

**THE DEVELOPMENT OF AN EDUCATION PROGRAM FOR LIVE KIDNEY
DONORS IN NEWFOUNDLAND AND LABRADOR**

by © Daisy D. Baldwin (practicum report) submitted to the School of Graduate Studies in
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Abstract

Background: Chronic Kidney Disease is on the rise worldwide. With the growing number of patients choosing transplant as a renal replacement therapy option, the need for a kidney donor is significantly higher than the number of transplants being performed. Newfoundland and Labrador has less live kidney transplants occur when compared to other Atlantic Provinces. It is unpredictable when a deceased donor kidney will become available, and there are not enough live kidney donors coming forward. Therefore, it is imperative to spread awareness and educate others on live kidney donation. **Purpose:** The purpose of this practicum project was to develop an education program on live kidney donation for potential donors and healthcare professionals in Newfoundland and Labrador. An education program can increase knowledge on the live kidney donation purpose, options, and process. **Methods:** An informal needs assessment, integrated literature review, and consultations with key stakeholders were conducted prior to developing the project. An education program was then developed. **Results:** Based on the findings of the methods utilized an education program was created. There were two identified frameworks used to guide the program's development: Knowles' Adult Learning Theory and the Transtheoretical Model of Behavioral Change. The program consisted of an online learning module, an information session, a pamphlet for health professionals, and a pamphlet for patients. **Conclusion:** There was no implementation or evaluation component for this practicum project due to the time restraints of the course. However, a plan for future evaluation will be outlined.

Keywords: live kidney donation, transplant, integrated literature review, education program

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Introduction

Transplant is the most coveted renal replacement therapy option chosen by patients living with end-stage renal disease. Patients who undergo a kidney transplant, experience a better quality of life, have a longer life expectancy, experience fewer side effects than dialysis treatments, and get the chance to live a more normal life than patients undergoing dialysis treatments (Abecassis et al., 2008; Kazley, Hamidi, Balliet, & Baliga, 2016; Locatelli, Pozzoni, & Del Vecchio, 2004; Prihodova et al., 2014; The Kidney Foundation, 2012). Therefore, there are increasing numbers of patients choosing kidney transplant, resulting in a greater demand for kidney donors. Unfortunately, there are not enough kidney donors available (Kazley et al., 2016).

I have identified lack of knowledge among patients and health care professions in Newfoundland and Labrador as a barrier to live kidney donation in the province. Lack of knowledge and support from health care professionals are also clearly defined as barriers to live kidney donation in the literature. The findings of an integrated literature review in conjunction with my experience with the Newfoundland and Labrador transplant team, and consultations with key stakeholders, justified the need for an education program encompassing an online module, information session, and information pamphlet. There are three appendices contained in this report. Appendix A is the integrated literature review, Appendix B is the consultation report, and Appendix C is the project development.

Background

The incidence of kidney disease is on a rapid incline among Canadians. In Canada, the number of people requiring a renal replacement therapy has tripled in the last

two decades (The Kidney Foundation of Canada, 2016). Therefore, it is becoming a population health concern. As a result of the growing number of patients choosing transplant as their primary renal replacement therapy option, the need for kidney donors is increasing. In fact, the need for kidney donors is 2.5 times higher than the number of transplants being performed. It cannot be predicted when a deceased donor kidney will become available, and there are not enough live kidney donors coming forward (Canadian Institute of Health Information, 2016).

Currently, the province of Newfoundland and Labrador has less live kidney transplants occur annually in comparison to the other Atlantic Provinces (Multi-Organ Transplant Program, 2016). One reason suggested for the lower rate is the lack of a formal education program on live kidney donation in the province. Education is currently being provided through discussions with a transplant coordinator and an information pamphlet. There are two transplant coordinators in Newfoundland and Labrador: one in St. John's and one in Corner Brook. One of their roles is to educate patients through discussions and meetings. Unfortunately, the province has a number of geographical barriers that prevent donors from being able to attend appointments in those two areas. This is concerning since donors may never meet a coordinator, and the only way to communicate would be through phone conversations each time the patient chooses to seek out information.

There is an information pamphlet that is provided to the Newfoundland and Labrador transplant team by Nova Scotia Health Authority. Besides verbal education through conversations with a transplant coordinator, this information pamphlet is the only educational resource used in Newfoundland and Labrador. Although the pamphlet does

contain valuable information, it is not available to the general public in clinics and community centers. The pamphlet is only distributed once a donor has contacted a coordinator. This prevents potential donors from being able to gain preliminary education on the donation process prior to making a decision to donate and contacting a coordinator. The information contained in the pamphlet is also vague in some areas and patients have requested more information particularly on finances and eligibility criteria. In addition, the information on live kidney donation in the pamphlet does not always correspond to what occurs in Newfoundland and Labrador. For example, the wait times on diagnostic tests tend to be longer than in other provinces. Newfoundland and Labrador patients also have to travel out of province for their transplant.

In addition, transplant coordinators are not responsible for educating other health professionals on transplant options and details. Healthcare professionals, particularly dialysis nurses, in other centers in the province, have limited knowledge on the transplant process and kidney donation. None of them have access to live donation information pamphlet, there are no continuing education sessions, and due to geographical barriers, many will not have the opportunity to meet with transplant coordinators to discuss live donation. This lack of knowledge poses barriers and missed opportunities for healthcare professionals being able to deliver adequate education to patients inquiring information on live kidney transplant.

Practicum Project Rationale

My nursing background is working with patients living with end-stage renal disease. I relieve for the St. John's transplant coordinator when she is on leave from her role, and I have gained valuable experience in this role over the past 3 years. Working as

a transplant coordinator, I have found that there are inadequacies evident within our current live donor education program. As discussed above, there is no formal education program in the province, and the education currently being provided is through an information pamphlet and discussions with a transplant coordinator. Therefore, I decided to bring this issue to the manager of the dialysis program, Ms. Cheryl Harding. An informal needs assessment was performed with Ms. Harding regarding the need for an education program for kidney donors. Ms. Harding agreed that this was an appropriate initiative for the Nephrology program and that a need exists. My practicum project stemmed from this informal needs assessment.

For the practicum project, I chose to develop an education program on live kidney donation that could be utilized by potential donors, recipients, and healthcare professionals in Newfoundland and Labrador to increase knowledge on the purpose, options, and process of live kidney donation. A literature search revealed that a combination of written, verbal, and online initiatives would be the best way to disseminate pertinent information to educate the target population. This way the information can be accessed in multiple ways, and meet the learning needs of a vast number of people (Kazley, et al., 2012; Powells, Inglis, Ronnie, & Large, 2011; Taylor et al., 2012; Waterman et al., 2014; Waterman et al., 2015; Waterman, Robbins, & Peipert, 2016). Therefore, the education program encompassed an online module, information session, an information pamphlet specifically for healthcare professionals, and an information pamphlet specifically for patients (potential donors, recipients, and their families).

Ethical Approval for the Project

Ethical approval was not required for the completion of this practicum project. To determine if ethical approval was needed, the Health Research Ethics Authority Screening Tool was completed prior to consulting with key stakeholders or completing any work with the project. A copy of the Health Research Ethics Authority Screening Tool can be found in Appendix B of this report.

Program Development

The program was developed based on a number of methods. An integrated literature review and consultations with key stakeholders were completed. The findings of both the integrated literature review and consultations will be discussed in this report. The completed copies of both methods can be found in Appendix A and B. Appendix A is the integrated literature review, and appendix B is the consultation report. After completing the methods and justifying the need for an education program on live kidney donation, the education program was then developed. A completed copy of the education program is provided in Appendix C.

Integrated Literature Review

An integrated literature review was completed prior to developing the practicum project. The integrated literature review revealed a number of themes that could be incorporated into the development of an education program for live kidney donation.

The Integrated literature review was completed using search engines: CINAHL, PubMed, Cochrane Library, and Google Scholar. A series of broad search terms included: *live kidney donation, barriers to live kidney donation, live donor education, and kidney transplant*. The literature was rich with studies and articles on kidney donation. The

initial search resulted in 1670 results. The search was then limited to research articles. Once applying this filter, the results decreased to 109, and consisted of mainly qualitative but quantitative studies were found as well.

The literature search also revealed articles on effective teaching strategies. I identified two frameworks to guide the education program's development: Knowles' Adult Learning Theory, and the Transtheoretical Model of Behavioral Change. The two frameworks were appropriate for the target population, and guided what content should be included in the education program.

There were two major barriers to live kidney donation revealed from the literature review: lack of knowledge/ education on live kidney donation, and insufficient support from healthcare professionals (Agerskov et al., 2015; Barnieh et al., 2011; Brown et al., 2008; Gill & Lowes, 2008; Pradel et al., 2003; Rodrigue et al., 2007; Rodrigue et al., 2008; Waterman et al., 2006). There was also an abundance of literature on existing education initiatives that discussed the importance of incorporating a combination of written, verbal, and online education tactics into a formal education program to meet the vast needs of those utilizing the material (Kazley et al., 2012; Powells et al., 2011; Taylor et al., 2015; Waterman et al., 2014; Waterman et al., 2015; Waterman et al., 2016)

Lack of knowledge/education. The transplant and donation process is a major life transition for both a kidney recipient and a kidney donor. Education on live kidney donation is crucial during the decision-making and evaluation process. Donors and their recipients ought to be fully informed on how donation will impact their lives, and what to expect during the process (Sites, Freeman, Harper, Waters, & Pruett, 2008). Effective healthcare strategies and resources need to be developed to ensure that anyone wishing to

be a kidney donor feels prepared and educated on live donor kidney transplant (Gill & Lowes, 2008).

Numerous qualitative studies discussed the need for donors to have adequate education during the decision-making process to become a live kidney donor (Agerskov et al., 2015; Brown et al., 2008; Gill & Lowes, 2008; Pradel et al., 2003; Waterman et al., 2006). Both donors and recipients felt that receiving adequate education during the live donation process was crucial (Sites et al., 2008). In order for patients to feel fully informed on the live kidney donation process, medical testing, and procedures, there is a definite need for effective healthcare strategies and resources (Gill & Lowes, 2008).

This theme was also indicated in a number of quantitative studies as well (Barnieh et al., 2011; Rodrigue et al., 2007; Rodrigue et al., 2008). Without a formal education program for donors and recipients utilizing a transplant center, patients receive little knowledge on live donation as a transplant choice, unless they pursue the information (Barnieh et al., 2011). In a randomized controlled trial by Barnieh et al. (2011) the study examined whether or not a formal education program would increase the number of recipients choosing live kidney donation as their primary transplant option. There were 100 participants in the study that consisted of 50 people in an intervention group and 50 people in a control group. Those in the intervention group received written education material and an education session. The education session was open to recipients, family, friends, and any potential donors seeking information on live kidney donation. The control group did not receive these methods of formal education. From baseline, the intervention group ($p=.02$) were more likely to choose live kidney donation than those in the control group ($p=.37$).

Likewise in a quantitative study by Rodrigue et al. (2007), a randomized controlled trial was performed to explore whether a home-based education program in conjunction with a clinic-based program would be effective for patients who have been reluctant to choosing live kidney donation due to lack of knowledge on the risks, benefits, eligibility, and process. The intervention group received the same clinic-based education as the control group in addition to a home education session conducted by a staff member who have extensive training on live kidney transplant. The intervention group (82.5%) had more inquiries on participating in live kidney donation post study, than those who were in the control group (63.8%).

Lack of support from healthcare professionals. Lack of support from healthcare professionals during the decision-making, testing, and pre-donation process is identified in a number of qualitative studies as a barrier to live kidney donation (Agerskov, Ludvigsen, Bistrup, & Pedersen, 2015; Brown et al., 2008; Gill & Lowes, 2008; Pradel et al., 2003). Gill & Lowes (2008) state that 25% of potential donors contemplate their decision to donate, and 5% postpone their decision indefinitely due to lack of support during the live kidney donation process. Therefore, support from healthcare professionals to answer questions and alleviate concerns is of utmost importance (Gill & Lowes, 2008).

Qualitative studies by Pradel et al. (2003) and Agerskov et al. (2015) found that patients' comfort levels and overall experiences throughout the transplant process was increased when they had support. In the study by Pradel et al. (2003) interviews and focus groups were conducted with donors and recipients. The participants revealed in the

methods that when they had received education and support from healthcare professionals, it alleviated concerns.

The results from the literature search also revealed that healthcare professionals do not always have an adequate knowledge base on live kidney donation, and this contributes to the lack of support and education that they can provide to patients (Waterman et al., 2015). Healthcare professionals are not adequately educated on live kidney donation due to: lack of training time, insufficient educational resources, and difficulty staying current with the new guidelines and practices (Waterman et al., 2015). The more education that healthcare professionals receive, the better support they would be able to provide to donors and recipients seeking information on live kidney donation.

Existing educational initiatives. Lastly, the effectiveness of written, verbal, and online resources was unveiled in the literature search as educational tools to increase knowledge on live kidney donation (Powells, et al., 2011; Taylor et al., 2012; Waterman et al., 2014; Waterman et al., 2015; Waterman et al., 2016). A combination of educational tools is needed to ensure that education is readily available, accessible, and meets a vast array of learning needs (Waterman et al., 2016). Online initiatives are growing in popularity and made easily accessible to the public. Kazley et al. (2012) examined the usefulness of an online social media site for patients seeking health related information. In the cross-sectional study, over half of participants stated they were comfortable using an online site as a tool to seek information. The study also found that using an online tool to seek information was very accessible and answered questions without having to contact a healthcare professional.

Similarly, in a mixed-methods study by Powell et al. (2011) participants considered online education tools as supplements to existing information such as pamphlets. Online education is also a simple way for patients' to seek information and review material whenever they desired.

Theoretical foundations. The Adult Learning Theory is based on a self-directed approach to learning. Adult learners are more motivated to seek out learning opportunities when it benefits them in some way (Abela, 2009). This was very appropriate for the target population for my practicum project. The education program is for donors, recipients, and healthcare professionals who are seeking information on live kidney donation. These people are motivated to get this information to be better educated and informed on live kidney donation whether it be to participate as a live kidney donor or educate others on the process. Self-directed education tools were developed for this purpose.

The Transtheoretical Model of Behavior Change is premised on the concept of change. When the change occurs, the person needs to be ready to accept the change, in order for the change to be beneficial (Lach, Everard, Highstein, & Brownson, 2004). Patients undergoing the live kidney donation process are going on a journey or transitional through the decision, medical testing, surgery, and recovery. Each of these concepts are important steps, and donors need to be fully informed and educated on each. Before a donor moves forward with the decision to donate, they should be educated and accepting of each step in the process to ensure that an informed decision is made. This theoretical framework guided me to include as much detail and information possible in the education program development.

Summary. In summary, the literature search revealed two themes as main barriers to live kidney donation: lack of knowledge/education and support from healthcare professionals. In addition, a number of existing educational initiatives were revealed.

Lack of education/knowledge on live kidney donation is an evident barrier to live kidney donation. Donors and recipients would benefit from a formal education program and increased availability to educational resources. More education was correlated to an increased number of donors and recipients deciding to participate in live kidney donation.

The literature review also emphasized the importance of the healthcare professional's role in supporting donors and recipients in the live kidney donation process. The studies revealed that patients feel they are not getting enough support from healthcare professionals. Increased support can alleviate stress and allow patients to feel more comfortable with participating in the live kidney donation option. Healthcare professionals can lack the education that they need to support their patients. Increased resources and training time would allow healthcare professionals to feel better prepared to educate patients on live kidney donation, and support them throughout their journey.

In addition, the literature revealed that the more educational tools that exist, the more informed that donors and recipients are on live kidney donation. Transplant programs would benefit from having a combination of written, verbal, and online materials for their patients. This way, education will always be available and accessible. The findings of the literature review did not undermine the need for an education program consisting of not only traditional written materials but an online component as well.

There were also two learning theories identified from the literature search that were useful to guide the development of an education program on live kidney donation:

the Transtheoretical Model of Behavior Change and Knowles' Adult Learning Theory.

