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Health Literacy and Medication Adherence of Solid Organ Transplant Recipients in Support Groups in Austria

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Acknowledgment

Zig Ziglar, an American motivational speaker once said, “Difficult roads often lead to beautiful destinations. The best is yet to come.” Everyone who has already made the experience of writing a master thesis can understand the highs and lows during the writing process. The participation in the double degree program has been very challenging and has contributed to my professional and personal development.

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Abstract

Background: In order to improve the long-term survival after a solid organ transplantation, a regular intake of immunosuppressive medication as well as comprehensive skills and knowledge about the disease are essential. Although limited health literacy is associated with a worse health outcome, its impact on medication adherence in solid organ transplant recipients remains poorly understood. Especially in Austria, no data is available about the prevalence and correlation of medication adherence and health literacy of solid organ transplant recipients.

Method: An online survey in eleven support groups for transplant recipients in Austria was conducted from October to December 2019. Medication adherence was measured by the means of Basel Assessment of Adherence to Immunosuppressive Medications Scale, and health literacy was determined by the Health Literacy Survey-EU-Q16. The results were analysed using Jeffreys's Amazing Statistics Program (JASP) and descriptive statistics and correlations were performed.

Results: 106 transplant recipients participated in the online survey. Most of them were kidney recipients (68%), male (73%), member of a support group (79%) and on average *M* = 57 (*SD* = 13) years old. The total non-adherence rate was 72%. Almost half of the participants (47%) showed limited health literacy. No significant correlations were detected, neither between medication adherence and health literacy level nor for sociodemographic factors. Only a weak correlation was found between the health literacy level and participants who received information and/ or training regarding their immunosuppressive medication.

Conclusion: Because of the high prevalence of medication non-adherence and limited health literacy in the study population, support groups should focus on raising awareness about medication adherence and consequently offer comprehensible information according to the health literacy levels of their members. In order to address the individual needs and risk factors of transplant recipients, it is recommended to implement multi-professional interventions in clinical practice with behavioural as well as educational components.

Keywords: Medication adherence, health literacy, transplantation, support groups

Zusammenfassung

Hintergrund: Um das Langzeitüberleben nach einer Organtransplantation zu verbessern, sind eine regelmäßige Einnahme von immunsuppressiven Medikamenten sowie umfassende Fähigkeiten und Kenntnisse über die Krankheit unerlässlich. Obwohl limitierte Gesundheitskompetenz mit schlechteren Gesundheitsoutcomes assoziiert wird, ist der Einfluss von Gesundheitskompetenz auf die Medikamentenadhärenz bei Menschen nach einer Transplantation wenig untersucht. Insbesondere für Österreich liegen keine Daten über die Prävalenz und den Zusammenhang zwischen der Medikamentenadhärenz und der Gesundheitskompetenz vor.

Methode: Von Oktober bis Dezember 2019 wurde eine Online-Erhebung in elf Selbsthilfegruppen für Menschen nach einer Transplantation in Österreich durchgeführt. Die Medikamentenadhärenz wurde mit Hilfe der „Basel Assessment of Adherence to Immunosuppressive Medications Scale“ gemessen und die Gesundheitskompetenz wurde mit dem „Health Literacy Survey EU-Q16“ ermittelt. Die Ergebnisse der Erhebung wurden anhand deskriptiver Statistik und Korrelationen mit „Jeffreys’s Amazing Statistics Program“ (JASP) analysiert.

Ergebnisse: 106 Menschen nach einer Transplantation nahmen an der Online-Erhebung teil. Der überwiegende Teil war Nierenempfänger (68%), männlich (73%), Mitglied einer Selbsthilfegruppe (79%) und durchschnittlich *M* = 57 (*SD* = 13) Jahre alt. Die Prävalenz der medikamentösen Non-Adhärenz betrug 72%. Etwa die Hälfte der Teilnehmer (47%) zeigte eine limitierte Gesundheitskompetenz. Es konnten keine signifikanten Korrelationen zwischen der Medikamentenadhärenz und der Gesundheitskompetenz sowie für soziodemographische Faktoren festgestellt werden. Eine schwache Korrelation wurde zwischen dem Gesundheitskompetenzlevel und den Teilnehmern gefunden, die Informationen und/ oder Schulungen bezüglich ihrer immunsuppressiven Medikamente erhielten.

Schlussfolgerung: Aufgrund der hohen Prävalenz medikamentöser Non-Adhärenz und limitierter Gesundheitskompetenz in der Studienpopulation, sollten Selbsthilfegruppen einen Fokus auf die Medikamentenadhärenz richten, um das Bewusstsein dafür zu stärken und folglich verständliche Informationen entsprechend dem Level der Gesundheitskompetenz ihrer Mitglieder anbieten. Um auf die individuellen Bedürfnisse und Risikofaktoren der Menschen nach einer Transplantation einzugehen, wird empfohlen, multiprofessionelle Interventionen mit Fokus auf Verhaltensveränderung und Wissenserweiterung in der klinischen Praxis zu implementieren.

Schlüsselwörter: Medikamentenadhärenz, Gesundheitskompetenz, Transplantation, Selbsthilfegruppe

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Introduction

Around 700 to 800 people in Austria receive transplants from deceased or living donors per year. Almost the same number of patients is enrolled in the transplant waiting list, which continuous to increase (ÖBIG-Transplant, 2019, p. 3). Due to the opt-out regulation in Austria, organ parts can be removed from any deceased person for the purpose of transplantation, unless the deceased person has expressly objected to this in writing during their lifetime (§ 5 sentence 1 OTPG). Consequently Austria has the second highest number of patients transplanted per million inhabitants in Europe (European Directorate for the Quality of Medicines & Health Care of the Council of Europe, 2018, p. 18). After the transplantation, several factors, partly depending on the organ, influence the long-term survival of the transplant recipient. One major factor is that transplant recipients follow a complex medication regimen to keep the organ functioning and to prevent rejection and graft loss. Nonetheless, many transplant recipients have difficulties when it comes to medication intake. Between 20% to 70% of all transplant recipients do not follow therapy recommendations and do not take their medication as prescribed (Neuberger et al., 2017, p. 7-8). This so-called medication non-adherence represents an increasing challenge, which can worsen the health outcome and lead to a higher healthcare expenditure. Around 125,000 deaths per year are estimated to be related to non-adherent behaviour (Kleinsinger, 2018). Adherence, defined by the World Health Organization (2003, p. 3) as “the extent to which a person’s behavior – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider”, is influenced by many factors. According to the five dimension model, these factors are for example poor socioeconomic status, the patient-provider relationship, the complexity of the medication regimen and patients’ knowledge and beliefs about their illness (World Health Organization, 2003). Many of these factors have already been thoroughly examined, resulting in statistically significant associations with higher percentages of medication non-adherence in transplant recipients who are aged bellow 50 years, suffer from depression and whose transplant happened a long time ago (Villeneuve et al., 2019, p. 1). Another reason why transplant recipients do not take their medication as prescribed is on the one hand a knowledge gap about the effects and side effects of their medication and on the other hand a lack of competence to fully understand the information regarding their transplantation and medication (Gellad et al., 2011, p. 7; Gordon and Wolf, 2009, p. 25). This so called health literacy has a huge impact on the health outcome and on the self-management competencies of patients with chronic diseases (Chisholm-Burns et al., 2018, p. 2325-2326). Furthermore, the level of health literacy of transplant recipients seems to be connected to the adherence to the therapy recommendations (Demian et al., 2016, p. 858). Although low health literacy is associated with poor health outcome, little is known about the level of health literacy in the transplant recipient population. Present studies show heterogeneous results and are thus not applicable to the general population of transplant recipients (Chisholm-Burns et al., 2018, p.2326). In order to offer effective interventions, which improve the level of health literacy and prevent medication non-adherence, more information about the Austrian transplant recipient population is needed to fully understand the scope of the problem.

1. Objective, Research Question and Methodology

As a result of this mentioned lack of information about the Austrian transplant recipients' population, the aim of this thesis is to gather data about medication adherence and health literacy from the current literature and from transplant recipients in support groups in Austria.

Therefore the following research questions arise:

1. What is the current status of research on health literacy and medication adherence in transplant recipients?
2. What are the findings about the prevalence and the correlation of self-reported medication non-adherence and the level of health literacy in Austrian transplant recipients in support groups?
3. Which sociodemographic factors and transplant-related factors are associated with medication adherence and the level of health literacy in Austrian transplant recipients in support groups?
4. Which kind of information and training with the focus on medication adherence did the Austrian transplant recipients in support groups receive after their transplantation?

Based on a systematic literature search, the first part of this thesis provides an insight into solid organ transplantation, support groups and the concepts of self-management, medication adherence and health literacy. The information resulting is used to identify appropriate measurement methods for health literacy and medication adherence in transplant recipients. Literature was searched in the Online-Public-Access-Catalogue and the Electronic-Journals-Library of the Carinthia University of Applied Sciences, in the databases PubMed, CINAHL and Medline, in google scholar and on websites from national and international organisations responsible for organ donations and solid organ transplantation without any limitation in time. For solid organ transplantation 26 sources were identified as relevant of which 12 sources were reports from national and international organisations for organ donations or solid organ transplantation or both, six sources were books and eight sources research reports. For support groups only eleven relevant sources could be found, and only one was about transplant recipients. For the concept of self-management four research report were identified as relevant. For the concept of adherence 39 sources were incorporated in the theoretical background. Four books explained adherence or compliance and one book medication adherence. 22 journal articles which examined the medication adherence in transplant recipients, the measurement tools or interventions were included. 12 journal articles examined medication adherence in general. 25 sources were used to describe the concept and measurement of health literacy. Three books and 15 research reports were included in elaborating the theory of health literacy. Two reports from national organisations about the health literacy in Europe, with a special focus on Austria, were taken into account as well. Four research reports investigating health literacy in transplant recipients and one database for health literacy measurements were also identified as relevant.

To answer the first research question, a literature review was performed (Baumeister and Leary, 1997, p. 312). In PubMed, CINAHL and Medline scientific papers were identified with the search terms “medication adherence” OR ”medication compliance” OR “drug compliance” OR “drug adherence” AND “health literacy” OR ”health competence” AND “transplant*”. A detailed description of the literature review is given in chapter 6.

The second part of the thesis is based on a quantitative research design and covers research question two, three and four. As the study population represents a convenience sample, support groups for transplant recipients in Austria were surveyed online on their medication adherence and health literacy. The online survey was divided into four parts, consisting of one validated test instrument for medication adherence, one validated test instrument for health literacy and further sociodemographic- and transplant-related questions. The answers given in the questionnaire were analysed with Jeffreys’s Amazing Statistics Program (JASP) 0.11.1., an open source statistic programme. All data were analysed descriptively and correlations for health literacy, medication adherence, sociodemographic- and transplant-related factors were calculated. Results are discussed with comparable studies, and finally practical recommendations for developing intervention strategies are given. Comprehensive summary of the methodological approach is given in chapter 7.

2. Solid Organ Transplantation

In the fourth century A. D. the first legend about a transplantation occurred mentioning that the Saints Cosmas and Damian thought about amputating an injured leg and replacing it with a leg from a death man. Whether this was just a dream or happened in reality is still not known for sure (Langer and Vértesaljai, 2018, p. 23). In Austria, the first organ transplantation was performed on a dog in 1902. Since then a lot has changed and for the last 40 years organ transplantations have become a standard treatment (Homburg, 2010b, p. 18).

Due to the rapid development, the Austrian Organ Transplant Law (OTPG) was passed in 2012. The OTPG describes transplantation as a transfer of one organ from the donor to the recipient to restore physiological functions (§ 3 Sentence 14 OTPG). Organ means a differentiated part of the human body consisting of different tissues and maintaining its structure, vascularization and ability to perform physiological functions with distinct autonomy (§ 3 Sentence 6 OTPG). A solid organ transplantation refers to transplanting "…a solid organ-eg., heart, liver, kidney, as contrasted to 'liquid' transplanted tissues-eg., […], pancreatic islets" (McGraw-Hill Concise Dictionary of Modern Medicine, 2002).

In general, organ transplantation differentiates between a living donation and a deceased donation. Living donation means the organ is coming from a living person, who is usually related to the transplant recipient and voluntarily donates his or her organ. This option is mainly used for kidney transplantations. In most cases an organ transplantation is performed after the death of the donor, which is called a deceased donation. Only individuals in whom a brain death has been established are eligible (Rödel, 2017). Based on the criteria from Harvard Medical School (1968, p. 85-86) brain death means that a patient is in deep, irreversible unconsciousness, has no reflexes and does not breath spontaneously. The brain death has to be diagnosed by an authorized doctor. According to the OTPG (§4ff) there are certain legal regulations that have to be considered when a living or deceased donation is planned.

Further on in this thesis the term "organ transplantation" refers to heart, kidney, liver, lung and pancreas transplantations and includes transplantations from living as well as deceased donors.

2.1. Distribution by Frequency, Age and Gender

Regarding the opt-out regulation in Austria, every citizen can automatically become a potential organ donor after death. Therefore international comparisons show that the availability of donor organs and the clinical outcomes have been described as good (Berlakovich et al., 2016, p. 1785-1787).

Around 700 to 800 people in Austria receive transplants from deceased or living donors per year. The organ transplantations are performed in four transplantation centres in the cities Graz, Innsbruck, Linz and Vienna (ÖBIG-Transplant, 2018). *Figure 1* shows the amount of transplanted organs per transplantation centre, illustrating that the transplantation center in Vienna has the highest number of transplantations per year (in total: 355). It describes kidney transplantation as the most frequently performed one in Austria (in total: 414) (ÖBIG-Transplant, 2019, p. 24).

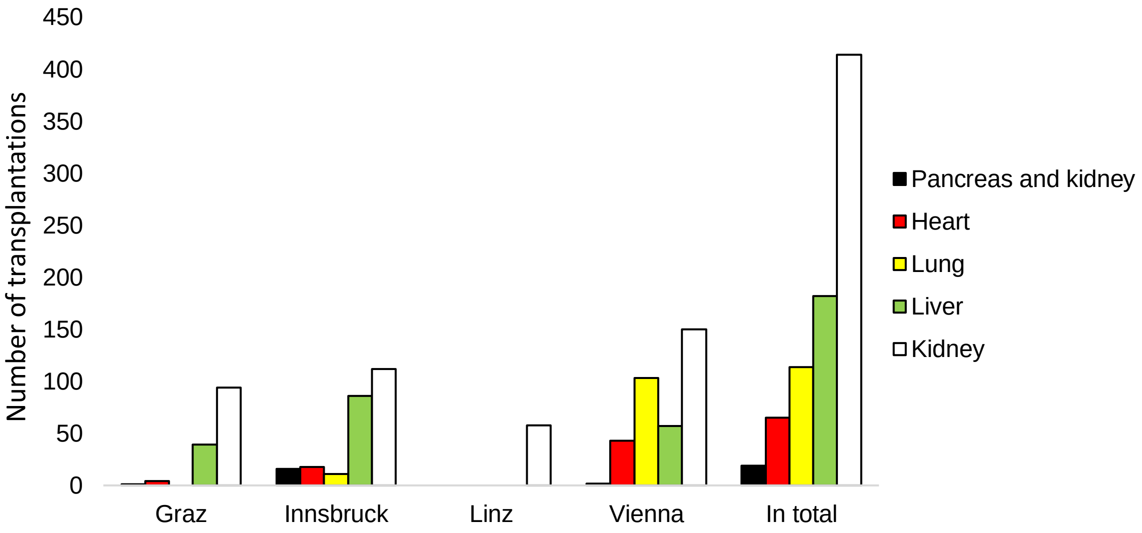


Figure 1. Transplantations in Austria divided by transplantation centres and organs (derived from ÖBIG Transplant, 2019, p. 24).

With 87.7 transplanted patients per million inhabitants, Austria has one of the highest numbers in comparison to the countries in Europe (European Directorate for the Quality of Medicines & Health Care of the Council of Europe, 2018, p. 18).

To support donor hospitals and transplantation centres with distributing the donor organs, Eurotransplant was founded in 1967, which Austria joined as a member already in 1970. Beside Austria, also Belgium (B), Germany (D), Hungary (H), Croatia (HR), Netherlands (NL) and Slovenia (SLO) are members of the Eurotransplant foundation. The main purpose of this non-profit organisation is to allocate a donor organ to the best match in order to keep the time on the waiting list as short as possible (Eurotransplant Foundation, 2016, p. 8-10). *Figure 2* shows the total number of transplanted organs per Eurotransplant member. The kidney transplantation represents the most frequently performed transplant in the Eurotransplant member countries, mirroring the situation in Austria.

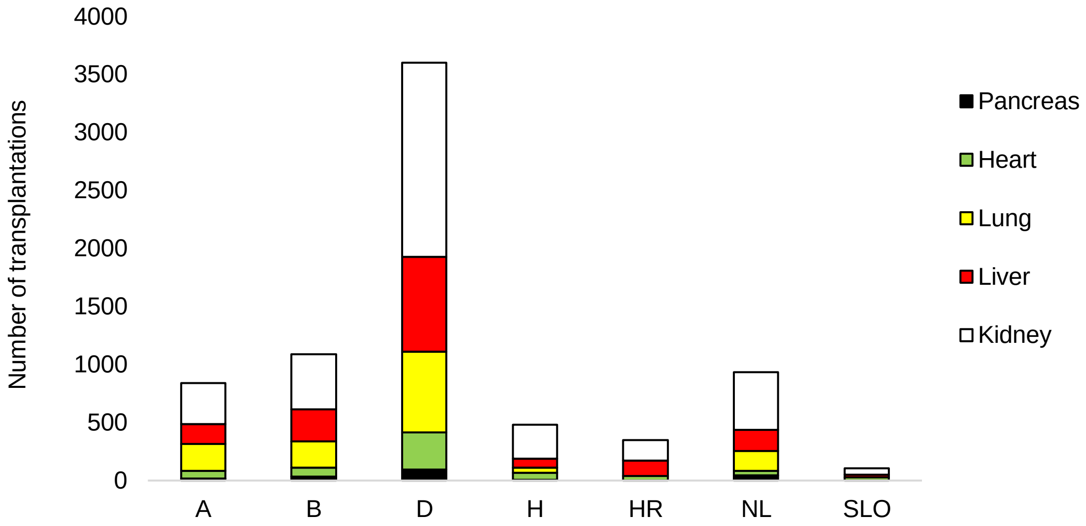


Figure 2. Number of organs transplanted in Eurotransplant (deceased donor) (derived from Eurotransplant International Foundation 2018, p. 21).

According to data from the United Network for Organ Sharing (2019a) majority of the transplant recipients are between 50 and 64 years old (*figure 3*). Distribution of the transplant recipients' gender is 38.2 % female and 61.8% male. (n= 804.604) (United Network for Organ Sharing, 2019b).

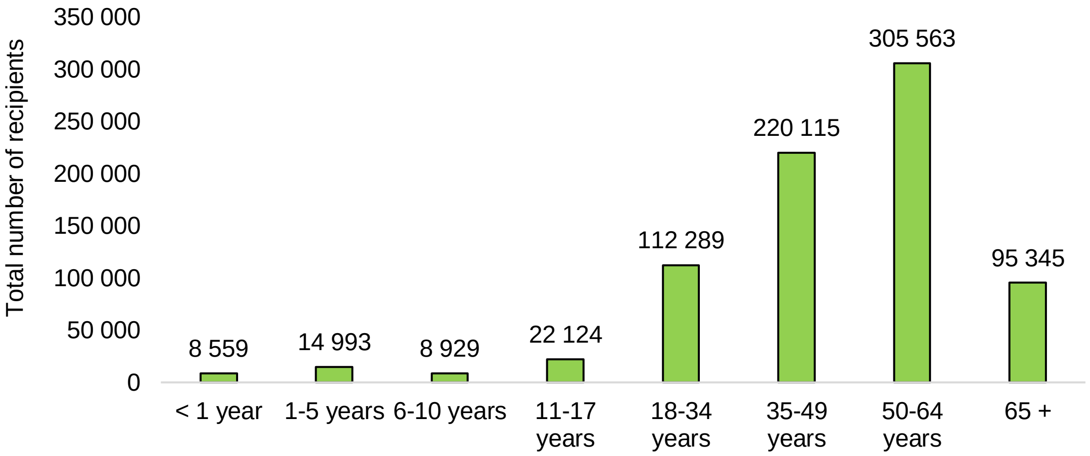


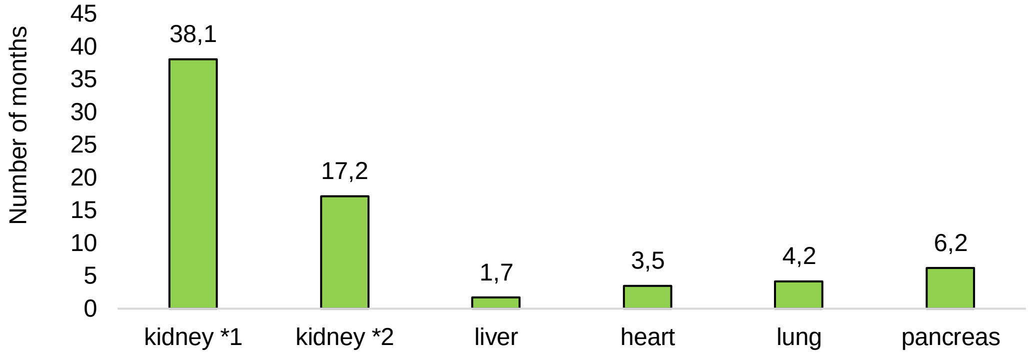
Figure 3. Number of organ transplantations by age of recipients (derived from United Network for Organ Sharing, 2019a).

Although the organ transplantation has become a standard treatment option and is frequently performed internationally, for the individual patient there is still a long process to live through before becoming a transplant recipient, which is the focus of the following chapter.

2.2. Becoming a Transplant Recipient

In order to receive a donor organ a potential transplant recipient must be referred to a transplant centre. The patient can choose a transplant centre which is specialising in the transplantation of organs. In Austria there are four transplant centres, based in Vienna, Linz, Salzburg and Graz. At the transplantation centre an examination is done on whether a transplantation is necessary and whether the patient is suitable as a recipient of an organ. In addition, medical data are collected which is essential for the allocation of organs. The decision whether a transplantation should be sought is made by the patient and the physician together after weighing all the benefits and risks. The decisive factors are the general health of the patient and the prospects of success of the procedure in their particular case. When the conclusion is made that the transplantation is medically indicated and possible, the data are transmitted to the Eurotransplant Foundation. The message to Eurotransplant through the transplant centre means that the patient is now on the waiting list for the required organ (Rödel, 2017).

The decision about who receives an organ is based on medical criteria and may not be influenced. For each new donor organ, Eurotransplant will create its own ranking list, which contains possible recipients of the organ. The ranking on the list depends on various criteria, depending on the organ. Important criteria for the selection of a recipient are an appropriate blood type of organ donors and recipients and - with some organs - the compliance of the human leukocyte antigens (HLA). The urgency of a transplant, which is assessed organ specifically, also plays an important role. For example, for a liver transplant a score system (MELD score) which predicts the urgency of a transplantation, is used. In general, “High Urgency” (HU) stands for utmost urgency. “Transplantable” (T) means that there is no extraordinary urgency. Consequently, HU recipients are given preferential treatment. The assignment to this group must be justified in each individual case. Another important criterion is the patients’ waiting time for an organ. The waiting time is equivalent to the period for which a recipient is on the waiting list. For patients listed for a kidney, the first day at dialysis counts as the beginning of the waiting period. The longer the waiting time, the higher the chance of getting a new organ allocated soon. However, the exact time that the recipient has to wait for an organ cannot be answered in general. The waiting times can vary widely depending on the organ, as show in *figure 4*. Generally, they are determined by the number of donors and the potential recipients (ÖBIG-Transplant, 2019, p. 49-50; Rödel, 2017).



*1 counting from the first dialysis
*2 counting from the moment on the waiting list

Figure 4. Median waiting time to transplant in months from 2013-2018 (derived from ÖBIG-Transplant, 2019, p. 50).

According to ÖBIG-Transplant (2019, p. 135-136) 826 patients were on the waiting list for a kidney, liver, heart, lung or pancreas transplantation in Austria in 2018. As shown in *Figure 4* due to the high level of demand, the median waiting time for a kidney is the longest, compared to the other organs.

When a suitable recipient is found, Eurotransplant informs the responsible transplant centre. The recipient of the organ is contacted by the transplant centre and has to arrive quickly at the hospital. After the preparations for the transplant, the organ is transplanted. The recipient is initially cared for in the intensive care unit and then at the normal ward. Regular examinations control whether the organ works well and the necessary immunosuppressive medications are administered in the correct dosage. It is particularly important to check for signs of rejection or infection. Most patients recover well after the transplantation and can be discharged home after two to four weeks (Öffentliches Gesundheitsportal Österreich, 2019).

2.3. Treatment Strategies for Transplant Recipients

For many years the main goal in transplantation was to ensure a high survival rate in the early transplant phase, however, nowadays the focus has shifted to the long-term survival of the transplants, to their function and to the therapy-related complications of long-term immunosuppressive treatment (Frei et al., 2001, p. 5). Due to the improvement of the therapy after transplantation, patient survival has increased over the last decades (Wadström et al., 2017, p. 2). Nonetheless the long-term survival rates decline over time and vary for different organs, as shown in *figure 5*.

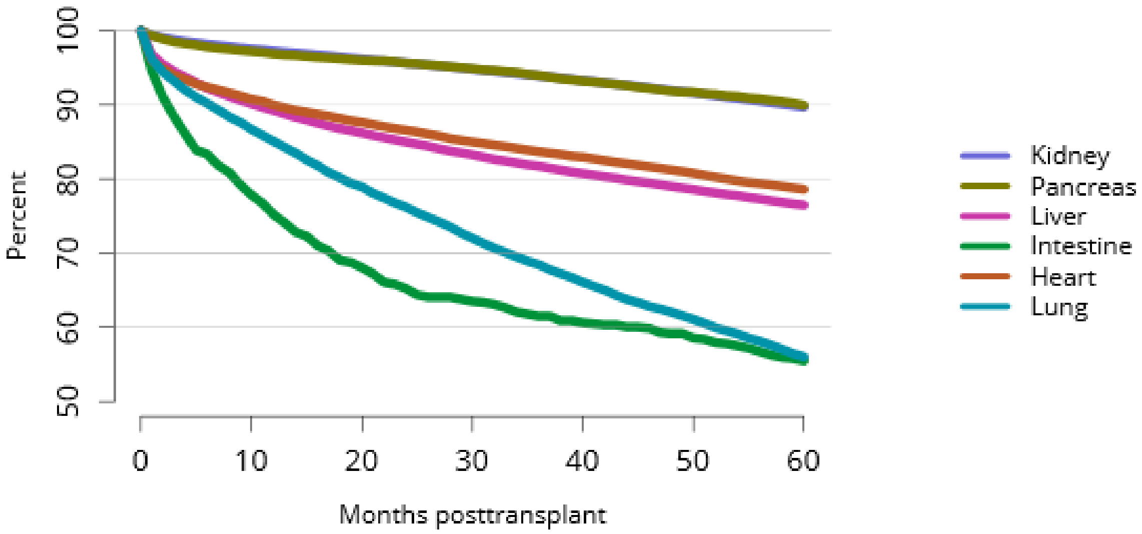


Figure 5. Patient survival among all transplant recipients, 2008-2012, by organ (Scientific Registry of Transplant Recipients, 2017, p. 9).

Recent data from Europe and United States show the five year graft survival rate per organ as following:

- **77%** for kidney transplants
- **64%** for liver transplants
- **69%** for heart transplants
- **54%** for lung transplants
- **73%** for pancreas transplants
- **64%** for simultaneous pancreas-kidney transplants (Gruessner and Gruessner, 2016, p. 377; Yusen et al., 2016, p. 1175; Lund et al., 2014; European Liver Transplant Registry, 2015; Gondos et al., 2013, p. 267)

This decline in graft survival is the major challenge in post-transplant treatment and is caused by many factors that directly influence the graft issue. *Figure 6* shows, exemplarily for liver transplant, the many different factors that can cause a late allograft loss.

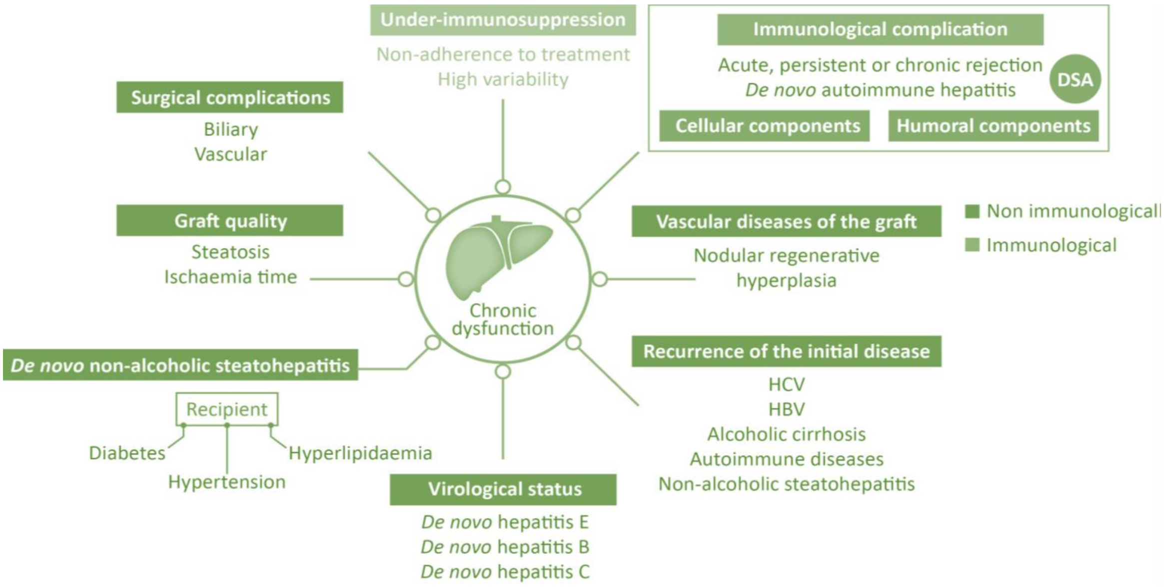


Figure 6. Causes of late allograft loss in liver transplant recipients (Neuberger et al., 2017, p. 5).

