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## Chapter

# The Dialogue between the Patient's Educational Needs and the Knowledge Transmitted by Nurses: The Case of the Transplanted Renal Patient

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## Abstract

Health education has been on the horizon of nursing professionals for decades. The design and development of new education programmes allied to the processes of ageing and chronic diseases have been sought after. In the twenty first century, the need to develop 'performant' policies that lead policymakers, health professionals and civil society to move towards new management of chronic disease marked by citizens' participation in decisions regarding their health and control of the management of their health condition has accelerated the urgency of citizen-centred health care and education programmes tailored to their needs, preferences, values, and condition. In this paper, we explore what has been done around patient education by nursing professionals and the results achieved. We observe a positive scenario where the patient is seen as an active partner, which leads to the integration of a new perspective, assisted and participatory disease management. There is still a need for more structured and systematised education programmes and training for health professionals involved in this process.

**Keywords:** renal recipients, renal transplantation, education, patient education, nurse, self-efficacy, knowledge

## 1. Introduction

A closer look at health education programmes shows a panoply of studies focusing on this issue and their influence on citizens' skills and abilities by giving them the tools for learning, taking into consideration their personal needs and problems.

Over time, perspectives and approaches have changed as health systems have evolved. The ageing population and the increase in chronic diseases have put health services under enormous pressure and generated the need to rethink supply in relation to demand. In the context of economic and social modernisation, which has led to an increase in the well-being of one and all, we have seen infectious diseases

under control, the infant mortality rate quite low and the death rate diminished. In this vision, resplendent with a better future, life expectancy increased significantly and with it, the proportion of elderly people in the population increased. This accelerated process of economic, social and health changes has considerably improved the living conditions and quality of life of the populations. We are therefore witnessing an increase in chronic diseases, many of which are the cause of high morbidity and mortality [1].

Many of these chronic diseases require long-term care, which contributes to increased healthcare expenditure. Associated with these issues are the high disability rates that affect the living conditions of this group of people.

The dividends of the growth of the elderly population and the conquests in the field of health have allowed the profound transformation of the condition of the population in general and the elderly group in particular. The State maintains support to eliminate social insecurity and ensure the population's conditions of subsistence in economic, social and health care terms [2].

Despite the complexity of this point, people are living longer with chronic diseases and disabilities and health systems are facing budgets under increasing pressure, so societies have sought solutions in order to guarantee the accessibility of their citizens to health care and, at the same time, the survival of health systems. Patient-centred care is thought to be the way forward. As a coordinated care process tailored to people's needs, it supports the development of people's knowledge, skills and confidence to manage their health in an informed way, i.e., the process promotes the means for self-care practice [3].

Now, more and more health systems advocate the path of patient empowerment and involvement, although there are divergences between countries on this issue, and the path of patient dependence on health professionals has not yet been fully abandoned. The issue is also related to rising healthcare costs due to the longevity of the population and the rising prices of drugs and technology, with the system at risk of collapse if the pre-existing models of care are maintained [4].

For Coulter & Magee, the collapse can be avoided if patient autonomy and involvement are encouraged. The emphasis on patient autonomy encourages citizens to adopt healthy lifestyles and consequently puts less pressure on health systems [5].

This idea takes us to the heart of the debate about moving healthcare from doing 'for' people to 'with' people, including them in decisions and making them accountable for their health. As part of this shift towards patient-centred care, health professionals need to focus on educating patients, their conditions and treatment options, and inviting them to participate and be involved in their health care.

The interest in health education results from the articulation of all these elements, longevity of the population that conditions a higher prevalence of chronic diseases, often disabling, related to lifestyles.

Thus, logic of the need to empower people to learn to take care of themselves throughout their lives underlies the process. The Declaration of Alma-Ata itself, resulting from the conference held by the World Health Organisation, underlines that 'People have the right and the duty to participate, individually and collectively, in the planning and execution of health care' ([6], p. 92).

In this declaration, health education is inscribed as the first priority for promoting tools to improve the health conditions of populations and meet their needs.

What happens is that, as seen previously, not all countries show changes in the way they provide care, still maintaining the characteristics of the past, despite the efforts to dialogically involve the patient in decision-making processes [4].

