 127) of the situation.

Both GT and SI aim to explore human behaviour based on an understanding of how these define their reality (Hutchinson & Wilson 2001). Regarding the conceptualisation of research questions, the difference between GT and SI is that SI asks ‘*how?*’ questions, whilst GT aims for a more abstract level, answering ‘*why?*’ questions (Bryant & Charmaz 2007b).

Despite frequent challenges to SI as the theoretical underpinning of GT (Bryant & Charmaz 2007b), they share a set of assumptions (Aldiabat & Navenec 2011):

- Humans live in a symbolic world of meanings. Theory, therefore, must be derived from data based on these meanings.
- Behaviour is an expression of the meanings attributed to something.
- Meanings are mainly influenced by social interactions.
- Meanings and attendant behaviour are not static but highly variable, as they develop through interaction with other humans or factors.
- Humans are actors that dynamically and continually adjust their behaviour in response to others’ expectations.

From these shared assumptions, it follows that research must take place in the social setting of the phenomenon researched, in order to understand the meaning and resulting behaviour of those studied (Bryant & Charmaz 2007b; Aldiabat & Navenec 2011).

### **4.3.3 Development of Grounded Theory**

Since its inception in the 1960's, GT has developed considerably as Glaser and Strauss, the latter together with Juliet Corbin, have each refined their version of GT (Strübing 2002), and has evolved into three major schools.

From its beginning, GT has been located in the area of conflict between two distinct research traditions. As Strübing (2008) argues, many of the differences between Glaser and Strauss were foreshadowed in their jointly published work and stem from their different paradigmatic backgrounds. One may argue that this development was predictable, given these different background assumptions of GT; however, the disagreement between Glaser and Strauss, and later Corbin, exceeds the realm of academic dispute. A strong emotional and personal touch has been added to the argument (Strübing 2008), with Glaser accusing Strauss and Corbin of distorting GT and neglecting its central ideas (Glaser 1992a), and denying Charmaz' version a position in the GT methodology (Glaser 2002). This dispute is not limited to Glaser, Strauss, Corbin, and Charmaz, but also catches most scholars who passionately take a side.

Strauss was influenced by the pragmatist interactionist tradition of the Chicago School, where he was introduced to the qualitative-interpretive research tradition and its orientation on theory (Annells 1996; Strübing 2008), whilst Glaser came from a tradition of critical-rationalist quantitative research methods (Jeon 2004; Bryant & Charmaz 2007a). Strübing (2008) argues that GT was based on the authors' least common denominator, their critique of the social science research of their time, which was oriented to the objective criteria used to judge quantitative research. Despite their later disagreements, it was their "ironic conjunctions of careers" (Glaser & Strauss 1967, p. vii) that combined these two disparate approaches and permitted the development of a qualitative approach producing results of rigour equal to quantitative approaches (Bryant & Charmaz 2007a).

#### **4.3.3.1 Traditional/Classical Grounded Theory**

Currently, "traditional" (Mills et al. 2006c, p. 3) or "classical" (Annells 1997, p. 121) GT is represented by Glaser, who asserts that this is the legitimate progression from the original GT. Ontologically his version falls in a positivist (Charmaz 2011) or post-positivist paradigm on the basis of critical realism (Annells 1996; Annells 1997; Mills et al. 2006b), assuming that different realities exist but can be understood, albeit imperfectly (Annells 1996).

Traditional GT thus applies an "objectivist" (Charmaz 2011, p. 364) epistemology, emphasising positivist features, such as the researcher's neutrality, objectivity towards the data, and the belief in truth to be discovered (Mills et al. 2007; Charmaz 2011). Research based on classical GT aims to generate middle-range theories that explain, rather than understand, the phenomenon of interest (Charmaz 2011).

Methodologically, classical GT is based on the assumption that reality exists, and theory therefore *is* in the data waiting to emerge (Glaser 1992a).

Consequently, the researcher must take a neutral point of view. This means not only hiding assumptions or pre-knowledge (Charmaz 2011), but also meeting participants objectively (Annells 1997) to eliminate potential sources of bias. Glaser (1992) emphasises the emerging theory to be a first step in a stepwise process of research that must be verified by further research, preferably experiments or surveys (Annells 1997).

#### **4.3.3.2 Evolved Grounded Theory**

Strauss and Corbin's version of GT, "evolved" GT (Mills et al. 2006c, p. 3), is closer to SI and its pragmatist roots (Strübing 2007), in assuming that there is no universal truth but that interpretations of interactions shape behaviour (Mills et al. 2007), which, in turn, must be interpreted by the researcher. However, there is disagreement in the literature on the ontology of this version. Whilst Annells (1996) suggests a relativist ontology, Charmaz (2011) argues that it is post-positivist in nature, with MacDonald & Schreiber (2001) observing that "people can find support in it for any ontology they wish" (p. 44). Mills et al. (2006c) argue that this disagreement is due to the fact that Strauss and Corbin have never explicated their ontological beliefs.

From epistemological and methodological points of view, evolved GT represents a subjectivist stance, emphasising the role and influence of the researcher in the research (Annells 1997). The researcher is also acknowledged to have certain experiences and personal meaning with regard to the phenomenon studied (Corbin & Strauss 2008). The research participants are valued as persons whose voices and perspectives, deriving from their personal realities, must be taken into account (Mills et al. 2006c). However, this limits the claim to generalisability of the research, as the reality of specific research participants may differ from their peers' and their views may differ from other persons in similar situations who are situated in distinct cultural or other backgrounds. Evolved GT also takes the stance that theory emerges from the data; however, at the same time, "analysis is the interplay between researchers and data" (Strauss & Corbin 1998, p. 13).



Glaser rejects this stance, viewing it as “forcing a preconceived conceptual description” (Boychuk Duchscher & Morgan 2004, p. 606). Indeed, the forcing vs. emerging debate is characteristic of the major differences between the versions of GT (Glaser 1992b; Boychuk Duchscher & Morgan 2004; Strübing 2008). Glaser’s (Glaser 1992b) main argument against the interpretive approach suggested by Strauss and Corbin is that, while it has merits and is important and valid (Boychuk Duchscher & Morgan 2004), it has nothing to do with GT.

#### **4.3.3.3 Constructivist Grounded Theory**

“Constructivist GT” (Charmaz 2011, p. 364) is the version of GT that has been developed most recently. It was put forward primarily by Charmaz (Mills et al. 2007), who takes a middle ground between traditional and evolved GT and aims to balance the positivist and postmodernist versions (Breckenridge et al. 2012). In this context, postmodernism can be defined as emphasising complexities, rather than trying to generalise, simplify, and homogenise as do modernist approaches (Clarke 2003). Charmaz, as a student of Glaser and Strauss (Mills et al. 2006c), critiques GT from a postmodernist point of view (Mills et al. 2007) and advances it toward constructivism. Constructive GT is also rooted in the work of Strauss and Corbin (Mills et al. 2007); however, Charmaz’ constructivist GT is critiqued as presenting a variation of evolved GT, based on its philosophical premises (Strübing 2007).

Constructive GT has a relativist ontology (Mills et al. 2007), taking into account existing pluralities of reality (Charmaz 2011), and regards reality as subject to redefinition (Bryant & Charmaz 2007a). Charmaz particularly emphasises the pragmatist approach taken by constructivist GT in the tradition of Strauss (Charmaz 2011). In comparison to evolved GT, Charmaz claims to move constructivist GT in the direction of an interpretivist research paradigm (Bryant & Charmaz 2007a). This, however, can be critiqued as simply a development of GT, as the Strauss and Corbin version of GT already used a relativist ontology (Annells 1996; Mills et al. 2006c).

Constructivist GT applies a subjectivist epistemology (Mills et al. 2006b; Mills et al. 2007), emphasising the researcher's need to take an emic perspective, which entails entering the participants' world to see it from the inside (Charmaz 2011). Findings are thus co-constructed by researcher and participant (Mills et al. 2006b; Breckenridge et al. 2012) and a high extent of reflexivity is needed (Mills et al. 2007; Charmaz 2008a). Charmaz emphasises this point as crucial:

*Researchers are part of the research situation, and their positions, privileges, perspectives, and interactions affect it [...]. In this approach, research always reflects value positions (Charmaz 2008a, p. 402).*

From this position stems the insight that GT research based on an interpretivist ontology, and subjectivist epistemology can only produce limited, and at the same time uncertain, generalisations (Bryant & Charmaz 2007a), and no universal statements can be made.

Constructivist GT emphasises the interpretive *construction* of theory (Charmaz 2008a), an approach that Glaser would reject as *forcing* in this context (Boychuk Duchscher & Morgan 2004). In contrast to both other versions of GT, constructivist GT does not necessarily focus on the identification of a core category (Birks & Mills 2011; Breckenridge et al. 2012), which can be defined as "the central phenomenon around which all the other categories are integrated" (Strauss & Corbin 1990, p. 116). This loss of importance is motivated by an increased emphasis on the description of how categories and sub-categories are formed and how they produce a substantive theory (Birks & Mills 2011).

#### **4.3.4 Grounded Theory in Relation to this Study**

The previous section of this work has introduced to the three best-known versions of GT: original, evolved, and constructivist. Evolved and constructivist GT overlap considerably in their philosophical assumptions, and hence share many approaches, such as the position of the researcher or the role of those participating in the research. I therefore tend to agree with Strübing (2007), who advises against an “unproductive dichotomy” (p. 597) in choosing between the different versions of GT following the work of Strauss and Corbin. While I find the difference between classical and evolved GT obvious, I cannot follow Charmaz’ interpretive claim, as I understand Strauss and Corbin’s version of GT to already take an interpretive approach.

Therefore, to align my own philosophical posture with those underpinning GT, the subsequent section will discuss how I interpreted and used GT in relation to my study. As will be justified, I lean toward an interpretivist, subjectivist version of GT, based on my philosophical stance. However, as the evolved and constructivist theories not only overlap but share some core principles, I will clarify my direct application of the methodology.

#### 4.3.4.1. Ontology

Following the premises of SI, I believe that realities are based upon shared symbolic meanings that determine an individual's behaviour. As adherence or non-adherence to medication and/or other medical advice are widely regarded as behavioural phenomena (Leventhal & Cameron 1987; Sabaté 2003; Munro et al. 2007), I needed to collect data illustrating the meaning that transplant recipients attribute to medication adherence in order to explain their behaviour. Both evolved and constructivist GT apply relativist ontology (Mills et al. 2006c) in an interpretivist paradigm. The ontological underpinnings of evolved and constructivist GT assume that "reality as we know it is constructed intersubjectively through [...] meanings" (Lincoln et al. 2011, p. 103), emphasising the need to engage both participant and researcher, rather than the researcher being an objective observer as postulated by classical GT. This stance clarifies why, in this research, I made every effort to interact and build a relationship with the participants to understand and share meanings regarding medication adherence. It is also important to clarify that in this context, *meanings* include those perceived by myself, those perceived by the participants, and shared meanings that could only be gained through our interaction.

#### 4.3.4.2 Epistemology

According to the epistemological underpinnings of both SI and GT, I regard meanings as strongly influenced by social interactions. Thus, I decided to build a relationship with the participants in order to learn through interaction about the meanings they attribute to adherence. Without this link, I could not have understood their behaviour. A similar consideration applies to the issue of my involvement as a researcher. Again, in accordance with both evolved and constructivist GT, I acted on the assumption that I could not stay objective, but rather had to engage with the participants in order to understand their behaviour. This included an awareness of my presumptions, experiences, and point of view regarding the data. Therefore, as Hall & Callery (2001) argue, I needed to apply a high extent of reflexivity in order to enhance the rigour of the research. In this context, reflexivity means that the “researcher engages in an explicit, self-aware meta-analysis of the research process” (Finlay 2002, p. 531), taking her personal history, presumptions and biases into account. This subjectivist epistemology of evolved and constructivist GT also distinguishes the method from the objectivist version of GT represented by Glaser, or even “reshapes the interaction between researcher and participants in the research process” (Mills et al. 2006b, p. 6).

The same argument can be applied to pre-reading prior to data collection: I am convinced that without pre-reading, research cannot take place (Holloway & Wheeler 2002; Bryant & Charmaz 2007b). This stance derives from my epistemological point of view, whereby I believe that my personal assumptions regarding the phenomenon of interest, which have been gained partly from pre-reading, shape the findings. Also, in a practical sense I believe reading is necessary not only in early stages, such as production of a research proposal, but also throughout the research process.

#### 4.3.4.3 Methodology

The aim of GT is to derive a theory from data (Bryant & Charmaz 2007b). Here, *theory* means “identifying the relationship between and among concepts, and presenting a systematic view of the phenomena being examined, in order to explain what is going on” (Wiener & Wismans 1990, p. 12). In other words, GT tries to explain human interaction in the context of the phenomenon under study. This interaction, expressed through behaviour, must be regarded in its natural environment.

With this research, my aim was to develop not a formal or grand theory (Chiovitti & Piran 2003) of the concept of adherence, but rather a “substantive” (Dey 2007b, p. 172) theory that would add to our understanding of how renal transplant recipients in Germany perceive adherence. A substantive theory is developed “from the study of [a] phenomenon situated in a particular situational context” (Strauss & Corbin 1990, p. 174). In this research, only the perceptions of the participants are taken into account, and the findings thus represent a small number of German renal transplant recipients from a specific area in Germany and cannot necessarily be generalised. Moreover, the evolving theory cannot claim objectivity, in contrast to classical GT where theories are regarded as objective knowledge that can be verified (Hildenbrand 2007). Nevertheless, I believe that this research can, at least to a limited extent, be transferred to similar circumstances and hence contribute to our knowledge of renal transplant recipients in Germany.

Methodology is also concerned with questions regarding the type of reasoning that is used. Whether GT is an inductive or abductive method remains unresolved. Whilst some argue that GT primarily uses inductive reasoning (Bryant & Charmaz 2007a), others do not necessarily perceive it as such (Strübing 2008). This controversy again can be traced back to the different approaches to GT: Reichertz (2007) argues that Glaserian GT mainly uses inductive reasoning, whilst Strauss' version of the method additionally utilises abduction. Abductive reasoning is

*a type of reasoning that begins by examining data and after scrutiny of these data, entertains all possible explanations for the observed data, and then forms hypotheses to confirm or disconfirm until the researcher arrives at the most plausible interpretation of the observed data (Bryant & Charmaz 2007c, p. 603).*

This definition clarifies that evolved and constructive GT must apply a certain degree of abduction to reach an interpretation of the findings. Abductive reasoning thus emphasises the importance of researchers' pre-engagement with the phenomenon under study, as well as their need to involve their personalities, experiences, and presumptions during the research. Furthermore, without researcher involvement, abductive reasoning would be impossible. In the case of GT, abductive reasoning includes considerations of how theory may fit to individual cases (Bryant & Charmaz 2007a) and consequently its results cannot be generalised (Strübing 2008; Breuer 2010; Reichertz 2010). However, this is not in contrast to the methodological considerations of evolved and constructive GT, whose aims are explicitly non-objective. Following these considerations, I used both inductive and abductive reasoning in this study.

#### **4.3.4.4 Axiology**

This research aims to understand some meanings German renal transplant recipients attribute to medication adherence. This knowledge, despite not necessarily being generalisable, will contribute to the care of other kidney transplant recipients in Germany, including those in my institution.

This work adheres fully to the International Council of Nurses Code of Ethics for Nurses (International Council of Nurses (ICN) 2012) and the Helsinki Declaration (World Medical Association 2013). Ethics will be discussed in more detail in Chapter Five.

#### **4.4 Summary of Chapter Four**

This chapter has addressed basic philosophical considerations regarding this research. First, the philosophical trinity, that is ontology, epistemology, and axiology was introduced. Following this framework, my personal philosophical posture was outlined: I lean towards a postmodernist and partly relativist ontology, a subjectivist epistemology, and an applied axiology.

Based on this philosophical stance, the chosen research methodology, GT, was introduced and its development discussed. As GT is a contested methodology with multiple versions, the most important versions – classical, evolved, and constructivist – were outlined. The chosen basis of an interpretivist, subjectivist version of GT was explained, and evolved GT, based on the work of Strauss and Corbin, and constructivist GT, based on the work of Charmaz, were followed. As there are considerable overlaps in evolved and constructivist GT, I also clarified the ontological, epistemological, methodological, and axiological premises of this specific research.

The next chapter will introduce the research design, including sampling and data management. This will be followed by considerations of language and ethical aspects of this research. Also, the measures ensuring the rigour of this research will be discussed.



## CHAPTER FIVE: RESEARCH DESIGN

This chapter will introduce the research design. First, the sampling strategy will be outlined, followed by the data management; that is, data collection and analysis. In accordance with GT, the latter are integrated into one section, yet discussed separately. Particular issues regarding the management of data that were collected in German but are presented in English will be addressed. This will be followed by a discussion of relevant ethical principles. Finally, measures ensuring rigour of the research will be introduced.

### 5.1 Sampling

The sampling for this research could not take place at my area of practice for a variety of reasons, one of which was a lack of support by the medical director and the physicians' general lack of awareness regarding problems with adherence. However, being unable to recruit participants at my own institution also presented two advantages. First, I hypothesised that patients with whom I am unfamiliar might be more open about shortcomings in nursing care than those I have cared for myself. Secondly, this research aims to explore the perspectives of renal transplant recipients in their daily lives, which requires them to have fairly stable health. The patients on the wards in my hospital typically are in bad states of health and hence would not satisfy the inclusion criteria outlined below.

The sampling for this research took place in cooperation with a large nephrology practice near an urban German centre. This practice is operated by two independent, collaborating nephrologists and two staff physicians. Care is provided for a range of nephrological and hypertensive diseases, including all stages of CKD. Affiliated with the practice is a dialysis centre that provides both types of dialysis to around 180 patients with ESRD. Additionally, care throughout the transplant process, from pre-transplantation to long-term follow-up, is provided. At the time of this research, 40 renal transplant recipients were regularly followed up at the nephrology practice.

Sampling was carried out in close collaboration with one of the leading nephrologists who had agreed to the research (see Appendix 4) and played an active role in the recruitment of participants. According to the sampling strategy that will be outlined below, potential participants were approached by the collaborating physician and asked on my behalf if they were interested in taking part in the study. These potential participants were also given information material (see Appendices 5 and 6). Afterward, participants had a consideration time of at least 24 hours, after which they were contacted by the nephrologist and asked whether they wanted to take part. Most participants were immediately willing to take part and signed the informed consent form (see Appendices 7 and 8). After informed consent was signed, I was informed of participants' personal details and called them to arrange an interview date and location. Although participants were free to choose a location of their choice, all chose to be interviewed via telephone.

The sampling procedure followed a stepwise process as outlined by Morse (2007). All renal transplant recipients were considered eligible for the research unless one or more of the following exclusion criteria applied:

- acute deterioration of the graft requiring dialysis treatment,
- under 18 years of age,
- unable to speak and understand German,
- cognitive impairment, or
- not having provided written informed consent.

The first step consisted of purposeful sampling to ensure the heterogeneity of the sample. In purposeful sampling, participants are invited who share a certain experience (Morse 2007). The first few participants were intended to cover a broad spectrum of transplant recipients and thus offer a range of perspectives. This approach enabled me to work with a comprehensive amount and depth of data from the beginning.

Therefore, the first participants needed to match the criteria below, which ensured that a variety of different perspectives could be taken into account.

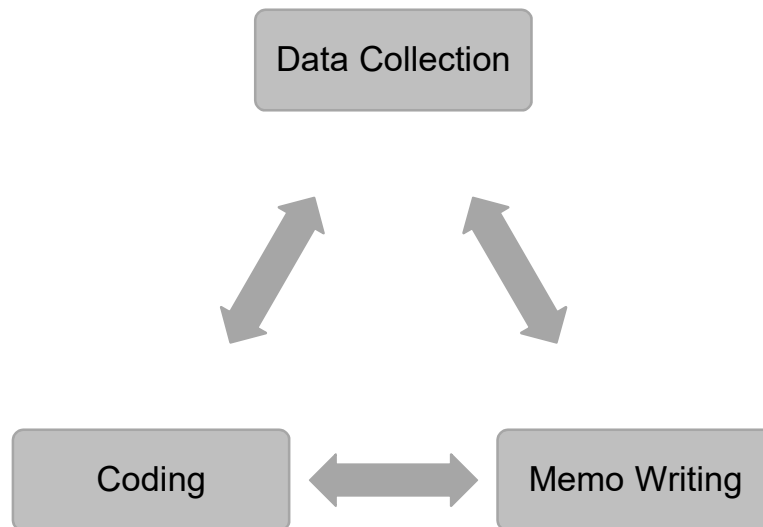
- experienced (> five years since transplant) and less experienced (< one year since transplant) transplant recipient
- female and male participant
- older (> 60 years of age) and younger (< 30 years of age) renal transplant recipient
- receipt of a living donation and of a deceased donor graft

This goal was reached after the first three participants covered all of the above criteria. Subsequently, the sampling method changed from purposeful to theoretical. In theoretical sampling, the researcher directs the sampling strategy toward the emergence of categories (Glaser 1978), and participants who may be able to contribute to the emerging categories are invited. These may also include “negative cases” (Morse 2007, p. 240), participants who might have contrary perspectives or challenge the emerging theory.

Theoretical sampling was carried out in close collaboration with the recruiting nephrologist. Based on the existent codes and categories at the respective stage of the research, I reflected on who might be able to add something to an emerging category, or who might have contrary perspectives, and the nephrologist helped to find a participant with the appropriate characteristic. The experience of dialysis, for example, emerged very soon as a major driver for medication adherence; however, all participants whom I had interviewed at that stage clearly articulated how dreadful their experience of dialysis had been. I wondered if someone who had coped very well with dialysis treatment would have a different perspective on this issue and how this affected medication-taking. The next person to interview was therefore a lady who clearly reported to miss dialysis because of loss of social bonds.

## 5.2 Data Management

A distinctive feature of GT is that data collection, and hence sampling, memo writing, and data analysis, proceed simultaneously and therefore represent a triadic and circular process that cannot be regarded separately (Hildenbrand 2010) (Figure 5). Therefore, data collection and analysis are integrated.



**Figure 5:** *GT as a triadic and circular process*

### 5.2.1 Data Collection Strategy

Data collection was carried out using semi-structured telephone interviews. Interviews were chosen as the means of data collection for several reasons. Qualitative interviews are deeply rooted in the tradition of SI and GT (Hopf 2010). In this regard, interviews are a helpful way to gain insight into peoples' subjective experiences and attitudes (Peräkylä & Ruusuvuori 2011). They also allow for the possibility of directly clarifying ambiguities and asking emerging questions (Hopf 2010). Another advantage for this particular research was that participants were likely to know each other from dialysis or post-transplantation follow-up, and might not have talked as openly in focus groups as in individual interviews (Birks & Mills 2011). However, there are some issues with interview research that must be acknowledged. For example, interviews are unpredictable to a large extent (Flick 2005) and highly reliant on the researcher's interviewing skills. In qualitative interviewing, the researcher must be aware that each party, the interviewer and interviewee, interacts with and influences the other and the course of the interview (Breuer 2010). This also applies if tacit assumptions or power imbalances arise during the interview (Mruck & Mey 2007). Distortions of memory may occur, especially if the interviewer "inadvertently misleads and reinforces inaccurate remembering" (Porter et al. 2000, p. 510). In all cases, a high extent of reflexivity must be applied.

Due to limited past experience, I opted to use semi-structured or "semistandardized" (Berg 2013, p. 109) interviews, or interviews allowing the researcher to be flexible during the interview within a set of guidelines. Semi-structured interview should include the following features (Berg 2013) I applied when conducting the interviews:

- reordering of questions during the interview
- questions may be asked using different terminology
- adjustment of language
- clarification and asking of questions by the researcher
- adaptation of the interview guideline as the research evolves

The decision to offer participants telephone interviews was made after weighing the advantages and disadvantages. The most obvious disadvantage of telephone interviews is the loss of the non-verbal expressions and visual cues that contribute considerably to the appreciation of face-to-face interviews (Opdenakker 2006, Nagy et al. 2010; Berg 2013). Also, contextual or social cues may appear covered, compared to face-to-face situations (Novick 2008). Another disadvantage of telephone interviews is the interviewer's inability to create a good interview environment, as she has no influence of the participants' choice of location and less influence on disturbing factors (Opdenakker 2006). It might have also been the case that participants would lack access to a telephone; however, in this sample all participants did have telephone access and most provided detailed information on how (mobile phone or landline) and when they wished to be called.

Novick (2008) argues that there is little evidence of the inferiority of telephone interviews compared with face-to-face interviews. Indeed, telephone interviews may also have advantages: for example participants may be more relaxed and open and thus reveal more intimate information. This may have to do with the researcher being more anonymous and therefore not being perceived as potentially threatening (Sweet 2002). Also, in telephone interviews, participants are able to choose a convenient interview location which may make them feel more relaxed (Novick 2008). Lastly, for this research, telephone interviews were pragmatic and logistically convenient (Birks & Mills 2011), as the town in which sampling took place is 275 km (171 miles) from where I am based.

Interviews were carried out following the guideline outlined in Appendices 9 and 10. After a short introduction to the research aims, the interview was opened by the main question “Please tell me how it is for you to take medication on a daily basis?” Participants were allowed as much time for this question as possible, to maximise information gain. The interview guideline also included further questions that specifically elaborated on the research aims. If participants touched on new concepts, however, the interview guideline was sidestepped in favour of this new information. If participants were reticent, follow-up questions such as “please tell me more about...” were applied. Interviews concluded with “Is there anything else you want to say?” to enable participants to add anything they considered worthwhile.

The issue of non-adherence in individual participants was deliberately not addressed, as this might have prompted participants to answer in a way they perceived to be 'right' socially, rather than openly, a tendency observed in other chronically ill patient groups (Wagner & Miller 2004). Also, a question regarding adherence could have evoked feelings of distress and shame, which could not be handled easily in an interview setting. Furthermore, individual participant adherence was not the primary interest of this research.

All participants were offered the opportunity to review a copy of their transcript, sent by post or email, and add or delete anything that did not accurately capture their point of view. If no feedback was received within two weeks, the participant's consent was assumed and the transcript analysed. All interviews were transcribed verbatim by me, using the software f4 (audiotranskription.de, Marburg, Germany, version 2012) following the transcription procedure described by Kuckartz et al. (2008).

This “simple” procedure includes the following features<sup>8</sup> (Kuckartz et al. 2008, p. 27):

- verbatim transcription
- existing dialects are not transcribed, language and punctuation are approximated to standard German; for example: „Da musst'ich noch'ne Tablette nehm'n”<sup>9</sup> becomes „Da musste ich noch eine Tablette nehmen“
- all statements regarding the interviewee are anonymised
- clearer and longer interruptions are marked as (...)
- distinctly emphasised terms are underlined
- affirmative and statements of the interviewer (such as mhm, aha) are not transcribed as long as the interviewee's flow of words is not interrupted
- interviewee's expressions emphasising the content (such as laughing or sighing) are put in brackets
- each change of speaker is indicated by a blank line

In addition to the interviews, fieldnotes and memos were written at all stages of data collection and analysis. Fieldnotes are “written records of observational data” (Montgomery & Bailey 2007, p. 67); that is, notes made in direct relation to data collection (Birks & Mills 2011). In this research, fieldnotes were made after each interview to describe the participant's non-verbal expressions, my own responses to the interview, and ideas on the most important issues covered by the participant. For this purpose, the interviews were listened to in parts or as a whole, either directly after the interview had taken place or after the first fieldnotes had been recorded.

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<sup>8</sup> Own translation and summary

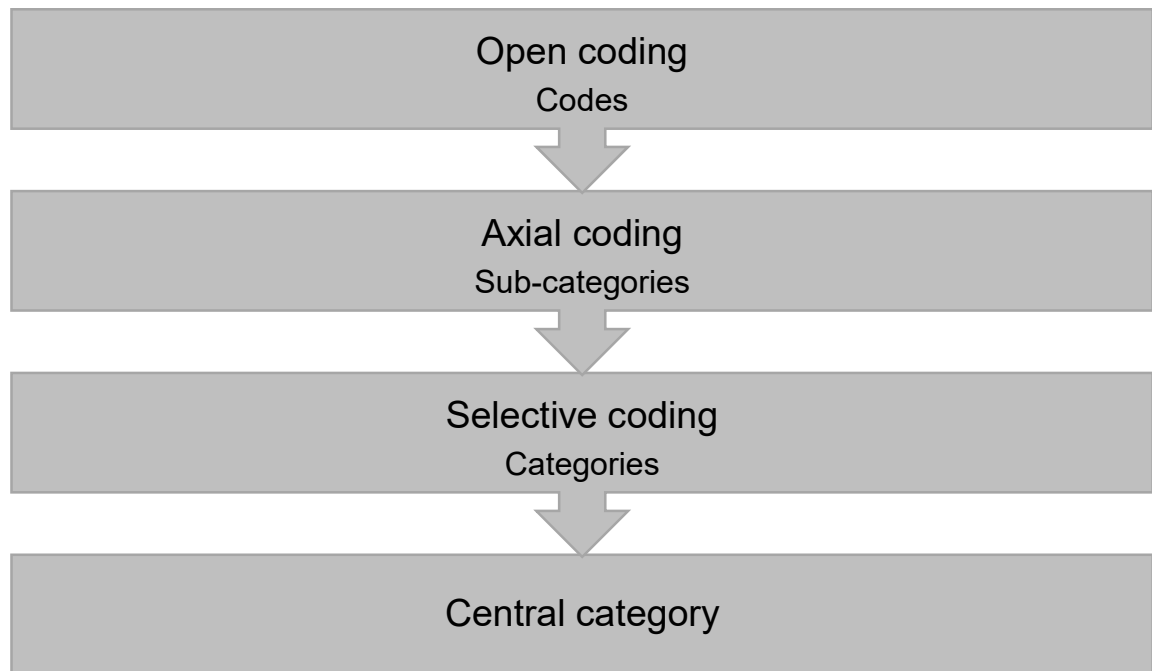
<sup>9</sup> “Then I needed to take one more tablet”



Memos represent the researcher's developing ideas regarding categories and facilitate abstraction of his/her ideas (Bryant & Charmaz 2007c; Montgomery & Bailey 2007). During this research, memos were written during data collection and analysis and helped me keep track of associations and findings, develop categories, and clarify their interconnections.

### **5.2.2 Data Analysis**

The software Nvivo 10 (QSR international, Doncaster, Australia) was used for data analysis. Following the tenets of GT (Hildenbrand 2010), data collection, data analysis and memo writing were carried out simultaneously (Figure 5). In this research, this meant that after each piece of data collection (that is interviews), data analysis (Figure 6) was immediately carried out using a three-step process (Strauss & Corbin 1998; Walker & Myrick 2006; Dey 2007a) as will be outlined below. For these purposes, the codes and categories of each interview were compared and contrasted to previous findings. On this basis, I produced a variety of memos that recapitulated, contrasted and compared the data and emerging findings. These enabled me to proceed to the next step of data collection using theoretical sampling, as outlined above. This circular process of data collection, data analysis and memo writing refined and abstracted the findings and led to the emergence of a central category. It was continued until theoretical saturation occurred (to be discussed in section 5.3.1).



**Figure 6: Process of data analysis**

The first step of data analysis, “open coding” (Walker & Myrick 2006, p. 551), consisted of a line-by-line-analysis of each transcript that, through the application of codes, aimed to identify concepts and their characteristics and dimensions (Strauss & Corbin 1998; Walker & Myrick 2006). This was followed by “axial coding” (Strauss & Corbin 1998, p. 123), in which the different codes were reorganised into sub-categories. This was intended to enrich the concepts (Hildenbrand 2010) and reveal how sub-categories belonged together or differed. The final step of data analysis, “selective coding” (Strauss & Corbin 1998, p. 143), abstracted the categories and grouped them all around a central theme (Walker & Myrick 2006), the “central category” (Strauss & Corbin 1998, p. 146). From this point on, the central category formed the key component of the findings and was continually verified by theoretical sampling.

Although I did most of the data analysis alone, two colleagues with experience in qualitative research were independently asked to read and code at least two interviews. Their associations and findings were discussed in relation to the categories I had already worked with. These colleagues' findings were closely related to the categories with which I had been working, and differences were resolved through discussion. The complete findings from this research, together with a multitude of direct quotes by participants, were used with a group of undergraduate nursing students at the University of Freiburg where I teach qualitative research. In this class, the quotes were independently reviewed and categorised by two groups of students and subsequently discussed. This did not reveal any significant departures from my previous work.

### **5.3 Participants and Data Collection**

Seventeen participants were invited to take part in this study, of whom all agreed. Given this high rate, in the first contact, I asked all participants again whether they agreed to take part, but no participant withdrew consent. All participants were comfortable with being interviewed by telephone.

Of the seventeen participants, fourteen had functioning grafts and three had suffered graft failure and were stably back on dialysis treatment (Table 8).

	Total Sample	Without Dialysis	With Dialysis
<i>Gender N (%)</i>			
Female	9 (52.9)	7 (50.0)	2 (66.7)
Male	8 (47.1)	7 (50.0)	1 (33.3)
<i>Age (yrs)</i>			
Median	52	53.3	48
Min	20	20	47
Max	74	74	64
<i>Underlying disease N (%)</i>			
Congenital ureter stenosis	1 (7.1)	1 (7.1)	N/A
Diabetic nephropathy	1 (7.1)	1 (7.1)	N/A
Focal segmental glomerulosclerosis	1 (7.1)	N/A	1 (33.3)
Glomerulonephritis	4 (28.6)	4 (28.6)	N/A
Idiopathic kidney disease	2 (14.3)	1 (7.1)	1 (33.3)
Interstitial nephrosis	1 (7.1)	N/A	1 (33.3)
Nephronophthisis	1 (7.1)	1 (7.1)	N/A
Polycystic kidney disease	2 (14.3)	2 (14.3)	N/A
Vascular nephropathy	4 (28.6)	4 (28.6)	N/A
<i>Donor characteristics N (%)</i>			
Deceased donor	12 (70.6)	10 (71.4)	2 (66.7)
Living related donor	5 (29.4)	4 (28.6)	1 (33.3)
<i>Number of transplants N (%)</i>			
1	16 (94.1)	13 (92.9)	3 (100.0)
2	1 (7.1)	1 (7.1)	N/A
<i>Type of transplant N (%)</i>			
KTx	16 (94.1)	13 (92.9)	3 (100.0)
PTx/KTx	1 (7.1)	1 (7.1)	N/A
<i>Working N (%)</i>			
Yes	7 (41.2)	5 (35.8)	2 (66.7)
No	10 (58.8)	9 (64.3)	1 (33.3)
<i>Time since Tx (yrs)</i>			
Median	N/A	11	N/A
Min	N/A	0	N/A
Max	N/A	24	N/A
<i>Time with functioning graft (yrs)</i>			
Median	N/A	N/A	10
Min	N/A	N/A	4
Max	N/A	N/A	21
<i>Time requiring dialysis treatment after graft failure (yrs)</i>			
Median	N/A	N/A	1
Min	N/A	N/A	1
Max	N/A	N/A	2

**Table 8: Participant characteristics**

Abbreviations: KTx = kidney transplantation, KTx/PTx = kidney-pancreas transplantation, Max = Maximum, Min = Minimum, N/A = not applicable, Tx = transplantation, yrs = years

The telephone interviews lasted from twelve to 60 minutes with a median of 26 minutes (Table 9). All participants were offered a transcript of their interview by either post or by email, but only ten participants indicated their interest; the remaining seven explicitly declined the opportunity to check the transcript and add comments. Of those who received their transcript, only one participant provided feedback. This feedback, which consisted mainly of linguistic changes, was worked into the original transcript prior to analysis.

	Total Sample	Without Dialysis	With Dialysis
<i>Interview duration (mins)</i>			
Median	26	24.5	26
Min	12	12	16
Max	60	60	32
<i>Transcript received N (%)</i>			
Yes	10 (58.8)	9 (64.3)	1 (33.3)
No	7 (41.2)	5 (35.8)	2 (66.7)
<i>Feedback provided N (% of those having received the transcript)</i>			
Yes	1 (10.0)	1 (11.1)	0 (0.0)
No	9 (90.0)	8 (88.9)	1 (100.0)

**Table 9: Interview characteristics**

*Max = Maximum, Min = Minimum, mins = minutes*

### 5.3.1 Theoretical Saturation

Theoretical saturation is the point at which additional data does not lead to new categories or further insight into existing categories (Strauss & Corbin 1998; Bryant & Charmaz 2007c). In GT, theoretical saturation occurs not abruptly but as a stepwise decision made by the researcher as the subcategories and categories develop (Morse 2007). At this point, sampling and data collection are terminated.

In this research, theoretical saturation began to show after approximately 13 interviews. From there, I reached the conclusion that theoretical saturation was attained, in part because the length of each interview began to decrease, while at the same time, the emerging sub-categories made sense and the central category emerged from the data. Additionally, I realised that although all participants told different stories, my attention during interviews decreased as repetition of themes and concepts increased.

At this point, I conducted some additional interviews to ensure that no new codes emerged. The last participant, in close collaboration with the recruiting nephrologist, was asked to take part as a “negative case” (Morse 1995, p. 149). According to the recruiting physician, this patient was someone who employed distinct coping and self-management strategies, including his perspective regarding medication-taking, compared to other renal transplant recipients. However, in the interview with this participant, no new categories emerged and existing categories could not be elaborated, and thus sampling and data collection were terminated.

### **5.3.2 Member Checking**

Aside from the opportunity to review and comment on their interview transcripts, participants did not review the research results. This was decided on the basis of GT literature arguing that following the methods of GT makes member checking redundant (Birks & Mills 2011; Charmaz 2014).

## **5.4 Considerations of Language**

Language plays a crucial role in any qualitative research (Squires 2008). In this study, language is considered from two perspectives: possible issues between the participants and me, and problems arising from translation of participants’ German quotes into English for this thesis.

Most participants’ language was strongly influenced by their local dialect. While I was able to understand what was being said, I was unable to communicate in participants’ own dialects. I do not believe this issue was severe enough to generate cross-language research problems (Temple & Young 2004; Squires 2008; Squires 2009), as no translator or interpreter was needed; however, this was one reason for employing the simple transcription rules outlined previously. These gave me the opportunity to fully understand what was said without having to refer too frequently to the original recordings. However, some dialectal features of the interviews may have been lost or local idioms may not have been recognised appropriately.

Although the main data analysis was conducted in a German-speaking environment, including issues related to research quality discussed below, translations of seminal quotes into English were needed for this thesis. Despite vast literature on cross-language qualitative research (Temple & Young 2004; Squires 2008; Squires 2009; Croot et al. 2011; Kruse et al. 2012), limited advice regarding original data in a thesis could be found.

Consequently, I decided to translate the quotes that were intended to illustrate the findings by myself, and to include the original quotes in Appendix 11. These footnotes may include explanations of context and the meanings of untranslatable proverbs. The translation itself was carried out as an “instrumental translation”<sup>10</sup> (Kruse et al. 2012, p. 111); that is, not literal translation but rather readable and understandable in English and conveying the intended information.

All translated quotes were independently reviewed and commented on by two German nurses who had excellent knowledge of the English language. Additionally, both have experiences in conducting and writing up qualitative research in English. After their individual review of the translated quotes, all disagreements were solved by discussion with a group of qualitative researchers from different disciplines, and ambiguous quotes were reviewed by a British nurse working in Germany who speaks German fluently.

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<sup>10</sup> Instrumentelle Übersetzung

## 5.5 Ethical Considerations

Although ethical issues were reflected throughout the research process and this work, the main ethical considerations will be outlined here. All research must follow basic ethical principles. These include autonomy, non-maleficence, beneficence, and justice (Beauchamp 2007). In other words, research must:

- respect participants' decisions,
- not harm participants,
- balance benefits against risks, and
- treat participants equally in terms of risks or costs.

Regarding qualitative research, Richards & Schwartz (2002) point out four potential risks: anxiety and distress, exploitation, misrepresentation, and identification of the participant. In this study, anxiety or emotional distress may have been provoked if participants admitted non-adherence and became fully aware of its consequences for the first time. In this case, in accordance with the participant's wishes I would have provided emotional support or terminated the interview. Additionally, list of nearby psychologists was available and the collaborating nephrologist agreed to refer participants to the psychologist of their choice. However, this circumstance did not occur during any interview.

To prevent exploitation, all potential participants were provided with an information sheet and consent form. They were also provided sufficient consideration time, and gave written informed consent before I obtained contact details. All but one participant completed the interview, with only one stopping it before all issues had been discussed. No participant withdrew from the study after the interview was conducted.



The risk of misrepresentation was minimised by offering all participants transcripts of their interviews; however, only one participant gave feedback, as will be outlined in more detail in Chapter Six. Every precaution to prevent recognition of participants was taken. All aspects of the research regarding individual participants were kept strictly confidential and were only available to the recruiting person and me. All data were handled confidentially and anonymised from transcription onward. All participants' names were replaced by common German names and care was taken that neither first nor second name would overlap with a real name. Throughout the research, the recruiting nephrologist was not informed about statements made by any individual participant or about any potential non-adherent behaviour that arose during the course of any interview.

Data protection was ensured by storing all data electronically on TÜV<sup>11</sup>-certified, Germany-based servers of Deutsche Telekom, and hardcopies were kept in a locked cupboard. To ensure ethical correctness and obtain clearance, the research proposal was reviewed by both the research ethics committee of the Cardiff University School of Healthcare Sciences and the Ethics Committee of the German Society of Nursing Science, who both approved the research (see Appendices 12 and 13).

## **5.6 Rigour of the Research**

The rigour of qualitative research following a constructivist-interpretivist research paradigm, including GT, is commonly assessed using the main standards of credibility, transferability or fittingness, confirmability, and auditability (Beck 1993; Chiovitti & Piran 2003; Denzin & Lincoln 2011a). Similar to ethical considerations, aspects of credibility, auditability, and fittingness are outlined throughout this work, but for clarity all three standards of rigour are outlined below.

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<sup>11</sup> TÜV = Technischer Überwachungsverein. German technical inspection company ensuring the safety of different kinds of products.

Credibility, the qualitative equivalent of the quantitative concept of internal validity (Beck 1993), measures how “vivid and faithful the description of the phenomenon” (Beck 1993, p. 264) is, or the trustworthiness of the research (Chiovitti & Piran 2003). Thus, credibility reflects the extent to which the participants, or other persons having experienced the studied phenomenon, can follow the researcher's description of it. This was ensured by utilising a multitude of direct quotes in the presentation of findings to stay as close to the original data as possible.

Transferability, or fittingness (Holloway & Wheeler 2002; Ryan et al. 2007), corresponds to external validity or generalisability of quantitative research (Beck 1993). As this research aimed to produce a substantive theory of renal transplant recipients' perception of medication-taking in their specific setting, generalisability was not intended. However, in this context, fittingness refers to the extent to which the findings from this specific group of people can be transferred to other persons in similar situations.