Both were applicable to the learning needs of my target population.

Consultation Report

The results of the consultations with key stakeholders had many implications for the development of this practicum project on an educational program for live kidney donors. To fulfill the requirements of this practicum project, and the competencies of an advanced practice nurse, consulting with key stakeholders involved in the care and education of live kidney donors was of utmost importance.

Stakeholders agreed to participate in semi-structured interviews. Interview questions were designed for all participants. In addition, specific questions were designed for dialysis staff members and the transplant coordinators. The interviews were held either in person or via telephone conversations, depending on the availability and geographical location of the stakeholders. Notes were taken during the interviews, and the data was transferred to tables in a Microsoft Word document for content analysis and to outline themes. The themes were developed based on participants' responses, and then summarized in the consultation report.

The stakeholders who were chosen to participate in the interviews confirmed that an education program was necessary. It was evident from the interviews that all stakeholders agreed that the education program is a worthwhile project and useful for the transplant program in Newfoundland and Labrador. All stakeholders identified that lack of education and insufficient support from healthcare professionals are barriers to the live kidney donation program in Newfoundland and Labrador. The stakeholders felt that both donors and recipients need adequate knowledge on live kidney donation in order to make

an informed decision. Currently, questions on live kidney donation are being directed to transplant coordinators due to the fact that dialysis staff members do not feel comfortable with their knowledge base on live kidney donation. Transplant coordinators provide education to patients across the province, but patients would benefit from having more healthcare professionals educated on transplant to provide supports when questions and concerns arise. Written, verbal, and online resources were identified as educational resources that would be an asset for the live kidney donor program.

Summary of consultation report. In summary, consultations were conducted with key stakeholders through semi-structured interviews. The themes were similar to the integrated literature review, in that lack of education and support from healthcare professionals, are two main barriers to live kidney donation. Written, verbal, and online resources were also identified as being needed for the live kidney donation program in Newfoundland and Labrador.

Education Program Development

I began the development of the education program for live kidney donors in March 2017. I decided to create two information pamphlets, one information session, and an online module, to ensure that I had written, verbal, and online material. One pamphlet was for patients (donors and recipients) wanting information on live kidney donation, while the other was for healthcare professionals. The information session was designed for healthcare professionals to present to anyone seeking information on live kidney donation. The online module was designed using e-portfolio and contained significant detail on the kidney donation process, medical testing, financial information, surgery,

recovery, and contact information. The full education program can be found in Appendix C. A short summary of each resource will now be discussed.

Information pamphlets. There were two information pamphlets developed. The patient pamphlet focused mainly on what live kidney donation is, who is eligible to be a kidney donor, what tests need to be completed, where the donation takes place, and who to contact. The resource should be placed in dialysis clinics and community centers to provide donors and recipients with a brief overview of live kidney donation. After gaining this information, they can then pursue more information through the developed information session, online module, and transplant team. Currently, the only pamphlet being used in the program is from Nova Scotia Health Authority, and it is not available to the public. In the future, the hope is that this pamphlet will be accessible in multiple clinics across the province of Newfoundland and Labrador.

Similarly, the pamphlet for healthcare professionals discusses the same topics as the one for the patients, but it is also a quick reference to help professionals answer patient questions. There is information on who health professionals should advise patients to contact, how to answer questions, and what to do when approached for information on live kidney donation. Dialysis nurses are often faced with a lot of questions on live kidney donation since many potential donors are family members attending dialysis treatments with loved ones. It is essential to ensure that these pamphlets are made available in dialysis centers province wide.

Information session. The information session was designed so that health professionals and transplant coordinators have a presentation developed to present to anyone seeking information on live kidney donation. The intent is for it to be presented at

least twice a year to give donors and recipients the opportunity to attend the sessions and have their questions answered. Prior to the information session, posters can be put up in dialysis units and clinics to advertise the dates, and the dates will also be uploaded unto the online module as well. For those not in the area, video conferencing can be considered to increase accessibility to the presentation.

Online education module. To choose a template to develop the online education module, I met with the Center for Innovation in Teaching and Learning and was introduced to e-portfolio. This online tool was used as the template to develop my module. The online module consisted of 7 sections, with 3-4 topics under each section. The information in the online module is very in depth and provides a multitude of information that both patients and healthcare professionals can have easy access to. There is a navigation bar located on the left hand side of the module to allow simple navigation between sections and topics. There are also links to the pamphlets and information session found within the module, and likert scale type questions to evaluate the module at the end.

Summary of education program development. Two information pamphlets, an information session, and online education module were developed for this practicum project. Therefore, the project encompassed written, verbal, and online material to meet the vast learning needs of anyone wanting to participate in live kidney donation. The online module contains links to both information pamphlets, and the Power Point presentation for the information session.

Discussion of Advanced Nursing Practice Competencies

The Canadian Nurses Association [CNA] (2008) outlined competencies for advanced practice nurses. Advanced practice nurses should incorporate these competencies into their practice. The competencies include: clinical competencies, research competencies, leadership competencies, and consultation and collaboration. “The advanced practice nurse provides expert care for specialized patient populations,” (CNA, 2008, p.16). When compared to the role of the registered nurse, the advanced practice nurse, takes the lead in developing appropriate clinical guidelines and support for patient care, instead of solely implementing resources. Therefore, the advanced practice nurse looks for barriers impacting a patient population, and works towards improving those barriers (CNA, 2008).

Throughout the development of this practicum project, I have been drawing on and incorporating the experience I have gained as a transplant coordinator to justify why there is a need for an education program for live kidney donors. Therefore, I have been incorporating clinical competencies throughout Nursing 6660 and 6661. Live kidney donation is a topic that I have been interested in working on for a couple of years now. A lot of my work in the transplant coordinator role has been working with live kidney donors. I have listened to their concerns and many of them voice the need for more education and support. I have seen first hand how important education is before and during the kidney donor work-up. Donors are giving an ultimate gift to the kidney recipient, but they owe it to themselves to make sure they are fully informed on their decision to participate and the whole donation process.

According to the CNA (2008) gathering and utilizing research is pivotal to advanced practice nursing. When nurses gather research, it is implemented to improve

patients' care, and should be current and from reputable sources. As discussed in this practicum report, I have completed a thorough literature review to gather research findings and incorporate evidence-based practice into the development of my learning resources for the education program for live kidney donors. Through completing the literature search, I identified two major barriers to live kidney donation: lack of education, and insufficient support from health professionals. I also gained insight into the importance of having written, verbal, and online resources incorporated into an education program. The qualitative and quantitative research studies that were found were incorporated into the integrated literature review that justified the need for an education program for live kidney donation. I also found two appropriate theoretical foundations to guide the program's development.

I have also incorporated consultation and collaboration in the Nursing 6660 and Nursing 6661 courses. Throughout the entire practicum, it was imperative to consult and collaborate with key stakeholders involved in the care and education of live kidney donors. I even got to disseminate my findings and collaborate with my fellow students and faculty on the need for the education program. Kidney Transplant is a specialized area of nursing where the patients involved undergo a major life transition. The information gathered from the consultations was a key indicator for the development of an education program on live kidney donation. Therefore, the dialysis program's manager, transplant coordinators, the live kidney donor coordinator in Halifax, and dialysis staff, were consulted to gain insight into their views on the importance of live kidney donor education. Consulting with these stakeholders was imperative to ensure that developing an education program for live kidney donation is warranted, and to explore

what content the resources should include. Collaboration and consultation will continue in the future as well. In addition, I would like to present the information session to donors, recipients, and healthcare professionals to receive their feedback.

Next Steps

Plan for Dissemination and Evaluation

Plan for dissemination. The components of the education program consist of: an information pamphlet for donors, an information pamphlet for healthcare professionals, an information session through power point presentation, and an online education module. I will first disseminate the pamphlets to dialysis units all over Newfoundland and Labrador. There are multiple dialysis units in each health authority in Newfoundland and Labrador. By putting the pamphlets in dialysis units, they will be easily accessible to those desiring a transplant and their families and friends who may choose to donate.

There will be dates set up for information sessions to be held. The information sessions will be open to the general public to target potential kidney donors, transplant recipients, and any healthcare professionals desiring more knowledge on live kidney donation. Participants can attend in person, and there will be an option to participate through teleconference. The sessions will include information on all components of the education program, and will go into detail on the live kidney donation process, medical testing, location, and finances. The information sessions will be made known through posters set up at dialysis units' province wide, and dates for the information sessions will be available on the developed online module.

The online module will be made public for anyone requiring information on live kidney donation. With approval, the module will be available on all health authority

websites in Newfoundland and Labrador. The online module could be presented at any of the information sessions being held, to give participants an opportunity to voice their opinions and ask questions. I would also like to present the online module at a number of conferences including: The Canadian Association of Nephrology Nurses and Technologists (CANNT) and Transplant Atlantic. I have already presented the online module through power point presentation to my fellow students and faculty members at a practicum conference.

Plan for evaluation. An evaluation will be conducted to examine whether or not implementing the education program on live kidney donation will increase knowledge and understanding on live kidney donation for donors, recipients, and healthcare professionals. A larger scale study such as a randomized control trial could then be a potential option for the future. The evaluation will include a sample of participants who consent to availing of all components of the developed education program. The evaluation will help determine whether or not the education program is feasible and beneficial for the target population. The copy of sample evaluation questions is available on the online education module under the closing remarks section. I developed a short survey using likert scale type questions to receive feedback on the various components of the education program.

Conclusions

In completing Nursing 6661, the goals and objectives for the practicum project have been met. An education program was developed that can be used to increase knowledge and awareness of live kidney donation in Newfoundland and Labrador. The program consists on an online module, information session, and two education pamphlets.

I have justified the need for this project through an informal needs assessment, completing an integrated literature review, and consulting with key stakeholders.

Advanced practice competencies were also incorporated into developing the education program. The program included: an online learning module, an information session, and two information pamphlets.

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Appendix A

Integrated Literature Review: Live Kidney Donation

Daisy D. Baldwin

200807360

Nursing 6660

Memorial University of Newfoundland

Abstract

Transplant is the most common renal replacement therapy option chosen by patients with end-stage renal disease. Due to the increasing number of end-stage renal patients choosing transplant as a renal replacement therapy choice, there is an increasing need for live kidney donors in the current healthcare system. Unfortunately, the demand for live kidney donors is greater than the number of people choosing to donate. One of the identified barriers to live kidney donation is lack of education. In Newfoundland and Labrador, there are currently two transplant coordinators who provide transplant education and support for the province. An integrative literature review revealed that lack of education on live kidney donation, and insufficient support from healthcare professionals, are underlying issues for lack of live kidney donors. The effectiveness of written, verbal, and online educational tools to increase knowledge on live donation was also reviewed. A combination of these tools is needed as part of an education program that will encompass an online module, information session, and education pamphlet. The program will be available to both donors and recipients, and available in dialysis units to increase the education of healthcare professionals. With increased education, healthcare professionals can provide more support to patients inquiring about live kidney donation. Knowles' Adult Learning Theory, and the Transtheoretical Model of Behavioral Change were also explored as theoretical foundations to guide this education program.

Keywords: live kidney donation, transplant, integrated literature review, education program

Introduction

Chronic kidney disease is a current health problem in the world today. In Canada, an average of 16 people are diagnosed daily with chronic kidney disease that requires a renal replacement therapy option (The Kidney Foundation, 2012). The most common renal replacement therapy option is transplant. Patients experience a better quality of life, have a longer life expectancy, experience fewer side effects than dialysis treatments, and get the chance to live a more normal life than having to depend on dialysis treatments three to four times a week (Abecassis et al., 2008; Kazley, Hamidi, Balliet, & Baliga, 2016; Locatelli, Pozzoni, & Del Vecchio, 2004; Prihodova et al., 2014; The Kidney Foundation, 2012). However due to the increasing number of patients choosing a kidney transplant, there is a greater demand for kidney donors than are available (Kazley et al., 2016).

A search of literature reveals barriers to the shortage of kidney donors, and alludes to lack of education on live kidney donation and insufficient support from healthcare professionals, as underlying issues (Pradel, Mullins, & Bartlett, 2003; Waterman, Robbins, & Pelpert, 2016; Waterman et al., 2006).

In my experience as a transplant coordinator, I have identified lack of education as a barrier to live kidney donation. Currently, in Newfoundland and Labrador, education is informal and limited to the use of an information pamphlet given to recipients and donors after contacting a coordinator. The pamphlet is not available to the general public. Two transplant coordinators, located in St. John's and Corner Brook, provide information through informal conversations or phone calls when questions arise. There are very few scheduled meetings, and some donors will never meet a coordinator in person, partly due

to difficulties travelling to the two areas where the coordinators are located. Otherwise, the transplant coordinators are responsible for the scheduling of tests that are necessary to get patients activated on the transplant list.

The transplant coordinators in Newfoundland and Labrador are not responsible for educating healthcare professionals on transplant options. Dialysis nurses are directly involved with recipients' care, and their support networks. Transplant recipients attend dialysis three to four times a week, and their support networks often accompany them. Dialysis nurses have baseline knowledge on transplant and live donation, but are not formally educated on the transplant process and options. Having additional educational resources to learn from would be assets for dialysis nurses. These nurses would be useful resources for patients inquiring about kidney transplant and live donation. Availability and accessibility to education should be improved to increase the comfort level and confidence of those participating in the live kidney donor program and to ensure an informed decision is made.

A review of literature was completed to gain insight into the barriers impacting live kidney donation. I explored past experiences of recipients and donors who have chosen the live donation option, gained insight into the education being provided in other transplant centers, and learned more about the education required by donors. That information will be valuable for the development of this practicum project. The barriers identified in the literature search correspond with those described by patients in my clinical experiences, and support the need for an education program on live kidney donation. I have also become familiar with effective educational strategies being utilized in other transplant centers. In this paper, an integrated literature review of the search

findings will be provided, as well as a background of the topic. The theoretical foundations that are appropriate to guide the development of the education program will also be discussed. Literature summary tables are provided in the appendices for any research studies that were found in the literature search.

Background of the Topic

Kidney Transplant Options

Patients choosing transplant for renal replacement therapy, have three options: deceased donor, live donor, or Living Donor Paired Exchange. The deceased donor option is available to all recipients on the transplant list, and occurs when the recipient is a match with an organ harvested through organ procurement. Therefore, the donor would have made the decision that at time of death, his or her organs will be donated to an anonymous person. This decision has to be made in advance and put in writing. Once the person dies, the organ would go to the person on the transplant list that is the best match for the organ. The average wait time for a person waiting for a deceased donor's kidney is at least 3 years. It can be longer depending on the person's blood type, amount of time of dialysis, and the number of organs that come available to the transplant center (The National Kidney Foundation, 2016).

There are two live kidney donation options, Living Donor Paired Exchange or through a compatible live donor. The Living Donor Paired Exchange option also known as the "paired exchange" option is chosen when a donor has an incompatible blood type with the intended recipient. This means that the donor cannot give a kidney to that recipient directly. Instead, by choosing the paired exchange option, the donor agrees to give a kidney to a recipient anywhere in Canada, as long as that person's donor is a match

for their recipient. The paired exchange option still requires the donor to go through all of the same testing, but unfortunately, the wait-time varies due to the mix of blood types and available donors and recipients in the match cycles. Match cycles occur three times a year and compatibility of pairs is determined through a computer-generated system (Canadian Blood Services, 2016). Having a compatible live donor on the other hand occurs when both the donor and recipient have compatible blood types and the donor can give directly to the recipient. The donor does not have to be a blood relative, but is often a person in the recipient's support network such as a friend, co-worker, family member, or spouse.