As we know, one of the goals of patient-centred care is to integrate the patient as a partner in healthcare. The success of this partnership depends on professionals taking patients' preferences into account. It is necessary to understand the philosophy of 'patient-centred care'. Can one have patient-centred care while excluding the patient from the process? These are two antinomic terms that cannot coexist simultaneously. The idea is to understand patients' preferences and support them in making decisions that meet those preferences [7].

As patient-centred care is a participatory process, which recognises the role of patients and their ability to assess and determine their needs, the voice of the professionals is not expected to be the privileged element for decisions on treatment/health care.

The reference to education, carried out in health facilities, aims to establish collaboration between the health team and patients in order to increase their effectiveness in relation to their needs and to support them in mobilising knowledge and skills in favour of disease management.

A brief historical review observes different trajectories related to the context of each era, which marked the way in which health systems developed healthcare.

In the 1960s and 1970s, the doctor was the authority, and the patient was a passive person, from whom no active participation in decision-making on health-related issues was expected. The process had as its structuring element a logic of domination/submission in which it was the professional who decided, without taking into account the patient's wishes and preferences, the latter conforming to the former's decisions [8].

Medical power prevailed as the dominant power, medical knowledge as central knowledge and patient knowledge as lay knowledge [9].

In response to the medical-centric model, various movements advocating the rights and interests of patients were set up, thus becoming a driving force for the defence of patients in their most diverse expressions. In the face of such movements, a new development process began from which the contours for a model transition were outlined, medical intervention has been extended to other spheres of social life and health professionals are no longer the only people involved in treating patients [10].

In the 1980s, patient education goes further by focusing on the totality of the patient's interests and the completeness of the patient's values. Several factors converged for this to happen, like the emergence of chronic diseases, the paradigm shift from the biomedical model to the holistic model in health care, the influence of ethics in health care, patients' dissatisfaction with health care, and the call for more information and participation in decisions related to their health [11].

At a political level, macro-trends were registered in the emerging model of people's information and education, the right of access to information, participation, and quality of health care, through systemic and contingent interaction in the face of the change of rethinking health care and the involvement of people who are consumers of health care. In this framework, a new ingredient is added, embodied in the application of technology to education programmes. Thus, education programmes have to be rethought and health organisations have to become organisations that listen to the future, using what can be called holistic teaching-learning systems [12].

In the 1990s, this trend continued, the paternalistic model was abandoned, and the patient became responsible for decisions regarding his/her health. The new logic led to a displacement of the central spaces of professional/patient interaction from the macrosocial, led by the health organisations, to the microsocial space, i.e., to the patient's home, because the patient's life takes place mostly outside the spaces of the

health organisations, with daily behavioural self-regulation becoming of indisputable importance in the treatment results. Thus, a model for teaching and training self-regulation behaviours based on a dialogue of equals between health professionals and patients was established [13].

In addition to the patient's involvement, the participation of their wider social network, such as spouse, children, friends, etc., should also be considered. Another relevant factor at this stage is the Internet, which has become a common space and source of information for patients.

The twenty first century, in the field of health, is characterised not only by the increase in chronic diseases but also by multiple comorbidities that complicate treatment and health costs. With this scenario in mind, a global collective project is considered important in health education, which implies the constitution of expressive solidarities between health systems and citizens, in order to act on a large scale and allow the development of integrated education programmes. Going back to Delors when he said that education, and in this particular case health education, is the treasure or the entrance to the twenty first century, it is considered that education is an essential dimension for well-being and for the development of all the person's capabilities [14].

The World Health Organisation's definition of health had already introduced these aspects by extending the concept to the psychological and social dimension of the individual in addition to the biological dimension [15].

It is for this reason that the holistic model is recognised and valued by all. Thus, it is necessary to consider the person and their needs and establish with them the actions that allow them to acquire knowledge and skills to change behaviours, with a view to a healthier lifestyle [16].

The first problem that arises is to determine whether there is currently a change of perspective and attitudes on the part of health systems/health professionals regarding patient education.

It is clear that the main figure in health education is the patient, it seems unequivocal that without autonomy there is no learning. It is important to remember that the person is the protagonist of his/her life project, the active agent of his/her educational process and state of health. Consequently, a relationship is established between illness and lifestyles in addition to other factors such as gender, family structure, environment, and socio-economic conditions [17].