Confirmability refers to the quality of the results (Williams 2015) and can be achieved by referring to the literature or consulting persons who are not directly involved in the research for their interpretation of the results. Here, the findings and some of the data were presented to a group of qualitative researchers and nurses, and to a group of nursing students, for discussion.

Auditability, or dependability (Holloway & Wheeler 2002; Ryan et al. 2007), describes the ability of the reader to follow the researcher's decisions in the process of data analysis (Beck 1993). This necessitates disclosure of each step and consideration made in the research.

## **5.7 Summary of Chapter Five**

This chapter has introduced the reader to the research design of the study; that is, sampling and data management. It has also outlined the characteristics of the sample and data. Considerations of language, ethics, and rigour were discussed. The next chapter will present the findings of this research.

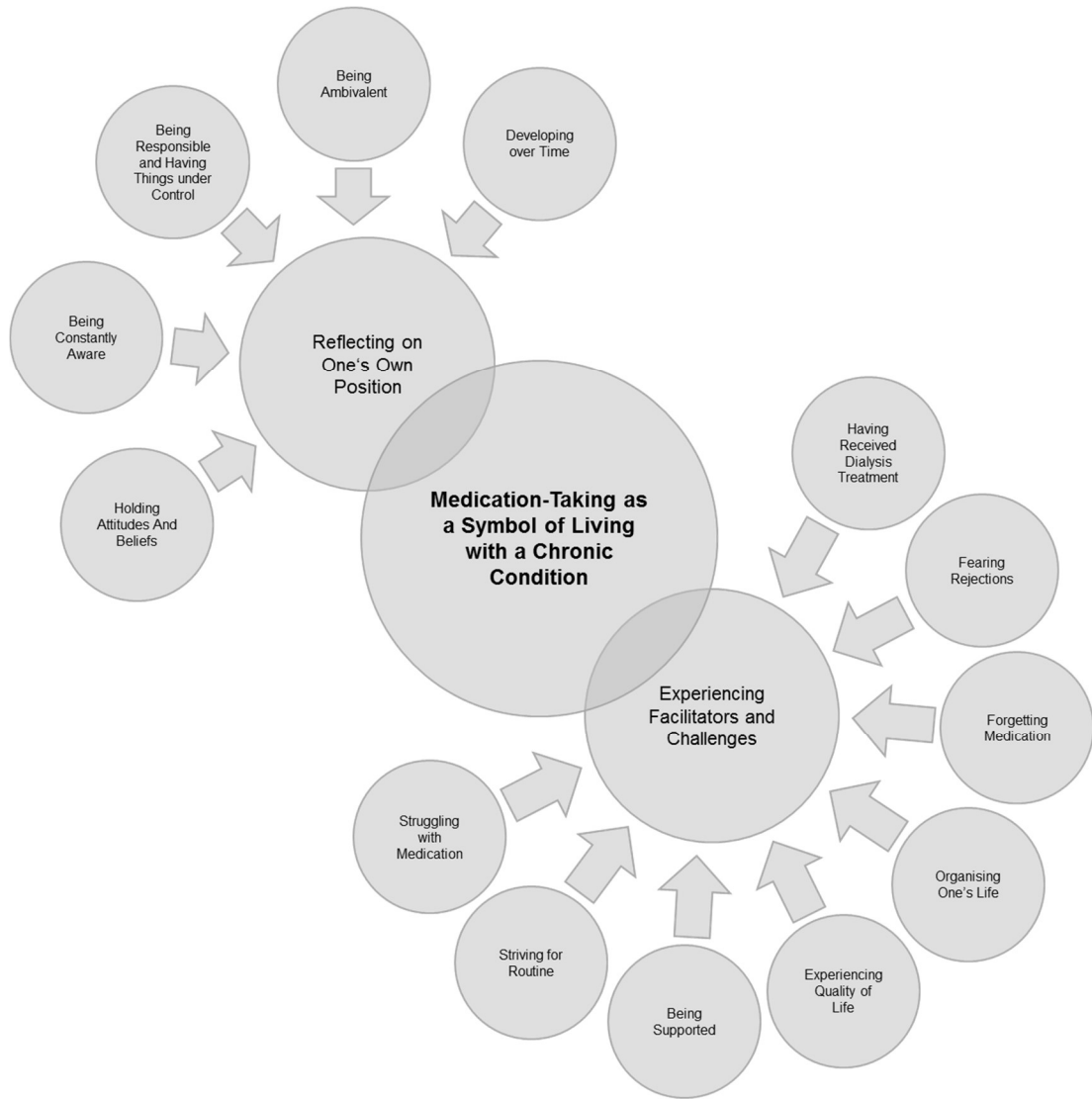
## CHAPTER SIX: FINDINGS AND SECONDARY LITERATURE REVIEW

This chapter will present the study's findings.

### 6.1 Findings

Here the findings of this research will be presented according to the data analysis principles outlined in Chapter Five. As suggested by Strauss & Corbin (1998), the data analysis followed a three-step-process consisting of open, axial, and selective coding. This led to the development of codes, sub-categories, categories, and finally the central category.

The central category of this work is *medication-taking as a symbol of living with a chronic condition*. This comprises two major categories, namely *reflecting on one's own position* and *experiencing facilitators and challenges*. Both categories have several sub-categories (Figure 7). The central category, both categories, and the sub-categories are interconnected, influence each other, and in some instances also stem from each other. Therefore, categories overlap in some instances, as the following section will outline.



**Figure 7: Theory of medication-taking as a symbol of living with a chronic condition**

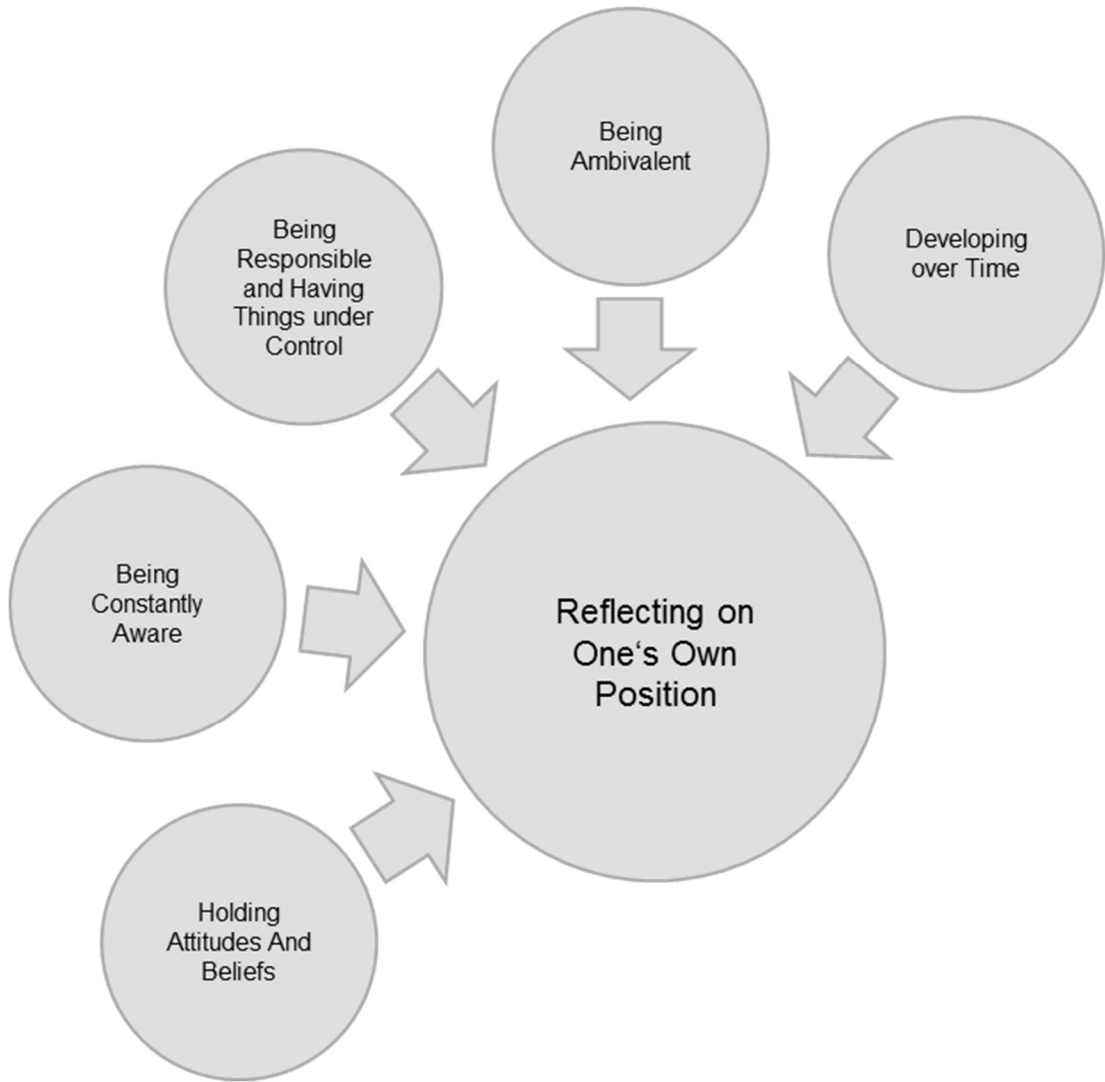
This section is organised as follows: first, I will introduce the two major categories that give rise to the central category of this research and with it the core of the data-derived theory. In accordance with the data analysis process, I will present each of the two categories using an inductive approach to enable the reader to follow my train of thought when developing these categories. This means that the presentation of each category and sub-category will include selected examples of participants' words. At this point, the reader will notice that some participants are overrepresented in the quotes; this does not imply that their contribution to the respective category exceeded those by participants quoted less, but rather has to do with speech. The presentation of findings will then evolve through the stage of open coding to the integration and refinement of codes into sub-categories. After the two categories have been outlined, the central category as the core of the theory emerging from this research will be introduced. At this point the emphasis will be on the presentation of how the two categories fit into the central category. Finally, I will briefly summarise the findings of this research.

All steps will be illustrated as figures in order to enable the reader to follow my audit trail throughout this research. Some of the memos I wrote in the process of data analysis will be presented as part of theory development. To avoid confusion with other sources, mainly interview excerpts, these memos will be presented in boxes.

However, before presenting the findings of this work, I invite the reader to recollect what this research is about. In previous chapters I outlined that internationally, many renal transplant recipients experience problems with adhering to their medication regimen. The literature review has shown that potentially modifiable factors, such as social support, experience of dialysis, experience of side effects, features of the treatment regimen, intentions to adhere, beliefs regarding medication, forgetfulness, and mental health issues are involved in the development of non-adherence following kidney transplantation. However, we know little about what motivates kidney transplant recipients in a variety of countries, and less still about what motivates their German peers. This research thus aims to understand the processes leading to adherence or non-adherence among German kidney transplant recipients and to generate a theory explaining these processes.

### **6.1.1 Reflecting on One's Own Position**

In this research, participants' answers regarding medication-taking and being chronically ill showed a high extent of reflection regarding the participants' own position and their role in the management of their condition, including medication-taking. Figure 8 illustrates the makeup of the category *reflecting on one's own position*.

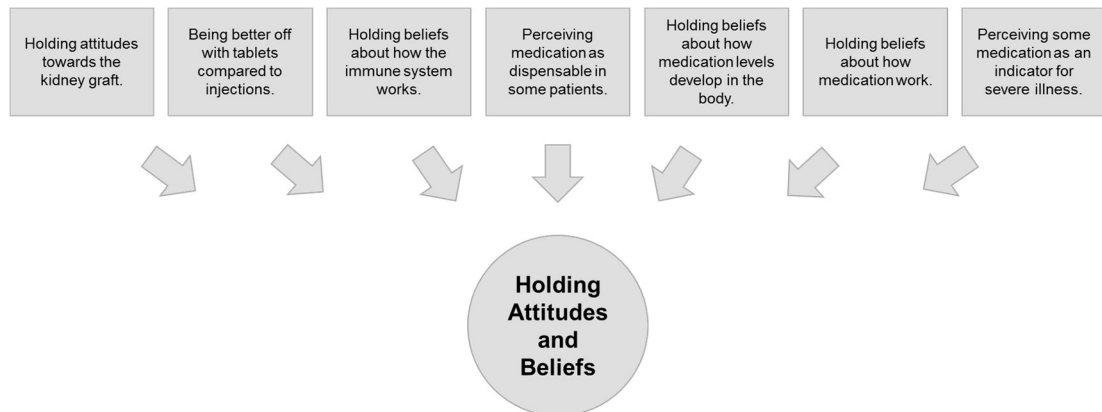


**Figure 8: Sub-categories of the category 'reflecting on one's own position'**

The category *reflecting on one's own position* is diverse, consisting of five sub-categories. However, as I will outline below, all form part of participants' reflection on their own position. All participants hold individual sets of attitudes toward and beliefs related to their condition. This goes along with the necessity for constant awareness of potential complications and a high demand for responsibility for their own health and strong emphasis on having things under control. However, this is accompanied by a high degree of ambivalence, which is not limited to medication-taking but also includes basic considerations regarding kidney transplantation. Finally, reflection on the participants' own position includes detailed considerations of how medication-taking has evolved since transplantation. Using an inductive approach to the process of data collection, the following section will outline how this category was built from the data.

### 6.1.1.1 Holding Attitudes and Beliefs

Participants' position regarding kidney transplantation, and specifically medication-taking, depends on their individual sets of attitudes and beliefs. This sub-category can be traced in Figure 9.



**Figure 9: Codes supporting 'holding attitudes and beliefs'**



Surprisingly, the relationship between donor and recipient was not addressed often during this research. Instead, whether their kidney came from a living or deceased donor is not an important factor to recipients. One participant whose living related kidney graft failed after a relatively short time will not accept another living related donor kidney, but all other participants who received related kidney donations are as concerned about their kidney as those who received a kidney from a deceased donor, as Ms Wolf illustrates:

*Whether it is my husband or anyone else who provided his kidney, that doesn't matter. Of course in this case, because it is my husband, very specially. But I wouldn't have a different attitude if it was a cadaver donation. (Ms Wolf, 20:17)*

In contrast, having received a combined kidney-pancreas transplant may be fundamentally different for medication-taking from a kidney transplant alone. For most kidney-only transplant recipients, the number of pills they must take post-transplantation exceeds the pre-transplant number, but the opposite may be the case for pancreas transplant recipients. Pancreas transplant recipients suffering from Type I diabetes have depended on medication for most of their lives. Furthermore, for these patients, as well as for patients suffering from other forms of insulin-dependent diabetes, regular insulin injections are perceived as more threatening than taking tablets:

*It's really an advantage that you can take this medication orally and don't have to inject. That's ... it's a mega-advantage. If you have to think now you had to inject every day or maybe even twice a day or three times. Then you're better off with a tablet. (Mr Hoffmann, 13:52)*

However, as only one kidney/pancreas transplant recipient took part in this research, these findings should not be overestimated.

Although side effects of medication can be debilitating, participants' attitudes towards medication and medication-taking are generally positive. Participants are aware of the importance of taking medication and therefore regard medication-taking as non-negotiable. However, this does not mean that participants are not critical of or careless toward their medication regimen. Almost all patients stated that the medication they take on a daily basis was the outcome of ongoing discussions and negotiations with their nephrologist. The aim of most participants is to take as few tablets as possible. Also, participants are aware of how specific tablets affect their well-being and openly discuss these concerns with their nephrologist whenever possible.

Many attitudes toward medication are rooted in participants' understanding of how the human immune system, IM, and other drugs work. These beliefs are constructed by participants' own interpretation of information acquired at some stage of their condition. Sources of information mainly include their transplant centre, their nephrologist, and in some cases independent information gained from books, journals, or the Internet. Participants' beliefs regarding how the immune system works vary considerably, and participants utilise different metaphors to understand the complex biomedical processes. One example of these beliefs was reported by Ms Schulz:

*For example, he [nephrologist] explained about the immune system given that I take immunosuppressants. [...] He said 'imagine a train that's being unloaded. And all the workers there, one's missing a leg, the other one only has one arm' [...] he said, 'and it's clear that they need more time than a complete person'. And just like that he explained that my immune system is a little weaker now. Well, I immediately got it this way. Maybe that sound funny, but for me that was graspable. (Ms Schulz, 09:59)*

These beliefs regarding how the immune system works give rise to beliefs concerning IM. Some participants question whether IM are necessary for survival of the graft, as Mr Hoffmann outlined:

*There's no study or no results that it doesn't work without medication. It will probably in some patients ... it will maybe work that they don't have to take these medicines. There is one study in America, there it's been in one patient, they have tested it and it worked. But the risk is much too high. You can just test, either the organs are preserved or they are rejected if you leave the medicine. And therefore no one will ever think about stopping the medication. (Mr Hoffmann, 06:54)*

Also, participants have varying understandings of how the level of medication in their blood changes over time. Some participants believe that the blood level takes hours to several days to decline, as the following quote illustrates:

*Most of the medication, the extremely important ones, develop a level [in the blood]. And this level doesn't decline towards zero when I take the medication half an hour later. I believe that 3 or 4 hours ... that's my non-medical opinion that the body tolerates that well. (Mr Becker, 23:28)*

Participants also make different assumptions of how medications interact in their bodies and attribute some of their medication-related symptoms to such interactions. One participant, for example, reported high levels of fatigue and traced these back to medication side effects:

*Yes, tolerability. Well I ... as I said, I ... Cynt [antihypertensive drug] and what else I take. I'm ... it takes at least ... when it then has an effect, I'm sleepy for half an hour. Until the effect has unfolded in the body [...] And when I then sit quietly and then ... I mean the fatigue, with my kidney, that's known anyhow, that clear anyhow and with my skin cancer. But when the tablets add to this, then I could recline<sup>12</sup> after half an hour. And that lasts about half an hour or 45 minutes, hour, and than it's over. (...) Which phenomenon that is ... but that's also due to my illness. And due to the many tablets, I don't know. You know, that's such a mixture, that's such a cocktail that needs to arrange in the body. (Mr Schneider, 10:27)*

Other misunderstandings of specific drugs are, from the participants' point of view, closely connected to being seriously ill, as Ms Müller outlines with regard to her intake of steroids:

*When it [kidney disease] started with my kidney, my own kidneys, I had to take 60 milligrams of cortisone daily. And the first one I took came back immediately. Because for myself I thought 'this is end-stage now'. Because in the past, for me, when it came to cortisone ... 'oh dear, then you're hanging on a silken string'<sup>13</sup>. (Ms Müller, 28:20)*

The beliefs held by the participants may have different effects, which I summarised in the following memo and will discuss below.

*Beliefs have very different consequences: (1) influence adherence, (2) influence the way patients scrutinise and discuss with their provider (3) but are also triggered by subjectively experienced symptoms (such as Mr Schneider's belief that IM are tiring).*

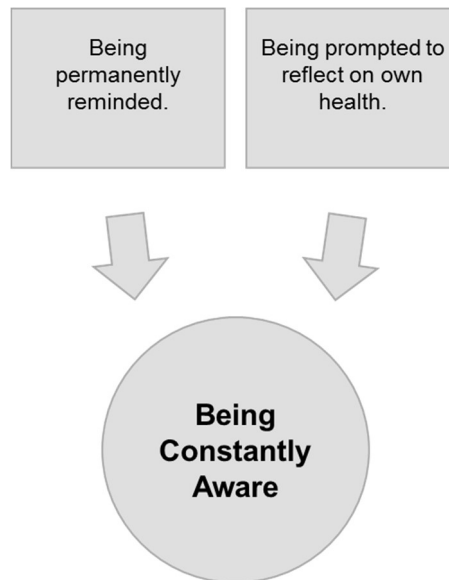
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<sup>12</sup> In the sense of "sleeping"

<sup>13</sup> Figurative proverb meaning *being in extreme danger*.

### 6.1.1.2 Being Constantly Aware

Taking medication on a regular basis acts for many participants as a constant reminder of their disease, which is mirrored in the sub-category *being constantly aware* (Figure 10).



**Figure 10: Codes supporting ‘being constantly aware’**

At each intake time, participants are reminded that despite a possible subjective sense of normality and health, their well-being depends on strict rules and the correct intake of medication. This notion of being reminded is shared by most participants, but their coping strategies differ considerably. Most participants do not experience this daily reminder as a threat, but remain aware of their situation, as this quote outlines:

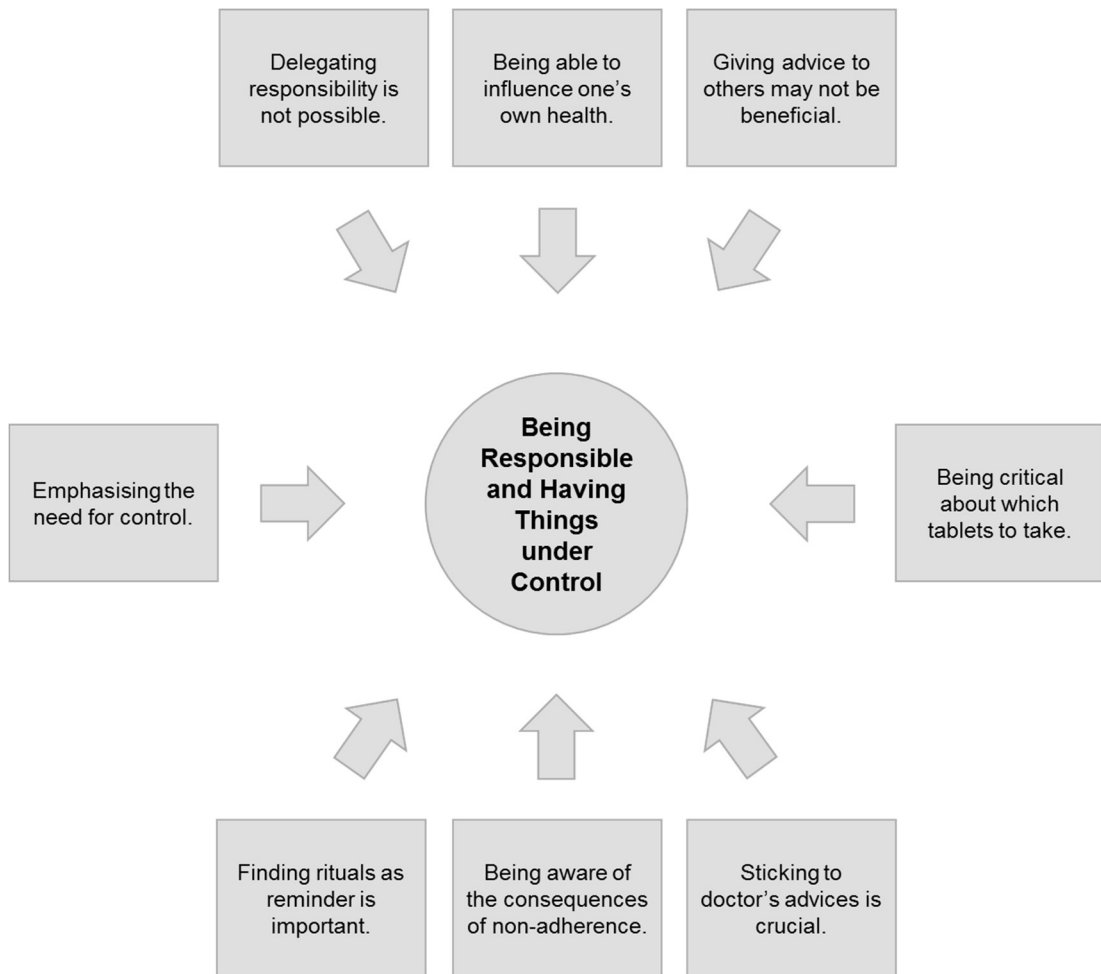
*And then there’s the awareness of having a new kidney, that also reminds you very much of your medication. That virtually is a permanent reminder. You don’t forget this that easily. (Mr Richter, 00:38)*

However, other participants emphasise that the daily intake of medication causes them to reflect on their life and health, and this puts them in charge of their own health and illness, which may also be satisfactory:

*I am always asked to care for myself, all the time. What am I doing, how am I doing, in any case. [...] What it does, this is just crossing my mind, is to take care of myself even more intensively. How I feel. To listen even more to my state of health, to my feelings. That's ... the intake of these tablets, especially these, provokes it. And that's what pleases me. That I always think how am I? Actually everyone should do that, I believe. Everyone in every moment, what am I feeling, what am I feeling? Am I still alive or am I dead already? (Mr Schröder, 13:40)*

#### **6.1.1.3 Being Responsible and Having Things under Control**

The sub-category *being responsible and having things under control* (Figure 11) mirrors participants' strong sense of holding ultimately responsibility for their medication-taking behaviour. This is connected with notions of participants' influence on their own health and their need to be in control of issues surrounding their condition and come to a decision that suits their perceived needs.



**Figure 11: Codes supporting 'being responsible and having things under control'**

Participants report receiving a great deal of support from family and friends, as well as from their transplant centre and nephrologists, regarding their medication intake. However, most participants also emphasise that medication-taking eventually is their own responsibility, as the following example shows:

*Both the attitude towards the illness as well as towards the regular intake of medication can be called responsibility for oneself you cannot delegate to someone else. (Ms Wolf, 06:40)*

This responsibility is not perceived as a threat, but rather as positive, enabling participants to truly be in charge of their health. This stems from the awareness that having a transplant offers the patient opportunity to influence his or her own health, rather than being at the mercy of the chronic condition that led to the transplantation:

*I have a long history of illnesses and I know ... well, I know what it's like to be ill and so on. And I know that there are so many diseases one cannot prevent and I always think [...] that I needed a kidney and that it's a donor kidney, I cannot influence that. But to take my medication regularly and with it help my kidney to longer ... that it works longer and better, that's something I can influence. (Ms Schmitt, 13:50)*

This stance, however, requires information for making decisions. In order to be informed regarding their condition and its treatment, participants use a variety of media. Some participants report reading transplant-related books or journals, while others use the Internet. However, the most important source of information is the transplant centre and, later, the nephrologist. No participants mention using self-help or patient support groups. Also one participant also avoids offering unsolicited support to peers for fear of forcing her point of view on others:

*I have realised that many pieces of advice that come without being asked are not favoured. Everyone is fixed in the way he does certain things. And if someone sees it totally differently, be it in terms of weight control, exercise, or others, that's never appreciated and will not be taken to heart. (...) I think that would be ... in my eyes that would rather be like dressage and that is only kept up as long as the person is present. It's just important that ... everyone knows how much personal responsibility he must have and that's the crux. (Ms Wolf, 17:27)*



Being informed not only helps patients to decide on their medication regimen, but also makes them careful regarding changes of medication doses or new medication they may need. This frequently applies when participants are prescribed additional medication by physicians from other disciplines. In these instances, participants usually double-check prescriptions with their nephrologist to ensure that no pharmacological interactions will affect their IM. This approach is outlined by Mr Schneider:

*But I'm relatively critical, whenever I'm talked into something, when they [physicians] say, 'this tablet and that tablet', I say 'stop, I already have so many tablets. Why, why, why?'<sup>14</sup> I tend to ask because I try to reduce the tablets more and more. I used to take more than 20 tablets a day, in the university hospital. Needed to take them. And little by little we reduced them. (Mr Schneider, 07:18)*

Being responsible and in control also requires a great deal of discipline, as all participants were well aware. This is exemplified by Ms Koch:

*To really stick to that how the doctor says and also correct [...] to take the tablets as one needs to, and also as the medic advises him. And not to say 'I don't take them today and I don't take them tomorrow', or something. Well, one should strictly stick to that. To do what the doctor says. Otherwise I couldn't have kept my kidney that long. (Ms Koch, 14:21)*

Despite this awareness, some participants admit to occasional lapses in discipline. In this case, however, participants fully realise the consequences of not being disciplined enough:

*I'm not such a consequent person that I think about it [medication-taking] all day long, 'you must now take your tablets at 8'. It's just like that. It ... as I said before, I haven't experienced any disadvantages by it yet. I'm aware of what happens and that's ok for me like that. (Mr Schröder, 03:49)*

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<sup>14</sup> The words *wieso*, *weshalb*, *warum*, all meaning *why* in English, are part of the German version of the Sesame Street song and have become a non-translatable proverb.

It is crucial to note that forgetfulness is an important issue with which most participants are familiar. Participants discuss a variety of strategies for reminding themselves of and controlling their medication intake. The most commonly reported reminders, apart from family members or friends, are acoustic alarms, such as alarm clocks or mobile phones, and pill-boxes. Additionally, rituals, and characteristics of medication such as colour or size, are used to keep track of whether medication has been taken. Combining multiple reminders, such as a rituals with a visual clue, is common. Rituals tie tablet-taking to routine events in daily life. This may consist, for example, of putting the medication box next to the television or taking medication directly after teeth brushing, as Mr Richter recommends:

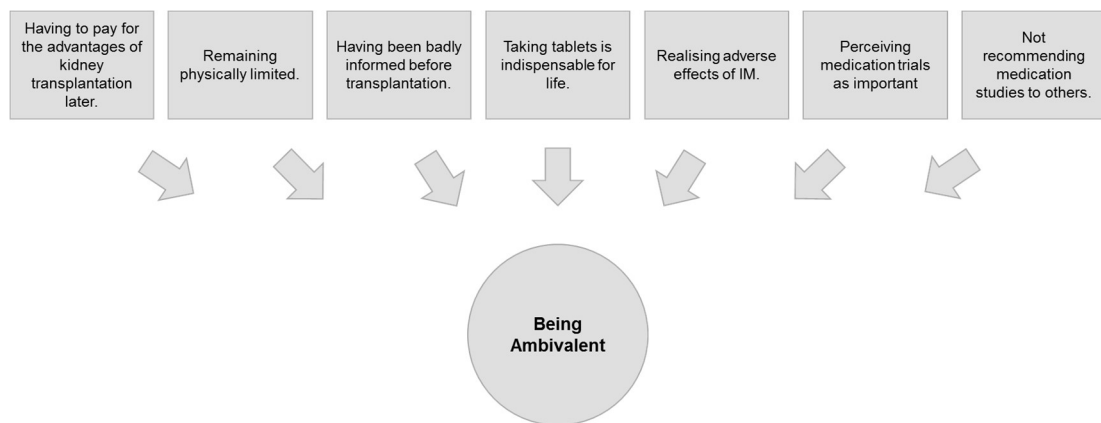
*I would also recommend them to tie it [medication-taking] to things you do regularly each day. If for example someone brushes his teeth in the morning and in the night, you should do that anyway [laughs], and he hasn't anything else to tie to, then maybe to tooth brushing. [...] You have to find anything to connect it to that it becomes a regular ritual. (Mr Richter, 21:45)*

Although not all participants use reminders, those who do use them emphasise that remembering medication without these devices is not feasible, suggesting that those not using reminders may fail to adhere, as Mr Huber stresses:

*And what certainly doesn't work is to fetch the tablets daily or at the assigned times, release them from the blister pack and then take them. There's no control whatsoever in there. Well, from my point of view ... the tablets need to be prepared (...) as I said, the weekly box and the daily box help enormously. (Mr Huber, 29:39)*

#### 6.1.1.4 Being Ambivalent

A common thread through all interviews is *being ambivalent*. Ambivalence, in this context, can be defined as “the coexistence in one person of contradictory emotions or attitudes (as love and hatred) towards a person or thing” (OED 2016a). Although other expressions, such as tension or ambiguity, might also have been appropriate, I opted for the term ambivalence, as it is not only of German origin (OED 2016a), but is used to express “Zwiespältigkeit; Spannungszustand; Zerrissenheit (der Gefühle und Bestrebungen)”<sup>15</sup>, as DUDEN (2016), the German equivalent to the OED, clarifies. Ambivalence arises in many different ways (Figure 12).



**Figure 12: Codes supporting ‘being ambivalent’**

Most importantly, the fact of having received a transplant and feeling extremely well compared to the pre-transplant stage, yet still suffering from a chronic disease, was hard to understand and articulate for most participants. This ambivalence was inherent in all interviews. Ms Maier was one of the few participants who clearly reported this ambivalence using a simple metaphor:

*I read somewhere that for this nice present you need to pay afterwards. Of course, that’s ... one’s always unhappy. You take something out like a loan. You basically take it out as like a loan. You take it and you need to pay for it afterwards. (Ms Maier, 54:01)*

<sup>15</sup> “conflicting or contradictory nature, state of tension, inner turmoil (of feelings or efforts)”

Ambivalence in most cases is either associated with kidney transplantation or with the need for daily intake of medication. On one hand, renal transplantation is perceived as a procedure that enables the recipient to lead a life close to normal. QoL is reported to be particularly high relative to pre-transplantation.

However, some participants do not seem to have fully captured what kidney transplantation implies in terms of limitations to their daily lives. Expectations of kidney transplantation regarding physical and social abilities have not fully been met in most cases:

*It's also that you ...as a transplant recipient you expect ... rather I have expected that because of the new kidney my physical condition [...] will re-gain the pre-dialysis status. That's not the case. Well, it's been 10 years since then. That's also deficits and 10 years of dialysis also make ... also afflict the body. That also lets ... or the new kidney, which is also just one of two originally, cannot compensate. It's still ... physically, you're still limited. Not like on dialysis but still, there are limitations that stay. (Mr Becker, 19:12)*

This awareness is extremely surprising for some participants, who tend to explain it as a lack of full prior information about possible challenges associated with kidney transplantation, as Ms Wagner emphasises:

*I was also so badly informed before transplantation. Have just told that the doctor this week. If I had known how all works and what I'd need to take and this and that. That's hard enough. I should have known that before. Afterwards, there are so many things where you're invited to [transplant centre], where you could have a look around. But it's behind you already. That's it. Those who are on dialysis should know that before. That would be better. (Ms Wagner, 18:31)*

However, despite all challenges and ambivalences associated with kidney transplantation, all participants except one are happy post-transplant and are willing to do whatever it takes to keep the kidney.

The second issue associated with high ambivalence is the need to take medication on a daily basis. I described this phenomenon in a memo after the fifth interview:

*Participants frequently report an ambivalence. It is expressed by the fact that on one hand tablets are important/vital, but, on the other hand, may have side effects that may be difficult. Mr Becker, for example, calls this ambivalence a "necessary evil", as the medication causes side effects, massive diarrhoea in his case, yet he knows that without medication he would have even worse health status. Also, there is some kind of reluctance given the high number and/or consequences of the tablets. They are not just any tablets.*

*This ambivalence gets especially clear in the case of Ms Maier and Ms Wagner. Ms Wagner needed a long time to maintain a stable organ function (5 years). Until this point, time was associated with many hospital stays and complications and interventions<sup>16</sup>. Also, after many years, she misses her common social environment at dialysis, of which she became fond. To this point (after 7 interviews), she is the only participant who doesn't report non-adherence. Also, her side effect-profile doesn't seem very distinct. Her strong ambivalence becomes apparent as her IM-intake is very scrupulous and she also says one has to get engaged with transplantation, which she does. At the same time she would not find it bad to return to dialysis because of the familiar environment.*

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<sup>16</sup> By interventions, I mean diagnostic or therapeutic procedures, such as kidney biopsies.

The need to take IM is often positively connected with living a new life or even having survived their underlying disease, as is the case for Mr Schneider:

*Yes, well, to be honest, I mean, I owe my life to that. I have ... I must tell you a story ... my father, I don't know whether you're familiar with polycystic kidney disease [...] and unfortunately he was 19 (...) 1965 he died from that. And that's a hereditary disease and I have that. I had that or still have it. And if dialysis hadn't existed, I'd be a has-been. And if there were no tablets, because of follow-up, I would have been more or less near death. That's for ... positive thoughts. That's basically why I take them. (Mr Schneider, 07:06)*

The participants agree that IM holds a special meaning to them. At the same time, medication-taking involves significant side effects in most participants, an issue which will be taken into account in the category *facilitators and challenges*. Also, participants are aware that some IMs are nephrotoxic and that the correct dosing of these drugs is always a delicate balance:

*Yes, and what I also have discovered regarding the effect of Sandimmun [Ciclosporin – immunosuppressive drug] is that it also destroys the kidney in the long term. (Mr Richter, 10:23)*

Another aspect of medication-taking that is discussed very ambiguously is the issue of taking part in medication studies. In Germany, many transplant centres are involved in international medication trials that test IM in order to ameliorate the medication regimens for kidney transplant recipients.

Therefore, most participants were either approached to take part in a study themselves or knew someone actually taking part in a medication trial.

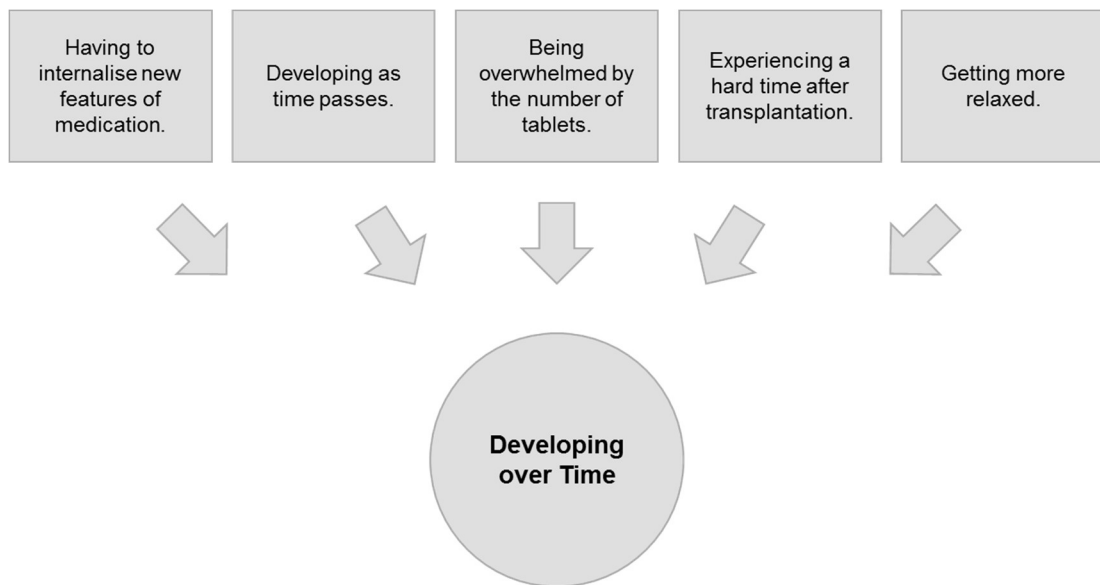
Generally, participants have a positive attitude towards these trials. However, they are also a subject of fears and anxieties:

*Once a year, or twice a year when I go to [name of the transplant centre], there are sometimes patients whose say, crea [serum creatinine] is high again, and changed a medicine. If they take part in that kind of study where medication is changed. Indeed, it's important for advancing progress and innovation but (...) you then think too much about what may go wrong, what happens, yes. Suddenly the crea rises, rejection. That's the kind of things that cross your mind. (Mr Huber, 26:00)*

Participants often ascribe deteriorations in patients taking part in medication trials to consequences of the trials. Therefore, due to their own or others' bad experiences, participants have resolved neither to take part in trials again nor to recommend them to others. An example of this is Ms Klein, who believes that the loss of her transplant was due to the medication trial in which she took part:

*I don't have anything against medics and transplantation. That's not the question. I would only recommend anyone not to take part in a study. And I neither have anything against medication. Everyone reacts upon another medicine, I'm open to that. But it has to be changed if you realise it doesn't work. (Ms Klein, 20:55)*

### 6.1.1.5 Developing over Time



**Figure 13: Codes supporting 'developing over time'**

Attitudes toward medication and medication-taking develop considerably with time elapsed after transplantation (Figure 13). In the first phase after transplantation, medication-taking is perceived as more difficult than it is later. The participants adjust to their medication in several aspects:

*The first few months up to a year post-transplant is frequently described as rather hard due to complications (Ms Wagner), tablet load (Ms Wagner), side effects (Ms Schmitt), and restriction due to immunosuppressive medication (Mr Becker).*

Initially, participants, although commonly accustomed to taking medication, are challenged by the number of tablets they have to take and struggle with the names, purposes, and intake times:

*It's not a big change because I had to take medicines before. I have 10 years of dialysis behind me, and of that 8 years of peritoneal dialysis and the rest haemodialysis. Well, I've always needed medication. I have suffered from kidney disease all my life. Well, drugs are not strange to me, though. The exact timeliness and accuracy of the medicines, that's partly new. (Mr Becker, 00:30)*



Taste, size, and other features of their medication are also strange in the beginning. Similarly, coping with the new situation of being a renal transplant recipient takes time for some participants. However, most participants state that with the time elapsed since transplantation, both medication-taking and coping with being a kidney transplant recipient become easier. Mr Weber, a participant who had severe problems coping with his kidney disease, exemplifies this well:

*In the beginning that was all, also the whole illness per se, very awkward. It took me long until I even told my family that I needed dialysis because I couldn't cope with that at all. And I didn't know and blamed myself. Of course, it's nonsense afterwards, but ... but you learn that as time passes (...) in the beginning I also had the tablets in a cupboard and hid them and so on but now, they just lie around openly, the packet I mean. That's ... that's just part [of it]. (Mr Weber, 06:44)*

Another challenge is the large number of tablets required in the first six months after transplantation. In this phase, the medication regimen is also changed and individually adapted, which, in this phase of developing a routine, is even more challenging, as Ms Wagner outlines:

*There were so many [tablets]. It was 30 different types. And you needed to come to grips with them. At what time and how. There were halves and you needed to [remember] the colour ... if you manage to remember the colours, you come to grips with that. [...] Right now, it's just 15 drugs I take. It was double that in the beginning. It's ok now. Now that's ... with 7 years, if you do that 7 years, then it works. (Ms Wagner, 17:55)*

Also associated with the high medication load in the first few months post-transplant is a higher extent and impact of side effects. Although these tend to decrease with the reduction of IM, some participants suffer considerably from side effects during this time. Additionally, complications are common in the first few months after transplantation and may cause repeated hospital stays, as was the case for another participant:

*I<sup>17</sup>: How long did it take until you didn't have any issue with taking these tablets, because of size and smell and so on?*

*P: About 7, 8 months [...] Until I really got used to it. The first year after the transplantation was very difficult for me. I was often in hospital with a fever of 40, 41 [degrees centigrade]. Oh, that was really difficult. Infections again and again. Urinary tract infections again and again and ill and ill. (Ms Maier, 53:29)*

However, participants agree that the phase of accommodation to the new situation ends at some point, and from then on, a less stressful, individual routine is established. Additionally, the perception of occasionally forgetting to take medication changes over time. At first, each forgotten tablet evokes feelings of distress, but participants later tend to be calmer:

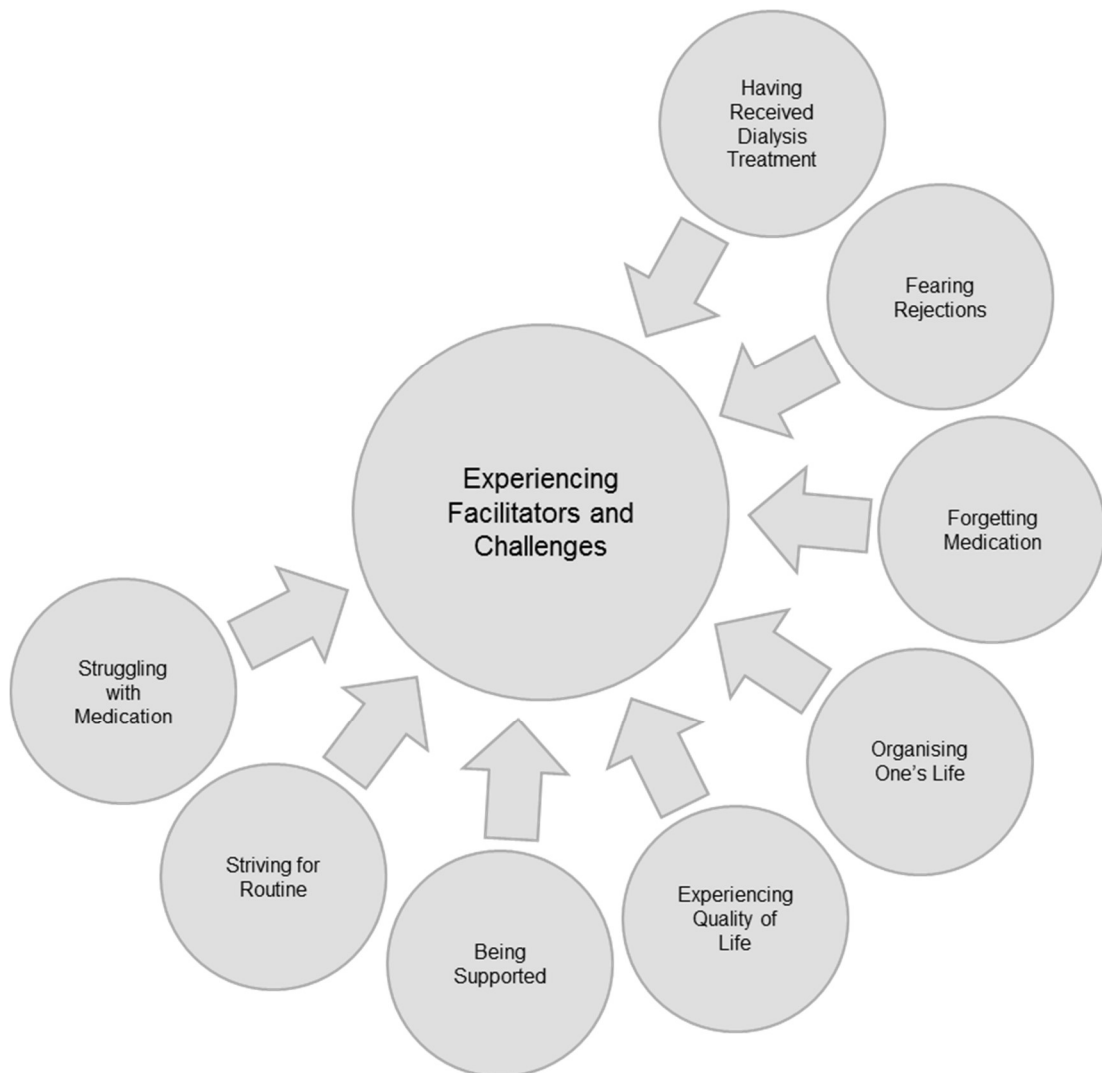
*That [taking medication too late] doesn't make me nervous or anything. Not over the years. In the beginning when I was newly transplanted, oh my God, that was 8 sharp, you could have set the alarm. In the evening, too. But the longer, you know, you're getting more relaxed. (Ms Schulz, 20:28)*

This may be connected with prior experiences that occasionally forgetting medication does not cause immediate rejection or any bodily symptoms for most participants.