There are numerous advantages of receiving either type of live donor kidney over a deceased donor kidney. Live donors are required to have extensive testing to ensure they are in optimal health. Donors undergoing both the compatible live donor option and the paired exchange undergo the same testing. If any of the tests are irregular, the donor is unable to participate. Therefore, live donor kidneys, are often healthier, have better longevity, and have less risk of rejection than deceased donor kidneys (Tong et al., 2012). The testing for both live options, takes 6 months to a year, and results in significantly less wait times than the deceased donor option. Once the 6 months of testing is complete, compatible live donors get to choose a transplant date and arrangements are made for travel to the transplant center. Therefore, recipients with a live donor, often receive their kidneys before having to start a dialysis regime (The Kidney Foundation of Canada, 2016). The paired exchange option does not guarantee a transplant can be performed as soon as the 6 months of testing is complete. However, recipients and donors utilizing the paired exchange option are put in a separate pool of people than the deceased list, and matches occur faster than the usual deceased wait-time.

Despite the advantages of live donation that are outlined above, in Canada, there are more deceased donor kidney transplants being performed than through the live donation options (Canadian Institute of Health Information, 2016). There is a greater demand for live kidney donors than the number of people who are willing to participate and donate a kidney (Kazley et al., 2016). Lack of education and awareness on live donation procedures, are possible reasons as to why there are not more live donors coming forward to donate (Sites, Freeman, Harper, Waters, & Pruett, 2008; Waterman et al., 2016).

Topic Relevance

Chronic kidney disease is on the rise worldwide. In Canada, the number of people requiring a renal replacement therapy has tripled in the last two decades (The Kidney Foundation of Canada, 2016). With the growing number of patients choosing transplant as their primary renal replacement therapy option, the need for a kidney donor is 2.5 times higher than the number of transplants that can be performed, since it is unpredictable when a deceased donor kidney will become available, and there are not enough live kidney donors coming forward (Canadian Institute of Health Information, 2016). Therefore, it is imperative to spread awareness and educate others on live kidney donation.

The province of Newfoundland and Labrador have less live kidney transplants occur on an annual basis when compared to the other Atlantic Provinces (Multi-Organ Transplant Program, 2016). There is no formal education program in the province. Education is currently being provided through a pamphlet and discussions with a transplant coordinator. Transplant coordinators in Newfoundland and Labrador are

located in St. John's and Corner Brook. As discussed earlier, one of their roles is to educate patients through informal discussions. Unfortunately, the province has a number of geographical barriers that prevent people from being able to attend appointments in larger cities. Some donors may never meet a coordinator, and discussion would have to occur through phone conversations if the patient chooses to seek out information.

The information pamphlet provided by the Nova Scotia Health Authority is the other educational resource used in Newfoundland and Labrador. It consists of information on dialysis options, required testing, information on the surgery, and life after donation. There is a lot of information included in the pamphlet, and many patients have voiced that they find it difficult to understand. In addition, when discussing required testing, the information does not always correspond to what occurs in Newfoundland and Labrador. For example, the wait times on diagnostic tests tend to be longer than in other provinces. Newfoundland and Labrador patients also have to travel out of province for their transplant, but the pamphlet lacks information on financial costs for the donor and recipient. The information pamphlet is also not available to the general public.

In addition to not having a formal education program, transplant coordinators are not responsible for educating other health professionals on transplant options and details. Healthcare professionals, particularly dialysis nurses, in other centers, have very limited knowledge on the transplant process. This also poses barriers to proper education and missed opportunity since they may be directly involved in the care of dialysis patients who are inquiring about information on live kidney transplant.

Integrated Literature Review

A literature review was completed using CINAHL, PubMed, Cochrane Library, and Google Scholar. A series of broad search terms included: *live kidney donation*, *barriers to live kidney donation*, *live donor education*, and *kidney transplant*. The initial search resulted in 1670 results. The search was then limited to research articles. After applying this filter, the results decreased to 109 results that consisted of mainly qualitative but some quantitative studies. I then reviewed abstracts and chose articles that were directly pertinent to the practicum project. There were few Canadian studies found, and none of the research studies were completed in Newfoundland and Labrador. The Public Health Agency of Canada's (PHAC) critical appraisal toolkit (2014) was utilized to develop summary tables to critique the quantitative studies that were found. Ryan, Coughlan, and Cronin (2007) provide a guide that can be utilized to critique qualitative research. I used this guide to develop summary tables for the qualitative studies that were found in the literature search. All literature summary tables can be found in the appendices.

The Experiences of Patients Undergoing Live Kidney Donation

Recipients undergoing live kidney donation. The literature search was rich with qualitative studies exploring the experiences of transplant recipients choosing live kidney donation as a renal replacement therapy option (Agerskov, Ludvigsen, Bistrup, & Pedersen, 2015; Bailey, Ben-Shlomo, Salis, Tomson, & Owen-Smith, 2016; Burroughs, Waterman, & Hong, 2003; Gill & Lowes, 2008; Gordon, 2001; Pradel et al., 2003; Ummel, Achille, & Mekkelholt, 2011; Waterman et al., 2006). A number of these studies have been summarized below and included in literature summary tables.

Recipients reported feeling anxiety and fear when pursuing a live kidney transplant (Pradel et al., 2003; Waterman et al., 2006). In a qualitative study by Pradel et al. (2003) focus group interviews were conducted to enhance understanding of recipients' experiences with live kidney donation. This was a single-center study that consisted of 25 participants. The study revealed, that the fear that recipients felt stemmed from not wanting to cause harm to others. Recipients were reluctant to ask their support networks to donate because they feared for their health and wellbeing post-transplant. This was identified as a barrier to live kidney donation. Participants were concerned that their donors would lose kidney function in their remaining kidney, and require a renal replacement option too. To overcome this barrier, the study suggests the need for information on the live kidney donation risks and process, to alleviate anxiety and concerns for recipients. Likewise, Waterman et al. (2006) utilized focus groups to get a better understanding of kidney recipients' concerns and educational needs when considering live kidney donation. Participants also identified that their biggest fear was risking the health of the donor. They too did not want to take an organ from a member of their support network not knowing if they would become unwell and need the kidney for themselves in the future.

Recipients also described feeling uncomfortable when discussing live donation with a potential donor (Gill & Lowes, 2008; Pradel et al., 2003; Waterman et al., 2006). In a qualitative study by Gill & Lowes (2008) a phenomenological, longitudinal approach was utilized to get a better understanding of the transplant experience from the recipient's perspective. Semi-structured interviews were conducted with 55 participants and thematic content analysis was used to analyze the data. The study identified that recipients were

not comfortable bringing up the initial conversation of live kidney donation with their support networks. Doing so was described as feeling as though they were begging donors, or putting pressure on them. Similarly, in the qualitative study by Waterman et al. (2006) the participants felt that bringing the topic up in person was awkward and uncomfortable. Participants felt that it is not a conversation that can be brought up casually, and that the timing was never right. Educating the general public was identified as solution to spread more awareness on donation so that people would be more familiar with the benefits and the process (Pradel et al., 2003; Waterman et al., 2006).

Recipients also experienced mixed emotions during the donation process (Pradel et al., 2003; Waterman et al., 2006). Emotions changed in the post-transplant period from the pre-transplant period. In the qualitative study by Pradel et al. (2003) embarrassment and guilt was experienced in the pre-transplant period when the decision making process was taking place. Guilt was common when a member of the recipients' support network approached them about giving a kidney. On the other hand, when recipients asked members of their support networks to donate but they did not want to, recipients felt anger and were upset.

Post-transplant emotions were different than emotions described pre-transplant. Once the kidney was received and functioning well, recipients felt gratitude towards the donor and experienced a better quality of life (Pradel et al., 2003; Waterman et al., 2006). Waterman et al. (2006) states that post-transplant is a time of appreciation where recipients often thank the donors for the functioning kidney they have received. It is a chance to get their lives back on track, and they often feel the best they have been in a long time.

Overall, findings from the studies show that recipients fear bringing harm to others and this is why they resist seeking live donors. They are unaware of what life will be like for donors post-transplant. Therefore, they do not want to take a kidney from a member of their support systems in fear that the donor would lose function in the remaining kidney, and end up on dialysis too. The fear that they experience is attributed to the lack of education on risks and testing. Recipients described feeling uncomfortable discussing the topic of live donation with their support systems. Without awareness and education, their support systems are unaware of the donation process, and therefore less likely to come forward as a donor.

Donors undergoing live kidney donation. A number of qualitative studies were found that explored the experiences of live kidney donors throughout the donation process (Agerskov et al., 2015; Brown et al., 2008; Gill & Lowes, 2008; Pradel et al., 2003; Waterman et al., 2006). These studies will be summarized and are included in literature summary tables.

Donors revealed being self-motivated and comfortable with their decision to donate a kidney (Agerskov et al., 2015; Gill & Lowes, 2008; Pradel et al., 2003; Waterman et al., 2006). For donors, donating a kidney is an act of kindness to give family and friends a better quality of life than one depending on dialysis treatments three to four times per week (Pradel et al., 2003; Waterman et al., 2006). In the qualitative study by Pradel et al. (2003), donors were not concerned for themselves during the donation process, but instead were most concerned about not being able to perform a procedure or having an abnormal test result that could prevent them from being accepted as a donor. In fact, once required testing was completed, donors were extra cautious prior to the

surgery to ensure that they did not become unwell or do anything that would jeopardize the transplant from occurring (Pradel et al., 2003).

Although donors described feeling comfortable with their decision to donate, stressors were also identified when going through the live donation process (Agerskov et al., 2015; Pradel et al., 2003; Waterman et al., 2006). Waterman et al. (2006) found that donors felt that they were not fully educated on the donation process, and lacked appropriate knowledge. Without the appropriate knowledge, donors feared the unknown. Similarly, other studies found that donors felt that not receiving support or being able to ask questions contributed to their knowledge deficit (Agerskov et al., 2015; Pradel et al., 2003). Participants felt that appropriate knowledge is crucial during each step of the donation process. Donors required more information on donation awareness, information on the surgical procedure, financial commitments, and information on the recovery process (Agerskov et al., 2015; Pradel et al., 2003; Waterman et al., 2006).

To ease stress during the donation process, optimism was described as a motive for donors to complete the required testing (Agerskov et al., 2015; Pradel et al., 2003). In the Agerskov et al. (2015) study, a phenomenological-hermeneutic approach was used to explore potential donors' experiences during the donor evaluation process. The sample consisted of 18 donors who underwent participant observation and semi-structured interviews. Participants revealed in the data collected, that although they considered themselves to be healthy and able to donate a kidney, they still felt powerless knowing that an irregular test result could prevent them from being able to donate. Therefore, they diverted their stress to optimism. They were optimistic that all test results would be normal and that they would get accepted as a donor.

In summary, the studies revealed that for donors, the decision to donate was often self-directed and in the best intention of the recipient. Donors decided to proceed with the live donation process to help loved ones get better, and have a better quality of life. However, many donors felt that they did not have enough knowledge during the live donation process. More information on the surgery, financial costs, and the donation process in general, would have made live donation a better experience. In addition, donors felt they lacked support and guidance through the process as well.

Barriers to Live Kidney Donation

Transplant is a major life transition for both recipients and donors. There are a number of requirements or needs that are important to identify for those choosing the live kidney donation option (Agerskov et al., 2015; Barnieh et al., 2011; Pradel et al., 2003; Rodrigue, Cornell, Kaplan, & Howard, 2008; Rodrigue, Cornell, Lin, Kaplan, & Howard, 2007; Waterman et al., 2006). Live kidney donation is not just a time of excitement, but also a time of uncertainty and fear (Pradel et al., 2003). There are two barriers to live kidney donation that were well defined in the literature search: lack of education, and insufficient support from healthcare professionals. Both barriers will be discussed in detail.

Lack of education. Using qualitative methods, a number of researchers discussed the need for education when making the decision to be a live kidney donor (Agerskov et al., 2015; Brown et al., 2008; Gill & Lowes, 2008; Pradel et al., 2003; Waterman et al., 2006). Education on live kidney donation is crucial during the decision-making and evaluation process. Donors and their recipients ought to be fully informed on how donation will impact their lives, and what to expect during the process (Sites et al., 2008).

Effective healthcare strategies and resources need to be developed to ensure that anyone wishing to be a kidney donor feels prepared and educated on transplant (Gill & Lowes, 2008).

Education on live kidney donation can be formal or informal depending on the transplant center. A formal education program would consist of developed resources and an education plan for anyone availing of the program, whereas informal education is often not planned out and has minimal resources. Education resources could include online, written, or verbal materials (Waterman et al., 2014; Waterman et al., 2015). Without a formal education program, those seeking information on live kidney donation, will have little to no knowledge on live donation as a transplant choice (Barnieh et al., 2011).

Quantitative studies have been reported that examine whether or not a formal means of education had an impact on the number of people choosing live kidney donation, and increased their knowledge of the live donation process (Barnieh et al., 2011; Rodrigue et al., 2007; Rodrigue et al., 2008). In a study by Barnieh et al. (2011) a randomized controlled trial was completed to examine whether or not a structured education strategy would be beneficial in increasing the number of recipients seeking live kidney donation. The secondary objective of the study was to explore recipients' preferences on live kidney donation as the best transplant option. There were 100 participants in the sample, 50 participants in the intervention group and 50 in the control group. The education initiative included both written materials and an education session. The education session was designed to be interactive for all transplant recipients, family members, and interested potential donors. Nurses and nephrologists also attended the education session. There was brainstorming on the benefits of live kidney donation, role-

playing, and a question and answer period provided (Barnieh et al., 2011). The study revealed that those who completed the intervention found it effective. From baseline, the intervention group ($p=.02$) were more likely to choose live donation than the control group ($p=.37$). Participants in the intervention group were also more comfortable with the live donation process and better informed than the control group (Barnieh et al., 2011).

Data from randomized controlled trials performed by other researchers supported the need for a formal education program on live kidney donation (Rodrigue et al., 2007; Rodrigue et al., 2008). Patients are reluctant to choose live kidney donation and approach others to be donors, due to lack of education and knowledge on risks and benefits, eligibility, and the transplant process (Rodrigue et al., 2007). Rodrigue et al. (2007) explored whether or not a home-based education program in conjunction with a clinic based education program would be more effective in increasing live kidney donation than using the clinic based education program alone. The sample consisted of 69 participants in the control group and 63 in the intervention group. Numbers in the groups differed due to dropout rates and participants not consenting to the study. Those in the control group received the clinic based education program that included: routine clinics visit with a nephrologist, a pamphlet, and a 60-minute education session with other transplant patients. The intervention group received the same education as the control group, but received a home visit where a member of the transplant team held an additional education session. The patient's support network could attend the session, and was given the same information pamphlet and educational resources as the recipients. Those who conducted the home visits had extensive training on live kidney transplant and answered any questions that were had as well.

The patients who received the intervention (82.5%) had more inquiries on wanting to participate in the live donor kidney transplant program than those in the control group (63.8%). Although both groups had increased knowledge on live kidney donor transplant, both recipients and their support networks who received the intervention demonstrated additional knowledge and understanding ($p < .00010$). Therefore, from the study findings, education in center in conjunction with education initiatives at home, were shown to be effective and worthwhile when educating recipients and their support networks on live donation.

Rodrigue et al. (2008) had similar findings in their study that explored the effectiveness of increased education for those choosing live kidney donation. The study was performed since the researchers identified that recipients were reluctant to seek live kidney donation due to the fear of having to discuss the topic with donors. The study found that increased education is correlated with a greater likelihood of support networks coming forward to donate and recipients discussing live donation with members of their support networks.

In summary, both kidney donors and recipients lack appropriate knowledge on live kidney donation. Transplant programs would benefit from increased availability of resources. Transplant is a life transition, and adequate education is pivotal for those choosing live kidney donation. There is a need for more information during the decision making process to ensure that donors make an informed decision on transplant. Currently, a number of programs use an informal means of providing education to patients. Therefore, developments of structured education programs would help to overcome the existing education barrier. More education was also linked to an increased number of

donors deciding to participate in live donation, and increased comfort levels of recipients discussing live donation with their support networks.

Lack of support from healthcare professionals. Lack of support from healthcare professionals during the decision-making, testing, and pre-donation process is identified in a number of qualitative studies, as a barrier to live kidney donation (Agerskov et al., 2015; Brown et al., 2008; Gill & Lowes, 2008; Pradel et al., 2003). Gill & Lowes (2008) state that although some donors do not hesitate to donate a kidney, 25% of potential donors contemplate their decision to donate and 5% postpone their decision all together. Therefore, support from healthcare professionals to answer questions and alleviate concerns is crucial during the decision-making process, and lack of support could impede a person's decision to donate (Gill & Lowes, 2008).

