OPTIMISING SUCCESS AFTER A KIDNEY TRANSPLANT: A PATIENT RESOURCE

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DEDICATION

My project is dedicated to the thousands of patients with kidney disease, kidney failure, and patients who have received a kidney transplant who I have had the honour and privilege to care for during my nursing career. In addition, it is also dedicated to my fellow nursing colleagues with whom I have had the pleasure to work with throughout the years. A special note of thanks to Dr. Shannon Spenceley for enthusiastically welcoming me to my first class as an Open Studies student, thereby allowing me to begin my graduate studies journey. Also, to Katherine Haight for her guidance, encouragement, help, and for just for being an all round good human. Your supervision and check-ins were most welcomed when I needed it most. Finally, to my son, Griffin, who has watched me year after year complete my university work at the kitchen table. Griffin, your mom is finally done!

ABSTRACT

The University of Alberta Hospital in Edmonton, Alberta is the location of one of the first successful kidney transplants in Canada. Since then, thousands of patients have received a kidney transplant in the same hospital. When patients receive a kidney transplant, they require a patient education reference tool to help them sustain their kidney function and to maintain it competently and safely. A new and improved patient information resource will help patients who have received a kidney transplant optimise the success of their new kidney. This new patient resource will ensure patients have the most current and precise information they need to take care of their new functioning kidney for years to come.

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SECTION 1: INTRODUCTION

"An investment in knowledge always pays the best interest."

~Benjamin Franklin, The Way to Wealth

In Alberta, the first organ transplant was a kidney transplant, performed at the University of Alberta Hospital in Edmonton in 1967. Since that time, more than 3000 kidney transplants have been completed at the same hospital; the only hospital in Edmonton that performs kidney transplantations (Alberta Health Services, 2021). Subsequently, the outcomes and life expectancy for patients who have undergone a successful kidney transplant have significantly improved. However, the tangible transplant information resource provided to patients to help them navigate their health journey after their kidney transplant has unfortunately not evolved over the same time. This project has endeavoured to update, refresh, and streamline the kidney transplant patient resource for all kidney transplant patients going forward in order to provide them with the most up-to-date health information possible to help keep their new kidney as healthy as possible for as long as possible.

Nursing Practice Problem

In order to achieve the goal of creating a relevant, concise and user-friendly patient resource for patients that have received a kidney transplant in Edmonton, a needs assessment addressed what was required by the priority population; patients who have received a kidney transplant in Edmonton, Alberta. During clinic visits with these patients, they said they needed a patient resource that was current and the information contained in the resource had to be consistent, easy to read, and understand. They felt frustrated using the current resource as it was lengthy, old, and difficult to navigate.

Currently, the information contained in the patient resource is a collection of material from different sources, written in different styles, from different years, and displayed in a multitude of different manners. Some of this material has not taken into consideration the health literacy of the reader. While some information is indeed easy to understand, more often than not, some of the information is written through a health professional lens. The recommended readability for patient health information resources should be written for patients with a less than grade 8 education (Oliffe et al., 2019). Thus, the patient resource needed to be disassembled, stripped down, reviewed, revised, and updated in order for the patient to receive the best information possible presented in the least complicated manner. The hope is that the patient will be able to easily understand and follow the instructions and recommendations contained therein. The information resource for patients who have received a kidney transplant is one of the greatest tools they have in order to be able to help them achieve the best outcome possible for their new kidney. Thus, the patient information resource needs to be accurate, current, easy to read, and comprehend to help patients achieve this goal. Anything less would be a disappointment.

SECTION 2: LITERATURE REVIEW

A systematic search and review of the literature surrounding educational resources for kidney transplant patients was completed taking advantage of numerous databases including but not limited to CIHNAL, PubMed, Medline, and Goggle Scholar. Key word searches included patient resources, kidney transplant patients, patient education, kidney transplantation, differences in patient resources, kidney transplant Canada, patient education gaps, kidney failure, educational resources, transplant coordinator, and patient teaching. This literature search of data and research began in September of 2018 and increased in intensity in September 2020 when my final nursing project was decided upon. Within this search, common themes were discovered in regards to types of patient resources for kidney transplant patients and how these resources were to be utilized.

Historical Context & Purpose

Throughout history, the kidneys and their function have been revered. Today, this concept still holds true, especially in the kidney transplant population. In ancient Jewish culture, animal sacrifices were performed to appease God(s). The kidneys possessed a vital role in the Jewish religion; the Jewish people believed that the location of thoughts and desires was found within the kidneys (Diamandopoulos et al, 2005). In early Egyptian times, important people were mummified and all their organs were removed, except the heart and the kidneys. The heart was considered the centre of human thought, emotion, and memory. The understanding was that the kidneys were assigned the critical role of advising the heart (Greydanus & Kadochi, 2016).

A kidney is approximately the size of a fist, but it is colossal in regards to the work that it performs. Kidneys, of which we have two, are bean-shaped organs located just below the rib cage, on either side of the spine. Two healthy kidneys together filter about 180 litres of blood every 24 hours, removing wastes and extra water to make urine (Kidney Foundation of Canada, 2020). One in ten Canadians has kidney disease. (Manns et al., 2020). Chronic kidney disease is associated with increased morbidity and mortality and represents a substantial burden to the health care system in Alberta. The number of people in Alberta with chronic kidney disease is continuing to grow with close to 191 000 Albertans being affected (Armstrong et al., 2019).

Scope & Nature of the Problem

Chronic kidney disease is classified into five stages with stage five, the final stage, indicative of kidney failure. Kidney failure is defined as a person's glomerular filtration rate (GFR) being less than 15, thus requiring some sort of renal replacement therapy for survival, including kidney transplantation. (Kidney Foundation of Canada, 2020).

Kidney transplantation is the preferred treatment for patients with end-stage kidney disease because it gives patients a better quality of life and an increased survival longevity compared to dialysis (Baker & Marks, 2019). Over the past 54 years, the rate of kidney transplantation has grown in Edmonton but unfortunately, the rate has recently stalled. Currently, the number of kidney transplants performed at the University of Alberta Hospital is about 105 transplants per year (Government of Alberta, 2021).

Successful kidney transplantation restores health and improves the quality of life of patients. However, it may also generate new challenges including self-care, medication adherence, graft rejection, and infection (Mahdizadeh et al., 2020). When patients receive a kidney transplant, they remain in hospital for five to seven days, depending on their circumstances, before being discharged from the hospital. During their hospital stay at the University of Alberta Hospital, the patient is usually admitted to the multi-organ transplant unit, 3G2, and is seen by the kidney transplant discharge coordinator on or about post-op day two. The discharge coordinator provides the current patient resource to the patients while they are admitted. This resource is currently a nondescript, blue binder containing information that tries to help patients maintain a healthy and lengthy transplant course. However, some of the information currently in this binder is old, outdated, and sometimes incorrect. This out-of-date patient resource binder has to be constantly ‘fixed’ by a coordinator prior to seeing their new transplant patient in the transplant clinic after the patient has been discharged from hospital. This can be a very tedious and wearing task for the coordinator.

After discharge, patients are seen in the transplant clinic by their kidney transplant coordinator. These clinic visits focus on transplant function, patient education, checking whether patients are taking their medications as prescribed, and reviewing preventative measures for health concerns such as diabetes and cancer as these sometimes arise in this high risk population (Nieto et al., 2016). These enormously important clinic visits involve the use of the present patient information resource that is woefully lacking in current and easy to understand information. Thus, these clinic visits involve not only correcting items in the present resource, but also informing patients how and where to find more useful and impactful patient information. Not really a good use of time for the patient nor the coordinator.

Needs Assessment

A needs assessment is the process of identifying, analyzing, and prioritizing the needs of the priority population (McKenzie et al., 2017). In this situation, the priority population are the kidney transplant patients who have received the gift of a kidney transplant at the University of Alberta Hospital in Edmonton, Alberta. The needs of this population involves the requirement of having a relevant, current, and accurate patient information resource. The content of the resource needs to describe for the patient how to take care of their new kidney transplant after they have been discharged from the hospital for the subsequent months and years thereafter.

Unfortunately, this need for relevant and accurate kidney transplant patient information still exists today. The present resource has not been updated as a whole for at least 15 years. The present resource continues to be photocopied, hand-corrected, and written over in order to try to rectify the errors contained therein and to try to fill in the information gaps of the present resource.

In order to help improve the patient resource, stakeholder engagement needed to be performed with all the stakeholders involved. There were meetings set up with all the kidney transplant coordinators, management, transplant nephrologists, the social worker, dietitians, and the pharmacist. All agreed that the current patient resource for kidney transplant patients required improvement, updating, and condensing. Their feedback led to my nursing practice project ultimate goal; creating a new and improved kidney transplant patient resource for patients who have received a kidney transplant at the University of Alberta Hospital in Edmonton, Alberta.

Impact of the Problem

One of the core tasks of transplant coordinators is to support self-management in the post-transplant period and promote optimal medical and psychosocial outcomes (Beck et al., 2019). Using a patient information resource that does not contain the most pertinent information can be detrimental to the entire transplant team and more especially, to the patient. The reality of a kidney transplant patient implies living with a chronic disease. Having a chronic disease often involves a patient’s self-management of their health to optimise their own wellness. Self-management of care is defined by a patient's participation and engaging in the planning of care, exchanging knowledge, setting own goals, and the carrying out of self-management activities (Dineen-Griffin et al., 2019). This means having the patient taking responsibility for their own care and treatment; by taking an active part in managing their health condition, and reacting to symptoms. This requires patients to have accurate information about their disease and confidence to manage the chronic conditions based on their own knowledge. This kind of patient involvement in treatment and care is significant if self-management is to be successful (Neilson et al., 2019). Continued use of this worn-out resource certainly does not help to promote self-managed care and optimal health outcome for the patient. It only complicates the process even further and that can be potentially dangerous for the newly transplanted patient because a lack of clear, concise, and accurate health information can lead to adverse patient outcomes (Aljabi et al., 2018). This is certainly not the intent of the current patient resource. However, this only further emphasises that the present resource needs to be improved.