A common cause for a late allograft loss, which can occur in every transplant recipient regardless of the organ, is under-immunosuppression due to non-adherence and acute or chronic rejection (Ingulli, 2010, p. 61; Wadström et al., 2017).

2.3.1. Rejection

Rejection refers to the reaction of the transplant recipient’s immune system against the transplanted organ (Lison and Krukemeyer, 2006, p. 11). This rejection of an organ can be classified in

- **Hyperacute** rejection
- **Acute** recjection
- **Chronic** rejection (Lison and Krukemeyer, 2006, p. 11-19)

The **hyperacute** rejection occurs usually in the first few minutes or hours after the transplantation due to donor-specific antibodies. With the development of the pre-transplant antibody-screening this type of rejection happens only in rare cases. Only removing the transplanted organ helps to stop the hyperacute rejection. The **acute** rejection appears usually in the first days or weeks after transplantation. A high dose immunosuppressive therapy can prevent further damages. The **chronic** rejection happens during months or years after the transplantation and leads to a progressive loss of organ function. Even with an intensified immunosuppressive therapy the loss of organ function cannot be prevented. To avoid the activation of the transplant recipients immune system in general, immunosuppressive therapy is necessary after transplantation (Lison and Krukemeyer, 2006, p. 11-19).

2.3.2. Immunosuppressive Therapy

Organ transplantation is a complex process. The success of the process is dependent on the condition of the organ which is going to be transplanted, the influence on the organ during its collection, its storage and its re-insertion, the local factors of its healing and the general reactions of the recipient to the contact with the transplant (Albert et al., 1981, p. 19). The transplantation of an organ into another body leads to an activation of the recipient's immune system. The consequence of this is an acute rejection which irreversibly damages the graft in a short time (Homburg, 2010a). To avoid this acute rejection the recipient's immune system has to be modulated with the so-called immunosuppressants. The immunosuppressive therapy can be divided in three phases. The **de novo therapy** (early phase), **maintenance therapy** (maintenance phase) and the **rejection therapy** (Kniepeiss et al., 2018, p. 39). After an induction phase with a high dose of immunosuppressants for the first few weeks to months, the number and dose of the medications can be reduced during the maintenance phase. In this phase two or three immunosuppressants are prescribed simultaneously (Stucker and Ackermann, 2011, p. 679). Current state of the art is a combination therapy with a calcineurin inhibitor (CNI) like tacrolimus, an antiproliferative agent like mycophenolat mofetil (MMF) and steroids (McKay and Steinberg, 2010, p. 137-138).

The optimal adjustment of immunosuppression is a complex task, which aims to balance the risk of rejection with the spectrum of side effects of immunosuppressants (shown in *table 1*) and therefore has a significant impact on the long-term outcome after transplantation (Kniepeiss et al., 2018, p. 43). The most common side effects of immunosuppressants are summarised in table 1 per substance.

Table 1

Most common side effects per substance (derived from Stucker and Ackermann, 2011, p. 682).

Substance	Common side effects
Steroids	Hypertension, hypercholesterolemia, diabetes, weight gain, (Cushing's syndrome), osteoporosis, gastrointestinal bleeding, psychosis, cataract, myopathy, oral candidiasis
Cyclosporine	Hypertension, hypercholesterolemia, renal insufficiency, gingival hyperplasia, hypertrichosis, tremor
Tacrolimus	Hypertension, diabetes, renal insufficiency, alopecia, tremor
Sirolimus	Hypercholesterolemia, pulmonary toxicity, proteinuria, anemia, thrombocytopenia, stomatitis, acne, eyelid edema

Substance	Common side effects
Everolimus	Hypercholesterolemia, pulmonary toxicity, proteinuria, anemia, thrombocytopenia, stomatitis, acne
Mycophenolat mofetil	Diarrhea, anemia, leukopenia
Azathioprine	Increased incidence of skin tumors, anemia, leukopenia
Belatacept	Increased incidence of post-transplant lymphoproliferative disorder

Currently the goal of the immunosuppressive therapy is to prevent a rejection with as few side effects as possible for the recipient (Kniepeiss et al., 2018, p. 46). An optimal adjustment of the immunosuppressant dose or combination must be performed individually for each patient, based on the type of the transplanted organ, period since transplant, type of combination therapy, immunisation and suspected rejection reaction. Dosing of the immunosuppressants is always based on trough level in CNI and Mammalian target-of-rapamycin (mTOR) inhibitors. Depending on the type of transplanted organ and the time since transplantation, the recommended target levels may differ significantly. Heart transplantation, for example, requires more intense immunosuppression than other organ transplants because of the higher risk of rejection. The liver, on the other hand, is regarded as an immunologically privileged organ, since rejection prophylaxis requires the least amount of immunosuppression (Beimler et al., 2014, p. 214, 222).

For the immunosuppressive therapy, in order to obtain the desired effect, it is necessary to apply medication regularly and on time. This adherence to the medical regimen seems a major challenge for many transplant recipients. Several factors influence the ability of transplant recipients to be adherent and to manage their life (Neuberger et al., 2017, p. 7ff).

3. Self-Management

In the 1960s the term self-management initially appeared regarding patient education programs for chronic conditions. Hence there was a paradigm shift from the passive patient who awaits instructions to the active patient who participates in the treatment process (Lorig and Holman, 2003, p. 1). According to Clark et al. (1991, p. 5) self-management is described "[…] as the day-to-day tasks an individual must undertake to control or reduce the impact of disease on physical health status." Haslbeck and Schaeffer (2007, p. 84) stated that because of the broad field of self-management there is no common definition or concept, however, certain competencies and abilities are necessary to successfully manage a chronic condition.

Particularly with chronic diseases, the promotion of self-management skills is important in order to help patients to cope with their condition and to strengthen their personal competence and autonomy (Haslbeck and Schaeffer, 2007, p. 82). Clark et al. (1991, p. 6) defined three requirements which seem important for a successful self-management. The patients should have **knowledge** about their disease and their treatment to make informed decisions, they should **complete tasks** to manage their disease, and they should **cope** with their psychosocial problems to stay mentally healthy. Lorig and Holman (2003, p. 1-2) describe three tasks which are important for self-managing a chronic condition. The first task is **medical management**, which refers to taking medication or maintaining a special diet. The second task is **role management**, which refers to necessary lifestyle changes due to the chronic condition. And the third task is **emotional management**, which refers to dealing with negative emotions that many patients with chronic conditions suffer from. To successfully manage these tasks, patients need to have problem solving and decision-making skills. Furthermore, patients have to know where they can find useful information. Additionally it is important to form partnerships with health care providers, report changes in their condition to them and that the patient can make informed choices about their treatment. Finally, to effectively change their behaviour, patients have to be able to take actions and follow their goals. Dealing with the negative side effects of chronic illness, such as complex medication regimens, represents another clinical problem area in which promotion of self-management skills is becoming increasingly important. At the same time it is necessary to strengthen the position and competence of the affected people and to enable them to move confidently in the care system and, in turn, to ensure that they receive the right support (Haslbeck and Schaeffer, 2007, p. 84f).

According to Schmid-Mohler et al. (2011) patients after a transplantation are not considered as cured, they enter just a new phase of the disease. Transplant recipients may reach a better quality of life, however, patients have to face new challenges such as the adjustment of the immunosuppressive medication, the recognition of signs of rejection and infection as well as the prevention of secondary diseases. Self-management tasks, which are directly linked to the transplantation, are medication taking, symptom-management, preventing and monitoring infections and measuring vital signs. Self-management tasks, which are linked to health promotion and prevention, are being aware of a healthy diet, regular exercising, using sun protection, managing the medical therapy, quit smoking, not using harmful substances and keeping appointments. An excellent self-management is essential for meeting these challenges in the best possible way.

Not all patients with chronic diseases are able to successfully manage these tasks by themselves. Thus they search help from peers who suffer from the same chronic condition. These peers, organised in support groups, are described in the next chapter.

3.1. Support Groups

Today the term support group or self-help group is generally used to describe a wide range of self-organised associations. Support groups are voluntary, mostly loose associations of people whose activities are aimed at jointly coping with diseases, psychological or social problems that affect them or their relatives (Kofahl and Trojan, 2016). Support groups are not alternatives to medical treatment or substitute for work that has not been done elsewhere in the health care system. These groups provide an additional and independent service for patients. They meet their need to take responsibility for their own health (Fonds Gesundes Österreich, 2005, p. 3). Main features of support groups are that all group members are equal, everyone decides for him-/ or herself, the group decides independently from other organisations, what is discussed in the group stays in the group and participation is voluntary. A support group only works well if patients give up their passive role in order to start working on their conditions self-responsibly (Daum et al., 1982, p. 362-363). Support groups offer advocacy, assistance and education and are led and managed by people living with health conditions. Traditionally support groups are location-based and meet regularly. The type and structure of the support groups differ widely, depending on the condition and context. Studies have shown that participating in professionally developed support groups can positively influence mental health illnesses, rheumatoid arthritis, cancer, heart attack and epilepsy. Despite the very limited data available, support groups are assumed to have an impact on health behaviour change and treatment adherence (Davison et al., 2000, p. 804ff).

Nickel et al. (2019, p. 41ff) surveyed the characteristics of people who are members of a support group. The study has found out that on average support group members are 64 years old, have been ill for 6 years and that women are more likely to join. Education and income seem to have no influence on the decision for a membership in a support group. Furthermore, people are more likely to become a member of a support group if they are severely affected or burdened by illness and not overly socially integrated.

According to the study from Fonds Gesundes Österreich (2005), support group members in Austria have been ill for 12 years on average. The mean age for men in support groups is 50 and for women 52. 70% of the study participants are female and 30% are male (n = 458). About two thirds of the participants are in a relationship and about one third is employed. In general, the personality structure of the support group members does not differ from the population as a whole, however, they tend to be more systematic and disciplined and more compassionate and empathetic.

Nickel et al. (2002) examined differences in the disease management of patients after liver transplantation considering the membership in a support group. Research has shown that members of a support group indicate a significantly higher level of active coping of the disease, but they do not differ in the level of coping with depression or in the quality of life compared to non-members.

3.2. Support Groups in Austria

In Austria there are about 1700 support groups (Braunegger-Kallinger et al., 2009, p. 11) and 164 federal self-help organisations (Rojatz and Nowak, 2017, p. III). Federal self-help organisations act nationwide and support local groups and regional self-help organisations (Rojatz and Nowak, 2017, p. III). Information on support groups in Austria can be found on the homepage of the Federal Association of Self-help Austria (Bundesverband Selbsthilfe Österreich) and the Austrian Competence and Service Centre for Self-help (Österreichische Kompetenz- und Servicestelle für Selbsthilfe). The Federal Association of Self-help Austria is the lobby group of topic-specific, nation-wide self-help and patient organisations. The mission of the Federal Association of Self-help Austria is to strengthen the role of patients in the health and social services as well as in society by promoting, supporting and representing the concerns of self-help and patient organisations at the federal level. The Austrian Competence and Service Centre for Self-help supports self-help organisations in their capacity building through training, networking and development of common contents. In addition, the Austrian Competence and Service Centre takes over the coordination and cooperation with the federal association (Öffentliches Gesundheitsportal Österreich, 2018).

Information about support groups for transplant recipients can be found on the homepage of the Austrian National Institute for Health Services Research – Transplant (ÖBIG-Transplant). This institution is responsible for the statistical processing of various data sources (data from Eurotransplant, from donor protocols and from transplantation centres) and prepares statistical analyses and evaluations in the field of transplants and organ donations for the "Annual Report of the Transplantation Coordination Office" and for the Transplantation Advisory Board (ÖBIG-Transplant, n.D.a). 26 contact details for support groups can be found on the homepage, of which ten are either an umbrella institution or not directly linked to solid organ transplantation. One support group explicitly refers to pediatric transplant recipients (ÖBIG-Transplant, n.D.b). On the homepage of selbsthilfe.at 17 contact details can be found related to transplantation. Three of these contact details again are umbrella institution or not directly linked to transplantation. There is also one support group only for pediatric transplant recipients and one for bone marrow transplantation (bestNET, n.D.).

After removing duplicates, 17 contact details of support groups for solid organ transplant recipients were found on these two homepages. The distribution per organ is shown in *figure 7*. A detailed list of the support groups can be found in appendix I.

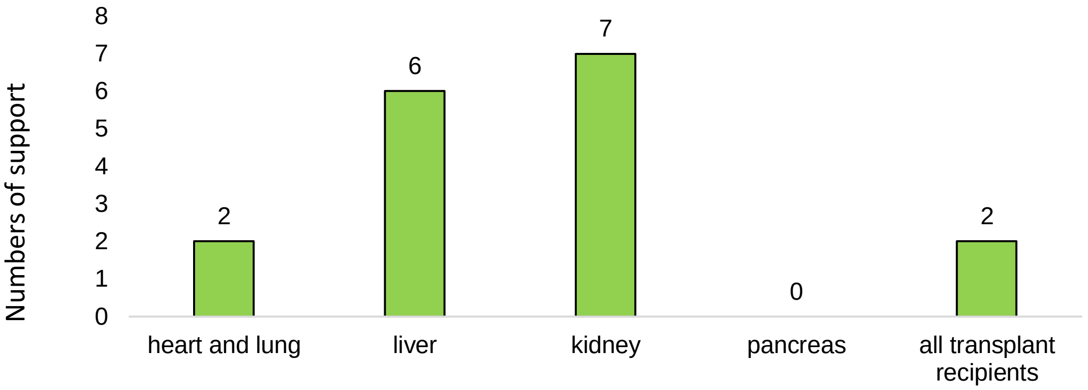


Figure 7. Number of transplant recipients support groups by organs in Austria (ÖBIG-Transplant, n.D.b; bestNET, n.D.).

Summarising the first chapters, it appears that transplant recipients face major challenges throughout their treatment and for their further lives. To overcome these challenges, a successful self-management is necessary. This requires a certain set of competencies and skills, such as taking their medication as prescribed and finding and understanding information regarding their chronic disease. The concepts of medication adherence and health literacy need further examination due to their relevance for the self-management after transplantation.

4. Adherence

Already 2600 years ago Hippocrates identified discrepancies between what the doctor recommended in order to treat a disease and what the patient really did to treat a disease (Haynes, 1986, p. 13). Therefore, over the decades a variety of terms were developed and used to describe this phenomenon.

At the beginning this phenomenon was referred to as “compliance” and according to Haynes (1986, p. 12) defined as…

> „Der Grad, in dem das Verhalten einer Person in bezug [sic!] auf die Einnahme eines Medikamentes, das Befolgen einer Diät oder die Veränderung des Lebensstils mit dem ärztlichen oder gesundheitlichen Rat korrespondiert.“ (“The degree to which a persons’ behaviour in relation to taking medication, following a diet, or changing the lifestyle corresponds to the medical or health advice”).

A similar perspective is used by the Medical Dictionary for the Health Professions and Nursing (2012) which describes compliance as “the consistency and accuracy with which a patient follows the regimen prescribed by a physician or other health care professional.”

So far there seems to be no clear or consistent definition of the term compliance. Moreover, the term is criticized for painting a passive role of the patient (Schuller, 2002, p. 18-19; Schäfer, 2017, p. 217ff). If a patient does not take his or her medication as prescribed, or does not follow the diet as recommended, he or she is called non-compliant. The North American Nursing Diagnosis Associations (NANDA) defined non-compliance as

> "Behavior of person and/or caregiver that fails to coincide with a health-promoting or therapeutic plan agreed on by the person (and/or family and/or community) and healthcare professional. In the presence of an agreed-upon, health-promoting, or therapeutic plan, the person's or caregiver's behavior is fully or partly nonadherent and may lead to clinically ineffective or partially effective outcomes." (Herdman and Kamitsuru, 2014, p. 150)

As the last revision of this diagnosis was back in 1998 and the present research is focusing on the concept adherence, the diagnosis "non-compliance" is not used anymore (Wayne, 2019).

Consequently, due to the negative connotation of the term compliance and because patients demand a more active role in their treatment process, the term adherence seems to be more appropriate. Adherence is defined by the World Health Organization (2003, p. 3) as

> "The extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider."

This definition explicitly includes the fact that the patient must agree to the recommended therapy, in contrast to the concept of compliance where it is not clear, if the patient's opinion is considered at all. Thus the patient gets a more active role and is involved in decision-making. Heuer et al. (1999, p. 11-12) defined three levels of adherence. If a patient follows more than 80% of the agreed recommendations they are called adherent patient. A patient who follows only 20-80% of the recommendations is considered partially adherent and as non-adherent if they follow less than 20% of the recommendations.

4.1. Different Types of Non-Adherence

Non-adherence can be classified as primary and secondary non-adherence. Primary non-adherence means that the prescribed medication is not picked up at the pharmacy. Secondary non-adherence describes the deviation from the medical prescription. This can be subdivided in different adherence types as shown in *table 2* (Heuer et al., 1999, p. 10-13):

Table 2

Types of non-adherence (retrieved from Heuer et al., 1999, p. 13).

Type of Non-Adherence	**Possible Causes**	**Possible Consequences**
Skips doses	Forgetfulness Complex medication regime	Descent of drug level Loss of effectiveness Rebound of the symptoms
Dosing errors		
a) Underdose	a) Fear of adverse effects	a) Descent of drug level Loss of effectiveness Rebound of the symptoms
b) Overdose	b) The “more the better” behaviour	b) Adverse, toxic effects
Drug holidays	Intermediate improvement of symptoms	Rebound of the symptoms
Taking at the wrong time	Forgetfulness Lack of information	Loss of effectiveness Adverse effects

Schäfer (2017, p. 168ff) classifies patients in four different adherence profiles. Based on their behavioural characteristics, the different profiles are shown in *table 3*.

Table 3

Description of the adherence profiles based on the behavioural characteristics (derived from Schäfer, 2017, p. 169).

Type of patient	**Confident**	**Involved**	**Unmotivated**	**Insecure**
Behavioural control	High	High	Medium	Low
Barriers	Medium	Low	Medium	High
Motivation	High	Medium	Low	Medium
Social environment	Supportive	Supportive	Hardly supportive	Not supportive
Confidence in the doctor	High	Medium	Medium	Low
Medical knowledge	High	Medium	Low	Low
Level of adherence	Adherent	Partly adherent	Partly adherent	Non-adherent

The first profile is the confident adherent patient. These patients have a broad knowledge about health, are highly involved in the treatment process and use a lot of various information sources. They want to be actively involved in decision-making and have a high trust in their health providers. The second profile is the involved, partly adherent patient. Their motivation to stay adherent is not as high as in profile one, probably because they do not see the therapy as highly effective as the confident adherent patient. Hence the level of trust in their doctor can be described as medium. The third profile is the unmotivated, partly adherent patient. Those patients have little incentive for self-managing their therapy and their medical knowledge is stated as low. Their own health is usually of low priority. The fourth profile is the insecure, non-adherent patient. This patient group has problems to identify good health information and is neither really motivated nor involved in the therapeutic decision-making process. Additionally, the patients in this group do not have social support, which increases the insecurity and decreases the trust in health professionals (Schäfer, 2017, p. 171-175).

4.2. Adherence-Influencing Factors

Adherence research is intensively examining the factors which influence the behaviour of patients positively or negatively when following therapeutic recommendations.

According to the World Health Organization (2003, p. 27) influencing factors can be allocated to five dimensions, as shown in *figure 8*. These dimensions do not act in isolation from one another, but are highly interdependent.

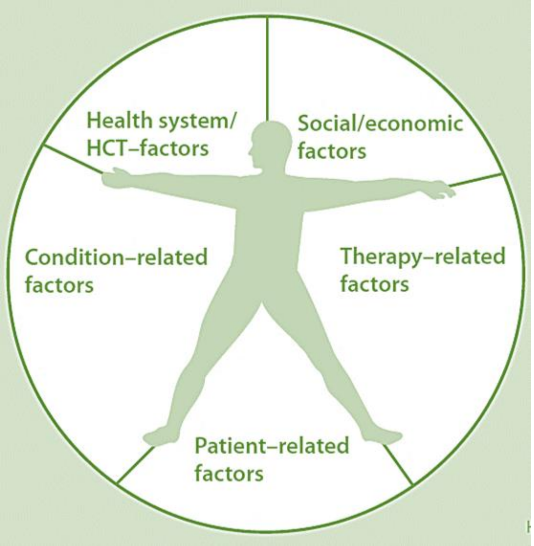


Figure 8. The five dimensions of adherence (World Health Organization, 2003, p. 27).

Social and Economic Factors

An important factor is the economic and social situation of the patient. Although study results do not allow a clear statement about the connection between social and economic factors and the adherence of a person, some factors, nonetheless, seem to have a significant influence on the adherence to therapy. Especially in less developed countries, poverty, a low social status, illiteracy, a low standard of education, unstable living conditions and a lack of helpful social networks are phenomena that contribute significantly to the patients' behaviour. The distance to the place of treatment and the costs for transport and medication also have an impact on the adherence of patients. Additional factors are cultural beliefs about the individual diseases and their treatment options. Depending on the country of origin, war can also play an important role in non-compliance, since the care of patients cannot be sufficiently guaranteed (World Health Organization, 2003, p. 28).

Non-adherence occurs at any age, however, people over 55 years old are more adherent compared to other age groups. On the other hand, cognitive and physical limitations, often developed at an older age, can also affect patient adherence. The influence of gender on adherence is unclear. While in some studies women were found more likely to be adherent, other studies concluded that men were more likely to be adherent. Some studies did not find a link between adherence and gender at all. What might have a positive impact on adherence is the relationship status. Patients who were in a relationship showed a better adherence (Jin et al., 2008, p. 272-276).

Health System and Health Care Team Factors

The dimension "health system and health care team factors" deals with the relationship between patients and health care providers. A good interpersonal relationship generally has a positive influence on adherence and promotes this through discussions and information. However, the relationship can also have a negative effect on adherence, for example, if the health care team is not competent in treating chronic diseases, they do not have enough time to speak with the patient, or when there is no good patient-provider relationship at all. Additionally, the daily overstraining of the nursing staff in clinics can influence adherence, as nursing often becomes routine and the patient with his or her individual needs takes a back seat (World Health Organization, 2003, p. 29).

The costs to be borne by the patient are a frequently mentioned cause of non-adherence. In addition to the costs, the accessibility of the healthcare system plays a major role. Many of these studies were carried out in the USA, and since there is no universal social health insurance to cover most of the costs, these results cannot be directly transferred to countries with a different health system (Jin et al., 2008, p. 280-281).

Condition-related Factors

Condition-related factors differ depending on the illness that the patient suffers from. The more severe the symptoms of the conditions are, the harder it seems for patients to be adherent. Additionally, depression has a significant influence on adherence (World Health Organization, 2003, p. 30). In general, adherence is better when the disease is acute, when it is more severe, when the disease manifests itself with noticeable symptoms, and when the patient suffers more intensively from the disease (Jin et al., 2008, p. 281).

Therapy-related Factors

The fourth dimension include therapy-related factors, which are, for example, the intensity of the side effects and the complexity of the medical therapy (World Health Organization, 2003, p. 30). The occurrence of side effects is one of the most frequently mentioned causes of non-adherence. Adherence is also negatively influenced by a higher complexity of the therapy. The number of prescribed drugs is less important than the frequency of taking them (Jin et al., 2008, p. 278-280).

Patient-related Factors

Finally, the patient-related factors are to be mentioned, for example, the knowledge that patients have about their condition, the motivation and the competence to manage this condition. These factors include the information provided by patients regarding their illness and therapy, but also the individual expectations that are placed on a therapy. Negative factors leading to non-adherence are the already mentioned problems of forgetfulness, fear of side effects, psychological stress, lack of information and of the ability to deal with the symptoms of the disease. In addition, some patients do not belief in the effectiveness of the therapy. The personal attitude towards taking medication is also influenced by expectations and knowledge about the disease. All these factors are interfering with each other and can differ depending on the condition. Consequently it can be said, that it is not exclusively the patients' decision if he or she is adherent or not (World Health Organization, 2003, p. 30-31).

4.3. Medication Adherence

As the number of people with chronic diseases increases, the extent of the difficulties regarding medication intake is becoming evident. Overall, more than 50-60% of all patients with chronic diseases do not take their medication as prescribed, which leads to an adverse health outcome and to a major challenge for the public health (Bosworth, 2013, p. 1-2). Medication adherence as one part of the adherence to therapy "[…] can be defined as the degree to which use of medication by the patient corresponds with the prescribed regimen." (World Health Organization, 2003, p. 47). A literature review of definitions conducted by

Cramer et al. (2008, p. 46) proposes the following definition for medication adherence: “The extent to which a patient acts in accordance with the prescribed interval and dose of a dosing regimen.” In addition to the one given by the WHO, this definition also explicitly refers to the time period within which a medication must be taken. The European Society for Patient Adherence, Compliance and Persistence recommends to define medication adherence as “the process by which patients take their medications as prescribed” (Vrijens et al., 2012, p. 696-697). This process can be divided in three parts including **initiation**, **implementation** and **persistence** as shown in *figure 9*.

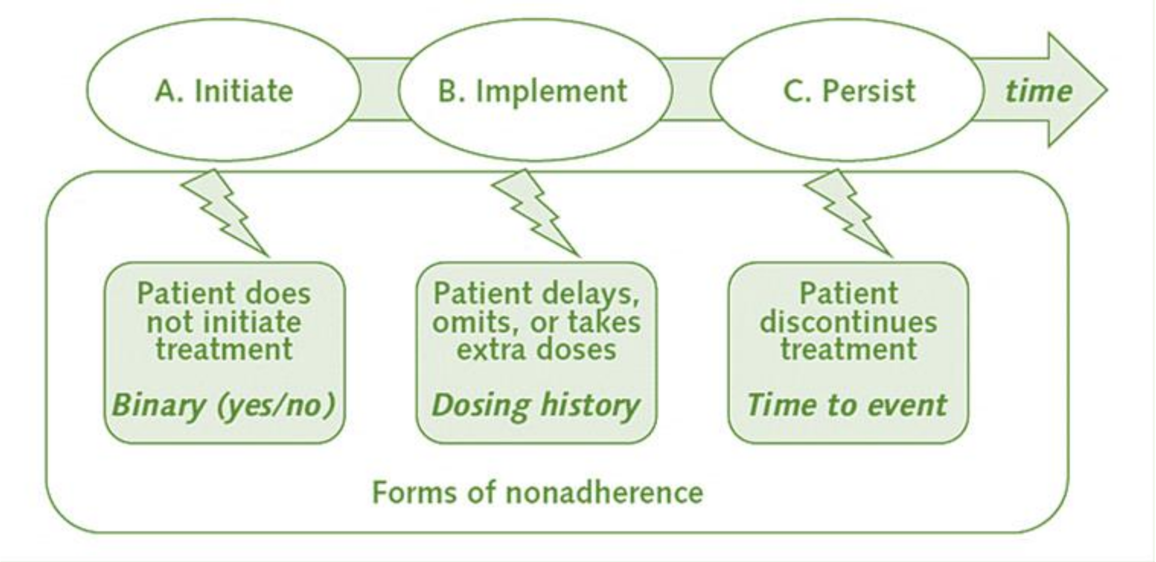


Figure 9. Conceptualisation of Medication Adherence (Geest et al., 2018, p. 31).

The first part, “initiation”, refers to the point, when a patient picks up the prescribed medication in the pharmacy and starts taking the medication. If the patient takes the medication regularly and on time as prescribed, the process continues with the “implementation”. The process ends with discontinuation, which means that a patient does not take the prescribed medication anymore, despite being recommended to continue. In fact, it can be measured if the patient can manage their adherence along this process. For the “initiation” and “discontinuation” faces the proportion of prescribed medication taken can be controlled. The phase of “implementation” can be measured, for example, with the proportion of days with the correct number of doses taken (Vrijens et al., 2012, p. 697-698). The various methods of measuring medication adherence are listed in the next chapter.

4.3.1. Measuring Medication Adherence

In order to find out if a patient is adherent to the medication regimen, several methods can be applied to measure and monitor adherence. So far, no gold standard is recommended in the literature. According to Neuberger et al. (2017, p. 10-11) medication adherence should be surveyed with a combination of various measurement methods and already before transplantation and regularly after transplantation. Measurement methods and tools can be divided in direct and indirect methods (Bosworth, 2013, p. 15; World Health Organization, 2003, p. 4). *Table 4* shows a summary of available direct and indirect measurement methods. Each method is described in the following paragraphs.

Determination of drug level

A useful direct method to examine patient's exact taking of the immunosuppressive medication is to measure the drug level. This is possible for many of the prescribed immunosuppressants and is usually routinely done during follow-ups. Therefore the current trough-level of the medication is compared with the target level defined by the transplantation centre. Over a certain period (eg. one year) it is also possible to calculate the variability of the drug level. However, not every variation and deviation to the target level is caused by the medication-taking pattern alone. There are other factors which may influence the drug level as well (Nöhre et al., 2018, p. 3). These include, for example, interaction with other medications, drug metabolism and diet. Nevertheless, high intrapatient variability of tacrolimus has shown to be associated with poor outcome and higher risk for rejection (Shuker et al., 2015, p. 82; Rayar et al., 2018, p. 3; Gueta et al., 2018, p. 2571; Rahamimov et al., 2019, p. 1). According to Shuker et al. (2015, p. 79) intrapatient variability of tacrolimus (Tac-IPV) "(…) is defined as the fluctuation in Tac blood concentrations within an individual over a certain period of time during which the Tac dose is left unchanged" and is usually measured with the variance or coefficient of variation of the tacrolimus trough level. Because of the possible underestimation of adherence due to the influencing factors, it is recommended to use it together with other measurement methods (Nöhre et al., 2018, p. 3; Lam and Fresco, 2015, p. 2; Lieber et al., 2015, p. 74).

Pharmacy/ Medical Records Review

Pharmacy and medical records can be used to quantify medication adherence with the present data, checking how often the patient is getting a refill or the time from getting the prescription to picking up the medication at the pharmacy. In order to work with this data properly, a computer system is needed (Lam and Fresco, 2015, p. 3). Otherwise evaluating the data can be time consuming. When used correctly in clinical practice, these records are precise and easy to use (Forbes et al., 2018, p. 6).

Table 4

Methods to measure medication adherence (retrieved from Heuer et al., 1999, p.23, Forbes et al., 2018; Nöhre et al., 2018; Lieber et al., 2015; Lam and Fresco, 2015).