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<sup>17</sup> I: interviewer; P: participant

### 6.1.2 Experiencing Facilitators and Challenges

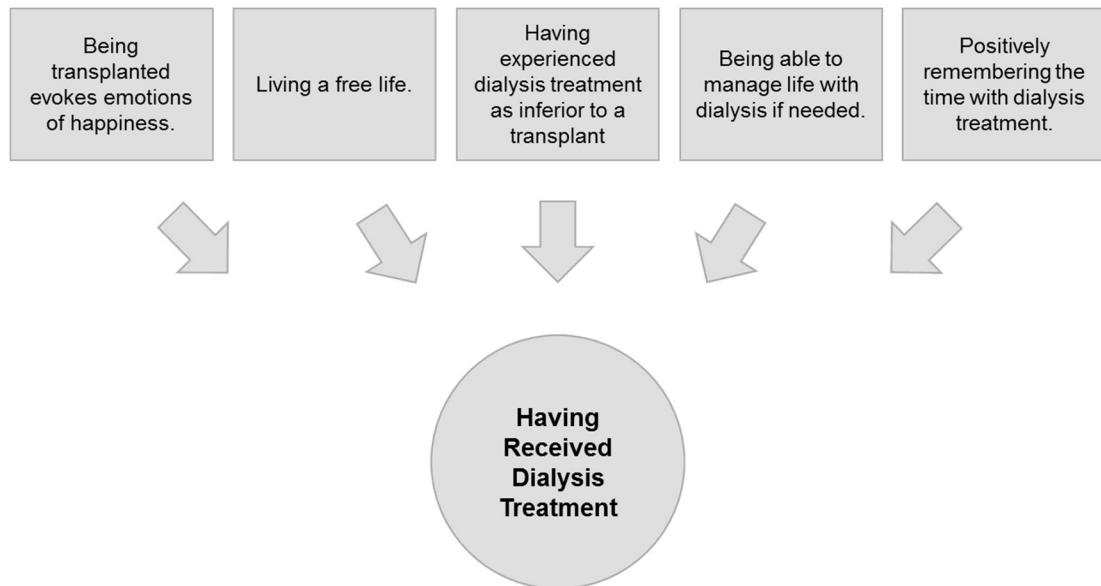


**Figure 14: Sub-categories of the category 'experiencing facilitators and challenges'**

Daily medication-taking is associated with severe ambivalence and a variety of distressing factors (Figure 14), but many participants also reported strong motivators that facilitated the regular intake of medication. Many participants reported similar factors that motivated or discouraged them to take their medication as prescribed. However, perception of these factors can be diverse: what one person perceives as motivating can represent a challenge for others. Therefore, this section will not be divided into facilitators and challenges, but rather describe the factors as reported by the participants.

### 6.1.2.1 Having Received Dialysis Treatment

All participants share the experience of having received dialysis prior to their transplantation (Figure 15).



**Figure 15: Codes supporting 'having received dialysis treatment'**

Without being asked explicitly, participants frequently mention past time on dialysis, which varied from a few months to more than ten years. The majority of participants emphasise that one of the best outcomes of taking tablets to prevent rejection of the transplanted kidney is no longer depending on dialysis. Some participants even hold that the kidney transplant has saved their lives. Most agree that the time on dialysis was a terrible experience and that the gift of a transplant outweighs all side effects and complications they might experience, which is often connected with strong emotions, as Ms Müller illustrates:

*That [kidney transplantation] was a real experience for me. I sometimes lay in my bed at night [...] sometimes tears in my eyes. Yes, that is such a wonderful emotion for me. I also went to church for the first time. I have cried so much. Because I was so lucky that one person gave me an organ. After such a long time. That was so emotional for me. And still today, again and again ... it's not that I now (...) would be somehow distressed or something. No, these are feelings of happiness. When I am moved to tears, that's happiness for me. (Ms Müller, 04:29)*

The following memo also reports the apparent contradiction between experiencing a new life on one hand and struggling with a variety of complications on the other:

*The aspect of experiencing a new life is especially impressive in Ms Koch, a transplant recipient whose graft has failed after 10 years. In these ten years Ms Koch has experienced a multitude of rejections and complications. However, after being back on dialysis for one year, she still emphasises that the experience of living with a transplant provides much more freedom than dialysis.*

Independence from dialysis is described as being free and able to lead a normal life with renewed enjoyment. In this context, even transplant-related constraints, medical complications, or medication-related side effects are predominantly perceived as less burdensome than dialysis. This aspect is even emphasised by participants who have experienced a variety of transplant-related complications or diverse rejection episodes, as was the case for Ms Koch, the participant mentioned in the above memo who had to return to dialysis:

*But still, I didn't have to go to dialysis any more. And I could live my life more freely and that was rather new, different life compared to the time on dialysis (Ms Koch, 06:22).*

This notion of freedom has two main components, the aspect of time and the aspect of the participants' physical condition. The notion of being free incorporates both aspects. On one hand, the time constraints associated with dialysis treatment lasting for hours are gone, and patients are free to decide what to do with their time. From their point of view, freedom also comes with the discontinuation of dialysis-related restrictions influencing daily life, such as fluid and dietary restrictions.

Regarding their physical condition, participants discuss the positive impact of a kidney transplant versus the dialysis treatment on their general state of health and well-being. They agree that they derive major physical benefits from the kidney transplant, as the following quote shows:

*Dialysis is far from being as good as a kidney. There are still differences. (Mr Becker, 09:51)*

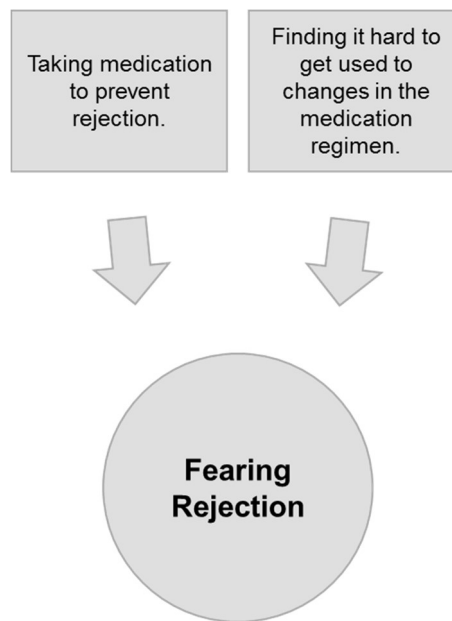
In contrast to this, there are hints that the time on dialysis may also be perceived differently. The prospect of returning to dialysis in case of rejection does not seem fearsome to some participants, as they know the circumstances well:

*I've always said if it's meant to be, that I need to go to dialysis again, then that's as it is. Then I wouldn't lie here and cry or something. Then I know what awaits me and then I will be able to manage that life too. (Ms Müller, 34:48)*

Moreover, the experience of dialysis may be perceived positively, especially in the context of the social support of peers and staff that develops in dialysis sessions, which are three times per week and last for hours. These close social ties may loosen after transplantation, as Ms Wagner experienced:

*I got on well, and they all liked me, too. That was kind of a little family where we lay with 5 people [...] still today, I think so often about that. And I still visit them. (Ms Wagner 2014, 17:17)*

### 6.1.2.2 Fearing Rejection



**Figure 16: Codes supporting ‘fearing rejection’**

Not surprisingly, a major facilitator of adherence is fear of rejection (Figure 16). Many participants have already experienced rejection episodes that have left a lasting impression. For participants who have not had rejection episodes requiring treatment, the possibility is a major threat. Most participants also state that the decision to take IM is based on the conscious consideration of preventing harm to the organ:

*Either I take the medication or I leave it, then the kidney gets broken. And therefore, I decided for myself to take this medication regularly. (Mr Bauer, 00:31)*

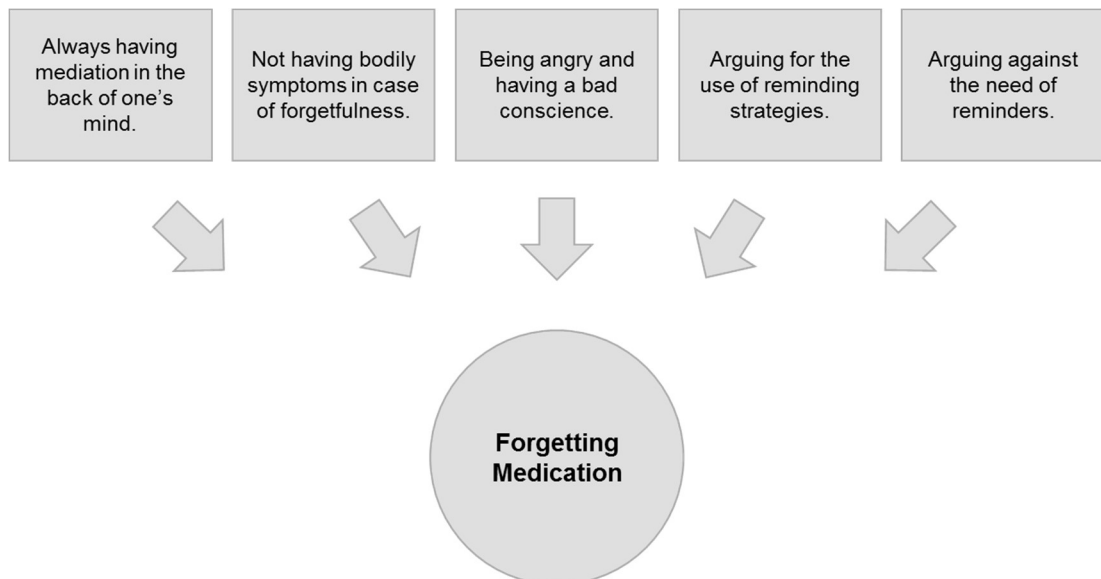
A further major challenge is deterioration of the graft requiring a change in medication. Rejections or deteriorations of the kidney are always worrisome and distressing as medication must be changed, which involves alterations to routine, the major facilitator of adherence. This situation is critical in at least two ways: first, the disruption is distressing, as Ms Koch states:

*And then there were changes in medication again and again and then you needed to get used to it over and over. [...] You constantly needed to get used to new medicines. (Ms Koch, 02:33)*

Secondly, adherence is challenged at times that require additions to the routine rather than subtractions.

### 6.1.2.3 Forgetting Medication

Although the issue of non-adherence in individual participants was deliberately not addressed in the interviews, most participants report being non-adherent at some point. The most commonly stated reason for non-adherence is trivial forgetfulness, which occurs in two forms: taking medication too late or accidentally omitting single doses of medication. Both are an issue that participants report as a problem in many instances. According to the participants, forgetfulness mostly occurs when their routine is broken for any reason, which is echoed by the codes leading to this sub-category (Figure 17). The aspect of routine will be outlined separately in this work, but it plays such an important role in forgetfulness that it must also be taken into account at this point.



**Figure 17: Codes supporting 'forgetting medication'**



Forgetfulness is mostly associated with the evening dose of medication. Most participants have a stable routine in the mornings, but at night, fluctuating eating times or social events, such as going out or having guests, may prove challenging. Although most participants report occasionally forgetting their medication, they also state that awareness of their medication is always present. Medication-taking is so deeply enrooted in their daily routine that in instances of forgetting to take tablets in the evenings, they are unconsciously aware that something is missing, as explained by Mr Weber:

*I also can ... when I'm tired early or something like that, I can go to bed and in any case, I wake up when it's time for my tablets. One always has it in the back of one's mind and [...] as I said, I don't set an alarm anymore or anything ... I wake up, take them, and then I can go back to sleep. (Mr Weber, 10:12)*

Adding to the issue of forgetfulness is a lack of physical symptoms in cases of forgotten medication:

*I don't notice anything. The immunosuppressives build a level in the blood and if you forget the medication and take it three or four hours later or maybe even not at all, that's not so bad that you feel pain or anything like that. You don't notice that. (Mr Hoffmann, 02:46)*

However, participants do report psychological or emotional consequences of forgetfulness. These include anger, bad conscience, and anxiety:

*But with me it's the case that I have a bad conscience rather quickly, or I just hope that nothing has happened [...] and then I'm angry with myself to a certain extent if I don't even manage to take them regularly. Also because that's really ... that's twice a day, I find that's really not asking too much. As I said before, I am a bit angry with myself and have a bit of a bad conscience because I think, actually it's ... one of the few things regarding illness you can really influence and then you should do that, whatever you can really do, you should do that, I think. (Ms Schmitt, 13:50)*

Interestingly, participants vary considerably in their use of reminders. Some use a variety of different reminders, such as visual or acoustical alarms, rituals, pill boxes, or the help of others. Mr Huber reports an example of a combination of different reminders:

*Well, by trying to control it [medication-taking] again before I go to bed. That I really say I put the box with the day's tablets back and get the new one out. And that's something where I can say I have self-control, if the box is empty [...] or I can also see at the small box where I just put in tablets for two different time points. In the meantime, when I go to bed at night, I shake the box to see whether something's inside or not. (Mr Huber, 07:00)*

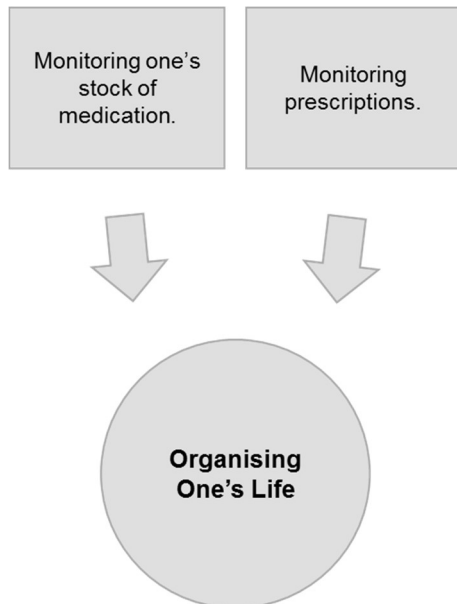
Generally, participants using reminder strategies emphasise their need for these and cannot imagine coping without them. On the other hand, participants who do not use reminder strategies argue that no strategy would replace the need to think about medication and intake times, and therefore they consider it more worthwhile to integrate tablet-taking into their daily lives. Some participants even report that reminders can easily be annoying in some situations:

*Now, you're in a meeting, and you are reminded in the meeting, you need to take your tablets. It rattles or the mobile rings or whatever. That's quite difficult. That's the problem. (Mr Schneider, 19:13)*

The concept of daily life will also be regarded in more depth below.

#### 6.1.2.4 Organising One's Life

Participants report two organisational issues related to medication-taking that may complicate adherence (Figure 18): monitoring medication stock and monitoring prescriptions.



**Figure 18: Codes supporting 'organising one's life'**

Gaining access to medication can be difficult in Germany, as IM is only dispensed by pharmacies upon prescription. Most pharmacies do not have IM on stock, but depend on delivery, which makes out-of-hours medication procurement difficult or even impossible. Moreover, pharmacies charge a relatively high emergency surcharge out-of-hours. This means that renal transplant recipients must monitor their stock of medication closely, especially prior to weekends or bank holidays, as receiving a prescription and ordering medication in a pharmacy may be time-consuming:

*As I said, one needs to think about it most when the weekend is due or a bank holiday. 'How long does that [medication] last and when do I need to get a prescription at the latest?' and so on. But then you check how many are left and than you know exactly it lasts for certain days, and done. In the meantime one knows that when I give the prescription to the pharmacy at this or that time, I'll definitely have it in on the specific day, or not. Well, in the meantime, I also know the pharmacy's delivery time and so on. (Mr Weber, 17:27)*

Another issue participants face with regard to organisational problems is the delivery of generic drugs. Participants report these drugs to have different characteristics compared to the original drug in terms of taste, size, or stability, making intake difficult. Some German insurance companies require the pharmacist to dispense IM in their generic form, despite IM being NTI drugs requiring close monitoring of blood levels. Physicians can prevent this, but they do not always fill out the prescription form as required, leading to disagreements between patients and pharmacists, as well as to higher co-payments, as Ms Maier reports:

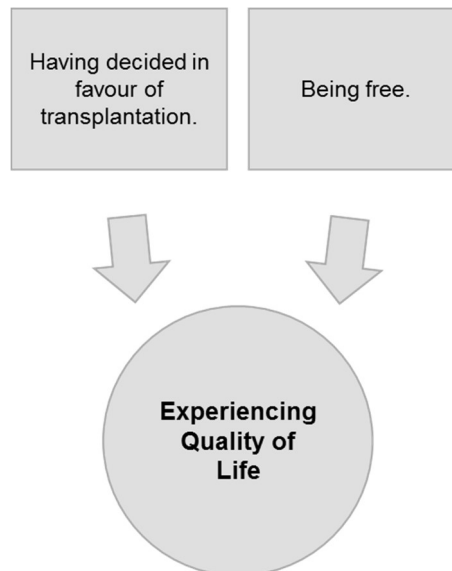
*And then I needed to tell my medic that he ticks the box, how do you say, idem<sup>18</sup>?[...] That he ticks the box and the pharmacist is not allowed to give me something different. But then I must pay the difference the health insurance doesn't cover. And that's expensive again. That's also not good. That's what also annoys me all the time. Some medication, they [pharmacists] say it's the same, same effect. I have experienced that, I have then taken the drug but it didn't help me. And then I told my medic [...] that he ticks the aut idem box to get me the original. (Ms Maier, 48:05)*

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<sup>18</sup> According to German law, pharmacists are required to dispense the cheapest version of the prescribed agent which is usually a generic formulation. If, however, physicians cross out the *aut idem* (Latin: or similar) box on the prescription the exact medication prescribed can be dispensed.

### 6.1.2.5 Experiencing Quality of Life

The experience of better QoL relative to pre-transplantation is a major facilitator of adherence (Figure 19).



**Figure 19: Examples of quotes and codes supporting ‘quality of life’**

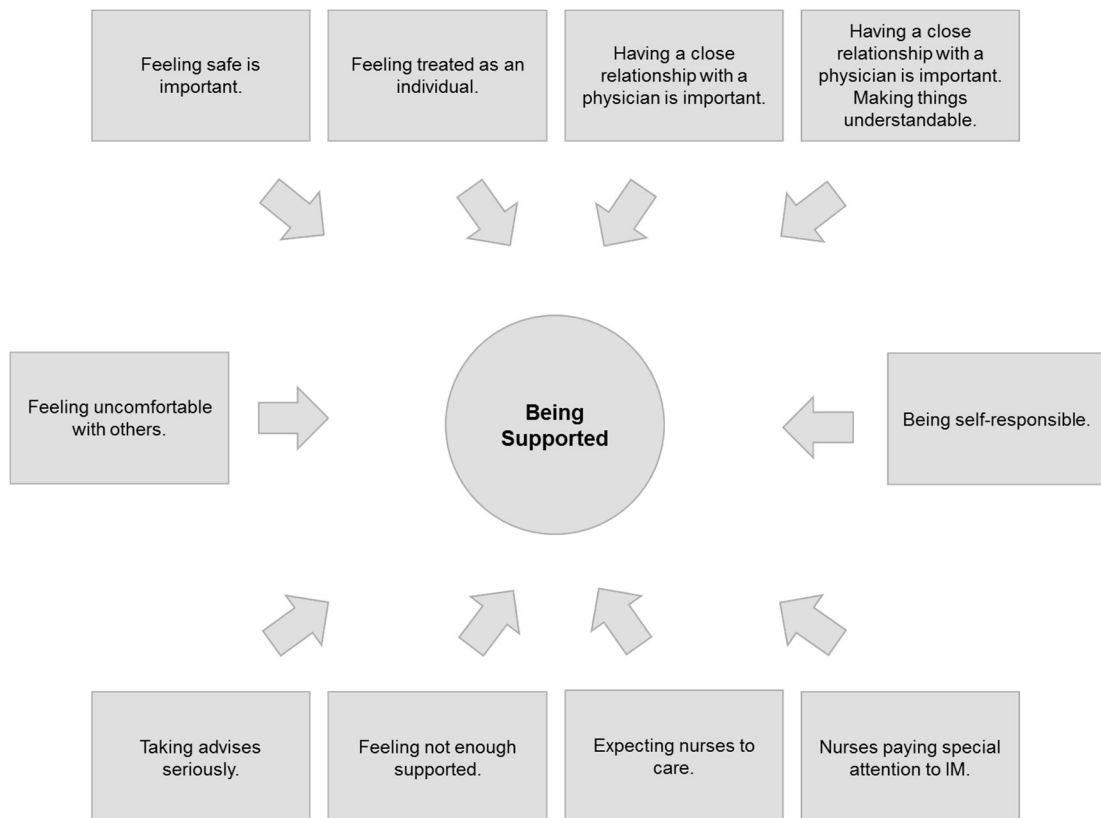
Medication adherence is described as a direct consequence of the participant's decision to accept a kidney transplant:

*I had to decide, when I registered for a transplant, that I take this medication and that they're not really harmless. However, you need to decide, do you want to go to dialysis forever as the young woman I was back then or do you want to live your life and then you just take this medication [...] Because if you are as young as I was then and you have a small child you must consider what the future holds. Because being away three times a week and there is a small boy at home, that's not really great. (Ms Schulz, 03:09)*

Many participants were aware of possible problems after transplantation but still decided to have a transplant. Generally, participants reported a high level of QoL. In most cases, the promises of kidney transplantation proved true despite the occurrence of complications or side effects of medication:

*I mean freer, not to go to dialysis every other day and I could say ‘yes, on Wednesday I will go there and there’ without planning much. And ... when you are on dialysis, that's not possible. (Ms Koch, 06:39)*

### 6.1.2.6 Being Supported



**Figure 20: Codes supporting 'being supported'**

Other people play an important role in the lives of most participants, and hence the sub-category *being supported* has a variety of notions and codes (Figure 20). Most commonly mentioned are healthcare professionals (physicians, surgeons, and nurses), followed by partners or spouses and other family members, as well as friends. Because all of these people play different roles in the lives of the participants, I will outline each group separately. However, despite the different roles, some aspects are shared in the view of this study's participants. These include impact on the transplant recipient and trust, caring, and continuity. Importantly, other people are not automatically regarded as support, but may instead be perceived as a source of distress or paternalism. People may be perceived both positively and negatively, as well as many shades in between. Also, the extent of external support is crucial: both too little and too much may easily be perceived as distressing or neglectful.

Participants meet medical staff, namely physicians, surgeons, and nurses, in a variety of different circumstances, where these staff perform different tasks throughout their transplant journey. Healthcare professionals are assigned diverse roles and expectations depending on the participant's medical status. Participants predominantly talk about physicians, particularly about the nephrologist responsible for their long-term follow-up. The relationship between participants and their nephrologists is often characterised by the fact that they are cared for by the same physician for a long time. Typically, long-term follow-up is carried out in the same practice where participants have been treated from the beginning of CKD through dialysis up to kidney transplantation, as one of my memos indicates:

*Another aspect [of the relationship with physicians] is being cared for by one person over a long period of time. Two participants (Ms Schulz and Ms Wagner) describe how difficult it was for them was to change their doctor after a long period of time.*

The most important aspects of the patient-physician relationship were trust and care. Trust and care are very tightly connected; one would not work without the other and both are crucial to the participant-physician relationship. Trust and care themselves have several aspects. One is a very close relationship that allows patients to express anything they might need:

*I deeply trust [name of the transplant centre]. By the doctors and I always say 'without them and without by two doctors here in [town] I would be nothing'. Well, they're really ... I can talk with them about everything, regardless of there or here, we (...) discuss that together and make and do. So, I'm really in the best hands. (Ms Müller, 13:39)*

Care also pertains to a feeling of being taken seriously. Participants appreciate not being treated impersonally and describe a close reciprocal relationship, as in the following example:

*Well, I wasn't the kidney but I was Ms [Schulz]. I mean, well ... I was 25 then, I could have been his daughter. He also had children of my age. He's also ... I have a little paddock at the edge of the woods and they [nephrologist and his wife] don't live very far from there. And when they went for a walk, he brought me a pot of tea and made me drink it. You know, transplant recipients need to drink a lot. And he cared like ... yes, cared a lot. And I could call him day or night. Whenever I wanted. That was never an issue. (Ms Schulz, 08:23)*

Because of this close relationship, the loss of the trusted physician after many years may be traumatic for many participants. Although a new physician is met openly and trustfully, the depth of the relationship cannot be replicated and patients need time to adapt to the new situation:

*The doctors also changed. That's then ... with her I was... with the first one I was 30 years. Yes, there's confidence in her. Now, it's men. Women are somehow ... I don't know ... it's a different relationship with each other. Although, the men are also alright, yes. But it's not like ... as intimate when you say something. It's not. But now it's ok again, I got over it now. (Ms Wagner, 02:28)*

I also noted the notions of being cared for as an individual in a memo at a very early stage:

*Ms Schulz nicely describes the role her former nephrologist played in her life. He acted as a teacher but also as a supporting person she could contact whenever possible. Also being perceived as a person and not as "the kidney" (Ms. Schulz) plays a role as also suggested by Ms. Schmitt.*

*This notion of caring has been mentioned by some participants, for example by Karin Schmitt who emphasised the need of feeling cared for.*



This close relationship does not rule out criticism; on the contrary, it facilitates encounters in which patients are respected as individuals and both sides can discuss the patient's therapy for optimal results. For example, many participants negotiate their medication regimen with their physician, as they feel they are the expert regarding their own well-being. This feeling of being one's own expert leads to different perceptions regarding the role physicians play in terms of patient education. Some participants state that their knowledge of disease, therapy, and medication predominantly comes from direct contact with healthcare professionals, mainly their nephrologist:

*Medical qualification is the biggest help one could provide by explaining the situation so that I can understand why it's reasonable to do it exactly this way. Not only to instruct but to try and explain the importance and context. (Ms Wolf, 14:38)*

The physician can thus play an important role in adherence, if participants regard it as supportive to have an insight into the necessity of medication-taking. In contrast, other participants argue that remembering medication and eventually the act of medication-taking is the responsibility of patients and in-depth education does not help in this regard. These participants argue that the main thing a physician needs to do is to fill out prescriptions:

*Because actually I am the person who is responsible for taking my medication. A doctor ensures that I get it and that he examines me and says you need this and that medication. That I take it in the end is actually my responsibility. (Ms Koch, 10:11)*

In contrast to participants' extensive experiences with physicians, their experiences with nursing care are mainly limited to direct post-operative time spent on the hospital ward and rare visits to the transplant centre. As their transplants occurred years ago, these participants could not say much about the role of nurses in medication-taking. Those who remember their time in hospital report that nurses were instrumental in educating them about transplant-related health issues, such as control of weight, vital signs, fluid intake, hygienic issues, or the correct intake of medication:

*And of course they [nurses] paid attention that you took the immunosuppressants. [...]. The immunosuppressants were personally brought to me, and also to the other patients, at the appropriate times. So that they were really taken. That was very well organised. Because these are the most important drugs you shouldn't forget. (Mr Hoffmann, 15:03)*

Most patients did receive training by nurses in how to dispense their medication properly, which is mainly perceived as helpful. Although participants expect individualised care, most were educated according to rather strict procedures, which is perceived as inappropriate by some patients. On the other hand, participants display a great extent of understanding as to why individualised care could not always be provided. For example, participants admit that individualisation is difficult because people need different levels of education, which is not easy for nurses to achieve. This is illustrated by Mr. Becker:

*But it ... it's a matter of individual nurses. There are some who, for my taste, perhaps did a bit too much [...] on the other hand [...] the nurses are instructed, yes, to educate everyone concerning these things. And I suppose they are experienced with that [...] well, maybe there are some [patients] who don't take things seriously. Let's call it like this. (Mr Becker, 27:32)*

Participants also report that nurses in the hospitals had high workloads that caused distress and sometimes prevented them from acting as expected and needed by patients. Participants assume that in the case of high workload, less-important tasks are skipped, but they criticise nurses for failing to care for patients who are supposed to be autonomous but may not be, due to illness or other causes:

*Well, when I'm in hospital, they [nurses] should have a look at that, depending on how ... your illness is at the moment. [...] But also, there are some who just put your daily ration there and then, devil may care. The next day, there's another nurse, and then ... they may say something. Not until midday, what's up with the tablets, why haven't you taken them? (Mr Schneider, 30:33)*

The extent of family involvement varies among this study's participants. Whilst for some, partner and family play an active role in medication-taking by acting as remembering agents, other participants do not involve family members at all. At the same time, partners and family may be perceived differently by different participants. Generally, these persons may be either appreciated as helpful and supportive or viewed as a threat to autonomy. They may also be related to feelings of shame, embarrassment, or difficulties in coping with being chronically ill:

*Ms Schmitt, for example, perceives support regarding medication-intake (reminding her) as very positive. On one hand, she sees the aspect of sheer reminding, and on the other hand, she feel noticed as a human being, as someone who is important to someone else. Exactly this aspect is missed by Ms Maier. She reports to not have anyone who cares or reminds her. Her husband, son, daughter-in-law have little sympathy for her illness. However, she mentions that despite this perceived deficit in caring, her husband does have interest in her illness and when she is very badly off, he brings her her tablets. That speaks in favour of his interest. [...] Is this a question of gender?*

In most cases, family involvement manifests as supporting participants when they prepare their medication or reminding them to take their medication. However, while the reminder function of partners and family is appreciated as helpful, even more important is the notion of being important and being cared for by someone. Partners or family not actively caring about participants' illness or tablet-taking may therefore be perceived as displaying a lack of interest in participants' illness or even in the participants as people. Of course, this phenomenon is very much associated with the relationship between individual participants and their partners or family:

*Sometimes it wouldn't be bad if my husband, when I fall asleep on the sofa watching telly, that he could bear in mind and say, 'have you taken your tablets? Do you want me to bring them to you?' That would be great. That would be very good, it would be very helpful and I think one gets this feeling that someone thinks about you. This warm feeling that someone ... you matter to someone who reminds you, who cares. Unfortunately, that's not the case. (Ms Maier, 22:24)*

Friends, from the participants' view, play a role similar to partners and family. In contrast to family members, their support is limited to reminding participants to take their medication. In this case too, the notion of being cared for is at least as important as being reminded:

*When someone reminds me, I take it really, really seriously. Especially when someone who is very close to me reminds me, then for me that's ... well, that means a lot to me [...] that this person thinks of me, that he cares, and that's what I see then. Therefore I actually find this ... for me, that's ... if someone tells me to take them [tablets], I find it great and I actually find that important then. (Ms Schmitt, 05:54)*

In contrast, friends may also be associated with feelings of shame or embarrassment, and efforts may be undertaken to hide medication-taking from them:

*If you go out with friends and ... I then try to retreat somehow. There's no need for everyone to know that I ... take my 2 tablets or however many it is, in the evening. In the meantime, I don't really care, in the beginning, that was a bit more difficult. I paid attention that no one watched and so on. Sometimes it is ... or you have the feeling that you are looked at strangely. No one knows what that [medication] is. (...) Sometimes, if you go out at night to the ... if you have an appointment, be it ... I also had it in cinema. Well, it's dark in there, no one watches. But as I said, I realised it at some football matches ... and then the [intake] time was also a bit delayed, because it didn't exactly fit the half time. But finally it has always worked quite well. Only, in the beginning I paid more attention that maybe not everyone notices. (Mr Weber, 05:40)*

### 6.1.2.7 Striving for Routine

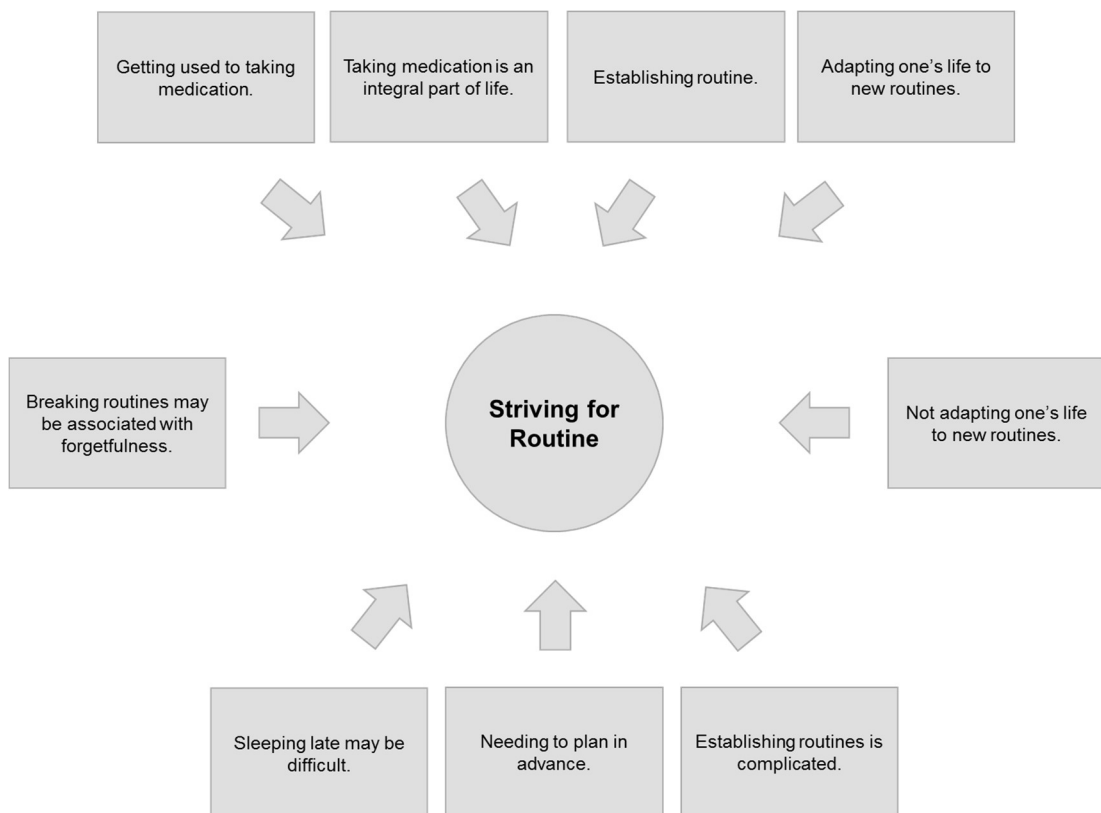


Figure 21: Codes supporting 'striving for routine'

A major facilitator of medication adherence is routine, as a wealth of codes illustrates (Figure 21). Most participants report that medication-taking has become routine after a familiarisation phase. Most participants were also used to medication-taking prior to having received their kidney transplant:

*Well, for me, it's no problem to take medication daily. I'm used to that already since I was a child. I have ... I had diabetes since I was seven and needed to inject [insulin]. At that time my mother did that. Of course, I did it myself later. Until the transplantation. That was daily medication too. Therefore, I'm used to that from a very young age, I don't have an issue with it. (Mr Hoffmann 00:32)*

The routine of medication-taking is analogous to everyday tasks such as eating or drinking, as Mr Huber exemplifies:

*That's not annoying that I take tablets. So, in the meantime I got used to that, that part of it [life] just like eating and drinking. (Mr Huber, 07:48)*

However, this routine must be established over a period of time. In this regard, one participant compares medication-taking with driving a car:

*It's just like driving a car. When the driver's licence is new and you get a new car, you are relatively insecure and at some point you don't think about what you do while driving but you do it all automatically and you are just calmer. (Mr Richter, 16:09)*

Participants use a variety of metaphors to illustrate how deeply medication-taking is internalised:

*Participants describe the significance of medication-taking as analogous to everyday tasks they perform, such as teeth brushing, washing their hands, combing their hair, driving a car, or taking their purse and keys when leaving the house. Interestingly, all of these metaphors compare medication-taking to the little things usually done without spending a thought. May this also prove problematic?*

*Compared to other everyday tasks: how many times have I been unsure whether the red light really turned to green because I could not remember?*

Immediately after their transplant, participants worked hard to establish individual routines for intake of their IM. Although most participants emphasise that renal transplantation has permitted them to lead a near-normal life, their daily life is still characterised by the strict intake times of IMs and other medication. Most participants hold the opinion that medication and their lifestyle have to match up, so that they do not forget their medication. Routine in daily life is thus a major facilitator of medication adherence.

Participants prioritise medication-taking differently. While some argue that medication-taking needs to be integrated into their lifestyle, others favour adapting their life to medication-taking. Most participants have chosen to combine these approaches to maintain as much of their freedom as possible whilst establishing personal routines that enable them to take their medication as prescribed, as outlined by Mr Becker:

*As far as possible without major problems, I can also adapt my life a bit. If I know I need to take my medication at 8, I can move my breakfast to after 8 because I'm not supposed to take them before breakfast. [...] One doesn't work without the other. But I'm trying to live my life as normally as possible. (Mr Becker, 15:22)*

Other participants also try to integrate medication-taking as far as possible but are less willing to make compromises regarding certain aspects of their life, as is the case for another participant:

*I cannot [change] my whole life [...] 'I cannot eat anything anymore tonight because I must take my medication at 9', well, I really don't want it this way. And that would stress me at some point and I think ... I try to integrate it as much along the way as possible and that I have as little problems with it as possible. And for me, that would ... well, it would be too stressful for me if I had to plan my life around this [medication-taking]. (Ms Schmitt, 11:11)*

The extent to which medication is adapted to daily life or *vice versa* differs considerably between participants.

One major challenge to adherence is the strict time frame in which IM must be taken. In addition to taking doses at twelve-hour intervals, participants also must coordinate medication intake with meals. Depending on their transplant centre, participants have internalised more or less strict rules for coordination of medication and mealtimes that may be difficult to follow. Moreover, the difficulty of intake times varied for some participants:

*The Advagraf [immunosuppressive drug] tablets were a bit inconvenient because they were taken at 10. And the other one, the Rapamune [IM] tablets, they are taken in the morning with all the other tablets. [...] It [Advagraf] shouldn't be in touch with the Cellcept and Myfortic [immunosuppressive drugs]. I don't know why it's like that. But it was annoying when you went somewhere. You absolutely needed to remember the 10 o'clock. (Ms Klein, 13:43)*

Different intake times usually arise due to possible drug interactions that necessitate taking two immunosuppressants two hours apart. Participants report that remembering gets more difficult with each additional intake time.