Medication non-compliance is common in kidney transplantation, emerging in the first few months after transplant, leading to poor patient outcomes (Williams et al., 2016). In the post-transplant period, self-management support interventions, such as the kidney transplant patient resource, help to promote kidney transplant patients' medication compliance and self-monitoring through information provision and repetition (Beck et al., 2019). The current patient resource does contain information regarding all medications, especially immunosuppressant medications, which are vital puzzle pieces for keeping and maintaining a successful kidney transplant. In addition, some of the medication information is outdated, not reflecting new and current immunosuppressant medications that are presently utilized in our program. This omittance of vital information only complicates the process of medication adherence even further when a patient's prescribed immunosuppressant medication is not part of the patient's transplant resource; thus, this hinders their ability to achieve independence in medication adherence.

Medication management is the most challenging component of a successful transition of a kidney transplant patient from hospital to home (Armstrong et al., 2019). Many patients are discharged with complex medication regimen instructions, highlighting the risk of medication errors that may cause readmission, adverse drug events, and a need for further health care (Kollerup et al., 2018). Immunosuppressant medication non-adherence can result in serious complications such as allograft rejection and loss (Cossart et al., 2019). This is the complete opposite outcome our program wants.

High-quality health information is needed to help patients make informed choices based on high-quality evidence and it must consider their own unique circumstances (Weeks et al., 2019). A new and improved patient information resource for kidney transplant patients in Edmonton will go a long way in achieving the goal of patients being able to make evidenced-based, informed choices in order to care for their new kidney in the best possible way.

Current Strategies

A scan of the other 12 kidney transplant centres throughout Canada shows many differences in how kidney transplant patient information is provided to the patients upon discharge from the hospital. Some centres, such as British Columbia Transplant, have a centralized kidney transplant website where patients can receive the bulk of their information even prior to transplantation where they can peruse the website at their leisure (Provincial Health Services Authority, 2021).

Other centres, such as St. Joseph's Healthcare in Hamilton, Ontario provide a link to a small, 4-page kidney transplant patient information booklet on their kidney transplant site (St. Joseph's Healthcare, 2021).

Larger centres such as the University Health Network in Toronto, Ontario which encompasses 10 hospitals, but only performs kidney transplants at the Toronto General Hospital, uses a very informative multi-layered website including a link to a video and a link to a 129 page patient information document for kidney transplant patients to use (University Health Network, 2021).

Unity Health, a Catholic health authority also based in Toronto, has a robust website including links to a multitude of videos and educational resources that can either be downloaded, read aloud, or printed for patients that have had a kidney transplant at St. Michael's Hospital. However, this website also includes information on the entire spectrum of kidney disease including the different sorts of kidney disease, types of dialysis, conservative management, and kidney transplantation (Unity Health Toronto, 2021).

Trillium Gift of Life Network (2021) based in Ontario has an all encompassing website that tries to educate people no matter what their transplanted organ is, be it kidney, heart, liver, etc. There is a multitude of links and a lot of very eye-catching graphics to help patients navigate their transplant journey, no matter the organ.

The Nova Scotia Health Authority based in Halifax, Nova Scotia is the hub of kidney transplantation for all of Atlantic Canada; Newfoundland, Prince Edward Island, New Brunswick, and Nova Scotia. This website includes a link to a 75 page document from the Queen Elizabeth II Health Science Centre in Halifax that focuses on the care of the transplant patient. Their website is also multi-focused on the entire nephrology population with links to a vast amount of educational material regarding types of dialysis, renal medications, and renal complications (Multi-Organ Transplant Program Atlantic Canada, 2017).

Finally, the kidney transplant patient resource from the Transplant Services program based out of the University of Alberta Hospital in Edmonton, Alberta was the initial spark for this project. This resource is a collection of material from different sources, written in different styles, from different years, and displayed in a multitude of different manners. It is outdated, lengthy and in dire need of a refresh.

Although more and more information is available through the internet, patients continue to ask for more written information (Sustersic, 2017). Consequently, this project focused on continuing to be a tangible resource and in paper format for now with visons of the format expanding into other platforms in years to come.

Gaps

Ineffective patient education resources can cause misunderstandings and place patients at risk for adverse events (Flanders, 2018). Schnock et al., (2017) also state that a major source of stress for patients and families is unclear, uncoordinated, or inconsistent communication and information. Patient education has generally become more complex in recent years, due to cultural diversity, decreased length of hospital stay and the increased demands on patients to self-care (Urstad et al., 2018). Therefore, providing patient education for kidney transplant patients can be challenging. This challenge is highlighted by the many forms, manners, and ways kidney transplant patients receive information from their kidney transplant teams throughout Canada.

Some of the kidney transplant programs in Canada only provide patient information via the internet with no tangible resources being provided to patients whatsoever. This can be problematic when patients have little or no computer experience or no access to the internet at all.

Despite some of its advantages, on-line information may not always be reliable. Some studies have reported the poor quality of many websites due to the dissemination of misleading, inaccurate, incomplete, and inappropriate information (Valizadeh-Haghi & Rahmatizadeh, 2018). This is certainly a concern because what patients may perceive to be factual information, may be just opinion based and not backed up by science.

There has also been a growth in online health information-seeking behavior of patients, yet the internet has remained an unregulated and non-standardized source of information, and the reliability, quality, and accessibility of the information found online remain major sources of concern (Fu et al., 2019). Furthermore, the readability of online materials remains too high for the corresponding health literacy rates among kidney transplant patients (Zhou et al., 2018). Thus, great care and a lot of caution has to be communicated with patients when they want to use the internet as their prime source of kidney transplant information. Despite increased interest and involvement from health providers, organizations, and patients to publish patient education materials online, the information is not valuable if the patient cannot understand it (Hansberry et al. 2017). There is a wide variety of information available on the internet without quality controls questioning the accuracy of the information presented. Therefore, if on-line information is the sole source of patient education that is disseminated by some kidney transplant centres in Canada, it should be clearly stressed to patients that not all the information found on the internet is indeed factual. Patients should be aware of information websites containing erroneous information and implore those patients that they should only concentrate on reputable websites, such as their own transplant centre's website, for their health information.

However, it is not all bad news when it comes to internet usage as an information resource; it just needs to be used appropriately and cautiously. With technological advances and more generations growing up using the internet, perhaps a combination of distributing patient information using a combination of both tangible sources coupled with reputable internet sources might be key going forward. (Pittman et al., 2017) state that web-based resources, if accurate and reliable, can be a viable option to supplement patient education. Thus, a balance of the two information sources for kidney transplant patients in Canada may become the norm for kidney transplant centres in the future. It is through the spread of factual and reliable information that patients can be successful in caring for their new kidney. However, for the present time, the patient resource provided to patients after undergoing a kidney transplant at the University of Alberta Hospital, in Edmonton, Alberta will continue to be a tangible information resource.

Chua & Ng, (2021) say that well-informed patients and caregivers have been reported to have reduced anxiety and increased sense of control, better coping, and an increased satisfaction with treatment. Education remains the cornerstone for successful patient care after kidney transplantation as patients need to acquire new self-care skills in order to help make their transplant successful (Murphy, 2007). A new, locally designed, up to date, evidence informed printed resource provided by Transplant Services at the University of Alberta Hospital in Edmonton, Alberta will enhance the ability of patients to self-manage their health care needs and desire for wellness following a kidney transplant at the University of Alberta Hospital. The development of patient-centred resources should be driven by patient needs (Schaffhausen et al., 2017). The ultimate need of a patient who has received a kidney transplant is to live a long life with a functioning, healthy kidney.

Future Directions

To support kidney transplant patients at the University of Alberta Hospital, a new locally designed, up to date, evidence informed printed resource was developed as a deliverable for this project. Following development and future implantation, a dedicated coordinator needs to review and update it consistently. Revisions need to be completed on a regular basis to ensure that patients are receiving the most accurate and most current information possible regarding their kidney transplant in order for them to care for it and for themselves properly. Obtaining input from patients and other kidney transplant coordinators will add to the usefulness of the patient resource (Gazarian et al., 2019). The patient resource needs to be reviewed and edited either yearly or every second year. A formal process to elicit feedback from other coordinators, transplant nephrologists, and current kidney transplant patients to further enhance this resource is needed. Conducting an evaluation of patient education resources allows for identification of improvement opportunities and enhances the patient experience with using it (Hoff & Tonne, 2017). Limited health literacy may detrimentally affect understanding and patient outcomes (Noblin & Rutherford, 2017), therefore regular literacy level reviews are needed. This collaborative and ongoing feedback process can help the resource become more user-friendly, easier to read and understand for patients, and more concise in its content in order to assist transplant coordinators in their role, thus leading to better patient outcomes.

Information provision plays a crucial role in empowering patients to confidently engage in shared decision-making around treatment (Pandya & Bajorek, 2016). As a kidney transplant coordinator, it is my job to help my patients feel comfortable in their knowledge base and to help them make informed decisions regarding their health going forward. This new patient information resource will enable my patients to do just that.