Type	Method	Strength	Limitations
Direct	Determination of drug level	Objective, accurate Easy to use when routinely assessed	Underestimation of adherence Influenced by diet, physical activity or absorption
Indirect	Pharmacy/ medical records review	Objective Easy to use Inexpensive	Time intensive Not sensitive to temporal changes
	Counting pills	Easy to use Inexpensive	Overestimation of adherence Do not identify medication-taking pattern Can be easily altered
	Electronic medication monitors	Highly accurate Easy to use Identifies medication-taking pattern	Expensive Can be easily altered
	Observer report	Easy to use Performed quickly Real-time feedback	Underestimation of adherence Subjective No validated instruments
	Patient diary	Inexpensive	Overestimation of adherence Subjective
	Patient self-report	Easy to administer Validated questionnaires Mostly inexpensive Real-time feedback	Overestimation of adherence Patient’s desirability can bias

Counting Pills

With this method the patient gets pills for a certain time period and the patient has to return the remaining pills. The number of the remaining pills is then compared to the number of pills dispensed. To quantify this method Heuer et al. (1999, p. 8) describes the following equation:

$$\text{Compliance (\%)} = \frac{\text{consumed quantity of drugs x 100}}{\text{prescribed quantity of drugs}}$$

Although this method is simple and objective, it does not give any information about the medication-taking behaviour, for instance, on whether the patient took the medication at the right time. That fact leads to the result that adherence is regularly overestimated. Therefore electronic medication monitors have widely replaced counting pills, although it is far more expensive (Forbes et al., 2018, p. 6; Lam and Fresco, 2015, p. 5).

Electronic Medication Monitors

The electronic medication monitoring is an indirect and highly accurate measurement method. From all available options Medication Event Monitoring System (MEMS) is the most frequent used one. Each opening of the electronic medicine box is recorded and stored in a database, in a way that an adherence report can be generated retrospectively. This helps to identify the medication-taking pattern and the type of non-adherence. However, it cannot be verified whether the patient has actually taken the medication. Although there seems to be a good acceptance in the tested patient population, because of the expensive supplies and the large medication containers it is not practicable in all cases. Consequently it is recommended for clinical trials rather than for everyday clinical practice (Forbes et al., 2018, p. 6; Nöhre et al., 2018, p. 3; Lam and Fresco, 2015, p. 4-5).

Observer Report

Another method of monitoring is to conduct a clinical assessment of adherence by the treatment team. As it is based on “feelings” and not conducted with validated instruments, it is mostly unreliable and tend to underestimate adherence (Nöhre et al., 2018, p. 3; Heuer et al., 1999, p. 26).

Patient Diary

A further method is to analyse patient diaries about medication adherence. This method is highly subjective and can be easily manipulated by the patient, resulting in a tendency to overestimate adherence (Nöhre et al., 2018, p. 3; Lam and Fresco, 2015, p. 5).

Patient Self-Report

The conversation with patients about their therapy, combined with specific questions to determine adherence, represents an important instrument for assessing the individual level of adherence. Only if the patient does commit that he or she is non-adherent to the recommended therapy it can be stated as true. For an objective determination of adherence, questionnaires should be used (Heuer et al., 1999, p. 34-35).

Although patient self-report instruments are subjective and partly described as instruments with poor sensitivity and specificity, they are widely recommended for clinical practice because of their low cost and easy handling. In order to standardise the measurement of adherence, different questionnaires for different populations, diseases and languages were developed and tested in clinical trials (Lam and Fresco, 2015, p. 6). Questionnaires should ideally be short, acceptable to patients, valid and reliable. Different types of non-adherence should be distinguished. Furthermore, it should be possible to complete the questionnaire together with the caregiver (Garfield et al., 2011, p. 7).

Dobbels et al. (2010) found three test instruments, which seem most suitable for the transplant recipient cohort. These instruments are described in *table 5.* The validity and reliability are tested for each instrument. Moreover, all these instruments are assessing the taking and timing dimension of medication adherence. The Medication Adherence Self-Report Inventory (MARSI) and the Brief Antiretroviral Adherence Index were both originally developed for Human Immunodeficiency Virus (HIV) medication, but are described as suitable for transplant recipients as well. The Basel Assessment of Adherence to Immunosuppressive Medications Scale (BAASIS) is targeted for immunosuppressive medication and is recommended to be used in the transplant recipient population by the Consensus on Managing Modifiable Risk in Transplantation (COMMIT) group guidelines (Neuberger et al., 2017, p. 10-11).

Table 5

Medication adherence self-report instruments for transplant recipient population (retrieved from Dobbels et al., 2010, p. 209-217).

Author	Scale	Items	Scoring
Leuven Basel Research Group, 2019	Basel Assessment of Adherence to Immunosuppressive Medications Scale (**BAASIS**)	• Self-report interview or questionnaire consisting of five items that need to be answered by yes or no • One month recall period	Any yes on any of the questions is considered non-adherent
Walsh et al., 2002	Medication Adherence Self-Report Inventory (**MASRI**)	• Twelve-item questionnaire addressing the frequency and the correct timing of medication intake. • One month recall period • Three visual analogue scales (VAS) to determine a numeric estimate of the adherence rate (0%–100%).	Scoring algorithm not published
Chesney et al., 2000	Brief Antiretroviral Adherence Index	• Questionnaire consists of four items • Four days recall period	Sum of answers on the items according to an algorithm published in the article are transformed into an index score ranging between 0 (worst adherence) to 100 (best adherence).

Measurements of medication adherence in transplant recipients show heterogeneous results caused by the low quality of the performed studies and the use of various measurement methods (Neuberger et al., 2017, p. 8; Dew et al., 2007, p. 858). An extract of available data per organ is shown in the next chapter.

4.3.2. Medication Adherence in Transplant Recipients

One key factor for a long graft survival that can be influenced by the transplant recipient, is the adherence to the immunosuppressive therapy, which is valid for every organ (Wadström et al., 2017). Despite the heterogeneity of the medication adherence studies, overall transplant recipients show percentages of non-adherence between 22% and 68%. Moreover, non-adherence to immunosuppressive medication is associated with poor health outcomes (Neuberger et al., 2017, p. 8). As adherence is influenced by many factors, as shown in chapter 4.2, several studies have examined these factors and have found significant associations to non-adherence. Results of these studies are shown in the following paragraph.

Villeneuve et al. (2019) examined adherence profiles in 712 kidney transplant recipients. Non-adherence was associated with age under 50 years, more depression episodes and a lower mental health quality of life. A systematic review determined risk factors for poor adherence in kidney transplant recipients as male, below the age of 50, low social support, unemployment, poor education, more than 3 months after transplant, more than five drugs per day, more than two intakes per day, negative beliefs and low satisfaction with the treatment, depression and anxiety (Belaiche et al., 2017, p. 591). In a study population of 524 heart transplant recipients a quarter reported non-adherent behaviour, which was associated with younger patients, lower mental health quality of life and depression (Brocks et al., 2017, p. 164). A meta-analysis of 147 studies including all kind of solid organ transplantations showed an average non-adherence rate between 19% and 25% and was highest in kidney transplant recipients (36%). Only little correlation with non-adherence was found with demographic data, social support and health status (Dew et al., 2007, p. 858). In the study population of kidney transplant recipients, examined by Alkatheri et al. (2016, p. 270) 49% were considered non-adherent and a significant association was found for a decreased satisfaction with treatment and female gender. A liver transplant recipient population showed 40% non-adherence (n = 154). Younger age and lower satisfaction with treatment was associated with non-adherence (Albekairy et al., 2016, p. 127). Drick et al. (2018) surveyed 504 lung transplant recipients, of whom 27% showed self-reported non-adherence. The complexity of the medication regimen and uncertainty about the efficacy of the immunosuppressive medication were reported as barriers to adherence.

After identifying transplant recipients with non-adherent behaviour, effective interventions are necessary in order to improve adherence and to support the self-management of transplant recipients (Neuberger et al., 2017, p. 9).

4.3.3. Interventions to Improve Medication Adherence in Transplant Recipients

According to (Bleser et al., 2009, p. 781) interventions to improve medication adherence can be performed on four different levels, as shown in *figure 10*.

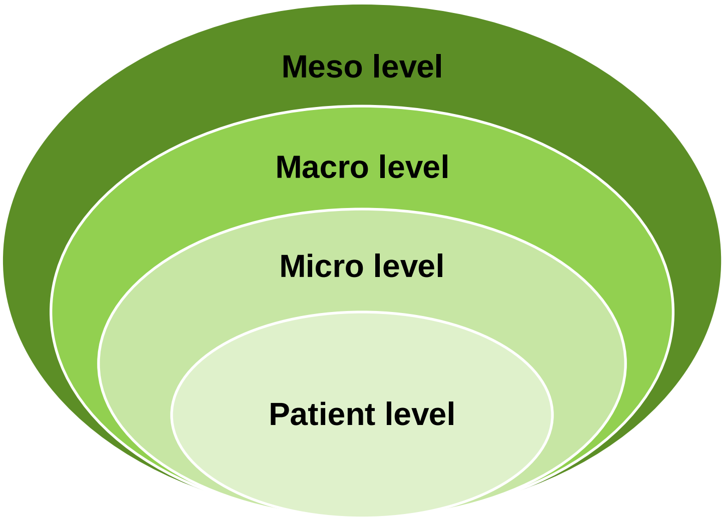


Figure 10. The four levels of interventions to improve adherence (derived from Bleser et al., 2009, p. 781).

At the **patient level**, interventions have so far been carried out with the aim of improving patient knowledge and thus increasing adherence by providing information. The interventions have been carried out either individually or in groups. On the patient level interventions are designed to help patients to reconcile the demands of therapy and their behaviour. As patients get more involved in the care, self-management skills improve and the daily routine is positively influenced. Interventions that provide a reduction in the frequency of dosage should also be included in this area. Medicine boxes, reminders and similar aids also belong to this category. Especially for the use of boxes and reminders an improvement in adherence can be traced. Psychological interventions are also carried out at the patient level, which can influence the patient's social relationships and so positively influence adherence by improving social support. A different approach is taken by interventions that work at the emotional level of the patients. In particular, interventions aimed at improving coping strategies should be mentioned here (Bleser et al., 2009, p. 792-793).

Neuberger et al. (2017, p. 9) also recommend to offer interventions on different patient levels depending on present risk factors. Examples for interventions are demonstrated in *table 6*.

Table 6
Patient-level interventions for non-adherence to immunosuppressive regimens (Neuberger et al., 2017, p. 9).

Patient-level Interventions	**Examples**
Counseling/ behavioural intervention	• Training patients during inpatient recovery on how to take medications • Providing adherence reminders during clinic visits • Medication schedules
Psychological/ affective intervention	• Involving family • Providing support with education and behavioural interventions • Establishing support groups directed at adherence
Educational/ cognitive interventions	• Providing printed medication instructions/ clear prescription instructions • Individual patient/ family teaching
Medical interventions	• Simplified regimens, eg. Monotherapy, once-daily dosing or long-acting parenteral administration • Medication reminder cues, prefilled/ easy-to-use pill boxes, contingency plans for missed doses • Clinicians need to be aware of concomitant medications and focus on prescribing the most essential medication

Interventions on the **micro level** attempt to increase adherence by improving the patient-provider relationship, in particular to improve the quality of the relationship and the communication style (Bleser et al., 2009, p. 781).

At the **meso level**, interventions can be conducted based on the conditions of the respective transplant centre. Interventions can focus on the composition of the interdisciplinary care team and on continuity of care (Bleser et al., 2009, p. 781, 794).

Interventions at the **macro level** are based on the respective national health system. These interventions are rare and are dependent on the social circumstances. Most interventions focus on the costs that a patient has to bear (Bleser et al., 2009, p. 781, 794).

Several systematic reviews analysed the effect of interventions to improve medication adherence in transplant recipients. Bleser et al. (2009) identified 12 studies which examined interventions to improve adherence in transplant recipients. Only the combination of interventions on different levels and with different approaches seem to improve the medication adherence. Because of the low quality of the analysed intervention studies, recommendations concerning interventions are stated as weak. Zhu et al. (2017, p. 1051) found out that interventions for kidney transplant recipients performed through a pharmacist, an intervention group or continuing education indicated significantly higher adherence rates compared to the control group. Mathes et al. (2017) demonstrated larger effects on medication adherence in multimodal interventions which also contain an individual part. A systematic review about interventions to improve medication adherence in heart transplant recipients showed limited evidence on the effectiveness of interventions. Only one study focusing on a change from twice daily to once daily immunosuppressive regimen showed a positive effect (Marcelino et al., 2015, p. 280). The studies reviewed by Duncan et al. (2018, p. 10) did not find any significant improvement on transplant outcomes, although some studies showed improvement in adherence rates. This is consistent with the results of the systematic review done by Shneider et al. (2018). No standard approach can be recommended to improve medication adherence, because it seems that none of the published randomized-controlled trials showed any improvement in transplant outcomes. However, medication adherence should be routinely monitored in clinical practice to further discuss barriers for adherence with the transplant recipient and to offer interventions on individual needs.

Another factor, which is highly important for the general population as well as transplant recipients to sustain and strengthen their health, is the patients’ competence of finding and understanding information regarding their disease and health and making decisions based on this information. This so-called concept of health literacy and the connection to transplant recipients is described in chapter 5.

5. Health Literacy

The term health literacy was first introduced in the context of school health education in the 1970s (Simonds, 1974, p. 9). Sørensen et al. (2012) already identified 17 definitions of health literacy. One of the first and most cited definitions was published by the World Health Organization (WHO). According to the World Health Organization (1998, p. 10)

> “Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health. Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Thus, health literacy means more than being able to read pamphlets and make appointments. By improving people’s access to health information, and their capacity to use it effectively, health literacy is critical to empowerment”.

Before this definition became widely accepted health literacy was often referred to solely functional skills such as the ability to read and write (Schaeffer and Pelikan, 2013, p. 11-12). Consistent with Nutbeam (2000, p. 263f) this type of health literacy can be classified as basic/ functional literacy. With the conceptual expansion and a deeper understanding of health literacy, two more types should be used to classify health literacy. The second type is called communicative/ interactive literacy, which represents the ability to use new information and social skills for everyday life. The third type is the critical literacy. This means that a person is able to evaluate information and can use it to empower him- or herself. Based on this classification, the degree of personal empowerment increases with each level. Progress through the different levels of health literacy depends on much more than the simple development of cognitive skills. Personal and social skills and self-efficacy play an equally important role.

After analysing the 17 definitions of health literacy, Sørensen et al. (2012, p. 12) concluded and recommended to use the following definition:

> “Health literacy is linked to literacy and entails people’s knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgments and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course.”

This decisions are not only restricted to personal health, they also consider health in certain groups, communities and settings (Abel and Sommerhalder, 2015, p. 923-924).

Therefore Kickbusch et al. (2005, p. 10) prefer to describe health literacy as "(…) the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the health care system, the market place and the political area" and sets health literacy into the following framework as shown in *figure 11*:

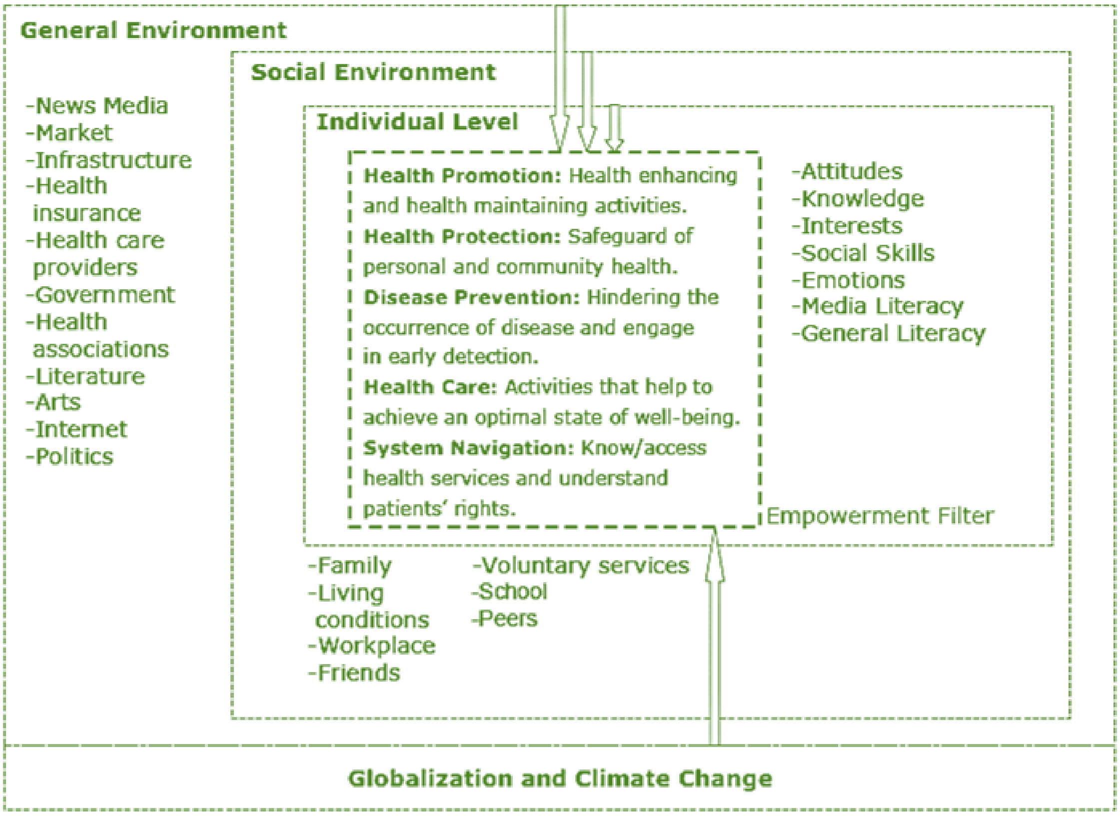


Figure 11. Health literacy framework: Dimensions and influencing factors (Kickbusch et al., 2005, p. 11).

This framework shows the dimensions within which everyone has to make decisions about their health. That starts from the individual level with basic knowledge about health and the competence to find an own way through the health care system. Influenced by the social environment, people have to decide, for example, where they live or what they work, which also has a direct impact on their personal health. On the macro level decisions about the general environment have to be made. Thus every dimension implies influencing factors on our health literacy (Kickbusch et al., 2005, p. 9-11).

5.1. Conceptual Perspective on Health Literacy

To fully understand the concept of health literacy, a multidimensional perspective is necessary. Sørensen et al. (2012) identified 12 conceptual models of health literacy in the monitored literature. One of the first conceptual models, which was already mentioned in chapter 5, is the one described by Nutbeam (2000). He distinguishes between three levels of health literacy. The functional health literacy, the interactive health literacy and the critical health literacy. Functional health literacy is understood as basic literacy. It includes sufficient basic skills in reading and writing to be able to function effectively in everyday life. One example for that is understanding health-related information. Interactive health literacy refers to more advanced intellectual abilities together with social skills. Important information can be obtained and new information can be applied if necessary, for example, acquiring more specific knowledge about one's illness by talking to a doctor. Critical health literacy is the ability to analyse information gathered or received with scrutiny, and to use it to promote health, prevent diseases or to manage disease. This can be, for example, analysing health related information from the internet, discussing it with the doctor or other health professionals and applying relevant information for a health-conscious lifestyle (Nutbeam, 2000, p. 263-264; Abel and Sommerhalder, 2015, p. 923-924).

Most of the identified conceptual models do not provide a thorough and broad overview of health literacy based on its definition. A comprehensively grounded theory is partly missing as well as the medical and public health perspective on health literacy (Sørensen et al., 2012, p. 8). Based on the findings, Sørensen et al. (2012, p. 8-10) developed an integrated model of health literacy, as shown in *figure 12*. At the core of the model four competencies which are necessary to process health-related information are illustrated. Those are accessing information, understanding information, appraising information and applying information. Being competent in all four dimensions depends on the quality of the provided information and on the presence of a certain set of cognitive skills.

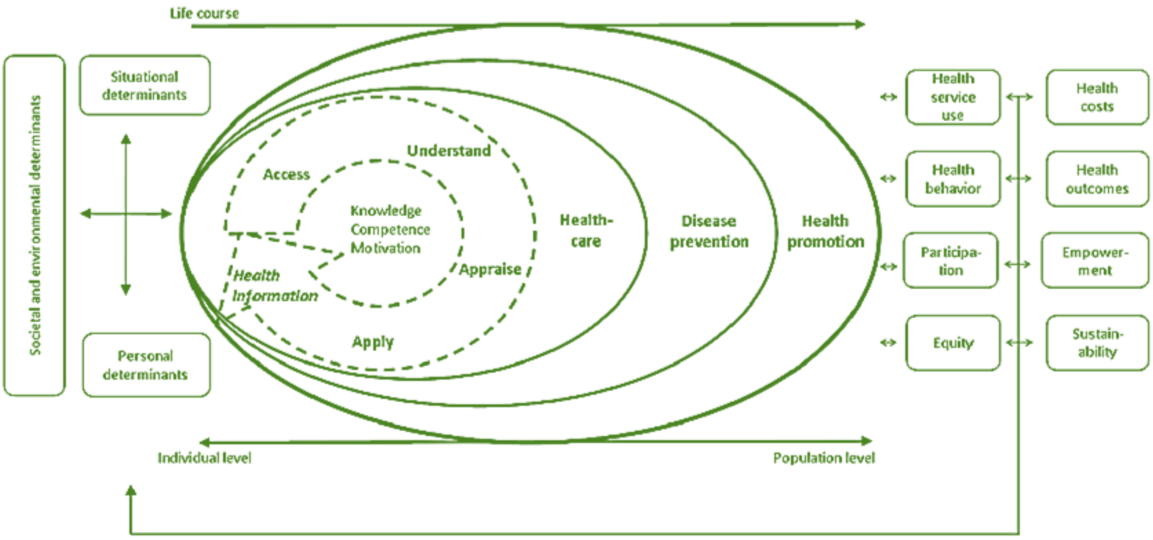


Figure 12. Integrated Model of Health Literacy (Sørensen et al., 2012, p. 9).

“Access” refers to the ability to search and find health information. Finding information depends on reading and writing skills and knowledge about the health care system. “Understanding” attributes to the ability of understanding the content of health information found and depends on the context in which the information was searched and the personal knowledge, believes and experiences regarding the information. “Appraise” describes the ability to critically interpret, filter, assess or evaluate the health information obtained. The assessment of the information depends mostly on its complexity. “Apply” indicates the ability to communicate and use the health information. The aim is to make decisions based on critical analysed information which maintain or improve health. These steps empower a person to take control over their health in relation to the whole health continuum. This applies to coping with an illness and navigating through the health care system, to prevent a disease which a person is at risk of and participate in health promotion activities, which are offered in different settings and environments (Sørensen et al., 2012, p. 8, 9). The information process applied to the three health domains health care, disease prevention and health promotion are shown in *table 7*.

Table 7

Matrix with four dimensions of health literacy applied to three health domains (Sørensen et al., 2012, p. 10).

	Access/ obtain information relevant to health	**Understand information relevant to health**	**Process/ appraise information relevant to health**	**Apply/ use information relevant to health**
Health care	Ability to access information on medical or clinical issues	Ability to understand medical information and derive meaning	Ability to interpret and evaluate medical information	Ability to make informed decisions on medical issues
Disease prevention	Ability to access information on risk factors for health	Ability to understand information on risk factors and derive meaning	Ability to interpret and evaluate information on risk factors for health	Ability to make informed decisions on risk factors for health
Health promotion	Ability to update oneself on determinants of health in the social and	Ability to understand information on determinants of health in the social and physical environment and derive meaning	Ability to interpret and evaluate information on health determinants in the social and physical environment	Ability to make informed decisions on health determinants in the social and physical environment

In all these dimensions certain abilities and competencies are necessary to successfully overcome the barriers in health care. Moreover, there are additional factors which influence health literacy. Those factors, shown in *Figure 12*, are social and environmental determinants such as demographic situation, culture, language, political forces and social system, as well as situational determinants such as social support, media use, influence of family and friends and personal factors, or individual determinants such as age, gender, race, socioeconomic status, education, occupation, employment and income. On the other hand, the level of health literacy has a strong influence on the use of health services, on health behaviour, on health costs and therefore, finally, on health outcomes. Accordingly, improving health literacy can lead to empowerment and participation on an individual level as well as equity and sustainability on the population level. This can be achieved through educating people and by producing easy accessible and understandable information and tasks (Sørensen et al., 2012, p. 9, 10).

5.2. Measuring Health Literacy

Because of the knowledge gap concerning health literacy in different populations, many health literacy tools were developed and tested. The first tools were developed to measure the individual skills and referred mainly to the functional abilities of writing and reading. They were short and easy to use in the health care sector. At present over 100 tools are available to measure individual health literacy. To analyse a broader perspective on health literacy, rather than solely writing and reading, instruments were developed to measure health literacy in whole populations. The first nationwide surveys started in the United States and Canada followed by the European Union (Rudd, 2013, p. 20-22).

Overall, the instruments can be differentiated by their measurement approach, scope and content. The measurement approach can rely on test instruments or self-assessment questionnaires. Test instruments capture health literacy through tasks and examination. Self-assessment questionnaires evaluate health literacy through the subjective evaluation by the individual. The scope can focus on the abilities to navigate through the health care system or it can focus on dealing with health and disease in everyday life. Finally, the measurement tool can assess either health literacy without any specific content-related reference or with focus on a particular health problem (Abel and Sommerhalder, 2015, p. 926). Haun et al. (2014) identified 51 health literacy measurement tools in their descriptive summary. 26 tools to assess general health literacy, 15 to assess disease-, or condition-specific health literacy, and ten to assess population- or language-specific health literacy. A database of health literacy measures, provided by the University of Boston, shows 198 results for health literacy measures. Through filter criteria like domain, context or language, appropriate tools can be found and, if available, permission to use the tool can be asked through the contact details on the database (Boston University, 2020).

In *table 8* an overview of the relevant tools and their applications is given. Because of the large variety of tools, only those with the focus on general population or the transplant recipient population were analysed.

Table 8

Health literacy measurement tools to measure general health literacy (retrieved from Abel and Sommerhalder, 2015, p. 26-27; Haun et al., 2014, p. 306ff)

Nr.	Name	Description	Target audience	Strengths	Limitations
1	Rapid Estimate of Adult Literacy in Medicine (**REALM**)	Health word recognition and pronunciation	Adults	Quick and easy to administer; short version available. Minimal training is required to administer the test. Has high concentration of items at lower literacy levels increasing discriminatory power when administered to patients with limited reading ability.	Only measures one dimension of health literacy. Presence of a ceiling effect. Does not measure the patient's understanding of the words.
2	Test of Functional Health Literacy for Adults (**TOFHLA**)	Close style reading comprehension of health-related content	Adults	Available in Spanish, German, French, and Italian. Short version available. Has been validated in several samples representing diverse populations.	Long versions are time-consuming=may overestimate health literacy. Longer version is more useful as a research tool than a clinical screening tool.
3	Newest Vital Sign (**NVS**)	Survey items about information presented on a nutrition label	Adults	Quick functional health literacy assessment that includes numeracy. Tested in English speaking and Spanish speaking sample.	Validation sample did not fully represent a demographically diverse population. Test format might intimidate respondents.
4	Health Literacy Questionnaire (**HLQ**)	Survey items measuring health literacy of individuals	Adults	Self-administered; measures multiple domains of health literacy.	Self-assessment has potential for self-report bias.
5	European Health Literacy Questionnaire (**HLS-EU**)	Survey items to assess the relation between abilities, system demands, and decision making	Ages 15+ years	Comprehensive, conceptual based measure of most dimensions of health literacy; available in 10+ languages.	Length of assessment increases response burden. Self-assessment has potential for self-report bias.
6	Health Activities Literacy Scale (**HALS**)	Used to estimate the distribution of literacy on health-related tasks among U.S. adults	Ages 16+ years	Computer adapted; sensitive to change post intervention; Short version available.	Designed to be used as a subscale of a larger instrument, length is time consuming; cannot be quickly administered.

As shown in table 8, REALM, TOFHLA and NVS are test instruments which measure only functional health literacy. The HLQ, HLS-EU and HALS are self-assessment instruments which are based on a multidimensional concept of health literacy. They try to assess all competencies which are necessary for health literacy. All instruments are validated in adult population. Only TOFHLA and HLS-EU are available in German (Abel and Sommerhalder, 2015; Haun et al., 2014).

Two measurement tools were identified in the literature to measure health literacy in transplant recipient population. One was an adapted version of the REALM, named Rapid Estimate of Adult Literacy in Medicine – Transplantation (REALM-T). The medical terms asked there are transplant-related. The tool is available in English and Spanish, and limited studies are available (Gordon and Wolf, 2009, p. 26-27; Dageforde and Cavanaugh, 2013, p. 314). Another instrument is an adapted version of the Newest Vital Sign, named Medication Health Literacy Measure. Patients were questioned about a label for the immunosuppressant drug Prograf®. It was tested only in one English speaking adult liver transplant recipient population (Stilley et al., 2014, p. 3).

So far, no gold standard for a health literacy measurement tool exists, neither for the general population nor for the transplant recipient population. Therefore the tool has to be chosen depending on the research context, the time frame and resources available (Haun et al., 2014; Abel and Sommerhalder, 2015; Liu et al., 2018).

5.1. Health Literacy in Austria

In 2012 the European Health Literacy Survey (HLS-EU) was conducted in eight member states of the European Union (EU). Those member states were Austria (AT), Bulgaria (BG), Germany (DE), Greece (EL), Ireland (IE), Netherland (NL), Poland (PL) and Spain (ES). The goal was to collect internationally comparable data on the health literacy level of the adult population. Health literacy was measured in a sample of 1000 people aged 15 years or older per country. With the self-developed HLS-EU-Q47 questionnaire, which consists of 47 items, health literacy was assessed. To evaluate health literacy, four different levels were defined. These four levels and the results per country are shown in *figure 13* (Sørensen et al., 2015, p. 1-3).