Another adjustment for participants is the organisation of their medication. This process includes an appointment with their physician, the prescription of medication, and the collection of medication at a pharmacy. As most pharmacies do not stock IM, participants must keep track of pharmacy delivery times. The organisation of medication may take several days and therefore must be planned in advance, particularly when participants want to have more medication with them than they would normally need, such as when they go away on holiday. This may not be easy to achieve:

*Yes, and when I go on holiday or occasionally visit someone for some days or a whole day, I take along everything. I count how many [tablets] I need, take a few more, you never know if you then need longer, then I take along some more and then I take them there as usual. Once it happened, I was in Spain, I took all ... and I wasn't allowed to take along so many things. There's ... I bought a ticket that only allowed hand luggage in certain measures. And then I counted all medications and I took along some extra of course. I then miscounted one medicine and that was lacking for 5 days, let's put it like that. At the end. (Ms Maier, 15:23)*

Moreover, in such a case, the full cost of the medication must be paid by the participant, which can be expensive. In addition to holidays away, smaller breaks in routine are challenging as well; these include the routines of daily living as well as changes in the medication regimen. Breaks in daily routines may include common or repeating occasions, such as weekends, or slightly rarer events, such as bank holidays. Weekends are described as potentially problematic by Mr Weber:

*I know exactly ... at 9 in the morning and at 9 at night I take the tables, regardless what I did before or what I'm going to do afterwards. That's just the way it is [...] That fits [life] nicely, and as I said, the timing worked out, worked out like that [...] directly after the hospital stay, that was a bit annoying at the weekends, if I wanted to sleep longer or something. (Mr Weber, 16:07)*

Working participants are particularly affected by this, as their routines tend to be more consistent than those of unemployed participants. Relatively common occasions, such as going out for dinner or visiting friends or family, demand some preparation and increase the risk of missed doses:

*When I was busy or away [from home] ... with the family and then you talked and then you sometimes forgot it [to take the medication]. (Ms Koch, 06:21)*

Despite the narrow margins for intake times and interaction with food that are characteristic of IM, most participants are aware of possible leeway offered by their drugs medication, and take advantage of these. Sometimes participants even deliberately exceed the margins they have been taught by their respective transplant centre. For example, most participants know that IMs commonly have a two-hour window in which they can be taken, and organise intake times accordingly.

### 6.1.2.8 Struggling with Medication

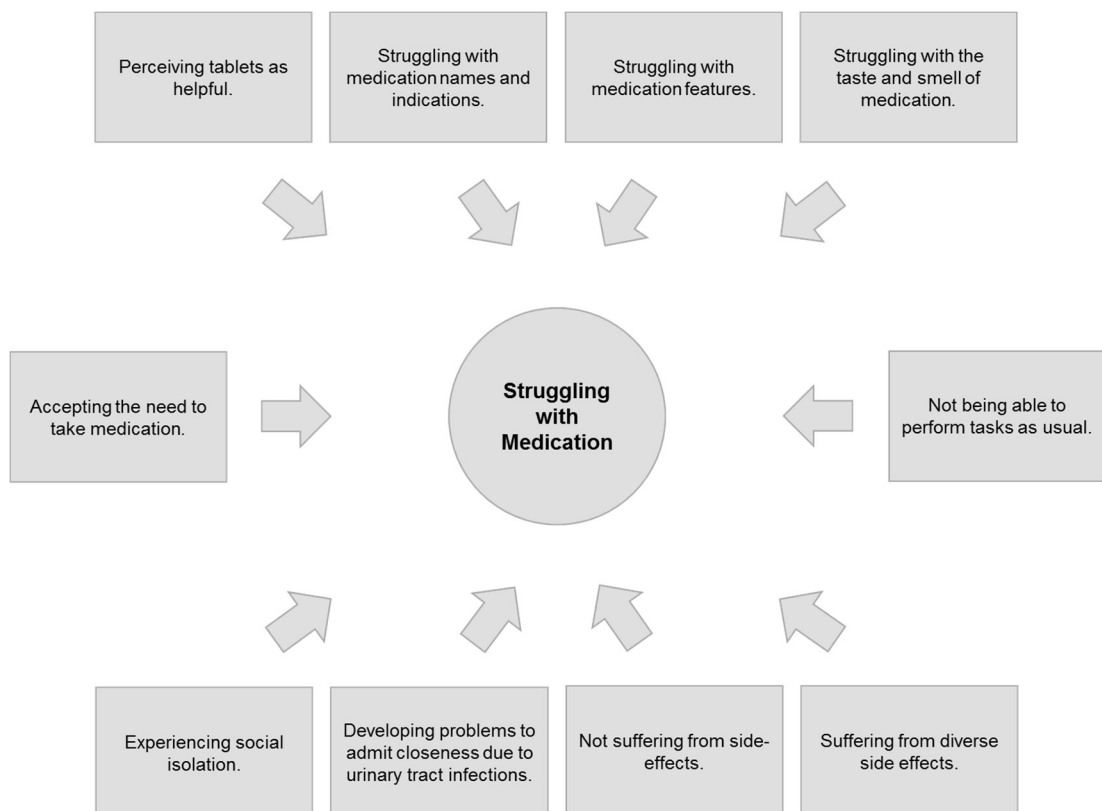


Figure 22: Codes supporting 'struggling with medication'

Participants report a variety of facilitators and challenges of their medication. These include features of the medication, drug interactions and side effects, and the complexity of the regimen (Figure 22). Despite these factors, most participants regard IM positively:

*The whole time I suffered from kidney disease I actually never gave a big thought to why, why, why I take the medication, instead I have always just found it helpful. (Ms Wolf, 05:42)*

This is irrespective of the extent to which the participants suffer from issues directly related to medication, as discussed previously.

Although most participants state that medication intake is not a problem for them, many IM have features that impede their intake. Medication names present difficulties, at least initially, as they rarely match the name of the active ingredient or even the chemical formula:

*Oh well, that's hard in the beginning. The strange words and what it's good for and everything. (Ms Wagner, 18:31)*

For example, Prograf<sup>®</sup>, one of the most common immunosuppressants, is widely known by its active ingredient, Tacrolimus, and even the abbreviation of its chemical formula, FK-506. This tends to confuse participants, who often do not know the correct names of the medication they take. Furthermore, some participants report problems with packaging. In Germany, tablets are usually dispensed in blister packs, such that each tablet is packed separately and patients must remove each tablet from its package.

External features of the medication are also problematic for some participants, with shape, size, and colour causing confusion:

*That there are so many tablets that are all white. They have the same size, almost the same size, maybe they are a bit flatter. Ok, now you sort the medication, if you have approximately 7 to 10, and sometimes you forget to put them in a certain compartment [of a medication box] and put them in another compartment. And you sometimes don't realise it. (Mr Schneider, 15:25)*

The size and rough surfaces of some tablets make them difficult to swallow. Participants typically regard larger size as more problematic, but small tablets may also cause difficulties. Also, some find the taste and smell unpleasant:

*Well, I don't have difficulties with swallowing these tablets, and besides the taste and smell it's no problem. And especially the Sandimmun [immunosuppressive medication], they don't smell very nice. [...] That's like any other tablet. If you don't pay attention, you get the smell in your nose and that makes it a little more unpleasant to swallow. But besides that, you can swallow it just as any other tablet, too. (Mr. Richter, 13:34)*

Most participants experience side effects from their IM. These vary considerably among participants and cover a broad spectrum of known side effects. Those most commonly reported include urinary tract infections, nausea, fatigue, skin cancer, and pain. These vary from unpleasant to debilitating, and in some cases become severe constraints on the participant's daily life. One participant, for example, suffers from chronic pain that hinders her in performing tasks she considers basic to her role as a housewife and interferes with her wish to lead a normal social life:

*I'm at home then and I want to clean the flat a little bit. And when I am done with that, the rest of the day is over for me, I am in pain, just pain. Then I rest and for two days following I am always in pain. Don't want to do anything, get up. It's really, very, very bad. (Ms Maier, 04:43)*

Weight gain, an issue often associated with corticosteroid intake, may impact the daily life and performance of the participants:

*I gained a lot of weight, you know. I don't like that. Because I'm fat, walking and working that's ... must be slow. No dress fits any more. That's morally [psychologically] not good. (Ms Yilmaz, 05:03)*

Some participants, though, feel lucky not to experience severe side effects:

*No (...) well, I don't have side effects, no detectable side effects. The only thing I have because of the medicines, low blood pressure. And I notice when I bend down and get up again and a little dizziness. Because the blood pressure is quite low. (...) But aside from this, because of the immunosuppressive drugs, I don't notice anything, thank God. (Mr Huber, 10:52)*

Side effects are often at their most severe in the immediate post-transplant phase and tend to lessen after some time.

Generally, participants seem to accept side effects as an unavoidable effect of having a transplant, an approach that helps them to cope more easily. However, participants show ambivalence toward side effects. One participant, for example, states that she does not experience any side effects except for needing to avoid the sun due to the heightened risk of skin cancer, yet describes how recurring urinary tract infections impact her sexuality:

*When I have a partner or a partner<sup>19</sup>, I need to be very, very careful that I don't catch an [urinary tract] infection for example, which is a little challenging. I cannot be unrestrained ... that's a real problem ... if you want to let yourself go and it doesn't work because the damned germs and the kidney are always in the back of your mind, that's not easy. Generally, you start to have problems allowing closeness. (Ms Schmitt, 04:46)*

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<sup>19</sup> Uses both the female and male forms of partner.

Other participants had not seen their relatives or friends for several months because they were told to abstain from close contact with others. Having to avoid small children has a particularly deep impact on participants' lives:

*Because of the medication and this and that one must, as I said before, accept enough limitations and shut oneself away from friends for half a year and tell them 'no, we can't meet at the moment'. Yes, partly friends would like to come and have a look how everything works. Visit me. But that's not possible because it's still too difficult. Or my little grandchildren for example. I can't see my little grandchildren at the moment, that's also not that easy. Well, yes, 6 months are bearable. (Mr Becker, 33:54)*

Although these participants accept the advice, they report that it affects their social lives:

*At some point, you just said it needs to be that way. I mean you have a new life because of the medicines and therefore I came to terms with ... the small disadvantages. I saw it as small disadvantages. I was frightened in the beginning, but as I said before, these were little disadvantages or little obstacles. (Ms Koch, 05:05)*

Generally, participants tend to accept medication-related side effects as the price they must pay for their new life.

### **6.1.3 Central Category: Medication-Taking as a Symbol of Living with a Chronic Condition**

From the sub-categories and categories presented above clearly emerged the central category of this research, *medication-taking as a symbol of living with a chronic condition*. Using the participants' words from each sub-category, Appendix 14 shows how the central category emerged stepwise from sub-categories and then categories.

Although the primary aim of this research was to develop a theory on processes leading to medication adherence in renal transplant recipients, the course of the research revealed that medication-taking was experienced as a symbol of having received a kidney transplant, which, in turn, implies that the participants perceive themselves as suffering from a chronic condition. I became aware of this at an early stage of data collection and analysis, as a memo written shortly after the eleventh interview illustrates:

*Issue for the discussion: The answers given by patients did not always regard the aspect of medication-taking. The issue is so interwoven in the daily lives of participants that differentiation between living with a kidney transplant in general and adherence specifically is impossible in many instances. Although this work aimed to explore medication adherence, it seems that I cannot exclude general issues of living with a kidney transplant or living with a chronic illness.*

Medication-taking, however, is rarely experienced as problematic by participants. Statements such as “well, [medication-taking] is no problem, it’s become routine, I take the medicines regularly” (Mr Huber, 00:33) are made by nearly all participants after the opening question.

Most participants report a variety of challenges arising from their status as chronically ill due to having received a renal transplant. In the course of the research it soon became clear that medication-taking was an integral part of being chronically ill, with most participants finding it difficult to focus their answers to medication-taking. Dependence on medication is an overall experience that does not differentiate easily into different tasks or experiences. Concurrently, being healthy has become an abstract construct for most participants:

*As a patient you only have an idea how healthy people feel. Because you have long forgotten how it was when you were healthy. And to relate this to medication now is really difficult. (Mr Richter, 26:08)*

The overall experience of being a kidney transplant recipient, including several notions of being chronically ill, therefore emerged as the central category of this work. How participants cope with this awareness differs between individuals and has led to lengthy memos:

*Participants deal with chronic illness very openly – or the contrary.*

*Coping with chronic illness, in this case kidney transplantation, is associated with the feeling of constant threat. The participants are aware that at all times, deteriorations, rejection, or other complications may occur.*

*Mr Fischer describes this as fear and “to give thoughts”. He mentions that for this reason he has not read any statistics regarding the life of a kidney transplant.*

*Ms Maier describes the “shock” that the first acute and then chronic kidney disease provoked – a shock she slowly recovered from many years after her transplant.*

*Ms Wagner is aware that a transplanted kidney is not indefinitely functional. However, her perception of threat is minor compared to other recipients’ as she knows the opportunity to get back to dialysis treatment, which is no threat for her. In contrast to all other participants.*



Participants' awareness of being chronically ill persists despite their view that kidney transplantation has saved their lives or given them a 'new' life that allows them to live more 'freely' without the constraints imposed by dialysis. They never forget their status as a kidney transplant recipient, and having to take medication on a daily basis apparently acts as a daily reminder of being chronically ill. Although all participants share the experience of having suffered from CKD and later ESRD, medication symbolises different things to them. For some participants, the tablets symbolise their illness and may be connected with feelings of helplessness or dependence. Some even store their medication out of sight to avoid the permanent visible reminder of their illness. The presence of a steady threat to health presents a further challenge. The participants are aware that deterioration, rejections, or complications may occur suddenly and unexpectedly, and this feeling is described as 'being worried'. Being worried, in German, is not necessarily connected with anxiety, but rather expresses thoughts regarding a problem or potential problem that does not present an acute danger:

*You shouldn't forget that there may be problems now and then and that the organ cannot last forever. (Mr Huber, 28:34)*

### **6.1.4 Summary of Research Findings**

The theory that has emerged from the data, is the finding that from the participants' point of view, medication-taking has a different significance for kidney transplant recipients than for healthcare professionals. For participants, medication adherence does not necessarily hold the same significance as a crucial issue post-transplantation that it does from healthcare professionals' perspective. That is mainly because participants regard medication-taking as just one of several issues they must deal with as renal transplant recipients. In many cases, they could not reflect exclusively on medication-taking, as this task is closely interwoven with issues such as eating habits, the attendance of regular follow-up appointments, and others. However, as will be apparent from the presentation of individual findings and as I will discuss in detail in Chapter Seven, medication-taking serves excellently as representative challenge associated with living with a chronic condition. In other words, this research has led to the theory that medication-taking, from the perspectives of a group of German renal transplant recipients, can be regarded as symbolic of living with a chronic illness.

## **6.2 Secondary Literature Review**

In GT, the literature review has been, and still is, subject to intensive debate (Bryant & Charmaz 2007b; McGhee et al. 2007; Dunne 2011; Giles et al. 2013). Whilst Strauss and Corbin (1990) opted in favour of an initial literature review, Glaser (1992b) strongly opposed this stance. Grounded theorists supporting Glaser argue that a literature review prior to data collection and analysis may distract the researcher and hinder the emergence of theory (Cutcliffe 2000). In contrast, Bryant and Charmaz (2007) argue that "an open mind does not imply an empty head" (p. 20).

The latter stance is certainly true in the case of this research, which is based on two years of intensive consideration of the issue of medication adherence in renal transplant recipients that occurred during the taught phase of the programme of study. During this, I produced a concept analysis of adherence, compliance, and concordance, as well as a literature review on underlying reasons for medication adherence in kidney transplant recipients. My decision to conduct a comprehensive literature review is supported by evolved GT. As McGhee et al. (2007) rightly argued, the initial literature review provided justification for the research and met the requirements of the ethics committees. However, after completing data collection and analysis, I realised that some of my findings were not covered by the initial literature review. These are primarily feelings of being ambivalent toward medication-taking given a chronic illness, and the extent of internalisation of medication-taking that has led to the emergence of the core category. Consequently, I conducted a secondary literature review to clarify these emerging concepts and relate them to other findings in similar areas. This approach is in line with the premises of evolved GT (Stern 2007; Urquhart 2007) and may even add to the credibility of the research (Charmaz 2014).

### **6.2.1 Inclusion and Exclusion Criteria**

As the first literature review did not find evidence of ambivalence toward or internalisation of medication-taking in renal transplant recipients, this new review was expanded to include all types of chronic conditions, as other chronically ill patient groups may have similar experiences with medication adherence (Sabaté 2003). Also, this review was limited to qualitative research to gain insight into patients' experiences and perceptions, and to omit prevalence studies and discussions of reasons underlying medication non-adherence. As with the initial review, only studies of adult patients in English or German were included, and no time frame was applied.

### 6.2.2 Search Strategy

The search terms *internalisation*, *ambivalence*, and *chronic conditions/illness* were used (Table 10). Where possible, the keywords indexed in the controlled vocabulary of the database were searched. Also, both British and American spellings were taken into account. The full search strategy can be followed in Appendix 15.

	Perspective	Intervention of Interest	Evaluation
<b>Search</b>	patients with chronic conditions	medication adherence	
<b>Relevant Search Terms</b>	<ul style="list-style-type: none"> <li>• chronic condition</li> <li>• chronic illness</li> </ul>	<ul style="list-style-type: none"> <li>• adherence</li> <li>• compliance</li> </ul>	<ul style="list-style-type: none"> <li>• internalisation/internalization</li> <li>• ambivalence</li> </ul>

**Table 10: Search terms used in the secondary review**

Medline, PsycInfo and CINAHL were searched using the procedures described in Chapter Three. Additionally, concept analyses on *internalisation* and *ambivalence* were searched in Medline and Google Scholar.

### 6.2.3 Literature Found in the Secondary Literature Review

This search revealed three relevant papers (Townsend et al. 2003; Gustafsson et al. 2005; Piguet et al. 2007) that had not been found during the initial literature review. Additionally, a concept analysis of *ambivalence* (Conner & Sparks 2002) was found. The selection of literature can be followed in Appendix 16 and the complete list of relevant papers can be found in Appendix 17. All three papers present qualitative studies of participants with varying chronic conditions and methods of treatment.

Gustafsson et al. (2005) report a qualitative study using an ethnographic approach to the attitudes toward healthy eating, and eating habits, of elderly women. Participants had three chronic conditions, rheumatoid arthritis, Parkinson's disease, or stroke, which required dietary advice and possibly a change in eating habits. The study by Pigué et al. (2007) used content analysis to examine the attitudes of patients with chronic pain toward antidepressants. Finally, using a constant comparative method, Townsend et al. (2003) examined attitudes toward medication among middle-aged participants with multiple chronic conditions. Although the aims and target groups of these three studies differed considerably from the research presented in this thesis, the findings are similar in some respects, as will be discussed further in Chapter Seven.

### **6.3 Summary of Chapter Six**

Here, the findings of this research have been presented. All findings were grouped around the core category of *medication-taking as a symbol of living with a chronic condition*. Subsequently, the need for a secondary literature review was discussed, and this secondary literature review was undertaken. The next chapter will discuss the findings of this research in relation to existing knowledge.

## CHAPTER SEVEN: DISCUSSION

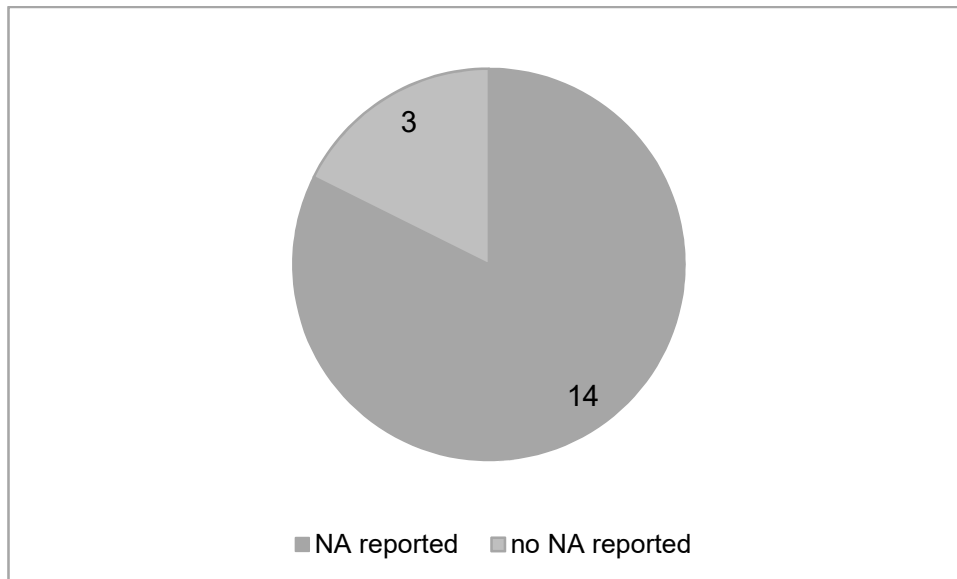
This chapter discusses the theory emerging from this research in relation to the literature on medication adherence among renal transplant recipients and other chronically ill groups of people. Medication-taking is a major part of the lives of most people suffering from chronic conditions. It is thus unsurprising that the emergent theory of this research is *medication-taking as a symbol of living with a chronic condition*. For participants in this study, medication-taking is strongly associated with living with a chronic condition, in this case having undergone renal transplantation, and this comprises a variety of categories and sub-categories as outlined in Chapter Six. Before placing the findings of this research in the context of existing knowledge, two issues will be addressed. First, characteristics of study participants in relation to other persons requiring dialysis or kidney transplantation in Germany will be discussed. Secondly, the extent of non-adherence among study participants will be outlined.

Although this work does not claim generalisability, in order to enable at least some transferability, the sample of this study must be set in the context of other renal transplant recipients and/or patients requiring dialysis treatment in Germany. The median age of persons undergoing kidney transplantation in Germany is 51 years (Frei & Schober-Halstenberg 2008). Participants in this study had a median age of 52 years and had been transplanted a median of eleven years ago, and hence are younger than the average German renal transplant recipient. The sample differed slightly from the general German renal transplant and dialysis population with respect to gender; in this study, nine of 17 participants were female, but in Germany generally, more men than women are affected by ESRD and only 38% of transplant patients and 42% of dialysis patients are female. However, again, these numbers are not meant to be generalisable but rather give an approximate picture of the general situation in Germany.

Regarding the underlying disease necessitating dialysis treatment, the participants differ from the general German dialysis population in one aspect. Only one of 17 participants suffered from diabetic nephropathy, a rate considerably lower than the general German dialysis population, where diabetes-related ESRD accounts for 28% of all patients requiring dialysis (Frei & Schober-Halstenberg 2008). The other underlying diseases in this sample (Table 8) are comparable to the general German dialysis population. Regarding the type of transplantation, 12 of 17 participants (70%) received their kidney transplant from deceased donors and five (30%) from living related donors. The latter proportion is higher than in the general German transplant recipient population, where 19.9% of transplanted kidneys came from living donors in 2013 (Deutsche Stiftung Organtransplantation 2014).

During the interviews, I did not ask participants whether or not they adhered to their medication. This was to avoid inducing socially desirable answers and euphemising of medication-taking behaviour, as self-reporting, particularly in interviews, does not reveal the same extent of non-adherence as other measures (Garber et al. 2004; Schäfer-Keller et al. 2008). Moreover, it was not within the scope of this research to assess the extent of non-adherence in the sample; rather, the salient issue was participants' meanings with regard to medication-taking, as outlined in Chapter One. A statistical evaluation of non-adherence in this research would not be feasible due to the small sample size. However, to my surprise, all participants talked openly about their adherence behaviour and hence the issue is worth discussing here, with the caveat that any numbers presented in this section lack statistical significance and cannot be used to draw conclusions on adherence of other renal transplant recipients.

During the interviews, all participants made at least one statement that allowed evaluation of their adherence. The majority of participants admitted to occasionally not taking their medication as prescribed (Figure 23). This exceeds the extent of non-adherence suggested by the literature, as outlined in Chapter Two (Dew et al. 2007; Hansen et al. 2007).



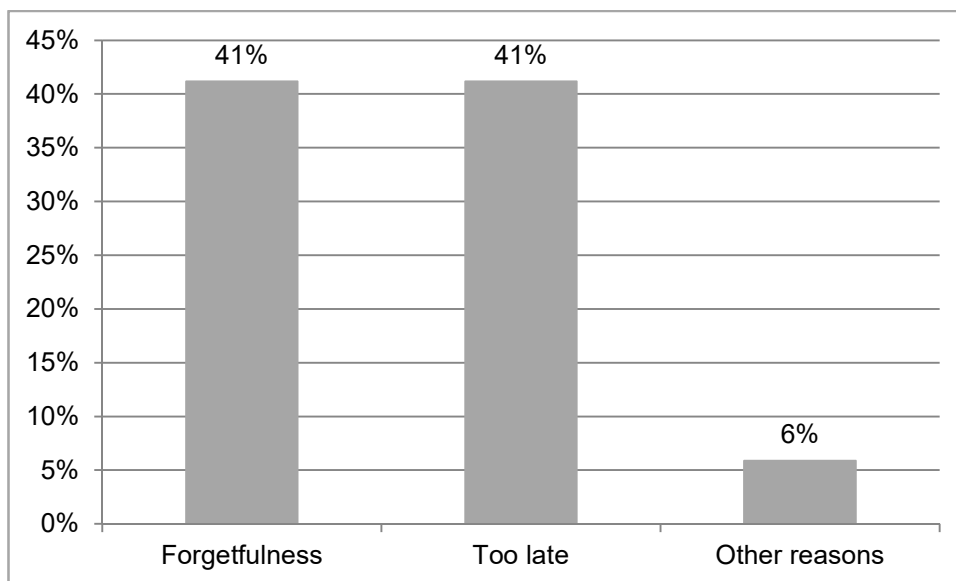
**Figure 23: Reported non-adherence**

*Abbreviation: NA = Non-Adherence*

The reasons behind the unprompted volunteering of this information remain unclear, but one possible explanation may be the use of telephone interviewing. Despite the method's disadvantages, telephone interviews may lead to open answers from research participants as they offer privacy that face-to-face interviews cannot provide (Sturges & Hanrahan 2004; Novick 2008). Further contributing factors may have been the assurance that no interview content would be reported to a third party and the fact that the interviews were conducted in an empathetic, non-threatening way.

In all cases, the disclosure of non-adherence was directly connected to a statement regarding the underlying reasons for this behaviour (Figure 24). This suggests that all participants were aware of the possible consequences of their occasional non-adherence and wanted to rationalise it. Of the 14 participants who admitted occasional non-adherence, all but one ascribed this to forgetfulness and/or taking medication too late.





**Figure 24: Reasons for non-adherence**

In most cases, 'too late' was only a few hours after the regular intake time, although an exact time span usually could not be specified. This was also directly associated with forgetfulness. As participants were not interrogated regarding their individual pattern of non-adherence, this cannot be further understood. However, some patients also admitted to accidentally skipping single doses, typically the evening dose.

A conflicting reason for openly admitting occasions of non-adherence may lie in underestimation of delays in medication-taking. While reports of forgetfulness were often accompanied by statements of anger or sorrow, taking medication late, more than two hours after the normal intake time in the case of IM, was not perceived as problematic.

Many of the issues raised by participants in this study can be seen in the systematic review and thematic analysis by Tong et al. (2011). However, some themes have emerged that have not been described previously in the literature. The following section discusses the findings in relation to existing knowledge in this field and in relation to evidence gained from research on medication adherence among patients with other chronic conditions.

## 7.1 Medication-Taking as a Symbol of Living with a Chronic Condition

Renal transplantation is often depicted as a cure for ESRD by the media and campaigns promoting organ donation. In addition to the general public, many people in the healthcare setting believe this. However, this is not the case. The participants in this research struggled with a variety of challenges that are typically associated with suffering from chronic conditions. Consequently, many participants were not able to differentiate between medication-taking and other health-related self-management tasks that they needed to follow in their daily lives, such as healthy eating or infection control. Indeed, medication-taking was perceived as important but did not have the significance of the most important issue following transplantation, as it was just one of the limitations and challenges they struggled with on a daily basis. This insight arises from the fact that the participants of this research had internalised medication-taking to a point comparable to everyday tasks that are carried out even without a single thought, such as taking the key when leaving the house. Therefore, the theory emerging from the findings of this research is that medication-taking is a symbol of living with a chronic condition.

Before discussing in detail the theory emerging from these findings of this research, I will broadly outline the main components of the central category, namely *chronic conditions* and the definition of *symbol*. This will introduce the reader to my thought process regarding the central category.

I use the term *chronic condition* here rather than *chronic illness* because this research, as well as related literature on the issue, shows that both terms represent different notions, at least in English. *Illness*, according to the OED (2015h), is “a disease or period of sickness affecting the body or mind”. In contrast, *condition* is “a person’s or animal’s state of health or physical fitness” (OED 2015i), incorporating a more neutral approach that does not necessarily imply ill health (Perrin et al. 1993). In contrast to English, the German language does not differentiate between *chronic illness* and *chronic condition*, as both can be translated as *chronische Krankheit* or even *chronisches Leiden*, with the latter literally meaning *chronic suffering*, emphasising the illness component of the concept.

Chronic conditions have been the focus of interest here, but given the multitude of conditions regarded as chronic that can differ in severity and duration, a comprehensive definition is not available. There is a vast amount of literature on the definition of chronic illness, but this can only be broadly discussed. As Carel (2013b) notes, there are two major approaches towards illnesses: naturalistic and normativist. The naturalistic approach reduces chronic illness to pathophysiological processes, but neglects that illness also incorporates a variety of other notions, such as how the victim of a condition perceives it. In contrast, the normativist approach concentrates on how illness is perceived by others, specifically on the negative evaluation of a condition. This is the prevailing approach from a sociological perspective (Turner 1995). Both approaches have their merits, but, as Carel (2013b) argues, neither takes into account how being ill is perceived by the one who is ill.

Generally, illnesses lasting more than three months that cannot be cured are regarded as *chronic* (Perrin et al. 1993) or *long-term* illnesses (Department of Health 2016), irrespective of the age of the person affected or the type of disease. Although I am aware that the term *chronic* may hold negative associations, especially in English colloquial speech (OED 2016b), I decided to use this term rather than *long-term* in this work, as there is no German equivalent to *long-term* in regard to disease. *Chronic* is also the term used by this research's participants when describing their state of health, showing it has no negative connotation in German.

The definition of chronic conditions has two main components. First, being qualified as chronic, an illness is not only expected to last longer than three months but also implies an impossibility of cure (Wellard 1998). Secondly, chronic illness regards not only the type of disease (for example, diabetes, cancer, or ESRD) but, crucially, its impact on the person affected; that is, "the level of functional impairment or the use of medical attention greater than that expected" (Perrin et al. 1993, p. 792).

All of the above preconditions, except the normativist approach, apply to renal transplant recipients, who consequently qualify as being chronically ill. From a naturalistic viewpoint, renal transplant recipients are clearly chronically ill, simply because the GFR of a transplanted kidney rarely falls to a normal level. Still, a transplanted kidney can work for many years, as transplantation is higher than in the normal population.

However, two issues may lead to a failure to regard renal transplant recipients as chronically ill; this research has demonstrated that even they may not regard themselves as chronically ill. First, the normative approach may not apply to renal transplant recipients. As one cannot tell by sight that someone has received a renal transplant, one may not perceive kidney transplant recipients as chronically ill. This view is also reflected by findings from a qualitative study on patients' perspectives and experiences of living with a chronic kidney disease (Tong et al. 2009) wherein some renal transplant recipients did not consider themselves to suffer from chronic kidney disease, despite their transplanted kidney working on a CKD level three or worse. Secondly, the level of functional impairment is closely connected to whether renal transplant recipients perceive themselves as ill.

Returning to the central category, *medication-taking as a symbol of living with a chronic condition*, the term *symbol* remains to be defined. According to OED (2015j), a *symbol* is "a thing that represents or stands for something else, especially a material object representing something abstract". In this case, medication-taking stands for the fact that the research participants can be considered chronically ill, independent of their own awareness of this. The participants in this research hold their medication responsible for many of their physical problems and imply that participants would be better off without the need to take tablets. At the same time, participants are aware that without their IM, they would certainly be in a much worse state of health than with it. A transplant is thus a sustained challenge in discipline and self-control.

The finding that medication may be perceived as a symbol of living with a chronic condition has not previously been described in the literature on medication adherence in renal transplant recipients. Also, no other research could be found that supported the strong feeling among participants that medication is an integral part of their lives. In this study, most participants' first statement emphasised how deeply medication-taking is integrated into their daily lives, irrespective of the difficulties they experience.

The experience of medication-taking being an integral part of life may be associated with the nature of CKD. All renal transplant recipients taking part in this study underwent dialysis prior to their transplantation. Although the question was not asked, one can assume that they share a long-term history of CKD and therefore have been accustomed to taking medication for years, which may have led to familiarity with the issue. Also, as one participant (Mr Richter) put it, after years of being chronically ill, they may have lost the ability to have a feeling for how healthy may feel.

Although no literature to support the perception of medication-taking being symbolic for living with a chronic condition in renal or other solid organ transplant recipients, there are hints that other groups suffering from chronic conditions requiring specific treatments or behaviours may also perceive these as an integral part of their daily lives. For example, Williams and Manias (2014) have found that medication-taking has become a routine in people with diabetes, CKD, and hypertension. Similar findings have been reported by Townsend et al. (2003), who found medication to occupy a central place in the lives of persons with multiple chronic conditions. In this study, the number of medications was also seen as representative of the severity of participants' conditions. The need to integrate treatment into daily lives is also confirmed by research on long-term paediatric conditions and cystic fibrosis (Tierney et al. 2013; Santer et al. 2014). Similarly, O'Hara et al. (2013) report that being in control of the illness is crucial for men with Type I diabetes. The sense of controlling Type I diabetes, rather than being controlled by it, implies that the associated treatment, in this case blood sugar monitoring, needs to be regarded as a part of one's self.

It seems as if medication-taking as symbolic for living with a chronic condition has not yet attracted much attention. This is surprising from my point of view, as many chronic conditions require life-long medication and other behaviours that potentially have an enormous influence on patients' everyday lives. Despite the lack of external evidence for this connection, I will outline the categories producing the core category, which will add to an understanding of the theory that medication-taking symbolises being ill.

## **7.2 Reflecting on One's Own Position**

The participants of this research report a high extent of self-reflection in regard to their condition and the associated need to take IM on a regular basis. The participants' self-reflection is predominantly concerned with the following major issues: (1) holding attitudes and beliefs, (2) the notion of being constantly aware, (3) the wish to be responsible and have things under control, (4) being strongly ambivalent, and (5) the development of participants' handling of their situation over time.

### 7.2.1 Holding Attitudes and Beliefs

The attitudes toward renal transplantation and regular intake of medication were largely positive in this sample. Most participants understood and perceived the medication as the only opportunity to keep their kidney transplant. This finding is supported by recent research (Hugon et al. 2014) that found medication adherence in solid organ transplant recipients to be connected with positive attitudes toward the medication. Tielen et al. (2014) found no statistically significant association between participants' attitudes regarding medication adherence. However, they concluded that Dutch renal transplant recipients' attitudes towards medication adherence may appear in three forms: "confident and accurate [...] concerned and vigilant and [...] appearance oriented and assertive" (p. 2). Confident and accurate renal transplant recipients were confident about being able to manage their medication regimen, which was reflected by good adherence. In contrast, the concerned and vigilant group displayed a comparably high extent of anxiety regarding their medication regimen, whilst appearance-oriented and assertive renal transplant recipients strove for normality, perceived themselves as being in control, and took good care of their kidney. However, these patients indicated higher burdens of (cosmetic) side effects (Tielen et al. 2014). These groups are visible in the present study. Although none of the participants could be put into the concerned and vigilant group, the attitudes reported in this research mirror the first two groups. In this setting, however, these two groups are not mutually exclusive, but rather another expression of the ambivalence connected with suffering from a chronic condition. To verify this hypothesis, this understanding could be examined in another sample using Q-methodology based on the work of Tielen et al. (2014).



One issue that contributed considerably to positive attitudes toward medication was the fact that most participants were intensively involved in negotiations with their nephrologist regarding their medication. This finding is supported by WHO's recommendation to treat patients as autonomous partners in the prescription process, rather than applying paternalistic approaches (Sabaté 2003). Both quantitative (Rudman et al. 1999; Gremigni et al. 2007; Massey et al. 2013) and qualitative (Russell et al. 2003; Tong et al. 2009) studies have stressed the importance of patient autonomy regarding medication adherence, but here the finding should be considered with caution, as all participants in this study were treated by the same team of nephrologists, who may display an extraordinary extent of patient orientation and may not be representative of other nephrologists.

This research included participants with living and deceased donor grafts. Participants did not articulate differences in attitude towards the graft, or toward medication-taking and with it medication adherence. In this context, only one participant whose living related graft had failed after a comparably short period of time was unwilling to accept another kidney from someone she knew. In the literature, feelings of guilt and indebtedness towards the donor, whether living or deceased, have been discussed as facilitators for medication adherence. For example, guilt is more pronounced in recipients with living related donors (Griva et al. 2012) and may be associated with better adherence (Achille et al. 2006). However, a similar study of German-speaking Swiss patients found fewer feelings of guilt toward the donor (Klaghofer et al. 2008). This is also reflected in other research from Switzerland, which found guilt toward the donor in a minority of solid organ recipients (Goetzmann et al. 2008). Whilst guilt is not explicitly addressed in this research, it hints that solid organ transplantation may involve a feeling of responsibility towards the donor. The same conclusion has been drawn by other research (Orr et al. 2007b; Goetzmann et al. 2008; Schipper et al. 2014). This perceived responsibility may lead to feelings of indebtedness towards the donor, which in turn has been shown to improve medication adherence (Achille et al. 2006).

This research also suggests that the attitudes and viewpoints of recipients of combined kidney/pancreas transplants may be fundamentally different from recipients of kidneys, as the burden of daily insulin injections may be heavier than tablet-taking. However, this research involved only one participant whose ESRD was caused by diabetes, and thus only this single perception can be reported here. Still, this finding is in congruence with other research on the topic (Boaz & Morgan 2014).

The participants of this research hold different beliefs as to how the immune system and IM work. These beliefs seem to be shaped mainly by the way their transplant centre, and later their nephrologist, simplify and explain complex biomedical concepts. Most participants had some extent of knowledge regarding their immune system and had constructed their own belief systems from pieces of information gathered from various sources. However, from a professional point of view, many beliefs regarding medication or other treatment characteristics could not be supported, as one of my memos emphasises:

*Beliefs of how medication work are rather different and in some cases interesting such as Mr Schneider's belief that medication can be compared to a cocktail that needs to arrange in the body. Mr Becker believes that the body defends itself against the strange organ and IM teaches the body not to exaggerate.*

*Also, beliefs of how IM work in the human body are very different. Some participants (Mr Hoffmann, Mr Becker) believe that that blood levels take some days to decline.*

*Another example is Ms Klein who has distinctive beliefs of what, from her point of view, has led to graft failure: each biopsy causes scars which in turn diminish the functioning kidney tissue.*

*I therefore believe that patient education as to the mode of action of IM is needed.*

From these belief systems stem participant's perceptions of why, how, and when medication has to be taken. Providing patients with basic knowledge of the reasons for medication-taking is recommended by work on patient education following solid organ transplantation (International Transplant Nurses Society 2007b; International Transplant Nurses Society 2007a; KDIGO 2009; Schäfer-Keller et al. 2009). However, as this research shows, many of the renal transplant recipients' beliefs are vague or even incorrect.

This research also demonstrates that the beliefs of kidney transplant recipients are directly connected to their medication-taking behaviour and adherence. If, for example, a kidney transplant recipient believes that the drugs' blood levels take several days to decline, as is the case here, it is conceivable that missing a single dose may not be ascribed its true significance. In accordance with the relevant guidelines (KDIGO 2009), it is thus important that renal transplant recipients have at least a broad understanding of the biomedical actions connected with IM. This understanding does not necessarily need to include all aspects of the immune system, but should provide patients with metaphors that make the complex issue accessible. This goal has been reached for some participants, but not all. This issue again shows how crucial individualised patient education is and to what extent misunderstandings may have fatal consequences. Still, the data suggest that most participants, according to their beliefs, discuss and negotiate their medication with their physician as outlined above, but some do not address their concerns. The latter may prove problematic in this case, as healthcare professionals may not be aware of concerns or issues highly relevant to the participant, who in turn may act in ways that may not be beneficial to their transplant, without realising it.

### **7.2.2 Being Constantly Aware**

Constant awareness is another good example of how medication-taking is representative of living with a chronic condition, especially given that most participants report being accustomed to medication-taking for a long time, in some instances for most of their lives. Although most participants perceive themselves as healthy and without problems regarding medication-taking, each instance of medication-taking reminds them of suffering from a chronic condition. The reverse is also true; that is, the constant awareness of having received a kidney transplant reminds them of taking their medication. This reciprocal effect raises different emotions; while some participants are reminded of their luck and chance of a new life (Ms Müller), others perceive a threatening reminder of the potential failure of the graft (Mr Richter). Others perceive tablet-taking as an opportunity to actively review their state of health or organise their lives (Mr Weber). This steady awareness also shows how deeply the participants have internalised their condition, and with it, medication-taking in their lives.

### **7.2.3 Being Responsible and Having Things under Control**

Despite the development from *compliance* to *adherence* (Sabaté 2003; Bissonnette 2008; Haynes et al. 2008) which shifted responsibility for medication-taking away from the patient, the transplant recipients in this research hold the view that they are responsible for taking their medication as discussed with their nephrologist. This finding is supported by other qualitative research on living with CKD or kidney transplants (Tong et al. 2009; Tong et al. 2011), wherein participants felt responsible for medication intake. This view is shared by many healthcare professionals who still believe that medication-taking is the patient's responsibility (Tarn et al. 2012).

This strong sense of patient responsibility may come from the fact that CKD is a disease whose progress usually cannot be influenced by the patient, such that receipt of a kidney transplant, often after years of waiting, is regarded as a chance that must be seized. Participants then do everything possible to protect their organ, feeling grateful to finally be able to contribute to their own health through adherence. However, I found no hints of this hypothesis in other qualitative research on living with a kidney transplant (Orr et al. 2007b; Goetzmann et al. 2010; Schipper et al. 2014). The only hint came from Boaz & Morgan (2014), who concluded that good self-care is associated with feelings of gratitude toward the donor. This association, however, has not been outlined further. It may therefore be helpful to investigate this question, as an association between the nature of CKD and adherence may be relevant for many renal transplant recipients.

The notion of responsibility is also connected to participants' desire to control their condition rather than let it control them. This is reflected not only in the research presented here, but also in other studies on living with a kidney transplant (Boaz & Morgan 2014; Schipper et al. 2014). The feeling of being in control is consistently expressed as an important component of individual coping strategies. Similar results have been seen for other chronic diseases as well, such as in men with Type I diabetes (O'Hara et al. 2013). In a study of adherence in patients with multiple chronic conditions, Mishra et al. (2011) also conclude that control is connected with successful self-management. Similarly, Gustafsson et al. (2005) found that elderly women who followed dietary advice believed they could control, or at least influence, their health by eating or omitting certain foods.

For the kidney transplant recipients studied here, being in control may include negotiating with their nephrologists on the type and dosage of tablets and scheduling of intake. The latter is supported by research on patients with multiple chronic illnesses (Townsend et al. 2003), who were found to be flexible with their medication regimens according to careful self-monitoring and perceived symptoms.