In a qualitative study by Pradel et al. (2003) the researchers found that adequate education provided by healthcare professionals is beneficial in easing fears and concerns around the donation process. The researchers performed interviews and focus groups with both kidney donors and recipients to explore their experiences. The participants, who had undergone some form of education from healthcare professionals on the live donation process, felt that it alleviated their concerns. For example, the transplant surgical procedure is a topic that worried a number of participants. However, when participants received the appropriate information from the transplant team on the risks involved for the donor and recipient, recipients were less reluctant to approach their support networks to donate. Similar findings were from a qualitative study by Agerskov et al. (2015) that identified that a donor's comfort level, decision-making process, and overall transplant experiences were greatly impacted by the support given by healthcare professionals.

Donors voiced that they seek emotional support, and feel the desire to have healthcare staff available for information and questioning (Agerskov et al., 2015).

Ensuring that healthcare professionals spend appropriate time assisting patients with understanding new learning material is crucial for those undergoing the live kidney donation process (Agerskov et al., 2015; Boulwarc et al., 2013). In a qualitative study by Agerskov et al. (2015) the researchers recognized that both recipients and donors have to undergo various testing and procedures, and may not be aware of what they entail. Participants in the study revealed that when healthcare professionals explain the procedure, they felt more supported. They also felt more comfortable knowing that their needs were addressed (Agerskov et al., 2015).

The donors' support systems are often present in the dialysis unit, and would benefit from education. However outside of the transplant team, healthcare professionals do not always have the appropriate knowledge base (Waterman et al., 2015). Barriers to prevent healthcare professionals from being able to provide this support include: lack of training time for healthcare professionals, insufficient educational resources available in dialysis centers, and difficulty staying current with new testing and guidelines (Waterman et al., 2015). Therefore, training sessions led by transplant coordinators or other members of the transplant team, would be helpful in overcoming lack of support and allowing patients to feel more supported when choosing a transplant option (Waterman et al., 2015).

In summary, healthcare professionals play a major role in patient care and understanding. Support from healthcare professionals was linked to reducing fear and concerns of donors and recipients undergoing the live donation process. Patients, who

chose live kidney donation, felt that they lacked support from healthcare professionals. Without this support, it left recipients and donors with questions and concerns during the live donation process. It is important that questions get answered, to ensure that patients feel comfortable with their donation decision. Healthcare professionals do not always have adequate education on live donation themselves. Training sessions and increased educational resources would be an asset for healthcare professionals. With access to these resources, healthcare professionals would feel more comfortable educating patients, and better able to provide the support that patients need during this transition in their lives.

Existing Educational Resources for Educating Donors and Recipients on Live Donation

Online Initiatives. To ensure patients are adequately educated, education resources need to be accessible and fit the needs of the population requiring them (Taylor et al., 2012). A number of online resources have been utilized to raise awareness and promote education on live kidney donation (Kazley, Hamidi, Balliet, & Baliga, 2012; Powells, Inglis, Ronnie, & Large, 2011; Taylor et al., 2012; Waterman et al., 2015).

Kazley et al. (2012) examined social media as a tool to advocate and educate others on live kidney donation. In the study, a cross-sectional design was utilized to examine participants' current use of social media for seeking both health-related and non-health related information. A survey was used that focused on social media use, and how willing participants were to use social media as a tool to seek donation from support networks. Social media was shown to be a simplified way to connect recipients with potential donors. Social media also raised awareness on live kidney donation (Kazley et al. 2012). Of the 199 participants who took part in the study, over half of the participants

(n=104) stated that they would be comfortable using social media as a tool to share information about their kidney disease and need for transplant. The social media tool was also shown to cause less anxiety than having to speak with a friend, family member, or loved one about being a kidney donor (Kazley et al., 2012). Social media is accessible through home computer, tablets, and cellular devices, giving people access to information at all times. Therefore, incorporating these tools into an education program for live kidney donation would be beneficial (Kazley et al., 2012).

Similarly, a number of studies explored the use of the Internet to spread awareness of health related topics (Powell et al., 2011; Taylor et al., 2012). Taylor et al. (2012) discussed an education and social support website as a way to provide education on live kidney donation. By combining online resources in conjunction with traditional methods such as videos, written materials, and conversations with healthcare professionals, recipients and potential donors, felt more comfortable with making informed decisions on live donation. Resources online are also accessible to vast audiences. They are an easier way to spread awareness on live kidney donation than having to approach family and friends about being a donor in person (Taylor et al., 2012).

Powell et al. (2011) had similar findings in their mixed-methods approach that explored Internet use for finding information on health-related topics. The study consisted of a survey and semi-structured interviews. Results indicated that the Internet is a convenient and accessible tool for answering questions without having to schedule an appointment with a healthcare professional. Results of the survey showed that 47.5 % of participants reported seeking help online for a new health issue. Participants under the age of 36 were also identified as being the most likely to choose online methods to gain

information on a health issue than consulting with a professional first, but other age groups were receptive as well. The interviews performed identified that the Internet provides re-assurance for people by providing information they may have forgotten from a clinic visit or were concerned about. The Internet was also considered a supplement to existing information that patients have received from consultations and other forms of education in the past.

Online resources are also a way for donors and recipients to connect with those who have gone through the experience in the past. If use of technology is expanded, it could be a promising initiative for increasing interest in live kidney donation. It will also provide more accessibility to educational resources for people living in rural and geographically disadvantaged areas (Waterman et al., 2015).

Written Material and Support Groups. The literature search revealed a number of clinical articles that suggested the importance of written materials and support groups in raising awareness and providing education on live kidney donation (Waterman et al., 2014; Waterman et al., 2015; Waterman et al., 2016). Engaging in verbal conversations with both recipients and donors is important in determining their readiness, and to explore their knowledge base (Waterman et al., 2016). Education pamphlets, videos, and one-on-one discussions are useful tools that should be available in all transplant programs, in an effort to meet the diverse learning needs of both recipients and donors (Waterman et al., 2016). Waterman et al. (2014) discuss the Explore Transplant initiative that was utilized in a previous study. It was a trial that utilized paper resources and video tactics to explore whether or not using these educational tools would make the decision-making process easier and improve overall knowledge on live kidney donation. The trial was shown to

increase knowledge in participants who received the educational tools over the participants who did not.

In summary educational resources need to exist, to ensure that patients are properly educated. Literature suggested the need for a combination of both written and online resources to meet the vast learning needs of those requiring information on live kidney donation. Online resources such as the Internet and social media applications are popular in today's society, and identified as useful tools to provide education on a vast array of health related matters including live donation. Online methods are easily accessible, and most people identified feeling comfortable using online tools to seek knowledge on both health related and non-health related topics. Along with online tools, study findings also highlight the need for written and verbal learning materials as well. The online methods should be provided in conjunction with written materials and support groups, to ensure there is a formal and structured education program on live kidney donation.

Theoretical Foundations to Guide the Practicum Project

Knowles' Adult Learning Theory

Concepts of Knowles' Adult Learning Theory will be incorporated into the development of an educational program for kidney donors. Knowles' Adult Learning Theory is premised on the way that adult learners incorporate new knowledge, skills, and attitudes into their learning experiences (Abela, 2009). First of all, to be a live donor, the person needs to be eighteen years of age or older. Therefore, this is an appropriate learning theory for the target population since all people who will avail of the education program, will be adults.

There are a number of assumptions that are part of the theory. Adult learners desire independence and come from different backgrounds and life experiences. They are also motivated when working towards a need, expect respect in the learning environment, and their desire to learn is driven by how the learning experience will benefit their lives at the time (Abela, 2009). Adult learners learn best when mutual respect exists among themselves and the educator (Aliakbari, Parvin, Heidari, & Haghani, 2015). I will need to consider these assumptions when developing the education program for live kidney donors or it could affect the learning experience of those utilizing it. Those inquiring about live kidney donation could come from all different knowledge backgrounds. Patients or members of their support systems tend to have minimal knowledge until given the appropriate resources, whereas healthcare professionals may have some baseline knowledge. Therefore, the information in the resources needs to be detailed and descriptive enough to provide adequate information for recipients and donors to make informed decisions on live donation, and for healthcare professionals to expand their knowledge base.

Adult learners get the most out of learning experiences when the topic and content is beneficial to them. Therefore, when educating and informing adult learners, it is important that any resources being utilized are based on the learners' needs (Candela, 2016). I will take the findings that I have gathered from the literature search and upcoming consultations, and incorporate what patients desire into the content included in the learning resources in the education program. It is also important to consider that since those utilizing the education program will be inquiring about live kidney donation, they should be motivated to learn more about the experience. However, I would encourage all

people considering live kidney donation to avail of the education program and ask questions. Providing the learners with adequate and appropriate learning resources is also being respectful of the learners' needs and shows the learners that they have support. If the learners have more support, it will make the education process an easier experience.

The adult learner is often self-directed in learning experiences (Aliakbari et al., 2015; Candela, 2016). Therefore I will need to ensure that I take this assumption into account in the development of this practicum project. This will be achieved by developing resources that use terminology that can be understood by people of all different learning levels. I will also develop resources that appeal to different learning needs. Not only will written materials be developed, but I will also develop an online learning resource, and an information session that is presented verbally. This way, participants can choose which resource best fits their learning needs and can be an active part of their own learning experience.

Transtheoretical Model of Behavior Change

The Transtheoretical Model of Behavior Change has been identified as an appropriate model to help guide educational initiatives for live kidney donors (Waterman et al., 2014; Waterman et al., 2016). The model is premised around the concept of change, and that when change occurs, a person needs to be ready to accept the change and work with it in order for the change to be beneficial (Lach, Everard, Highstein, & Brownson, 2004). The model discusses change in terms of five stages: pre-contemplation, contemplation, preparation, action, and maintenance (Waterman et al., 2014). Like the adult learning theory, self-efficacy and self-directed learning is encouraged and considered an important aspect of the model (Lach et al., 2004). The person experiencing

the change works through the stages, and the educator needs to ensure that the person is ready to move on to the next stage (Waterman et al., 2016).

This model is suitable for the development of an educational program on live kidney donation. Becoming a kidney donor is a major life transition that involves numerous changes for the donor and recipient. Both donors and recipients have very little knowledge on the transplant topic, process, and testing involved. Many donors are not even sure if they are ready to donate. As healthcare professionals, we need to take these concerns into consideration. This model will help guide how patients transition through the various stages on the live donation process. This will be particularly important to consider during the decision-making process. It would be considered the pre-contemplation and contemplation phase. At this phase, the recipients are choosing whether or not live donation should be their primary transplant option, and donors consider whether or not donation is right for them. Education is crucial at this phase and this can be a fearful and uncertain time for patients. Therefore, through this transition, proper education is pivotal to help patients get the information they desire, and help everyone involved make an informed decision.

Ensuring there are appropriate and sufficient educational resources is also important during the preparation phase of the transplant transition. Patients cannot prepare for live donor transplants if they do not have the materials to prepare with. We currently have an informal education program and limited resources. Therefore, developing the formal education program and incorporating additional resources will be an asset for patient planning and their comfort level during the transplant experience.

Summary of Themes and Concepts

After completing a review of current literature, a number of themes and concepts were revealed. Firstly, undergoing a transplant is a major life transition causing both fear and uncertainty for the kidney donor and recipient. There is a lack of education on live donation for the general public. Therefore, without education, there is little awareness.

The experiences of donors and recipients were discussed in detail. Recipients fear bringing harm to others and resist seeking live donors because of this reason. This is attributed to the lack of education on risks and testing. Recipients also feel uncomfortable bringing the topic of live donation up to their support systems. Without awareness and education, their support systems are unaware of the donation process, and therefore less likely to come forward as a donor. Donors identified wanting to go through the donation process to help loved ones get better. They wanted their loved ones to have a better quality of life, and not have to depend on dialysis to live. The decision to donate was often self-directed and in the best intention of the recipient. However, many felt that did not have enough knowledge during this transition in their lives. In addition, donors felt they lacked support and guidance from healthcare professionals through the process as well.

Lack of education and insufficient support from healthcare professionals were identified as two major barriers to live donation. Both kidney donors and recipients lack appropriate knowledge. There is a need for more information during the decision-making process to ensure that donors make an informed decision on transplant. Transplant programs would benefit from increased availability of resources. Currently, a number of programs have informal means of providing education to patients. Therefore,

developments of formal education programs would be an asset to help and overcome the existing education barrier.

Literature also suggested a need for a combination of both written and online resources to meet the vast learning needs of any individuals requiring information on live kidney donation. Internet use and social media is becoming more popular in today's society, and has been identified as appropriate tools to provide education on kidney transplantation and live donation. Online methods are also easily accessible, and users identified feeling comfortable using the Internet to seek knowledge on both health related and non-health related topics. The findings do not undermine the need for written and verbal learning materials as well. The online methods should be provided in conjunction with written materials and support groups, to ensure there is a formal education program.

Knowles' Adult Learning Theory would be appropriate to guide this practicum project, and help develop an education program for live donation. The learning theory focuses on self-directed learning and is appropriate for the target population. In addition to the Adult Learning Theory, the Transtheoretical Model of Behavioural Change has been discussed in literature as an appropriate model to guide educational initiatives for transplant and live kidney donation. This model will help guide how patients transition through the various stages of the live donation process. Since transplant is a transition that involves a lot of emotions and the need for education, the people undergoing the transition need to be willing to embark on this journey, and accept the transition, before they should move forward with the decision to participate in the live donation program. Therefore, they need to be fully educated on the live donation process to ensure an informed decision is made.

Limitations

There are a number of limitations that should be considered in the completion of this integrated literature review. Despite the abundance of literature available on live donation, there were a limited number of quantitative research studies that have been completed on live kidney donation. Although, the quantitative studies found were randomized controlled trials and strong study designs, the research studies did suggest further research on the topic. The quantitative studies that were utilized were all single-center designs. Therefore, generalizability was limited. Sample sizes were also small and initial sample sizes did decrease due to a number of people dropping out of the study or not meeting the eligibility criteria. In addition, some of the data, such as surveys, was self-reported which could have yield inaccurate or incomplete information.

There were a number of qualitative studies found during the literature search. However, there are limitations to note for these studies as well. Qualitative studies lack generalizability due to single-center designs and small sample sizes. With the use of small sample sizes, it is also difficult to know if data saturation is reached in the studies.

There were no research studies found on healthcare professionals experiences with educating patients on live kidney donation. In addition, minimal research was found on supports for healthcare professionals. The literature search did not yield quantitative studies performed to explore the benefits of written and verbal education sessions. The studies that were found focused primarily on online education initiatives. This could be an indication for the importance of future research on these topics. There were a limited number of Canadian studies found during the literature search, and no studies completed

in NL. This deliberates the need for future research on the topic. A complete synopsis of each study can be found in literature summary tables located in the appendices.

Conclusions

This literature review yields a number of themes and implications that can be incorporated into the development of this practicum project on an education program for those participating in live kidney donation. The literature provided insight into barriers to live kidney donation and past experiences of both recipients and donors choosing the live donation option. Live kidney donation is a major life transition for those choosing the option. Therefore, it is crucial that all participants involved, have appropriate information and resources available (Pradel et al., 2003). Education on live kidney donation is needed and important. The need for this practicum project exists to ensure that knowledge and awareness on kidney donation is increased in NL. There is also a need for collaboration and support from healthcare professionals (Gill & Lowes, 2008). Not only do the transplant team need to provide formal education on the topic, but there is a need for dialysis unit staff to be informed and educated as well. There are also implications for the need to have both written resources in conjunction with online education to ensure that education is readily available, accessible, and meets a vast array of learning needs. This justifies the need for the development of not just a pamphlet and education session, but an online component as well.