Looking ahead, the patient resource for kidney transplant patients may be able to evolve into a virtual resource. However, there are some logistical concerns regarding this modality at this time. Potentially, this resource could possibly transform into a valid and informative virtual resource. This new resource could conceivably take the shape of a stand-alone patient portal where patients can log-in to view patient educational material. It could also become a smart phone app that patients can download and be readily available to them at all times. It could also evolve into a Q-scan document that once scanned by the patient, the link would connect them to all the information contained in the new tangible kidney transplant patient resource. Furthermore, the resource could be linked to an Alberta Health Services approved kidney transplant website for patients. This website could be patient-specific and contain all the educational material and relevant information each patient needs to know regarding their transplant by logging in with a unique patient identifier such as their Alberta health card number. Of course. all of these ideas cost money but they could be investigated as future ways for kidney transplant patients in Edmonton to obtain accurate health information pertaining to the care of their kidney transplant.

SECTION 3: Project Description

Target Population & Stakeholders

The target population for this patient information resource are patients who have received a kidney transplant at the University of Alberta Hospital, in Edmonton, Alberta. However, the resource can also be readily available to patient families, health care teams, and other close relations of the patient.

The stakeholders involved in this redevelopment of the kidney transplant patient information resource include all of the kidney transplant coordinators, management, transplant nephrologists, dietitians, a pharmacist, and a social worker.

Ethics Screening

A pRoject Ethics Community Consensus Initiative (AREECCI) tool is used to help address potential gaps in the ethical framework of quality improvement, evaluation, and service projects which do not encompass research. The AREECCI tool addresses and mitigates the level of risk of a project, types of ethical risks, and flushes out if there is a need for a formal type of ethics review. After completing the ARECCI, it deemed my project to be quality improvement in nature. It also scored an ethics screening score of 0, thus indicating minimal risk to the participants in this project. The tool helped emphasise that my project did not require any need for review by a second opinion reviewer.

Theoretical Framework: ADDIE Model

High-quality health information needs to help patients make informed choices based on good quality evidence and in consideration of their own unique circumstances (Weeks et al., 2019). The model chosen to guide development of high quality health information such as the kidney transplant patient information resource is an instructional design model called the ADDIE model. ADDIE stands for Analysis, Design, Development, Implementation and Evaluation (Ab Latif & Mat Nor, 2020). This type of instructional design model can help provide guidelines or frameworks to organize and structure educational activities such as patient teaching.

Figure 1: ADDIE design model. The Perfect Meeting, (2021)

This design model was the best fit for the project as it logically follows a step-by-step process to help ensure the project follows in a logical order with a beginning (Analysis, Design, and Development), middle (Implementation), and end (Evaluation). The ADDIE model is reminiscent of the well-known nursing process including assessing, diagnosing, planning, implementing, and the evaluation steps. (Rajabpoor et al., 2018) The nursing process is habitual for seasoned transplant coordinators due to many years of nursing; thus, this makes the ADDIE model more applicable to this nursing project. Additionally, ADDIE is a cycle; this means it is flexible enough to allow anyone to revisit a step and refine it (Davis, 2013).

Phase one is analysis of the ADDIE model and began with stakeholder consultations at the outset of the project. Analysis involves the designer identifying and considering the learning problem, the learning environment, the goals and objectives, the audience's needs, existing knowledge, delivery options, the timeline for the project, additional relevant information, and any constraints (Reinbold, 2013). The identified problem is the outdated patient information resource, and the environment is the kidney transplant program in Edmonton. The overall goal is to keep and maintain optimum transplant kidney function and the objective is to provide essential information for patients to maintain optimal kidney transplant function. The delivery method is the print based tangible resource itself, and the timeline to complete this project was through the spring and summer of 2021.

Phase two is the design phase and consists of specifying learning objectives, with decisions made concerning the look and feel, user interface, and content (Reinbold, 2013). These decisions were all made based on stakeholder consultation. The consultations revealed that the resource needed to take into consideration the literacy level of the reader. It also suggested the use of a consistent design of each section with the inclusion of images where possible to appeal to the different learning styles and learner needs. The resource also required a sequential flow of content, and it is meant to be utilised as the primary teaching tool for the kidney transplant coordinators.

Phase three is the development phase and involves creating or producing the educational and instructional materials. All of this was done with the patient in mind in order to help make the information easy to read and understand.

Phase four is the implementation phase and consists of putting the plan into action and developing a training procedure (Reinbold, 2013). In this case, the scope of the project was to develop a new patient information resource but it is not yet implemented with patients. However, the resource was pre-tested with all the stakeholders which is an essential step to complete before implementation

Phase five is evaluation. Formative evaluation evaluates the effectiveness of the materials which provides data concerning what to revise and improve, and is present during each stage of the ADDIE model. McKenzie et al., (2017) state that a formative evaluation is how the quality of program components is measured and improved prior to or during implementation. In this case, my feedback questionnaire was utilized as the formative evaluation tool. All stakeholders were provided the questionnaire after reading the new patient information resource and they were asked to evaluate it using mainly quantitative questions. However, a final qualitative question was asked on the evaluation tool to give stakeholders an opportunity to respond organically and freely in reference to their feelings about the new patient information resource.

The results of the program evaluation can be fed back, closing the loop, facilitating further refining of the resource. It is also evaluated through a summation evaluation which compares outcomes of the process to the stated goals (Reinbold, 2013). Revisions can be made during the evaluation stage, if necessary. The evaluation results can be then fed back again, thus further refining the resource. Continual feedback is critical to improving the ADDIE model during its use (Reinbold, 2013).In this case, by combining the results of the project evaluation tool, the responses were taken into consideration and the new patient information resource was adjusted again, thereby honing its content. This feedback loop helps to make the resource as fine-tuned as possible every time it is evaluated.

This cyclic type of model, such as the ADDIE model, is vital in order for the project to be reviewed, refreshed, and revised at regular intervals. The ADDIE model was a powerful tool to track the development of creating the new post-kidney transplant patient information resource and it helped the project follow in an orderly and logical manner. Nurses' strategies regarding patient education should be informed by the best available research evidence. It is my hope that by using the ADDIE model as my project design framework, I achieved the most structured and logical educational resource developed using this instructional design model. The ADDIE model provides practitioners a flexible, systematic, and versatile approach for the development of a resource (Patel et al., 2018). This aligns with best practice in producing high quality health information and relevant patient teaching tool for patients who have received a kidney transplant at the University of Alberta Hospital in Edmonton.

Project Plan & Format

Following a thorough review of the existing patient resource binder provided by Transplant Services at the University of Alberta Hospital in Edmonton and collaborations with all stakeholders, it was determined that some pages of the current resource are applicable to all patients while some patients need a lot less of that information, depending on their health circumstances. My project is not intended to create a new resource or be tailored to each individual transplant patient, rather the existing resource was revised, updated, reformatted for easy reading so information contained in the resource was streamlined to reflect the essential information required for all patients but not to overwhelm them with extraneous details. According to Ramondt & Ramirez (2019), information overload can potentially prevent patients from reading educational materials for self-care management. Thus, the amount of information contained in the resource was taken into careful consideration.

Education and literacy is one of the 12 determinants of health in Canada (Government of Canada, 2021). A patient's level of education is an important determinant of health that influences their understanding of health information pertinent to their own condition (Abraham et al. 2020). This speaks to the need that the patient resource had to be written in a manner that they can understand. Limited health literacy may detrimentally affect understanding and patient outcomes (Noblin & Rutherford, 2017). Currently, the patient resource does not take into consideration the education of the audience reading it. The Canadian Medical Protective Association (2018) suggests that health messages in handouts and other medical materials should be written at or below a grade six level. The Flesch-Kincaid grade level index determines how difficult reading a passage in the English language is to understand (Kher et al., 2017). It has also been widely used in assessing the readability of patient focused websites and educational material (Azur et al., 2017). The new patient resource takes the patient's education level into important consideration. Thus, according to the Flesch-Kincaid grade level index, the new patient resource is written at a grade seven level, which is admirable considering it contains a lot of information concerning immunosuppressant medications.

The resource needs to be informative and current but also concise and clear. (Sustersic et al., 2017). As the resource was updated and reformatted, stakeholders were involved in every step. Ustad et al., (2018) say that kidney transplant coordinators play an essential role in helping to implement new patient education information for kidney transplant patients. They are all knowledge experts in their own individual roles and thus were imperative to the development of this resource. All of the knowledge experts were questioned and had opportunity to include, clarify, and exclude any information from the resource they deemed to be important or not. This process was invaluable to the evolution of the new patient information resource.

The formatting of the patient information resource for kidney transplant patients begins with the very first page; it contains all the correct contact information of all the members of the kidney transplant team. This contact information contains all the telephone numbers of the kidney transplant office, the University of Alberta Hospital telephone operator, and all the other team members such as the social worker, dietitians, pharmacy, and the pharmacist. The contact information for team members are enormously crucial to kidney transplant patients because they are full of important knowledge that can aid and educate the kidney transplant patient when needed.

The second section is perhaps the most important of all sections; it is about medications. This section contains a list of immunosuppressant medications, images to demonstrate what they look like, their role in transplantation, and the reason why these medications are vitally important to the transplant patient. It is of the utmost importance that kidney transplant patients know their medications, how much they take them, and why they take them. The effectiveness of a process that allows patients to identify medication understanding and adherence helps to reduce readmissions (Covert et al., 2016). This resource with the accompanying pictures of all the immunosuppressant medications will most likely lead to better adherence to medications and thus lowering readmission rates to hospital. Accurate patient knowledge of the what, when, and why of their medications will assist patients in the correct administration of them, thus leading to better transplant kidney health; the decisive goal for all kidney transplant patients.

The third section of the kidney transplant patient resource contains information relating to possible kidney transplant complications such as kidney rejection, infections, cancer susceptibility, diabetes, and bone disease. Sunscreen is addressed in this section as it helps to prevent skin cancers which is a complication of patients' immunosuppression medications (Kearney et al. 2017). It also contains information regarding the importance of calcium in regards to bone health since the kidney transplant population, as potentially lifelong steroid users, tend to have an increased risk of developing low bone density (Thongprayoon et al., 2019). All these difficulties and associated prevention strategies are essential to include in the revised patient resource as some kidney transplant patients, not all, do develop some of these complications.