Despite claiming responsibility and control, most participants studied here utilised only limited sources of information, of which the most important were their transplant centres and later their nephrologists. Only two participants obtained information from transplant-related books or journals, and none used patient support groups. The latter is interesting, as Germany has a lively culture of patient support or self-help groups; currently there are between 70,000 and 100,000 self-help groups in more than 300 locations for a variety of conditions, including for kidney transplant recipients (NAKOS 2015). Such groups may lend social support, improve patients' psychosocial wellbeing, and help with management of chronic conditions (Hoey et al. 2008; Van Uden-Kraan et al. 2009; Kirk & Milnes 2015). Not taking part in patient support groups may be associated with the feeling of not being ill and hence not needing support from peers. This hypothesis is supported by Ms Wolf, who cancelled her subscription to *Der Nierenpatient*<sup>20</sup>, a journal for patients suffering from CKD, after her transplant.

The Internet was used only by some participants for health-related information gathering. The main source of information was the nephrologist, to whom patients ascribed expertise in simplifying complex issues and using understandable metaphors. However, as all participants were cared for by the same team of nephrologists, this finding cannot be generalised.

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<sup>20</sup> English: The Kidney Patient

As discussed in Chapter Six, although all participants intend to adhere to their prescribed treatment regimen, instances of forgetfulness occur despite rigorous self-discipline. Many participants thus employ a variety of reminder strategies, with or without help from others, and some combine multiple strategies and rituals. For example, Mr Richter uses pill boxes, keeps these visible on a table, and has tied tablet-taking to mealtimes, and furthermore relies upon his wife to remind him if these other three strategies fail. This type of approach is common to renal transplant recipients (Gordon et al. 2009; Ruppap & Russell 2009; Tong et al. 2011). While many studies have examined reminder devices, such as text messages or beepers, for long-term treatment, there is no convincing evidence that these improve adherence (Demonceau et al. 2013; Nieuwlaat et al. 2014).

Interestingly, participants in this study are either strongly in favour of reminder strategies, such as mobile phones or pill boxes, or strongly against them. Those in favour refer to the helpfulness of such devices and some even feel lost without them or believe it is impossible to follow a complicated regimen without any reminder. In contrast, those against reminders say they have internalised their intake times to an extent that they can rely solely on their inner clock. From their perspective, being reminded can seem disruptive, especially if medication-taking is not possible at that time. This study did not hint at whether one strategy is more successful than the other.

#### **7.2.4 Being Ambivalent**

Although ambivalence was a dominant enough issue to assign it an own category, it was involved in other categories to an extent that did not permit differentiation, and thus it was integrated into *reflecting on one's own position* – particularly as strong ambivalence was exhibited by most participants, in contrast to the consistently high extent of reflexivity.

Ambivalence has been widely discussed with regard to holding attitudes or exhibiting certain behaviours (Conner & Sparks 2002). It is the “existence of simultaneous or rapidly interchangeable positive and negative feelings toward the same object or activity, with the added provision that both the positive and negative feelings be strong” (Meehl 1964, p. 8). According to Conner and Sparks (2002), ambivalence is especially common in health-related behaviours, where the immediate effect of a behaviour may differ from its long-term outcomes. This is the case for IM, for which immediate unpleasant side effects may mask the positive long-term effect, which is the protection of the transplant.

For most participants in this study, medication-taking is a constant cause of ambivalence derived from a variety of sources. First, and importantly, most participants regard themselves as healthy. However, at the same time, most also face, and struggle with, many challenges. As outlined in Chapter Six, these can be attributed to underlying diseases, co-morbidities, medication side effects, and organisational or other issues related to medication-taking. Participants sometimes are not fully aware of reporting such challenges, which can be attributed to the fact that most rate their health as satisfying and their QoL as good.

This leads us to the impact of a chronic condition on the patient, and specifically the question of what it is like to live with a chronic condition. This is often regarded as the crucial point in research on chronic conditions, and has been studied extensively over the past 40 years (Thorne & Paterson 1998). People affected by a chronic condition are often striving for normality (Wellard 1998), and being ill and well at the same time is not as contradictory as it may seem at first glance. In their study on men diagnosed with Type I diabetes, O'Hara et al. (2013) used a participant's quote to illustrate a general stance towards living with diabetes: “it's not a disease, it's a nuisance” (O'Hara et al., p. 1227). Although only implicitly expressed, this attitude reflects the views of participants in the study presented here.



Supporting this, there is evidence that chronic conditions do not necessarily have a negative impact on the perceived wellbeing of those affected (Carel 2013a). Similarly, subjectively perceived happiness may depend not on physical health, but rather on daily functioning and the absence of social stigma (Angner et al. 2009), regardless of the objective severity of the illness. People with chronic diseases are most affected when a change in the objective condition occurs, such as at diagnosis or if the disease progresses; but even in these cases, adaptation occurs quickly and the subjective wellbeing is restored (Angner et al. 2009). These insights support the findings presented here, in which participants struggle with daily functioning (for example, Ms Maier suffers from her inability to do housework), social isolation (Mr Becker misses seeing his grandchildren), or changes in health status, such as medication changes or rejection episodes.

The sense of being ill and well simultaneously is also reflected by the fact that, although the aim here was not to evaluate the impact of renal transplantation on participants' lives, most stress that they feel normal and healthy. In particular, most participants do not differentiate between taking medication regularly and having a chronic condition. These two factors are so interwoven that they cannot, and in my view should not, be treated separately. This is one of the most important conclusions from this research.

Another issue leading to ambivalence is the fact that expectations held prior to transplantation regarding the life as a renal transplant recipient have not been fully met. As with the public, participants had expected renal transplantation to be a cure for ESRD. However, to their regret and surprise, this expectation has proven false, as they have experienced a variety of limitations or complications showing them quite plainly that they are still affected by a chronic condition. One participant feels that she was badly informed prior to transplantation, a view supported by other participants who were not educated regarding transplantation before it took place. Consequently, most participants were not fully aware of what would happen when they were put on the waiting list. After transplantation, participants were then confronted with failed expectations on one hand, and gratitude and happiness over their new lives on the other. Similar views have been seen in other studies, in which subjects were surprised that post-transplant life did not meet their expectations of normality (Boaz & Morgan 2014). This may result from a general overestimation of QoL after kidney transplantation in other research (Smith et al. 2008; Schulz et al. 2014). Smith et al. (2008) also concluded that expectations may be created by the public and “impact bias – a tendency to overestimate the influence that events will have on one’s QoL” (Smith et al. 2008, p. 653). However, renal transplant recipients may also experience a phenomenon known as “theory based recall bias” (Wilson et al. 2003p. 425), which is a biased recall of how people think they should have felt or reacted. Moreover, recollection of past events decreases naturally as time progresses.

A further source of ambivalence is that whilst IM prevents rejection of the transplanted kidney, it also has nephrotoxic effects that may eventually damage the graft. Some participants are aware of this and find it difficult to concentrate on the positive aspects of IM. These patients weigh medication-taking against the risk of rejection and decide in favour of medication-taking. Also causing ambivalence are the side effects experienced by most participants. Similar findings were recently published by Yagasaki et al. (2015) who saw that cancer patients had difficulty reconciling their rational knowledge of and emotional responses to oral chemotherapy. Patients with a variety of other conditions exhibit the same ambivalence, stemming from understanding that a given health-related behaviour is beneficial and, at the same time, feeling reluctance (Britten 1994; Townsend et al. 2003). Participants of these studies had in common a sense of ambivalence that stemmed from their cognition that the advised behaviour was beneficial for them, but, similar to this research's participants, at the same time this behaviour generated feelings of reluctance to take medication (Britten 1994; Townsend et al. 2003), perceived loss of control (Piguet et al. 2007) or insecurity regarding health-related behaviours (Gustafsson et al. 2005).

The final source of ambivalence in the study presented herein is participation in medical trials. The general attitude toward these studies is positive, with participants aware that trials are necessary for development of transplant-related medication. Hence, in the past, participants had agreed to take part in one if asked; however, they now say that they would never repeat the experience and would advise others against it. My impression was that participants had not been well-informed regarding the studies. For example, they were not aware that the study drugs were not new, but rather existing drugs that the respective study aimed to refine or were given in different combinations. Furthermore, many participants could not differentiate between symptoms caused by the trial medication and those that would likely have occurred in any case. Similar results were found by a meta-analysis on barriers to participation in clinical trials in cancer (Mills et al. 2006a). As a researcher, I sympathise with this scepticism among patients, as they should receive sufficient information on an appropriate level of health literacy before entering a trial. Similar conclusions were also drawn by Mills et al. (2007).

### **7.2.5 Developing over Time**

The final category contributing to the core category of this research concerns the development of medication-taking over time. Participants in this study agree that the period immediately following transplantation was challenging for a variety of reasons and required adjustment. This adjustment includes both their new status as a kidney transplant recipient and medication-taking. The time needed to become accustomed to medication and develop routines may vary between individuals. While the first weeks were difficult for some participants, others experienced difficulties for up to two years post-transplant. In the first six months following surgery, kidney recipients must heal and adjust to new medication and lifestyle changes, and this time is also characterised by frequent changes in the medication regimen to find the best individual dose and by a gradual reduction in levels of IM (KDIGO 2009).

Despite the fact that many renal transplant recipient's state of health is better and QoL is higher than pre-transplant (Dew et al. 1997; Neipp et al. 2006), renal transplant recipients remain chronically ill (Luk 2004; Schäfer-Keller et al. 2006; Dobbels 2009; Drent 2009), and their new normality requires an enormous extent of adaptation, as also suggested by Boaz and Morgan (2014). Livneh (2001) argues that three models dominate adaptation to a chronic condition: the stepwise model assumes that adaptation takes place in phases; the circular model suggests a cyclical and repetitive pattern, and a third model assumes that individual adaptations cannot be generalised. Briefly, my impression is that for the patients studied here, adaptation is a gradual process that follows different phases but also depends on the individual. In this regard, I can easily follow Corbin and Strauss's (1998) Chronic Illness Trajectory model that describes multiple phases of chronic conditions, including "pre-trajectory, trajectory onset, stable, unstable, acute, crisis, comeback, downward and dying" (Corbin 1998, p. 36). Most participants have experienced many of these phases. Living with a kidney transplant is not only a creeping process, but may also be characterised by a wavelike occurrence of different phases. In this context, a particular challenge faced by renal transplant recipients is the need to cope with a state of health that is considerably better than before, yet still challenging.

Returning to medication adherence, the findings here are ambiguous; on one hand, participants agree that with time, medication-taking becomes easier as it is integrated into their daily lives, but on the other hand, some participants relax as time passes and no direct physical consequences of forgetfulness are experienced. This relaxation may be associated with some degree of carelessness, particularly with regard to the timing of medication-taking, the importance of which is frequently underestimated by participants.

In the quantitative literature, there are conflicting results regarding the development of medication adherence. While some studies found that adherence decreases with time after transplantation (Vasquez et al. 2003; Chisholm et al. 2005; Denhaerynck et al. 2005; Chisholm et al. 2007; Chisholm-Burns et al. 2008a; Gelb et al. 2010; Germani et al. 2011; Lin et al. 2011; Massey et al. 2013), others found no association (Vlaminck et al. 2004; Russell et al. 2006; Russell et al. 2010; Griva et al. 2012). In contrast, the qualitative literature has found similar issues regarding the challenge of adaptation post-transplant. For example, Boaz and Morgan (2014) recently studied renal transplant recipients at different stages post-transplant. Without focusing specifically on medication adherence, they found that their participants were at different stages of normality. Medication-taking has also been perceived as becoming easier as time passes (Ruppar & Russell 2009). In contrast, a systematic review of qualitative studies on renal transplant recipients' perspectives on medication-taking did not find any indicators for the development over time.

### **7.3 Experiencing Facilitators and Challenges**

In this research, most participants openly report problems causing occasional lapses in adherence. These participants, but also the few participants reporting complete adherence, describe a variety of factors facilitating or hindering regular medication intake. Interestingly, factors some participants perceive as helping are perceived by others as hindering. The most commonly reported factors are: (1) having received dialysis treatment, (2) fearing rejection, (3) forgetting medication, (4) organising one's life, (5) experiencing improved QoL, (6) being supported, (7) striving for routine, and (8) struggling with medication. Because perceptions differ considerably between individuals, these factors were not separated as facilitators and/or challenges in Chapter Six, but will be summarised together here.

### **7.3.1 Having Received Dialysis Treatment and Fearing Rejection**

In this research, all participants share the experience of having had dialysis prior to their kidney transplant, and all but one share the strong belief that one of the biggest advantages of transplantation is independence from dialysis. This belief stems from a sense of freedom related to both having more free time and escaping dialysis-related limitations.

Despite the ambivalence discussed previously, freedom from dialysis exceeds any other negative emotions or circumstances related to kidney transplantation. In this regard, this study confirms findings from other qualitative research that suggests dialysis to be distressing and the threat of returning to it to be a major driver of adherence (Russell et al. 2003; Orr et al. 2007a; Tong et al. 2009). Although this has not been verified explicitly by quantitative research (Lin et al. 2011), a longer duration of dialysis is associated with better adherence after transplantation (Griva et al. 2012) suggesting that the perceived burden of dialysis increases with time. This may be due to a heavy symptom burden (Almutary et al. 2013) and low QoL (Fukuhara et al. 2003) among haemodialysis patients.

Unsurprisingly, participants fear rejection, as it may result in a return to dialysis. Rejection episodes had been experienced by some participants and were cause for severe concern. Fear of rejection is thus a major drivers of regular IM intake among these patients. Similarly, a major driver of adherence was found to be prevention of long-term complications among patients treated with oral antidiabetic medication (Guénette et al. 2015).

Comparably high rates of non-adherence among renal transplant recipients may arise from the fact that these patients, unlike recipients of most other solid organs, have a life-saving procedure (dialysis) available in case of graft failure, and hence they may not be exposed to the same pressure for adherence (Rodin & Abbey 1992). Here, however, the opposite is observed, with past experience of dialysis motivating adherence.

Two participants differ from the majority regarding dialysis. Ms Müller argues that a return to dialysis would be bearable because it is familiar, although she also emphasises the advantages of having a transplant. In contrast, Ms Wagner moves beyond this to suggest an extent of regret in having undergone a transplant, feeling that she was not sufficiently informed prior to surgery and missing the social support of her peers in the dialysis centre. Social ties to peers and dialysis staff are important (Hughes et al. 2009; Morton et al. 2010) and may be strong (Chenitz et al. 2014), and should not be underestimated. At the same time, however, Ms Wagner is one of the few participants who claims that she has not missed a single tablet in the seven years since her transplant, suggesting a high extent of ambivalence. With the exception of Ms Wagner's stance, all other evidence supports the general preference for transplantation over dialysis.

### **7.3.2 Forgetting Medication**

In this study, the most common reason for non-adherence is forgetfulness. This finding is in accordance with other qualitative studies of kidney recipients (Gordon et al. 2007; Orr et al. 2007a; Gordon et al. 2009; Tong et al. 2011) and people with other chronic illnesses (Sabaté 2003; Guénette et al. 2015). Weng et al. (2013) also suggest a strong association between forgetfulness and breaks in routine. This is seen in the present study, as participants try to overcome forgetfulness by connecting their medication-taking to routine daily activities, such as having meals or watching TV. Importantly, while such strategies are effective, they fail if the daily routine is disrupted for any reason. Renal transplant recipients are aware of this danger, however, and tend to implement backup strategies, such as requesting reminders from family members or friends.



The reaction to occasionally missing doses differs not only between participants but also changes with time after transplantation. Shortly after transplantation, each instance of forgetting causes distress. This tends to decrease over time, presumably because most participants do not perceive any direct physical consequences, such as bodily symptoms or immediate rejection episodes. Research has indicated, however, that occasional missed doses or alteration of intake times may cause substantial damage to the transplanted graft (Takemoto et al. 2007). It is thus surprising that more studies of underlying reasons for forgetfulness have not been conducted.

Given the potential impact of forgetfulness, patients should be counselled to develop strategies to minimise it. Such counselling should not be limited to patients with newly transplanted kidneys, but must also be repeated over the longer term, as the absence of direct symptomatic consequences may lead patients to underestimate the importance of adherence.

### **7.3.3 Organising One's Life**

This research has found that renal transplant recipients may face organisational issues that challenge medication adherence. In contrast to other countries, such as the USA (Evans et al. 2010), the German healthcare system provides financial security for patients. Renal transplant recipients contribute, at most, comparatively low co-payments for their medical care, and nothing for their medication, and hence financial concerns are not generally a problem. Participants face other organisational challenges, however, related mainly to pharmacy opening times. Employed participants in particular report that these opening times do not match their working hours. Additionally, the need to organise and/or order medication in advance can prove problematic; these challenges similar to those faced by transplant recipients in other healthcare systems (Gordon et al. 2009). As one participant notes, having to organise oneself may also be perceived as an advantage that may contribute to personal growth; but this idea could not be followed in the literature.

The issue of generic medication after solid organ transplantation has been discussed both in Germany and internationally (Harrison et al. 2012; Lehner & Budde 2012; Johnston 2013). Rising financial pressure on healthcare systems leads to calls for generic medication; but, as IMs are “critical dose drugs” (Harrison et al. 2012, p. 657) with narrow therapeutic margins (Krämer et al. 2012; Johnston 2013), switching to generic types may introduce problems. The international guideline on the care of kidney transplant recipients (KDIGO 2009) therefore recommends that nephrologists be cautious in switching their patients' drugs to generic formulations. However, in Germany, pharmacists are legally required to dispense the least expensive formulation. Hence, participants must renew their prescription in order to get their accustomed drug, which can cause emotional distress and organisational issues and may also be associated with a decrease in attention during discussions if participants perceive the issue of generic drugs as unimportant.

### **7.3.4 Experiencing Quality of Life**

This research has found that despite ambivalence toward their kidney transplant and the occurrence of complications or rejections, renal transplant recipients report having a good QoL. This is in accordance with other research that has found kidney transplantation to be associated with improvements in QoL (Dew et al. 1997; Jofré et al. 1998; Fiebiger et al. 2004; Muehrer & Becker 2005; Habwe 2006; Ogutmen et al. 2006; Cukor et al. 2009). While participants do not explicitly describe a relationship between perceived QoL and medication-taking behaviour, their remarks on their current QoL compared to when they were on dialysis indicate that QoL is a major facilitator of medication adherence, a finding supported by other research (Rosenberger et al. 2005).

However, when regarding QoL among renal transplant recipients, one should be aware of its comparative nature. Studies often compare the transplant recipients' QoL with the QoL of dialysis patients, in which case it is favourable. However, comparison of post-transplant QoL with healthy control groups generates a different conclusion. Dew et al. (1997) suggest that post-transplant QoL may be partially comparable to that of healthy groups, but other studies (Whiting 2001; Nilsson et al. 2010) conclude that solid organ transplant recipients seldom reach the QoL of a perfectly healthy person.

### **7.3.5 Being Supported**

This study has shown that social support plays a major role in medication intake, with trust and care revealed as particularly important factors. If relationships are not trustful and caring without being paternalistic, they tend not to work, or at least are perceived as less important than relationships that do meet these criteria. In this context, the nature of the relationship matters less than how it is characterised.

Social support is provided by three categories of people: healthcare professionals (nurses, physicians, and transplant surgeons); partners, spouses, and other family members; and friends or acquaintances. These people can impact the medication-taking process differently. While some participants, such as Ms Schmitt and Ms Müller, perceive people as helpful, others may see any offer of support as overbearing.

These results are in accordance with two reviews of the association between social support and medication adherence in chronic illness (DiMatteo 2004; Scheurer et al. 2012), which indicate that social support may be emotional or practical. Emotional support includes the notion of 'being there' or provision of emotional care and nurturance. Practical support is any activity provided by others that facilitates medication-taking, such as assistance, reminders, or taking over organisational issues (DiMatteo 2004). Although both forms facilitate medication adherence, the impact of practical support may be higher than that of emotional support (DiMatteo 2004; Scheurer et al. 2012).

This study supports these conclusions. Participants value emotional support given by physicians, family members, or friends, but also stress the importance of practical help, such as giving reminders or getting drugs. Practical or emotional support is not only valued, but also missed if absent:

*It would be great if I then had a husband who really helped me more [...] sometimes prepares everything for me. I never get this [...] and I never got it, that anyone prepares things [medication] for me and cares and cares for me. Well, when I'm very, very ill, really ill, with a cold or a fever, for example. And when it's on a weekend and my husband is home, he fetches my [medication] box and brings it to me. He does that, not gladly, but then he does. But not with the emotion [...] he only does, because he must do. Not because of great love or care, let's say. (Ms Maier 2014, 45:46)*

In this study, social support is mostly perceived as helpful and important; there is a delicate balance to strike with each individual, as too much or too little support may be perceived as distressing or neglectful, respectively. This is supported by research (DiMatteo et al. 2012; Guénette et al. 2015) concluding that “social support may not be universally helpful; its value may depend at least partially on situational demands” (DiMatteo 2004, p. 212).

This is true in this study for healthcare professionals. The physician, in most cases the nephrologist undertaking the long-term follow-up, is acknowledged as instrumental in the medication-taking process. Despite home care, nurses rarely work outside hospitals in Germany, and thus the participants can only refer to their experiences with nurses in hospitals. In spite of this, both professions are valued as contributing to medication adherence. Participants particularly emphasise importance of long-term relationships and aspects of patient education for their relationships with healthcare professional.

As with most renal transplant recipients in Germany, participants are seen regularly by the nephrologist who treated them before transplantation, including dialysis. Visits at the transplant centre are usually bi-annual, and the nephrologist is the main contact. The physician and patient thus share a long history that is often characterised by a familiarity stemming from many years of collaboration.

Participants report three aspects to be of exceptional importance: being taken seriously, trusted, and feeling cared for. This is the case not only in well-functioning patient-provider relationships, but also in instances where these aspects are absent, as Mr Schröder stresses:

*It [the patient] is a person there [...] it's not a number. It's a person who has emotions, demands, appreciation [...] and all that. I haven't experienced that with many doctors. Rather the contrary. Also at the unis [university hospitals] [...] also there, I [faced] such behaviour ... I had to put up with this. (Mr Schröder 2014, 26:50)*

Although these three aspects of the healthcare-patient relationship are so closely interwoven that participants can hardly distinguish between one another, trust and care should be examined more closely. Trust is one of the most important aspects of the patient-healthcare relationship, particularly for chronic conditions (Thorne & Robinson 1988; Johns 1996; Bell & Duffy 2009). *Trust* is “the optimistic acceptance of a vulnerable situation, following careful assessment, in which the truster believes that the trustee has his best interests as paramount” (Bell & Duffy 2009, p. 50). Here, participants emphasise the necessity of talking openly with their physician and the possibility of immediate contact if needed.

This finding is in accordance with other research that has found the style of communication between patients and their healthcare provider to be crucial for medication adherence (Sabaté 2003; Tong et al. 2011; Pasma et al. 2015; Peláez et al. 2015). However, healthcare professionals should keep in mind that while an empathetic, person-centred communication style improves adherence, the opposite might also occur (Sabaté 2003; Safran et al. 1998).

Caring is also seen as the core of healthcare (McCance et al. 1997; Brilowski & Cecilia Wendler 2005), at least for the nursing profession. No concept analysis of caring in the medical profession could be found, but I hypothesise (and hope) that the attitude of many physician toward caring is similar to that of nurses. McCance et al. (1997) identified attributes critical for caring: “serious attention, concern, providing for and getting to know the patient” (p. 247). Ms Schmitt provides a comprehensive summary of what she, and others, expect of her providers:

*The most important thing is that I ... when I feel safe with a doctor and know he cares and even if something doesn't work as it should, he still is there for me. (Ms Schmitt, 16:40)*

The second major issue participants of this research emphasise with regard to support provided by healthcare professionals is transplant-related patient education. Patient education, in this context, comprises education on issues regarding self-management, including “medical and behavioural management, role management and emotional management” (Lorig & Holman 2003, p. 1). The transplant literature agrees that self-management, including medication-taking behaviour, is a crucial point following solid organ transplantation (Schäfer-Keller et al. 2009; Schmid-Mohler et al. 2014).

Participants are aware of needing to understand the effects of medication and consequently make decisions regarding their health behaviour. For example, participants know they often must make short-term decisions regarding medication-taking, such as when they miss a dose. In these cases, transplant-related patient education helps them to make decisions and avoid too frequent contact with their nephrologist. Most participants try to reserve emergency contact for true emergency situations.

The extent, content, and quality of transplant-related education varies greatly among participants. Their statements on this topic suggest that their education depends on several issues, primarily the transplant centre's policy and the commitment and workload of physicians and nurses. Different transplant centres seem to have different ideas of what they want their transplant recipients to know and how strictly they want patients to adhere to certain rules. Undoubtedly, IM requires some knowledge of features of medication, the necessity of adhering to intake times, possible interference with meals, and other concerns. However, this study suggests that strict adherence to all medication-related rules and regulations may interfere with living a nearly-normal life and thus may not facilitate medication adherence, as this memo illustrates:

*Daily life is to a large extent affected according to how strict different hospitals teach their patients. Although patients were not actively asked where their transplantation took place, participants frequently mentioned the hospital (of which only one was not university-based). Obviously, the hospitals have fundamentally different policies regarding hygiene, mealtimes, and advice on daily living.*

*According to how strictly hospitals teach their patients to follow advice, patients are more or less limited in their daily lives. Mr Becker, for example, did not see his grandchildren or any other visitor in his home in the first six months post-transplant!*

Some centres prioritise integration of medication-taking into patients' daily lives, rather than adapting the patients' lives around medication-taking. Such centres seem to apply patient-education strategies that aim to enable them to understand the basic rules of, and be responsible for, medication-taking. Other centres teach their patients strict rules regarding their medication, although this research suggests that this strategy may hinder rather than facilitate adherence.

One example of different strategies for patient education is provided by medication intake times. Many participants have been educated regarding intake times in very strict margins that even fall below evidence on clinically-relevant time windows. Also, some centres emphasise the coordination of mealtimes and medication intake, referring to the pharmacokinetics of IM that may be influenced by certain foods. While each approach can be understood as a protective measure, this study suggests that any complication of the regimen increases the chance of non-adherence. Also, participants are aware of relevant time windows and use these very carefully, and hence advice regarding medication intake times should be balanced between pragmatic allowances and strict rules that are more likely to fail. Interestingly, no publications on this hypothesis could be found.

A typical example of how advice may interfere and impact participants' daily lives is provided by Mr Becker, who was not allowed to see friends or even his grandchildren for the first six months post-transplant. This was clearly intended to minimise his risk of acquiring infections while IM levels were high, but left Mr Becker unhappy and is not supported by guidelines (KDIGO 2009; Kommission für Krankenhaushygiene und Infektionsprävention beim Robert Koch-Institut 2010).

While participants' experience with nurses is limited to inpatient hospital stays, in most transplant centres, nurses are responsible for patient education following transplantation. From the accounts of participants who recently underwent a transplant, it does not appear to matter which profession carries out the task of education, as long as the doctor or nurse acts in an emphatic, trustful, individualised, and caring manner. This is reflected in a memo I wrote after two participants reported how hard they found it to change physicians when their long-term nephrologist retired:

*Ms Wagner's remark is interesting. After the "loss" of her long-term physician, she experiences continuity in the doctor's receptionist. In this case, continuity seems to be one aspect of trust.*



This hypothesis is supported by research on other chronic conditions in healthcare systems outside Germany showing that patients may value care from nurses equally to that from physicians (Litaker et al. 2003; Health Quality Ontario 2013).

Some participants who recently stayed in hospital observe that nurses had high workloads and were stressed, which led to situations where care was not delivered as it should have been. Generally, participants are understanding about this high workload, but from a professional point of view, some of the reported events are unacceptable. As nurses provide the majority of patient education following transplantation, a high workload may lead to poor education and, in the worst case, to patients being discharged without adequate medication-related knowledge. Participants' remarks on the high workload in hospitals mirror the current situation in German hospitals, where the number of nurses has been cut in recent years and, at the same time, patients' length of stay has significantly decreased (Bartholomeyczik 2007), leaving fewer nurses to care for more patients. In fact, German hospitals have the highest patient-to-nurse ratio across Europe, and German nurses suffer from a high degree of burnout (Aiken et al. 2012). This situation is well-known to nurses and nurse managers, but I find it alarming that patients also notice which tasks are not carried out.

In addition to healthcare professionals, participants are supported by spouses or partners, family members, friends, and acquaintances<sup>21</sup>. Although the nature of this support differs from that provided by healthcare professionals, support provided by partners and family members does not differ significantly from that provided by friends or acquaintances. Crucially, for participants in this study, support by partners, family members, friends, or acquaintances is not automatically regarded as supportive, as became clear at an early stage:

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<sup>21</sup> In German culture, as also reflected in colloquial speech, friends and acquaintances are carefully differentiated: while friends are emotionally very close, acquaintances are often people sharing the same interests but usually not as intimate as friends. People commonly tend to have few close friends, but many acquaintances.

*Other people can have considerably different influences – from positive via neutral to negative. Important is the extent of reminding: too much is as bad as too little.*

Importantly, partners, family members, friends or acquaintances may also make the patient feel that he or she is under surveillance, or evoke shame, embarrassment, or guilt about the chronic condition. This finding contrasts with research from other cultural backgrounds, which has stressed the positive impact of social support on medication adherence (Denhaerynck et al. 2005; Gordon et al. 2009; Tong et al. 2011; Scholz et al. 2012).

However, most participants do emphasise the positive impact of others on their medication-taking behaviour, both functional and emotional. Most participants associate external support with being cared for in a similar way to healthcare professionals. However, support provided by close relations exceeds that provided by healthcare professionals. The participants value being taken seriously and accepted even in instances of forgetfulness. The importance of social support is also stressed by the contrary case of Ms Maier, who perceives a lack of support from her husband and other family members. This finding is in line with previous research emphasising the importance of social support for medication adherence (Rosenberger et al. 2005; Gordon et al. 2009; Tong et al. 2011).

From the participants' point of view, the exact nature of the relationship does not play a great role; it does not matter whether the support comes from a spouse or friends. This makes sense as social support is not limited to family members or spouses, but usually includes other persons with whom one feels closely connected (Taylor 2011; Wills & Ainette 2012). In contrast to past research conceptualising social support as being married or living as a couple (De Geest et al. 1995; Bunzel & Laederach-Hofmann 2000; Butler et al. 2004b; Lin et al. 2011; Lennerling & Forsberg 2012), the study presented here suggests that social support can be provided by a variety of people. Moreover, the mere presence of a partner does not necessarily imply a supportive environment, a finding supported by Scheurer et al. (2012).

### 7.3.6 Striving for Routine

The ability to follow routine has emerged as one of the major facilitators of medication adherence. All but one participant emphasises the importance of routines for medication intake, and most assert that they would advise newly transplanted patients to establish a routine. Thus, despite following restrictive regimens, patients are able to manage their medication-taking behaviour. This may be done by either adapting their daily lives to the medication schedules, integrating their medication-taking behaviour into their routines, or a combination of these strategies.

The choice of strategy depends on the patient education that participants received in their transplant centre. Although not asked where their transplantation took place, most participants mention the location of their transplant centre. The data suggest that participants largely did not have great support regarding the establishment of individual routines for medication-taking.

Evidence from other fields suggests that self-management in chronic conditions, of which medication-taking is a crucial part for renal transplant recipients (Schäfer-Keller et al. 2009), relies on five core competencies: problem-solving, decision-making, the utilisation of resources, establishment of a relationship with a healthcare provider, and action-taking (Centre for the Advancement of Health 2002). However, to achieve these competencies, patients do not need to be taught strict rules or solutions, but rather skills that enable them to manage their problems (Lorig & Holman 2003b). This must be done in a very individualised manner so that patients can find their own solutions (Lorig & Holman 2003b; Schäfer-Keller et al. 2009).

Despite the assumed lack of individualised support provided by their transplant centres, all participants have established their own routines and have internalised medication-taking as part of their lives. They use analogies to common activities, such as taking the key and purse when leaving the house (Ms Schmitt), driving a car (Mr Richter), getting up in the morning (Ms Koch), or having breakfast and dinner (Ms Schulz), to convey this.

Internalisation has been widely discussed in models of motivation and behaviour change. Kelman (1958) proposed a theoretical model assuming internalisation to be the last step in behaviour change, preceded by compliance and identification. Compliance, in this regard, occurs when people act in order to get favourable reaction or to avoid punishment, and identification refers to action that is based on a relationship with an influential person (West & Feldman 2013). Both behaviour patterns are likely to cease in the absence of the person of influence. Internalisation, in contrast, occurs when a certain behaviour is intrinsically rewarded (Kelman 1958).

Similarly, in a study on medication adherence in HIV-positive individuals (Laws et al. 2012), the authors concluded that adherence was only possible when patients internalised the need for medication-taking by accepting themselves as ill and developing a will to live. Laws et al. (2012) related their findings to identity theory, arguing that adherence to medication or other health-related behaviour must be accompanied by the transformation of the individual, which leads to the acceptance of the self as suffering from a chronic condition. Similar conclusions have been suggested by research in other fields (Charmaz 1991; Baumgartner 2007; Aujoulat et al. 2008).

Internalisation and the acceptance of being chronically ill may therefore facilitate medication adherence through incorporation of medication-taking into the daily routines of renal transplant recipients. This integration, however, is vulnerable to forgetfulness, as discussed previously; and in order to overcome these instances, participants adapt their schedules to their needs, showing a high extent of flexibility. Research on patients with other chronic conditions has demonstrated that flexibility enables participants to bridge the gap between reluctance to take drugs and their wish to fulfil social roles (Townsend et al. 2003). From a medical perspective, this flexibility may prove problematic if, for example, intake times are too variable, it also avoids complete missing of medication. Therefore, transplant centres, and later healthcare professionals concerned with follow-up, should encourage patients to discuss individual strategies to identify potentially problematic behaviour at an early stage.

### 7.3.7. Struggling with Medication

Participants report a surprisingly high number of difficulties related to medication, though not medication-taking itself. These can be grouped as features of the medication, medication-related symptoms, or side effects. Features include drug names, packaging, shape, size, colour, haptics, taste, and smell. Dispensation of German medication in blister packs, rather than bottles, may exacerbate some issues with adherence, as unit-dose packaging is lacking and preparing pill boxes may cause confusion between different drugs with similar size or shapes. Moreover, the handling of drugs may be difficult, given that tremors of the hands are a common side effect of IM (Rote Liste® Service GmbH 2014).

As systematic reviews suggest, some of these difficulties could be overcome by providing unit-of-use packets, an intervention that may also enhance medication adherence (Connor et al. 2004; Mahtani KR et al. 2011; Boeni et al. 2014). Alternatively, the conversion from twice-daily to once-daily formulation of certain medication could improve adherence (Kuypers et al. 2013). However, a patient who forgot a pill would then be without the immunosuppressive agent for 24 hours rather than twelve. Moreover, findings on potential simplification of immunosuppressant medication neglect the fact that IM regimens, at least in Germany, typically comprise a triple therapy, of which some drugs are not available in a once-daily formulation. Renal transplant recipients also typically take tablets for co-morbidities or side effects, such that even if the IM could be reduced to a once-daily formula, patients would still need take other tablets at other times throughout the day.

This research confirms other evidence that the evening dose may be more problematic than the morning dose (Kuypers et al. 2013), particularly in instances when activities outside the normal routine are carried out. In the mornings, participants, especially those who are employed, have routines that are rarely broken during the week. In contrast, the evenings are somewhat more flexibly handled and filled with social commitments, such as visiting friends and families, going out, or attending club meetings.

A second, surprising, issue is the breadth and extent of side effects reported by participants in this study. This is a clear example of how ambivalently renal transplant recipients regard their condition and related symptoms. Although most participants describe their state of health as comparably good, especially relative to the pre-transplant state, and do not experience any problems with medication-taking, most participants (N = 12) also experience at least one side effect, with only five reporting no side effects. Nearly all reported side effects could be ascribed to IM (Table 5).

Both the number and severity of the side effects vary, from one to four and from mild to extremely distressing, respectively. This finding is in accordance with other research that found high frequencies of side effects and distress among solid organ transplant recipients (Drent et al. 2008; Kugler et al. 2009; Lanuza et al. 2012). While the study presented here cannot directly answer questions regarding the association between side effects and medication adherence, nevertheless, as with previous qualitative research (Russell et al. 2003; Orr et al. 2007a; Gordon et al. 2009; Tong et al. 2011), this study has shown that side effects remain problematic for kidney transplant recipients.

## **7.4. Summary of Chapter Seven**

In this chapter I have discussed the findings of this work in relation to the literature in the fields of renal transplantation and other chronic conditions. Although many findings have been observed among renal transplant recipients in other countries, this study of German kidney transplant recipients has also raised previously unaddressed issues.

This study has given rise to the theory of medication-taking symbolising life with a chronic condition. Participants explicitly or implicitly confirmed other research that kidney transplantation can be regarded a chronic condition. The study also shows a deep internalisation of medication-taking, but highlights a variety of tensions associated with having received a kidney transplant. This theory explains the processes facilitating or hindering medication adherence in kidney transplant recipients. As a substantive theory, it goes beyond a description of the participants' experiences to offer an explanation for the processes resulting in medication-taking behaviour in this group of German kidney transplant recipients.

Chapter Eight will make recommendations for how the theory of medication-taking as a symbol of living with a chronic illness can be applied in clinical practice. It will also discuss the strengths and weaknesses of this research and offer some suggestions on areas for further research.

## CHAPTER EIGHT: RECOMMENDATIONS AND CONCLUSION

This final chapter will start with a summary of how this research contributes to original knowledge in the field of medication adherence in renal transplant recipients. Following this, I will offer recommendations for applying the theory to clinical practice. I will further discuss strengths and weaknesses of this study and recommend areas for further research. However, before progressing to the final part of this thesis, I will recap the theory here, by illustrating how I moved from codes to sub-categories to the theory.

The first step of data analysis consisted of open coding where the transcripts were read and analysed line-by-line. This process derived codes from the data, which were supported by previous research in this field, particularly those that formed an integral part of the sub-category *experiencing facilitators and challenges*, discussed in Chapter Seven. Attitudes and beliefs as reported by the participants, as well as the experience of dialysis, could be easily followed in this research. However, as the dataset grew, it began to seem richer than those previously described in this field.



This perception was confirmed by the process of axial coding, whereby, in clarifying the sub-categories, some issues became prevalent that were not made explicit by participants but were inherent in the data. These included ambivalence, or tension, as well as the high extent of internalisation of medication-taking by participants. I further found it striking that participants found it difficult to differentiate their need to take daily medication from other condition-related behaviours or limitations they experienced. From the insights gained from open and axial coding emerged two categories: *reflecting on one's own position* and *experiencing facilitators and challenges*. Once these two categories were crystallised from the data, it became clear that the core category, the common denominator, was that medication-taking was regarded as a symbol of living with a chronic illness. This awareness is the spine of the theory explaining the processes leading to medication-adherence or non-adherence in this cohort of German renal transplant recipients, and integrates all meanings and implications from the categories, sub-categories, and quotes.

## **8.1 Original Contribution to Knowledge**

This research has contributed to original knowledge in the field of renal transplantation in two main aspects. First, this research is the first to explore the processes facilitating or impeding medication adherence after kidney transplantation from the perspectives of German renal transplant recipients. Although some research has been conducted on this topic elsewhere, very little research has been conducted in German-speaking countries (especially Austria and Switzerland) and no research has previously been done in Germany. Although this research has confirmed many findings from other countries and healthcare systems, it has also highlighted some issues that have not been reported in renal transplant recipients before. For example, these include the extent of ambivalence that has been reported in other chronically ill patients before but not in kidney transplant recipients.

The second contribution to knowledge that this research clearly adds is the theory of medication-taking being symbolic for living with a chronic condition. Although, as discussed previously, there are hints from other chronic conditions that medication-taking may be deeply integrated into the lives of those concerned, no research has yet described it as unambiguously as a symbol of living with a chronic condition as this research has done. By using the participants' voices in establishing the theory, this research has added considerably to the knowledge base on renal transplant recipients.

## **8.2 Recommendations for Clinical Practice and Education**

Recommendations for clinical practice and further research have been made in Chapter Seven where appropriate. Here, I will outline how the developed theory can be applied in practice settings and nurse education. Possible areas for further research will be recommended subsequently.

This research has revealed four major aspects of medication adherence following kidney transplantation that healthcare professionals should keep in mind when caring for kidney transplant recipients in Germany. The first is the necessity of individualised care, the second is the importance of patient education, the third is the choice of terms for patients not taking medication as prescribed, and the fourth is the importance of collaboration among healthcare professionals, patients, and families.

Participants in this study have clearly and repeatedly demanded to be taken seriously and to be treated as individuals. Ambivalence and support needs of the participants continue even after years of post-transplant experience. This research has also demonstrated that there are no universal solutions regarding medication adherence. Approaches that may work for one renal transplant recipient may not work, and may even impede the intended outcome, for others. Therefore, I regard it as necessary to approach each kidney transplant recipient on a basis that allows for development of individual strategies. These strategies, however, must be reviewed, and if necessary adapted, if the situation of the transplant recipient changes.

This individualised care in relation to medication adherence should include discussion about intake times and the development of personal routines, and furthermore should engage with in-depth issues, such as the individual's belief system or attitudes toward medication-taking. This is especially important given the significance participants ascribe to medication-taking in relation to their chronic condition. Crucially, these topics must be taken up at regular intervals to avoid missing any development the kidney transplant recipient may have experienced. This research has also demonstrated the need for continuous, long-term support, and emphasises the necessity of counselling and medication-related patient education even for patients who received their transplant years earlier and are in a stable phase. For this, trust, care, and continuity are vital.

With regard to the challenges faced by renal transplant recipients, the need for continuing education and information on health-related topics is clear in this study. This transplant-related patient education should be provided throughout the transplant process, from the point of entry onto the waitlist and for as long as the transplant continues to function. This research has revealed the transformation a kidney transplant recipient experiences, but has also outlined the challenges related to medication adherence that may especially not emerge until some years after transplantation. Also, this patient education should not be limited to medication-related topics. The issue of medication-taking is so deeply integrated into the perception of being chronically ill that renal transplant recipients, at least those involved in this research, cannot differentiate between medication-taking and other aspects of chronic illness management.

Patient education should not be limited to the time after transplantation, but is needed as soon as waitlisting is discussed. At this point, in addition to medical information on technical and (patho)physiological aspects of kidney transplantation, such as the immune system, potential renal transplant recipients should also be informed about the consequences and possible risks of kidney transplantation. In particular, kidney transplant candidates should be educated about forthcoming everyday challenges they may face after receiving a renal transplant. Due to long waitlist times and the fact that in Germany, dialysis can take place far from the transplant centre, it may not be feasible to involve all kidney transplant candidates in such discussions. However, this obstacle can be solved by providing rigorously developed information material that paints a realistic picture of life after transplantation.