The second question relates to the nature of the health education programmes promoted by nurses to kidney transplant patients. The hypothesis considered is the following: the programmes organised to inform the dialysis patient about waiting list, and to empower them about transplant process, those mobilised around other issues such as daily life management, medication, complications, rejection, and quality of life [18–24].

The object, scope and practices regarding the teaching-learning process change according to the stage the patient is at, i.e., whether the focus is on the pre-transplant or post-transplant period.

Our starting point is post-transplantation. The aim is to analyse in-depth the various education programmes developed in this field of knowledge, identifying their most visible aspects and characteristics. It is, above all, a panoramic survey of the most striking aspects of education programmes in the field of post-transplantation.

Self-determination, motivation, and free choice are important concepts in patient education. The person assumes an active role in this process, through the choices they make, and their accountability for the decisions made. In other words, he/she is free to

decide from a range of possible choices. Health professionals involved in this process should bear these aspects in mind because they are extremely important. They should identify the difficulties and constraints that the person faces on a daily basis and promote the means and tools to overcome them [25, 26].

The subjectivity, personal experience, situational, social, economic, cultural, temporal and spatial-geographic factors of the patients are also aspects to be considered by health professionals due to their influence on the teaching-learning process [27].

Health education implies the recognition and identification of the person's symbolic frames, which help professionals to understand their decisions and alert them to the need to anticipate consequences that could be disastrous for them.

In this context, we propose to make an incursion to the studies carried out in this field and dissect the key points of the various education programmes. It seems important to identify the various models and education programmes aimed at transplanted renal patients, not only to verify the differences and similarities but also to disseminate the information already produced towards the transformation of practices.

Underlining the relevance of health education in patient empowerment and self-efficacy, it is essential to define the concept, explore the education programmes implemented in the area of post-renal transplantation and identify their contributions to patient learning.

Before advancing with the proposed objectives, another aim was added: to highlight the nurses' role in this process. Having said this, we now move on to the next section.

## **2. Health education: defining a concept**

The concept of health education has changed over time. In fact, it is an expanding and evolving field. Several authors have defined the concept, and the analysis of some of these definitions allows us to verify the presence of common aspects, such as the cognitive (knowledge), and behavioural dimensions.

The role of the person and the community in advocating for their health is also introduced. Other aspects highlighted were the combination of teaching methods, the introduction of the term 'facilitating', which emphasises the role of the educator as a facilitator of behaviour change, as well as the reference to the participation of the patient in behaviour change towards the adoption of healthy behaviours [26].

What is health education:

*"All intentional activities leading to learning related to health and disease [...], producing changes in knowledge and understanding in ways of thinking. It can influence or clarify values, provide changes in beliefs and attitudes, facilitate the acquisition of skills, and also lead to changes in behaviour and lifestyles" ([26], p. 25) (1st ed.).*

Whitehead and colleagues health education is:

*"An activity that seeks to inform the individual about the nature and causes of health/disease and the individual's level of personal risk associated with their lifestyle-related behaviour. Health education seeks to motivate the individual to accept a process of behaviour change through the direct influence of their value, belief and attitude systems, where it is deemed that the individual is particularly at risk of or has already been affected by illness/disease or disability" ([28], p. 313).*

Both definitions bring together essential factors of health education, namely, to inform, motivate, change, and facilitate, aiming at the acquisition of skills and knowledge to change behaviours and lifestyles that are unhealthy for the person.

In this sense, health education is a teaching and learning process focused on wellbeing, prevention and health promotion. The main focus is on changing and improving health behaviours. It is very similar to patient education, but in this case, the focus is on assessment, diagnosis, and the individual needs of the person. In both approaches, patients take a more active and informed role in decisions related to their health. The role of health professionals is to support the patient in this journey.

This clearly refers to the World Health Organisation's definition of health education: "The process which enables populations to exercise much greater control over their health and to improve it" [15].