Concepts of Knowles' Adult Learning Theory, and the Transtheoretical Model of Behavioral Change will be utilized to help guide the development of this practicum project. These theoretical foundations are appropriate for the target population, and will help to guide what content should be included in the education program and how patients

transition through the various stages of the live donation process. Literature summary tables have also been included for all research studies utilized in the development of this paper, and can be found in the appendices.

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Appendix A

Author/Date	Objective/Study Design/Sampling Characteristics	Relevant Outcome Measures	Results of Study	Conclusions/ Strengths and Limitations/ Overall Study Rating
Rodrigue, Cornell, Lin, Kaplan, & Howard, 2007	<p>Objective: To test whether or not a home-based education program in conjunction with a clinic-based program would be more useful in increasing live kidney donation</p> <p>Study Design: Randomized Controlled trial</p> <p>Sampling Characteristics:</p> <ul style="list-style-type: none"> -Location was Shands Hospital, University of Florida. -Setting was in an outpatient kidney transplant clinic (single-center study) -Participants were all potential transplant recipients awaiting transplant and without a live donor Control group received just clinic-based education n=69 Intervention group received clinic and home-based education n=63 	<ul style="list-style-type: none"> -Descriptive statistics were utilized for continuous variables -T-tests and chi-square tests were used to demonstrate differences between the control and intervention group at baseline, halfway, and at the end. -Logistic regression analyses was utilized to depict any variables pertaining to live kidney donation -All data was analyzed using SPSS software. 	<ul style="list-style-type: none"> -Home-based intervention was more effective for increasing knowledge and education -Both the intervention and control groups' education methods were effective for increasing knowledge - Intervention group demonstrated additional knowledge and understanding ($p<.00010$). -Post-study the intervention group was found to be more likely to discuss live donation with others. -The intervention group wanted to participate in the live donor kidney transplant option more than those in the control group (82.5% vs. 63.8%). 	<p>Conclusions:</p> <p>The study revealed that those in the intervention group had more knowledge and willingness to discuss live donation options with their support networks.</p> <p>Strengths:</p> <ul style="list-style-type: none"> -Strong study design -Appropriate sample size <p>Limitations:</p> <ul style="list-style-type: none"> -Self-selection bias. -Since it was a single-center study the participants who chose to take part may have been considering live donation or had some knowledge prior to the study -A high number of participants chose to not complete the study 10% dropped out of control 30% from intervention -The generalizability of the study is limited since it is a single-center study <p>Overall Study:</p> <p>Strong Study Design Strong Study Quality</p>

Appendix B

Author/Date	Objective/Study Design/Sampling Characteristics	Relevant Outcome Measures	Results of Study	Conclusions/ Strengths and Limitations/ Overall Study Rating
Rodrigue, Cornell, Kaplan, & Howard, 2008	<p>Objective: To explore transplant recipients' readiness to discuss live kidney donation with their support network</p> <p>Study Design: Randomized Controlled trial</p> <p>Sampling Characteristics: Participants- n=132 -Medical and socio-demographic information was collected on each participant.</p> <p>Inclusion criteria: Over the age of 21, accepted for the transplant list, live close to transplant center, White or African American, and need to have telephone service</p> <p>Exclusion Criteria: Unable to speak English -Participants completed a baseline questionnaire upon enrollment to the study regarding their willingness to donate</p>	<p>-Data was analyzed using SPSS software</p> <p>-Descriptive statistics were utilized in order to summarize the medical and socio-demographic information of the entire sample</p> <p>-The mean standard deviation was calculated in order to get results for: willingness to talk about live donation, knowledge about live donation, concerns about live donation, and perceived health ratings</p>	<p>-Over half of participants (56.1%) did not want to discuss live donation with their support networks</p> <p>-The mean standard deviation of recipients' willingness to discuss donation was 3.9 on a 7 point scale.</p> <p>-More Education does increase the likelihood that recipients will discuss donation with possible donors</p> <p>-Having educational resources readily accessible to the general public, improves recipients' confidence to talk about live donation</p>	<p>Conclusions: More education is correlated with a greater likelihood that potential transplant recipients will discuss transplant with potential donors</p> <p>Strengths: -Strong study design -The study demonstrates the importance of education for increasing the comfort level and willingness of recipients discussing live donation with potential donors. -Large sample size for a single-center study</p> <p>Limitations: -Single-center study -Patients were self-selected and therefore generalizability is limited -Patients' views and willingness to discuss transplant only represents their views at that point in time and further studies are suggested</p> <p>Overall Study: Strong Study Design Strong Study Quality</p>

Appendix C

Author/Date	Objective/Study Design/Sampling Characteristics	Relevant Outcome Measures	Results of Study	Conclusions/ Strengths and Limitations/ Overall Study Rating
Barneih et al., 2011	<p>Objective: To explore whether using a formally developed education session would increase the number of patients pursuing live kidney donation.</p> <p>Study Design: Randomized Controlled trial</p> <p>Sampling Characteristics: -Setting: Southern Alberta Transplant Program. -Control group n=50 received standard care) -Intervention group n=50 (received the education session) -Participants were randomized</p> <p>-Inclusion Criteria: have medical clearance by a physician to complete transplant work-up, sign a written consent</p> <p>-Exclusion Criteria: do not speak English, cognitive dysfunction, younger than 18, already have a live donor.</p>	<p>-The education intervention was comprised of written materials and an education session.</p> <p>-Participants had to complete a baseline questionnaire which included asked knowledge based questions rated on a likert scale.</p> <p>-A follow-up questionnaire post intervention for intervention group and standard care for control group that contained the same content.</p> <p>-The primary outcome was to explore whether any potential living donors would call the program to be worked up for a recipient</p> <p>-The secondary outcome was to see if more recipients would choose live donation as their main transplant option.</p> <p>-Fisher exact tests were utilized to compare the number of new live donors who came forward in control versus intervention group.</p> <p>-Data was analyzed using SPSS software</p>	<p>-There was no significant difference in the number of live donors who came forward for recipients in the control versus intervention group (4 for intervention versus 2 for control)</p> <p>-A significant increase was noted in the intervention group in the number of recipients who would choose live donation as their transplant option (p=.02)</p>	<p>Conclusions: -Patients who receive adequate education are more likely to choose live donation as their transplant option and pursue live donors</p> <p>-There is a need for further studies investigating the benefits of educating on live donation</p> <p>Strengths: -Strong study design -Data collectors were blinded to the study</p> <p>Limitations: -Authors noted that recruitment was slow and they ended enrollment for the study early. -Small study size -Generalizability of sample</p> <p>Overall Study Design: Medium Quality Strong Study Design</p>

Appendix D

Author/Date	Objective/Study Design/Sampling Characteristics	Relevant Outcome Measures	Results of Study	Conclusions/ Strengths and Limitations/ Overall Study Rating
Powell, Inglis, Ronnie, & Large, 2011	<p>Objective: To explore use of health-related Internet use to get health related information</p> <p>Study Design: Mixed-methods approach</p> <p>Sampling Characteristics: -A survey and questionnaire were used as data tools</p> <p>-All participants wanting to participate in the study, had to consent by entering their e-mail addresses in order to receive the survey</p> <p>-Maximum variation sampling was utilized to select interview participants -n=792 for survey -n=26 for interview</p>	<p>- A self-administered open cross-sectional survey was administered to anyone visiting the National Health Service Direct website.</p> <p>-Semi-structured interviews were conducted using 2 interviewers and consisted out open-ended questions</p> <p>-Interviews were done via telephone or instant messaging</p>	<p>-Online information provides re-assurance for patients</p> <p>-Online is a convenient way to get health information</p> <p>-Online resources help answer questions without having to see a healthcare professional.</p> <p>-47.5 % of participants reported seeking help online for a new health issue</p> <p>-19.6 % use seek information online for a long-standing health issue</p> <p>-44.9% reported seeing a doctor prior to looking online for health information</p> <p>-Participants <36 years of age were less likely to consult with a professional prior to using the internet</p>	<p>Conclusions: Health-related Internet use is beneficial for getting the health related information that is desired</p> <p>Strengths: -Cookies prevented multiple submissions of the survey coming from the same computer -Interviews were done at least a week after using the site to avoid recall bias. -The interviews allowed participants experiences to be discussed in depth</p> <p>Limitations: -There were issues with survey link throughout the allotted time period</p> <p>-Large number of people opted out of study</p> <p>-Since interviews were used, researchers' personal biases may influence participants' responses</p> <p>Overall Study: Medium Quality and a Strong Study Design</p>

Appendix E

Author & Date	Objective, Study Method & Data Collection	Sample/Setting	Results of Study	Conclusions/ Strengths and Limitations
Agerskov, Ludvigsen, Bistrup, & Pedersen (2015)	<p>Objective: The study explores experiences of kidney donors during the donation work-up</p> <p>Study Design: Qualitative study using a phenomenological-hermeneutic approach</p> <p>Participant Observation -The observation occurred over 12 weeks and was done for 6 hours per day. -Field notes were transcribed after each observation</p> <p>Semi-structured Interviews -Semi-structured interviews were completed with all participants. -Open ended questions were utilized for the interviews and held in participants' homes and in the hospital setting -12 interviews were held -interviews were recorded and transcribed.</p> <p>Data Analysis: The analysis of the study was completed through naïve reading, structural analysis, and critical interpretation and discussion</p>	<p>Setting: -The setting was Danish University hospital in an outpatient transplant clinic</p> <p>-Inclusion criteria: was limited to being over the age of 18 and able to speak Danish</p> <p>Sample: N=16</p>	<p>-The study revealed that donors felt that interactions with healthcare professionals were not always positive when getting educated and receiving information on testing.</p> <p>-Donors feel vulnerable, hope and concern</p> <p>-The evaluation phase is a crucial time when the proper education and support is required.</p> <p>-Donors were sometimes confused by healthcare professionals explanations</p> <p>-Donors' experiences were most positive when they could collaborate well with the health professionals that they were involved with.</p>	<p>Conclusions: The donor's experiences were strongly impacted by their relationship and information received from the healthcare professionals assigned to them. -Donors have a lot of questions that need to be addressed when completing their work-up. -Further studies on the experiences of kidney donors is recommended</p> <p>Strengths: -Interviews allowed participants to discuss their own experiences</p> <p>Limitations: -Sample size -Generalizability -Single-centered study -Researchers' personal biases may influence participants' responses</p>

Appendix F

Author/Date	Objective, Study Method & Data Collection	Sample/Setting	Results of Study	Conclusions/ Strengths and Limitations
Waterman et al., 2006	<p>Objective: To explore the educational needs of recipients when considering live kidney donation</p> <p>Study Design: Qualitative study using focus groups.</p> <p>Data Collection: -Focus groups were used to gather information from participants -Utilized standard focus group analysis techniques for the content analysis of the groups. -All audiotapes were transcribed and themes were identified.</p>	<p>Setting: Barnes-Jewish Transplant Center, St. Louis</p> <p>Sample: Participants: n=33 (26 transplant recipients, 4 donors, 3 family members) -All participants had access to the standard patient education program that was being utilized (video, meeting with coordinator, nephrologist, social worker, and transplant surgeon)</p>	<p>-This study shows that a number of barriers and concerns on live donation. -Recipients are scared to ask family and friends to donate -Recipients worry about donors' health. -More education needs to be provided regarding the donor's risk post-transplant. -Donor's voiced feeling personal benefits from donating to a loved one. -If there was more education available, then donors would have more information on the donation process, and recipients would feel more comfortable discussing the topic with others.</p>	<p>Conclusions: -Education on live donation is valuable and can address a number of questions that pose barriers to live donation.</p> <p>Strengths: -Focus groups allow for group interaction -Focus groups does not exclude participants from the study who cannot read or write.</p> <p>Limitations: -Single-center study -Additional quantitative research was suggested to study the prevalence of the concerns that participants discussed. -Generalizability -More recipients than donors participated -Sample size</p>

Appendix G

Author/Date	Objective, Study Method & Data Collection	Sample/Setting	Results of Study	Conclusions/Strengths and Limitations
Pradel, Mullins, & Bartlett, 2003	<p>Objective: To explore the experiences of kidney donors and recipients with regards to live donation and laparoscopic surgery</p> <p>Study Design: Qualitative using focus groups</p> <p>Data Collection Methods -Focus group topics: decision-making, eligibility and screening, the surgical process, and life after transplant -8 focus groups took place. -There were 2 focus groups per participant category -Interviews were taped and recorded and consent was obtained. -Content was transcribed -The content analysis was guided by a phenomenological approach</p>	<p>Setting: University of Maryland, Baltimore</p> <p>Sampling Characteristics: The participants were chosen and placed into 4 categories: considering donation, already donated, need a kidney, and received a kidney -Mailed a letter of invitation if they met the study eligibility criteria -If potential recipients did not respond, they were called once and explained the purpose N=161 were contacted N=25 participated</p>	<p>Decision-making: -Donors were self-motivated, and did not feel pressured and wanted to be a donor to help a loved one -They found the work-up stressful with lack of information on some topics. -Recipients felt fear and uncertainty -More information on finances would have been an asset -The public would benefit from more awareness on live kidney donation. This would also aid in decision making</p> <p>Life After Kidney Removal -Donors felt that the experience strengthened their relationship with the recipient -There was little attention given to them by the healthcare team post surgery</p>	<p>Conclusions: -Overall, donors and recipients have positive attitudes about live donation. -More awareness needs to be made available for the general public on live donation -More information needs to be provided on finances</p> <p>Strengths: -Content was reviewed by two independent researchers, and then findings were compared to develop themes -Research question answered via appropriate methods -Ethics Approval</p> <p>Limitations: -There were a small number of participants in the focus groups -Single-center study -Generalizability</p>

Appendix H

Author/Date	Objective, Study Method & Data Collection	Sample/Setting	Results of Study	Conclusions/ Strengths and Limitations
Kazley, Hamidi, Balliet, & Baliga, 2016	<p>Objective: To explore the use of social media as a way to increase education on living kidney donation.</p> <p>Study Design: Cross-sectional design</p> <p>Data Collection: -Interviewed participants using survey questions -Descriptive analyses were calculated for all study variables (means, frequencies, and ranges) -Chi-square tests and 1-way analysis of variance was used in order to take into consideration any demographic differences and social media use among participants.</p>	<p>-Setting: Medical University of South Carolina Renal Access Clinic</p> <p>Sample: -200 surveys were sent to kidney transplant candidates and recipients seen at the clinic. -Participants: N=199</p>	<p>- A significant difference in social media use between younger and older adults. This was the only demographical variable that made an impact on results.</p> <p>-The study did reveal that some people had already used social media as a way of seeking live donation.</p> <p>-Half of participants felt comfortable with using social media to promote live donation</p> <p>-Social media is an innovative and fast way to spread awareness on health information and can reach a vast audience</p>	<p>Conclusions: -Social media increases awareness on health related matters and education</p> <p>Strengths: -Appropriate sample size -The interview allowed participants to express their experiences.</p> <p>Limitations -Was a single-center study -Self-reported results -There were no specific outcomes of the study</p>

Appendix I

Author/Date	Objective, Study Method & Data Collection	Sample/Setting	Results of Study	Conclusions/ Strengths and Limitations
Gill & Lowes, 2008	<p>Objective:</p> <ul style="list-style-type: none"> -To explore live transplantation experiences from donors and recipients -To get a better appreciation of a theoretical understanding of living transplantation <p>“Theory of Gift exchange”</p> <p>Study Design:</p> <p>Qualitative Phenomenological Longitudinal study</p> <p>Data Collection</p> <ul style="list-style-type: none"> -3 Semi-structured interviews were performed -The semi-structured interviews were recorded -Interviews were conducted in private and done separately -Interviews were completed pre and post transplant to get participants views at both points during their transplant experience -Thematic Content analysis was utilized to analyze data in the study 	<p>Setting:</p> <ul style="list-style-type: none"> -Single-center study -South-West England <p>Participants:</p> <ul style="list-style-type: none"> -11 families undergoing live kidney transplant participated in the study n=22 participants (11 recipients and 11 donors) -There were 20 possible families who were eligible to participate 	<ul style="list-style-type: none"> -Many recipients described donation as an emotional time and had concern for the donor’s well-being -Donors should be encouraged to reassure the recipient that they are comfortable with the decision to donate -Overall, recipients and donors found the transplant experience a positive experience -The transplant increased quality of life for the recipient -The donation process led to positive family dynamics between the donor and recipient - Based on the “Theory of Gift Exchange” the live transplant experience involves many of the same components as a gift exchange 	<p>Conclusions:</p> <ul style="list-style-type: none"> -Experiences of donors and recipients were provided -Motives, feelings, and concerns were noted -The participants’ experiences related to the dynamics described in the “Theory of Gift Exchange.” <p>Limitations:</p> <ul style="list-style-type: none"> -Single-centered study -Generalizability -The abundance of the recipient/donor pairs were spousal and most of the experiences shared with positive. -They questioned whether results would have been different if relationships were non-spousal or distant relatives <p>Strengths:</p> <ul style="list-style-type: none"> -Ethics Approval -The researcher was blinded to the participants and not involved in their care -Longitudinal study that was able to study experiences at different points during the transplant experience