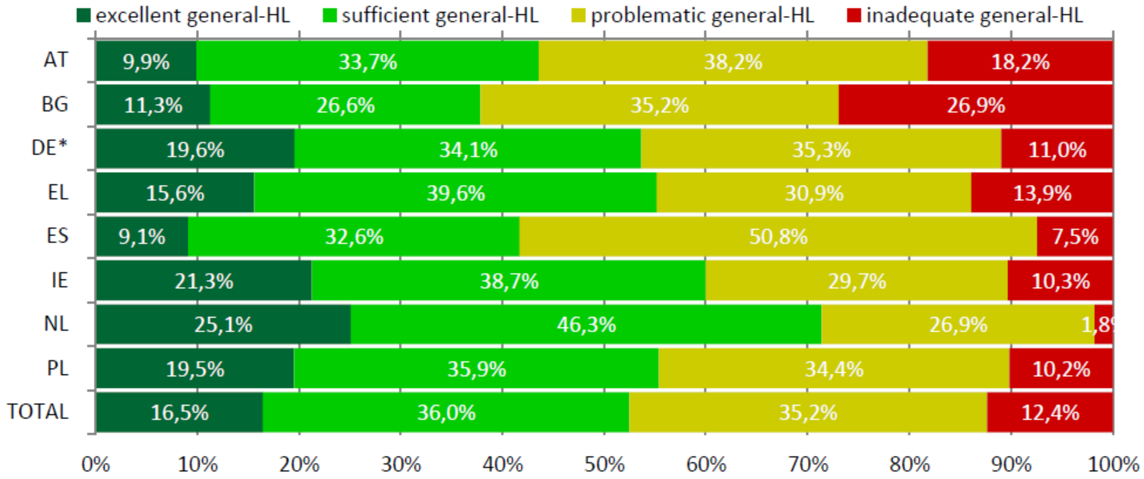


Figure 13. Levels of general health literacy index by country and for the total sample (HL: health literacy) (n= 8000) (HLS-EU Consortium, 2012, p. 32).

In Austria over 50% of the respondents were classified as possessing limited (inadequate or problematic) health literacy. Compared to other participating countries, the Austrian results are below average and significantly worse than those in the best country, the Netherlands. That means, overall, every second Austrian inhabitant is affected by limited health literacy and in some particularly vulnerable groups, such as the elderly, educationally disadvantaged or chronically ill people, limited health literacy even rises to over 76%. Furthermore, limited health literacy was associated with a low socioeconomic status, a lower education, a poor health status and older age. This indicates that health literacy is socially unequally distributed and not just depending on the actual health status (Röthlin et al., 2017, p. 8; Pelikan et al., 2013, p. 15-19; Sørensen et al., 2015, p. 3-4).

5.2. Causes and Consequences of Limited Health Literacy

The level of health literacy is stated to have an influence on health related factors. Berkman et al. (2011) demonstrated that limited health literacy is associated with a higher rate of hospital admissions, an increased medication non-adherence, a worse health status in elderly and an increased mortality. Due to the fact that limited health literacy has an negative impact on health outcomes, Paasche-Orlow and Wolf (2007) developed a conceptual model based on present literature. This model, shown in *figure 14*, tries to explain the factors which link health literacy to health outcomes.

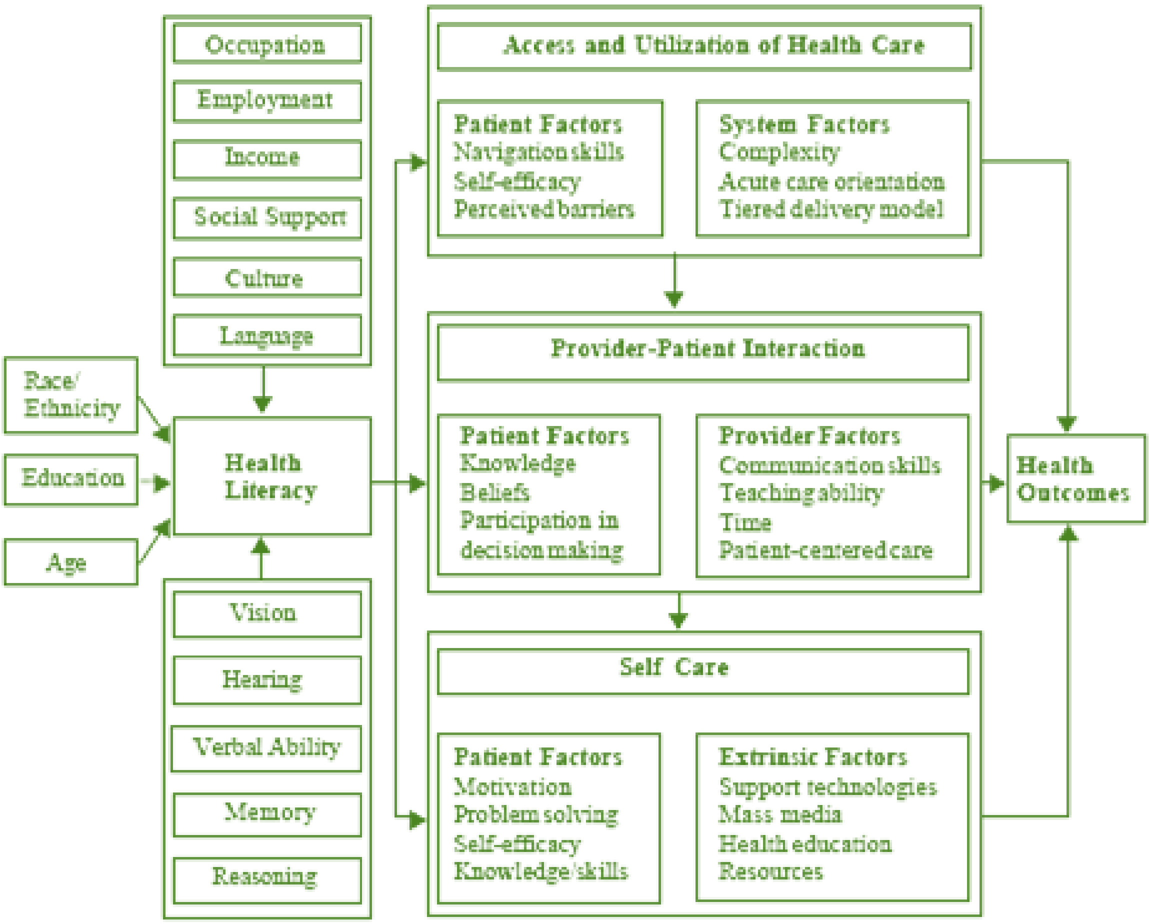


Figure 14. Causal pathways between limited health literacy and health outcomes (Paasche-Orlow and Wolf, 2007, p. 21).

The left column shows the factors which directly influence the level of health literacy, such as education, age and race. The right column shows factors or areas which are influenced by the level of health literacy, like self-care, patient-provider relationship and access to and utilization of health care. People with limited health literacy tend to wait longer before they get professional help, the reason being the missing ability to interpret symptoms and signs. Usually they show a lower degree of confidence in health care providers and lower satisfaction with treatment. They are also more inactive when it comes to their treatment process and they ask fewer questions regarding their disease, which often leads to poor communication between the patient and the health care provider. Moreover, people with limited health literacy show difficulties with their self-management. Medication adherence, which is an important compound of self-management, has shown heterogeneous results. No final conclusion can be made on whether limited health literacy leads to increased medication non-adherence. Finally, not every factor presented in the model can be causally linked to health outcomes because of missing evidence and a lack of longitudinal empirical research (Paasche-Orlow and Wolf, 2007).

5.3. Health Literacy in Transplant Recipients

Due to the lack of a comprehensive theortical framework for health literacy in transplant recipients, the conceptual causal model shown in *Figure 14* was further developed by Chisholm-Burns et al. (2018). Studies in transplant recipients were reviewed to find associations between health literacy, patient-level factors, healthcare-level factors and health outcomes. The adapted model is shown in *figure 15*.

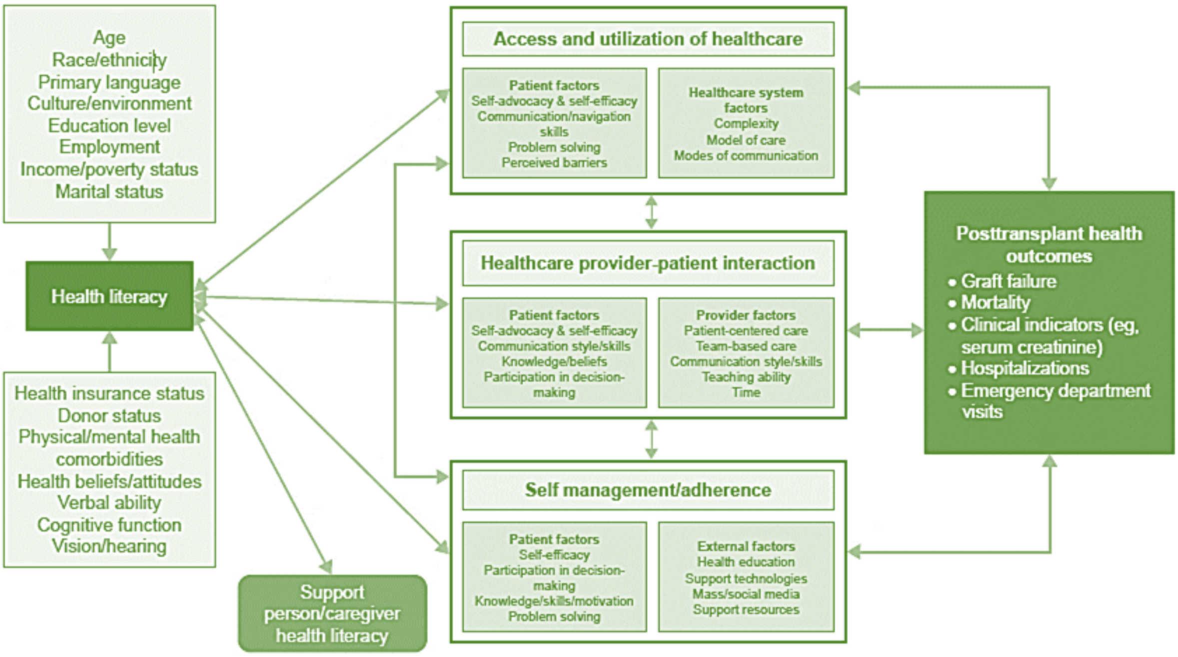


Figure 15. Health literacy model in transplantation (HeaL-T) (Chisholm-Burns et al., 2018, p. 2326).

Regarding patient-related factors Chisholm-Burns et al. (2018, p. 2327) found associations between limited health literacy in transplant recipients and older age, minorities, lower education level, unemployment, lower income, not married, deceased donor, poorer mental health status, increased comorbidities, negative health beliefs and limited cognitive function. Not only the patient factors seem to have an impact on post-transplant outcome, but also limited health literacy of the health care provider can prevent competent support. Additionally, the quality of communication with patients and explanation of information to enable the patient to understand also have an influence on the health behaviour. Relating to post-transplant outcomes, shown in *Figure 15*, associations were found between limited health literacy and higher creatinine levels in kidney transplant recipients as well as increased mortality and an increased number of hospital admissions. The authors also indicate a connection between the level of health literacy and the self-management competencies, especially those regarding medication adherence.

5.4. Health Literacy and Medication Adherence

So far medication adherence has prevalently focused on the medication taking behaviour. Based on the findings from the health literacy research, a conceptual model was developed to additionally include also the knowledge and skills necessary for enabling the patient to take the medication correctly and as long as needed (Bailey et al., 2013, p. 22). The conceptual model is shown in *figure 16* as an endless process consisting of six steps starting with "Fill".

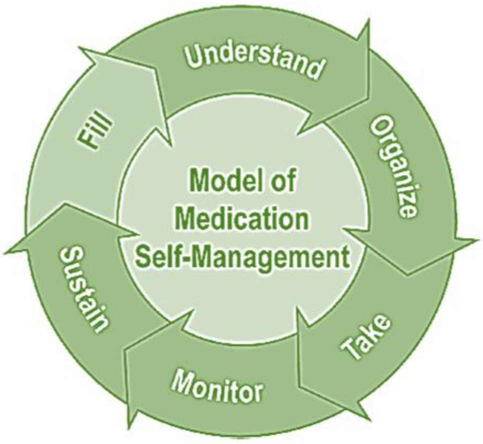


Figure 16. A Health Literacy–Informed Model of Medication Self-Management (Bailey et al., 2013, p. 23).

Haslbeck (2017) suggests using the term "medication literacy" for health literacy regarding the use of medication. Medication literacy is the ability to access and understand medication information and then make medication-related decisions. This ability should enable the patient to use medication safely and effectively. Starting with the patients' entering the pharmacy to collect the prescribed medication, they have to understand the information given by the pharmacist ("Fill"). Patients must be able to understand which drugs have to be taken, why and in which way. This includes the names of the drugs as well as relevant information on distinguishing the different medications, as package leaflets are often complex and not easy to comprehend for patients ("Understand"). Another competence which is indispensable is the ability to integrate the medication regime into everyday life ("Organise"). Thus strategies for a regular medication intake have to be developed and applied ("Monitor"). Patients also need knowledge about side effects and adverse medication reaction. Only then patients are able to discuss them with their health care providers ("Monitor"). Finally the importance of the long-time intake of the medication must be addressed to the patient ("Sustain") (Bailey et al., 2013, p. 22-24).

Key to the promotion of medication literacy and self-management of medications is the trustworthy and patient-centered health information in order to enable patients to better understand the purpose of prescribed medicines (Haslbeck, 2017, p. 269).

In a meta-analysis Miller (2016) examined the correlation of medication adherence and health literacy and analysed interventions aimed at improving those factors in chronic and acute illness. It emerged that people with a higher health literacy level tend to be more adherent, especially with conditions that require lifestyle changes. Furthermore, patients who participated in an intervention for improving health literacy showed a higher rate of treatment adherence afterwards. Interventions were effective when the focus was on the communication with the patient and the disease and instructions were explained matching the patient’s health literacy level. Moreover, a teach-back method was recommended to ensure that the patient understood the content of information. Also a shared decision approach could help to set realistic goals regarding the treatment plan.

The current status of research regarding health literacy and medication adherence in transplant recipients is demonstrated in detail in the following chapter.

6. Current Status of Research of Health Literacy and Medication Adherence in Solid Organ Transplant Recipients

To identify studies about medication adherence and health literacy in transplant recipient population, a literature search was conducted. From September to December 2019 PubMed, CINAHL and Medline databases were searched. To find eligible data, the search terms were separated by Boolean operators “AND” and “OR”. Studies were included if they were published during the last ten years (2009 and 2019), written in German or English, carried out as cross-sectional studies and surveyed solid organ transplant recipients aged over 18 years. The total hits are shown in *table 9*.

Table 9

Number of hits from database search.

Search term	**PubMed**	**CINAHL/ Medline**
Medication adherence AND health literacy AND transplant*	17	21
Medication compliance AND health literacy AND transplant*	17	10
Drug compliance AND health literacy AND transplant*	4	2
Drug adherence AND health literacy AND transplant	6	1
Medication adherence AND health competence AND transplant*	0	0

78 potential studies (*figure 17*) were identified of which 34 were excluded due to being duplicates. Eight studies underwent full-text review and three were eliminated for being a development of medication health literacy measure, being a study protocol or if health literacy was not measured explicitly.

A total of five studies were included encompassing 669 transplant recipients (ranging from 96 to 252 transplant recipients per study). All the studies were based on a cross-sectional survey design. Three studies surveyed kidney transplant recipients, one study liver transplant recipients and one study lung transplant recipients. The percentage of female participants ranged from 33% to 50%. Test instruments used to measure non-adherence were the Transplant Effects Questionnaire-Adherence subscale (TxEQ), the Basel Assessment of Adherence to Immunosuppressive Medications Scale (BAASIS), the Immunosuppressive Therapy Adherence Scale (ITAS) and twice the Patient Medication Adherence Questionnaire (PMAQ). Non-adherence rates ranged between 14% and 75%.

One study did not publish the percentage of non-adherence. Test instruments used to measure health literacy were the Health Literacy Questionnaire (HLQ), the Rapid Estimate of Adult Literacy in Medicine (REALM), the short Test of Functional Health Literacy in Adults (sTOHFLA) and two times the Newest Vital Sign (NVS). Limited health literacy ranged between 2.4% and 24%. One study did not provide any percentage of limited health literacy. Characteristics of included studies are shown in *table 10*.

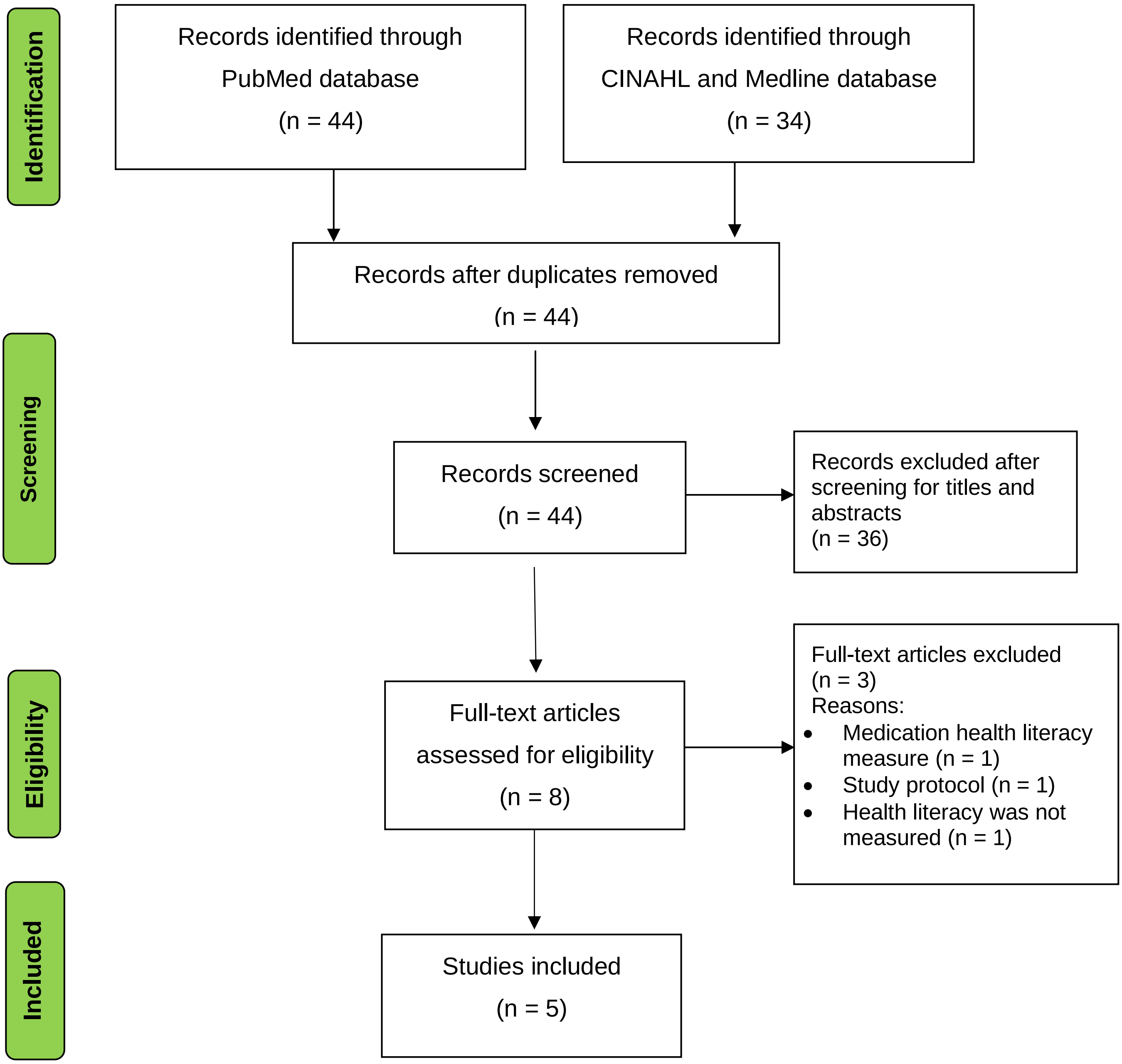


Figure 17. PRISMA flow diagram for literature review (Moher et al., 2009, p. 3).

Table 10

Characteristics of included studies.

Author	**Sample size**	**Mean age years (*SD*)**	**Female (%)**	**Time since Tx years**	**Methods of assessment**	**Non-adherence rates (%)**	**Level of Health Literacy**
Demian et al. (2016)	96	53 (13)	44	*M* = 9 (*SD* = 7.00)	HLQ, TxEQ	75	Low level of health literacy in active health management and critical appraisal of information
Lennerling et al. (2018)	117	54 (13)	50	1 to 5 years	NVS, BAASIS	n/a	6% low literacy, 16% possibly limited literacy, 79% adequate literacy
Serper et al. (2015)	105	57 (13)	41	*MD* = 2 (*IQR* 1-5)	NVS, PMAQ	14	15% with limited health literacy
Patzer et al. (2016)	99	53 (13)	33	*MD* = 4 (*IQR* = 1-7)	REALM, PMAQ	35	24% with limited health literacy
Weng et al. (2013)	252	*MD* = 55 (*IQR* =45-63)	40	*MD* = 3 (*IQR* = 1-6)	sTOFHLA, ITAS	14.3	2.4% with limited health literacy

Demian et al. (2016) demonstrated a significant correlation between low levels of health literacy and medication non-adherence in kidney transplant recipients. Furthermore, non-adherence was also found to be more frequent with male transplant recipients, younger age and higher levels of employment. Patzer et al. (2016) also stated that limited health literacy was associated with non-adherence in kidney transplant recipients, as well as shorter times since transplant were associated with non-adherence. Serper et al. (2015) described that results from liver transplant recipients showed indeed a correlation between health literacy and non-adherence according to tacrolimus levels, but not with self-reported non-adherence. Lennerling et al. (2018) did not find any association between health literacy and medication adherence in lung transplant recipients. Health literacy was also not associated with other measured variables such as age or gender. Weng et al. (2013) could equally not detect any correlation between non-adherence and low levels of health literacy in kidney transplant recipients, probably due to the homogeneity in health literacy scoring.

Based on the theoretical background and the current status of research, a model was constructed to show the connections and risk factors of the concepts self-management, medication adherence and health literacy in transplant recipients (*Figure 18*).

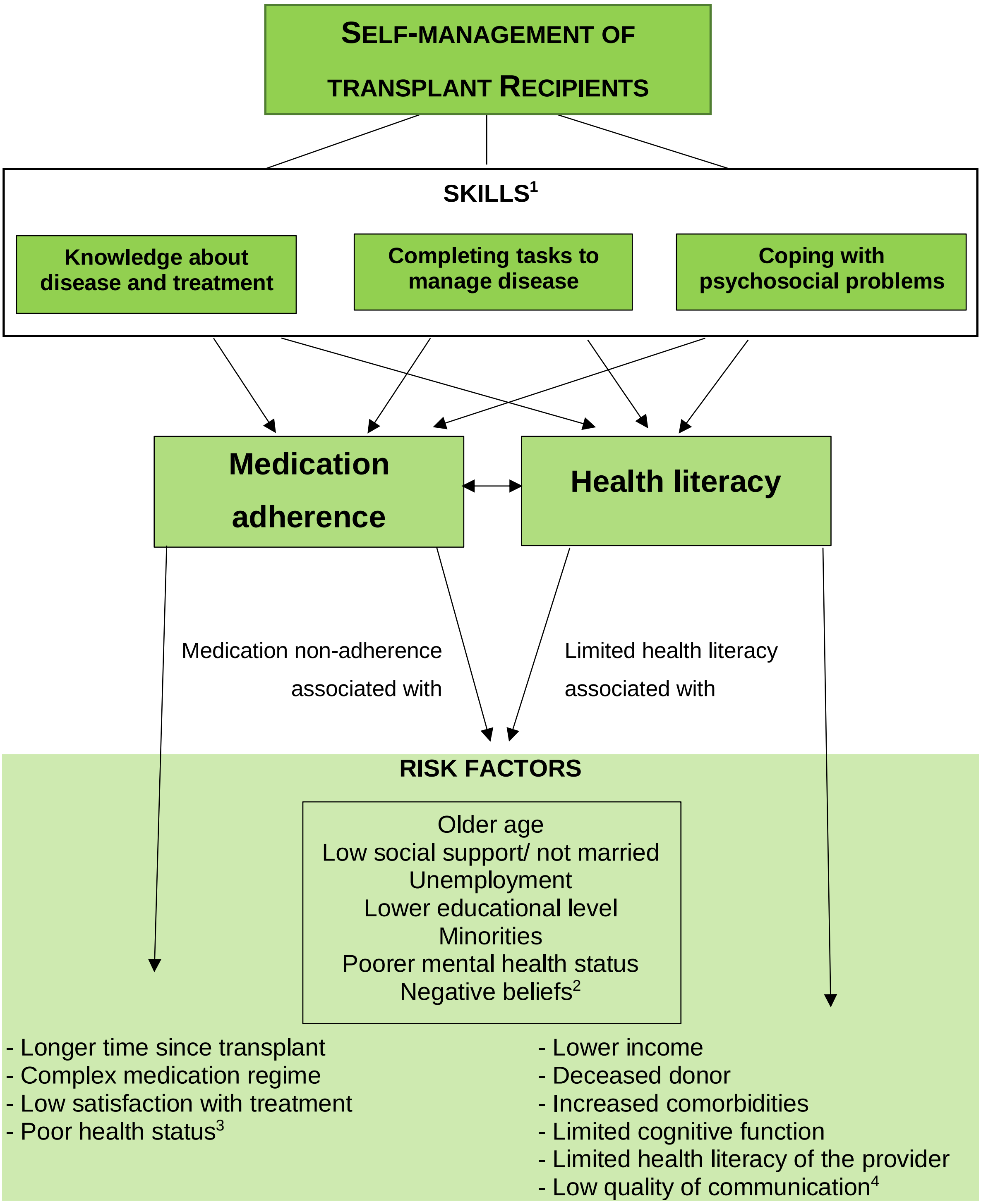


Figure 18. An integrated risk factor model for medication adherence and health literacy regarding self-management skills after transplantation.

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[1] Clark et al., 1991; Lorig and Holman, 2003.

[2] Villeneuve et al., 2019; Belaiche et al., 2017; Brocks et al., 2017; Dew et al., 2007; Albekairy et al., 2016; Demian et al., 2016; Chisholm-Burns et al., 2018.

[3] Drick et al., 2018; Alkatheri et al., 2016; Belaiche et al., 2017; Dew et al., 2007; Patzer et al., 2016.

[4] Chisholm-Burns et al., 2018.

According to Clark et al. (1991, p. 6) three self-management skills are necessary for a successful self-management. These skills are directly linked to medication adherence and health literacy. The first skill, the “knowledge about the disease and treatment”, can have an influence on medication adherence. This knowledge again is depending on the level of health literacy of the transplant recipients. The second skill, “completing tasks to manage disease”, is necessary for a regular medication intake, for which a patient has to understand and critically analyse information regarding the medication intake. The third skill, “coping with psychosocial problems”, also requires (depending on the extent of the psychosocial problem) medication adherence as well as the competence to find the right information and help regarding mental health. Furthermore, risk factors for medication non-adherence and limited health literacy are presented in this model based on the results from the studies presented in chapters 4.3.2, 5.3 and 6. Risk factors illustrated in the box were found to be connected with medication non-adherence as well as limited health literacy.

In the next chapter the methodological approach is described regarding how medication adherence and health literacy was measured and analysed in solid organ transplant recipients in Austrian support groups.

7. Methods

There are several methods to investigate complex situations in research. It can done by using a quantitative, a qualitative and a mixed-methods approach (Döring and Bortz, 2016, p. 184).

For the following study a quantitative research approach was chosen. In quantitative research theoretically derived research hypotheses are examined on many study units using structured data collection methods. The goal is usually to test the hypothesis. The collected quantitative data are statistically evaluated (Döring and Bortz, 2016, p. 184). The different quantitative research approaches are shown in *figure 19*.

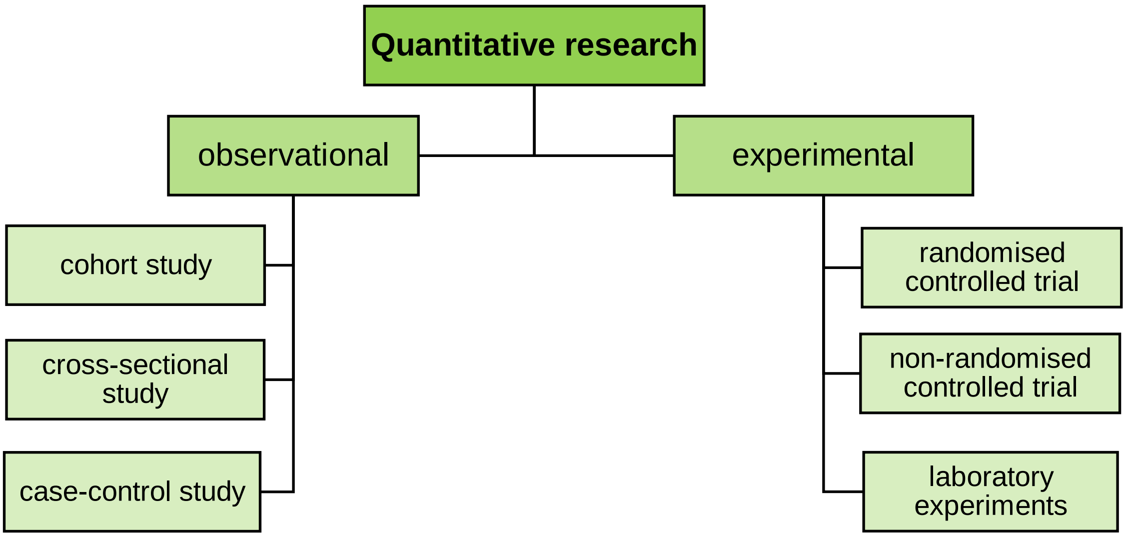

Figure 19. Quantitative research approaches (Döring and Bortz, 2016, p. 193-215).

The study design characterises the methodological approach of a study in general. Within a specific research design different types of samples and data collection and analysis procedures can be used (Döring and Bortz, 2016, p. 182). The detailed process of the performed study is explained in the following chapters.

7.1. Study Design

The present study is based on a cross-sectional survey design of solid organ transplant recipients in support groups in Austria. Cross-sectional study designs refer to a quantitative research within the group of observational methodologies. It enables data gathering from a selected population at a set period of time. This study design is often used to determine prevalence or to investigate an association between a risk factor and an outcome. However, it cannot address causal relationships (Döring and Bortz, 2016, p. 210-211).

The study participants were surveyed once over a certain period of time with a questionnaire consisting of one validated test instrument for medication adherence, one validated test instrument for health literacy and further questions regarding sociodemographic data, influencing factors and experience with interventions.