In this field, three generations of health education have emerged alongside socio-political changes and risk factors: the first generation, based on information and inspired by the biomedical model, the patient should follow the doctor's indications and recommendations; the second generation, centred on behaviour, takes into consideration the need to reduce high morbidity and mortality due to unhealthy lifestyles, while information is only part of the process; the third generation takes participation as the main focus and advocates alternatives for social change, given that not everything depends on the people [29].

Several models support the many perspectives of health education; however, we will only refer to some of these models because they go beyond the scope of this work.

The medical model belongs to the first generation and is characterised by the mechanistic view of medicine, which sees the body as a machine whose parts need to be repaired. It is associated with the authoritarian and paternalistic line of medicine.

The Health Beliefs Model assumes that people act if they perceive (i) they are susceptible to the disease-health condition (ii) the condition would seriously affect their lives (iii) the benefits of their action outweigh the difficulties and (iv) they can perform the action. It means that the person's behaviour is influenced by their beliefs [30].

The Diagnostic Assessment of Predisposing Factors, Reinforcers, Facilitators and Educational Causes Model is used to diagnose and plan educational practices, based on the analysis of the predisposing, facilitating, and reinforcing factors of behaviour, and should be combined with behaviour change models [31].

The Critical and Participatory Models present the proposal of social change and integrate the dialectical interaction between people and their context, promoting the participation of the person and the group [26].

The Empowerment Model seeks to develop the person's capacity to control their health status in their environment. The model seeks to develop life skills, such as decision-making and problem solving, so that the person can take control of their own life. People are encouraged to develop critical thinking and to create critical awareness. Creating critical awareness implies that the person is empowered in their beliefs, feelings, and skills. The model argues that the targets of education are people in general, health professionals and others involved in social and environmental change resulting from political pressures. The main aim is to maximise genuine and voluntary choice. The model also stresses that it does not matter what choice a person makes, as long as it is a rational choice [26].

### **3. Health education: the dialectic between professionals and patients**

Worldwide, citizens' participation in health issues has gained relevance, as has the recognition that it is important to invest in each citizen's ability to make informed decisions about their health throughout their life trajectory.

The current Health System is anchored on a patient-centred model of care, a model that focuses on patients' needs, concerns and subjective experience of illness. The first agent to play an active role is precisely the patient. The new role advocated for those seeking healthcare is that of a person who collaborates with healthcare professionals on decisions related to their health and evaluates the results achieved [27, 32].

Patient education is established in a dialectic between health professionals and the patient/caregiver. Different health professionals are involved in this process, but, in this particular case, the nurse's role stands out as particularly important. Health education and patient education are at the core of nursing practice. Nurses make a difference by helping patients and their families to maintain their health, while sharing knowledge, clarifying daily issues, and training patients/caregivers to cope with illness [33].

The teaching-learning process occurs due to an unmet need. This implies that both, professional and patient, establish a dialogue. The latter indicates to the former, implicitly or explicitly, what their learning needs, preferences and conditions are and, based on this information, both outline teaching and/or training plan that meets the outlined goals [27].

The holistic philosophy of nursing care gives nurses a crucial role in patient education. It is precisely within this framework that the key principles that characterise patient education are highlighted: involvement, knowledge, values, and preferences. This ends up objectively and subjectively delimiting the horizons of the new millennium, whose starting point is the investment in the person, promoting the development of their talents and abilities and the opportunity to practice them. The ultimate goal is to prepare the patient/caregiver for his or her return to family and society [27].

From this perspective, it is important to identify the contributions of education to patient self-efficacy.

The literature shows multiple benefits resulting from patient teaching-learning, such as the reduction of anxiety, the patient's satisfaction with health care, the reduction of the incidence of complications, and the accountability for self-care. It is a process that promotes high degrees of skills and multiple functional versatility, enhancing autonomy, creativity, and empowerment [34–36].

On the other hand, through education and training, it is possible to promote adjustment and adaptability to the new condition. Success results from the promotion of its potential benefits and positive reinforcement. It is evident that the dialectics established between the nurse and the patient/caregiver will tend to positively reinforce the learning and, consequently, promote the development of competencies, knowledge, skills and abilities. However, it is necessary to consider other requirements, such as continuity and follow-up to avoid possible paradoxical effects, especially unlearning and non-adherence to long-term care [37].