The fourth section of the patient resource addresses how to live safely after a kidney transplant. Baker et al., (2017) emphasizes the importance of hand washing, travelling safely, safe sex, food and water safety, and animal and pet safety which are covered in this section. For example, patients who once had to attend a stringent dialysis schedule are now free to travel. Kidney transplant patients are encouraged to ask for a travel letter from the office before travelling as it lists all their medications and the contact information to the kidney transplant office in case it is needed during their travels. Sexual health can be very significant to patients. The information in the resource discusses when to resume sexual activity, birth control, and pregnancy (Baker et al., 2017).

Water intake is also an important tool to help maintain the health of the transplanted kidney. To help ensure the proper functioning and longevity of a kidney transplant, staying well-hydrated is critical (Gorden et al., 2009). Adequate water intake can be especially challenging when a patient was previously undergoing hemodialysis and was prescribed daily fluid restriction of one litre or less.

The fifth section of the kidney transplant patient resource talks about the importance of routine dental check-ups and addresses the question whether a patient requires prophylactic antibiotics prior to some dental procedures or not. Most transplant patients do not require prophylactic antibiotics but this section addresses this question in detail (College of Dental Hygienists of Ontario, 2016).

The sixth section is significant and can be emotional for some patients as well. Colarusso, (2006) speaks to the fact that writing to the donor family is a powerful instrument to express thanks and appreciation for their new kidney. The education resource provides essential information to patients on how to write to their donor family and how to explain how the kidney transplant has changed their life. All communication is anonymous and the correspondence is relayed to the Human Organ Procurement and Exchange Program (HOPE) (Alberta Health Services, 2021). HOPE then passes on the letter/card on to the donor families.

Finally, the last section of the patient resource provides patients links to reputable and factual websites regarding kidney transplantation. Links to sites such as The Kidney Foundation of Canada and Alberta Health Services can aid patients in exploring more information regarding their new transplanted kidney on their own time.

Project Evaluation & Results

After developing the new patient information resource, the need for a formal formative evaluation of the new resource format, content and overall utility of the resource was evidant. An evaluation tool using a Likert scale was supplied to the kidney transplant coordinators and management to evaluate the new resource as compared to the one in use at present. All 10 evaluation tools were returned completed and the results were overwhelmingly positive. All evaluators either agreed or strongly agreed that the new patient resource was a huge step forward in the right direction of updating the present patient resource. All nine close-ended question results were positive, and no evaluator disagreed with any of the content in the new draft patient resource.

The first question if the new resource was reflective of the information we coordinators provide to our patients on a regular basis. Everyone overwhelming agreed that the resource did just that.

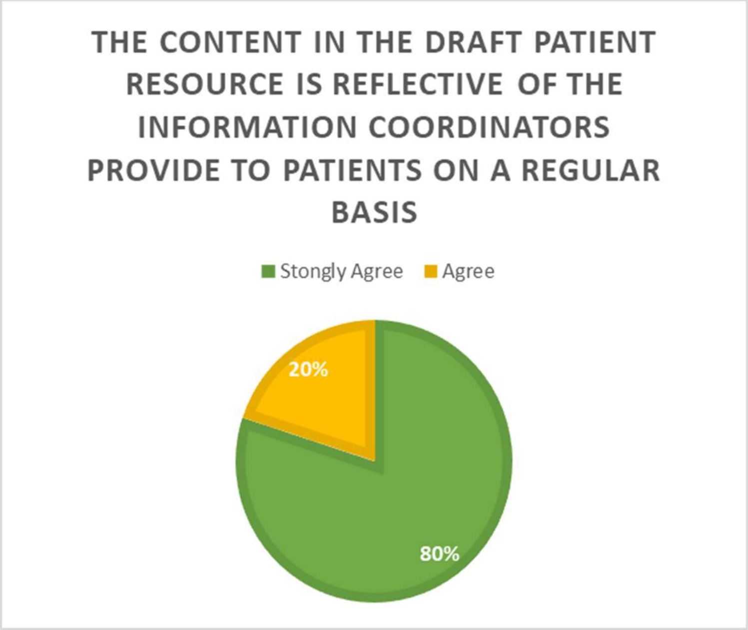


Figure 2: Evaluation Question 1

The second and third questions asked if the new resource was clear and concise. It also asked if the resource was written in language that our patients could understand. Again, the responses were positive and confirmed that the resource was clear and succinct. It also confirmed that the language of the new resource was written with the patient’s ability to understand all of its content in mind.

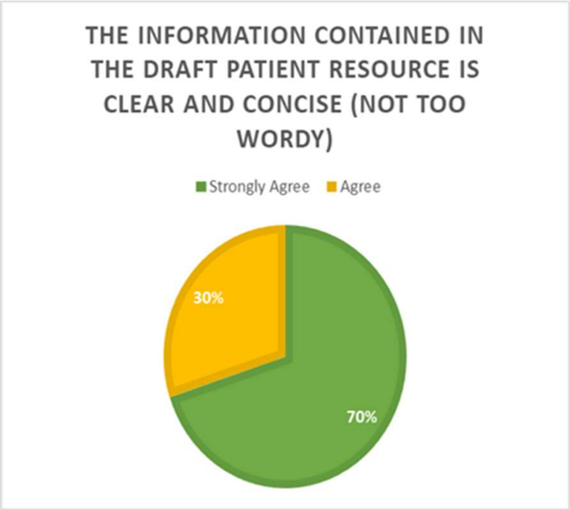


Figure 3: Evaluation Question 2

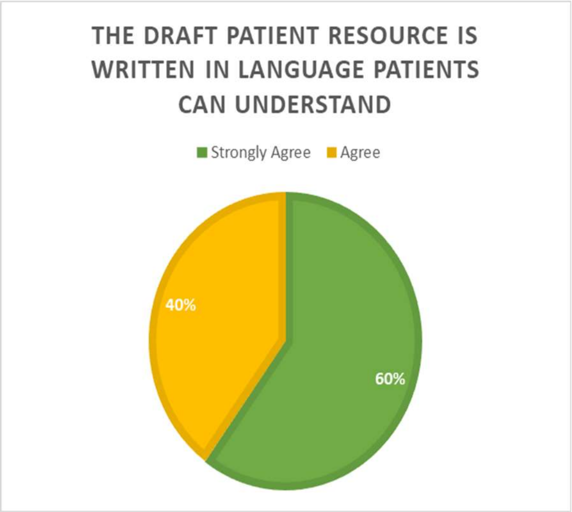


Figure 4: Evaluation Question 3

The next four questions on the evaluation asked about the content contained with specific questions on sections concerning medications, complications of kidney transplantation, safe living after a kidney transplant, and additional patient resources. Once more, the results were positive with Figures 5 to Figure 8 illustrating the responses.