7.2. Questionnaire Development

The scientific questionnaire method is a goal-oriented, systematic and rule-guided generation and recording of verbal and numerical self-declarations of interviewees on selected aspects of their experience and behaviour in written form. Within a short time questionnaire responses can be collected from many respondents for a very large number of characteristics. Filling out a questionnaire is more discreet and anonymous from the interviewee's perspective. The construction of the standardised questionnaire instrument is carried out in two steps, first as a rough and then as a detailed conception. The constructed questionnaire is finally subjected to a pre-test and revised if necessary. Usually a standardised questionnaire consists of a title, questionnaire instruction, topic-related questions, statistical data, questionnaire feedback opportunity and an end-of-questionnaire-phrase (Döring and Bortz, 2016, p. 398). To gather information about the sociodemographic data of the study participants, medication adherence, the level of health literacy, their influencing factors and the experience with interventions on medication adherence, a questionnaire with 43 items was developed. The time requirements of the survey was estimated to between 10 to 15 minutes. The number of items and their literature reference per subject area are shown in *table 11*.

Table 11

Item sets and reference.

Subject area (measurement tool)	Items	Author
Solid organ transplantation	3	Self-constructed
Health status	1	Derived from Bullinger (1995)
Medication adherence (BAASIS)	10	Leuven Basel Research Group (2019)
Side effects	2	Atkinson et al. (2004)
Experience with interventions referring to immunosuppressive medication	5	Self-constructed
Health literacy (HLS-Q16)	16	Pelikan and Ganahl (2017)
Sociodemographic data	5	Self-constructed
Questionnaire feedback	1	Derived from Döring and Bortz (2016, p. 406)

Questions About Solid Organ Transplantation

As introductory questions three items surveyed statistical data about the solid organ transplantation. The first item asked about the kind of solid organ which the study participant received. Answer options given were “heart”, “lung”, “liver”, “kidney”, “pancreas” and “others”. The last answer option was to filter study participants who did not receive a solid organ. The second item asked about time since transplant given in years and months. The third item asked about the participation in a support group for transplant recipients and gave the answer options “yes” and “no”.

Questions About Health Status

One item surveyed the self-assessed current health status of the study participants. Wording of the item was based on the health related quality of life questionnaire (Bullinger, 1995). Study participants rated their current health status on a five-point-rating-scale from excellent to poor.

Test Instrument for Medication Adherence

Non-adherence to immunosuppressive medications was assessed using the Basel Assessment of Adherence to Immunosuppressive Medications Scale. This scale was developed to assess adherence to immunosuppressive medications in adult and adolescent transplant recipients and is available as questionnaire as well as interview guideline in several languages (Leuven Basel Research Group, 2019, p. 1). Psychometric properties were tested by Marsicano et al. (2013). A systematic review and the COMMIT group recommended this validated scale as the most appropriate self-report instrument for measuring non-adherence in transplant recipients because of its simplicity and ease of scoring (Dobbels et al., 2010, p. 217; Neuberger et al., 2017, p. 10-11). Permission to use the scale was requested directly from one of the authors, Sabina de Geest and received on 5th October 2019 (Geest 10/5/2019). The BAASIS consists of five items, of which four assess issues with the implementation and one the non-persistence of immunosuppressive medication use. Additionally there is one optional item relating to non-initiation of a prescribed medication. However, this item was not included in the present questionnaire, because it is of no relevance to the research question. Three items have a sub-question regarding the frequency of occurrence. Any “yes” on any of the items 1a, 1b, 2, 3 or 4 indicates that the study participant is non-adherent (Leuven Basel Research Group, 2019). Additionally, the percentage of items answered with “yes” were scored as well. All five items answered with “yes” were scored with 0% (means non-adherence) and all five items answered with “no” were scored with 100% (means perfect adherence). Items of BAASIS are shown in *table 12*.

Table 12

BAASIS Items and Answer Options (derived from Marsicano et al., 2013, p. 4).

BAASIS Items	Answer options
1a. Taking dimension Do you recall not having taken your immunosuppressive medications some times in the past 4 weeks?	☐ Yes ☐ No
Sub-Question: Could you tell me how often this happened?	☐ Once a month ☐ Every two weeks ☐ Every week ☐ More than once a week ☐ Every day
1b. Drug holidays Have you skipped several consecutive doses of your immunosuppressive medications in the past 4 weeks?	☐ Yes ☐ No
Sub-Question: Could you tell me how often this happened?	☐ Once a month ☐ Every two weeks ☐ Every week ☐ More than once a week ☐ Every day
2. Timing dimension Do you recall having taken your immunosuppressive medications with more than 2 hours' time difference from the prescribed dosing time, in the past 4 weeks?	☐ Yes ☐ No
Sub-Question: Could you tell me how often this happened?	☐ Once a month ☐ Every two weeks ☐ Every week ☐ More than once a week ☐ Every day
3. Reduction of dose Have you reduced the prescribed amount of your immunosuppressive medications on your own initiative in the last 4 weeks without your doctor asking you to? For example, did you take more or fewer tablets or change the dose, perhaps by halving a tablet?	☐ Yes ☐ No
4. Persistence Have you stopped taking any of your immunosuppressive medications on your own initiative within the last year without your doctor asking you to?	☐ Yes ☐ No

Additionally, item 1a and 2 were completed with one self-constructed open-label question to discover the reasons why study participants missed a dose of the immunosuppressive medication. In terms of research strategy, open questions are particularly suitable for exploring the problem field and generating relevant answer categories with regard to closed questions (Raithel, 2008, p. 70).

Questions About Side Effects

Two items surveyed the extent of side effects and the feeling of restriction through side effects. They were based on the Treatment Satisfaction Questionnaire for Medication (TSQM) (Atkinson et al., 2004). Study participants rated both items on a four-point scale, describing the extent of side effects from no side effects to strong side effects and the restriction from no restriction to strong restriction.

Questions About the Experience with Interventions

Due to the lack of scientific literature on interventions regarding immunosuppressive medications after solid organ transplantation in Austria, five self-constructed items were added to the questionnaire. Three items surveyed whether the study participant did receive information and/ or training about immunosuppressive medication after the transplantation, in which form they received it and if it was sufficient. Another two items surveyed from whom the study participant received the information and/ or training and what form of information and/ or training was most effective in their opinion. Answer options were derived from Neuberger et al. (2017).

Test Instrument for Health Literacy

Currently there is no gold standard for measuring health literacy (Haun et al., 2014; Abel and Sommerhalder, 2015). The HLS-EU-Q was chosen, because it measures all dimensions of health literacy, not only functional literacy, because it is available in German and easy to score and administer online (Haun et al., 2014, p. 310, 322). Röthlin et al. (2017, p. 5-6) state that the HLS-EU-Q is the most frequently used instrument to measure overall health literacy on an individual level. The self-assessed health literacy was surveyed with the HLS-EU-Q16 scale, which is a shortened version of the HLS-EU-Q47 instrument, consisting originally of 47 items and now comprising 16 items. The short form was developed and validated based on the HLS-EU data and verified in the course of the Austrian Health Literacy Youth Study. Not only is it much shorter and takes up considerably less time in surveys, but it also obtains the results of the longer and more complex instrument to a sufficient extent. It is simple to use and easy to calculate (Pelikan et al., 2013). Permission to use the Health Literacy Survey was granted by Jürgen M. Pelikan on 21st September 2019 by e-mail (Pelikan 2019, September 21). This scale operationalises the definition of health literacy by Sørensen et al. (2012) and is divided according to the conceptual model into the dimensions of disease management, disease prevention and health promotion. The focus is on the four dimensions of processing health-related information. The three health domains and the four dimensions together form a 12-cell matrix (see *table 13*), which was used as a basis for the selection of the HLS-EU-Q items. Each of the 12 cells of this matrix was operationalised with a minimum of three or maximum of five items. In total, the HLS-EU-Q instrument comprises 47 items. For the short form 16 items were found to meet the psychometric properties. Only for the dimension apply/ use information and health promotion no eligible item was found. The items were formulated as direct questions that test how easy or difficult it is to perform selected health-related activities and tasks (Pelikan and Ganahl, 2017).

Table 13

Matrix of the sub-dimensions of the conceptual model of comprehensive health literacy, according to Sørensen et al. (2012), with the items of the short form HLS-EU-Q16 (derived from Pelikan and Ganahl, 2017, p. 99).

Health literacy	**Find/ Access information**	**Understand information**	**Evaluate/ Appraise information**	**Apply/ use information**
Health Care	**Q1**…find information on treatments of illnesses that concern you? **Q2**…find out where to get professional help when you are ill?	**Q3**…understand what your doctor says to you? **Q4**…understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?	**Q5**…judge when you may need to get a second opinion from another doctor?	**Q6**…use information the doctor gives you to make decisions about your illness? **Q7**…follow instructions from your doctor or pharmacist?
Disease Prevention	**Q8**…find information on how to manage mental health problems like stress or depression?	**Q9**…understand health warnings about behaviour such as smoking, low physical activity and drinking too much? **Q10**…understand why you need health screenings?	**Q11**…judge if the information on health risks in the media is reliable?	**Q12**…decide how you can protect yourself from illness based on information in the media?
Health Promotion	**Q13**…find out about activities that are good for your mental well-being?	**Q14**…understand advice on health from family members or friends? **Q15**…understand information in the media on how to get healthier?	**Q16**…judge which everyday behaviour is related to your health?	No adequate items identified

The scale value of the short scale HLS-EU-Q16 is calculated as a simple total score and can vary between a minimum of 0 and a maximum of 16. To calculate the health literacy score from the answers, the answer categories of the 16 items are dichotomized. Answers "very easy" and "easy" are assigned the value 1, "difficult" and "very difficult" answers are assigned the value 0. The health competence value is then simply calculated as a "sum score". No scale value can be calculated for individuals with more than two missing values (Pelikan and Ganahl, 2017, p. 112; Röthlin et al., 2013, p. 87).

For the HLS-EU-Q16 scale only three levels are defined for this short form:

- **0-8 points:** inadequate health literacy
- **9-12 points:** problematic health literacy
- **13-16 points:** sufficient health literacy (Pelikan and Ganahl, 2017, p. 112; Röthlin et al., 2013, p. 87).

The categories „inadequate health literacy“ and „problematic health literacy” can be summarised to “limited health literacy” (0-12 points) (Sørensen et al., 2015, p. 3).

Sociodemographic Data

Five items were used to gather relevant sociodemographic data. One item surveyed the study participants’ age in years. The second item surveyed the gender. Another item surveyed the employment status with the answer options “employed”, “unemployed”, “not able to work” and “retired”. The third item surveyed the highest obtained educational level with the answer options “ninth grade”, “apprenticeship diploma”, “vocational middle school without Matura”, “Matura[5]”, “University” and “others”. The fourth item asked about the relationship status giving “in a relationship” or “not in a relationship” as the two options.

Feedback Question

The last item was an open-label question and gave the study participants the opportunity to comment or add their opinion on medication adherence and health literacy. The questionnaire was closed with a thank you note (Döring and Bortz, 2016, p. 406).

Pre-test

After constructing the questionnaire, the German version was proofread by Mag. Dr. Margit Höfler, research associate at Danube University Krems and the formulation of self-constructed items was modified due to her recommendations. Finally, a qualitative pre-test was run to get feedback on technical problems, lack of comprehensibility or the suitability

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[5] Final exams young adults (aged 18 or 19) take at the end of their secondary education in certain European countries.

of different response formats (Döring and Bortz, 2016, p. 411). The link to the online-pretest was send to the chairmen and chairwomen of the support groups by e-mail. Based on their feedback, one item about household income was removed from the questionnaire.

The complete questionnaire in English can be found in appendix II. Because of the fact that the mother tongue of the participants is German, the questionnaire was developed and distributed in German.

7.3. Study Sample

As a self-selective convenience sample the adult members of support groups for transplant recipients were surveyed anonymously in this study. A convenience sample is a very common sample type in quantitative academic social research. In this case, persons or objects that are currently available or easily accessible are randomly selected for the sample of an investigation (Döring and Bortz, 2016, p. 305).

In order to guarantee the anonymity of the study participants (Döring and Bortz, 2016, p. 128), chairmen and chairwomen of all support groups for transplant recipients in Austria were asked to personally forward the online survey to their members by e-mail. Therefore, the researcher could not track back the collected data to a certain study participant. This so-called snowball sampling is suitable for populations that are difficult to reach for researchers, but whose members are well networked. In this case individual members of the population are asked to recruit further research participants via their personal social networks (Döring and Bortz, 2016, p. 308).

17 support groups were found eligible to participate in the survey, as mentioned in chapter 3.2. In August 2019, chairmen and chairwomen of support groups for transplant recipients in Austria were contacted via e-mail, if available, or by phone. Eleven support groups agreed to participate in the survey. A detailed description of contacting the support groups is shown in appendix I. These eleven support groups contained one hosting members with different kinds of organ transplants, with the focus on sport after transplantation, one for heart- and lung transplant recipients, two support groups for liver transplant recipients and seven for kidney (and pancreas-kidney) transplant recipients.

7.4. Data Collection and Recruitment Process

To reach study participants all over Austria, an online survey was created. In an online survey an electronic questionnaire is distributed via the Internet and usually processed on stationary computers. The selected answers of the respondents are stored on a survey server and are available as digital data sets (Döring and Bortz, 2016, p. 414). In accordance to the ethical principles in human research from Sales & Forkmann, 2000 (as cited in Döring and Bortz, 2016, p. 123) participation in the survey was voluntary and informed consent was given with the completion of the survey. Because no risk or harm was expected, written informed consent was not necessary as stated by Döring and Bortz (2016, p. 124-125). At the beginning of the questionnaire, study participants were informed about the objective and process of the online-survey. E-mail address of the researcher was also published on the questionnaire, in case participants had questions regarding the online survey or wanted to withdraw from the study (see appendix II). Data was gathered completely anonymous and furthermore IP addresses could not be tracked back.

The data collection process took place over two months between October 12, 2019 and December 12, 2019. Two e-mails containing the link of the survey were send to the chairmen and chairwomen who confirmed to participate in the survey. They were asked to forward the link to their members. The first e-mail was sent at the beginning of the survey and the second mail after one month. The link of the survey was also printed on flyers and distributed at a patient symposium for transplant recipients, which took place on October 12, 2019. The response curve is shown in *Figure 20*.

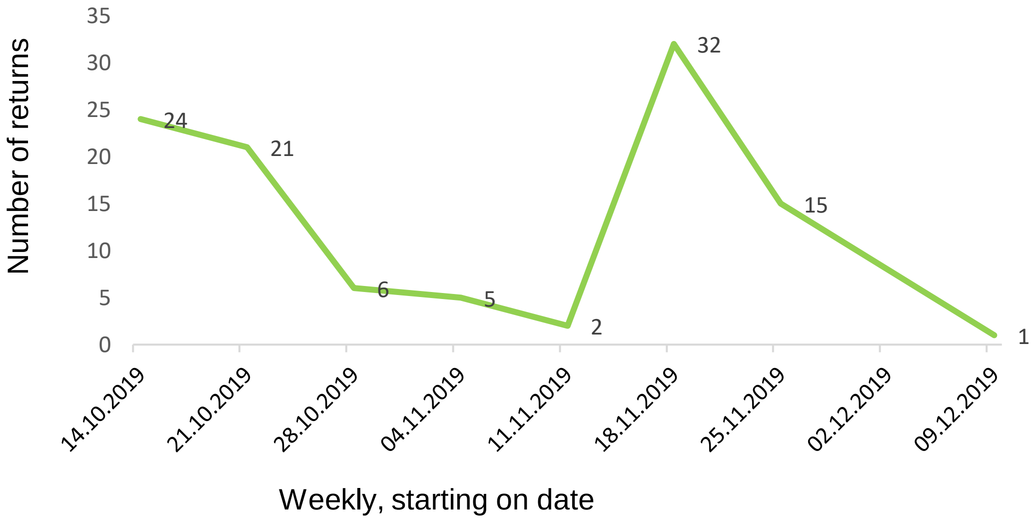

Figure 20. Online survey response rate per week.

7.5. Confidentiality and Ethical Consideration

Based on the ethical principles of psychologists and code of conduct, research ethics and scientific ethics were considered during the research process of this thesis (American Psychological Association, 2016). In context of research ethics, the ethical treatment of the research participants was on focus. No physical or psychological risks, harm, or strain to the study participants were expected in the survey. In addition, further ethical concerns could be dispelled through the voluntary nature of the research. The people surveyed were informed about the subject matter and the objectives of the study in an understandable form at the beginning of the questionnaire. On this basis agreement to voluntary participation in the study was obtained. Chairmen and chairwomen of the support groups forwarded the link for the online survey to their members. In this way research data could be collected anonymously. Within scientific-ethical considerations, ethical rules of good scientific practice were considered, such as the application of the research method based on the current status of research, no manipulation or falsification of the documents or data sets and no plagiarism, and the results were carefully and correctly handled (Döring and Bortz, 2016, p. 122-133).

Consistent with the current Austrian law and international guidelines, all research projects involving patients and identifiable data, or human material, that are taken for the purpose of gaining knowledge and do not exclusively serve the health of the patient, must be submitted to an ethics committee for evaluation. However, no vote of an ethics committee is necessary for final theses without identifiable patient data (Medizinische Universität Wien, 2017, p. 31).

7.6. Data Analysis

The gathered data were exported to MS Excel and analysed with Jeffreys's Amazing Statistics Program (JASP) 0.11.1. For descriptive statistics mean (*M*) and median (*MD*) was used depending on the scale-level. BAASIS and HLS-EU-Q16 were evaluated as indicated by the authors. For the correlation between BAASIS, HLS-EU-Q16 and sociodemographic and transplant-related factors chi-square tests, Pearson and Spearman correlation were used, depending on the scale-level.

Chi-square tests were performed for categorical variables and when expected frequencies for each cell were at least one and no more than 20% of the expected cell frequencies were below five. Categories were summarised, if possible, when more than 20% of the expected cell frequencies were below five. For significant chi-square tests, Cramer's V was calculated to determine the strength of the correlation. Pearson correlation was used for metric variables and Spearman correlation for ordinal variables. The significance level was set at 5% (Universität Zürich, 2019).

For open label questions, categories were defined based on the answers and the frequency distribution was illustrated (Döring and Bortz, 2016, p. 605).

8. Results

The following chapters presents the results emerging from the online survey conducted from October to December 2019 in Austrian support groups for transplant recipients. 106 transplant recipients participated in the online survey and fully completed the questionnaire. To calculate the response rate, information about the number of members was requested from the chairmen and chairwomen. Response from seven support groups was received. Those seven support groups amount to 1091 members altogether, however, 90% of the members in one support group (Austrian Transplant Sports Federation) were also a member in other support group, according to their chairmen. Other chairmen and chairwomen stated that they also have members who are relatives of transplant recipients, or members prior transplantation. Furthermore, the chairmen and chairwomen stated that not for every member an e-mail address is available and not every member had access to the internet. Therefore, calculating a response rate was not appropriate due to the missing of comprehensive information.

8.1. Participant Characteristics

106 transplant recipients participated in the online survey. Most of the participants were male (72.6%), member of a support group (79.2%) and kidney transplant recipients (67.9%). The frequency distribution by organ is shown in *figure 21*.

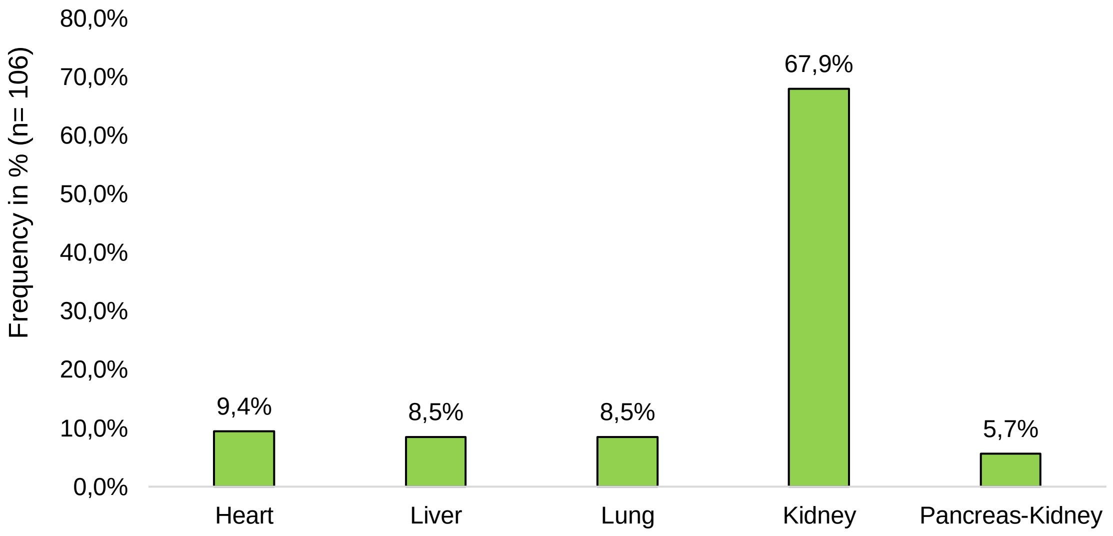

Figure 21. Frequency distribution by organ in %.

Time since transplant was on average *M* = 12.2 (*SD* = 10.0) years. The mean age of the participants was *M* = 57.3 (*SD* = 13.1) years. The youngest participant was 23 years old and the oldest participant 83 years old. 75.5% of the participants were over 50 years old. The majority of the participants were in a relationship (81.1%) and either employed (52.8%) or retired (39.7%). 18.9% of the participants reported to have a university degree, 16.0% “Matura”, 20.8% had attended a vocational training college without “Matura”, 33.0% had an apprenticeship diploma, 4.7% finished with ninth grade and only one person (0.9%) without compulsory education. Most of the participants described their health status as very good (37.7%) and good (34.0%), no one as poor. A detailed description of participants’ characteristics can be found in appendix III.

8.2. Side Effects

69 (65.1%) from 106 participants reported side effects caused by their immunosuppressive medication. Mild side effects were the most commonly occurring extent of side effects as shown in *figure 22*.

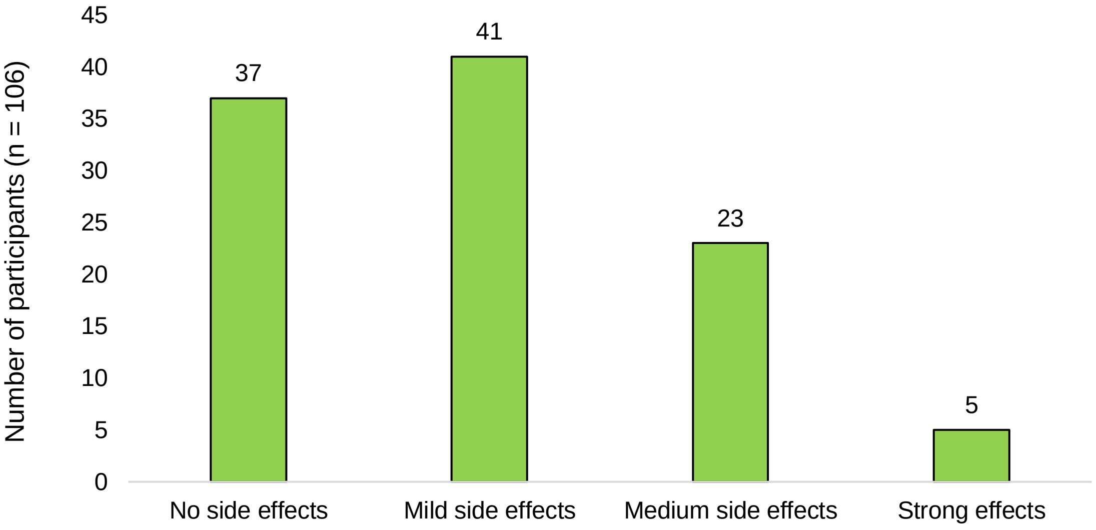

Figure 22. Extent of side effects of immunosuppressive medication reported by the participants.

Half of the participants (50.9%) reported to feel restricted due to their side effects. Only five participants reported a strong restriction. The extent of side effects and the feeling of restriction in everyday life due to side effects correlates significantly, $r_s = .737$ $p = .001$, $n = 106$. According to Döring and Bortz (2016, p. 820) the correlation can be stated as strong.

8.3. Experience with Interventions

84 (79.2%) participants indicated that they got information and/ or training regarding their immunosuppressive medication after the transplantation. Most of the participants received information and/ or training through a conversation (84 times). Multiple selection was possible resulting in 55 participants choosing only one answer option, 28 participants choosing two answer options and eight participants choosing three answer options. A detailed distribution of answers is shown in *figure 23*.

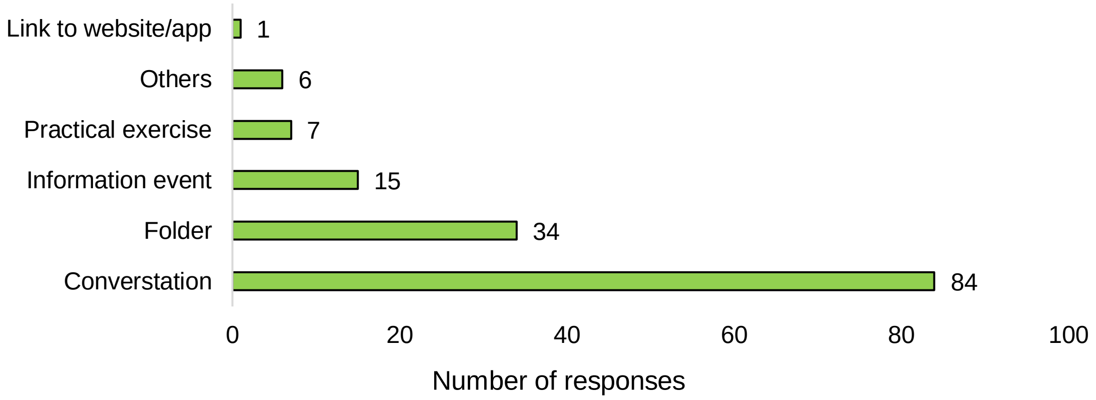

Figure 23. Types of information and/ or training participants received after transplantation.

Six participants chose answer option "others". One of them reported that he or she is a medical doctor. One participant reported to have received information and/ or training through the medical doctors and reading. Another participant reported that he or she got information and/ or training only through their own initiative. One participant specified that he or she got information and/ or training through a nurse, another one through the package leaflet of the medication and the last one during cure.

76 (71.1%) of the participants think the information and/ or training they received were adequate. As illustrated in *figure 24* 85 times participants received information and/ or training through doctors, followed by nurses, which option was chosen 32 times. Information and/ or training regarding immunosuppressive medication received at the pharmacy was reported only two times.

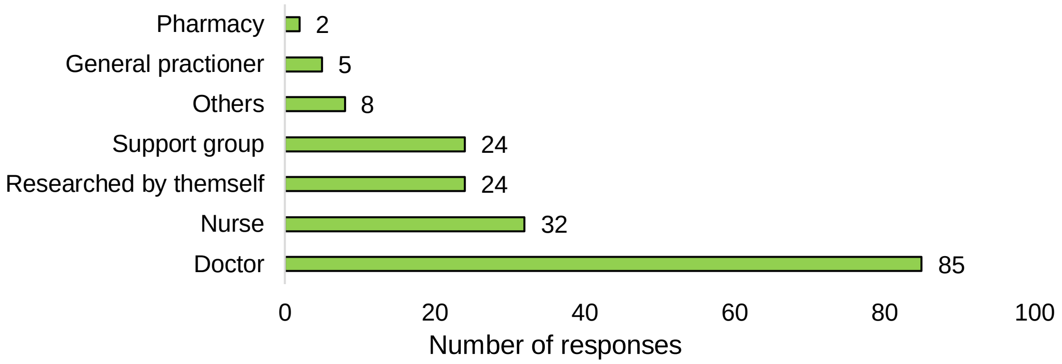

Figure 24. Person or institution that provided information and/ or training regarding immunosuppressive medication.

Eight participants selected the answer option “others”, with one participant stating that he or she got information from another transplant recipient. Another participant reported that in the support group they did not discuss medical aspects of the medication, but rather exchange experiences. One participant wrote that she or he also works as a medical profession and another one that the cure doctor was the main source of information. Information only about the dosage of the medication did one participant remark. One participant mentioned a psychologist who provided him or her with information and/ or training, another one researched in the internet, and the last one got information and/ or training during rehabilitation.

Participants had the possibility to choose the type of information and/ or training regarding immunosuppressive medication which they considered most effective. As illustrated in *figure 25* most frequently selected was the type “in person during inpatient stay” with 92 times chosen, followed by the type “in person during outpatient follow-up” with 72 times. Multiple selections were possible.

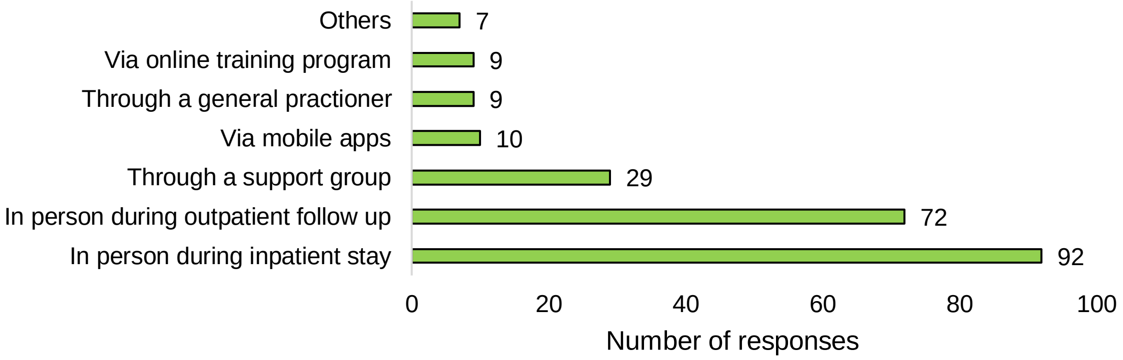

Figure 25. Most effective types of information and/ or training regarding immunosuppressive medication in the participants’ opinion.

Seven participants selected the answer option “others”. One participant mentioned the rehabilitation centre as the most effective source. Two participants recommended the conversation with a doctor they trust. Another two participants suggested using support groups only for sharing experiences. One participant wanted to have an information event at the hospital and the last one requested an information brochure issued by the transplant centre.