For some authors, people are always looking for an opportunity to learn cognitive (knowledge) and instrumental daily living skills that will enable them to cope with new situations, of which illness and hospitalisation fall into this situation. The



absence of health education during the patient's hospitalisation contributes to their dissatisfaction with the health system [37].

Despite the predictable coexistence of the various benefits of patient education promoted by nurses in health organisations, other factors submerge and condition the implementation of the intervention or its effectiveness, such as the shortage of nurses, work overload, organisational culture and low rates of patient compliance [38].

While it is expected in the new system that people will care more for themselves, the efficiency of teaching resources to ensure that learning is adequate and makes patients and carers competent and confident to 'care at home' has not been fully ensured [30].

In fact, the greater or lesser success of any health education process may be related to the way education programmes are designed and administered in different health institutions. Little is known about how this process is carried out by health professionals. This implies the evaluation of possible deviations, in order to try to maintain congruence between the professionals involved in this process [30].

For the author, inhomogeneity may lead to risks for the patient, such as confusion or loss of self-confidence. What seems to be clear in the literature is that this process does not occur in a similar way.

This fact led to the creation of a mnemonic to assist nurses in developing an educational program. This method helped these professionals not to forget any of the steps of the educational process and to develop the process in a systematic and standardised way. This approach proved to be effective and efficient as it increased the nurses' knowledge and behaviours in patient education [39].

The education programme starts at the beginning, but during the process, steps are omitted that can make a difference in the results obtained, which means that the suppression of any step can lead to the established objectives not being achieved. Therefore, training is considered a key element for the professionals' proficiency in this field [30].

In fact, nurses' education is a decisive factor for the success of teaching. It is not only about the positive impact of education on patient experience, but also on clinical outcomes: decreased length of hospital stay, decreased symptoms, increased levels of knowledge and improved levels of patient satisfaction [40, 41].

There is a consensus in the literature that patient education is beneficial to both parties, patients and healthcare, but for education to be effective healthcare professionals need resources and skills to provide it [38, 40].

As a personal development factor, education should be seen as an active component in disease management, which does not seek a simple transmission of knowledge, disconnected from the daily life and the patient's needs, but rather as a means to create synergies that allow professionals to accompany and respond to the patients' demands with existing capacities.

This will be achieved, in part, by adopting the same 'tailored education programme'. As the literature shows great variability in teaching programmes for groups of patients similar in terms of pathology and socio-demographic characteristics, it is difficult to reproduce them in different settings [42, 43].

The evaluation of the effectiveness and efficiency of these programmes is also made more difficult due to the heterogeneity of the programmes and the conditions of their implementation, such as the size of the sample, studies carried out in a single centre - which does not allow the generalisation of results—the variability of measurement instruments - often validated only for that study—among other factors.

Nurses face an important challenge: to create a unifying model in their organisations that support a teaching approach based on systematic, integrated, and collaborative learning. A model that allows for its replication in similar contexts.

One of the advantages of such an approach is that with the introduction of technology it is increasingly easy to share models and trends across organisations to educate the patient.

What is understood from what has been said so far is that health education is understood as an essential part to achieve health outcomes such as the empowerment of the patient/caregiver in disease management.

Nurses have a vital role in the teaching-learning process and the hospital, as an organisation committed to developing the acquisition of skills and knowledge, is a privileged space where, individually or in groups, patients and caregivers learn to effectively manage their health condition and act on the factors that influence it.

An integrated and holistic strategy, based on patients' needs, is crucial for the patient education process. In order to better understand this process and, above all, to capture in the literature the education programmes developed for renal transplant patients due to their relevance to our practice, we have analysed the various studies targeting this population and explored the different types of programmes developed around which we will reflect.

#### **4. Education of the renal transplant patient**

Studies show that the education of the transplanted patient is a concern of professionals of the different health disciplines and is considered an important element in the sense that the learning that the patient does inside the health establishments does not remain only inside these places, as it also takes place outside these contexts through the transfer of knowledge to solve day-to-day issues.

These processes of articulation/adequacy between what is taught and what is learned and applied constitute an effective mechanism of success for the different intervening parties. For the patient, it represents knowledge and mastery of new skills to deal with the challenges brought by the disease; for the health institutions it represents a reduction in the number of readmissions, complications, and treatment costs; for society, it means rapid integration of the person in family, work, relational and social life.