Appendix J

Author/Date	Objective, Study Method & Data Collection	Setting/Sample	Results of Study	Conclusions/ Strengths and Limitations
Brown et al., 2008	<p>Objective:</p> <ul style="list-style-type: none"> -To explore feelings of donors during the decision-making process <p>Study Design:</p> <p>Qualitative Phenomenological Approach</p> <p>Data Collection:</p> <ul style="list-style-type: none"> -Semi-structured interviews were performed -11 face-to-face interviews were conducted -Only 1 participant was interviewed over the phone -Transcripts from the interviews were coded and themes were created 	<p>Setting:</p> <p>Ontario, Canada</p> <p>Participants:</p> <p>N=12</p> <p>Donors who had already donated a kidney</p> <p>-Part of a larger sample utilized in a previous study</p> <p>-Maximum variation sampling was used to choose participants from larger sample</p> <p>-A psychosocial assessment was performed on participants prior to the study starting</p>	<ul style="list-style-type: none"> -Seeing a loved one have better quality of life post-transplant was described as a rewarding experience -There were both interpersonal and intrapersonal factors that made an impact on the donors' decision to participate in live donation -Psychosocial needs should be addressed -Social support was important -A sense of loss was described post-transplant. Some felt gratitude from the recipient they gave to while others did not. -Improved relationships between the donor and recipient -Seeing the improvement in quality of life for the recipient was beneficial for the donor -Education is needed to address concerns -Most participants felt that if they had to make the decision to donate again, then they would have made the same decision 	<p>Conclusions:</p> <ul style="list-style-type: none"> -Helping a loved one was a motive to donate -Social support and education is important -Donation is an emotional and live changing event -Healthcare professionals need to address psychosocial needs of donors. <p>Limitations:</p> <ul style="list-style-type: none"> -small sample size -Single-center study <p>Strengths:</p> <ul style="list-style-type: none"> -Researcher was blinded to study participants and not directly involved in their care -Prior to interviews being conducted, interview questions were reviewed and revised -Study was approved by University of Western Ontario Review Board for Health Sciences Research -Data saturation was reached after 11th interview

Appendix B

Consultation Report: Educating Live Kidney Donors

Daisy Baldwin

200807360

Memorial University of Newfoundland

The Canadian Nurses Association [CNA] (2008) has outlined consultation and collaboration as competencies for advanced practice nurses. These competencies are achieved through effective communication by consulting with members of the healthcare team, to develop a plan that keeps the patient's best interests in mind. Therefore, advanced practice nurses should consult and collaborate with anyone directly impacting their patients' care.

"The advanced practice nurse provides expert care for specialized patient populations," (CNA, 2008, p.16). When compared to the role of the registered nurse, the advanced practice nurse, takes the lead on developing appropriate clinical guidelines and support for patient care, instead of solely implementing resources. Therefore, the advanced practice nurse looks for barriers impacting a patient population, and works towards improving the barriers (CNA, 2008). To develop guidelines, and improve patient care, the advanced practice nurse would need to review current research, and consult with other healthcare professionals involved with educating the specific patient population.

To fulfill the requirements of this practicum project, and the competencies of the advanced practice nurse, it was imperative to consult and collaborate with key stakeholders involved in the care and education of live kidney donors. Kidney Transplant is a specialized area of nursing where the patients involved undergo a major life transition. The information gathered from the consultations, in conjunction with an in depth literature review will be key resources for the development of an education program on live kidney donation. The consultations were held with the dialysis program's manager, transplant coordinators, the live kidney donor coordinator in Halifax, and

dialysis staff, to gain insight into their views on the importance of live kidney donor education. Consulting with these stakeholders is imperative to ensure that developing an education program for live kidney donation is warranted, and to explore what content the resources should include.

An overview of the practicum project will be summarized, and the rationale for the consultations will be outlined. I will also discuss the roles of the key stakeholders, provide an overview of the consultation process, describe how the information was processed and analyzed, and discuss the relevance of the consultations in relation to the practicum project.

Background of the Practicum Project

Chronic kidney disease is a current health problem in our world today. In Canada, an average of 16 people are diagnosed daily with chronic kidney disease that requires a renal replacement option (The Kidney Foundation, 2012). The most common renal replacement option is transplant. Compared to patients on dialysis, patients who have received a transplant experience a better quality of life, get a longer life expectancy, experience fewer side-effects than receiving dialysis treatments, and get the chance to live a normal life (Abecassis et al., 2008; Kazley, Hamidi, Balliet, & Baliga, 2016; Locatelli, Pozzoni, & Del Vecchio, 2004; Prihodova et al., 2014; The Kidney Foundation, 2012). However due to the increasing number of patients choosing a kidney transplant, there is a greater demand for kidney donors than are available (Kazley et al., 2016).

Transplant is a major life transition for both recipients and donors. There are a number of requirements or needs that are important to identify for those choosing the live kidney donation option (Agerskov, Ludvigsen, Bistrup, & Pedersen, 2015; Barnieh et al.,

2011; Pradel, Mullins, & Bartlett, 2003; Rodrigue, Cornell, Kaplan, & Howard, 2008; Rodrigue, Cornell, Lin, Kaplan, & Howard, 2007; Waterman et al., 2006). A search of literature revealed barriers to the shortage of kidney donors, and alludes to lack of education on live kidney donation, and insufficient support from healthcare professionals as underlying issues (Pradel et al., 2003; Waterman et al., 2006).

Education on live kidney donation is crucial during the decision-making and evaluation process. Donors and their recipients ought to be fully informed on how donation will impact their lives, and what to expect during the process (Sites et al., 2008). Effective healthcare strategies and resources need to be developed to ensure that anyone wishing to be a kidney donor feels prepared and educated on transplant (Gill & Lowes, 2008).

Lack of support from healthcare professionals during the decision-making, testing, and pre-donation process is identified in a number of qualitative studies as a barrier to live kidney donation (Agerskov et al., 2015; Brown et al., 2008; Gill & Lowes, 2008; Pradel et al., 2003). Gill & Lowes (2008) state that although some donors do not hesitate to donate a kidney, 25% of potential donors contemplate their decision to donate, and 5% postpone their decision indefinitely. Therefore, support from healthcare professionals to answer questions and alleviate concerns is crucial during the decision-making process (Gill & Lowes, 2008).

To ensure patients are adequately educated, educational resources need to be accessible, and fit the needs of the population (Taylor et al., 2012). The effectiveness of written, verbal, and online resources was unveiled in the literature search as educational tools that increase knowledge on live donation (Powells, Inglis, Ronnie, & Large, 2011;

Taylor et al., 2012; Waterman et al., 2014; Waterman et al., 2015; Waterman et al., 2016). A combination of educational tools is needed to ensure that education is readily available, accessible, and meets a vast array of learning needs.

In my experience as a transplant coordinator, I have also identified lack of education as a barrier to live kidney donation. Currently, in Newfoundland and Labrador, education is informal and limited to the use of an information pamphlet given to recipients and donors after contacting a coordinator. The pamphlet is not available to the general public. Two transplant coordinators, located in St. John's and Corner Brook, provide the other information that patients receive. The information provided, is through informal conversations or phone calls when questions arise. There are very few scheduled meetings, and some donors will never meet a coordinator in person due to geographical restraints. Otherwise, the transplant coordinators are responsible for the scheduling of tests and appointments necessary to get patients activated on the transplant list.

In addition, dialysis nurses are directly involved with patients' care, and in contact with their family and friends. These nurses have baseline knowledge on transplant and live donation, but are not formally educated on transplant options. They are also not educated by the transplant coordinators. Availability and accessibility to education should be improved to increase the comfort level and confidence of those participating in the live kidney donor program, to ensure an informed decision is made.

The finding of the literature review in conjunction with previous nursing experience with this patient population, justifies the need for an education program encompassing an online module, information session, and education pamphlet. This education program will be available to both donors and recipients, and accessible in

dialysis units to increase the education of healthcare professionals. With increased education, healthcare professionals can provide more support to patients inquiring about live kidney donation.

The Purpose of Consulting with Key Stakeholders

Consulting with key stakeholders is important to gain a better understanding of their perspectives, and whether or not their opinions correspond with the findings of the literature search that highlighted the need for an education program on live kidney donation. The key stakeholders identified for this practicum project include: the dialysis program manager, the nephrologist involved with donor care, two transplant coordinators, the live donor coordinator in Halifax, and dialysis nurses. Their names and formal titles will be discussed in detail later. If these stakeholders feel that those choosing live kidney donation are not adequately educated, I will explore the stakeholders' perspectives on whether or not an education program would be beneficial for this patient population. I will also explore the information that would be appropriate to include in the development of an education program, and how stakeholders feel the information should be relayed.

Information on Participants

For the purpose of this practicum project, there were a number of individuals who were identified as key stakeholders to consult with: Ms. Cheryl Harding who is manager of the dialysis program, Ms. Marion Coffey who is the transplant coordinator for Eastern and Central Newfoundland and for Labrador, Ms. Sheri Sheppard who is transplant coordinator for Corner Brook, Dr. Sean Murphy who is the Nephrologist for all donors in Newfoundland and Labrador, Ms. Heather Travis who is the live kidney donor coordinator in Halifax, and dialysis unit staff members. To recruit the participants, I

explained the purpose of the practicum, and asked each participant if they were willing to complete an interview. I was able to get in contact with all stakeholders except Dr. Sean Murphy. I will try consulting with him prior to the development of the education program. All other participants consented to participate in the study.

Ms. Harding was selected for consultation seeing that she is the manager of the dialysis program, has a dialysis background, and has worked with the Kidney Foundation. Therefore, she could offer important input on our current transplant program and the education being provided to patients. I also needed to get her approval to complete this practicum project. Consulting with her, and keeping her up to date on the practicum development was of utmost importance, and required by agency policy.

Ms. Coffey and Ms. Sheppard are the two full-time transplant coordinators responsible for donor and recipient transplant assessments in Newfoundland and Labrador. They provide patient teaching, and are actively involved in patient care during the transplant decision-making process and testing. These coordinators are also the patients' primary contact for any concerns or questions. They need to be fully informed on any new educational initiatives that are being developed, since they could be utilizing the resources in the future.

Dr. Murphy is the chief of the Nephrology program and the doctor responsible for donor assessments and testing in Newfoundland and Labrador. He meets with each donor, performs a health assessment, and has an in depth conversation on donation risks. Therefore, he was an appropriate stakeholder for consultation for the practicum project.

Ms. Travis is the live donor kidney coordinator in Halifax, where all Newfoundland and Labrador kidney transplants occur. We currently provide our patients

with the education pamphlet that is utilized in Nova Scotia. The transplant team in Newfoundland and Labrador are in regular contact with Ms. Travis. Consulting with her on this practicum project may identify other educational initiatives that Halifax uses in their center.

Since the literature search identified lack of support from healthcare professionals as a barrier to live kidney donation, I felt that it was necessary to consult with staff members in the dialysis unit, to gain their input on providing education to those seeking information on live kidney donation. I also wanted to identify their current knowledge on transplant. Dialysis staff members provide direct care to recipients considering transplant options. This is because they attend dialysis treatments on a regular basis. The recipients' family and friends often accompany them to the dialysis units as well, and may have questions. These healthcare professionals need the necessary knowledge on transplant in order to educate their patients. Being properly informed and educated on transplant would be very beneficial for the patients because rather than depending on coordinators, all nurses would have a responsibility for teaching.

Data Methods, Management, and Analysis

Semi-structured interviews were conducted with key stakeholders to gather their input on live kidney donation. Semi-structured interviews, commonly used in healthcare, often consist of a number of important questions that the interviewer wants addressed, but are structured so that the interviewee can expand on their answers, and give more detail in their responses (Gill et al., 2008). "The flexibility of this approach allows for discovery or elaboration of information which is important for participants" (Gill et al., 2008, p.291). To collect the data, the interviews were held either in person or via telephone

conversations, depending on the availability and geographical location of the stakeholders. Ms. Coffey and Ms. Harding's interviews were held in person while the other interviews were completed on the phone. I have not completed an interview with Dr. Murphy yet due to his availability. I will complete Dr. Murphy's interview at a later date. The list of semi-structured interview questions asked during the interviews can be found in the appendices.

Prior to commencing the interviews, consent to participate in the interview was read and agreed to by all participants. The consent explained the purpose of interview, the benefits of the interview, and discussed privacy and confidentiality. A copy of the consent can be found in the appendices. The interviews took 20-25 minutes to complete, and I ensured that participants were given the opportunity to elaborate on their responses. To ensure the clarity of the information being relayed, I had the participants repeat any answers that were unclear. Notes were taken during the interviews, and the data was transferred to tables in a Microsoft Word document for content analysis and to outline themes. The themes were developed based on participants' responses. A summary of the themes will be discussed in the consultation results section of this paper. I have also provided copies of the developed summary tables outlining the themes in the appendices.

Ethical Considerations

When developing my consultation plan, I completed the Health Research Ethics Authority Screening Tool. A copy of the Health Research Ethics Screening Tool and my responses to the tool can be found in the appendices. After completing the screening tool, I discovered that I did not need health research ethics approval.

Prior to approaching participants, I described the purpose of the practicum project and asked for participants' consent. I ensured that participants knew that their privacy and confidentiality was of utmost importance. There was no identifying information associated with any of the information that I gathered, and I did not identify which stakeholder stated specific information in this consultation report. Data from the word document is kept on my password-protected computer. No one is aware of the password, and the password will not be shared with anyone else. I informed participants that any information collected is for the purpose of this practicum project, and will not be shared with anyone outside of those involved with its development. Once the practicum project is complete, I will ensure that all data from the interviews will be deleted.

Consultation Results

Interview Themes Based on Questions asked to all Participants

There were semi-structured interview questions that were asked to all participants and can be found in Appendix A2. After completing the interview questions with the key stakeholders, a number of themes were identified.

Education for recipients and donors. When asked about barriers to recipients and donors choosing the live kidney donor program, all stakeholders agreed that the lack of education and knowledge on live kidney donation is the main barrier. They discussed that there are limited resources and educational initiatives currently being provided for both donors and recipients, and that creating more resources would be of great benefit to patients going through the transplant process. All stakeholders identified that recipients and donors are often unaware of what live donation is and who is eligible to be donor, as eligibility criteria are not clearly identified to patients. Having more resources containing

information on eligibility criteria were highlighted by the interviewees as a topic that patients need more education on. They felt that the eligibility criteria should be clearly outlined in an available resource.

All stakeholders discussed the importance of donors being educated on live kidney donation to ensure they make an informed decision. In one interview, a transplant coordinator discussed that donors have identified feeling pressured and forced into donating because family members are asking them to donate. The coordinator stated, “Sometimes I feel like donors are only donating because a wife or husband says they have to.” She felt that despite agreeing to donate, family members voiced feeling uncomfortable with the donation process. The coordinator also talked about the need for more education resources for donors. She felt that being educated on the donation process, would assist donors in knowing they are making the right decisions to help loved ones, instead of donating just because they feel they feel pressured.