8.4. Results From the Medication Adherence Questionnaire

All 106 participants completed the BAASIS. A detailed description of the results is given in *table 14*. Scoring of the results was conducted following the specification of the authors (Leuven Basel Research Group, 2019). For any “yes” on item 1a, 1b, 2, 3 or 4 the participant was rated as non-adherent (Leuven Basel Research Group, 2019). Therefore 71.7% of the participants were categorized as non-adherent to their immunosuppressive medication. Furthermore, the percentage was calculated to show adherence rate. No item answered with “yes” was rated with 100% adherence, one item answered with “yes” was rated with 80% adherence, two items answered with “yes” was rated with 60% adherence, three items answered with “yes” was rated with 40% adherence, four items answered with “yes” was rated with 20% adherence and five items answered with “yes” was rated with 0% adherence. No participant answered all the items with “yes”. Most of the participants (55.7%) answered only one item with “yes”. The distribution of adherence rate is shown in *figure 26*.

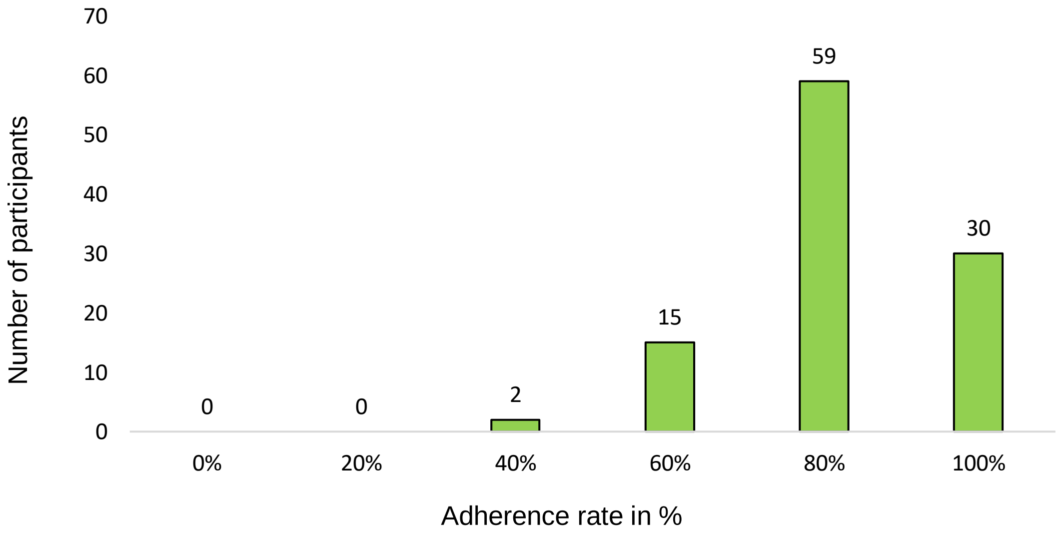

Figure 26. Distribution of frequency of items from BAASIS answered with "yes" (0% = complete non-adherence, 100% = complete adherence).

Table 14

Prevalence of non-adherence measured by BAASIS (Evaluation derived from Kobayashi et al., 2019).

Item	**BAASIS Items (n=106)**	**Responses n (%)**	**Categorized as non-adherent n (%)**
1a	**Taking dimension:** Do you recall not having taken your immunosuppressive medications some times in the past 4 weeks?		28 (26.4)
	Once	28 (26.4)	
	Twice	1 (0.9)	
	3 times	1 (0.9)	
	4 times	0 (0.0)	
	More than 4 times	2 (1.9)	
1b	**Drug holidays:** Have you skipped several consecutive doses of your immunosuppressive medications in the past 4 weeks?		1 (0.9)
	Once	5 (4.7)	
	Twice	0 (0.0	
	3 times	0 (0.0)	
	4 times	0 (0.0)	
	More than 4 times	0 (0.0)	
2	**Timing dimension:** Do you recall having taken your immunosuppressive medications with more than 2 hours’ time difference from the prescribed dosing time, in the past 4 weeks?		62 (58.5)
	Once		
	Twice	22 (20.8)	
	3 Times	16 (15.1)	
	4 times	13 (12.3)	
	More than 4 times	2 (1.9)	
		8 (7.5)	
3	**Reduction of dose**: Have you reduced the prescribed amount of your immunosuppressive medications on your own initiative in the last 4 weeks without your doctor asking you to? For example, did you take more or fewer tablets or change the dose, perhaps by halving a tablet?		3 (2.8)
4	**Persistence:** Have you stopped taking any of your immunosuppressive medications on your own initiative within the last year without your doctor asking you to?		1 (0.9)
1A, 1B, 2, 3, 4	**Categorized as non-adherent**		
	One item	59 (55.7)	
	Two items	15 (14.2)	
	Three items	2 (1.9)	
	Four items	0 (0.0)	
	Five items	0 (0.0)	
1A, 1B, 2, 3, 4	**Overall non-adherence** “Yes” answer to at least one of implementation or persistence items		**76 (71.7)**

The majority of the participants (70.8%) reported problems within the implementation phase of immunosuppressive medication (Item 1a, 1b, 2, 3). Only one participant stopped taking the immunosuppressive medication (Item 4). 28 participants reported issues with the taking dimension, but the sub-question "Could you recall how often this happened?" 32 participants reported one event. 35 participants reported a reason why they did not take their medications. The answers were coded in five categories and are shown in *figure 27*.

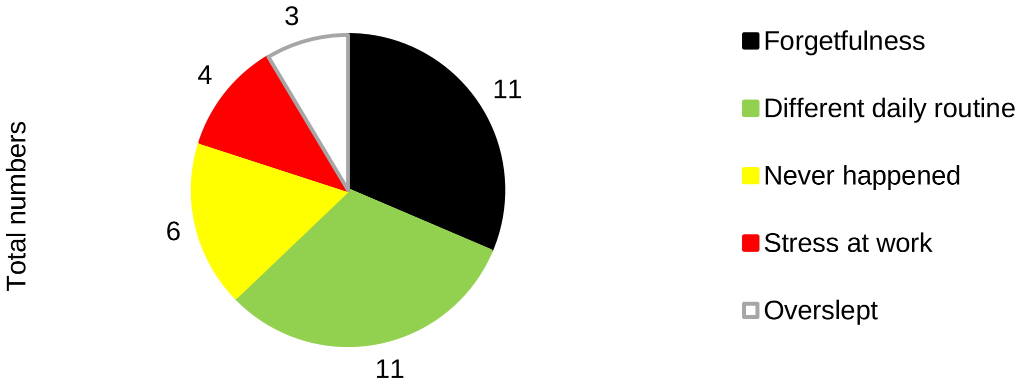

Figure 27. Categories and frequency of mentioned reasons for taking issues.

The most frequent reported reasons were forgetfulness or a different daily routine than usual. Six participants explicitly reported that they always take their medication. Only one participant reported a drug holiday, although in sub-question "Could you recall how often this happened?" five participants reported a drug holiday happening once. The majority of the participants (58.5%) reported problems with timing, although in most cases it happened only once. 54 participants commented on reasons why they had problems with timing. These reasons were coded in six categories and are shown in *figure 28*.

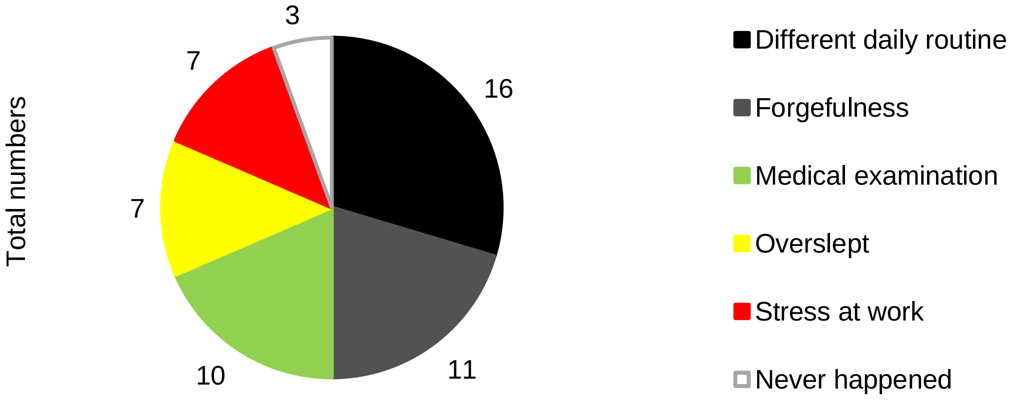

Figure 28. Categories and frequency of mentioned reasons for timing issues.

16 times the participants stated that they had timing issues due to a different daily routine, followed by forgetfulness with eleven times. Additionally ten participants reported timing issues due to the fact that they had to have an empty stomach for a medical examination or had to wait for a blood draw.

8.4.1. Correlation Between Sociodemographic Data and Adherence

To determine which sociodemographic-related factors show a correlation with adherence, chi-square tests were performed for nominal and ordinal data and the Pearson correlation for metric data. Results of the tests are shown and described in the following paragraphs.

Gender and Adherence

In this paragraph the issue whether the gender has an influence on adherence is examined. Distribution for gender and adherence is shown in *figure 29*. 72.4% of the female participants are categorised as non-adherent ($n = 29$) and 71.4% of the men are categorised as non-adherent ($n = 77$). No correlation was detected between the gender and adherence, $\chi^2(1) = 0.010$, $p = .920$, $n = 106$.

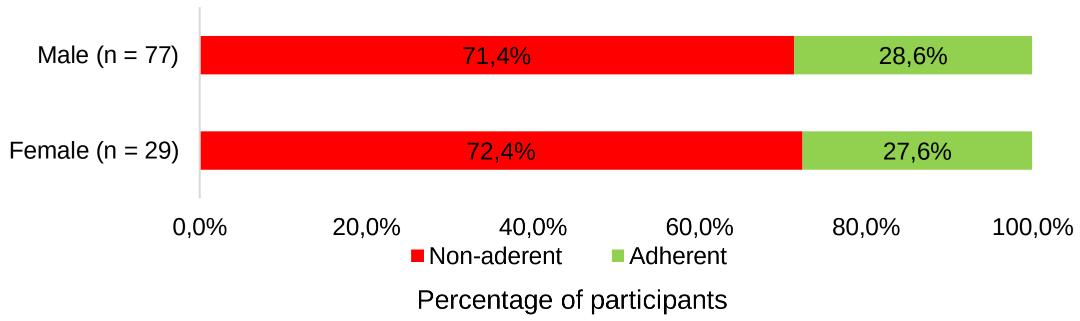

Figure 29. Distribution of adherence and non-adherence per gender.

Age and Adherence

To examine the correlation between age and adherence, the adherence rate was used to perform a Pearson correlation. No significant correlation was detected between the age of the participants and adherence, $r_p = .043$, $p = .665$.

To show whether the youngest or oldest quartile of the participants differ regarding adherence, extreme groups were formed and tested. The median age was $MD = 60$ ($IQR = 16$), the 25th percentile was at 50 years and the 75th percentile at 66 years. The extreme group one ranged from the youngest participant, who was 23 years old, to the 25th percentile. The extreme group two reached from 75th percentile to the oldest participant, who was 83 years old. 73.3% in the age group ranging from 23-50 were categorised as non-adherent (*n* = 30) and 78.8% in the age group ranging from 66-83 were categorised as non-adherent (*n* = 32). The results show no significant correlation in group comparison, $\chi^2(1) = 0.194$, $p = .660$, $n = 62$.

Education and Adherence

To examine the correlation between education and adherence, two categories were formed for education. Participants whose highest education level was “no compulsory education”, “ninth grade”, “apprenticeship diploma” or “vocational middle school” were summarised to “without Matura”. Participants whose highest education level was “Matura” or “university” were summarised to “with Matura”. Distribution of adherence between these two categories is shown in *figure 30*. 69.6% of the participants in category “without Matura” were categorised as non-adherent (*n* = 69). 75.7% of the participants in category “with Matura” were categorised as adherent (*n* = 37). No significant correlation was detected between these two levels of education and adherence, $\chi^2(1) = 0.443$, $p = .506$, $n = 106$.

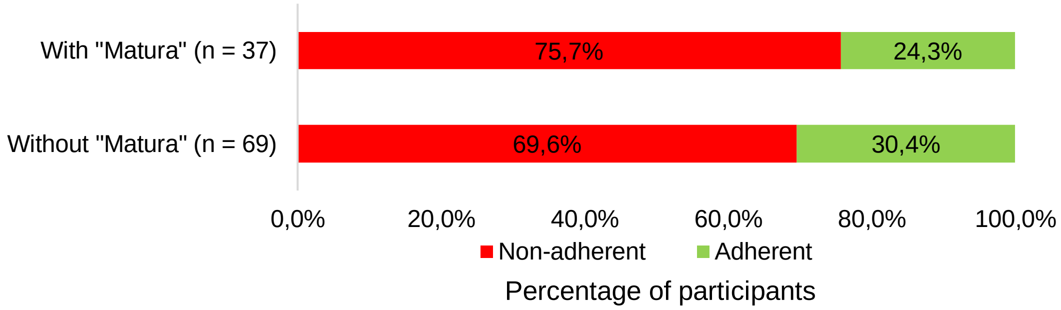

Figure 30. Distribution of adherence and non-adherence per educational level.

Work Status and Adherence

Here the aim was to determine whether the work status has an influence on adherence. For that purpose two categories were formed. The first category included participants who reported to be “employed”, the second category included all participants who either reported to be “unemployed”, “unable to work” or “retired”. Distribution of adherence between these two categories is shown in *figure 31*. 71.4% of the participants from category one were categorised as non-adherent (*n* = 56). 72.0% of the participants from category two were categorised as non-adherent (*n* = 50). There was no significant correlation between work status and adherence, $\chi^2(1) = 0.004$, $p = .948$, $n = 106$.

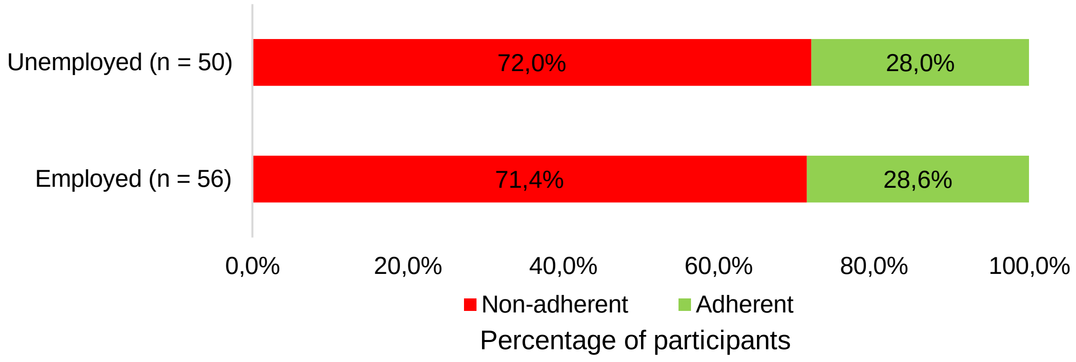

Figure 31. Distribution of adherence and non-adherence for work status.

Relationship Status and Adherence

The correlation of the relationship status and adherence was examined. Distribution of adherence for relationship status is shown in *figure 32*. 70.9% of the participants in a relationship were categorised as non-adherent (*n* = 86) and 75% of the participants not in a relationship were categorised as non-adherent (*n* =20). A significant correlation between relationship status and adherence could not be detected, $\chi^2(1) = 0.132$, $p = .716$, $n = 106$.

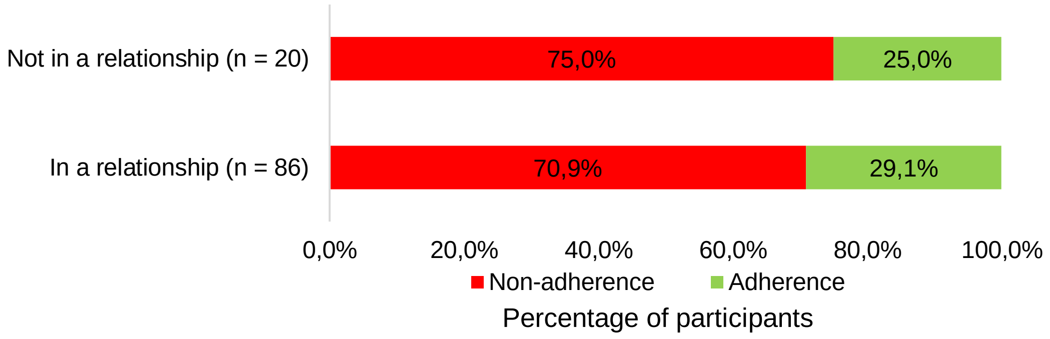

Figure 32. Distribution between adherence and non-adherence for relationship status.

Health Status and Adherence

The correlation between the self-reported current health status and adherence was examined. Distribution of adherence for health status is shown in *figure 33*. The highest percentage of non-adherence was detected in individuals who mentioned a “very good” health status. No significant correlation was detected between the health status and adherence, $\chi^2(3) = 3.866$, $p = .276$, $n = 106$.

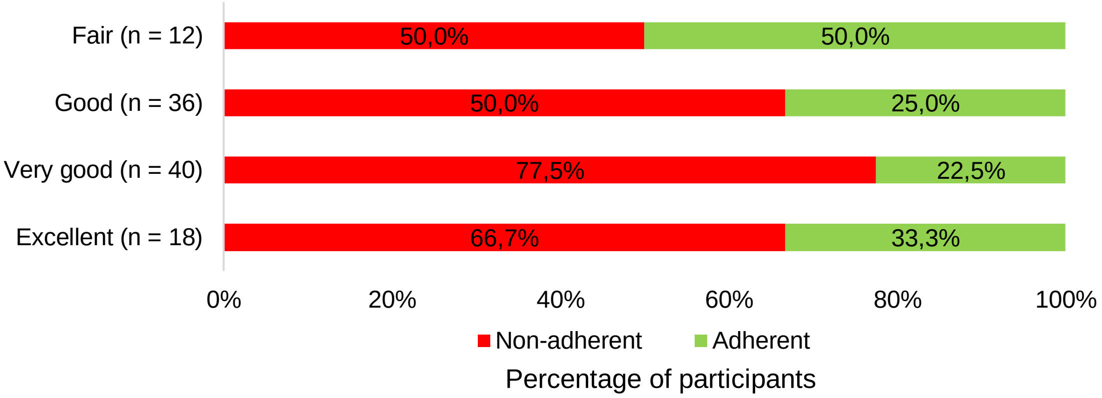

Figure 33. Distribution of adherence and non-adherence for health status.

8.4.2. Correlation Between Transplant-related Factors and Adherence

To determine which transplant-related factors show a correlation with adherence, chi-square tests were performed for nominal and ordinal data and the Pearson correlation for metric data. The results of the tests are shown and described in following paragraphs.

Type of Organ and Adherence

The distribution between the type of organ the participant received and the categories “adherent” or “non-adherent” based on the results of BAASIS was examined and is presented in *figure 34*. Pancreas-kidney transplant recipients showed the highest percentage of non-adherence (83.3%, *n* = 6) and lung transplant recipients showed the lowest percentage of non-adherence (66.7%, *n* = 9). A chi-square test could not be used, because more than 20% showed expected cell frequencies below five.

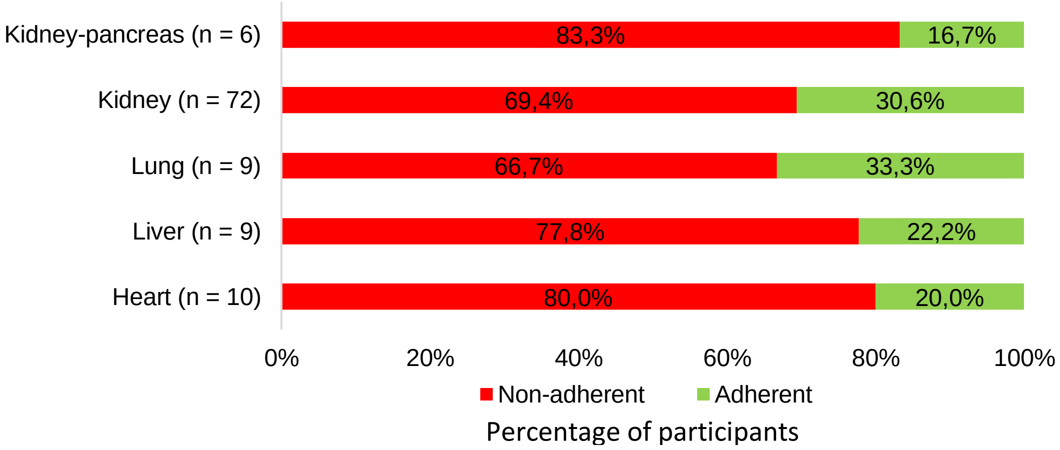

Figure 34. Distribution of adherence and non-adherence for type of organ.

Support Group Membership and Adherence

Here the question was whether the membership in a support group influences the adherence. Distribution of adherence for support group membership status is shown in *figure 35*. Participants who reported not to be in a support group showed a lower percentage in non-adherence than participants in a support group. However, no significant correlation was detected between transplant recipients who were or were not members of a support group and their adherence $\chi^2(1) = 2.175$, $p = .14$, $n = 106$.

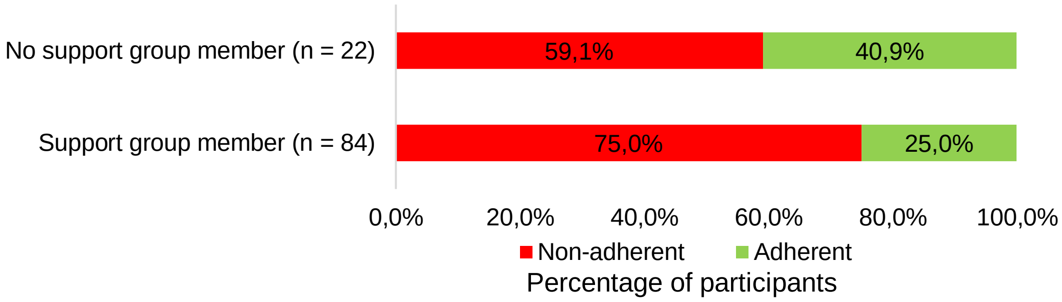

Figure 35. Distribution of adherence and non-adherence for support group membership status.

Time since Transplant and Adherence

To examine a correlation between time since transplant and adherence, the adherence rate was used to perform a Pearson correlation. No significant correlation was detected between the time since transplant in years and adherence rate, $r_p = .073$, $p = .458$.

To show whether a short time or a long time since transplant have an influence on adherence, extreme groups were formed and tested. Median time since transplant was *MD* = 9 years (*IQR* = 4.3). 25th percentile was at 4.3 years since transplant and 75th percentile at 18 years since transplant. Extreme group one ranged from the shortest time since transplant, which was 9 months to the 25th percentile. Extreme group two reached from 75th percentile to the longest time since transplant which was 42 years. 76.7% in extreme group one were categorised as non-adherent ($n = 30$) and 59.3% in extreme group two were categorised as non-adherent ($n = 27$). Results show no significant correlation in group comparison, $\chi^2(1) = 1.993$, $p = .158$, $n = 57$. Distribution of adherence for time since transplant is shown in four groups in figure 36.

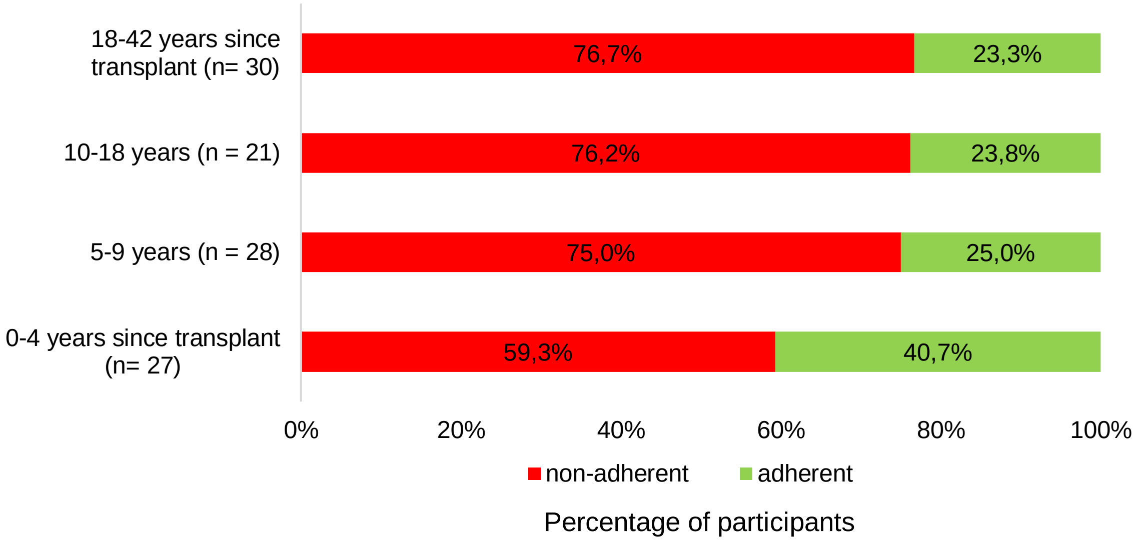

Figure 36. Distribution of adherence for time since transplant.

Extent of Side Effects and Adherence

To examine the correlation between the extent of side effects caused by the immunosuppressive medication and adherence, two categories were formed. Category one summarised answer options "no side effects" and "mild side effects" and category two summarised answer options "medium side effects" and "strong side effects". Distribution of adherence for the extent of side effects is shown in *figure 37*. 71.8% of category one were categorised as non-adherent (n = 78) and 71.4% of category two were categorised as non-adherent (n = 28). No significant correlation was detected between the extent of side effect and adherence, $\chi^2(1) = 0.001$, $p = .971$, $n = 106$.

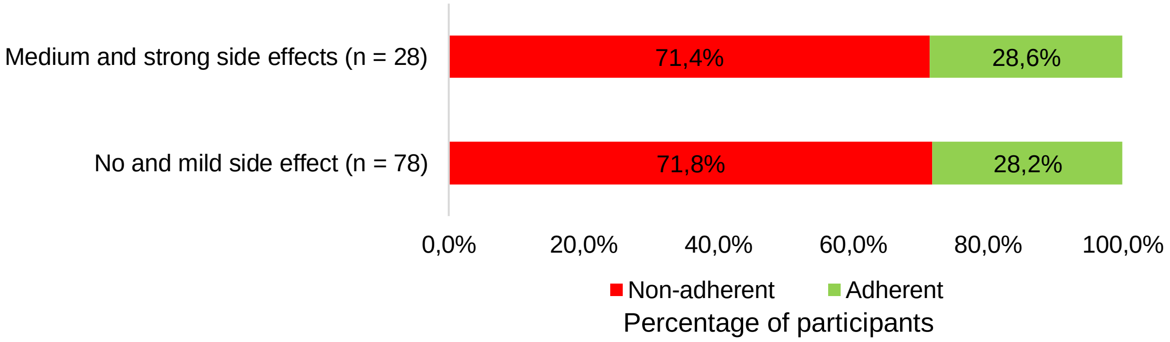

Figure 37. Distribution of adherence and non-adherence for the extent of side effects.

Restrictions Through Side Effects and Adherence

To examine the correlation between the restrictions through side effects caused by the immunosuppressive medication and adherence, two categories were formed. Category one summarised answer options “no restriction” and “slight restriction” and category two summarised answer options “medium restriction” and “strong restriction”. Distribution of adherence for restrictions through side effects are shown in *figure 38*. 72.9% of category one were categorised as non-adherent (*n* = 85) and 66.7 % of category two were categorised as non-adherent (*n* = 21). No significant correlation was detected between the extent of side effect and adherence, $\chi^2(1) = 0.32$, $p = .568$, $n = 106$.

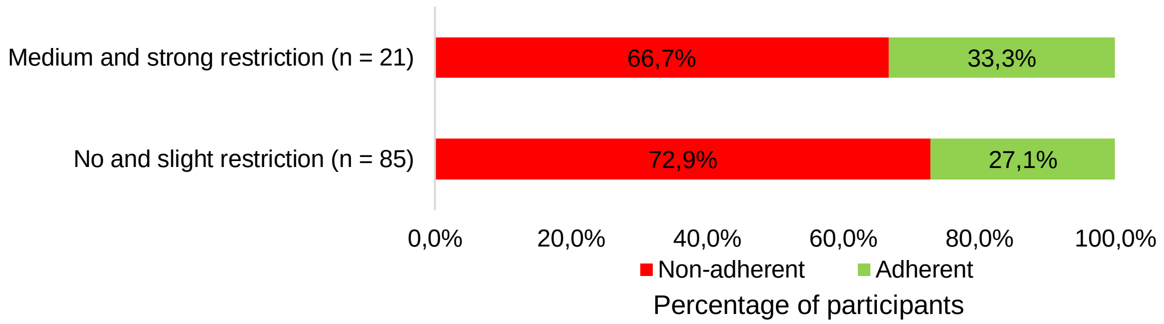

Figure 38. Distribution of adherence and non-adherence for restriction through side effects.

Information and/ or Training Received and Adherence

The aim here was to find out whether the information and/ or training received influence the adherence. Distribution of adherence is shown in *figure 39*. No significant correlation was detected between a transplant recipient who received information and/ or training regarding immunosuppressive medication or a transplant recipients who did not receive information and/ or training and their adherence, $\chi^2(1) = 0.169$, $p = .681$, $n = 106$.

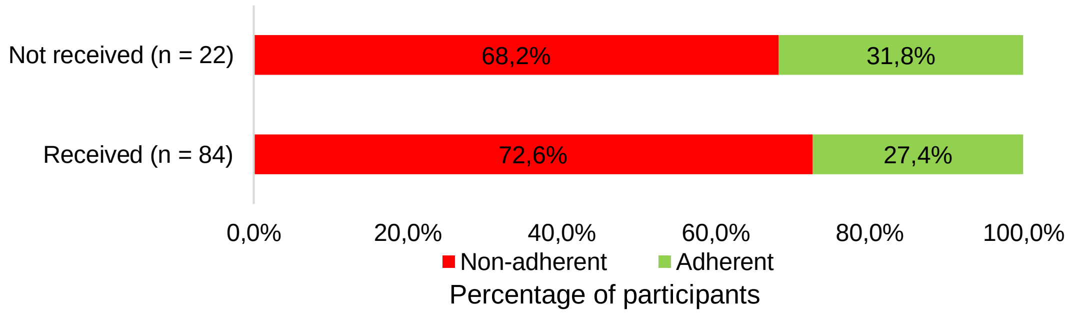

Figure 39. Distribution of adherence and non-adherence for Information and/ or Training received or not.