The third issue emphasised by this research is the need for German healthcare professionals to reconsider their terminology for patients (potentially) not taking their medication as prescribed. Whilst the German equivalent of adherence, *Adhärenz*, has not yet found its way into colloquial medical speech, my clinical experience and engagement with the literature have led me to the view that *incompliance* (as well as *compliance* in English) is a pejorative descriptor that neglects patients' situation as persons affected by a chronic condition. This research has clearly revealed that despite a high degree of non-adherence, participants are not careless, irresponsible, vicious (as non-adherers were judged one hundred years ago (Lerner 1997)), or too stupid to take their medication on a regular basis – they are simply human. Using *incompliance* not only depreciates them but also neglects that a transplanted kidney requires an enormous extent of self-management, of which medication-taking is one part, and does not acknowledge the complexity of chronic illness management. Consequently, my recommendation is to teach nurses and physicians to listen to their patients rather than label them.

Finally, this research suggests that healthcare professionals should rethink their modes of action, from working in parallel to working collaboratively and incorporating all parties involved: patients, families, nurses, physicians, and pharmacists. Participants do not mind which professional they see, as long as the person displays an empathetic and professional manner. Any conflicting information adds to patients' uncertainty and impedes their efforts to find an individual way to cope with their situation; therefore, healthcare professionals should concentrate their work on their patients, not on potential professional boundaries. In this team approach, pharmacists may play an important role, as research on medication adherence demonstrates (Chisholm-Burns et al. 2008b; Joost et al. 2014).

Not only do the findings of this research need to be implemented into nursing practice, they must also be incorporated into the education of nurses, especially in the field of kidney transplantation. This will hopefully positively impact the care of renal transplant recipients. Although the German transplant nursing course already has an emphasis on patient education (Rebafka 2013), the curriculum needs to be revisited regarding two topics. First, greater attention must be paid to the need for all activities related to patient education on medication adherence to be developed allowing the broadest possible extent of individualisation. Second, this goes along with the need to incorporate transplant recipients' experiences, as found in this research, as an integral part, not only of nurse and/or patient education, but also crucially as the starting point for any nursing intervention related to medication adherence.

### **8.3 Strengths and Weaknesses**

The main strength of this work is that it offers a first explanation of German renal transplant recipients' point of view concerning medication adherence, a previously unaddressed topic. Although this work cannot be generalised, many of its findings are supported by prior research in other countries; therefore, I hypothesise that the new insights into medication adherence, and the theory derived from this data, may indeed apply to renal transplant recipients from different backgrounds or even recipients of other solid organs.

Another strength of this work is its application of GT, as this approach moved beyond pure description of the participants' point of view and allowed me to generate a theory explaining the deep impact of medication-taking on renal transplant recipients. GT also enabled me to address issues beyond a reductive understanding of medication-taking and illustrate the tensions, ambivalences, and ambiguities connected with being a kidney transplant recipient. This work thus contributes to a general understanding of the impact of medication-taking, as symbolic of living with a chronic condition, on the patient. This insight may be valuable to researchers and healthcare professionals from other countries and/or dealing with other populations.

However, this research also has weaknesses. For example, although I aimed to ensure the rigour of this research, as outlined in Chapter Five, I cannot exclude the possibility of having favoured previous hypotheses and dismissed new ones. I found discussions with my colleagues, who read random interviews and commented on them, valuable, as they helped me to stay focused while being open to new things. I also found it difficult to remain a researcher and not fall into my familiar role as a nurse and educator. This occurred especially when participants' beliefs regarding their medication or condition were incorrect and I felt the urge to educate them.

Presentation of this work in English, although the interviews were conducted in German, raises additional difficulties. As German is my native language and that of most participants, there were no major language barriers in interpreting the participants' information. However, the translations of participants' quotes may not fully capture what they wanted to express.

Lastly, I did not utilise a second member check after the main findings were identified, which may have affected the reliability of the research.

## **8.4 Areas for Future Research**

This study has raised a number of questions that should be examined in further research. To my knowledge, this is the first research on German renal transplant recipients' perspectives on medication adherence. Some of its findings could be confirmed by research from other countries, but for verification, it should be replicated with renal transplant recipients in other regions of Germany.

Also, being qualitative in nature, this research could not establish any causal relationships between its findings and medication adherence. In order to draw such conclusions, other research approaches are needed, such as quantitative measurement in much larger samples. For example, the association between perceived QoL and adherence has not yet been widely studied and may be worth investigation using quantitative methods.

This research suggests that pragmatic, individualised patient education that empowers patients may be more beneficial for medication adherence than giving strict advice. However, no existing research could be found on this hypothesis. It should therefore be tested using a comparative quantitative design that compares medication adherence in patients with care as usual and patients educated as described above.

ESRD is commonly associated with a chronic underlying disease, such as diabetes or hypertension, and a variety of co-morbidities, that must be treated even after a kidney transplant, and thus it is surprising that little research has examined the relationship between these co-morbidities and medication adherence post-transplant. Of particular interest is the association between adherence to treatment of co-morbidities and adherence to IM.

The findings of this study suggest that the depth of a relationship between patient and healthcare professional was considerably more important than which profession the healthcare professional belonged to. A feeling of being cared for and having trust in a healthcare professional was vital, not whether the healthcare professional was a physician or a nurse. This is especially interesting as nurses are uncommon outside of hospitals in Germany. International research, however, shows that care provided by advanced practice nurses in some fields may be equally effective and significantly more cost-effective (Fulton & Baldwin 2004; Bauer 2010; Newhouse et al. 2011) than care provided by physicians, as is the case in Germany. It should therefore be considered whether some aspects of post-transplant follow-up can be carried out in Germany by advanced practice nurses with transplant-related expertise rather than by nephrologists.

A larger sample of participants should be examined using quantitative methods to determine whether reminder strategies promote or interfere with adherence. Additionally, healthcare professionals should involve their patients in finding an individually suitable way to manage their medication.



This research has raised several issues related to tensions or ambivalence that should be examined in further research. For example, participants reported no problems with medication-taking, but most also reported occasional non-adherence. This seeming contradiction is worth examining to facilitate a better understanding of what patients (or healthcare professionals) talk about. Another issue is varying perceptions of social support as positive or negative. A deeper insight into kidney transplant recipients' perspectives may help families and friends, and healthcare professionals, find a balance. Finally, participants' ambivalence toward their medication, stemming from the fact that IM protects a transplanted kidney but can eventually destroy it, should be explored.

## 8.5 Conclusion

This research is the first to examine factors involved in medication adherence for German renal transplant recipients. The main finding is encapsulated in the theory that *medication-taking is a symbol of living with a chronic condition*. All subsequent findings from the categories *reflecting on one's own position* and *experiencing facilitators and challenges* were interwoven with this main outcome. This theory can be instrumental in explaining medication adherence or non-adherence among German kidney transplant recipients, and has not previously been described in the literature. In suggesting that medication-taking is deeply internalised and interwoven with other transplant-related behaviours and challenges, and therefore subject to tensions and ambivalences, this study stresses the need for patients to develop personal strategies that allow them to cope with these ambiguities.

There are two lessons I will take from this study as crucial for my future clinical practice. First, people with transplanted kidneys still have a chronic condition, even if they no longer experience it on a day-to-day basis. Their condition shares some commonalities with other chronic conditions, but also includes unique challenges, one of which is that a transplant is not a cure for ESRD. I am deeply indebted to the participants in this study for teaching me that being chronically ill and at the same time perfectly healthy are not as disparate as I thought despite having been involved more than ten years in the care of chronically ill patients.

Second, there is no universally optimal way of doing things after kidney transplantation, including taking medication. In fact, there are so many different approaches that I now believe every renal transplant recipient should be supported in negotiating medication-taking with a healthcare professional. Healthcare professionals in turn should enable our patients to manage their own health, which includes supporting them in finding their individual strategy for facing the challenges their chronic condition holds in store for them.

## **8.6 Summary of Chapter Eight**

This chapter has summarised the original contributions to knowledge stemming from this research. Following that, it provided recommendations for how the theory of medication-taking as a symbol for living with a chronic illness can be applied in practical settings. These include the application of individualised care and patient education, as well as a shift in terminology among healthcare professionals to convey a willingness to work with kidney transplant recipients as individuals. I also recommend strengthening teamwork in order to provide the patient with the best possible care. The strengths and limitations of this work have been addressed, and further research recommended verify the findings from this study in larger samples and using quantitative methods to enable generalisation.

A final conclusion is that renal transplantation indeed is a chronic condition in the setting of this study, and that strategies for coping are highly individual.

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## APPENDICES

### Appendix 1: Search Strategy

Medline via OvidSP		
Search #	Query	Number of hits
1	exp Kidney Transplantation/	13842
2	kidney transplant.mp.	1093
3	adherence.mp	7472
4	exp Patient Compliance/	7043
5	compliance.mp.	17419
6	concordance.mp.	2843
7	1 or 2	13973
8	3 or 4 or 5 or 6	27161
9	7 and 8	109

PsychInfo via OvidSP		
Search #	Query	Number of hits
1	exp Kidney Transplantation/	0
2	kidney transplant.mp.	233
3	adherence.mp	18152
4	exp Patient Compliance/	0
5	compliance.mp.	27033
6	concordance.mp.	4772
7	1 or 2	233
8	3 or 4 or 5 or 6	43328
9	7 and 8	25

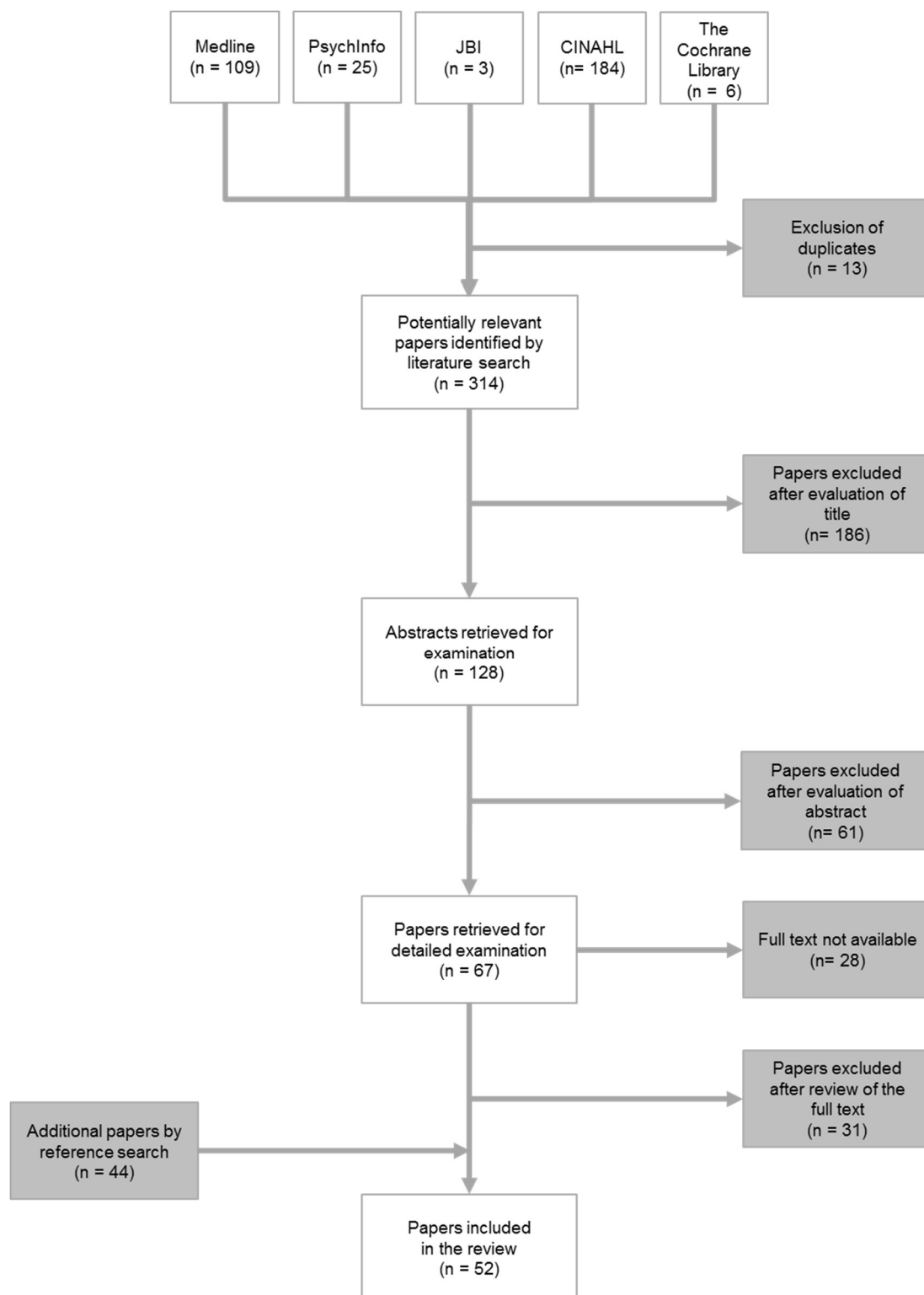
<b>The Joanna Briggs Institute Database via Ovid SP</b>		
<b>Search #</b>	<b>Query</b>	<b>Number of hits</b>
1	exp Kidney Transplantation/	4
2	kidney transplant.mp.	8
3	adherence.mp	425
4	exp Patient Compliance/	5
5	compliance.mp.	503
6	concordance.mp.	53
7	1 or 2	8
8	3 or 4 or 5 or 6	773
9	7 and 8	3

<b>CINAHL via EBSCO</b>		
<b>Search #</b>	<b>Query</b>	<b>Number of hits</b>
1	(MM "Kidney Transplantation") OR (MM "Pancreas-Kidney Transplantation")	4890
2	kidney transplantation	6960
3	(MM "Patient Compliance")	9154
4	adherence	24661
5	compliance	51145
6	concordance	3473
7	S1 or S2	6960
8	S3 or S4 or S5 or S6	68181
9	S7 and S8	184

<b>The Cochrane Library</b>		
<b>Search #</b>	<b>Query</b>	<b>Number of hits</b>
1	MeSH descriptor: [Kidney Transplantation] explode all trees	3299
2	MeSH descriptor: [Medication Adherence] explode all trees	993
3	#1 and #2	6



## Appendix 2: Selection of Literature



### Appendix 3: Literature Included in the Review

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Achille et al. (2006)	The degree to which patients follow medical recommendations.	<ul style="list-style-type: none"> <li>To identify negative impact of general stress, transplant-related stress and psychological distress on adherence</li> <li>To examine the hypothesized positive impact of feelings of indebtedness and guilt on adherence</li> </ul>	Primary research	Quantitative research design (cross-sectional study)
Bunzel & Laederach-Hofmann (2000)	The extent to which the patient's behavior coincides with the clinical prescriptions.	Not provided	Literature review	Research design not specified.
Butler et al. (2004a)	Subjects missing at least 20% of days of medication were defined as nonadherent according to missed medication, and an SD of interdose intervals of at least 6 hr was used to indicate erratic dosing.	<ul style="list-style-type: none"> <li>To assess the frequency of nonadherence</li> <li>To identify the best method for clinical practice by assessing its sensitivity and specificity compared with electronic monitoring.</li> </ul>	Primary research	Quantitative research design (cross-sectional study)
Butler et al. (2004b)	Non-adherence: missing at least 20% of days medication.	Not clearly outlined	Primary research	Quantitative research design (cross-sectional study)
Chisholm et al. (2007)	Not provided	To examine the impact of certain renal transplant recipients' characteristics on immunosuppressive medication adherence	Primary research	Quantitative research design (retrospective cohort analysis)
Chisholm et al. (2005)	The extent to which a person's behavior conforms to medical or health advice.	<ul style="list-style-type: none"> <li>To determine the prevalence of IST nonadherence in a statewide sample of Georgia renal transplant recipients</li> <li>To assess relationships between self-reported IST adherence and patient sex, age, kidney donor type (deceased [cadaveric] or living), income, marital status, race or ethnicity, time since transplantation, rejection episode, serum creatinine concentrations, adherence rate according to immunosuppressant refill records, and serum immunosuppressant concentrations</li> </ul>	Primary research	Quantitative research design (cross-sectional study)

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Chisholm-Burns et al. (2008)	Adherence rate = $1 - \left( \frac{\text{days between refills} - \text{total days supply}}{\text{days between refills}} \right) \times 100\%$	<ul style="list-style-type: none"> <li>To examine relationships between sex, race, age, time posttransplant, and immunosuppressant therapy nonadherence</li> <li>To determine more definitive age ranges (among adult recipients) and posttransplant time periods during which recipients are at increased risk for nonadherence.</li> </ul>	Primary research	Quantitative research design (cross-sectional study)
Chisholm-Burns et al. (2010)	Adherence rate = $1 - \left( \frac{\text{days between refills} - \text{total days supply}}{\text{days between refills}} \right) \times 100\%$	To assess the relationship between social support and immunosuppressant therapy adherence among adult renal transplant recipients.	Primary research	Quantitative research design (cross-sectional study)
Cukor et al. (2008)	Not provided	To determine whether depressive affect plays a role in nonadherence in inner-city kidney transplant patients.	Primary research	Quantitative research design (cross-sectional study)
Cukor et al. (2009)	Not provided	To expand our understanding of this cohort [from (Cukor et al. 2008)] by comparing it with a broadly similar cohort of hemodialyzed patients.	Primary research	Quantitative research design (cross-sectional study)
Da Silveira Maissiat et al. (2013)	Not provided	To verify the adherence to immunosuppressive treatment on the part of post-renal transplant patients	Primary research	Quantitative research design (descriptive-explorative study)
De Geest et al. (1995)	Noncomplicance: patients admitted [...] to having skipped immunosuppressive medication on a regular basis during the last 12 month (i.e. having missed several doses a month or taking "drug holidays".	To investigate the incidence, determinants and consequences of subclinical noncompliance with immunosuppressive therapy among renal transplant recipients.	Primary research	Quantitative research design (descriptive cross-sectional study)
De Geest et al. (2014)	Not provided	<ul style="list-style-type: none"> <li>To prospectively describe the evolution of non-adherence from pretransplant until 3 years post-transplant in liver, renal, lung and heart transplant recipients</li> <li>To determine whether pre-transplant non-adherence is predictive of post-transplant non-adherence.</li> </ul>	Primary research	Quantitative research design (prospective cohort study)

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Denhaerynck et al. (2005)	The extent to which a person's behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with the agreed recommendations from a health care provider.	To summarize the existing evidence on nonadherence with the immunosuppressive therapy in adult renal transplant recipients, more specifically to summarize and discuss: <ul style="list-style-type: none"> <li>• measurement methods for assessing nonadherence,</li> <li>• prevalence,</li> <li>• clinical as well as economical consequences</li> <li>• determinants of nonadherence.</li> </ul>	Literature review	Research design not specified
Denhaerynck et al. (2007)	<ul style="list-style-type: none"> <li>• Drug holidays: Number of drug holidays per 100 monitored days.</li> <li>• Taking adherence= <math>\frac{\text{number of taken doses}}{\text{number of prescribed doses}} \times 100</math></li> <li>• Dosing adherence= <math>\frac{\text{number of days with correct dosing}}{\text{number of days monitored}} \times 100</math></li> <li>• Timing adherence= <math>\frac{\text{number of correct inter-dose intervals}}{\text{number of openings}} \times 100</math></li> </ul>	To comprehensively assess and test non-adherence risk factors in kidney transplantation patients by using state-of-the-art measures of non-adherence.	Primary research	Quantitative research design (prospective cohort study)
Evans et al. (2010)	Non-adherence: Patients not taking their maintenance immunosuppressive drugs as prescribed because of difficulties associated with their ability to pay for their medications. Not provided	To establish the prevalence and consequences of cost-related immunosuppressive medication nonadherence.	Primary research	Quantitative research design (descriptive study)
Gelb et al. (2010)	Not provided	<ul style="list-style-type: none"> <li>• To assess the role of both traditional and everyday measures of cognitive abilities as predictors of medication adherence and employment status.</li> <li>• To assess the relative ability of these two approaches to predict medication adherence and ability to return to work following kidney transplantation.</li> <li>• To determine whether cognitive measures have additive value beyond that of noncognitive predictors of the two functional outcomes.</li> </ul>	Primary research	Quantitative research design (cross-sectional study)

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Germani et al. (2011)	The extent to which a person's behavior corresponds with the agreed recommendations from a health care provider.	To assess nonadherent behaviors to immunosuppressive therapy, to correct lifestyle, and to general medical prescriptions among a sample of organ transplant patients.	Primary research	Quantitative research design (prospective cohort study)
Gheith et al. (2008)	Not provided	To identify compliance of kidney transplant patients to the recommended lifestyle behaviours.	Primary research	Quantitative research design (cross-sectional study)
Goetzmann et al. (2006)	Not provided	<ul style="list-style-type: none"> <li>• Die Konstruktion und Testung eines praktischen und leicht einsetzbaren Screeninginstruments, das die subjektiven Erfahrungen und Überzeugungen bezüglich einer immunsuppressiven Medikation erfassen sollte.</li> <li>• Die Untersuchung von Zusammenhängen zwischen diesem Screeninginstrument und psychosozialen Variablen.</li> <li>• Zusammenhang zwischen dem Screeninginstrument und der fremd eingeschätzten Compliance.</li> </ul>	Primary research	Quantitative research design (prospective cohort study)
Gordon et al. (2009)	Not provided	<ul style="list-style-type: none"> <li>• New kidney transplant recipients' rates of self-reported adherence, their levels of self-efficacy for medication-taking, and barriers to and strategies for remembering medication-taking.</li> <li>• Examine the social (interpersonal) and structural (e.g., access to care, organization of work time) contextual factors that shape how kidney transplant recipients make taking medications fit into their daily routines using both quantitative and qualitative methods.</li> </ul>	Primary research	Mixed methods research design (cross-sectional study/content analysis)

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Gordon et al. (2007)	Not provided	To examine medication adherence over time and the factors associated with adherence/nonadherence	Primary research	Mixed methods research design (prospective cohort study/thematic analysis)
Gremigni et al. (2007)	The extent to which patients take medication as prescribed by their health care providers.	To identify the impact of coping, potential barriers related to medication regimen and objective factors, such as sociodemographic characteristics and time since transplantation on non-adherence in long-term renal post-transplant. <ul style="list-style-type: none"> <li>To determine the frequency of intentional and unintentional non-adherence to medication in kidney transplant patients</li> <li>To explore the associations between self-report adherence and serum immunosuppressive levels</li> <li>To determine factors that are associated with self-report and biochemical markers of non-adherence.</li> </ul>	Primary research	Quantitative research design (cross-sectional study)
Griva et al. (2012)	Not provided	<ul style="list-style-type: none"> <li>What is the extent of noncompliance with immunosuppressive and antihypertensive drugs after renal transplantation?</li> <li>Can the level of noncompliance be predicted from demographic or clinical variables?</li> <li>Does noncompliance increase the incidence of acute rejections?</li> <li>Does the occurrence of an acute rejection alter the degree of compliance?</li> </ul>	Primary research	Quantitative research design (prospective cohort study)
Hilbrands et al. (1995)	Compliance rate = $\frac{\text{number of tablets taken} \times 100\%}{\text{number of tablets prescribed}}$	To investigate psychosocial and social variables that may affect compliance behaviors among kidney transplant recipients.	Primary research	Quantitative research design (retrospective study)
Kiley et al. (1993)	Compliance: Ciclosporine level > 30 ng/ml			

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Kuypers et al. (2013)	Not provided	To compare medication adherence between tacrolimus once-daily and twice-daily regimens	Primary research	Quantitative research design (randomized controlled trial)
Lennerling & Forsberg (2012)	The extent to which a person's medication, behaviour – taking following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.	To explore non-adherence among Swedish kidney transplant recipients.	Primary research	Quantitative research design (cross-sectional study)
Lin et al. (2011)	Not provided	To examine self-reported health promotion behaviours and identify the risk factors predicting the non-adherence to post-transplant recommendations within 1–5 years post kidney transplant.	Primary research	Quantitative research design (cross-sectional study)
Massey et al. (2013)	Not provided	To prospectively investigate the relationships between goal cognitions, illness representations, and treatment beliefs on the one hand and self-reported adherence after kidney transplantation on the other.	Primary research	Quantitative research design (prospective cohort study)
Nevins & Matas (2004)	Not provided, however issue discussed.	Not clearly outlined.	Primary research	Quantitative research design (prospective cohort study)
Orr et al. (2007)	Not provided	To explore patient attitude and adherence to medication.	Primary research	Qualitative research design (constant comparison method)
Raiz et al. (1999)	Not provided	To investigate variables associated with medication noncompliance after renal transplantation.	Primary research	Quantitative research design (cross-sectional study)

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Rosenberger et al. (2005)	Noncompliance: the situation when a patient dramatically violates the immunosuppressive regime with following rejection episode and graft loss as a consequence.	<ul style="list-style-type: none"> <li>To examine the prevalence of subclinical noncompliance in kidney transplant recipients and to explore its characteristics.</li> <li>To identify risk factors for noncompliant behaviour.</li> </ul>	Primary research	Quantitative research design (cross-sectional study)
Rudman et al. (1999)	The extent to which patient behavior conforms to the HCP's order.	<ul style="list-style-type: none"> <li>To investigate prevalence rates and determinants</li> <li>To address the problem of measuring noncompliance in renal transplant recipients.</li> </ul>	Primary research	Quantitative research design (retrospective chart study/cross-sectional study)
Ruppar & Russell (2009)	The extent to which a person's behaviour (taking medications, following a recommended diet and/or executing life-style changes) corresponds with the agreed recommendations of a health care provider.	To explore the medication-taking behavior of successful kidney transplant recipients and determine what adherence-influencing behaviors were common among this unique group.	Primary research	Qualitative research design (grounded theory)
Russell et al. (2010)	The extent to which the patient's medication-taking behavior coincides with the prescription of the health care provider.	To examine the patterns, predictors, and outcomes of medication adherence in older renal transplant recipients.	Primary research	Quantitative research design (exploratory, descriptive, longitudinal study)
Russell et al. (2006)	The extent to which the patient's medication-taking behavior corresponds with the recommendations of a health care provider.	To examine immunosuppressive medication adherence patterns in adult renal transplant recipients.	Primary research	Quantitative research design (prospective cohort study)
Russell et al. (2007)	Not provided	To explore the patterns of intrasubject (between medication) adherence using electronic monitoring of two similarly timed, twice-daily immunosuppressive medications in adult renal-transplant recipients.	Primary research	Quantitative research design (prospective cohort study)
Russell et al. (2003)	Not provided	To describe the medication taking beliefs of younger and older adult renal transplant recipients.	Primary research	Qualitative research design (content analysis)



Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Scholz et al. (2012)	Not provided	To examine the added value of partner provided social support to the variables of the Theory of Planned Behavior for the prediction of intention and adherence behavior in organ transplant patients. Not clearly outlined	Primary research	Quantitative research design (cross-sectional study)
Schweizer et al. (1990)	Not provided		Primary research	Quantitative research design (retrospective chart review/prospective cohort analysis)
Takemoto et al. (2007)	Assuming each prescription was for 30 days, and multiplying the number of prescription fills during the previous 360 days by 30 and then dividing the product by 360.	<ul style="list-style-type: none"> <li>To examine patient characteristics and transplant factors associated with patient-directed (poor compliance) and physician-directed (prescription changes) dose reductions.</li> <li>To examine whether three competing factors; poor compliance, dose reductions and discontinuation are independently associated with increased risk of graft loss.</li> </ul>	Primary research	Quantitative research design (not specified)
Tielen et al. (2014)	Not provided	<ul style="list-style-type: none"> <li>To gain greater insight into attitudes towards the immunosuppressive medication regime shortly after kidney transplantation.</li> <li>To explore the relationship between adherence to medication and clinical outcomes in the years following transplantation.</li> </ul>	Primary research	Mixed methods research design (Q-methodology)
Tong et al. (2011)	Non-adherence: the extent to which the patients' actions do not accord with medical recommendations	To summarize and synthesize published qualitative studies on the experiences, perspectives, beliefs and attitudes of kidney transplant recipients on medicine taking.	Literature review	Qualitative research design (meta-synthesis)

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Tong et al. (2009)	Not provided	To describe the range and depth of experiences and perspectives from patients with CKD stages 1 to 5, CKD stage 5D, and CKD stages 1 to 5T about the meaning of CKD and its treatment, its impact on lifestyle and relationships, and the coping strategies adopted by patients.	Primary research	Qualitative research design (methodology not specified)
Van Boekel et al. (2013)	Not provided	<ul style="list-style-type: none"> <li>To investigate the effect of introducing a simplified medication regimen in Tacrolimus treated renal transplant patients on treatment satisfaction, in particular, convenience.</li> <li>To study the effect of simplification on the self-reported adherence.</li> <li>To quantify the proportion of an unselected cohort of tacrolimus-treated renal transplant recipients who would be eligible for a simplified drug regimen.</li> </ul>	Primary research	Quantitative research design (prospective cohort study)
Vasquez et al. (2003)	Not provided	To identify factors that may affect medication noncompliance in kidney transplant patients, including the duration of treatment and patients' knowledge of medications.	Primary research	Quantitative research design (cross-sectional study)

Author (Year)	Definition/Conceptualisation of Adherence	Aims	Type of Study	Research Paradigm (Methodology)
Vlaminck et al. (2004)	Not provided	To compare the incidence of late acute rejections (acute rejection more than 1 year post transplantation) as well as the changes in serum creatinine over time between compliers and non-compliers with immunosuppressive medication, and to explore the relative contribution of non-compliance and other known risk factors in the occurrence of these late acute-rejection episodes after renal transplantation. To investigate if it was possible to identify potential non-compliers in daily clinical practice using self-report at an arbitrary time point after transplantation.	Primary research	Quantitative research design (prospective cohort study)
Wainwright & Gould (1997)	The concept of adherence is used to imply a more active and collaborative relationship between patient and health care professional [compared to compliance].	Not clearly outlined	Literature review	Research design not specified
Weng et al. (2013)	Not provided	To determine, among a population of stable, adult kidney transplant recipients who were more than 6 months post-transplant, <ul style="list-style-type: none"> <li>the prevalence of self-reported medication non-adherence</li> <li>psychosocial correlates of non-adherence</li> <li>self-reported barriers to medication adherence.</li> </ul>	Primary research	Quantitative research design (cross-sectional study)
Williams et al. (2014)	Not provided	To review the literature on non-adherence to immunosuppressive medicines in kidney transplantation	Literature review	Research design not specified

Abbreviations: CKD = chronic kidney disease, CKD 5D = chronic kidney disease stage five undergoing haemodialysis or peritoneal dialysis treatment, CKD 1-5T = kidney transplant recipients, HCP = health care provider, MEMS = medication event monitoring system

## Appendix 4: Declaration of Approval

BAG Dres. Ribel/Walther/Lutz

Dr. med. Thorsten Walther

Facharzt für Innere Medizin/Nephrologie

Diabetologie DDG/Hypertensiologie DHL

Wilhelmstraße 5

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Dr. med. T. Walther \* Wilhelmstraße 5\*55543 Bad Kreuznach

Anne Rebafka

Schauinslandstraße 31

79100 Freiburg

07. Juni 2013

### Kenntnisnahme/Zustimmungserklärung

Sehr geehrte Fr. Rebafka,

mit dem Erhalt Ihres Research Proposals bestätige ich Ihnen, dass ich Ihr Forschungsvorhaben im Rahmen Ihrer Dissertation an der Universität Cardiff, Wales, UK „*Medication Adherence Following Kidney Transplantation: Patients' Perspective*“ kenne und unterstütze.

Insbesondere werde ich

- nach den von Ihnen festgelegten Ein- und Ausschlusskriterien Patienten für die Studie anfragen,
- Ihnen, die Einwilligung der Patienten voraus gesetzt, Kontaktdaten der Patienten zukommen lassen,
- Ihnen für die Dauer der qualitativen Interviews eine geeignete Räumlichkeit zur Verfügung stellen.

Mit freundlichen Grüßen

477801300  
Berufsausübungsgemeinschaft  
Drs. med. J. Ribel, T. Walther  
Fr. L. Lutz  
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Dr. med. T. Walther

## Appendix 5: Information Sheet – German Version

Information zur Studie (Version 3)

13.02.2014



**Anne Rebafka**

School of Healthcare Sciences  
College of Biomedical and Life Sciences  
Cardiff University

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### INFORMATION ZUR STUDIE

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#### **Medikamententreue nach Nierentransplantation: Die Sichtweise der Patienten**

Ich würde Sie gerne einladen, an einer Studie teilzunehmen. Diese Studie wird als Teil meiner Doktorarbeit an der Universität von Wales in Großbritannien durchgeführt. Ich selbst bin als Pflegende seit vielen Jahren in der Betreuung von Menschen vor und nach Nierentransplantation an einer großen deutschen Uniklinik tätig.

Bevor Sie sich entscheiden, möchte ich aber, dass Sie verstehen, wieso diese Studie durchgeführt wird und was eine Teilnahme für Sie bedeuten würde. **Jemand aus dem Team von Dr. Walther wird dieses Informationsblatt mit Ihnen durchgehen und alle Ihre Fragen beantworten.** Das wird ungefähr 15 Minuten dauern.

Sprechen Sie mit anderen über die Studie wenn Sie möchten und kontaktieren Sie mich wenn irgendetwas unklar ist.

**Was ist das Ziel dieser Studie?**

Seit Ihrer Nierentransplantation müssen Sie Medikamente nehmen, die Ihren Körper daran hindern, Ihre neue Niere zu bekämpfen. Diese Medikamente werden Immunsuppressiva genannt. Von Forschungsarbeiten in anderen Ländern ist bekannt, dass manche Nierentransplantierte es schwierig finden diese Medikamente wie verschrieben zu nehmen. Es ist jedoch nicht klar, wie deutsche Patienten die Notwendigkeit diese Medikamente zu nehmen empfinden. Das Ziel dieser Studie ist es deshalb zu erforschen was die Medikamenteneinnahme für deutsche Nierentransplantierte bedeutet.

**Warum werde gerade ich zu der Studie eingeladen?**

Sie wurden eingeladen an dieser Studie teilzunehmen weil Sie nierentransplantiert sind. Ich wüßte gerne, was Sie über Medikamenteneinnahme denken.

**Muss ich teilnehmen?**

Es liegt ganz an Ihnen ob Sie sich dazu entscheiden teilzunehmen. Ich werde die Studie beschreiben und dieses Informationsblatt mit Ihnen durchgehen. Wenn Sie sich dazu entschließen teilzunehmen werden Sie gebeten eine Einverständniserklärung zu unterschreiben. Diese Einverständniserklärung umfasst die Teilnahme an einem Interview und die Erlaubnis das Interview auszuwerten. Sie haben jederzeit das Recht ohne Begründung die Teilnahme an der Studie abzubrechen. Das würde keinerlei Einfluss auf Ihre weitere Betreuung haben.

**Was passiert wenn ich mich entscheide an der Studie teilzunehmen?**

Wenn Sie sich entscheiden an der Studie teilzunehmen werde ich Sie anrufen und um einen Termin für ein Interview bitten. Dieses Interview wird ungefähr eine Stunde dauern, wenn Sie es jedoch früher beenden möchten können Sie das jederzeit sagen. Das Interview wird in der Praxis von Dr. Walther, bei Ihnen zuhause oder wo immer Sie möchten stattfinden. Weil ich das Interview aufnehmen werde, sollte es jedoch ein möglichst ruhiger Platz sein. Es ist auch möglich, das Interview per Telefon durchzuführen. In diesem Fall werde ich Sie zu einem festgelegten Zeitpunkt anrufen.

Nach dem Interview werde ich Wort für Wort aufschreiben, was Sie gesagt haben und Sie werden eine Kopie davon per Post oder Email erhalten. Sie werden daraufhin zwei Wochen Zeit haben dieses Transkript zu lesen. In dieser Zeit haben Sie noch einmal die Möglichkeit zu prüfen ob das Interview das beinhaltet, was Sie sagen wollten. Wenn nicht, können Sie mir mitteilen ob Sie etwas ergänzen oder löschen möchten. Wenn ich während dieser beiden Wochen nichts von Ihnen höre, gehe ich davon aus, dass Sie mit dem Inhalt des Transkripts einverstanden sind. In diesem Fall werde ich das Interview analysieren.

**Ausgaben und Bezahlung**

Wenn Sie an dieser Studie teilnehmen werden Sie außer der Zeit und ggf. Fahrtkosten keine Ausgaben haben. Leider ist es mir nicht möglich Ihnen etwas für Ihre Teilnahme zu bezahlen.

**Worin bestehen mögliche Risiken und Nachteile wenn ich an der Studie teilnehme?**

Wenn Sie an der Studie teilnehmen kann es sein, dass Sie sich emotional belastet fühlen. In diesem Fall werde ich das Interview sofort abbrechen und Ihnen emotionale Unterstützung anbieten. In Fällen schwerwiegender Belastung besteht außerdem die Möglichkeit, dass Sie an einen Psychologen Ihrer Wahl überwiesen werden. In diesem Fall halte ich eine Liste von Psychologen in Ihrer Nähe bereit.

Der Verlauf des Interviews wird völlig von Ihnen kontrolliert. Wenn Sie sich unwohl fühlen, können Sie das Interview jederzeit abbrechen. Sie müssen keine Fragen beantworten, die Sie nicht beantworten möchten. Auch können Sie Ihre Teilnahme an der Studie jederzeit abbrechen.

**Worin bestehen mögliche Vorteile wenn ich teilnehme?**

Die Studie versucht herauszufinden was deutsche Nierentransplantierte darüber denken regelmäßig Medikamente einzunehmen. Damit kann sie kann dazu beitragen, die Betreuung von Nierentransplantieren in der Zukunft zu verbessern.

**Wird meine Teilnahme an der Studie vertraulich behandelt?**

Ja! Ich werde alle ethischen und rechtlichen Vorschriften beachten und alle Informationen über Sie werden vertraulich behandelt. Alle Informationen, die ich im Laufe der Studie von Ihnen erhalte, werden streng vertraulich behandelt. Ich werde Ihren Namen und Ihre Adresse von allen Informationen über Sie, die die Praxis verlassen, entfernen, so dass Sie von niemandem identifiziert werden können. Bei der Auswertung des Interviews und bei allen wörtlichen Zitaten werde ich Ihren Namen mit einem gängigen deutschen Namen ersetzen.

Alle Daten werden sicher auf Servern der Universität Cardiff gespeichert sein und nach 15 Jahren gelöscht werden. Ausdrucke werden in einem verschlossenen Schrank aufbewahrt, zu dem nur ich Zugang habe. Niemand wird Zugang zu den Aufnahmen des Interviews haben und vertrauliche Informationen werden niemandem mitgeteilt.

**Was passiert wenn ich mit der Studie aufhören möchte?**

Wenn Sie während des Interviews von der Studie zurücktreten möchten, werde ich nicht mit dem Interview fortfahren und alle bereits gesammelten Daten löschen. Wenn Sie von der Studie zurück treten möchten nachdem das Interview bereits ausgewertet ist, werde ich die Aufnahme des Interviews löschen. Wenn Ihr Interview bereits ausgewertet wurde, wird es mir leider nicht möglich sein alle Ihre Daten aus den Ergebnissen zu entfernen, jedoch wird kein direktes Zitat von Ihnen verwendet.

**Was wird mit den Ergebnissen der Studie geschehen?**

Die Ergebnisse dieser Studie sind die Grundlage für die meine Doktorarbeit. Es ist außerdem beabsichtigt, die Ergebnisse auf Kongressen vorzustellen und in Fachzeitschriften zu veröffentlichen. Falls Sie Interesse haben, bekommen Sie eine deutsche Zusammenfassung der Ergebnisse.



**Wer hat die Studie genehmigt?**

Jede Forschung, die an der Universität von Cardiff durchgeführt wird, wird von einer unabhängigen Kommission, die Ihre Interessen schützen soll, begutachtet. Diese Kommission nennt man Ethikkommission. Sie hat die Studie begutachtet und genehmigt. Auch die Ethikkommission der Deutschen Gesellschaft für Pflegewissenschaft e.V. hat die Studie begutachtet und genehmigt.

**Weitere Informationen und Kontaktdetails**

Wenn Sie weitere Fragen haben, zögern Sie nicht mich anzurufen oder eine E-Mail zu schreiben. Ich werde Ihnen gerne weitere Fragen beantworten.

Telefon privat: 0160 94464005

Telefon dienstlich: 0761 27034190

E-Mail: [rebafkaak1@cardiff.ac.uk](mailto:rebafkaak1@cardiff.ac.uk)  
[anne.rebafka@gmx.de](mailto:anne.rebafka@gmx.de)

## Appendix 6: Information Sheet – English Version

Information about the research (version 3)

13.02.2014



**Anne Rebafka**

School of Healthcare Sciences  
College of Biomedical and Life Sciences  
Cardiff University

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### INFORMATION ABOUT THE RESEARCH

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#### **Medication Adherence Following Kidney Transplantation: Patients' Perspective**

I would like to invite you to take part in a research study. This study is part of my doctoral thesis at Cardiff University, UK. I am a nurse who works at a major German university hospital in the care of patients before and after kidney transplantation.

Before you decide I would like you to understand why the research is being done and what it would involve for you. **One of Dr Walther's team will go through the information sheet with you and answer any questions you have.** We'd suggest this should take about 15 minutes. Talk to others about the study if you wish. Ask me if there is anything that is not clear.

**What is the purpose of the study?**

Since your kidney transplant you need to take medication that prevents your body to fight against your new kidney. These medications are called immunosuppressive medication. From research in other countries it is known that some kidney transplant recipients find it difficult to take this medication as prescribed. However, it is not clear how recipients of kidney transplants in Germany perceive the need to take medication. The purpose of this study is therefore to explore the meaning medication-taking has for kidney transplant recipients in Germany.

**Why have I been invited?**

You have been invited because you are a kidney transplant recipient. I would like to know what you think about medication-taking.

**Do I have to take part?**

It is up to you to decide to join the study. I will describe the study and go through this information sheet. If you agree to take part, I will then ask you to sign a consent form that allows me to interview you and analyse the interview. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

**What will happen to me if I take part?**

If you decide to take part in the study, I will call you by telephone and will ask you for an appointment for being interviewed. This interview will last about one hour, however, if you wish to stop earlier, you can indicate this any time. The interview will take place in the practice of Dr Walther, your home or at any place you prefer. As I will need to record the interview, this place should be quiet enough. You may also be interviewed by telephone. In this case, I will call you at a determined time.

After the interview, I will write down word for word what you have said and you will receive a copy of this via mail or email. You will have two weeks of time where you can read this transcript. During this period you will have the opportunity to check whether the interview contains what you have wanted to express. If not, you can indicate if you want to have anything added or deleted. If I do not hear anything from you in these two weeks, I assume that you agree with the content of the transcript. In this case, I will proceed to the analysis of the interview.

**Expenses and payment**

By taking part in this research, you will not have any expenses besides the time you invest and travel costs to the place the interview will take place. Unfortunately, I am not able to pay you anything for taking part in this research.

**What are the possible risks and disadvantages of taking part?**

By taking part in the research it may occur that you feel emotionally distressed. In this case, I will immediately stop the interview and will be available to provide emotional support. Also, in the case of severe emotional distress, you may be referred to a psychologist of your choice. In this case I will provide you with a list of psychologists close to you.