All Stakeholders identified that many of the recipients need more education because they are unaware of their transplant options. Recipients have identified to the stakeholders, that they would find it easier to discuss options with potential donors if they had more information on the live donation process, risks involved, and how it would impact the donors’ life. Many recipients have told the stakeholders that without education, they do not feel comfortable asking family members to donate for fear of causing them harm.

Education for healthcare professionals. The importance of education for healthcare professionals on the live kidney donor program was also discussed with key stakeholders. Patients rely on healthcare professionals for guidance and answers during

the transplant process. Stakeholders felt that educating healthcare professionals was imperative to allow them to answer patients' questions or share the knowledge that patients need, to help them make an informed decision on live donation. It was also identified that when healthcare professionals are not adequately educated on live kidney donation, they feel uncomfortable discussing the topic, and feel that patients should re-direct questions and concerns to transplant coordinators.

The transplant coordinators felt that other healthcare professionals in Newfoundland and Labrador have limited knowledge on the eligibility criteria for patients undergoing live kidney donation, and this is why they have difficulty answering questions. The coordinators also expressed concern that some patients have difficulty meeting with them due to their locations, and this impedes them from being able to ask questions in person. One coordinator stated, "If more dialysis nurses received training it would really help me out. Dialysis nurses are located all across the province, and patients would have more access to them than myself."

During the interview, dialysis staff identified finding it difficult to answer some of the questions because they felt that they did not know enough information about the live kidney donor program. Dialysis staff members also felt that donors and recipients do not have enough support from healthcare professionals during the transplant process. It was identified that patients' locations played a major role in the amount of support they could receive. The dialysis staff described transplant coordinators as being able to provide the most support for patients during the donation process. However, if patients are not living close to where the transplant coordinators are located, then it is difficult to seek support. One dialysis staff member who was interviewed stated, "I would love to be able to

educate patients more on their transplant options, but I just do not know enough about it. I feel bad because I find myself directing questions to Marion. If I had access to more information, then I would not need to do this.”

Both dialysis staff members and the transplant coordinators felt that recipients have more contact with the dialysis staff than donors, since they attend dialysis units three to four times per week for treatments. However, the transplant coordinators identified that if the nurses in the dialysis units are not comfortable discussing transplant topics with the patients, then they are just as disadvantaged as donors. Therefore, the interviews revealed that healthcare professionals have to take the initiative to learn what live donation entails, and be given the education and resources that they need, to share their knowledge with the patients that they care for. Thus, these findings support the need for education for health professionals as well, to ensure that they have the knowledge to educate their patients.

The need for increased education on live kidney donation. All stakeholders alluded to more education on the donation process as being important for people undergoing the live kidney donation process. One area of discussion by stakeholders, focused on the current education pamphlet being utilized. A number of stakeholders felt that the current education pamphlet should be simplified. In addition, the stakeholders identified that more educational resources are needed to reduce the number of questions and concerns that donors have for health professionals. It was recognized that other transplant centers outside of Newfoundland and Labrador have more resources available than what we are using. Some programs have an educator role devoted specifically to educating donors and recipients to ensure that they are comfortable with the transplant

process. Thus, to ensure patients and healthcare professionals in Newfoundland and Labrador also have adequate resources the interview results substantiate the need for an education program on live kidney donation.

There were numerous suggestions from all stakeholders for important information to include in future resources. First, all stakeholders agreed that financial information needs to be discussed with patients and included in written educational resources. Donors and recipients need to be aware that many costs have to be paid upfront using patients' credit cards. The money does get reimbursed in full for donors, but not everything is covered for recipients. However, this reimbursement process does not happen right away and patients need to prepare for the added finances when considering their budget. Secondly, important contact information and phone numbers would be beneficial in future resources. The current pamphlet comes from Halifax and as such, there is no Newfoundland and Labrador contact information included. Thirdly, the risks and eligibility criteria should be highlighted in any new educational resources. It should also be made aware that Newfoundland and Labrador transplants occur in Halifax, and that both recipients and donors would be expected to travel there.

Interview Themes Based on Questions Specifically for Dialysis Staff

Along with the list of semi-structured interview questions that were asked to all participants, there were additional questions developed for dialysis staff. A list of these questions can be found in appendix A3.

When dialysis staff members were asked if they felt comfortable discussing live kidney donation with patients, they felt that they were not. The staff members attributed being uncomfortable to having limited knowledge on the live donation process, and fear

they would tell patients the wrong information. Some participants stated that they redirect all questions to transplant coordinators by providing their contact information to patients. Considering the role of the registered nurse and patient accountability, this finding was very concerning. As an advanced practice nurse, this finding gave me incentive to develop an education program that would be available to the healthcare professionals as well as patients. I will advocate for the need for healthcare professionals to utilize the resources developed in the education program as well.

All dialysis staff that participated in the interviews felt that they knew very little about live kidney donation. They identified a number of resources that would be beneficial to gain knowledge on live kidney donation such as video, written materials, in service, and online resources.

Dialysis staff members felt that a short video would be a resource that could be taken home to watch, and an interesting way to learn. The staff members also highlighted the need for written materials such as an educational module in dialysis units so that nurses would have access to material that would answer simple questions that patients may have. One interviewee stated, “I would love to have a pamphlet or module available in our unit that I could use as a quick guide when a question arises. It would also be nice to have something to hand out to the patients.”

In service education was also discussed as a great way to educate dialysis staff and other healthcare professionals while they are at work. Dialysis staff members felt that an in service on live donation would be beneficial to help answer a lot of questions on live kidney donation. Lastly, participants also mentioned having information online through

the health authority websites. If there were an online resource, information on live kidney donation would be accessible to all healthcare professionals at any time.

Dialysis staff was also asked about whether or not they get question from patients' family or friends on live kidney donation. Patients' family members and friends often accompany them to dialysis treatments, and are usually their potential donors. Dialysis staff identified that they do receive questions from support systems from time to time. All participants stated that they try to answer the questions to the best of their ability, but often tell patients to double check with a transplant coordinator. One participant stated, "I am not confident in my responses enough for the patients to rely solely on what I tell them." Again, this answer substantiates the need for the advanced practice nurse to develop and provide additional resources and advocate for their use in the dialysis setting.

Interview Themes Based on Questions Specifically for Transplant Coordinators

I did have a number of questions that were designed specifically for transplant coordinators and for Ms. Heather Travis, since she is the live kidney donor coordinator for Halifax. A list of these questions can be found in Appendix A4.

When the transplant coordinators were asked if they had heard any positive experiences from donors and recipients that have undergone the current live donation program, they stated that they have not received a lot of positive feedback. However, they had received negative feedback. The coordinators identified that patients stated that they do not have adequate resources, and that they desire more information on live kidney donation. Both coordinators felt that there should be a greater variety of resources for their patients than the current education pamphlet that they have been receiving.

The transplant coordinators were asked if donors had enough support during the live donation process. Before the coordinators answered this question, I defined support as meaning did the donors have enough educational resources and access to healthcare professionals to talk to when they had questions or concerns. The transplant coordinators responded by stating that they felt that they were providing as much support as they could with the resources that they have. However, the coordinators felt that patients lacked support beyond the transplant team. One coordinator stated, “along with preparing patient charts and attending meetings, I find it difficult to see multiple people in the run of a day. I also do not have the funding to travel to the various dialysis units and communities where donors and recipients reside, and there is no one else who can really answer my patient’s questions.” The transplant coordinators felt that donors and recipients are not satisfied with the current educational resources, and there was a definite need for more resources. Therefore, there should be more written material available in conjunction with verbal education and support.

Consultation Implications and Conclusions

The results of the consultations with key stakeholders have many implications for the development of this practicum project on an educational program for live kidney donation. To fulfill the requirements of this practicum project, and the competencies of an advanced practice nurse, consulting with key stakeholders involved in the care and education of live kidney donors was of utmost importance. The consultations, along with the results of the literature search, substantiated the need for an education program for live kidney donation. Key stakeholders who participated in the interviews confirmed that an education program was necessary. It was evident from the interviews that all

stakeholders agreed that the education program is a worthwhile project and useful for the transplant program in Newfoundland and Labrador.

The key stakeholders identified in this practicum project all play a major role in the care of patients going through the live kidney donation process. All stakeholders have backgrounds and experience working with patients with end-stage renal disease and their families. The semi-structured interviews were developed to explore the stakeholders' experiences with live kidney donation, thoughts on the current educational resources being utilized, and to identify current barriers and benefits of the resources available in Newfoundland and Labrador. I also explored future educational initiatives that would improve the current program, and content that would be beneficial to include in future educational resources. From the semi-structured interviews, I was able to gather an abundance of valuable information, formulate themes, and use this information for consideration in the development of my practicum project.

In summary, the consultations with key stakeholders had identified lack of education and insufficient support from healthcare professionals as barriers to the live kidney donation program in Newfoundland and Labrador. Both donors and recipients need adequate knowledge on live kidney donation in order to make an informed decision. Currently, questions on live kidney donation are being directed to transplant coordinators due to the fact that dialysis staff members do not feel comfortable with their knowledge base on live kidney donation. Transplant coordinators provide education to patients across the province, but patients would benefit from having more healthcare professionals educated on transplant to provide supports when questions and concerns arise. Written,

verbal, and online resources were identified as educational resources that would be an asset for the live kidney donor program.

To achieve the results of the consultation, all stakeholders underwent semi-structured interviews, and agreed to an interview consent prior to its' commencement. All interview questions have been included in the appendices. The appendices also contain a copy of the participant consent form, and tables summarizing the themes that resulted from the interviews.

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Appendix A1

Introductory Letter

Consent to Participate in the Interview

TITLE: Developing an education program for live kidney donation in Newfoundland and Labrador: Healthcare professional consultation interview

Interviewer: Daisy Baldwin

You are invited to take part in an interview. Please note that taking part in this interview is on a voluntary basis. You can decide whether or not to participate, and can end the interview at anytime. Before deciding to take part, you should be aware of what the interview is for, and the benefits that may arise as a result of the interview. This consent form will explain the interview process and significance.

Please read this consent carefully, and take as much time as you would like to review it. Please write down anything that you do not understand, or require further explanation on. After you have read the consent, please ask questions about anything that is unclear.

1. Introduction and background:

Currently, in Newfoundland and Labrador, education on live kidney donation is informal and limited to the use of an information pamphlet given to recipients and donors after contacting a coordinator. The pamphlet is not available to the general public. Availability and accessibility to education should be improved to increase the comfort level and confidence of those participating in the live kidney donor program, to ensure an informed decision is made.

2. Purpose of the interview:

The interview's aim is to consult and collaborate with other healthcare professionals involved with patients choosing the live kidney donor option or choosing to be a live kidney donor. The interview will explore past experiences, current education initiatives, and brainstorm future educational initiatives surrounding live kidney donation.

3. Description of the interview procedures:

Participants who wish to proceed will be asked a number of interview questions either in person or via telephone conversation. If necessary, I will contact you again to clarify any of your statements to ensure they have captured your thoughts, feelings, and emotions.

4. Length of time:

The interview will take approximately 25-35 minutes.

6. Benefits:

- To improve education on live kidney donation in Newfoundland and Labrador.
- To help live kidney donors make an informed decision on kidney donation
- To provide recipients with more information on live kidney donation as a primary transplant option
- To provide education for healthcare professionals

7. Liability statement:

Signing this form gives your consent to participate in this interview. It tells me that you understand the information about the interview.

8. Privacy and confidentiality?

Protecting your privacy is important, and I take your privacy very seriously. Therefore, every effort to protect your privacy will be made. Your interview will be assigned to a number that is associated with your name. This way, your name cannot be identified and your privacy will not be breached. Your responses will be kept on a computer protected by a password. I will only have access to this password. The information will be destroyed at the end of this practicum project. A copy of this consent will also be put in your health record.

9. Questions or problems:

Please feel free to contact me (Daisy Baldwin, BN RN) if you have questions at any time. Daisy Baldwin (709-589-4857)

After signing the consent you will be given a copy.

_____ Signature of participant Day	_____ Name printed	Year Month
_____ Signature of Interviewer Day	_____ Name printed	Year Month

Appendix A2

Interview Questions for all Participants

1. Have you identified any barriers to recipients choosing the live kidney donor program as their primary transplant option?
2. Have you identified any barriers to people choosing to be a live kidney donor?
3. In your opinion, how important is education on live kidney donation for healthcare professionals?
4. In your opinion, how important is education on live kidney donation for potential donors?
5. In your opinion, how important is education on live kidney donation for transplant recipients?
6. Do you feel you have adequate learning resources for patients on live donation?
7. Would recipients choosing the live donation option, benefit from an education program on live kidney donation? Why or why not?
8. Would potential donors, benefit from an education program on live kidney donation? Why or why not?
9. What are some important aspects to include in educational resources on live kidney donation?
10. Do you feel that donors have enough education to make an informed decision on choosing to be a live donor?
11. Do you feel that donors have enough support from healthcare professionals during the live donation process?

12. Do you feel that recipients have enough support from healthcare professionals during the live donation process?

Appendix A3

Interview Questions for Dialysis Staff

1. How comfortable do you feel discussing live kidney donation and transplant options with your patients?
2. Describe your current knowledge base on live kidney donation?
3. What resources would you find beneficial to gain knowledge on live kidney donation?
4. Do patient's support systems often have questions on becoming live kidney donors?
5. Do you feel kidney donors have enough support from healthcare professionals during the transplant experience?

Appendix A4

Interview Questions for Transplant Coordinators and Heather Travis

1. Have you identified any positive experiences that potential donors and recipients have had in the current live donation program?
2. Have you identified any negative experiences that potential donors and recipients have had in the current live donation program?
3. Do you feel donors have enough support during the transplant experience?
4. Do donors often express satisfaction with the current educational resources provided? Why or why not?
5. What are some obstacles with the current educational resources being utilized within our program?

Appendix B

Health Research Ethics Authority Screening Tool

	Question	Yes	No
1.	Is the project funded by, or being submitted to, a research funding agency for a research grant or award that requires research ethics review	<input type="checkbox"/>	<input checked="" type="checkbox"/>
2.	Are there any local policies which require this project to undergo review by a Research Ethics Board?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	IF YES to either of the above, the project should be submitted to a Research Ethics Board. IF NO to both questions, continue to complete the checklist.	<input type="checkbox"/>	<input checked="" type="checkbox"/>
3.	Is the primary purpose of the project to contribute to the growing body of knowledge regarding health and/or health systems that are generally accessible through academic literature?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
4.	Is the project designed to answer a specific research question or to test an explicit hypothesis?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
5.	Does the project involve a comparison of multiple sites, control sites, and/or control groups?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
6.	Is the project design and methodology adequate to support generalizations that go beyond the particular population the sample is being drawn from?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
7.	Does the project impose any additional burdens on participants beyond what would be expected through a typically expected course of care or role expectations?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
LINE A: SUBTOTAL Questions 3 through 7 = (Count the # of Yes responses)			
8.	Are many of the participants in the project also likely to be among those who might potentially benefit from the result of the project as it proceeds?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
9.	Is the project intended to define a best practice within your organization or practice?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
10.	Would the project still be done at your site, even if there were no opportunity to publish the results or if the results might not be applicable anywhere else?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
11.	Does the statement of purpose of the project refer explicitly to the features of a particular program, Organization, or region, rather than using more general terminology such as rural vs. urban populations?	<input checked="" type="checkbox"/>	<input type="checkbox"/>
12.	Is the current project part of a continuous process of gathering or monitoring data within an organization?	<input type="checkbox"/>	<input checked="" type="checkbox"/>
LINE B: SUBTOTAL Questions 8 through 12 = (Count the # of Yes responses)			

	SUMMARY See Interpretation Below	4	
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Interpretation:

- If the sum of Line A is greater than Line B, the most probable purpose is **research**. The project should be submitted to an REB.
- If the sum of Line B is greater than Line A, the most probable purpose is **quality/evaluation**. Proceed with locally relevant process for ethics review (may not necessarily involve an REB).
- If the sums are equal, seek a second opinion to further explore whether the project should be classified as Research or as Quality and Evaluation.