8.5. Results From Health Literacy Survey

The HLS-EU-Q16 consisting of 16 items was completed by 106 participants. There was no missing value. Detailed Information about the self-assessment per item is given in *table 15*. The number and percentage of answers from the four answer categories were summed up in two categories ("very easy/ easy" and "difficult/ very difficult").

Table 15

Self-assessment of HLS-EU-Q16 of transplant recipients in support groups in Austria (n = 106).

	Item	***n***	**%**	***n***	**%**
Nr.	**On a scale from very easy to very difficult: How easy is it in your opinion to…**	**Very easy/ easy**		**Difficult/ very difficult**	
1	…find information on treatments of illnesses that concern you?	75	70.8	31	29.2
2	…find out where to get professional help when you are ill?	84	79.2	22	20.8
3	…understand what your doctor says to you?	92	86.8	14	13.2
4	…understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?	104	98.1	2	1.9
5	…judge when you may need to get a second opinion from another doctor?	65	61.3	41	38.7
6	…use information the doctor gives you to make decisions about your illness?	89	84	17	16.0
7	…follow instructions from your doctor or pharmacist?	104	98.1	2	1.9
8	…find information on how to manage mental health problems like stress or depression?	55	51.9	51	48.1
9	…understand health warnings about behaviour such as smoking, low physical activity and drinking too much?	103	97.2	3	2.8
10	…understand why you need health screenings?	106	100.0	0	0.0
11	…judge if the information on health risks in the media is reliable?	46	43.3	60	56.6
12	…decide how you can protect yourself from illness based on information in the media?	57	53.8	49	46.2
13	…find out about activities that are good for your mental well-being?	60	56.6	46	43.4
14	…understand advice on health from family members or friends?	73	68.9	33	31.1
15	…understand information in the media on how to get healthier?	71	67.0	35	33.0
16	…judge which everyday behaviour is related to your health?	91	85.8	15	14.2

Items 1 to 7 survey the dimension of “health care”. To understand the instruction provided by a doctor or pharmacist on how to take a prescribed medicine and to follow the doctor’s or pharmacist’s instructions is easy or very easy for 98.1% of the participants. 38.7% of the participants find it difficult or very difficult to judge if they need to get a second opinion from another doctor. Items 8 to 12 survey the dimension “disease prevention”. All the participants find it easy or very easy to understand why they need health screenings. 56.6% of the participants find it difficult or very difficult to judge if the information on health risks in the media is reliable. Items 13 to 16 survey the dimension “health promotion”. 85.8% find it easy or very easy to judge which everyday behaviour is related to their health. Almost half of the participants (43.4%) find it difficult or very difficult to find out about activities that are good for their mental well-being.

Figure 40 shows the comparison of the data from the Austrian Health Literacy Survey and from the transplant recipients’ answers. The percentages of the answer categories “difficult” and “very difficult” were combined. About the same percentage of participants find it “difficult” or “very difficult” to find information on treatments of illnesses that concern them (Q1). 12.7% of the participants of the Austrian HLS find it “difficult” or “very difficult” to find out where to get professional help when they are ill, compared to 20.8% of the transplant recipients (Q2). Fewer transplant recipients (13.2%) find it “difficult” or “very difficult” to understand what their doctor tells them (Q3). Almost no transplant recipient (1.9%) find it “difficult” or “very difficult” to comprehend their doctor’s or pharmacist’s instruction on how to take a prescribed medicine, compared to the 7.9% of the participants in the Austrian HLS (Q4). 38.7% of the transplant recipients and 46.7% of the participants in the Austrian HLS find it “difficult” or “very difficult” to judge when they may need to get a second opinion from another doctor (Q5). Only 16.0% of the transplant recipients find it “difficult” or “very difficult” to use information the doctor gives them to make decisions about your illness, compared to 30.0% of the participant of the Austrian HLS (Q6). Almost no transplant recipient (1.9%) finds it “difficult” or “very difficult” to follow instructions from their doctor or pharmacist, compared to 7.4% of the participants of the Austrian HLS (Q7). About half of the transplant recipients (48.1%) find it “difficult” or “very difficult” to find information on how to manage mental health problems like stress or depression, compared to 37.0% of the participants of the Austrian HLS (Q8). Almost no transplant recipient (2.8%) finds it “difficult” or “very difficult” to understand health warnings about behaviour such as smoking, low physical activity and drinking too much, compared to 13.8% of the participants of the Austrian HLS (Q9). No transplant recipient finds it “difficult” or “very difficult” to understand why they need health screenings, compared to 11.1% of the participants of the Austrian HLS (Q10). More transplant recipients (56.6%) find it “difficult” or “very difficult” to judge whether the information on health risks in the media is reliable, compared to 47.7% of the participants of the Austrian HLS (11). About the same percentage find it “difficult” or “very difficult” to decide how they can protect themselves from illness based on information in the media. Double the percentage of transplant recipients (43.4%) find it “difficult” of “very difficult” to find out about activities that are good for their mental well-being, compared to 26.2% from the participants of the Austrians HLS (Q13). 31.1% of the transplant recipients find it “difficult” or “very difficult” to understand advice on health from family members or friends, compared to 17.9% of the participants of the Austrian HLS (Q14). About the same percentage find it “difficult” or “very difficult” to understand information in the media on how to get healthier (Q15). 14.2% of the transplant recipients find “difficult” or “very difficult” to judge which everyday behaviour is related to their health, compared to 19.3% from the participants of the Austrian HLS (Q16).

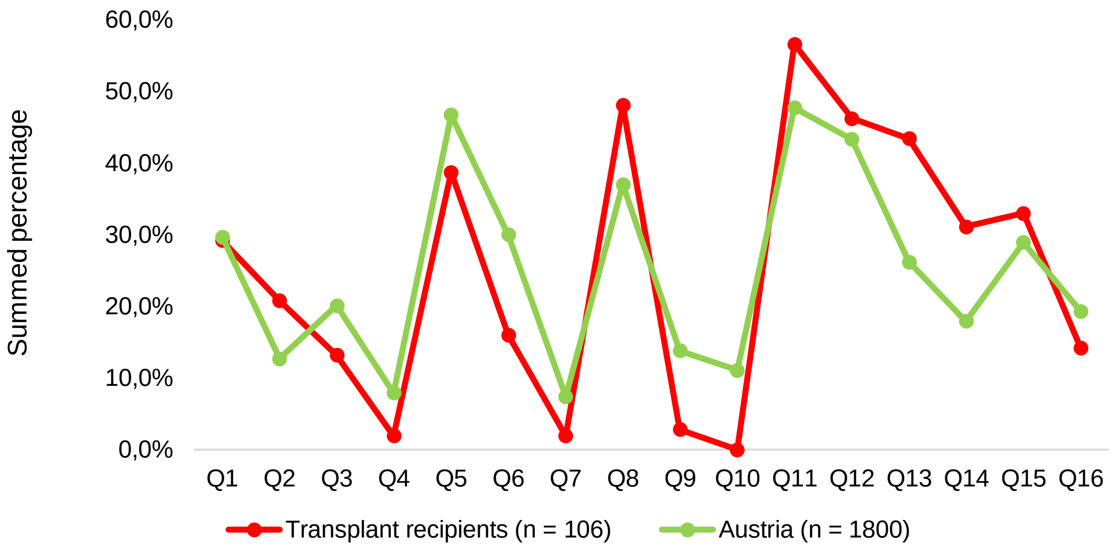

Figure 40. Self-assessment of health literacy, 16 questions (HLS-EU-Q16). Summed percentages of the answer categories "difficult" and "very difficult" for the transplant recipient sample and the Austrian sample. Austrian data from Ganahl et al. (2016, p. 49).

As explained in chapter 7.2, the health literacy score can range from 0 to 16 points. Fewer or equal 8 points is defined as inadequate health literacy, 9 to 12 points as problematic health literacy and more 12 points is defined as sufficient health literacy. The mean score achieved was *M* = 12 (*SD* = 3.0), which is defined as problematic health literacy. Half of the participants (52.8 %) showed sufficient health literacy. The other half (47.2 %) showed limited (inadequate or problematic) health literacy. The distribution over these three categories is shown in figure 41.

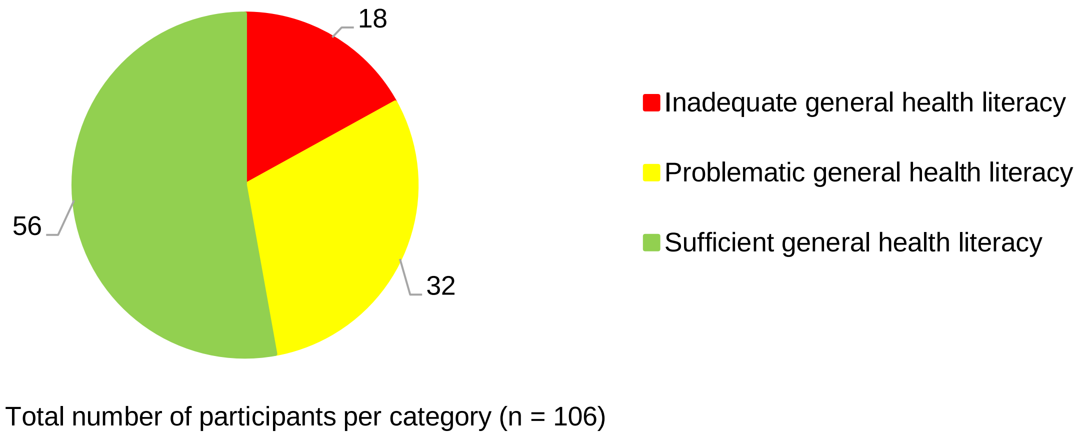

Figure 41. Number of participants per health literacy level.

In comparison to the Austrian-HLS population percentage of distribution of health literacy levels differ only slightly from the surveyed transplant recipients in support groups. 47.2% of the transplant recipients showed limited health literacy, compared to 48.4% in the Austrian HLS (see *figure 42*).

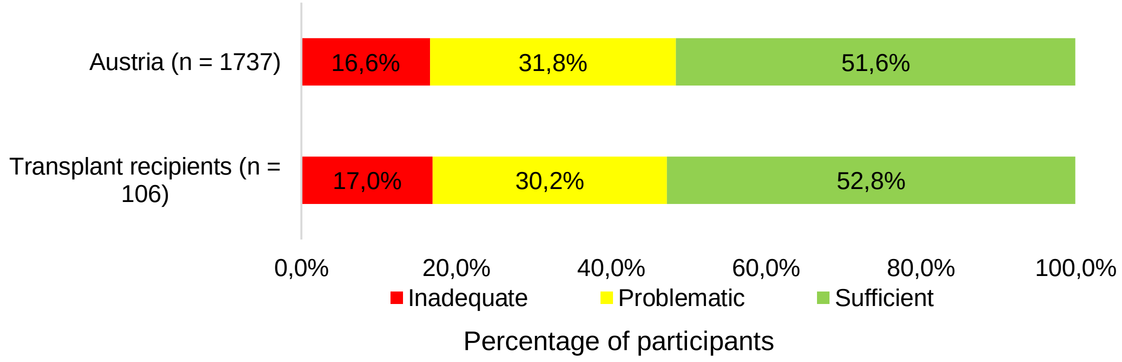

Figure 42. Percentage distribution per health literacy level, Austrian data from Ganahl et al. (2016).

8.5.1. Correlation Between Sociodemographic Data and Health Literacy

To determine which sociodemographic-related factors show a correlation with health literacy, chi-square tests were performed for nominal and ordinal data, a Pearson correlation for metric data and a Spearman correlation when both variables where ordinal scale. The results of the tests are shown and described in the following paragraphs.

Gender and Health Literacy

The aim in this part was to examine whether gender has an influence on the level of health literacy. A detailed distribution of the answers is shown in *figure 43*. 37.9% of all female ($n = 29$) and 27.3% of all male ($n = 77$) participants show problematic health literacy. No significant correlation was found between gender and health literacy levels, $\chi^2(2) = 1.278$, $p = .528$, $n = 106$.

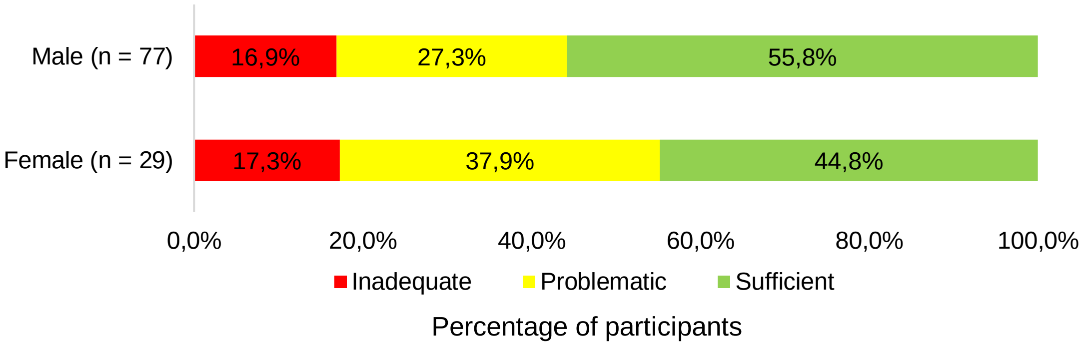

Figure 43. Distribution of health literacy levels per gender.

Age and Health Literacy

To detect a correlation between age and health literacy, the mean age was correlated with the total score from the health literacy survey. No significant correlation was found between age and health literacy, $r_p = .025$, $p = .796$.

Education and Health Literacy

The distribution of health literacy levels over the two categories “with Matura” and “without Matura” is shown in *figure 44*. Participants who have reported to have a “Matura” or “University degree” as highest educational level show a higher percentage, 21.6%, of inadequate health literacy than the rest of the participants with 14.5%. Levels of education were correlated with the total score from the health literacy survey. No significant correlation was found between education and health literacy, $r_s = .011$, $p = .914$.

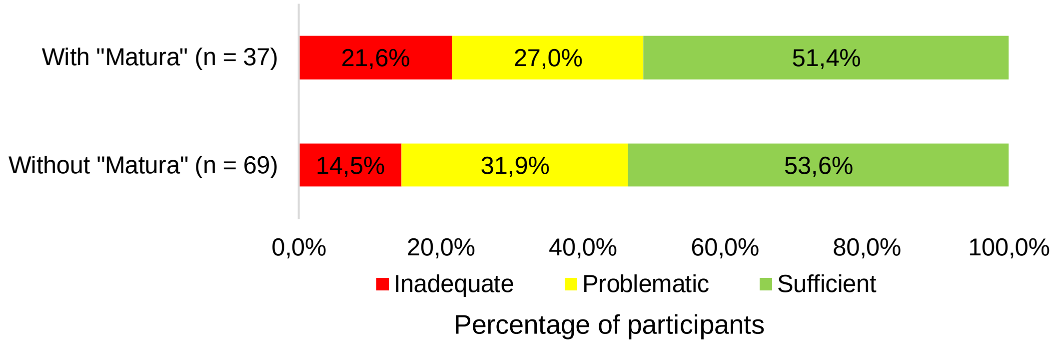

Figure 44. Distribution of health literacy levels per education category.

Work and Health Literacy

The objective was to examine whether the study participants' work status has an influence on the health literacy level. Therefore two categories were formed. The first category included participants who reported to be "employed", the second category combined participants who either reported to be "unemployed", "unable to work" or "retired". 56 participants were assigned to category one and 50 participants to category two. No significant correlation was detected between work status and health literacy level, $\chi^2(2) = 5.177$, $p = .075$, $n = 106$. 62.5% of the category one and 42% of the category two showed sufficient health literacy. The detailed information is shown in *figure 45*.

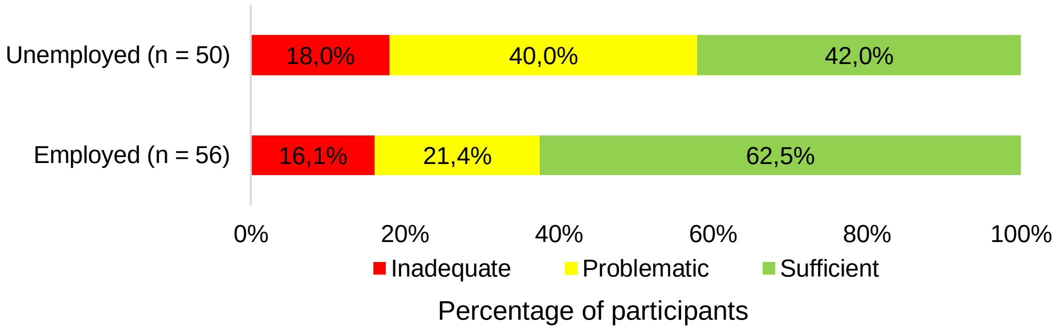

Figure 45. Distribution of health literacy level depending on work status.

Relationship and Health Literacy

The correlation of the relationship status and the health literacy level was examined. A detailed distribution of results is shown in *figure 46*. 15.1% of the participants in a relationship ($n = 86$) and 25.0% of those not in a relationship ($n = 20$) show inadequate health literacy. No significant correlation could be detected between relationship status and adherence, $\chi^2(2) = 1.191$, $p = .551$, $n = 106$.

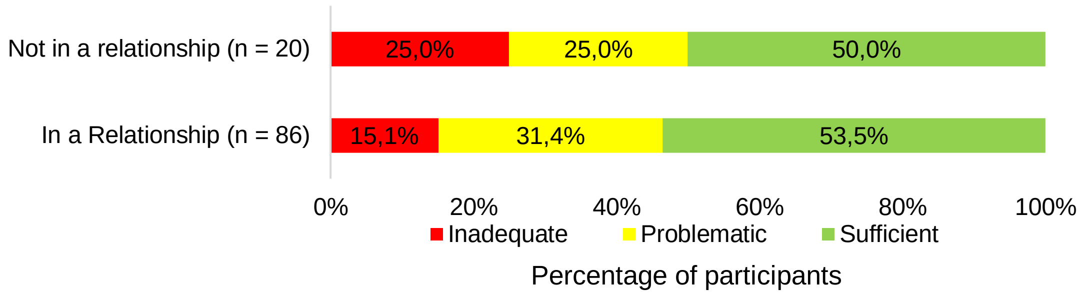

Figure 46. Distribution of health literacy levels depending on relationship status.

Health Status and Health Literacy

Here the survey focuses on whether the self-reported health status correlates with the health literacy score. No significant correlation could be detected between the health status and the health literacy score, r_s = -.158, p = .105. Distribution of health literacy levels for health status is shown in *table 16*.

Table 16

Contingency table of health literacy levels and health status.

	Health status				
Health literacy level	**Excellent**	**Very good**	**Good**	**Fair**	**Total**
Sufficient	15	17	19	5	56
Problematic	2	16	11	3	32
Inadequate	1	7	6	4	18
Total	18	40	36	12	106

8.5.2. Correlation Between Transplant-related Factors and Health Literacy

To determine which transplant-related factors show a correlation with health literacy, chi-square tests were performed for nominal and ordinal data, the Pearson correlation for metric data and the Spearman correlation when both variables were ordinal scale. The results of the tests are shown and described in the following paragraphs.

Support Group and Health Literacy Level

This part concentrates on the question in how far the membership in a support group has an influence on the level of health literacy. The percentage of inadequate health literacy is higher in the participants who reported no membership in a support group. The detailed distribution of answers is shown in *figure 47*. No significant correlation was found between support group membership and health literacy levels, $\chi^2(2) = 0.742$, $p = .690$, $n = 106$.

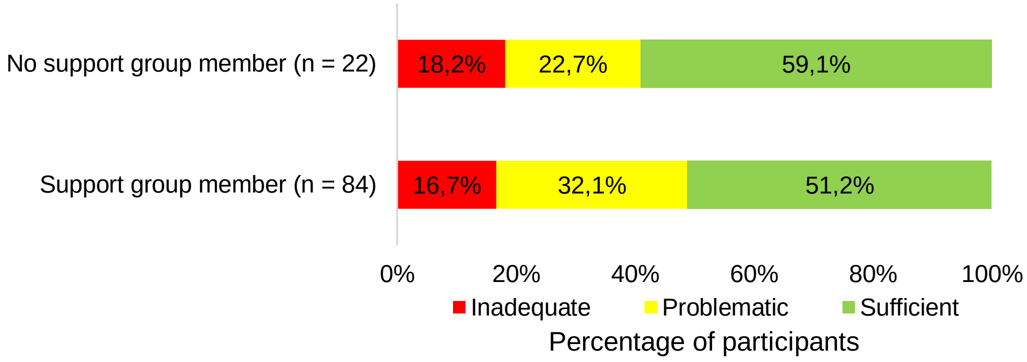

Figure 47. Distribution of health literacy levels depending on support group membership.

Information and/ or Training Received and Health literacy

A possible correlation between received or not received information and/ or training regarding immunosuppressive medication and adherence was examined. Participants who reported not having received any information and/ or training show a higher percentage (31.8%) of inadequate health literacy than those who received information and/ or training. A detailed distribution of answers is shown in *figure 48*. A significant correlation could be detected between information and/ or training received and health literacy level, $\chi^2(2) = 7.898$, $p = .019$, $n = 106$. However, the detected correlation is assumed as weak, *Cramer's V* = .273.

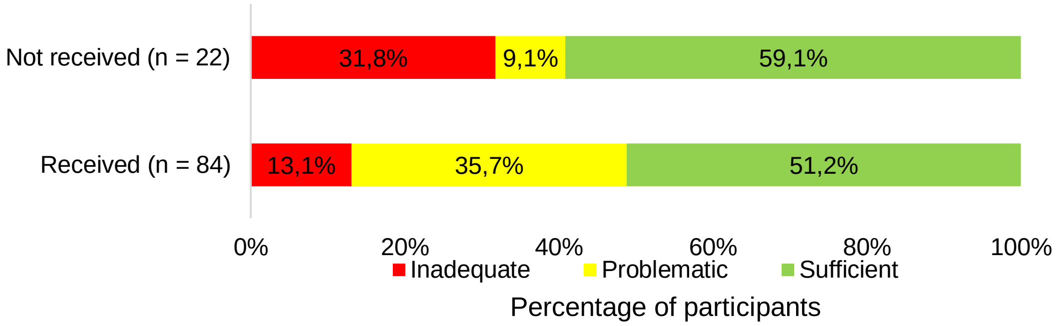

Figure 48. Distribution of health literacy levels depending on information and/ or training received or not received.

8.6. Correlation Between Medication Adherence and Health Literacy

This chapter examines whether there is a correlation between medication adherence measured by BAASIS and the health literacy measured by HLS-EU-Q16. Categories “adherent” and “non-adherent” were correlated with health literacy levels “sufficient”, “problematic” and “inadequate”. As shown in *Figure 49* 36.6% from the participants categorised as adherent dispose of an inadequate or problematic health literacy, whereas of the participants categorised as non-adherent 51.3% have a problematic or inadequate health literacy level. No significant correlation was detected between adherence and health literacy level, $\chi^2(2) = 1.853$, $p = .396$, $n = 106$.

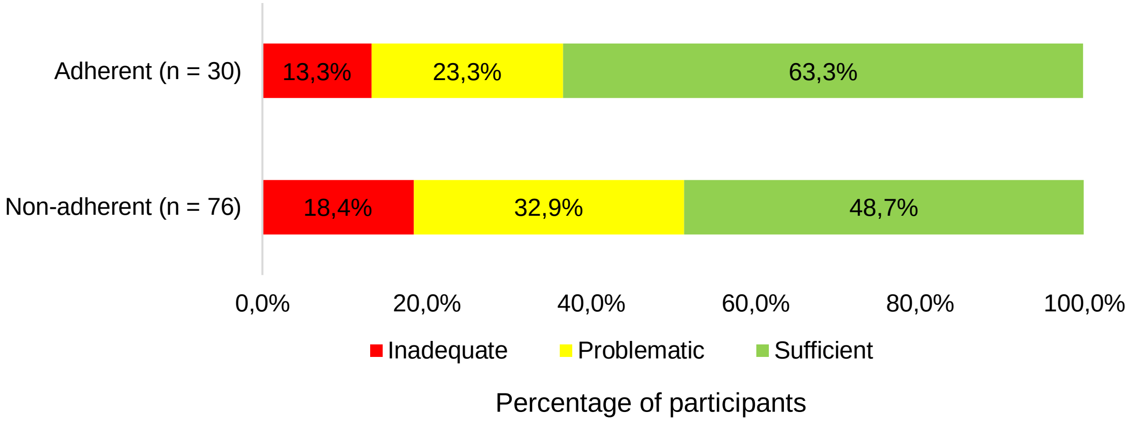

Figure 49. Distribution of health literacy levels in adherent and non-adherent participants.

The percentage of the combined answer categories “difficult” and “very difficult” from the HLS-EU-Q16 for adherent and non-adherent transplant recipients is shown in *figure 50*. The biggest differences, given in percent, between adherent and non-adherent transplant recipients can be found in Q1, Q8, Q11, Q13 and Q16. A lower percentage of adherent compared to non-adherent transplant recipients find it “difficult” or “very difficult” to find information on treatments of illnesses that concern them (23.3%), to find information on how to manage mental health problems like stress or depression (36.7%), to judge if the information on health risks in the media is reliable (50.0%), to decide how they can protect themselves from illness based on information in the media (30.0%), and to find out about activities that are good for their mental well-being (36.7%). A lower percentage of non-adherent compared to adherent transplant recipients find it “difficult” or “very difficult” to judge which everyday behaviour is related to their health (11.8%).

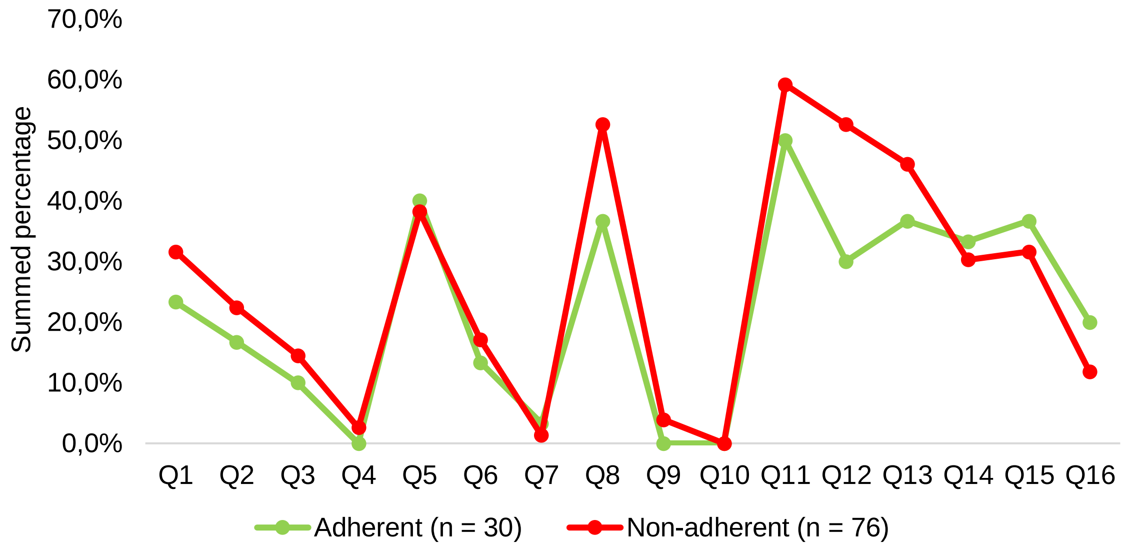

Figure 50. Self-assessment of health literacy, 16 questions (HLS-Q16). Summed percentages of the answer categories "difficult" and "very difficult" for transplant recipients categorised as adherent and transplant recipients categorised as non-adherent.

The last question was an open label question asking whether the participant wanted to add anything related to the topics medication intake and health literacy. 37 (34.9%) participants answered this open label question. Based on the answers, 12 categories were formed and afterwards the answers were allocated to one or more categories. The frequency of occurrence per category is shown in *figure 51*.

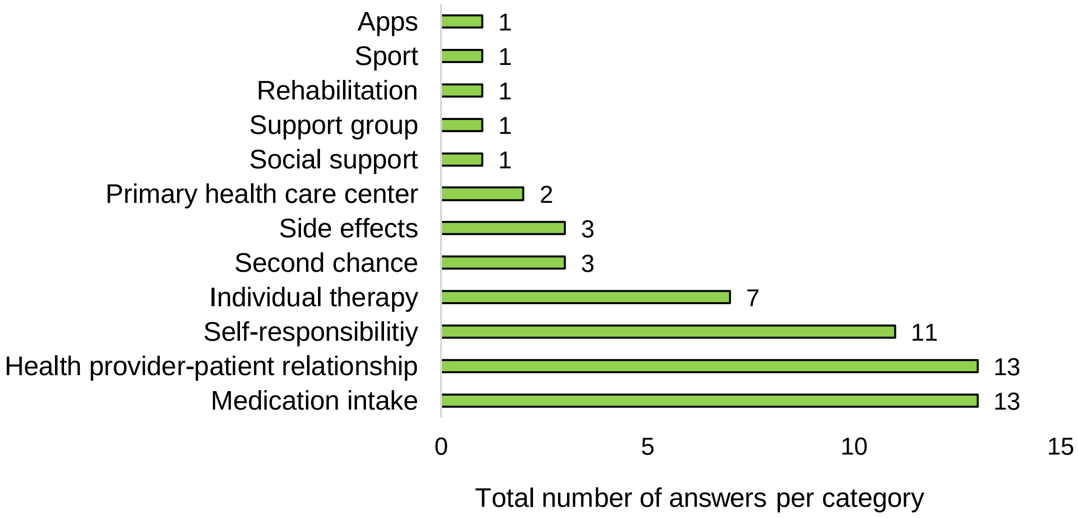

Figure 51. Frequencies of answers per category.

Answers in reference to medication intake were given 13 times. One participant, for example, wrote that a reliable intake of the medications is very important. Another one mentioned that a certain discipline as well as a positive attitude are necessary. Three participants were worried about bottlenecks in the supply of medication.

The health-care provider – patient relationship was mentioned 13 times. Participants claimed that a trustful relationship and time spent with the health-care provider (a doctor was explicitly mentioned seven times) is crucial to them. Ten participants mentioned that more support from there health-care provider is necessary.