The above is part of the problem that health education can play in the empowerment of transplanted renal patients.

The literature recognises that renal transplantation, although the best treatment option for the chronic renal patient, can nevertheless represent a major challenge for this population [42–44].

Kidney transplantation determines a path marked by the need for immunosuppressive medication throughout life, risk of infection and complications due to immunosuppressive medication, risk of organ rejection, obesity, hypertension, diabetes, malignancy, etc. [24, 43].

In this context, the issue of autonomy becomes relevant to the extent that the patient needs to cope with many of these challenges brought about by the transplantation. The answer lies in learning skills that facilitate self-care, such as learning to recognise the signs and symptoms of rejection and the need to adhere to immunosuppressive medication [43].

Chronic disease often affects the patient's ability to perform the activities of daily life, a situation that is associated with kidney transplantation. Patients experience emotional and instrumental difficulties after transplantation, which are often a burden for them and their families [45].

Therefore, patient education is relevant in structuring the patient's day-to-day life and in the transition process. The implementation of a teaching-learning approach to strengthening the patient's ability to cope with the transformations resulting from transplantation highlights the nurses' role in preventing complications and promoting the health of this population group. The purpose of the educational process is to promote the skills and training necessary for the patient's return to normality [43, 46].

Education programmes take on different features according to the places where they take place. For instance, in Turkey, transplant units show dysfunctionalities regarding the way teaching is provided to transplanted renal patients. Patient education does not take place in the postoperative period and sometimes only a single education session is offered to the patient at discharge. Follow-up after discharge and patient's adherence to treatment are not assessed. However, nurses are in an excellent position to recommend and counsel the patients at the different stages of the transplantation process [43].

Been-Dahmen, and colleagues evaluated the effectiveness of a nurse-led support intervention for post-transplant patients. The intervention brought together several key elements, such as a holistic approach, assessment of patients' needs and preferences, shared decision-making principles and empowerment. They held four sessions: the first session focused on self-care assessment (a web-based program was created for this purpose); the second and third sessions focused on problem-solving identified by patients, in the fourth and final session, they discussed the progress made in relation to the results achieved, skills learned and other challenges that arose. They also carried out telephone follow-ups. Results showed in the experimental group, problem-solving skills, higher levels of medication adherence and higher levels of perceived quality of life. The authors concluded that the intervention was feasible and acceptable for patients and professionals. However, the small sample size did not allow predicting the potential effects of the intervention on patients' well-being and self-care behaviours [23].

The relevance of an educational programme tailored to the patient's needs is highlighted in the study by Anderson and colleagues. The programme is based on the patient-centred approach and the principles of Academic detailing. Consisting of three educational sessions on medication, rejection and healthy lifestyles. The sessions were started in the seventh week post-transplant and were conducted by nurses from the Norwegian Transplant Unit. Prior to the implementation of the programme, all nurses involved in the programme were trained to better understand the programme. All interviewees showed unanimity regarding the added value of the programme in increasing knowledge and adaptation to the new situation. For them, the patient-centred approach is highly appreciated as it addresses what is important for each person, taking into account the person's situation before starting the sessions. The existence of a programme designed according to the patients' preferences, values and needs are of great importance, as it means developing actions more focused on their uniqueness as individuals. Guided by the goal of reconciling education with personal needs, lifestyles and family context, this type of programme is particularly appreciated by patients and has positive effects on self-care [44].

Lillehagen, and colleagues present the results of their study. They explore how the new educational programme for transplant recipients is rooted in the daily routine of

the ward. The idea was to change the way patients are educated. The new programme differs from the traditional by calling for patient involvement, claiming their individuality and differentiated knowledge according to their preferences, values and needs and includes education sessions. It consisted of five individual teaching sessions delivered by a trained nurse. The topics covered were medication, rejection and healthy lifestyles. The principles of Academic Detailing underpinned the programme. Patient involvement was developed through focus groups between the research group, the healthcare professionals, and a representative from the Norwegian Transplant Patients Association. The authors concluded that the patient-centred approach, tailored education and patient involvement proved insufficient when implementing the programme. In response, patients and nurses extended this approach to the patient's world. The context in which the programme was developed presented limitations to its implementation. With all this, they concluded that the tailored patient education programme involves a more complex understanding of practice than mapping patient needs. The contrast between the virtues of the programme and its failure led the authors to argue that in implementing a programme it is important to critically analyse the effects of adaptations, their impacts, and the underlying reasons [46].