The course of the interviews will be controlled by you. If you feel uncomfortable for any reason, it is your right to stop the interview at any time. You will not have to answer any questions you do not wish to answer. Also, you can withdraw from the study at any time without giving reasons.

**What are the possible benefits of taking part?**

The study aims to find out how kidney transplant recipients in Germany perceive the need to take medication on a regular basis. This may help to improve the care of people with kidney transplants in the future.

**Will my taking part in the study be kept confidential?**

Yes! I will follow ethical and legal practice and all information about you will be handled in confidence. All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the surgery will have your name and address removed so that you cannot be recognised. When analysing the interview and in any verbatim quotation, I will replace your name with a very common name so that you will not be identified.

All data will be stored securely on Cardiff University servers and be deleted after fifteen years. Print outs will be locked in a cupboard only I have access to. No-one will have access to the recordings of your interview and confidential information you may have provided will not be shared with anyone.

**What will happen if I don't want to carry on with the study?**

If you withdraw from the study during the course of the interview, I will not proceed with the interview and delete all data collected. If you withdraw after the interview has been analysed I will destroy all records. However, after your interview has been analysed, I will not be able to completely remove all of your information from the study results, but I will not use any of your quotes.

**What will happen to the results of the research study?**

The results of this study will be the basis for my doctoral dissertation. It is also intended to give speeches about them on conferences and to publish the study in a professional journal. If you are interested in the results of the study you will be provided with a German summary.

**Who has reviewed the study?**

All research in Cardiff University is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by this Research Ethics Committee. Also, the Research Ethics Committee of the German Society of Nursing Science has reviewed this study.

**Further information and contact details**

If you have any further questions, please do not hesitate to call or send me an email. I will be happy to provide you with more details.

Phone (private): +49 160 94464005

Phone (work): +49 761 27034190

Mail: [rebafkaak1@cardiff.ac.uk](mailto:rebafkaak1@cardiff.ac.uk)  
[anne.rebafka@gmx.de](mailto:anne.rebafka@gmx.de)

## Appendix 7: Consent Form – German Version

Einwilligungserklärung (Version 3)

13.02.2014

Patientenidentifikationsnummer: \_\_\_\_\_

### EINWILLIGUNGSERKLÄRUNG

**Titel des Projekts:**

**Medikamententreue nach Nierentransplantation: Die Sichtweise der Patienten**

**Name der Forscherin:**

**Anne Rebafka**

Bitte alle Kästchen abzeichnen

1. Ich bestätige, dass ich die Information zur o.g. Studie vom 13.02.2014 (Version 3) gelesen und verstanden habe. Ich hatte Gelegenheit mir über die Information Gedanken zu machen und Fragen zu stellen und bekam diese zu meiner Zufriedenheit beantwortet.
2. Ich verstehe, dass meine Teilnahme freiwillig ist und dass ich jederzeit ohne Angabe von Gründen mein Einverständnis zurückziehen kann ohne dass meine medizinische oder pflegerische Versorgung oder meine Rechte beeinträchtigt werden.
3. Ich stimme der digitalen Aufnahme meines Interviews zu.
4. Ich bin damit einverstanden, dass meine Daten in schriftlicher oder mündlicher Form verwendet werden und dass möglicherweise wörtliche Zitate verwendet werden.
5. Mir ist bekannt, dass, falls ich von der Studie zurücktrete nachdem meine Daten ausgewertet wurden, es nicht möglich sein wird, alle von mir stammenden Informationen zu ignorieren.
6. Ich willige ein an der o.g. Studie teilzunehmen. Dies schließt ein Interview und die Auswertung des Interviews ein.







\_\_\_\_\_  
Name des Teilnehmers

\_\_\_\_\_  
Datum

\_\_\_\_\_  
Unterschrift

\_\_\_\_\_  
Name desjenigen, der  
die Einwilligung einholt

\_\_\_\_\_  
Datum

\_\_\_\_\_  
Unterschrift

## Appendix 8: Consent Form – English Version

Consent Form (version 3)

13.02.2014

Patient Identification Number for this trial: \_\_\_\_\_

### CONSENT FORM

**Title of Project:**

***Medication Adherence Following Kidney Transplantation: Patients' Perspective***

**Name of Researcher:**

***Anne Rebafka***

Please initial all boxes

- |    |   |                          |
|----|---|--------------------------|
| 1. | I confirm that I have read and understand the information sheet dated 13.02.2014 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.   | <input type="checkbox"/> |
| 3. | I consent to the use of digital recording of my interview.  | <input type="checkbox"/> |
| 4. | I agree that my data may be used in written form or speeches, with possible use of verbatim quotation.  | <input type="checkbox"/> |
| 5. | I understand and agree that if I withdraw from the study after my data has been analysed, it will not be possible to delete all of my information from the study results.   | <input type="checkbox"/> |
| 6. | I agree to take part in the above study. This includes an interview and the analysis of the interview.  | <input type="checkbox"/> |

Name of Participant	Date	Signature
---------------------	------	-----------

Name of Person taking consent	Date	Signature
-------------------------------	------	-----------

## Appendix 9: Interview Guideline – German Version

Patientennummer		Echter Name		
Datum		Platzhalter Name		
Uhrzeit Beginn		Geschlecht	weiblich	männlich

Guten Tag Frau/Herr \_\_\_\_\_,

Danke, dass Sie sich bereit erklärt haben und sich die Zeit genommen haben, bei dem Interview teilzunehmen. Bevor wir mit dem eigentlichen Interview anfangen, möchte ich noch ein paar organisatorische und persönliche Dinge klären.

Es ist wichtig, dass Sie wissen, dass Sie keine Fragen beantworten müssen, die Sie nicht beantworten möchten. Wenn Sie das Interview abbrechen möchten können Sie das auch jederzeit sagen.

Ich möchte auch nochmal daran erinnern, dass ich dieses Interview aufnehmen werde, damit ich es später auswerten kann. Falls Sie möchten kann ich Ihnen das aufgeschriebene Interview zusenden. Sie hätten dann zwei Wochen Zeit um mir eine Rückmeldung zu geben.

Möchten Sie das Interview zugesandt haben?	ja	nein
Wenn ja, bräuchte ich bitte Ihre Emailadresse oder Postadresse		

Ok, wenn ich also bis zum \_\_\_\_\_ nichts von Ihnen gehört habe, werde ich das Interview auswerten.

Wann sind Sie geboren?		
Sind Sie berufstätig?	ja	nein
Wenn ja, als was?		
Wieso mussten Sie nierentransplantiert werden?		
Wie oft wurden Sie schon transplantiert?		
Wann war die letzte Transplantation (Datum)?		



Haben Sie nur eine Niere oder noch ein anderes Organ transplantiert bekommen (Pankreas)?	Niere	Niere/Pankreas
Haben Sie eine Lebendspende erhalten?	postmortal	lebend
Wenn Lebendspende, wer war Ihr Spender?		

So, wenn Sie einverstanden sind schalte ich jetzt das Aufnahmegerät ein und wir beginnen mit dem Interview.

### **Einleitung**

Nach Ihrer Nierentransplantation müssen Sie Medikamente nehmen, die Ihr Immunsystem daran hindern Ihre neue Niere abzustößen. Aus Untersuchungen in anderen Ländern wissen wir, dass manche Nierentransplantierte es schwierig finden, regelmäßig Ihre Medikamente zu nehmen. Leider wissen wir noch nicht viel darüber, was deutsche Nierentransplantierte dazu denken und sind deswegen an Ihrer Meinung als Nierentransplantierte/r interessiert.

### **Eröffnungsfrage**

Bitte erzählen Sie mir wie es für Sie ist, täglich Medikamente zu nehmen.

### **Weitere Fragen**

Was sind die Vor- und Nachteile der täglichen Medikamenteneinnahme??

Bitte erzählen Sie mir was bei der Einnahme Ihrer Medikamente gut klappt. Was klappt weniger gut?

Was denken Sie, welchen Einfluss die Medikamenteneinnahme auf Ihr tägliches Leben hat?

Welchen Einfluss haben Menschen, die Ihnen wichtig sind auf ihre Medikamenteneinnahme?

Was können Ärzte oder Pflegende (Schwestern oder Pfleger) aus Ihrer Sicht tun um Sie dabei zu unterstützen Ihre Medikamente regelmäßig zu nehmen?

Bitte erzählen sie mir, was Sie tun um Ihre Medikamente nicht zu vergessen.

Bitte erzählen Sie mir wie es für Sie ist, wenn Sie Ihre Medikamente mal nicht genommen haben.

Was würde es für Sie einfacher machen Ihre Medikamente regelmäßig zu nehmen? Was würde es schwerer machen?

Erzählen Sie mir bitte, was Sie gerne an Ihrer Medikamenteneinnahme verändern würden.

### **Aufrechterhaltungsfragen**

Bitte erzählen Sie mir zu ... noch mehr.

Fällt Ihnen dazu noch etwas ein?

Können Sie mir zu ... ein Beispiel nennen?

Wie geht es Ihnen damit?

Können Sie mir ... noch näher beschreiben?

### **Schluss**

Gibt es irgendetwas, das sie noch ansprechen wollen?

## Appendix 10: Interview Guideline – English Version

patient number		real name		
date		pseudonym		
start time		gender	female	male

Hello Mr/Ms \_\_\_\_\_,

Thank you very much for taking your time to participate in this interview. Before we start, I would like to raise some organisational and personal questions.

It is important for you to know that you must not answer any questions you do not want to answer. If you want to stop the interview you can indicate this at any time.

I want to remind you again, that I am going to record the interview in order to being able to analyse it later. If you wish I will sent you the transcript. In this case, you will have a fortnight to give feedback.

Would you like a copy of the transcript?	yes	no
If yes, please give me your email address or postal address.		

Ok, if have not heard anything from you by \_\_\_\_\_, I will analyse the interview

date of birth		
employment status	yes	no
profession (if applicable)		
reason for kidney transplantation		
numbers of kidney transplants		
date of (last) transplant		
type of organ	kidney	kidney/pancreas
type of donor	deceased	living
who was the donor (if living donor)		

Well, if you agree, I turn on the recorder now and we start the interview.

### ***Introduction***

Following your kidney transplantation you need to take medication that prevents your immune system to reject your new kidney. From research in other countries, we know that some kidney transplant recipients find it difficult to take their medication regularly. Unfortunately we don't know very much what German transplant recipients think about this. We are therefore interested in your point of view as a renal transplant recipient.

### ***Opening Question***

Please tell me how it is for you to take medication on a daily basis.

### ***Further Questions***

What are the benefits and disadvantages of taking medication on a daily basis?

Please tell me what works out well in regard to your medication-taking. What does not work as well?

How do you think your medication influences your daily living?

How do people who are important to you influence your medication-taking?

From your point of view, what could doctors and nurses do to help you take your medication regularly?

Please tell me what you do to not forget to take your medication.

Please tell me how you feel in instances when you have not taken your medication.

What would make it easier for you to take your medication? What would make it more difficult?

Please tell me what you would like to change regarding your medication-taking.

### ***Follow-up Questions***

Please tell me more about ....

Does something else cross your mind?

Can you give an example of ...?

How do you feel in relation to ...?

Can you please specify ...?

### ***Closing Remark***

Is there anything else you want to say?

## Appendix 11: Original German Quotes and English Translations

English	German
<p>Whether it is my husband or anyone else who provided his kidney, that doesn't matter. Of course in this case, because it is my husband, very specially. But I wouldn't have a different attitude if it was a cadaver donation (Ms Wolf, 20:17).</p>	<p>Ob das jetzt mein Mann ist, ob das irgendjemand anderes ist, der seine Niere zur Verfügung stellt, das spielt dabei keine Rolle. In dem Fall, weil es mein Mann ist natürlich, ganz besonders. Aber ich hätte keine andere Einstellung, wenn es eine Totspende gewesen wäre.</p>
<p>It's really an advantage that you can take this medication orally and don't have to inject. That's ... it's a mega-advantage. If you have to think now you had to inject every day or maybe even twice a day or three times. Then you're better off with a tablet (Mr Hoffmann, 13:52).</p>	<p>Es ist doch schon mal ein Vorteil, dass Sie das Medikament oral nehmen können und sich nicht spritzen müssen. Das ist alles ... das ist schon ein riesen Vorteil. Wenn Sie jetzt denken müssen, Sie müssten sich jeden Tag wieder spritzen oder dann vielleicht sogar zweimal am Tag oder dreimal. Dann doch lieber eine Tablette.</p>
<p>For example, he [nephrologist] explained about the immune system given that I take immunosuppressants. [...] He said 'imagine a train that's being unloaded. And all the workers there, one's missing a leg, the other one only has one arm' [...] he said, 'and it's clear that they need more time than a complete person'. And just like that he explained that my immune system is a little weaker now. Well, I immediately got it this way. Maybe that sound funny, but for me that was graspable (Ms Schulz, 09:59).</p>	<p>Er hat mir zum Beispiel erklärt, wie das ist mit dem Immunsystem, da ich jetzt Immunsuppressiva nehme. [...] Sagte er zu mir, stellen Sie sich einen Zug vor, der wird entladen. Und die ganzen Arbeiter wo da stehen, dem einen fehlt ein Bein, dem anderen fehlt der Arm [...] sagt er, und es ist ja klar, dass die länger brauchen als wie ein kompletter Mensch. Und so hat er mir erklärt, wie das Immunsystem, das jetzt etwas geschwächt ist, wo ich habe. Also ich habe es jetzt gleich so richtig verstanden. Das hört sich vielleicht komisch an, aber für mich war es greifbar.</p>
<p>There's no study or no results that it doesn't work without medication. It will probably in some patients ... it will maybe work that they don't have to take these medicines. There is one study in America, there it's been in one patient, they have tested it and it worked. But the risk is much too high. You can just test, either the organs are preserved or they are rejected if you leave the medicine. And therefore no one will ever think about stopping the medication (Mr Hoffmann, 06:54).</p>	<p>Es gibt ja keine Studie oder keine Ergebnisse darüber, dass es auch nicht ohne diese Medikamente geht. Es wird wohl bei verschiedenen Patienten ... wird es wohl auch funktionieren, dass sie diese Medikamente nicht nehmen müssen. Da gibt es wohl in Amerika eine Studie, da ist das bei einem Patienten, da haben sie es getestet, das hat funktioniert. Aber dieses Risiko ist halt viel zu groß. Sie können das ja nur austesten, entweder die Organe bleiben erhalten oder sie werden abgestoßen, wenn Sie das Medikament weglassen. Und deswegen wird nie jemand auf den Gedanken kommen die Medikamente abzusetzen.</p>

English	German
<p>Most of the medication, the extremely important ones, develop a level [in the blood]. And this level doesn't decline towards zero when I take the medication half an hour later. I believe that 3 or 4 hours ... that's my non-medical opinion that the body tolerates that well (Mr Becker, 23:28).</p>	<p>Bei den meisten Medikamenten, die extrem wichtigen, die bauen ja einen [Blut]Spiegel auf. Und der Spiegel fällt nicht auf 0 wenn ich eine halbe Stunde später die Medikamente nehme. Also ich denke, dass da drei, vier Stunden ... das ist meine nicht-medizinische Meinung, dass das bestimmt noch der Körper toleriert</p>
<p>Yes, tolerability. Well I ... as I said, I ... Cynt [antihypertensive drug] and what else I take. I'm ... it takes at least ... when it then has an effect, I'm sleepy for half an hour. Until the effect has unfolded in the body [...] And when I then sit quietly and then ... I mean the fatigue, with my kidney, that's known anyhow, that clear anyhow and with my skin cancer. But when the tablets add to this, then I could recline after half an hour. And that lasts about half an hour or 45 minutes, hour, and then it's over. (...) Which phenomenon that is ... but that's also due to my illness. And due to the many tablets, I don't know. You know, that's such a mixture, that's such a cocktail that needs to arrange in the body (Mr Schneider, 10:27).</p>	<p>Ja, Verträglichkeit. Also ich ... wie gesagt, ich ... Cynt und was ich da alles nehme. Ich bin ... dann dauert es mindestens ... wenn die dann wirkt, dann bin ich eine halbe Stunde schläfrig. Bis die Wirkung sich total entfaltet hat im Körper [...] Und wenn ich dann ruhig sitze und dann ... ich meine, die Müdigkeit, mit meiner Niere, das ist sowieso bekannt, das ist sowieso klar und mit meinem Hautkrebs. Aber, wenn dann die Tabletten dazukommen, dann könnte ich mich nach einer halben Stunde erstmal wieder hinlegen. Und das dauert so eine halbe, dreiviertel Stunde, Stunde, und dann geht das wieder. (...) Welches Phänomen das ist ... aber das liegt auch bei mir an der Krankheit. Und an den vielen Tabletten, ich weiß es nicht. Wissen Sie, das ist auch so ein Mix, das ist ja so ein Cocktail, der muss sich ja auch erst im Körper finden.</p>
<p>When it [kidney disease] started with my kidney, my own kidneys, I had to take 60 milligrams of cortisone daily. And the first one I took came back immediately. Because for myself I thought 'this is end-stage now'. Because in the past, for me, when it came to cortisone ... 'oh dear, then you're hanging on a silken string' (Ms Müller, 28:20).</p>	<p>Wie es damals mit meiner Niere angefangen hatte, mit meinen eigenen Nieren, da musste ich 60 Milligramm Cortison täglich nehmen. Und die erste, die ich geschluckt habe, die kam sofort wieder raus. Weil ich für mich gedacht habe 'das ist Endstadium'. Weil früher war für mich Cortison wenn es geheißen hat ... Cortison ,oh je, dann hängst Du am seidenen Faden'.</p>
<p>And then there's the awareness of having a new kidney, that also reminds you very much of your medication. That virtually is a permanent reminder. You don't forget this that easily (Mr Richter, 00:38).</p>	<p>Und dann ist auch das Bewusstsein, eine neue Niere zu haben, das erinnert einen auch dann sehr stark an die Medikamente. Das ist so quasi so eine permanente Erinnerung. Das vergisst man nicht so leicht.</p>

English	German
<p>I am always asked to care for myself, all the time. What am I doing, how am I doing, in any case. [...] What it does, this is just crossing my mind, is to take care of myself even more intensively. How I feel. To listen even more to my state of health, to my feelings. That's ... the intake of these tablets, especially these, provokes it. And that's what pleases me. That I always think how am I? Actually everyone should do that, I believe. Everyone in every moment, what am I feeling, what am I feeling? Am I still alive or am I dead already? (Mr Schröder, 13:40)</p>	<p>Ich bin ständig gefordert auf mich selber aufzupassen, ununterbrochen. Was ich tue, wie es mir geht, sowieso [...] was es so macht, fällt mir jetzt gerade so ein, ist, noch intensiver auf mich aufzupassen. Wie ich mich fühle. Noch mehr auf meine, auf mein Befinden und auf meine Gefühle zu achten. Das ... dazu fordert mich die Einnahme dieser Tabletten, jetzt speziell diese heraus. Und das ist was, was mir Spaß macht. Dass ich ständig kucke wie geht's mir. Das sollte sowieso jeder tun, denke ich. Jeder in jedem Moment, was spüre ich, was fühle ich. Lebe ich noch oder bin ich schon tot?</p>
<p>Both the attitude towards the illness as well as towards the regular intake of medication can be called responsibility for oneself you cannot delegate to someone else (Ms Wolf, 06:40).</p>	<p>Sowohl die Einstellung zu einer Erkrankung als auch zur regelmäßigen Medikamenteneinnahme kann man kurz als Verantwortung für die eigene Person bezeichnen, die man nicht an andere delegieren kann.</p>
<p>I have a long history of illnesses and I know ... well, I know what it's like to be ill and so on. And I know that there are so many diseases one cannot prevent and I always think [...] that I needed a kidney and that it's a donor kidney, I cannot influence that. But to take my medication regularly and with it help my kidney to longer ... that it works longer and better, that's something I can influence (Ms Schmitt, 13:50).</p>	<p>Ich habe schon eine lange Krankheitsgeschichte und ich weiß ... also ich weiß wie es ist, wenn man krank ist und so. Und ich weiß, dass es so viele Krankheiten gibt, die man nicht verhindern kann und ich denke mir immer [...] dass ich jetzt diese Niere kriegen musste, dass es eine Spenderniere ist, das kann ich nicht beeinflussen. Aber dass ich meine Medikamente regelmäßig nehme und damit eben meiner Niere helfe, dass sie länger ... dass es ihr länger gut geht und dass sie besser arbeitet, das ist was, das kann ich beeinflussen</p>
<p>I have realised that many pieces of advice that come without being asked are not favoured. Everyone is fixed in the way he does certain things. And if someone sees it totally differently, be it in terms of weight control, exercise, or others, that's never appreciated and will not be taken to heart. (...) I think that would be ... in my eyes that would rather be like dressage and that is only kept up as long as the person is present. It's just important that ... everyone knows how much personal responsibility he must have and that's the crux (Ms Wolf, 17:27).</p>	<p>Ich habe gemerkt, dass viele Ratschläge, die ungewollt kommen, nicht gewünscht sind. Jeder ist an für sich festgefahren in seiner Art wie er bestimmte Sachen macht. Und wenn jetzt jemand das so vollkommen anders sieht, sei es mit Hinblick auf Gewichtskontrolle, sei es mit Hinblick auf Bewegung und anderes, das kommt nie sehr gut an und wird auch nicht beherzigt. (...) Ich glaube das wäre ... in meinen Augen wäre das eher eine Dressur und die hält nur solange wie der Dompteur dabei ist. Wichtig ist es einfach ... jeder weiß, wie viel Eigenverantwortung er sich gegenüber haben muss und genau das ist die Crux.</p>

English	German
<p>But I 'm relatively critical, whenever I'm talked into something, when they [physicians] say, 'this tablet and that tablet', I say 'stop, I already have so many tablets. Why, why, why?' I tend to ask because I try to reduce the tablets more and more. I used to take more than 20 tablets a day, in the university hospital. Needed to take them. And little by little we reduced them (Mr Schneider, 07:18).</p>	<p>Wobei ich relativ kritisch bin, wenn ich immer wieder etwas aufgeschwatzt bekomme, wo sie sagen dann, die Tablette und die Tablette, sage ich <u>stopp</u> ich habe schon so viele Tabletten. Warum, wieso, weshalb? Da frage ich schon eher, weil ich versuche dann immer mehr die Tabletten zu reduzieren. Ich habe mal an einem Tag bis zu 20 Tabletten genommen in der Uniklinik. Musste ich nehmen. Und so nach und nach haben wir die abgebaut</p>
<p>To really stick to that how the doctor says and also correct [...] to take the tablets as one needs to, and also as the medic advises him. And not to say 'I don't take them today and I don't take them tomorrow', or something. Well, one should strictly stick to that. To do what the doctor says. Otherwise I couldn't have kept my kidney that long (Ms Koch, 14:21).</p>	<p>Sich wirklich dran zu halten so wie der Arzt das sagt und auch richtig [...] die Tabletten einnehmen so wie es jeder braucht, so wie der Arzt es ihm auch empfiehlt. Und nicht sagen ich nehme die heute nicht und morgen nehme ich die nicht, oder so. Also man sollte sich schon strikt dran halten. So was der Arzt sagt, dass man das auch tut. Sonst hätte ich so lange nicht die Niere behalten können.</p>
<p>I'm not such a consequent person that I think about it [medication-taking] all day long, 'you must now take your tablets at 8'. It's just like that. It ... as I said before, I haven't experienced any disadvantages by it yet. I'm aware of what happens and that's ok for me like that (Mr Schröder, 03:49).</p>	<p>Weil ich bin halt nicht so ein konsequenter Mensch, dass ich da jetzt den ganzen Tag dran denke, um 8 Uhr musst Du jetzt deine Tabletten einnehmen. Das ist einfach so. Das ... wie gesagt, ich habe bisher ja noch keine Nachteile erlebt dadurch. Bin mir dessen bewusst, was passiert und das ist für mich okay so.</p>
<p>I would also recommend them to tie it [medication-taking] to things you do regularly each day. If for example someone brushes his teeth in the morning and in the night, you should do that anyway [laughs], and he hasn't anything else to tie to, then maybe to tooth brushing. [...] You have to find anything to connect it to that it becomes a regular ritual (Mr Richter, 21:45).</p>	<p>Ja, ich würde denen auch empfehlen, das an irgendwelche Dinge zu knüpfen, die sie regelmäßig am Tag machen. Wenn einer sich zum Beispiel immer morgens und abends die Zähne putzt, das sollte man ja sowieso (lacht), und er hat nichts anderes, wo er das dran anknüpfen könnte, dann eben vielleicht ans Zähne putzen. [...] Also man muss irgendetwas finden, womit man das verbindet, damit es zum regelmäßigen Ritual wird.</p>
<p>And what certainly doesn't work is to fetch the tablets daily or to at the assigned times, release them from the blister pack and then to take them. There's no control whatsoever in there. Well, from my point of view ... the tablets need to be prepared (...) as I said, the weekly box and the daily box help enormously (Mr Huber, 29:39).</p>	<p>Und was mit Sicherheit nicht geht, täglich oder zu den angegebenen Zeiten die Tabletten zu holen, dann aus der Packung zu lösen und dann einzunehmen. Da ist überhaupt keine Kontrolle drin. Also es muss meiner Meinung nach ... die Tabletten müssen schon gerichtet sein (...) wie gesagt, die Wochenbox und die Tagesbox, die hilft enorm.</p>



English	German
<p>In the beginning, I entered it [alarms] into my cell phone, but that's rather annoying, because it's the same every day and also at the same time (Mr Becker 2014, 05:58).</p>	<p>Ich hatte mal am Anfang mal im Handy das [Alarm] eingegeben, aber das ist auch eher nervig, weil da steht jeden Tag das selbe drin und auch zur selben Uhrzeit.</p>
<p>I read somewhere that for this nice present you need to pay afterwards. Of course, that's ... one's always unhappy. You take something out like a loan. You basically take it out as like a loan. You take it and you need to pay for it afterwards (Ms Maier, 54:01).</p>	<p>Habe ich was irgendwo gelesen, für diese schöne Geschenk dann musst du dann nachher zahlen. Das ist natürlich ... der Mensch ist immer unzufrieden. Du nimmst was praktisch so wie in Kredit. Du nimmst das und nachher musst du dann dafür zahlen</p>
<p>It's also that you ... as a transplant recipient you expect ... rather I have expected that because of the new kidney my physical condition [...] will re-gain the pre-dialysis status. That's not the case. Well, it's been 10 years since then. That's also deficits and 10 years of dialysis also make ... also afflict the body. That also lets ... or the new kidney, which is also just one of two originally, cannot compensate. It's still ... physically, you're still limited. Not like on dialysis but still, there are limitations that stay (Mr Becker, 19:12).</p>	<p>Es ist auch so, dass man ... als Transplantiertes erwartet man ... oder ich habe erwartet, dass die körperliche Verfassung durch die neue Niere, sagen wir mal, wieder den Zustand wie vor der Dialyse herstellt. Dem ist halt auch noch nicht so. Gut, das sind ja mittlerweile über 10 Jahre ins Land gegangen. Das sind auch Defizite und 10 Jahre Dialyse machen schon ... setzen dem Körper schon zu. Das lässt sich auch ... oder kann die neue Niere, die auch nur eine ist von zwei im Original, auch nicht in Anführungszeichen rausreißen. Das ist halt schon noch ... körperlich ist man schon auch noch eingeschränkt. Nicht so wie bei der Dialyse aber trotzdem es sind schon Einschränkungen, die man auch immer noch hat. (...) Aber das lässt sich auch nicht mit den Medikamenten irgendwie ... das hat jetzt aber nichts mit den Medikamenten zu tun.</p>
<p>I was also so badly informed before transplantation. Have just told that the doctor this week. If I had known how all works and what I'd need to take and this and that. That's hard enough. I should have known that before. Afterwards, there are so many things where you're invited to [transplant centre], where you could have a look around. But it's behind you already. That's it. Those who are on dialysis should know that before. That would be better (Ms Wagner, 18:31).</p>	<p>Man ist auch vor der Transplantation so schlecht aufgeklärt gewesen. Habe ich diese Woche noch dem Arzt gesagt. Wenn man das gewusst hätte, wie das alles funktioniert und was man nehmen muss und dies und jenes. Das ist schon schwer. Man hätte müssen vorher mal was wissen. Hinterher, dann kommen so viele Sachen, wo man eingeladen wird nach [Name des Tx-Zentrums], wo man sich ankucken könnte. Aber man hat es ja schon hinter sich. Das ist das. Das müssten die, die an der Dialyse sind, vorher wissen. Das wäre besser.</p>

English	German
<p>Yes, well, to be honest, I mean, I owe my life to that. I have ... I must tell you a story ... my father, I don't know whether you're familiar with polycystic kidney disease [...] and unfortunately he is was 19 (...) 1965 he died from that. And that's a hereditary disease and I have that. I had that or still have it. And if dialysis hadn't existed , I'd be a has-been. And if there were no tablets, because of follow-up, I would have been more or less near death. That's for ... positive thoughts. That's basically why I take them (Mr Schneider, 07:06).</p>	<p>Ja, also ich muss ganz ehrlich sagen, ich meine, das tut ja mein Leben verdanken. Ich habe ja ... da muss ich Ihnen eine Geschichte erzählen ... mein Vater, ich weiß nicht ob Sie sich auskennen mit Zystennieren [...] und der ist leider 19 (...) 1965 dran gestorben. Und das ist eine Erbkrankheit und die habe ich. Die hatte ich oder habe sie noch. Und wenn es die Dialyse nicht gegeben hätte, wäre ich weg vom Fenster. Und wenn es jetzt nicht die Tabletten gäbe, wegen der Nachsorge, und dann wäre wahrscheinlich auch schon für mich mehr oder weniger schon etwas dem Tod nahe gewesen. Das ist für ... positive Gedanken. Deshalb nehme ich das auch.</p>
<p>Yes, and what I also have discovered regarding the effect of Sandimmun [Ciclosporin – immunosuppressive drug] is that it also destroys the kidney in the long term. (Mr Richter, 10:23).</p>	<p>Yes, and what I also have discovered regarding the effect of Sandimmun [Ciclosporin – immunosuppressive drug] is that it also destroys the kidney in the long term. (Mr Richter, 10:23).</p>
<p>Once a year, or twice a year when I go to [name of the transplant centre], there are sometimes patients whose say, crea [serum creatinine] is high again, and changed a medicine. If they take part in that kind of study where medication is changed. Indeed, it's important for advancing progress and innovation but (...) you then think too much about what may go wrong, what happens, yes. Suddenly the crea rises, rejection. That's the kind of things that cross your mind (Mr Huber, 26:00).</p>	<p>einmal im Jahr, oder zweimal im Jahr, wenn ich nach [Name des Tx-Zentrums] gehe, da gibt es schon mal Patienten die dann sagen, Krea ist wieder hoch, habe ein Medikament gewechselt. Wenn die entsprechend in einer Studie drin sind wo ein Medikament gewechselt wird. Ist zwar wichtig um weiter zu kommen im Fortschritt, in der Innovation aber (...) man denkt dann zu sehr was kann schief gehen, was passiert, ja. Geht plötzlich das Krea hoch, Abstoßreaktion. Das sind immer so Sachen, die einem durch den Kopf gehen.</p>
<p>I don't have anything against medics and transplantation. That's not the question. I would only recommend anyone not to take part in a study. And I neither have anything against medication. Everyone reacts upon another medicine, I'm open to that. But it has to be changed if you realise it doesn't work (Ms Klein, 20:55).</p>	<p>Ich habe jetzt nichts gegen Ärzte und Transplantation. Das steht außer Frage. Ich würde nur jedem empfehlen, keine Studie mitzumachen. Und gegen Medikamente habe ich auch nichts. Es reagiert jeder auf ein anderes Medikament, da bin ich offen dafür. Nur muss es gewechselt werden, wenn man merkt, das klappt nicht.</p>

English	German
<p>It's not a big change because I had to take medicines before. I have 10 years of dialysis behind me, and of that 8 years of peritoneal dialysis and the rest haemodialysis. Well, I've always needed medication. I have suffered from kidney disease all my life. Well, drugs are not strange to me, though. The exact timeliness and accuracy of the medicines, that's partly new (Mr Becker, 00:30).</p>	<p>Also es ist keine besonders große Umstellung, weil ich vorher schon Medikamente nehmen musste. Ich hatte 10 Jahre Dialyse hinter mir und davon 8 Jahre Bauchfell- und den Rest Hämodialyse. Also war ich auch immer schon auf Medikamente angewiesen. Ich war mein Leben lang nierenkrank. Also Medikamente sind nichts Fremdes. Die genaue Pünktlichkeit und die Genauigkeit der Medikamente, das ist teilweise etwas neu.</p>
<p>In the beginning that was all, also the whole illness per se, very awkward. It took me long until I even told my family, that I needed dialysis because I couldn't cope with that at all. And I didn't know and blamed myself. Of course, it's nonsense afterwards, but ... but you learn that as time passes (...) in the beginning I also had the tablets in a cupboard and hid them and so on but now, they just lie around openly, the packet I mean. That's ... that's just part [of it] (Mr Weber, 06:44).</p>	<p>Am Anfang war das alles, auch die gesamte Erkrankung überhaupt, sehr unangenehm. Ich habe lange gebraucht, bis ich überhaupt meiner Familie gesagt habe, dass ich an die Dialyse muss und so, weil ich damit gar nicht zurecht gekommen bin. Und nicht wusste und mir irgendwie auch die Schuld gegeben habe. Was natürlich alles Quatsch ist im nachhinein, aber ... aber das lernt man dann mit der Zeit (...) am Anfang habe ich auch immer die Tabletten im Schrank gehabt und versteckt und so und jetzt liegen die auch immer offen da rum, also die Packung oder so. Das ist, ja ... das gehört einfach dazu.</p>
<p>There were so many [tablets]. It was 30 different types. And you needed to come to grips with them. At what time and how. There were halves and you needed to [remember] the colour ... if you manage to remember the colours, you come to grips with that. [...] Right now, it's just 15 drugs I take. It was double that in the beginning. It's ok now. Now that's ... with 7 years, if you do that 7 years, then it works (Ms Wagner, 17:55).</p>	<p>Weil das so viele waren. Das waren ja 30 verschiedene Sorten gewesen. Und mit denen dann zurecht zu kommen. Wann und wie. Da waren dann halbe dabei und dann musste man dann als an die Farbe ... wenn man dann die Farbe ungefähr sich zusammenstellt, dann kommt man auch ganz gut zurecht. [...] Jetzt sind es ja nur noch 15 Medikamente, die ich nehme. Das war ja schon das doppelte am Anfang. Aber jetzt geht es. Das ist jetzt ... mit 7 Jahren, wenn man das 7 Jahre macht, dann geht das</p>
<p>I : How long did it take until you didn't have any issue with taking these tablets, because of size and smell and so on? P: About 7, 8 months [...] Until I really got used to it. The first year after the transplantation was very difficult for me. I was often in hospital with a fever of 40, 41 [degrees centigrade]. Oh, that was really difficult. Infections again and again. Urinary tract infections again and again and ill and ill (Ms Maier, 53:29)</p>	<p>I: Wie lange hat das gedauert, bis Sie keine Probleme mehr hatten diese Tabletten zu schlucken, also wegen der Größe und dem Geruch und so? P: So circa 7, 8 Monate [...] Bis ich mich richtig so angewöhnt habe. Also erstes Jahr nach der Transplantation war sehr schwierig für mich. Ich war sehr oft im Krankenhaus. Mit Fieber, vierzig, einundvierzig. Oh das war wirklich schwierig. Entzündungen immer wieder, Blasenentzündung immer wieder und krank und krank.</p>

English	German
<p>That [taking medication too late] doesn't make me nervous or anything. Not over the years. In the beginning when I was newly transplanted, oh my God, that was 8 sharp, you could have set the alarm. In the evening, too. But the longer, you know, you're getting more relaxed (Ms Schulz, 20:28).</p>	<p>Also das [Medikamente zu spät nehmen] macht mich nicht nervös oder irgendwas. Also über die Jahre nicht mehr. Am Anfang, wo ich natürlich neu transplantiert war, mein Gott, das war natürlich Punkt 8, da konnte man den Wecker danach stellen. Und auch abends. Aber je länger, wissen Sie, da wird man ja ein bisschen lockerer.</p>
<p>That [kidney transplantation] was a real experience for me. I sometimes lay in my bed at night [...] sometimes tears in my eyes. Yes, that is such a wonderful emotion for me. I also went to church for the first time. I have cried so much. Because I was so lucky that one person gave me an organ. After such a long time. That was so emotional for me. And still today, again and again ... it's not that I now (...) would be somehow distressed or something. No, these are feelings of happiness. When I am moved to tears, that's happiness for me (Ms Müller, 04:29).</p>	<p>Das war für mich also ein Erlebnis. Ich habe als abends im Bett gelegen [...] als mal Tränen in den Augen. Ja, das ist für mich so ein wunderbares Gefühl. Ich war auch das erste Mal in der Kirche. Ich habe so geweint. Weil ich so ein Glück hatte, dass ein Mensch mir ein Organ gespendet hat. Nach so langer Zeit. Das war für mich so emotional. Auch heute immer wieder ... das ist jetzt nicht, dass ich jetzt (...) irgendwie jetzt gestresst wäre oder so etwas. Nein, das sind für mich Glücksgefühle. Wenn man ... mir die Tränen kommen, dann ist das für mich Glück.</p>
<p>But still, I didn't have to go to dialysis any more. And I could live my life more freely and that was rather new, different life compared to the time on dialysis (Ms Koch, 06:22).</p>	<p>Aber trotzdem, ich musste nicht mehr zur Dialyse. Und konnte freier mein Leben gestalten und das war ziemlich ein neues, anderes Leben wie die Dialysezeit.</p>
<p>Dialysis is far from being as good as a kidney. There are still differences (Mr Becker, 09:51).</p>	<p>Dialyse ist halt bei weitem nicht so gut wie dass eine Niere selbst kriegen kann. Das sind ja schon noch Unterschiede.</p>
<p>I've always said if it's meant to be, that I need to go to dialysis again, then that's as it is. Then I wouldn't lie here and cry or something. Then I know what awaits me and then I will be able to manage that life too (Ms Müller, 34:48).</p>	<p>Ich habe auch schon immer gesagt wenn es dann so sein sollte, dass ich wieder zu Dialyse muss, dann ist das so. Dann würde ich auch nicht hier liegen und weinen oder sonst irgendwas. Ich weiß dann, was auf mich zukommt und dann komme ich auch mit diesem Leben wieder klar.</p>
<p>I got on well, and they all liked me, too. That was kind of a little family where we lay with 5 people, well, that was really ... still today, I think so often about that. And I still visit them (Ms Wagner 2014, 17:17).</p>	<p>Ich kam gut zurecht und die hatten mich auch alle gern. Das war eine kleine Familie wo wir gelegen haben mit 5 Personen, also, das war wirklich ... heute noch, ich denke so oft dran. Und ich besuche die auch immer noch.</p>
<p>Either I take the medication or I leave it, then the kidney gets broken. And therefore, I decided for myself to take this medication regularly (Mr Bauer, 00:31).</p>	<p>Entweder nehme ich die Medikamente oder ich lasse sie sein, dann geht die Niere kaputt. Und deswegen habe ich für mich beschlossen ich nehme regelmäßig diese Medikamente.</p>

English	German
<p>And then there were changes in medication again and again and then you needed to get used to it over and over. [...] You constantly needed to get used to new medicines (Ms Koch, 02:33).</p>	<p>Und dann gab es immer wieder Tablettenumstellungen und dann musste man sich halt immer wieder dran gewöhnen. [...] Man musste sich halt ständig an neue Medikamente gewöhnen.</p>
<p>I also can ... when I'm tired early or something like that, I can go to bed and in any case, I wake up when it's time for my tablets. One always has it in the back of one's mind and [...] as I said, I don't set an alarm anymore or anything ... I wake up, take them, and then I can go back to sleep (Mr Weber, 10:12).</p>	<p>Ich kann mich auch ... wenn ich jetzt mal abends irgendwie früher müde bin oder so, ich kann mich auch schon hinlegen und ich werde auf jeden Fall um den Zeitpunkt der Tabletteneinnahme wach. Das hat man immer so im Hinterkopf und ... also muss mir auch ... ich stelle mir auch wie gesagt keinen Wecker mehr und so ... ich werde dann wach, nehme die dann und kann dann auch weiter schlafen.</p>
<p>I don't notice anything. The immunosuppressives build a level in the blood and if you forget the medication and take it three or four hours later or maybe even not at all, that's not so bad that you feel pain or anything like that. You don't notice that (Mr Hoffmann, 02:46).</p>	<p>Da merke ich nichts davon. Die Immunsuppressiva baut ja im Blut einen Spiegel auf und wenn Sie das Medikament jetzt mal vergessen und nehmen das 3 oder 4 Stunden später oder auch vielleicht mal gar nicht, dann ist das nicht so gravierend, dass Sie jetzt Schmerzen kriegen oder was. Das merken Sie nicht.</p>
<p>But with me it's the case that I have a bad conscience rather quickly, or I just hope that nothing has happened [...] and then I'm angry with myself to a certain extent if I don't even manage to take them regularly. Also because that's really ... that's twice a day, I find that's really not asking too much. As I said before, I am a bit angry with myself and have a bit of a bad conscience because I think, actually it's ... one of the few things regarding illness you can really influence and then you should do that, whatever you can really do, you should do that, I think (Ms Schmitt, 13:50).</p>	<p>Aber bei mir ist es dann schon so, dass ich dann ziemlich schnell ein schlechtes Gewissen habe oder so oder hoffe, dass einfach nichts passiert ist [...] und dann ärgere ich mich immer so ein Stück weit über mich selber wenn ich das nicht einmal mehr hinkriege die regelmäßig zu nehmen. Weil das ist auch wirklich ... das sind <u>zweimal</u> am Tag, das ist wirklich nicht zu viel verlangt finde ich. Wie gesagt, ich ärgere mich dann immer ein bisschen über mich selber und habe so ein bisschen schlechtes Gewissen weil ich denke eigentlich ist es ja das ... eins von den wenigen Dingen was Krankheiten angeht, die man wirklich beeinflussen kann und dann sollte man das, was man eben wirklich machen kann auch machen, finde ich.</p>