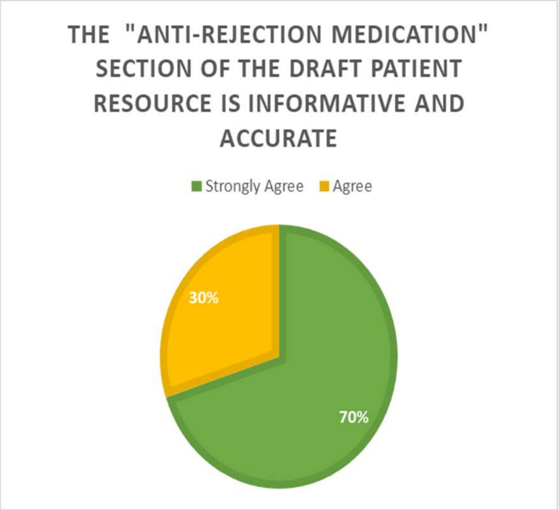


Figure 5: Evaluation Question 4

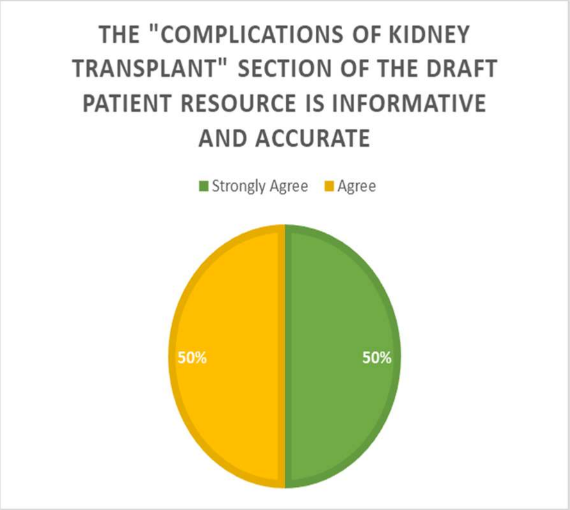


Figure 6: Evaluation Question 5

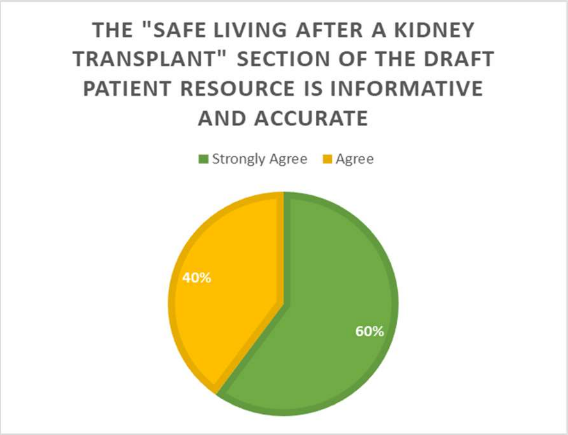


Figure 7: Evaluation Question 6

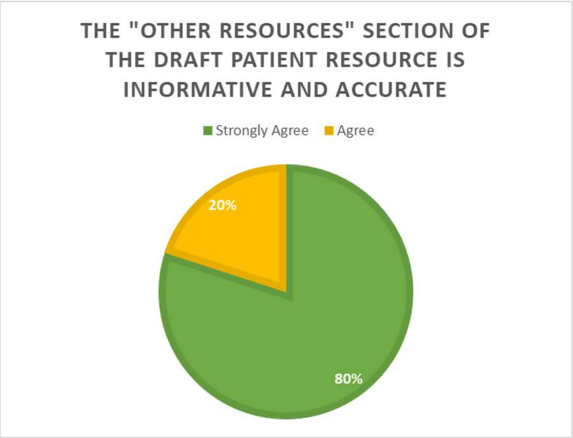
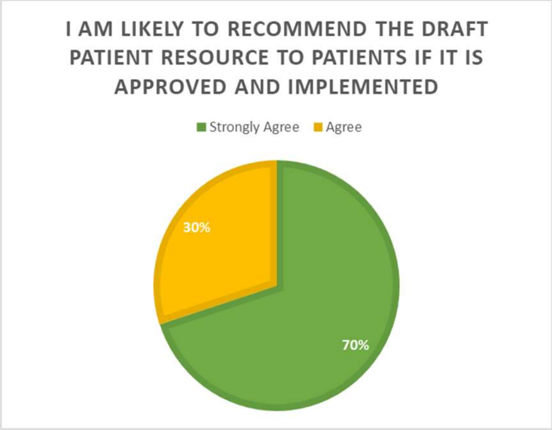


Figure 8: Evaluation Question 7

Questions 8 and 9 on the evaluation tool asked if the new patient resource was likely to be recommended for use and if the resource was satisfactory. For these two questions, 70% of the evaluators responded that they strongly agreed. Thus, providing more evidence that the new patient resource meets stakeholder needs and should be recommended for use with patients.



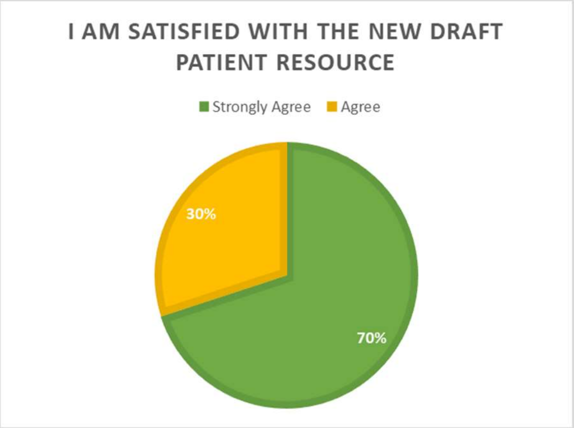


Figure 9: Evaluation Question 8

Figure 10: Evaluation Question 9

Finally, at the end of the evaluation tool, the open-ended question of "What improvements would you recommend to improve the draft patient resource?" led to some welcomed recommendations, minor tweaks to the revised resource, and some unsolicited positive comments. The following are suggestions by all the other transplant coordinators and management to improve the revised resource:

"Change the wording of some items."

"Add information regarding return to work/school/regular activities."

"Add more information regarding why compliance is so important."

"Include the importance of having a family doctor for non-kidney related issues."

"Add information on when/why/how of a kidney biopsy."

The following are general comments regarding the revised resource made by the same respondents:

"Well done!"

"Looks good!"

"This patient information draft is excellent."

“Very well done.”

“Great job!”

“Amazing and more user friendly!”

“This change is long overdue.”

When well written and used at the appropriate time, patient information resources can improve patients' knowledge and satisfaction whatever the clinical situation and induce better adherence to treatment, diet, and lifestyle advice (Sustersic, 2017). I believe my project has achieved this goal.

SECTION 4: REFLECTION

This project has been a challenging undertaking. It has been time consuming, thought provoking, tedious, demanding, and formidable. However, through it all I kept my patients both past and present in the forefront of my mind in order to hopefully transform a patient resource into one that is both educational and easy to understand. Upon reflection of the project development process, I had many initial ideas concerning a project relating to my current role as a kidney transplant coordinator when the concept of a project was first proposed. However, due the time constraints of working with a semestered timeline, the project of developing a new patient resource for patients that have had a kidney transplant was deemed to be the best fit and would have the most impact on my patients in my nursing practice role.

The project used a systematic and orderly approach in developing a resource to help address a nursing practice problem. I integrated this evidence-based knowledge to plan, implement, and evaluate this very credible and very much needed project of an updated and revised patient information resource for kidney transplant patients. The instructional design theoretical framework of the ADDIE model reminded me of the nursing process that we have all learned throughout our initial nursing education. Thus, it was not complicated for me to evolve and grow my project. Consequently, I believe I successfully updated and revised the patient resource for the kidney transplant patient population in Edmonton and that it will be useful and valuable for years to come.

The continued use of old, outdated, and sometimes inaccurate health information in 2021 is inappropriate and potentially dangerous. According to the Health Professions' Act (2021), based on the ethic of caring and the goals and circumstances of those receiving nursing services, registered nurses apply nursing knowledge, skill, and judgment to assist individuals to achieve their optimal physical, emotional, mental, and spiritual health. The Act goes on to say that registered nurses teach, counsel and advocate to enhance health and well-being, as well as coordinate, supervise, monitor and evaluate the provision of health services. This patient resource validates all of these factors. The updated and revised resource will help patients achieve their optimal health by applying nursing knowledge and teaching patients about how to keep themselves healthy after a kidney transplant. Furthermore, the Canadian Nurses Association Code of Ethics (2017), states that registered nurses are responsible to provide safe, competent, and ethical care to patients. This updated and revised patient resource is a useful, beneficial, and valuable tool to help achieve just that.

I believe I achieved my goal of creating an information resource for patients who have received a kidney transplant at the University of Alberta Hospital, in Edmonton, Alberta. This information resource is one of the most important tools patients have in order to help them achieve the best outcome possible for their new kidney. Hence, the patient resource needed to be accurate, current, and easy to read, and comprehend to help patients try to achieve their best kidney function. The updated and revised resource is concise, user-friendly, and factual as evidenced by the formative evaluation completed for this project. Thus, it can be used by transplant coordinators in the future when promoting optimal kidney health for the kidney transplant patient.

Lessons Learned

Throughout this project development process, I discovered that it is much easier to write about what one has a passion for rather than writing about what one does not have an affinity for. As I have worked my entire nursing career with patients who have kidney disease, kidney failure, and who have received a kidney transplant, it was not an arduous task to write about what I know. However, throughout this project evolution, there were times when this was not the case. Writing about the ‘how’ of the project was a laborious chore. I knew what I wanted to achieve but trying to formulate a process of how I was going to achieve it and writing it down on paper was not easy to do. However, the ‘who’, ‘what’, ‘where’, and ‘why’ of the project was much easier to write about. Working as a kidney transplant coordinator for many years, I knew the need was there for a new and improved patient resource, I just didn’t know the actual process of how I was going to create it or how I was going to articulate it .

With regards to project development, I knew what I wanted to do and what information I was going to use to try to develop my project. However, I sometimes lacked in routinely sharing this important information with my instructor without prompting. I have never been the best communicator in all aspects of my life and I usually blame my lack of communication on my independent and willful nature. However, according to the course syllabus, I was obliged to communicate to different groups using a plethora of means and I think I achieved this goal. I did effectively communicate with stakeholders in the nursing practice setting using both formal and informal communication methods regarding my project and the evaluation thereof. I believe my project deliverable to be well written, composed for a specific target audience, and it took into consideration the appropriateness of the reader, such as literacy level. I believe I also exemplified keen verbal communication skills, as I had to present my project and the results of its stakeholder evaluation to an academic audience of my peers, instructor, along with invited guests.

The nursing care of kidney transplant patients is challenging, complex and rewarding (Murphy, 2007). One of the most important lessons I have learned throughout this entire process is that the updated and revised kidney transplant patient resource has the potential to be a crucial asset for the patients in our program. From my many years of working as a kidney transplant coordinator, and working with patients with kidney disease in general, I knew that an updated and revised patient information resource was desperately needed for the program, but I could not accurately express its necessity. However, while creating the patient resource, and the results gathered with the formative evaluation tool that all stakeholders completed, this need was echoed unreservedly. The evaluations for this updated and revised patient resource developed for those who received a kidney transplant at the University of Alberta Hospital in Edmonton, Alberta overwhelmingly validated this long-desired change. I am looking forward to undoubtedly having this patient resource adopted as the new and decisive patient information tool for kidney transplant patients in our program. This resource will be key in helping kidney transplant patients achieve their optimal kidney health.

Throughout this project development timeline, I have also learned that it is a multi-step process and there is always a need to revise a set-in-stone plan. No matter how complete you think your plan may be, unfortunately, there may be times when it may need to be revised, re-evaluated, transformed and changed again, and again, and again. There were weekly writing targets that I wanted to hit. However, it was frustrating at times when what I thought I wrote was acceptable and suitable for inclusion in my paper, sometimes was not and needed reviewing.

However, in looking back through this entire process, it has most certainly improved my writing skills, it has increased my confidence in seeking feedback on my written work, and it has helped me develop a deeper understanding of the project evolution process. When I began this project, I really didn’t know all the steps, effort, and hard work required in order to produce a worthwhile project. Nevertheless, I have now come to appreciate the effort and care it takes to produce a quality project.