Eleven times self-responsibility was described as necessary during the whole process, for example, the demand to critically question information, to keep the regular follow-up appointments and to follow the rules set by the health-care providers.

Seven times individuality was pointed out as important regarding the treatment strategy. Three times the side effects were mentioned, as often as the transplantation as a second chance. Two participants demand more primary health care centres with longer opening hours. One mention each receive the statements that every transplant recipient should be admitted to a rehabilitation centre, should be a member of a support group, that sport is important for the health, and that apps are useful for medication reminders.

9. Discussion

To the authors knowledge the present study is the first of its kind performed in Austria. The results of the present thesis provide empirical findings and data that are available for transplant recipients in support groups in Austria and allow statements about their medication adherence and health literacy. In addition, the influence of socio-demographic and transplant-related factors on medication adherence and health literacy was examined. Based on the research questions from chapter 1, the results are interpreted and discussed in the following paragraphs.

Research question 1: What is the current status of research on health literacy and medication adherence in transplant recipients?

In reference to the literature review in chapter 6, five studies with a cross-sectional survey design were found which examined medication adherence and health literacy in transplant recipients. The studies were published between 2013 and 2018 and analysed 669 transplant recipients in total. Transplant recipients showed rates of non-adherence between 14 and 75%, but the highest rate of non-adherence was found in kidney transplant recipients (Demian et al., 2016). The percentage range of non-adherence in the five studies were wider than those stated by Neuberger et al. (2017, p. 8) (22-68%), Belaiche et al. (2017, p. 582) (50-33%) and Bleser et al. (2011, p. 882) (23.9%-70%). The percentage rate of limited health literacy in the analysed five studies was between 2.4 and 24%, and the highest one was found in kidney transplant recipients (Patzer et al., 2016, p. 1). This is not consistent with the findings of Chisholm-Burns et al. (2018, p. 2326), who observed a wider percentage range (9-72%) for limited health literacy in transplant recipients, the highest one again found in kidney transplant recipients. Two studies which surveyed kidney transplant recipients, found a correlation between medication adherence and health literacy (Demian et al., 2016; Patzer et al., 2016). Chisholm-Burns et al. (2018, p. 2332) concluded, based on their literature findings that health literacy is associated with medication adherence. According to the results from the literature review in chapter 6, however, this cannot be comprehensively presumed. Only two of five studies examined this association found a correlation between limited health literacy and medication non-adherence. Assumptions can only be made for kidney transplant recipients, because, as mentioned above, a correlation was found in kidney transplant recipients by Demian et al. (2016) and Patzer et al. (2016). Due to the different measurement tools for medication adherence (Lieber et al., 2015, p. 74) and health literacy (Haun et al., 2014, p. 326), a comparability of the study results is only given to a limited extent. Regarding the different health literacy instruments used, only the study of Demian et al. (2016) surveyed multiple domains of health literacy. Studies by Lennerling et al. (2018), Serper et al. (2015), Patzer et al. (2016) and Weng et al. (2013) surveyed only functional health literacy. Additionally, the different medication adherence self-report instruments used measured non-adherence for a different time frame, for example, non-adherence in the last four weeks (Lennerling et al., 2018, p. 2) or in the last four days (Serper et al., 2015, p. 4; Patzer et al., 2016, p. 5).

Research question 2: What are the findings about the prevalence and the correlation of self-reported medication non-adherence and the level of health literacy in Austrian transplant recipients in support groups?

106 transplant recipients participated in the online survey. Most of them were kidney transplant recipients (67.9%), which was to be expected, because kidneys represent the most frequent transplanted organs (ÖBIG-Transplant, 2019, p. 24) and most of the support groups that participated in the survey were founded for kidney transplant recipients. Additionally to support group members, also individuals without a membership in a support group (20.8%) participated in the survey, due to snowball-sampling as described in chapter 7.3.. The distribution between genders in the conducted study shows similar results to the data issued by the United Network for Organ Sharing (2019b) (2019a), however, male transplant recipients are overrepresented. The mean age in the conducted study was *M* = 57.3 (*SD* = 13.1), which also corresponds with the data from United Network for Organ Sharing (2019a), the age category from 50 to 64 years showing the highest number of transplant recipients.

Overall non-adherence rate measured by means of BAASIS were found to be 71.7% in all participants and 69.4% (*n* = 72) for kidney transplant recipients. Non-adherence rates state for participants with other organs transplanted have to be interpreted with caution because of their underrepresentation. This results show a high prevalence of non-adherence in comparison to the results described in the literature review in chapter 6 and the non-adherence rates published by Belaiche et al. (2017, p. 582), Neuberger et al. (2017, p. 8) and Bleser et al. (2011, p. 882). One possible explanation for the high proportion of non-adherent participants might be that a longer time since transplant (*M* = 12.2 years, *SD* = 10.0) appears to be linked with poorer adherence (Belaiche et al., 2017, p. 589). Another reason could be that the anonymity guaranteed in the survey made the participants feel confident not to get judged by their health care provider, and therefore answered the questions honestly. Kobayashi et al. (2019) also conducted an internet-based-survey, but the non-adherence rate, also measured with BAASIS was only 42.7% in kidney transplant recipients. Although the conducted study might be seen as biased due to the fact of including participants with a higher motivation, since they found and completed the questionnaire online, a relatively high rate of non-adherence was observed. Due to the fact that it was the first time a study was conducted in support groups for transplant recipients, no comparable results are available.

Results from the HLS-EU-Q16 showed a mean score of *M* = 12.0 (*SD* = 3.0) points, which is defined as problematic health literacy. 47.2% of the participants showed a limited health literacy, which can be considered as high prevalence compared to the figures resulting from the literature review in chapter 6 and those mentioned by Chisholm-Burns et al. (2018, p. 2326). However, the results are similar to the once of the Austrian Health Literacy Survey stating a limited health literacy of 48.4% (Ganahl et al., 2016). About 50% of the participants find it “difficult” or “very difficult” to obtain information on how to manage mental health problems, such as stress or depression, and to judge if the information on the health risks in the media is reliable, which is considerably higher than the percentage for the participants in the Austrian HLS. Also twice as many transplant recipients find it “difficult” or “very difficult” to explore activities that are good for their mental well-being, compared to the participants in the Austrian HLS. Especially the percentage for mental health problems is tremendous due to the fact that depression and anxiety are directly linked with non-adherent behaviour (Belaiche et al., 2017, p. 582). Almost no transplant recipient finds it “difficult” or “very difficult” to understand their doctor’s or pharmacist’s instruction on how to take a prescribed medicine and to follow their instructions. Furthermore, no transplant recipient find it “difficult” or “very difficult” to understand why they need health screenings. Both are important factors for their medication adherence and disease prevention (Chisholm-Burns et al., 2018, p. 2326). Nonetheless, no study so far has applied the HLS-EU-Q16 in either a transplant recipient population or in support groups. Therefore no final conclusion can be made about the representativity of the results.

Comparing adherent with non-adherent participants based on their health literacy level, it appears that adherent participants show a lower percentage of limited health literacy (36.6%, *n* = 30) than non-adherent participants (51.3%, *n* = 76). Nonetheless, no significant correlation could be detected between medication adherence and level of health literacy. This is consistent with the results described by Weng et al. (2013), Serper et al. (2015) and Lennerling et al. (2018), although their studies showed a lower percentage of non-adherence and a lower percentage of participants with limited health literacy. The fact that no correlation was found between medication adherence and health literacy can possibly be explained by the overrepresentation of non-adherent participants in the study population and the small sample size.

Research question 3: Which sociodemographic factors and transplant-related factors are associated with medication adherence and the level of health literacy in Austrian transplant recipients in support groups?

Based on the influencing factors described for medication adherence (chapter 4.2) and health literacy (chapter 5.3), correlations were examined.

A significant correlation was neither found for gender and non-adherence nor for other sociodemographic factors. The studies observed also showed heterogeneous results. According to Belaiche et al. (2017) and Kobayashi et al. (2019), non-adherence was significantly higher in men. Alkatheri et al. (2016) and (Demian et al., 2016), however, found a higher rate of non-adherence in women. Several studies did not find any association between gender and adherence (Lennerling and Forsberg, 2012; Massey et al., 2013; Reber, 2016; Albekairy et al., 2016; Reber et al., 2016). Overall, very different, sometimes contradictory results were reported. A systematic review from Belaiche et al. (2017) analysed 37 studies considering factors relevant to medication non-adherence in kidney transplant recipients. They conclude that non-adherence occurs more likely for younger and unemployed recipients with lower social support and lower educational level.

Further no significant correlation was detected for transplant-related factors. Support group members show a higher level of non-adherence (75.0%, *n* = 84), compared to other participants (59.1%, *n* = 22). No other studies are available to compare results. The high prevalence of non-adherence in support group members was not expected, because support group members are described as better prepared to cope with the disease, and also to know more about their illness (Fonds Gesundes Österreich, 2005, p. 12; Nickel et al., 2019, p. 289). Participants with a longer time since transplant (>4 years since transplant) had a higher prevalence of non-adherence, which is similar to the results obtained by Villeneuve et al. (2019) and Drick et al. (2018). Although the group of participants with a very long time (from 18 to 42 years) since transplant showed the highest rate of non-adherence (76.7%, *n* = 30), they nonetheless managed to survive a long time with the transplanted organ (Demian et al., 2016, p. 863).

Analysing the associations between sociodemographic factors and health literacy, no significant correlation could be found, but female transplant recipients show a higher prevalence of limited health literacy than men. This outcome is contradictory to the results issued by the Austrian HLS, according which women tend to have a significant better health literacy level (Pelikan et al., 2013, p. 16). Lennerling and Forsberg (2012, p. 1) did not find any relation between health literacy and gender in transplant recipients. Chisholm-Burns et al. (2018, p. 2326) did not refer to gender as influencing factor for health literacy either. Unemployed transplant recipients show a higher rate of limited health literacy than employed transplant recipients. This is consistent with the results from the Austrian HLS (Pelikan et al., 2013, p. 17) and those provided by Cajita et al. (2017, p. 272) who surveyed heart transplant recipients. According to the Health-Literacy Model in Transplantation by Chisholm-Burns et al. (2018, p. 2327), unemployment is one factor which is related to limited health literacy.

Support group members show a higher prevalence of limited health literacy, which was an unexpected outcome, as, according to Fonds Gesundes Österreich (2005, p. 14) support groups help to increase knowledge and strengthen disease-related competence. However, no significant correlation was found between a support group membership and the health literacy level. A possible explanation for this result may be the overrepresentation of support group members and again small sample size. The answers regarding information and/ or training about immunosuppressive showed that transplant recipients who did not receive information and/ or training have a much higher prevalence of inadequate health literacy compared to the group who received the information and/ or training. A weak correlation was found between these two groups. This result may support the assumption that a person with a better level of health literacy is more likely to find information about their health or disease.

Research question 4: Which kind of information and/ or training with the focus on medication adherence did the Austrian transplant recipients in support groups receive after their transplantation?

Most of the participants reported that they received information and/ or training regarding the immunosuppressive medication in form of a conversation, followed by being informed through a folder. 20.8% reported that they did not receive any information and/ or training which is alarming considering the fact that usually medication regimen is complex after transplantation and often overstraining for transplant recipients (Neuberger et al., 2017, p. 7). The majority of the participants received information and/ or training through a doctor. Support groups did provide 24 transplant recipients with information and/ or training regarding their immunosuppressive medication. Thus the conclusion can be drawn that medication adherence is not the primary focus during their support group meetings. Only two participants received information and/ or training from their pharmacist, which has to be seen as alarming, as every transplant recipient is provided with medication at the pharmacy and interventions led by a pharmacist showed positive results (Low et al., 2015, p. 760). Moreover, according to Bleser et al. (2009, p. 796), a multiprofessional approach is recommended for a long-term improvement of medication adherence.

Regarding the preferred time when information and/ or training should take place, over three-quarters of the transplant recipients chose during their inpatient stay or their outpatient follow-up as their options. Most of the studies examining the effect of interventions to improve medication adherence were conducted in the outpatient setting (Neuberger et al., 2017, p. 9), although transplant recipients are already confronted with a complex medication regimen during their inpatient stay (Kniepeiss et al., 2018, p. 39). The inpatient stay and the outpatient follow-ups are also appropriate settings to implement multidimensional and individual interventions, which are recommended by Bleser et al. (2009, p. 796), Neuberger et al. (2017, p. 9-10) and Shneider et al. (2018, p. 944). The importance of individuality was also explicitly reported by the participants. Only 36 answered that they received two or more types of information and/ or training. 55 participants only received one type of information and/ or training. Interventions should not only focus on patient education to impart knowledge, but also on behaviour change and psychological support (Neuberger et al., 2017, p. 10). These interventions can help transplant recipients to find a daily routine, to elaborate strategies how not to forget the medication, and how to cope with stress during work, as these were the most frequently given reasons (see *figure 27* and *figure 28*), for why the immunosuppressive medication was not taken in time or not at all. Furthermore, interventions on the meso-level should be implemented to improve the patient-provider relationship (Bleser et al., 2009, p. 796), which is crucially important for participants with limited health literacy, because appropriate and understandable information and instructions from the health care provider can help to improve medication adherence (Miller, 2016, p. 1085). 13 participants were of this opinion reporting that support and explanations from their health care provider are necessary and is often non-sufficient. Medical examinations or appointments were also mentioned as reasons why participants did not take the immunosuppressive medication on time. Therefore, health care providers have to treat patients with immunosuppressive medication with special consideration, when scheduling an appointment. This is an effective way to ensure that recommendations from health care providers are taken seriously.

Limitations

Several limitations have to be reported regarding the conducted study. Although the design of the cross-sectional study is suitable for obtaining information at a specific point of time, it does not demonstrate any causal relationships between the factors analysed (Döring and Bortz, 2016, p. 204).

Furthermore only self-reported instrument were used, for medication adherence as well as for health literacy, which can lead to overestimation of adherence and health literacy because of a socially desirable behaviour (Döring and Bortz, 2016, p. 989). Although the high prevalence of non-adherence and limited health literacy leads to the assumption that this may not be the case for the conducted study, self-report bias cannot be entirely excluded. Furthermore, a recall period of four weeks for medication adherence might be too long, leading to recall bias and less response accuracy (Döring and Bortz, 2016, p. 255). Despite the fact that for measuring medication adherence a combination of methods is recommended, for example combination of self-report instrument and trough level (Neuberger et al., 2017, p. 9), due to the feasibility only the self-report instrument could be applied. Moreover, additional questions were partly self-constructed and are considered less accurate, and they do not fulfil psychometric criteria (Döring and Bortz, 2016, p. 407).

Another limitation may be the recruitment bias (Döring and Bortz, 2016, p. 385), which may be caused by the convenience sampling of transplant recipients only in support groups. In addition only transplant recipients with an e-mail address had access to the questionnaire and no information is available about non-respondents (participation bias) (Döring and Bortz, 2016, p. 125). Therefore the transferability of the results to all transplant recipients in Austria is limited.

10. Practical Recommendations

The purpose of the present study was to determine the prevalence and correlation of medication adherence and health literacy level in transplant recipients in support groups in Austria. Although a high prevalence of non-adherence and limited health literacy was detected, no significant correlation was found. Nonetheless, due to the high prevalence and therefore higher risk for rejection and graft loss, effective interventions are needed to support transplant recipients with their complex medication regimen and their self-management in Austria. Furthermore, health care provider should routinely assess medication adherence and health literacy levels, before and after transplantation, to develop individual interventions based on their results. In terms of these individual interventions and especially regarding general information about the medication, it is necessary to offer these already during their inpatient stay and continue in their outpatient follow-ups. Multi-level interventions consisting of educational as well as behavioural components and offered by doctors, nurses, psychologists and pharmacists, need to be implemented. In particular transplant recipients, who show limited health literacy and signs of medication non-adherence, interventions based on their individual needs are necessary to achieve long-term success.

In terms of the content discussed in support group meetings, a focus on medication adherence should be included. This may help to increase awareness concerning the problem of medication non-adherence. In addition, information events should provide comprehensible information according to the respective level of health literacy of their members. Transplant recipient should be able to find the contact details of a support group for transplant recipients in the respective federal state in Austria easily, therefore it is recommended to standardise and update the nationwide homepages on support groups for transplant recipients in Austria.

The results of the present study indicate the need for further studies with a larger sample size in order to better understand the connection between medication adherence and health literacy. Therefore, a longitudinal, multicentre study carried out at transplant centres in Austria would be recommended. Due to the limited scope of this thesis, it was not possible to examine all risk-factors for medication non-adherence and limited health literacy. Since mental health problems are known to be a risk factor for limited health literacy as well as for medication non-adherence and since study participants highlighted the importance of a good patient-provider relationship, future research should additionally focus on these issues.

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List of Abbreviations

BAASIS	Basel Assessment of Adherence to Immunosuppression Medications Scale
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CNI	calcineurin inhibitor
COMMIT	Consensus on Managing Modifiable Risk in Transplantation
CUAS	Carinthia University of Applied Sciences
et al.	et alii, et aliae, et alia (and others)
EU	European Union
HALS	Health Activities Literacy Scale
Heal-T	Health Literacy Model in Transplantation
HIV	Human immunodeficiency virus
HLA	human leukocyte antigen
HL	Health Literacy
HLS-EU	European Health Literacy Survey
HLS Q16	Health Literacy Questionnaire 16
HLQ	Health Literacy Questionnaire
HU	high urgent
ITAS	Immunosuppressant Therapy Adherence Scale
JASP	Jeffreys’s Amazing Statistics Program
M	Mean
MARSI	Medication Adherence Self-Report Inventory
MELD	Model of End Stage Liver Disease
MEMS	Medication Event Monitoring System
MMF	mycophenolat mofetil
mTOR	Mammalian target-of-rapamycin
n	sample size
NANDA	North American Nursing Diagnosis Associations
Nr.	number
NVS	Newest Vital Sign
OTPG	Organtransplantationsgesetz
	Federal Act on the Transplantation of Human Organs (Organ Transplantation Act), Federal Law Gazette I No. 108/2012 as last amended by Federal Law Gazette I No. 37/2018

ÖBIG	Österreichisches Bundesinstitut für Gesundheitswesen
p	p-value
PMAQ	Patient Medication Adherence Questionnaire
Q	question
REALM	Rapid Estimate of Adult Literacy in Medicine
REALM-T	Rapid Estimate of Adult Literacy in Medicine-Transplant
SD	Standard Deviation
sTOFHLA	short Test of Functional Health Literacy in Adults
T	transplantable
Tac	Tacrolimus
Tac-IPV	intrapatient variability of tacrolimus
TOFHLA	Test of Functional Health Literacy in Adults
TSQM	Treatment Satisfaction Questionnaire for Medication
TxEQ	Transplant Effects Questionnaire
UNOS	United Network for Organ Sharing
USA	United States of America
WHO	World Health Organization
χ^2	Chi-square test

Appendix I

Contacted support groups for transplant recipients in Austria:

Nr.	Support group	Contact date	Confirmed/declined/ no answer
1	Austrian Transplant Sports Federation	August 30, 2019	Confirmed
2	Österreichischer Verband der Herz- und Lungentransplantierten	August 30, 2019	Confirmed
3	Club HLTX Selbsthilfegruppe für Herz- und Lungentransplantierte, Wartende und Angehörige	No mail address available, phone number do not exist	
4	Verein der Lebertransplantierten Österreichs	August 30, 2019	No answer
5	Selbsthilfegruppe für Leberkranke und Lebertransplantierte Oberösterreich	August 30, 2019	Confirmed
6	Selbsthilfegruppe für Leberkranke und Lebertransplantierte Salzburg	August 30, 2019	Confirmed
7	Selbsthilfegruppe für Leberkranke und Lebertransplantierte Vorarlberg	Mail address and phone number do not exist	
8	Gesellschaft Nierentransplantierter und Dialysepatienten, Wien, Niederösterreich und Burgenland	August 30, 2019	Confirmed
9	Niere Kärnten	August 30, 2019	Confirmed
10	Verein Niere Oberösterreich	August 30, 2019	Confirmed
12	Niere Salzburg - Selbsthilfegruppe für Nierenpatienten	August 30, 2019	Confirmed
13	Interessengemeinschaft Niere Steiermark	August 30, 2019	Confirmed
14	Verein Nephro Tirol	August 30, 2019	Confirmed
15	Verein Niere Vorarlberg	August 30, 2019	Confirmed
16	Transplant Club Steiermark	October 16, 2019	Declined
17	Selbsthilfegruppe für Leberkranke und Lebertransplantierte Innviertel	August 30, 2019	No answer

Email inquiry (in German):

Sehr geehrte Frau/Herr XY

Mein Name ist Nadja Fink und ich bin Studentin des Masterstudiengangs „Gesundheitsmanagement“ an der Fachhochschule Kärnten und Pflegeexpertin für Transplantationspflege am LKH-Univ. Klinikum Graz. Im Rahmen meiner Masterarbeit führe ich eine Befragung von transplantierten PatientInnen in einer Selbsthilfegruppe durch. Die Themen, welche dabei bearbeitet werden, umfassen die Medikamentenadhärenz und Gesundheitskompetenz von transplantierten PatientInnen. Meine Arbeit zielt auch darauf ab, Handlungsempfehlungen für das Behandlungsteam von transplantierten PatientInnen abzuleiten.

Ich würde mich sehr freuen, wenn Ihre Selbsthilfegruppe mich bei der Durchführung der Befragung unterstützt. Diese wird voraussichtlich im Oktober/November 2019 stattfinden. Ihre Aufgabe als Obmann/Obfrau würde darin bestehen, meine Onlinebefragung an Ihre Vereinsmitglieder weiterzuleiten. Wenn Sie prinzipiell Interesse daran haben, bitte ich Sie kurz mit mir Kontakt per Mail oder per Telefon aufzunehmen. Gerne auch, wenn Sie noch nähere Informationen benötigen.

Herzliche Grüße

Nadja Fink

Appendix II

Questionnaire about the connection between health literacy and medication intake of transplant recipients

Dear participant,

As part of my master's thesis (health management), I examine the health literacy and the regular medication intake after transplantation. Therefore, I am conducting this survey.

What is health literacy?

Health literacy is the ability of individuals to make decisions about their health in their daily lives.

The aim of this study is to survey your self-assessment of your health literacy and your medication intake habits so that targeted action in this area can be planned, developed and implemented for transplant recipients.

Duration and length:

The following questionnaire contains a total of 43 questions. To complete the questionnaire takes about 12 minutes on average.

Agreement and anonymity:

By completing the questionnaire, you consent to voluntarily participate in the study, and agree that the data and research results collected are used in anonymous form for research purposes.

Completeness:

In order to ensure meaningful results, I would ask you to complete the questionnaire in its entirety.

Of course, I am happy to answer any questions. You can reach me by e-mail.

Many thanks for your support and assistance.

Best regards,

Nadja Fink

Student at the Carinthia University of Applied Sciences and JAMK University of Applied Sciences, master program Health Management
Advanced practice nurse for transplantation care at University Hospital Graz

Thesis supervisor:

FH-Prof. Dr. Ralf Reiche
Carinthia University of Applied Sciences

Mari Punna, Msc
JAMK University of Applied Sciences

1. Which organ did you receive?

- ☐ heart
- ☐ liver
- ☐ lung
- ☐ kidney
- ☐ pancreas
- ☐ other (please specify)

  ____

2. How long have you been transplanted?

years ____

months ____

3. Are you a member of a support group for transplant recipients?

- ☐ yes
- ☐ no

4. In general, would you say your current health status is:

- ☐ excellent
- ☐ very good
- ☐ good
- ☐ fair
- ☐ poor

Questionnaire about Medication Intake

Source: Leuven-Basel Research Group (2005). The Basel Assessment of Adherence to ImmunoSuppressive medIcations Scale (BAASIS©) – Written questionnaire (self-report). Unpublished Document. Basel: University, Institute of Nursing Science, Department Public Health.

Now some questions about taking medication. Anti-rejection drugs (= immunosuppressants) are the tablets you take to prevent your body from rejecting your transplanted organ. The proper use of anti-rejection drugs, i.e. taking them daily and always at the same time, can be difficult for many patients. I would like to know how you handle the use of these drugs in daily life.

Please answer the following questions as correctly and honestly as possible.

5. Do you recall not having taken your immunosuppressive medications some times in the past 4 weeks?

- ☐ yes
- ☐ no

6. Could you tell me how often this happened?

- ☐ once
- ☐ twice
- ☐ 3 times
- ☐ 4 times
- ☐ more than 4 times

7. Can you name the reasons why you missed the dose?

____

8. Have you skipped several consecutive doses of your immunosuppressive medications in the past 4 weeks?

☐ yes
☐ no

9. Could you tell me how often this happened?

☐ once
☐ twice
☐ 3 times
☐ 4 times
☐ more than 4 times

10. Do you recall having taken your immunosuppressive medications with more than 2 hours time difference from the prescribed dosing time in the past 4 weeks?

☐ yes
☐ no

11. Could you tell me how often this happened?

☐ once
☐ twice
☐ 3 times
☐ 4 times
☐ more than 4 times

12. Can you name the reasons why you missed the dose?

____

13. Have you reduced the prescribed amount of your immunosuppressive medications on your own initiative in the last 4 weeks without your doctor asking you to? For example, did you take more or fewer tablets or change the dose, perhaps by halving a tablet?

☐ yes
☐ no

14. Have you stopped taking any of your immunosuppressive medications on your own initiative within the last year without your doctor asking you to?

☐ yes
☐ no

15. To what extent do you experience side effects of anti-rejection drugs?

☐ no side effects
☐ mild side effects
☐ medium side effects
☐ strong side effects

16. To what extent do you feel restricted by these side effects in your everyday life?

☐ no restriction
☐ slight restriction
☐ medium restriction
☐ strong restriction

17. Did you receive information/ training on immunosuppressive medication after the transplantation?

☐ yes
☐ no

18. In what form did you receive this information/ training?

☐ folder
☐ conversation
☐ practical exercise
☐ information event
☐ link to website/ app
☐ others (please specify)

____

19. Did you find this information/ training sufficient?

☐ yes
☐ no

20. By whom or who did you receive information/ training on immunosuppressive medication? (Multiple answers possible)

☐ doctor
☐ nurses
☐ pharmacist
☐ support group
☐ general practitioner
☐ self-researched information
☐ other (please specify)

____

21. In what form do you find information/ training after transplantation most effective? (Multiple answers possible)

☐ personally, during the inpatient stay
☐ personally, during the outpatient follow-ups
☐ via an online training program
☐ via mobile apps
☐ through the general practitioner
☐ through a support group
☐ other (please specify)

____

Questionnaire about Health Literacy (European Health Literacy Survey Q16)

Source: Ganahl, K.; Dahlvik, J.; Röthlin, F.; Alpagu, F.; Sikic-Fleischhacker, A.; Peer, S.; Pelikan, J. M. (2016) Health literacy of people with migration background from Turkey and former Yugoslavia in Austria. Results of a quantitative and qualitative Study. LBIHPR Research Report.

In everyday life we have to deal with situations that are important for our health. You may experience some of these situations as difficult, others as simple. On a scale from very simple to very difficult:

How easy is it in your opinion to…

Nr.	**On a scale from very easy to very difficult:**	**Very easy**	**Easy**	**Difficult**	**Very difficult**
22	…find information on treatments of illnesses that concern you?				
23	…find out where to get professional help when you are ill?				
24	…understand what your doctor says to you?				
25	…understand your doctor's or pharmacist's instruction on how to take a prescribed medicine?				
26	…judge when you may need to get a second opinion from another doctor?				
27	…use information the doctor gives you to make decisions about your illness?				
28	…follow instructions from your doctor or pharmacist?				
29	…find information on how to manage mental health problems like stress or depression?				
30	…understand health warnings about behaviour such as smoking, low physical activity and drinking too much?				
31	…understand why you need health screenings?				
32	…judge if the information on health risks in the media is reliable?				
33	…decide how you can protect yourself from illness based on information in the media?				
34	…find out about activities that are good for your mental well-being?				
35	…understand advice on health from family members or friends?				
36	…understand information in the media on how to get healthier?				
37	…judge which everyday behaviour is related to your health?				

38. How old are you? (information in years)

_____

39. What is your gender?

- ☐ female
- ☐ male

40. What is your current employment status?

- ☐ employed
- ☐ unemployed
- ☐ not able to work
- ☐ retired

41. What is your highest level of education?

- ☐ no compulsory education
- ☐ ninth grade
- ☐ apprenticeship diploma
- ☐ vocational middle school without „Matura“
- ☐ “Matura” (eg. AHS/ HAK))
- ☐ university
- ☐ others (please specify)

  ____

42. Do you live in a relationship?

- ☐ yes
- ☐ no

43. Is there anything that you would like to add conclusively to the topic of medication intake and health literacy?

____

Appendix III

Detailed description of study participants:

Variable	**Study participants (*n* = 106)** **total**	**%**
Gender		
Female	29	27.4
Male	77	72.6
Age, years *M* (*SD*)	57.3 (13.1)	
Received Organ		
Heart	10	9.4
Liver	9	8.5
Lung	9	8.5
Kidney	72	67.9
Pancreas and Kidney	6	5.7
Time since transplant, years *M* (*SD*)	12.2 (10.0)	
Work status		
Employed	56	52.8
Unemployed	4	3.8
Not able to work	4	3.8
Retired	42	39.6
Education		
Without compulsory education	1	0.9
Ninth grade	5	4.7
Apprenticeship diploma	35	33.0
Vocational training college without “Matura”	22	20.8
“Matura” (eg. AHS/ HAK)	17	16.0
University	20	18.9
Others	6	5.7
Relationship		
Yes	86	81.1
No	20	18.9
Support group members		
Yes	84	79.2
No	22	20.8
Health status		
Excellent	18	17.0
Very good	40	37.7
Good	36	34.0
Fair	12	11.3
Poor	0	0.0

Glossary

HLA antigens: The human leukocyte antigen (HLA) system or complex is a gene complex encoding the major histocompatibility complex (MHC) proteins in humans. These cell-surface proteins are responsible for the regulation of the immune system in humans.

Matura: Final exams young adults (aged 18 or 19) take at the end of their secondary education in certain European countries.

MELD Score: The Model for End-Stage Liver Disease, or MELD, is a scoring system for assessing the severity of chronic liver disease.

Shared decision making: Is an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences.

Teach back method: The teach-back method, also called the "show-me" method, is a communication confirmation method used by healthcare providers to confirm whether a patient (or care takers) understands what is being explained to them. If a patient understands, they are able to "teach-back" the information accurately.