English	German
<p>Well, by trying to control it [medication-taking] again before I go to bed. That I really say I put the box with the day's tablets back and get the new one out. And that's something where I can say I have self-control, if the box is empty [...] or I can also see at the small box where I just put in tablets for two different time points. In the meantime, when I go to bed at night, I shake the box to see whether something's inside or not (Mr Huber, 07:00).</p>	<p>Gut, indem ich es [Medikamenteneinnahme] auch versuche nochmal zu kontrollieren, bevor ich zu Bett gehe oder so. Dass ich wirklich sage, ich lege die Tablettenschachtel mit den Tabletten von dem Tag lege ich zurück und hole schon die neue raus. Und das ist zum Beispiel was, wo ich sage, dann habe ich praktisch Selbstkontrolle, ob auch die Schachtel leer ist [...] oder ich sehe es auch immer wieder an meinen ... an der kleinen Schachtel, wo ich nur für zwei Zeiten die Tabletten reinfülle. Mittlerweile ist es so, dass, wenn ich abends zu Bett gehe, dass ich auch noch mal an der Schachten wackle um zu sehen ist noch etwas drin oder ist nichts mehr drin.</p>
<p>Now, you're in a meeting, and you are reminded in the meeting, you need to take your tablets. It rattles or the mobile rings or whatever. That's quite difficult. That's the problem (Mr Schneider, 19:13).</p>	<p>Jetzt haben Sie aber eine Sitzung, und Sie werden dann in der Sitzung erinnert, Sie müssen jetzt die Tabletten nehmen. Es rappelt oder irgendetwas oder das Handy bimmelt oder was auch immer. Das ist ziemlich schwierig. Das ist die Problematik.</p>
<p>As I said, one needs to think about it most when the weekend is due or a bank holiday. 'How long does that [medication] last and when do I need to get a prescription at the latest and so on?' But then you check how many are left and than you know exactly it lasts for certain days, and done. In the meantime one knows that when I give the prescription to the pharmacy at this or that time, I'll definitely have it in on the specific day, or not. Well, in the meantime, I also know the pharmacy's delivery time and so on. (Mr Weber, 17:27).</p>	<p>Am meisten überlegen muss man noch, wie gesagt, wenn jetzt ein Wochenende vor der Tür steht oder auch mal Feiertage, wie lange komme ich denn damit noch und wann muss ich denn mir allerspätestens ein Rezept holen oder so. Aber da kuckt man halt einmal wie viele noch da sind und dann weiß man genau das reicht noch so und so viele Tage und fertig. Man weiß auch mittlerweile in der Apotheke, dass wenn ich das Rezept um die oder die Uhrzeit abgebe, habe ich es auf jeden Fall noch an dem Tag oder auch nicht. Also ich kenne mittlerweile auch die Lieferzeiten von der Apotheke und so.</p>

English	German
<p>And then I needed to tell my medic that he ticks the box, how do you say, <i>idem</i>? [...] That he ticks the box and the pharmacist is not allowed to give me something different. But then I must pay the difference the health insurance doesn't cover. And that's expensive again. That's also not good. That's what also annoys me all the time. Some medication, they [pharmacists] say it's the same, same effect. I have experienced that, I have then taken the drug but it didn't help me. And then I told my medic [...] that he ticks the <i>aut idem</i> box to get me the original (Ms Maier, 48:05).</p>	<p>Und dann musste ich meinem Arzt das erzählen, dass er dann immer da Kreuzchen macht, wie sagt man, idem? [...] Da ein Kreuzchen macht, dass Apotheker darf nicht anderes geben. Aber da muss ich zum Beispiel diesen Betrag, was die Krankenkasse nicht zahlt, selber zahlen. Das wird wieder teuer. Das ist auch nicht so gut. Das was mich immer so, was soll ich sagen, nervt. Einige Medikamente, die sagen nein, das ist das gleiche, die gleiche Wirkung. Ich habe schon einmal erlebt, ich habe dann Medikament genommen und der hat mir nicht geholfen. Und da habe ich dann meinem Arzt gesagt [...] dass er dann <i>aut idem</i> angekreuzt hat, dass ich dann Original gekriegt hatte.</p>
<p>I had to decide, when I registered for a transplant, that I take this medication and that they're not really harmless. However, you need to decide, do you want to go to dialysis forever as the young woman I was back then or do you want to live your life and then you just take this medication [...] Because if you are as young as I was then and you have a small child you must consider what the future holds. Because being away three times a week and there is a small boy at home, that's not really great (Ms Schulz, 03:09).</p>	<p>Ich musste mich ja entscheiden, wie ich mich angemeldet habe für die Transplantation, dass ich solche Medikamente nehmen und dass die nicht gerade ungefährlich sind. Aber da muss man sich entscheiden halt, will man jetzt ewig an die Dialyse gehen als junge Frau damals oder willst du noch ein bisschen was vom Leben haben und man nimmt halt diese Medikamente. [...] Weil wenn man halt so jung ist wie ich damals war und ein kleines Kind hat, musste man ja kucken, was man in die Zukunft bringt. Weil dreimal die Woche weg zu sein mit einem kleinen Bub daheim, das ist nicht ganz toll.</p>
<p>I mean freer, not to go to dialysis every other day and I could say 'yes, on Wednesday I go there and there' without planning much. And ... when you are on dialysis, that's not possible (Ms Koch, 06:39)</p>	<p>Freier meine ich damit, nicht jeden zweiten Tag zur Dialyse und dann konnte man schon sagen, ja am Mittwoch gehe ich mal dahin, ohne was groß zu planen. Und ... das ist ja, wenn an der Dialyse ist, nicht gegeben Ms Koch (06:39)</p>
<p>I deeply trust [name of the transplant centre]. By the doctors and I always say 'without them and without by two doctors here in [town] I would be nothing'. Well, they're really ... I can talk with them about everything, regardless of there or here, we (...) discuss that together and make and do. So, I'm really in the best hands (Ms Müller, 13:39).</p>	<p>Ich schwöre auf [Name des Tx-Zentrums]. Auf die Ärzte und ich sage immer "ohne die und ohne meine beiden Ärzte hier in [Stadt] wäre ich nichts". Also die sind wirklich ... ich kann mir denen über alles reden, egal ob dort oder hier, wir (...) tun dann zusammen das dann ausdiskutieren und machen und tun. Also ich bin eigentlich in den besten Händen.</p>

English	German
<p>Well, I wasn't the kidney but I was Ms [Schulz]. I mean, well ... I was 25 then, I could have been his daughter. He also had children of my age. He's also ... I have a little paddock at the edge of the woods and they [nephrologist and his wife] don't live very far from there. And when they went for a walk, he brought me a pot of tea and made me drink it. You know, transplant recipients need to drink a lot. And he cared like ... yes, cared a lot. And I could call him day or night. Whenever I wanted. That was never an issue (Ms Schulz, 08:23).</p>	<p>Also ich war nicht die Niere, sondern ich war die Frau [Schulz]. Also ich meine ... gut, er hat mich ... ich war damals 25, ich hätte auch können seine Tochter sein. Der hatte auch Kinder in dem Alter. Also er ist auch ... ich habe so eine kleine Pferdekoppel oben am Waldrand und die wohnen nicht so ganz weit weg. Und wenn sie spazieren gekommen sind, hat der mir als eine Kanne Tee mitgebracht und den musste ich dann trinken. Sie wissen ja, Transplantierte müssen viel trinken. Also er hat sich gekümmert wie ... ja, hat sich sehr gekümmert. Und ich konnte ihn anrufen Tag und Nacht. Wann immer ich wollte. Da gab es gar kein Thema.</p>
<p>The doctors also changed. That's then ... with her I was... with the first one I was 30 years. Yes, there's confidence in her. Now, it's men. Women are somehow ... I don't know ... it's a different relationship with each other. Although, the men are also alright, yes. But it's not like ... as intimate when you say something. It's not. But now it's ok again, I got over it now (Ms Wagner, 02:28).</p>	<p>Die Ärzte haben auch gewechselt. Das ist dann ... bei ihr war ich ... bei der ersten war ich 30 Jahre. Das ist ja doch ein Zutrauen zu ihr. Jetzt sind das Männer. Frauen sind doch irgendwie ... ich weiß nicht ... man hat doch irgendwie ein anderes Verhältnis zueinander auch. Obwohl die Männer gehen auch, ja. Aber es ist nicht so wie ... so intim wie wenn man irgendetwas sagt. Das ist es nicht. Aber es geht jetzt wieder, jetzt habe ich das überwunden</p>
<p>Medical qualification is the biggest help one could provide by explaining the situation so that I can understand why it's reasonable to do it exactly this way. Not only to instruct but to try and explain the importance and context (Ms Wolf, 14:38).</p>	<p>Medizinische Qualifikation [...] die größte Hilfestellung, die man mir geben kann, indem man mit die Situation so erklärt, so dass ich verstehen kann weshalb es vernünftig ist dies jetzt genau so zu tun. Nicht nur anweisen, sondern die Notwendigkeit und die Zusammenhänge versuchen zu erklären.</p>
<p>Because actually I am the person who is responsible for taking my medication. A doctor ensures that I get it and that he examines me and says you need this and that medication. That I take it in the end is actually my responsibility (Ms Koch, 10:11).</p>	<p>Weil eigentlich bin ich ja der Mensch, der verantwortlich ist meine Medikamente zu nehmen. Ein Arzt sorgt ja dafür, dass ich sie bekomme und dass er mich untersucht und sagt die und die Medikamente brauchen Sie. Dass ich sie letztendlich einnehme ist ja eigentlich meine Verantwortung.</p>



English	German
<p>And of course [nurses] they paid attention that you took the immunosuppressants. [...] The immunosuppressants were personally brought to me, and also to the other patients, at the appropriate times. So that they were really taken. That was very well organised. Because these are the most important drugs you shouldn't forget. Yes, they have solved that very well (...) and then it slowly got integrated into daily life, every day (Mr Hoffmann, 15:03).</p>	<p>Und die [Pflegerinnen] haben natürlich auch drauf geachtet, dass man die Immunsuppressiva nimmt. [...] die Immunsuppressiva, die hat man mir dann, und auch den anderen Patienten, persönlich um die Uhrzeit gebracht. Damit die auch genommen worden. Weil das war sehr gut gemacht. Weil das sind die wichtigen Medikamente, die man nicht vergessen sollte.</p>
<p>But it ... it's a matter of individual nurses. There are some who, for my taste, perhaps did a bit too much [...] on the other hand [...] the nurses are instructed, yes, to educate everyone concerning these things. And I suppose they are experienced with that [...] well, maybe there are some [patients] who don't take things seriously. Let's call it like this. (Mr Becker, 27:32).</p>	<p>Das ist halt eine Frage vom einzelnen Pflegepersonal. Es gibt so welche, die für meinen Geschmack vielleicht so ein bisschen zu viel da [...] auf der anderen Seite [...] das Pflegepersonal ist angehalten ja auch das jedem beizubringen. Und ich nehme an, die haben da ihre Routine drin, [...] sind auch halt [...] vielleicht welche dabei, die das nicht so ernst nehmen. Nennen wir es mal so.</p>
<p>Well, when I'm in hospital, they [nurses] should have a look at that, depending on how ... your illness is at the moment. [...] But also, there are some who just put your daily ration there and then, devil may care. The next day, there's another nurse, and then ... they may say something. Not until midday, what's up with the tablets, why haven't you taken them? (Mr Schneider, 30:33).</p>	<p>Ja gut, wenn ich im Krankenhaus liege, da sollten die schon mal drüber kucken, je nachdem wie der grad ... Ihre Krankheit ist. [...] Es gibt aber auch welche, die stellen einfach die Tagesration hin und nach mir die Sintflut. Am nächsten Tag kommt eine andere Schwester, und dann ... die sagen dann vielleicht etwas. Erst gegen Mittag, was haben Sie denn mit den Tabletten, warum haben Sie die nicht genommen?</p>
<p>Sometimes it wouldn't be bad if my husband, when I fall asleep on the sofa watching telly, that he could bear in mind and says, 'have you taken your tablets? Do you want me to bring them to you?' That would be great. That would be very good, it would be very helpful and I think one gets this feeling that someone thinks about you. This warm feeling that someone ... you matter to someone who reminds you, who cares. Unfortunately, that's not the case (Ms Maier, 22:24).</p>	<p>Manchmal wäre schon nicht schlecht, wenn dann mein Mann würde, wenn ich so, auf dem Sofa einschlafe, beim Fernsehen kucken, ob er dann dran denkt und sagt hast Du Medikament genommen? Soll ich Dir bringen? Das wäre toll. Das wäre sehr gut, das wäre große Hilfe und ich denke dadurch Du kriegst Gefühl jemand denkt über Dich. Das, so diese, wieder so ein warme Gefühl, dass jemand, wie soll ich das sagen, dass dann jemand so ... Du bist nicht egal jemand, dass auch mitdenkt, dass er auch mitsorgt. Das leider nicht.</p>

English	German
<p>When someone reminds me, I take it really, really seriously. Especially when someone who is very close to me reminds me, then for me that's ... well, that mean a lot to me [...] that this person thinks of me, that he cares, and that's what I see then. Therefore I actually find this ... for me, that's ... if someone tells me to take them [tablets], I find it great and I actually find that important then (Ms Schmitt, 05:54).</p>	<p>Und was mit Sicherheit nicht geht, täglich oder zu den angegebenen Zeiten die Tabletten zu holen, dann aus der Packung zu lösen und dann einzunehmen. Da ist überhaupt keine Kontrolle drin. Also es muss meiner Meinung nach ... die Tabletten müssen schon gerichtet sein (...) wie gesagt, die Wochenbox und die Tagesbox, die hilft enorm.</p>
<p>If you go out with friends and ... I then try to retreat somehow. There's no need for everyone to know that I ... take my 2 tablets or however many it is, in the evening. In the meantime, I don't really care, in the beginning, that was a bit more difficult. I paid attention that no one watched and so on. Sometimes it is ... or you have the feeling that you are looked at strangely. No one knows what that [medication] is. (...) Sometimes, if you go out at night to the ... if you have an appointment, be it ... I also had it in cinema. Well, it's dark in there, no one watches. But as I said, I realised it at some football matches ... and then the [intake] time was also a bit delayed, because it didn't exactly fit the half time. But finally it has always worked quite well. Only, in the beginning I paid more attention that maybe not everyone notices (Mr Weber, 05:40).</p>	<p>Ja, wenn Sie jetzt mal mit Freunden weg sind oder so und ... ich versuche dann schon mich irgendwie zurück zu ziehen. Das muss ja dann nicht jeder sehen, dass ich da ... mir meine 2 Tabletten oder wie viele es sind, abends, da einnehme. Mittlerweile ist mir das auch ziemlich egal, am Anfang war das ein bisschen schwieriger. Da habe ich dann schon gekuckt, dass es keiner sieht oder sowas. Es wird auch manchmal ... oder man hat dann das Gefühl, man wird dann gleich komisch angekuckt. Es weiß ja keiner, was das ist, oder so. (...) Also manchmal so, wenn man abends halt weggeht und in die ... einen Termin hat, sei es jetzt ... ich hatte es auch schon im Kino. Gut, da ist dunkel, da sieht es ja keiner. Aber wie gesagt, bei einigen Fußballspielen oder so, da ist es mir halt aufgefallen ... da war dann auch die Zeit ein bisschen verschoben, weil halt mit der Halbzeit es nicht ganz gepasst hat oder so. Aber schlussendlich hat es immer auch ganz gut funktioniert. Nur, dass ich am Anfang mehr darauf geachtet habe, dass es vielleicht nicht jeder mitbekommt oder so.</p>
<p>Well, for me, it's no problem to take medication daily. I'm used to that already since I was a child. I have ... I had diabetes since I was seven and needed to inject [insulin]. At that time my mother did that. Of course, I did it myself later. Until the transplantation. That was daily medication too. Therefore, I'm used to that from a very young age, I don't have an issue with it (Mr Hoffmann 00:32)</p>	<p>Gut, also für mich ist das jetzt kein Problem, täglich die Medikamente zu nehmen. Also ich bin da schon dran gewöhnt seit Kindesbeinen auf. Ich habe ... ab dem siebten Lebensjahr hatte ich Diabetes und musste spritzen. Damals hat das meine Mutter gespritzt. Später habe ich es dann natürlich selbst gemacht. Das ist bis zur Transplantation gegangen. Das waren auch täglich Medikamente. Von daher, ich bin das von klein auf gewöhnt, ich habe kein Problem damit.</p>

English	German
<p>That's not annoying that I take tablets. So, in the meantime I got used to that, that part of it [life] just like eating and drinking (Mr Huber, 07:48).</p>	<p>Das ist auch jetzt nicht störend, dass ich da Tabletten nehme. Also, mittlerweile habe ich mich da so dran gewöhnt, das gehört dazu wie essen und trinken. Huber 7:48</p>
<p>It's just like driving a car. When the driver's licence is new and you get a new car, you are relatively insecure and at some point you don't think about what you do while driving but you do it all automatically and you are just calmer (Mr Richter, 16:09).</p>	<p>Das ist wie beim Autofahren. Wenn man den Führerschein neu hat und ein neues Auto kriegt, dann ist man halt noch relativ unsicher und irgendwann denkt man beim Autofahren gar nicht mehr was man da macht, sondern es geht alles automatisch und man ist halt ruhiger.</p>
<p>As far as possible without major problems, I can also adapt my life a bit. If I know I need to take my medication at 8, I can move my breakfast to after 8 because I'm not supposed to take them before breakfast. [...] One doesn't work without the other. But I'm trying to live my life as normally as possible (Mr Becker, 15:22).</p>	<p>Sofern es ohne große Probleme möglich ist, kann ich auch mein Leben ein bisschen anpassen. Wenn ich weiß ich muss um 8 Uhr meine Medikamente nehmen, dann kann ich mein Frühstück dann auf nach 8 verlegen, weil ich soll die ja vor dem Frühstück nicht nehmen. [...] es geht halt das eine ohne das andere nicht. Aber ich versuche es halt mein Leben so gut es geht irgendwie zu leben</p>
<p>I cannot [change] my whole life [...] 'I cannot eat anything anymore tonight because I must take my medication at 9', well, I really don't want it this way. And that would stress me at some point and I think ... I try to integrate it as much along the way as possible and that I have as little problems with it as possible. And for me, that would ... well, it would be too stressful for me if I had to plan my life around this [medication-taking] (Ms Schmitt, 11:11).</p>	<p>Ich kann nicht mein ganzes Leben [...] ,ich darf heute Abend nichts mehr essen weil ich muss um 9 meine Medikamente nehmen', also das will halt überhaupt gar nicht haben. Und das würde mich dann auch irgendwann stressen und ich glaube ... ich versuche es halt einfach so nebenbei wie möglich zu machen und dass ich da so wenig Probleme wie möglich mit habe und das würde mir ... also wäre für mich anstrengend wenn ich da immer mein Leben danach planen müsste.</p>
<p>The Advagraf [immunosuppressive drug] tablets were a bit inconvenient because they were taken at 10. And the other one, the Rapamune [IM] tablets, they are taken in the morning with all the other tablets. [...] It [Advagraf] shouldn't be in touch with the Cellcept and Myfortic [immunosuppressive drugs]. I don't know why it's like that. But it was annoying when you went somewhere. You absolutely needed to remember the 10 o'clock (Ms Klein, 13:43).</p>	<p>Die Advagraf war ein bisschen dumm, weil die um 10 Uhr genommen worden ist. Und die andere, die Rapamune, die wird morgens mit den anderen Tabletten genommen. [...] Die durfte mit der Cellcept und der Myfortic nicht in Berührung kommen. Warum das jetzt so war, das weiß ich nicht. Aber das war jetzt halt blöd, wenn man unterwegs war. Da musste man unbedingt an die 10 Uhr denken.</p>

English	German
<p>Yes, and when I go on holiday or occasionally visit someone for some days or a whole day, I take along everything. I count how many [tablets] I need, take a few more, you never know if you then need longer, then I take along some more and then I take them there as usual. Once it happened, I was in Spain, I took all ... and I wasn't allowed to take along so many things. There's ... I bought a ticket that only allowed hand luggage in certain measures. And then I counted all medications and I took along some extra of course. I then miscounted one medicine and that was lacking for 5 days, let's put it like that. At the end (Ms Maier, 15:23).</p>	<p>Ja, und wenn ich dann verreise oder mal jemanden besuche da für paar Tage oder für einen Tag, einen ganzen Tag sagen wir so, nehme ich einfach mit alles. Ich zähle wie viele [Tabletten] ich brauche, nehme ich ein bisschen mehr, man weiß es nicht, ob man dann doch länger braucht, dann nehme ich dann ein bisschen mehr und nehme ich da auch immer wieder weiter. Einmal ist mir passiert, ich war in Spanien, ich habe alle ... und ich durfte nicht so viel mitnehmen. Da ist ... ich habe so ein Ticket gekauft, da darf man nur die Handgepäck nehmen, so immer so bestimmte Maße haben. Und da habe ich alle Medikamente gezählt und ein bisschen mehr genommen natürlich. Ich habe dann mit einem Medikament mich verzählt und das hat mir so 5 Tage gefehlt, sagen wie so. So am Schluss.</p>
<p>I know exactly ... at 9 in the morning and at 9 at night I take the tables, regardless what I did before or what I'm going to do afterwards. That's just the way it is [...] That fits [his life] nicely, and as I said, the timing worked out, worked out like that [...] directly after the hospital stay, that was a bit annoying at the weekends, if I wanted to sleep longer or something (Mr Weber, 16:07)</p>	<p>Ich weiß genau ... morgens um 9 und abends um 9 nehme ich die Tabletten, egal was ich vorher gemacht habe, was ich danach noch mache. Das ist einfach so. [...] Das passt gut rein [in sein Leben] und wie gesagt, das mit der Uhrzeit, das hat sich dann, das hat sich dann so ergeben [...] direkt nach dem Krankenhaus, aber das war dann halt am Wochenende ein bisschen nervig, wenn man dann mal länger schlafen wollte oder so.</p>
<p>When I was busy or away [from home] ... with the family and then you talked and then you sometimes forgot it [to take the medication] (Ms Koch, 06:21).</p>	<p>Und wenn ich dann halt beschäftigt war oder mal weg war und ... bei der Familie und dann hat man geredet und dann hat man das auch mal vergessen</p>
<p>The whole time I suffered from kidney disease I actually never gave a big thought to why, why, why I take the medication, instead I have always just found it helpful (Ms Wolf, 05:42).</p>	<p>Aber in der ganzen Zeit meiner Nierenerkrankung hatte ich mir an für sich nie groß Gedanken gemacht, warum, weshalb und wieso ich die Medikamente nehme, sondern ich habe das immer nur als Hilfe empfunden.</p>
<p>Oh well, that's hard in the beginning. The strange words and what it's good for and everything (Ms Wagner, 18:31).</p>	<p>Ach ja, das ist schon schwer am Anfang. Mit den fremden Wörtern und für was es sein sollte und alles.</p>

English	German
<p>That there are so many tablets that are all white. They have the same size, almost the same size, maybe they are a bit flatter. Ok, now you sort the medication, if you have approximately 7 to 10, and sometimes you forget to put them in a certain compartment [of a medication box] and put them in another compartment. And you sometimes don't realise it (Mr Schneider, 15:25).</p>	<p>Dass es viele Tabletten gibt, die sind alle weiß. Die haben die gleiche Größe, fast die gleiche Größe, sind vielleicht ein bisschen flacher. Gut, jetzt sortieren Sie die Medikamente wenn Sie so 7 bis 10 haben und vergessen manchmal in das eine Fach [des Medikamentendispensers] die reinzulegen und tun sie in das andere Fach. Und das merken Sie manchmal nicht.</p>
<p>Well, I don't have difficulties to swallow these tablets, and besides the taste and smell it's no problem. And especially the Sandimmun [immunosuppressive medication], they don't smell very nicely. [...] That's like any other tablet. If you don't pay attention, you get the smell in your nose and that makes is a little more unpleasant to swallow. But besides that, you can swallow it just as any other tablet, too (Mr. Richter, 13:34).</p>	<p>Also ich habe keine Schwierigkeiten so Tabletten zu schlucken und abgesehen vom Geschmack und Geruch ist es keine Schwierigkeit. Und speziell die Sandimmun, die riechen ja nicht sehr schön. [...] Das ist wie mit jeder anderen Tablette auch. Das ist halt wenn man nicht aufpasst, dann kriegt man den Geruch in die Nase und das macht das ein bisschen unangenehmer zu schlucken. Aber ansonsten, schluckt sich das wie jede andere Tablette auch. Mr Richter 13:34</p>
<p>I'm at home then and I want to clean the flat a little bit. And when I am done with that, the rest of the day is over for me, I am in pain, just pain Then I rest and for two days following I am always in pain. Don't want to do anything, get up. It's really, very, very bad (Ms Maier, 04:43).</p>	<p>Ich bin dann zuhause und dann möchte ich einfach bisschen die Wohnung putzen. Und wenn ich das gemacht habe, dann Rest von dem Tag ist für mich vorbei. Das kann man sagen, ich habe nur Schmerzen, nur Schmerzen. Dann lege ich mich hin, also dann nachher zwei Tage, ich habe nur Schmerzen. Habe keine Lust was zu machen, aufzustehen. Ist richtig ganz, ganz schlimm.</p>
<p>I gained a lot of weight, you know. I don't like that. Because I'm fat, walking and working that's ... must be slow. No dress fits any more. That's morally [psychologically] not good (Ms Yilmaz, 05:03).</p>	<p>Ich habe viel zugenommen, wissen Sie das. Gefällt mir nicht mehr. Deswegen das ist immer dick und laufen oder arbeiten das ist ... langsam machen. Kein Kleid mehr passen. Das ist moralisch nicht gut.</p>
<p>No (...) well, I don't have side effects, no detectable side effects. The only thing I have because of the medicines, low blood pressure. And I notice when I bend down and get up again and a little dizziness. Because the blood pressure is quite low. (...) But aside from this, because of the immunosuppressive drugs, I don't notice anything, thank God (Mr Huber, 10:52).</p>	<p>Nein (...) also ich habe keine Nebenwirkungen, keine feststellbaren Nebenwirkungen. Das einzige, was ich habe durch die Medikamente, niedrigen Blutdruck. Und da merke ich schon wenn ich mich bücke und stehe wieder auf und dann ein bisschen Schwindel. Also weil der Blutdruck recht niedrig ist. (...) Aber ansonsten von den Immunsuppressiva, da merke ich nichts, Gott sei Dank.</p>

English	German
<p>When I have a partner or a partner, I need to be very, very careful that I don't catch an [urinary tract] infection for example, which is a little challenging. I cannot be unrestrained ... that's a real problem ... if you want to let yourself go and it doesn't work because the damned germs and the kidney are always in the back of your mind, that's not easy. Generally, you start to have problems allowing closeness (Ms Schmitt, 04:46).</p>	<p>Wenn ich irgendwie eine Partnerin habe oder einen Partner, dass ich da eben mega, mega aufpassen muss, dass ich einfach keinen Infekt kriege zum Beispiel, das einfach ein bisschen schwierig ist. Und dass ich da nicht uneingeschränkt also... ich habe nämlich ein Problem ... wenn man sich irgendwie fallen lassen möchte oder sowas und das ist dann einfach nicht so toll klappt weil mal immer noch im Hinterkopf hat verdammt da sind dann wieder die Keime und die Niere und das ist nicht so einfach dann eben geht das natürlich ... allgemein bei mir dann auch ...generell fängt man dann an, dass man Probleme hat Nähe zuzulassen und so.</p>
<p>Because of the medication and this and that one must, as I said before, accept enough limitations and shut oneself away from friends for half a year and tell them 'no, we can't meet at the moment'. Yes, partly friends would like to come and have a look how everything works. Visit me. But that's not possible because it's still too difficult. Or my little grandchildren for example. I can't see my little grandchildren at the moment, that's also not that easy. Well, yes, 6 months are bearable (Mr Becker, 33:54).</p>	<p>Durch die Medikamente und dies und da und sell und jenes genug Einschränkungen hinnehmen und sich von den Bekannten erstmal ein halbes Jahr abkapseln und sagen nein, Treffen können wir im Moment keins machen und so. Ja, teilweise würden Bekannte schon gerne kommen und sagen ja, kucken wie es geht, Besuch machen und so. Aber ist halt nicht, weil im Moment ist noch zu schwierig. Oder wie die Enkelchen zum Beispiel, dass ich die Enkelchen im Moment nicht sehen kann, das ist auch nicht so einfach. Ja gut, 6 Monate sind ja auszuhalten.</p>
<p>At some point, you just said it needs to be that way. I mean you have a new life because of the medicines and therefore I came to terms with ... the small disadvantages. I saw it as small disadvantages. I was frightened in the beginning, but as I said before, these were little disadvantages or little obstacles (Ms Koch, 05:05).</p>	<p>Irgendwann hat man gesagt, das muss so sein. Du kriegst durch die Medikamente ein neues Leben, sage ich mal und da habe ich mich eigentlich damit abgefunden, dass das ... die kleinen Nachteile halt waren. Ich sah es als kleine Nachteile. Ich bin zwar am Anfang erschrocken, aber ansonsten, wie gesagt, waren es dann für mich kleine Nachteile oder kleine Hindernisse.</p>
<p>Well, [medication-taking] is no problem, it's become routine, I take the medicines regularly (Mr Huber, 00:33).</p>	<p>Also, das [Medikamenteneinnahme] ist kein Problem, das ist eine Routine geworden. Ich nehme die Medikamente regelmäßig.</p>
<p>As a patient you only have an idea how healthy people feel. Because you have long forgotten how it was when you were healthy. And to relate this to medication now is really difficult (Mr Richter, 26:08).</p>	<p>Also als Patient hat man ja eigentlich nur eine Vorstellung, wie andere sich fühlen, die gesund sind. Weil man schon längst nicht mehr weiß wie es war als man gesund war. Und das jetzt an Medikamenten festzumachen ist ganz schwierig.</p>

English	German
<p>You shouldn't forget that there may be problems now and then and that the organ cannot last forever (Mr Huber, 28:34).</p>	<p>Aber man darf nicht vergessen, dass es immer wieder zu Problemen kommen kann und dass das Organ auch nicht unendlich halten kann.</p>
<p>It would be great if I then had a husband who really helped me more [...] sometimes prepares everything for me. I never get this [...] and I never got it, that anyone prepares things [medication] for me and cares and cares for me. Well, when I'm very, very ill, really ill, with a cold or a fever, for example. And when it's on a weekend and my husband is home, he fetches my [medication] box and brings it to me. He does that, not gladly, but then he does. But not with the emotion [...] he only does, because he must do. Not because of great love or care, let's say (Ms Maier 2014, 45:46).</p>	<p>Es wäre schon toll, wenn ich dann einen Mann hätte, der wirklich mehr mir hilft [...] mal vorbereitet alles für mich. Das kriege ich nie [...] das kriege ich nie und habe ich auch nie gekriegt, dass jemand alles für mich vorbereitet und sorgt und sorgt für mich. Gut, wenn ich sehr, sehr krank bin, richtig krank, so mit Erkältung und zum Beispiel Fieber. Und wenn dann gerade Wochenende ist und mein Mann zuhause ist, dann holt der schon meine Box raus und bringt mir. Das macht er, nicht so gerne, aber dann macht er das. Aber nicht so mit einem Gefühl [...] er macht nur, weil er, ja muss so tun. Nicht aus großer Liebe und Sorge, sagen wir so.</p>
<p>It [the patient] is a person there [...] it's not a number. It's a person who has emotions, demands, appreciation [...] and all that. I haven't experienced that with many doctors. Rather the contrary. Also at the unis [university hospitals] [...] also there, I [faced] such behaviour ... I had to put up with this (Mr Schröder 2014, 26:50).</p>	<p>Da ist ein Mensch [...] da ist keine Nummer. Da ist ein Mensch, der hat Gefühle, Ansprüche, Wertschätzung [...] und all das. Das habe ich ... Ärzten nicht erlebt. Eher das Gegenteil. Auch in den Unis [...] ich bin auch da bin ich solchem Verhalten ... musste ich mir gefallen lassen.</p>

## Appendix 12: Ethical Approval – German Society of Nursing Science

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Frau  
Anne Rebafka  
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Sehr geehrte Frau Rebafka,

die E-DG-P hat Ihren Antrag „Medication Adherence Following Kidney Transplantation: Patients' Perspective“ (Nr. 14-002, eingereicht am 15.01.2014) geprüft und erteilt Ihnen hiermit das ethische Clearing.

Wir wünschen Ihnen viel Erfolg!

Witten, den 26.02.2014

A handwritten signature in blue ink, which appears to read 'Sabine Bartholomeyczik'. The signature is written in a cursive style.

Prof. Dr. Sabine Bartholomeyczik  
Vorsitzende der Ethikkommission der DGP



## Appendix 13: Ethical Approval – Ethics Committee of the Cardiff University School of Healthcare Sciences

School of Health Care Sciences  
Head of School and Dean Professor Sheila Hunt

*Ysgol Gwyddorau Gofal Iechyd*  
*Pennaeth yr Ysgol a Deon Yr Athrawes Sheila Hunt*



07 March 2014

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Dear Anne

### Application for School Research Ethics Committee approval

Your project entitled **'Medication Adherence Following Kidney Transplantation: Patients' Perspective'** has now been approved by the School of Healthcare Sciences Research Ethics Committee of Cardiff University. This approval is based on the amended documents submitted on 2 January 2014 identified as:

- research proposal dated 31.2.14 in the running header,
- version 3 of the participant information sheet, dated 31.2.14,
- version 3 of the consent form, dated 31.2.14.

If you make any substantial changes with ethical implications to the project as it progresses you need to inform the SREC about the nature of these changes. Such changes could be: 1) changes in the type of participants recruited (e.g. inclusion of a group potentially vulnerable participants), 2) changes to questionnaires, interview guides etc. (e.g. including new questions on sensitive issues), 3) changes to the way data are handled (e.g. sharing of non-anonymised data with other researchers)

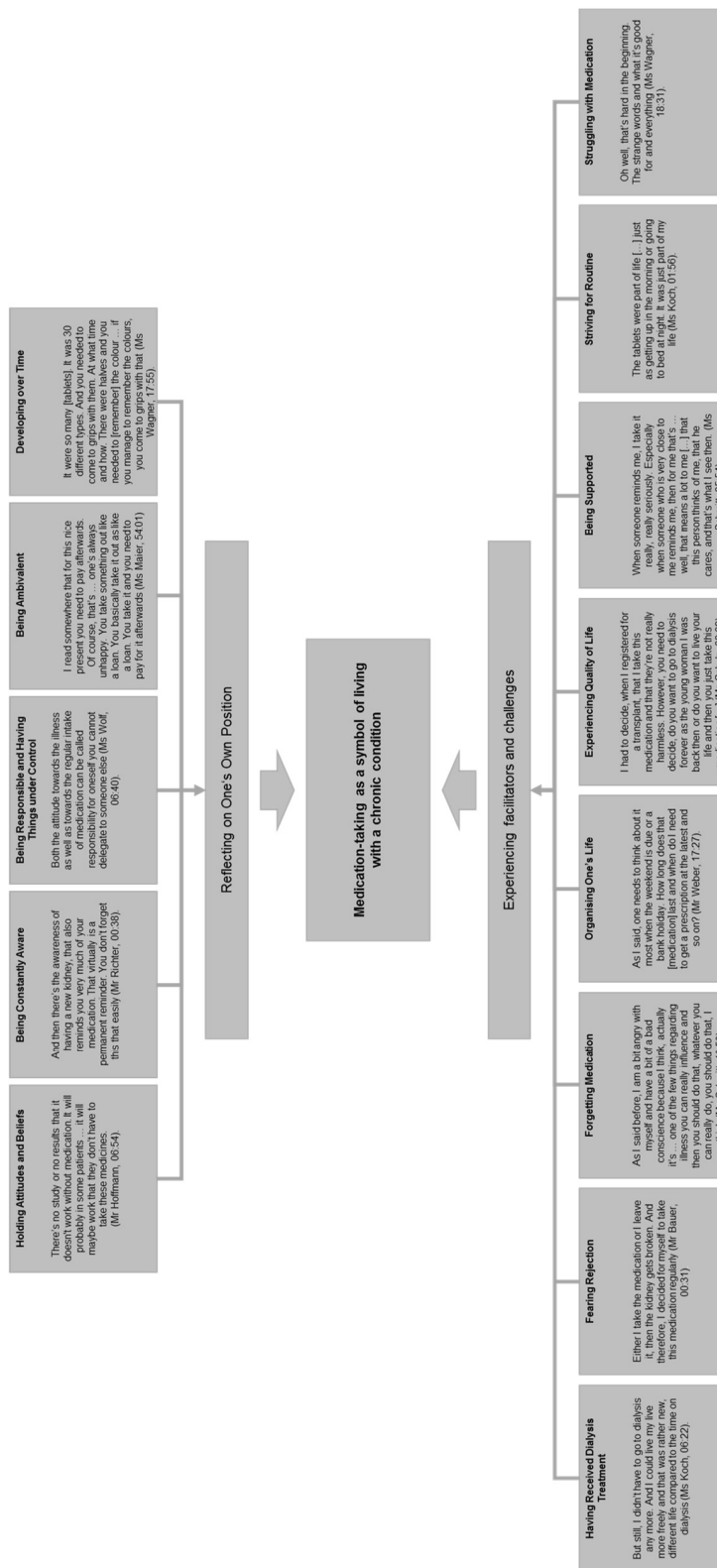
All ongoing projects will be monitored every 12 months and it is a condition of continued approval that you complete the monitoring form.

Please inform the HCARE REC when the project has ended.

Yours sincerely,

Dr Ben Hannigan  
Co Chair of the School of Healthcare Sciences Research Ethics Committee

# Appendix 14: Integration of Sub-Categories and Categories in the Central Category



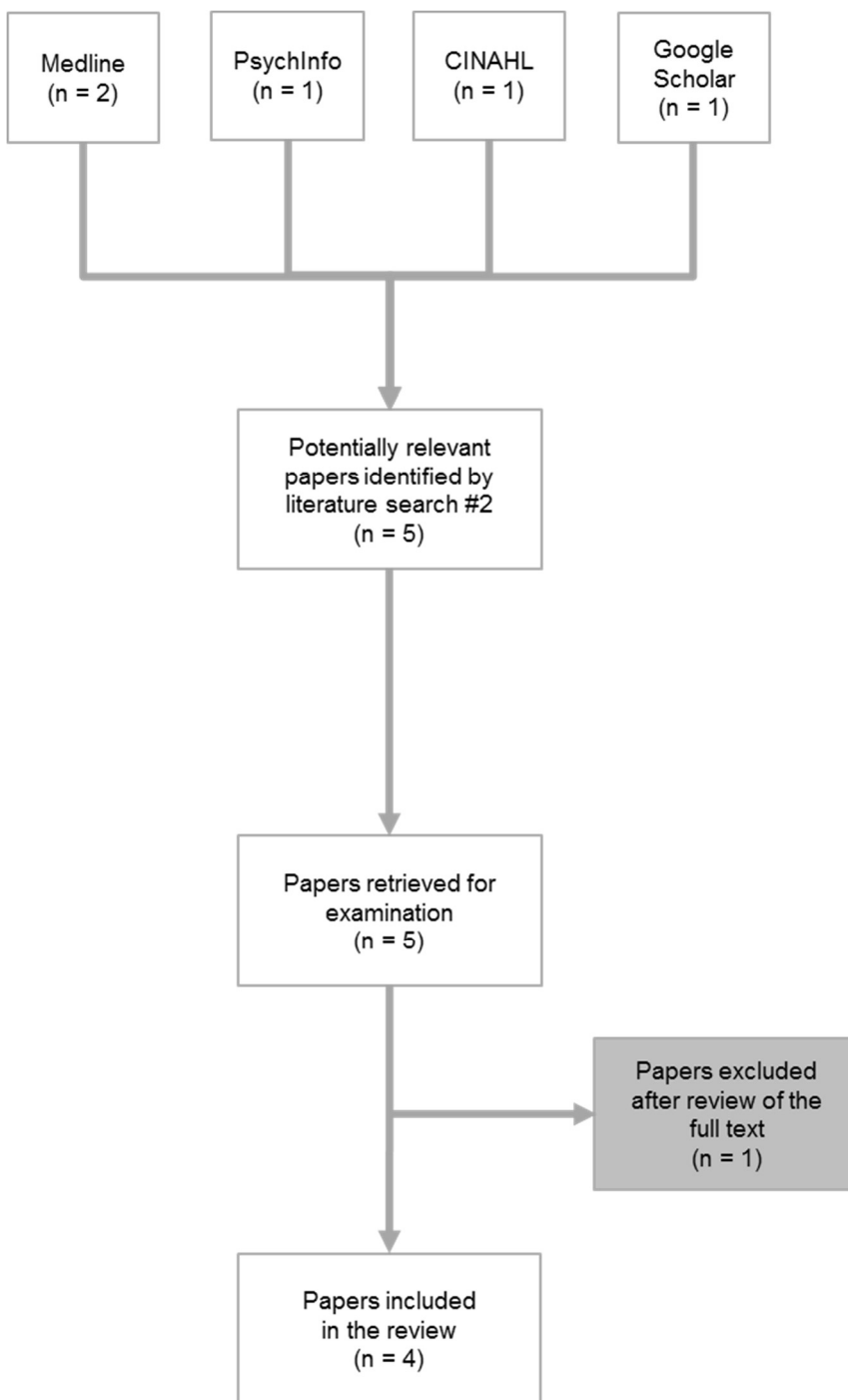
## Appendix 15: Search Strategy of the Secondary Literature Review

Medline via OvidSP		
Search #	Query	Number of hits
1	Chronic Disease/	230152
2	Patient Compliance/ or Medication Adherence/	59861
3	internalisation.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	1015
4	internalization.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	27566
5	ambivalence.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]	2110
6	3 or 4	28542
7	5 or 6	30647
8	1 and 2 and 7	2

PsychInfo via OvidSP		
Search #	Query	Number of hits
1	exp Chronic Illness/	22685
2	exp Treatment Compliance/ or medication adherence.mp.	13263
3	exp Internalization/ or internalisation.mp.	3258
4	ambivalence.mp. or exp Ambivalence/	6107
5	3 or 4	9354
6	1 and 2 and 5	1

<b>CINAHL via EBSCO</b>		
<b>Search #</b>	<b>Query</b>	<b>Number of hits</b>
1	(MM "Chronic Disease") OR "chronic illness or chronic disease"	14202
2	"chronic conditions"	3489
3	MM "Medication Compliance") OR (MM "Patient Compliance+")	16368
4	"internalization"	608
5	"ambivalence"	1002
6	S1 or S2	16612
7	S4 or S5	1610
8	S3 or S6 or S7	1

## Appendix 16: Selection of Literature in the Secondary Literature Review



## Appendix 17: Literature Included in the Secondary Literature Review

Author (Year)	Aims	Research Paradigm (Methodology)
Gustafsson et al. (2005)	To investigate perceptions of receiving dietary advice, the occurrence and comprehension of such advice and compliance among older women diagnosed with PD, stroke or RA.	Ethnographic approach
Piguet et al. (2007)	To investigate chronic pain patients' representations of antidepressants as compared with pain-free controls	Content analysis
Townsend et al. (2003)	To examine attitudes towards drug use among middle aged respondents with high levels of chronic morbidity.	Constant comparative method