The education of transplant patients is a key nursing intervention that integrates information and training. This set of variables circulates, irrigates and fertilises the patient's knowledge, skills and abilities to deal with transplantation. The entry of the patient into the world of transplantation is a particular aspect of the universe of kidney disease, which requires change, alliances and strategies, completely changing the way patients live, work and relate to each other.

Mollazadeh, and colleagues used teach-back training (TBT) to teach kidney transplant patients to acquire self-care skills. The method was applied to kidney transplant patients attending the clinic of an Iranian hospital. The study evaluated patients with 3–12 months of transplantation. The programme consisted of five sessions. The researchers assessed patients' self-care needs using a checklist, self-monitoring, daily self-care behaviours, early detection of abnormalities, coping strategies after transplantation, and stress management. In the different sessions, patients were asked to repeat in their own words what had been taught to ensure that the information was understood. The training sessions lasted 3 months. The results showed that this teaching method (TBT) proved to be effective, with higher mean scores on self-care behaviours in the experimental group compared to the control group. Before the intervention, no statistically significant differences were found in the self-care scores of both groups. The small sample size and its implementation in a single centre do not allow generalising the results to other settings [47].

Hu, and colleagues, describe the effects of an education programme on the transition from hospital to home in a group of kidney transplant patients. The study took place at a hospital in Chengdu, China. Patients in the control group received routine care, teaching given orally on admission and during hospitalisation, and a written medical and nursing summary related to medication, diet, exercise, etc. at discharge. A telephone follow-up was performed by the nurse 1 week after discharge, and for 1 month, reminding the patient of aspects regarding outpatient follow-up and general health issues [45].

The experimental group was submitted to a care transition programme at admission and during hospitalisation. On admission, a booklet on transplant management issues was distributed and the patient received an individual teaching session based on the TBT method. Several assessments were performed, namely the risk of early admission and the patient's drug profile history as a reference point. Educational material was sent online and answers to doubts were sent via WEB-Chat.

During hospitalisation, the patient received information about the preoperative, surgery and postoperative care. He also received a new book, now dedicated to preoperative, surgery and postoperative issues. A session on post-operative care was administered, informing the patient about possible complications and adverse effects of medication. The teaching programme ended with sessions directed at self-care behaviours at home and medication management at home. Along with the individual sessions the patient received a new booklet on these issues. The online educational material and the WEB-Chat for clarification of questions were maintained. At discharge, an individualised discharge plan was developed involving the doctor, the nurse, the patient, and a family member. The post-discharge period was followed by a follow-up once a week for 1 month. The follow-up was carried out in a structured way, using a follow-up form. Patients could contact doctors and nurses via WEB-Chat whenever necessary. The teachings were performed by a registered nurse. The experimental group was better prepared for discharge than the control group and had a lower readmission rate.

Video education was another of the alternatives that some authors found to educate the patient. Authors used storytellers told by 25 patients who had been transplanted for at least 8 months and had success stories of medication adherence. Through filmed interviews, the selected group informed their peers about aspects considered essential for medication adherence. The interviews were semi-structured and guided by a script composed of questions about medication. The final product was the creation of a video based on the theory of planned behaviour and consisting of 11 storytellers acting as role models in the management of medication in daily life. Messages were left in the video to encourage patients to adhere to medication. However, the effects of this teaching method were not evaluated [48].

When aligning the methods of the previous study with the study of Mansell and colleagues, it can be seen that the use of the video to stimulate medication adherence, plus the adherence contract after kidney transplantation, was another of the teaching methods thought to ensure medication adherence in transplanted kidney patients. The effectiveness of the planned strategies was not evaluated [49].

The literature also contains a wide variety of studies on therapeutic adherence in the post-transplant period. Some have used behavioural techniques [50] others supportive interventions [51] and others medication administration aids. What is noted is the lack of a standardised approach to educating the patient or strategies facilitating medication adherence [52].