Personal Insights

This project development process confirmed with me that you could not please everyone, no matter how hard you try. One cannot revise a resource that captures every single element a kidney transplant patient needs to know and understand. The resource is ultimately a guide that tries to touch on the important key points that kidney transplant patients should know. The resource is only one piece of the patient education puzzle; it is in addition to the numerous clinic visits with kidney transplant coordinators, appointments with transplant nephrologists, and visits with the other subject matter experts such as the dietitian and pharmacist. The updated and revised kidney transplant patient resource is an educational tool that enhances and compliments all of these other important and necessary patient encounters.

Developing this project also substantiated my understanding that patients with kidney disease, kidney failure, and patients who have received a kidney transplant are the bravest and most resilient patients with whom I have ever had the honour to work with. These patients are strong-willed, insightful, and deal with health challenges fervently and with grace on a daily basis. Caring for them has been the mainstay of my nursing career for close to 30 years and I am grateful for that.

Finally, working full-time, going to school part-time, being a single mom, completing all the required course work of a Master of Nursing degree, and accomplishing some of it through the COVID-19 pandemic, takes resolve, dedication, resilience, and tenacity. I spent many evenings and countless weekends sitting at the kitchen table working on assignments and other schoolwork either after finishing a busy day at work, after coming home from my son’s soccer or rugby games, or after running errands and completing household chores on weekends. I also had to excuse myself from some social events and plans in order to complete my university requirements on time. All of this was difficult to do, but I am confident and optimistic that it was all worth it. Hopefully, I also effectively demonstrated to my son throughout this process that hard work does indeed pay off.

Conclusion

Neither the early Jewish people nor the ancient Egyptians considered the kidneys to be excretory organs. The functionless and well-hidden kidneys were given a spiritual role of vigour, strength, emotions, and wisdom (Eknoyan, 2005). It is not necessary to travel back to ancient times to know that the kidneys are powerful, valued, and respected structures. However, it is for certain that people with normal kidney function do not think about their kidneys or the extraordinary work they do on a minute-by-minute basis. Nevertheless, it is also certain that for patients who have received a kidney transplant, their new kidney is at the forefront of their minds every single day. The newly updated and revised kidney transplant patient information resource will be a vital tool to help enhance kidney health for kidney transplant patients going forward. Essentially, by utilising this relevant and purposeful patient resource can their success be optimised.

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APPENDIX A: PATIENT RESOURCE

Kidney Transplant Patient Resource: Optimising Success after a Kidney Transplant

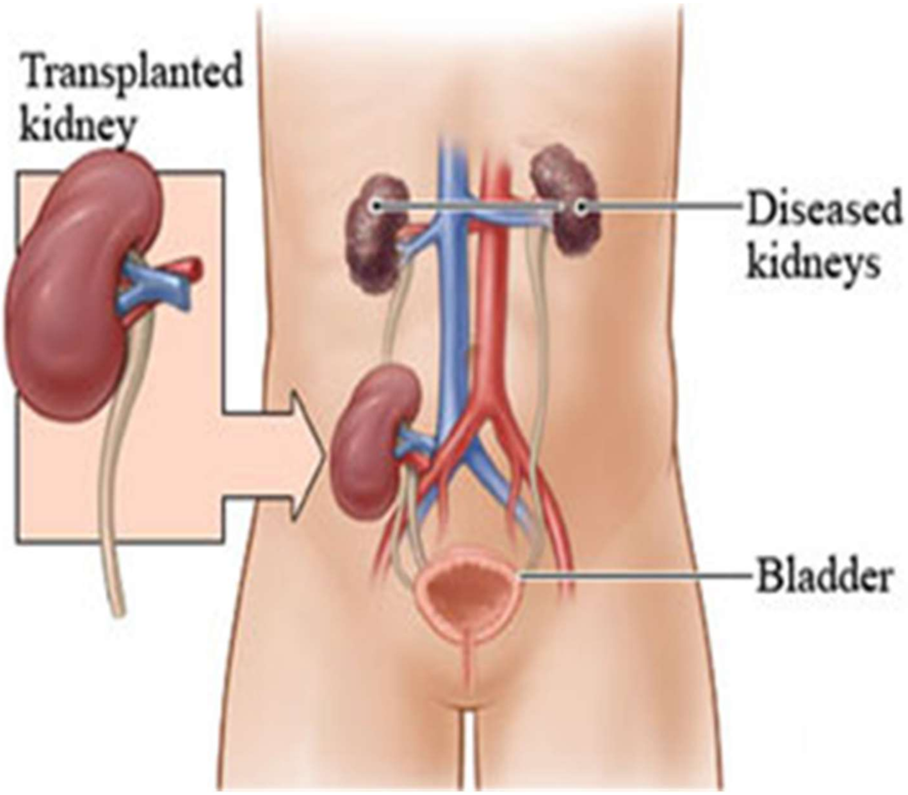

Figure 1. Kidney Transplant. Adapted from NephCure Kidney International, Inc. (2021)

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Important Kidney Transplant Phone Numbers

Kidney Transplant Office (Press #1, #2, or #3)	**780-407-8099**
Toll Free (for long-distance patients)	**1-866-407-8099**
University of Alberta Hospital Operator (To contact the kidney transplant doctor after hours)	**780-407-8822**
Inpatient Transplant Unit-3G2	**780-407-8302**

My doctor is: ___________________

My coordinator is: ___________________

Rexall Pharmacy	**780-407-6990**
Pharmacist	**780-407-1658**

My pharmacist is: __________________

Social Worker	**780-407-1285**

My social worker is: __________________

Dietitian	**780-407-1116**
Dietitian	**780-407-3348**

My dietitian is: __________________

Congratulations, you have received a kidney transplant!

You must be wondering, “Now what?”. Kidney transplantation is the ideal choice of treatment for most patients with chronic renal failure. Successful transplantation offers patients a better quality of life without the need for dialysis. As well as feeling better, most patients enjoy greater freedom, including work, and travel. The flowing pages are a patient resource to help you and your new kidney function to the best of its ability for as long as possible. It will help explain to you the importance of your anti-rejection medications, food safety, infection, rejection, other possible complications, etc.

Please familiarise yourself with the information contained in the pages and contact your transplant team with any questions regarding this resource.

Figure 2. Organ donor awareness ribbon, The Kidney Foundation of Canada (2021).

Anti-Rejection Medications

Brand Name: Advagraf®

Generic name: tacrolimus extended release

Figure 3. Advagraf capsules, Astellas (2021)

What is it?

Advagraf is an immunosuppressive drug which helps prevent you from rejecting your transplanted kidney. You will probably have to take it for the rest of your life. You may be taking other medications along with Advagraf to prevent rejection.

How should it be taken?

Advagraf is an extended-release capsule specially designed to be taken only once a day. It works best if taken in the morning, and at the same time every day. You may take it either with or without food. Do not open, cut, crush, or chew the capsule. Advagraf the extended-release tacrolimus, should not be confused with Prograf, the regular release tacrolimus. They cannot be interchanged.

Dose changes:

For the first few months after your transplant, your dose of Advagraf will change often. Dose changes are based on the amount of Advagraf in your blood. The dose will vary among different people. Your transplant coordinator/doctor will tell you what dose you should take.

When you go to the lab for blood tests, DO NOT take your Advagraf® dose that morning. Bring it with you and take it after your blood is drawn.

If you miss a dose:

Take it as soon as you remember, as long as it is within 14 hours of your usual time. If you remember more than 14 hours later, skip the missed dose and carry on the next day as usual. DO NOT double the dose. It is important to remember to take this medication regularly and on time to that is can work most effectively for you. Missing too many doses can lead to rejection.

If you are sick:

If you take your Advagraf and vomit soon after, you should take the Advagraf again only if you saw the pills in your emesis.

How should Advagraf be stored?

Keep your medications away from extremes of temperature (very hot or very cold). Keep them at room temperature, away from children. Do not keep medication in your vehicle. When you travel, take your medication in a carry-on bag and keep it with you at all times.

What are the side effects?

Advagraf can cause nausea, stomach discomfort, diarrhea, constipation, headache, tremors, difficulty sleeping, flushing, or tingling in your hands and feet. All anti-rejection medications can increase your risk for infections and certain types of cancers, especially skin cancer. Many of these side effects can also occur when your blood levels of Advagraf are too high, which is why it is important for your kidney transplant team to continue to monitor your blood levels.

If you have questions regarding your medication, please contact your coordinator or your pharmacist.

Brand Name: Prograf®

Generic Name: tacrolimus regular release

5mg 1mg 0.5mg

Figure 4. Prograf capsules, Astellas, (2021)

What is it?

Prograf is a very potent immunosuppressive drug, which helps prevent your body from rejecting your transplanted kidney. You may be taking other medications along with Prograf to prevent rejection, such as prednisone, mycophenolate or sirolimus.

How should it be taken?

Prograf is taken twice a day, every 12 hours. You may take it either with or without food, as long as you take it the same way every day.

Prograf should not be confused with the Advagraf brand of tacrolimus. They cannot be interchanged.

DO NOT take Prograf with grapefruit, grapefruit juice or pomegranates. This may cause the amount of Prograf in your blood to increase. Orange juice has no effect and is safe to drink.

Dose changes:

For the first few months after your transplant, your dose of Prograf may change often. Dose changes are based on the amount of Prograf in your blood. The dose will vary among different people. Your transplant team will tell you what dose you should take. Take this medication exactly the way you are told by your transplant team.

When you come to the clinic for blood tests, DO NOT take your Prograf® dose that morning. Bring it with you and take it after your blood is drawn.

If you miss a dose:

Take it as soon as you remember, as long as it is within 6 hours of your usual time. If you remember more than 6 hours later, skip the missed dose and take your next dose as scheduled. NEVER double the dose. It is important to remember to take this medication regularly and on time so that it can work most effectively for you. Missing too many doses can lead to rejection.