Given the nature of this work, we do not expect to find unique solutions that will reveal a singular method to teach the transplanted renal patient. The literature consulted revealed a panoply of studies addressing this topic and all of them seek to stimulate the patient towards self-care behaviours within the framework of empowerment.

On the other hand, the variety of themes is extensive, and many studies have a very particular focus. In our analysis, we sought to focus mainly on the studies with broader themes in order to allow for a broader reflection on this issue.

Patient education is undoubtedly considered crucial in the management of transplantation because it is a challenging condition for the patient. Many aspects are at stake, and all are interrelated. Knowing how and when to do it is crucial for a healthy transition and adaptation to the new condition and for the success of the transplant.

This set of reasons may support the thesis that not only patients need to be trained, but also health professionals, so that the teaching delivered to the patient is more structured and facilitates its continuity among peers [53].

While it is true that the variability of programs, as well as the issues related to the sample size, the diversity of the instruments used to assess the patients' knowledge and behaviours in addition to their reliability and validity, does not allow for the generalisation of results. In fact, Urstad, and colleagues analysed nine controlled clinical trials on the effectiveness of educational interventions in the kidney transplant population. The analysis showed that, as a rule, the interventions were not properly detailed, making replication in other settings difficult. The quality of the studies is also questioned due to the lack of transparency and inadequacies in the details of the documentation of the interventions and their effects on outcomes [54].

Another factor to take into consideration is the measurement of outcomes over time because most follow-ups do not go beyond 1 months and therefore do not guarantee their effectiveness on the timeline. Longitudinal studies are recommended to assess whether changes persist over time.

The heterogeneity of the interventions makes a comparison between interventions difficult and therefore limits the determination of the strength and quality of each intervention.

## 5. Conclusion

Throughout our analysis, we have highlighted the type of education programmes developed to teach kidney transplant patient and how these programmes are delivered in terms of structure, content, and outcomes.

After kidney transplantation, patients are heading towards a new path that requires them to adapt to the changes in their lives [55]. The continuity of the functioning of the new organ is ensured through the adherence to immunosuppressive medication, early detection of signs and symptoms of complications, organ rejection, infections, adverse effects of medication and other conditions present in their daily lives [48].

The literature shows that about 36–55% of transplant recipients do not comply with what may be the cause of organ dysfunction and risk of rejection [56].

The lack of knowledge, skills, support for self-care activities and demotivation represent contexts that are not conducive to learning and participation, thus raising the need for interventional spaces in the organisational fabric of health [56].

As highlighted by Bertram and colleagues, how can one deal with the disease if one does not know how to do it? [57].

The dialectic between patients/caregivers and health professionals is conditioned by the information/knowledge needs of the patient and the holistic view of professionals towards the former. In this context, the value of participation is visible, firstly in the identification of needs and, secondly, in the development of educational programs focused on the patient and the identified needs [27].

Due to the characteristics already mentioned in this study, nursing professionals represent a privileged group in the field of patient education. By designing and managing education programs, they teach patients in a space of negotiation between different actors (patients and caregivers), identify needs, and interact with everyone in the search for solutions and strategies to restore patients' autonomy and empowerment to properly manage their disease [54].

Education programmes are situated in a collaborative modality between the health system and the patients and their family and social system. It requires a bilateral and interactive collaboration. They are designed according to the organisational model

of care and can be based on a more traditional model or a more innovative model, such as the patient-centred model. The combination of sometimes differentiated but negotiable interests is important as a privileged form of relationship between the health system and the patient.

Our analysis has shown that education programmes vary between different countries and even within each country they often vary between institutions and within the same institution. Hence the importance of programmes being structured and trained by the professionals delivering them to avoid negative consequences for learners, such as confusion and loss of confidence [30].

Our final message refers to the fact that educating, teaching and instructing are three fundamental and crucial concepts for patient autonomy and empowerment, especially for chronic patients, such as kidney transplant patients.

Underlying this statement is education with the patient rather than for the patient. This is the most effective way to achieve the transfer of knowledge and skills essential for the patient to properly care for him/herself. It is important to remember that nursing professionals assume only the role of facilitators and mediators in the educational process and that the rest of the process belongs to the patient.

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