If you are sick:

If you vomit within 30 minutes of taking Prograf, you should take it again. If you vomit more than 30 minutes after taking your dose, it is not necessary to take another dose. If you have diarrhea for several days or continue to vomit, you should contact your transplant team.

How should Prograf be stored?

Keep your medications away from extremes of temperature (very hot or very cold). Keep them at room temperature, away from children. Do not keep medication in your vehicle. When you travel, take your medication in a carry-on bag and keep it with you at all times.

What are the side effects?

Nausea, stomach discomfort, diarrhea, constipation, headache, tremors, difficulty sleeping, flushing or tingling in hands and feet, and high blood pressure are all potential side effects of Prograf.

If you have questions regarding your medication, please contact your coordinator or your pharmacist.

Brand Name: Myfortic®

Generic Name: mycophenolic acid

180mg

Figure 5. Myfortic tablet, Novartis (2021)

What is it?

Mycophenolate sodium is an immunosuppressive drug used to prevent rejection in patients who have had a kidney transplant. You will need to take other anti-rejection medications, such as prednisone and tacrolimus, along with mycophenolate.

How should it be taken?

Mycophenolate is taken twice daily, every 12 hours. It works best when taken on an empty stomach. Do not crush the enteric coated tablets. Keep the tablets in the blister pack foil until you are ready to take them. Mycophenolate should be stored at room temperature. Keep this medication away from children.

If you miss a dose:

Take the missed dose as soon as you remember. If it is almost time for your next dose, skip the missed dose. Do not double up the next dose.

What side effects can this medicine cause? What can I do about them?

You may experience nausea or vomiting, diarrhea or constipation, heartburn, acne, tremors, or headache. Heartburn and stomach upset is quite common. If this happens to you, you can try taking this medication with food.

Cautions/Other advice:

If you are pregnant or plan to become pregnant, you must inform your physician. Mycophenolate may be harmful to the unborn baby. Breastfeeding is not advised as mycophenolate may pass into the breast milk and harm your baby.

If you have questions regarding your medication, please contact your coordinator or your pharmacist.

Brand Name: CellCept®

Generic Name: mycophenolate mofetil (MMF)

250mg

Figure 6. Cellcept capsule, Roche (2021)

What is it?

CellCept is an immunosuppressive drug used to prevent rejection in patients who have had a kidney transplant. You will need to take other anti-rejection medications, such as prednisone and tacrolimus, along with CellCept.

How should it be taken?

CellCept is taken twice daily, every 12 hours. Keep the tablets in the blister pack foil until you are ready to take them. Do not open or chew the capsules. CellCept should be stored at room temperature. Keep this medication away from children.

If you miss a dose:

Take the missed dose as soon as you remember if it is within 6 hours of the time it was due. If it is beyond the 6-hour mark, skip the missed dose and take your next dose as scheduled. Do not double up the next dose.

How should CellCept® be stored?

Keep your medications away from extremes of temperature (very hot or very cold). Keep them at room temperature, away from children. Do not keep medication in your vehicle. When you travel, take your medication in a carry-on bag and keep it with you at all times.

What are the side effects? How can I manage them?

You may experience nausea or vomiting, diarrhea or constipation, heartburn, acne, tremors, or headache. Heartburn and stomach upset is quite common. If this happens to you, you can try taking this medication with food. Notify your doctor immediately if you have any unusual stomach pain or blood in the stool, or if you have had any serious stomach problems in the past. As with all immunosuppressive drugs, you will be more prone to getting infections. CellCept may cause some types of blood cells to decrease (specifically, white blood cells), so it is important to keep all your blood work appointments.

Cautions/ Other Advice:

If you are pregnant or plan to become pregnant, you must inform your physician. CellCept may be harmful to the unborn baby. Breastfeeding is not advised because this drug may pass into the breast milk and harm your baby.

If you have questions regarding your medication, please contact your coordinator or your pharmacist.

Brand Name: Deltasone

Generic name: prednisone

5mg

Figure 7. Prednisone tablet, Apotex, (2021)

What is it?

Prednisone is a corticosteroid hormone. Your body produces a form of prednisone called cortisol, which helps your body respond to stress, such as infection. When you take prednisone tablets to prevent rejection, your body produces less cortisol and relies on you to take prednisone tablets regularly. If you stop taking prednisone suddenly, your body cannot produce cortisol quickly enough and you may become ill. Your kidney transplant team will decrease your prednisone dose gradually (taper) to allow your body to adjust. Although prednisone is used to prevent rejection in kidney transplant recipients, it also has many other uses such as treating arthritis, asthma, allergies, and inflammation.

How should it be taken?

Prednisone is taken once daily, usually in the morning. It should be taken with food or milk to prevent stomach irritation. Your coordinator/doctor will tell you when to reduce your dose. DO NOT STOP TAKING PREDNISONE SUDDENLY. If you forget a dose, take it as soon as you remember. If it is time for your next dose, skip the missed dose and carry on as usual. Do not double your dose.

What side effects may occur? What can I do about them?

Prednisone has many side effects, particularly with long-term use. Your kidney transplant team is aware of these side effects and will try to decrease your does as much as possible without causing rejection. If you experience nausea, vomiting, stomach irritation, or heartburn, take this medication with food or milk. If these effects persist or your stools become black and tarry, contact your doctor. Mood swings may occur at high doses. Acne, round face, thin skin, easy bruising, slow wound healing, headache, insomnia, weight gain, blurred vision, cataracts, weak bones, increase appetite and thirst may also occur. If you are diabetic, prednisone may make it more difficult to control your blood sugar and require you to use more insulin. If you are not diabetic, prednisone may require you to temporarily or permanently take insulin or pills to control your blood sugar levels.

Are there any other special precautions to take?

Be sure to tell any doctor, dentist, surgeon, nurse, or pharmacist who is involved with your health care that you are taking prednisone.

If you have questions regarding your medication, please contact your coordinator or your pharmacist.

Brand Name: Rapamune®

Generic name: sirolimus

1mg

Figure 8. Rapamune tablet, Pfizer (2021)

What is it?

Sirolimus is an immunosuppressive medication that is used to prevent rejection of transplanted kidney. You may be taking other anti-rejection medications along with sirolimus.

How should it be taken?

Sirolimus is usually taken once a day. You should take it at the same time every day, for example in the morning. You may take it either with or without food; however, you should be consistent. Sirolimus is available as a tablet or a liquid. If you are using the liquid form, your pharmacist will show you how to take it.

Dose changes:

Your dose of sirolimus may change often after your transplant. Dose changes are based on the amount of sirolimus in your blood or if you are experiencing any side effects from the medication. The dose will vary among different people. Your coordinator/doctor will tell you what dose you should take. When you go to the lab for blood tests, DO NOT take sirolimus until AFTER you have had your blood work taken. You should bring it with you and take it after having your blood drawn.

When you go to the lab for blood tests, DO NOT take your Sirolimus dose that morning. Bring it with you and take it after your blood is drawn.

If you miss a dose:

If you miss a dose, take it as soon as you remember. If it is almost time for the next dose, skip the missed dose and carry on with your usual dose. Do not double the dose to catch up.

If you are sick:

If you take your sirolimus and vomit soon after, you should take the sirolimus again only if you saw the pills in your emesis.

What are the Side Effects?

The side effects of Sirolimus may cause nausea. diarrhea, tremors, dizziness, high blood pressure, high cholesterol and triglycerides, unusual heartbeat, infections, acne, excess hair growth, anemia, unusual bleeding or bruising, certain types of cancers (e.g., skin cancer) or mouth sores. You should rinse your mouth with water several times after taking sirolimus as this may help prevent mouth sores. Women taking sirolimus should talk to their transplant team before becoming pregnant as sirolimus may be harmful to the unborn baby.

If you have questions regarding your medication, please contact your coordinator or your pharmacist.

Other Medication Instructions

Safe Handling of Anti-Rejection and Anti-Viral Medication
Kidney transplant patients are prescribed medications such as

- Valganciclovir (Valcyte)
- Mycophenolate (Cellcept or Myfortic)

- ✓ These medications need to be handled in a special way. You should always wash your hands before and after handling these medications.
- ✓ These medications should be stored in the container(s) it was provided. Return any unused medication to the pharmacy where you received it.
- ✓ Pregnancy planning and prevention is important when taking medications. Prior to trying to conceive, both males and female patients should discuss this with their kidney transplant team.

Vaccinations:

You should also check with your kidney transplant team before receiving any vaccinations. Kidney transplant patients should not receive any live attenuated vaccines. Some examples of
live vaccines are…

- MMR (Measles, Mumps, Rubella)
- Varicella (Chicken Pox)
- Yellow Fever

Over-the-counter medications:

- Avoid using non-prescription medications(over-the-counter) without first contacting your transplant coordinator or your pharmacist.
- The use of herbal medications while taking any anti-rejection medications is not recommended as it can interfere with your anti-rejection medications.

If you have questions regarding your medication, please contact your coordinator or your pharmacist.

Possible Complications After a Kidney Transplant

Rejection:

Rejection is an attempt by your immune system to attack your transplanted kidney and to destroy it. Rejection can occur any time, but the risk is greatest during the first 6 months after your kidney transplant. It is not uncommon for kidney transplant patients to experience a rejection episode. Most rejection episodes are successfully treated. It is important to treat the rejection episode as soon as possible. The longer treatment is withheld, the more likely permanent damage will be done.

Rejection episodes can be treated with either a large dose of IV steroids (methylprednisolone)
for 3 days or, in more severe cases, treatment with Thymoglobulin®. In some cases, you may require intravenous immune globulin (IVIg) and/or Plasmapheresis. Most times, it is necessary to perform a kidney biopsy to identify rejection. You may or may not have any signs or symptoms to suggest that you are rejecting your new kidney. Sometimes, the only clue is abnormal kidney function tests. This is why it is very important to attend all laboratory appointments.

Kidney transplant patients should be aware of some of the signs and symptoms that may indicate rejection. If you experience any of these, do not wait until your next clinic appointment. Call your kidney transplant team promptly if you experience any of the following:

- pain or tenderness over the transplant kidney site
- fever or chills (temperature ≥ 38°C)
- sudden weight gain
- decreased urine output
- unusual swelling of feet, hands, and eyelids

Infection:

Anti-rejection medication interferes with a person's natural immunity making you more prone to infections after your kidney transplant. There are different types of infections:

- Viral [CMV, EBV, BKV, Herpes simplex (cold sores), Herpes zoster (shingles), chickenpox, etc.]
- Fungal (candida)
  - Bacterial (signs of bacterial infection include fever, cough, sore throat, burning sensation
  - when voiding, redness, swelling or drainage around an incision)
  - Pneumocystis jirovecii pneumonia (PJP): A type of pneumonia that immune-suppressed patients are more prone to get. You will be given medication to help prevent this.

Cancer:

There is a slightly increased risk of cancer associated with the use of any immunosuppressive drug. It is very important to have yearly health check-ups with your family doctor. Preventative measures such as pap smears, mammograms, and prostate check-ups can all be arranged by your family doctor.

Skin cancer is the more common type of cancer seen in kidney transplant patients. Report any new moles or any skin changes to your kidney transplant team. Always wear sunscreen when you are out in the sun.

Another type of cancer is a blood cancer called PTLD (Post-Transplant Lymphoproliferative Disorder). Report any unusual lumps or bumps, unexplained weight loss or night sweats to your kidney transplant team.

Diabetes:

Glucose, a simple sugar, is the main source of energy in the body's cells. Diabetes occurs if sugar accumulates in your body because either your body is not using it properly or your body is not producing enough insulin. Some of your prescribed drugs (prednisone, Advagraf, Prograf) can cause diabetes or make diabetes worse. If you were taking insulin, after the transplant you may require higher doses. If you were taking pills or watching your diet to control your blood sugar before transplant, you may need to take insulin after transplant. If your blood sugar goes high immediately after your transplant, it may return to normal as your dose of medication is decreased.

Bone Disease:

Kidney transplant patients have an increased risk of bone disease (osteoporosis), which can increase the risk of bone fracture. To lower your risk, make sure you are getting enough calcium and vitamin D in your diet (unless your doctor says not to). Please feel free to consult your dietitian for good dietary sources of calcium

Safe Living After a Kidney Transplant

These are general recommendations to decrease the risk of some infections. These recommendations do not address all potential exposures and any questions or matters that relate to your specific situation should be discussed with your kidney transplant team.

Hand Washing:

Frequent hand washing with soap and water can prevent many infections. Your hands should be carefully washed before preparing food or eating food. They should also be washed after touching potentially soiled items such as wounds, diapers, toilets, etc. Gloves should be worn if handling really dirty material and your hands should be washed again after removing the gloves.

Travel Safety:

You should inform your kidney transplant team of your travel plans at least a month prior to travel in order to receive a Travel Letter. This letter is used to inform others when necessary (such as airline employees, first responders, etc.) that you have had a kidney transplant. The letter also lists all your current medications and your most recent lab values.

Safe Sex:

You should use a latex condom if you are not in a long-term monogamous relationship. Avoidance of fecal matter during sexual activity is also recommended.

Food & Water Safety:

You will need more fluids after your kidney transplant than before to help your kidney filter wastes and clear out toxins. Usually, patients are asked to drink 2L of water every day, not including milk, juice, etc.
Fruits and vegetables should be washed or peeled and damaged areas should be cut away. Municipal tap water is safe to use. Cooked food and raw food should be kept separate when preparing them.

However, the following should be avoided…
- Raw/undercooked eggs or foods containing them
- Any unpasteurised food
- Raw/undercooked seafood
- Raw seed sprouts
- Raw meat
- Drinking water from lakes or rivers

Animal & Pet Safety:

Wash hands after handling pets. Avoid cleaning cages, aquariums, or litter boxes and if it is unavoidable, please wear gloves when you do. The following should be avoided…
- Contact with any animals with diarrhea
- Stray animals
    - Contact with reptiles, chicks, hedgehogs, ducklings, and monkeys

Recommendations for Dental Work after a Kidney Transplant

Scheduling Dental Work:

- Kidney transplant patients should delay routine dental work until 3 months after transplant.
- If urgent dental work is required within 3 months after transplant, the patient and/or dentist should discuss with the kidney transplant team.

Antibiotics Prophylaxis:

There is no evidence that taking immunosuppression medications because of having a kidney transplant increases the risk of infectious complications related to dental procedures. Kidney transplant patients should not routinely receive antibiotics prophylactically. However, they should receive antibiotics only if they have one or more of the following…

- A mechanical heart valve
- History of endocarditis
- History of congenital heart abnormalities

For more information, dentists and dental offices can contact the kidney transplant office to discuss specific cases.

Writing to your Kidney Donor Family

You may want to write to your kidney donor family to thank them for their generous donation. This is not required and it is very much a personal choice. Some transplant patients find it hard to write down their thoughts in a card or letter. You can begin with "Dear Donor Family" and write a simple expression of thanks signed "from a grateful Recipient". This can be very meaningful and appreciated by the family.

When should I write?

If you decide to write, you can do so at any time after your kidney transplant. The card or letter should not include any of the following:

- Information that can identify you such as your name, family member names, home address, city, telephone number, etc.

When your card or letter is finished, put it in an unsealed envelope. Give it to or mail it to your transplant coordinator. Your transplant coordinator will review the card or letter to make sure it has no personal information before sending it to the HOPE (Human Organ Procurement and Exchange Program) to pass on to the donor family.

Will I hear from the donor family?

You may or may not receive a card or letter from the family. If they write first, you are not obligated to write them back. If the donor family sends a card or letter to you, HOPE will first review it to make sure it has no personal information. If it is suitable, it will be sent to your transplant coordinator, who will then contact you to send the card or letter to you.

Other Resources

There is a great deal of information intended for kidney transplant patients found on the internet. However, not all the information you read on the internet is factual or correct. Below is a list of reputable websites that are great resources for accurate and relevant information for kidney transplant patients.

• Kidney Foundation of Canada	https://kidney.ca/
• Canadian Blood Services	https://www.blood.ca/en
• MyHealth.Alberta.ca	https://myhealth.alberta.ca/KidneyTransplant
• Alberta Health Services	https://www.albertahealthservices.ca/
• Medic Alert	https://www.medicalert.ca/

Again, congratulations on your new kidney! This resource is your guide to help you and your kidney function to the best of its ability for as long as possible. Enjoy!

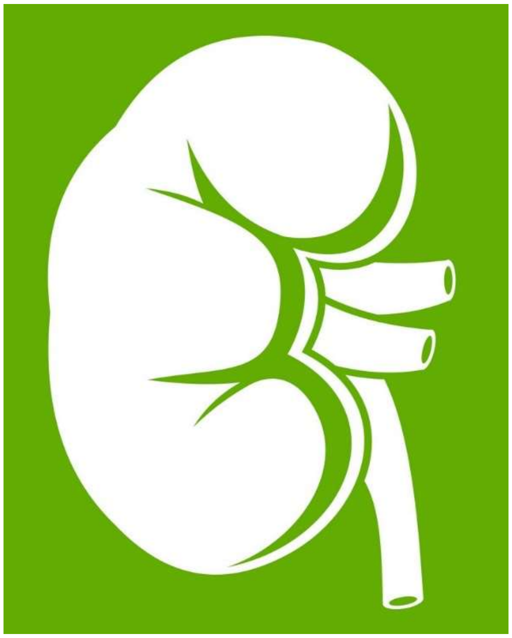

Figure 9. Vector Stock, (2021)

APPENDIX B: PROJECT EVALUATION TOOL

As you know, I am completing my Master of Nursing degree through the University of Lethbridge. As a requirement of my program, I am completing a project of revamping the patient information resource that our kidney transplant patients receive. Your feedback regarding this resource will be a valuable tool for me to use to measure the success of my project. Thank you for taking the time to complete this evaluation.

Please circle your response that corresponds to the following statements.

1. Overall, the content in the draft patient resource is reflective of the information coordinators provide to patients on a regular basis:

   Strongly Agree Disagree Strongly Disagree

2. Overall, information contained in the draft patient resource is clear and concise (not too wordy):

   Strongly Agree Agree Disagree Strongly Disagree

3. Overall, the draft patient resource is written in language patients can understand:

   Strongly Agree Agree Disagree Strongly Disagree

4. Overall, the anti-rejection medication section of the draft patient resource is informative and accurate:

   Strongly Agree Agree Disagree Strongly Disagree

5. Overall, the complications of kidney transplant section of the draft patient resource is informative and accurate:

   Strongly Agree Agree Disagree Strongly Disagree

6. Overall, the safe living after a kidney transplant section of the patient resource is informative and accurate:

   Strongly Agree Agree Disagree Strongly Disagree

7. Overall, the other resources section of the draft patient resource is informative and accurate:

   Strongly Agree   Agree   Disagree   Strongly Disagree

8. I am likely to recommend the draft patient information resource to patients if it is approved and implemented:

   Strongly Agree   Agree   Disagree   Strongly Disagree

9. I am satisfied with the new draft patient information resource:

   Strongly Agree   Agree   Disagree   Strongly Disagree

10. What other recommendations do you suggest to improve the draft patient resource?