These guidelines are used at Memorial University of Newfoundland and were adapted from ALBERTA RESEARCH ETHICS COMMUNITY CONSENSUS

INITIATIVE (ARECCI). Further information can be found at:

<http://www.hrea.ca/Ethics-Review-Required.aspx>.

Appendix C1

Interview Results Based on Questions for all Participants

Interview Questions Themes	Interview Responses Overall
Barriers to recipients choosing the live kidney donor program	<ul style="list-style-type: none"> • Unsure what live donation is • Unsure of their eligibility and who can be a donor • Very little education in dialysis units • Unable to meet with coordinators depending on their location • Lack the education on live donation
Barriers to donors choosing the live kidney donor program	<ul style="list-style-type: none"> • Do not know what live kidney donation is • Do not know if they are eligible • Lack resources • Lack education
Importance of education on live kidney donation for healthcare professionals	<ul style="list-style-type: none"> • Very important • Without education they cannot share their knowledge with patients • Without education they are not comfortable discussing live donation
Importance of education on live kidney donation for potential donors	<ul style="list-style-type: none"> • Very important • Without education they cannot make informed decisions • Without education they would be unaware of the donation process • Currently do not understand the educational resource that we have
Importance of education on live kidney donation for transplant recipients	<ul style="list-style-type: none"> • Very important • Without education they are unaware of their options • Without education, they would not feel comfortable asking family members because they are not fully aware of the donation process • Could have false hopes on transplant thinking a family member could donate but if they were educated properly, would have realized they did not meet the eligibility criteria
Are there adequate learning resources for patients on live donation?	<ul style="list-style-type: none"> • There could be more • There are more resources in other

	provinces than Newfoundland and Labrador
Would recipients choosing the live donation option, benefit from an education program on live kidney donation?	<ul style="list-style-type: none"> • Absolutely • It is imperative • Would find it easier to discuss options with potential donors if they had more information • Have less questions for healthcare professionals • Feel more comfortable with transplant process, testing, and risks
Would potential donors, benefit from an education program on live kidney donation?	<ul style="list-style-type: none"> • Absolutely • It is imperative • Need it to make an informed decision for themselves not based on helping the recipient • Would have more information on the process, risks, eligibility, and testing
Important aspects to include in educational resources on live kidney donation	<ul style="list-style-type: none"> • Finances • Important phone numbers, roles, and information on those involved in their care • Highlight that Newfoundland and Labrador transplants happen in Halifax • Risks • Eligibility • Amount of time spent in Halifax
Do you feel that donors have enough education to make an informed decision on choosing to be a live donor?	<ul style="list-style-type: none"> • Hard to comment on this question because I do not know enough about it. • They have enough verbal education, but not enough take-home information, and easily accessible resources
Do you feel that donors have enough support from healthcare professionals during the live donation process?	<ul style="list-style-type: none"> • Depends on where they are geographic locations play a major role • Depends on who they ask coordinators can provide more support than other healthcare professionals • No, there is a need for more • Donors deserve more follow-up during and after the transplant process
Do you feel that recipients have enough support from healthcare professionals during the live donation process?	<ul style="list-style-type: none"> • Depends on if the person they ask feel comfortable discussing the topic • More than donors do

	<ul style="list-style-type: none">• No, there is a need for more
--	--

Appendix C2

Interview Results Based on Questions for Dialysis Staff

Interview Questions Themes	Interview Responses Overall
Comfort discussing live kidney donation and transplant options with patients	<ul style="list-style-type: none"> • Limited knowledge • Know less about live donation than deceased donor option • Unsure how to answer questions • Re-direct questions to transplant coordinator • Do not discuss live donation because I am not educated on it
Current knowledge base on live kidney donation	<ul style="list-style-type: none"> • I know nothing about this area of transplant • I do not feel comfort with my knowledge base on live kidney donation • I cannot really comment on this question because I know very little about it • I re-direct all questions to the transplant coordinators
Resources that would be beneficial to gain knowledge on live kidney donation	<ul style="list-style-type: none"> • Video • Written materials that would be available in the dialysis units • An in service on live kidney donation • Online information on our health authority websites • Pamphlet in unit
Do patient support systems have questions on live kidney donation?	<ul style="list-style-type: none"> • This has happened a few times and I have always given them the transplant coordinators' numbers • Whenever they ask questions I try and answer them but tell them to contact transplant coordinator • I get questions from time to time, but I am usually unsure how to answer the questions
Do you feel kidney donors have enough support from healthcare professionals?	<ul style="list-style-type: none"> • Recipients have more • Cannot comment since I do not

	<p>know much about live kidney donors and the process</p> <ul style="list-style-type: none">• No, they could have a lot more
--	--

Appendix C3

Interview Results Based on Questions for Transplant Coordinators and Heather Travis

Interview Questions Themes	Interview Responses Overall
Positive experiences that potential donors and recipients have identified in the current live donation program	<ul style="list-style-type: none"> • Do not receive a lot of feedback
Negative experiences that potential donors and recipients have identified in the current live donation program	<ul style="list-style-type: none"> • Do not always receive a lot of feedback • Not a lot of resources available • Need for a greater variety of resources to meet learning needs • Want more resources • Have requested information pamphlets in dialysis units
Do you feel donors have enough support during the live donation process?	<ul style="list-style-type: none"> • They have support from transplant coordinators • They lack support outside of the transplant team • Need more written material in conjunction with verbal education and support
Are donors satisfied with the current educational resources provided?	<ul style="list-style-type: none"> • Voice that they want more resources • There is a need for more
What are some obstacles with the current educational resources in our program?	<ul style="list-style-type: none"> • Need information in “layman” terms • Find the current pamphlet hard to understand • The information in the pamphlet is not based on Newfoundland information

Appendix C
Components of the Education Program

The Development of an Education Program for Live Kidney Donors in Newfoundland
and Labrador
Daisy Baldwin
200807360
Nursing 6661
Memorial University of Newfoundland

Appendix C1

Information Session to be used by Healthcare Professionals



INFORMATION SESSION ON LIVE KIDNEY DONATION

KIDNEY DONATION IN NEWFOUNDLAND AND
LABRADOR

This information session is adapted with permission from Nova Scotia Health Authority © 2015 by Daisy Baldwin © in Partial fulfillment of the Masters of Nursing Program, Memorial University School of Nursing.

OBJECTIVES

- To educate the general public, transplant candidates, and health care members on live kidney donation
- To provide a brief overview on kidney donation options
- To discuss eligibility criteria for the live kidney donation options
- To discuss required testing for the live kidney donation options
- To increase knowledge on the live kidney donation process in Newfoundland and Labrador
- To increase knowledge on the financial portion of live kidney donation
- To provide up to date contact information on transplant coordinators in Newfoundland and Labrador

THE PURPOSE OF THIS INFORMATION SESSION



INFORMATION GUIDE

- Please note that the information given throughout this presentation is a brief background to educate you on live kidney donation.
- Questions on this presentation or any other questions can be discussed with a transplant coordinator in detail at a later time



INTERESTING FACTS

- There is a greater demand for live kidney donors than the number of people who are willing to participate and donate a kidney (Kazley, Hamidi, Balliet, & Baliga, 2016).
- Chronic Kidney Disease is currently on the rise in Canada. The number of Canadians requiring renal replacement therapy has tripled in the last 2 decades (The Kidney Foundation of Canada, 2016).
- 1 in 10 Canadians are diagnosed with Chronic Kidney Disease (The Kidney Foundation of Canada, 2017).
- An average of 15 people are diagnosed with Chronic Kidney Disease on daily basis in Canada (The Kidney Foundation of Canada, 2017).
- The need for kidney transplants is 2.5 times higher than the number of donated kidneys that are available through deceased and live kidney donation (Canadian Institute of Health Information, 2016).
- The province of Newfoundland and Labrador has less kidney transplants occur on an annual basis compared to other Atlantic provinces (Multi-Organ Transplant Program, 2016).

WHAT IS KIDNEY DONATION?



AVOIDING COERCION IN THE KIDNEY DONATION PROCESS

- A kidney donor should want to willingly give a kidney to the intended recipient without feeling “coerced” which means feeling pressured, forced, or unsure (The Kidney Foundation of Canada, 2016).
- If a donor is having these feelings, then he or she needs to speak with a family doctor, or a live kidney donor coordinator about these feelings.

(Nova Scotia Health Authority, 2015)

BRIEF OVERVIEW OF DECEASED KIDNEY DONATION

- Anyone can be a deceased kidney donor
- The donor makes the decision that the kidneys will be donated at time of death
- The donor does not get to choose who gets the donated kidney
- The average wait-time for a recipient on the transplant list for a deceased donor kidney is 3-5 years.
- For more information on deceased donation or to consider deceased kidney donation, contact the Organ Procurement Exchange of Newfoundland and Labrador (OPEN) program at 777-6600

(The National Kidney Foundation, 2016)

COMPATIBLE LIVE KIDNEY DONOR

- This form of live kidney donation occurs when both the donor and recipient match on blood type and tissue typing (genetics) and the donor can give directly to the intended recipient
- The donor does not need to be a blood relative
- This option has the highest success rate and live donors kidneys tend to last long when transplanted
- Recipients with a compatible live donor get their transplants quicker than the other two options
- It can be a very rewarding experience for the donor and a life changing event for the recipient

(The Kidney Foundation, 2016)

PAIRED-EXCHANGE OPTION (KPD)

- It is an option made possible by Canadian Blood Services.
- This option is chosen when the donor has an incompatible blood type or tissue typing (genetics) with the recipient
- The donor cannot give to the recipient directly
- The donor gives a kidney to another recipient on the paired-exchange list if the person's recipient is a match for their recipient as well. It is essentially a "swap."

(Canadian Blood Services, 2016).

LIVE KIDNEY DONORS IN NL



NEWFOUNDLAND AND LABRADOR COORDINATORS

- Marion Coffey- St. John's

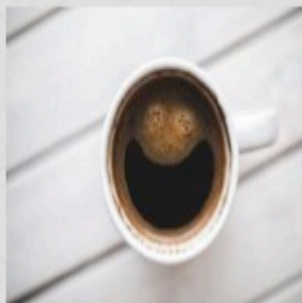
709-777-3601

marion.coffey@easternhealth.ca

- Sheri Sheppard- Corner Brook

709-637-5000

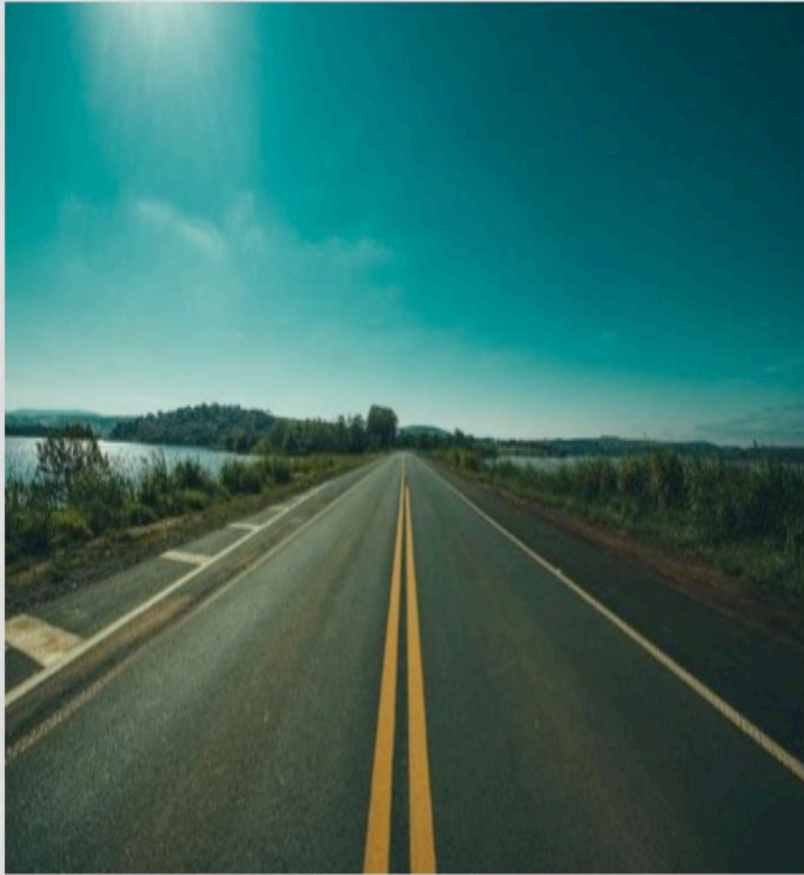
sherisheppard@westernhealth.nl.ca



WHICH COORDINATOR SHOULD I CONTACT?



THE KIDNEY DONATION PROCESS WHERE DO I START?



THE KIDNEY DONATION PROCESS: THE ROLES OF YOUR FAMILY DOCTOR AND TRANSPLANT COORDINATOR

- It is very important to have a family doctor prior to contacting a transplant coordinator or beginning the live kidney donation journey.
- The transplant coordinators are both registered nurses but not permitted to order testing. Your family doctor can order tests.
- The transplant coordinators organize the testing and send a list of tests to your family doctor to order. These will be discussed later.
- The transplant coordinators then follow-up with you regarding your results.
- Without a family doctor the testing would not get completed in a timely manner

THE KIDNEY DONATION PROCESS

WHAT HAPPENS AFTER SEEING MY FAMILY DOCTOR?

- After finding out your blood type, contact a transplant coordinator to discuss if your blood type is compatible with the recipient's.
- If your blood type is compatible, you can be a compatible live kidney donor.
- If your blood type is not compatible, you can consider the paired-exchange option.
- Once the type of the kidney donation is decided on, your kidney donation journey will begin.

ELIGIBILITY CRITERIA
WHAT MAKES SOMEONE QUALIFIED TO BE A
LIVE KIDNEY DONOR?



REASONS WHY YOU MAY NOT BE ELIGIBLE TO BE A KIDNEY DONOR

- History of kidney stones
- History of kidney disease
- Actively seeing a nephrologist
- High blood pressure (if under the age of 50). If over the age of 50, you can be taking one non-combination blood pressure drug. This can be discussed further with a transplant coordinator.
- History of heart disease or cardiac issues
- Actively seeing a psychiatrist or psychologist.
- If you are pregnant, considering becoming pregnant, or lactating.
- Actively abusing street drugs or alcohol
- Diabetic or pre-diabetic
- Diagnosed with or previously diagnosed with cancer
- Body mass index greater than 35

(Nova Scotia Health Authority, 2015)

REQUIRED TESTING

- If you meet the eligibility criteria, then you will need to complete a list of required medical tests
- This testing takes 6 months to a year to complete.



SEQUENCE OF REQUIRED TESTING

Blood work to determine blood type and tissue typing (If the blood type or tissue typing does not match, you can consider the paired-exchange option).



Two blood pressure readings, a height and weight (Body mass index must be below 35).



Two 24 hour urine samples & Two urinalysis



Blood work to test kidney function, liver function, cholesterol, and serology



Glucose Tolerance Test to check for diabetes



Chest x-ray and EKG



(Nova Scotia Health Authority, 2015)

SEQUENCE OF REQUIRED TESTING CONTINUED

Renal Ultrasound and CT scan of abdomen (These appointments can take up to a few months to get booked and are arranged by the coordinator).



Stools for occult blood (if over the age of 50)



See a cardiologist (if over the age of 50)



Meet with a Social Worker



History and Physical with a Nephrologist to check your overall health and review all testing that has been completed. (This is done last).

(Nova Scotia Health Authority, 2015)

ABNORMAL RESULTS

What happens if the donor has an abnormal test result?



DONATION/TRANSPLANT LOCATION



FINANCIAL INFORMATION



FINANCIAL INFORMATION CONTINUED

- There is a social work assistant who can answer questions and provide guidance through the donor's financial process.



Susan Galway

709-777-3623

Susan.galway@easternhealth.ca

- Donors should schedule an appointment or call Susan to discuss financial aspects.

LIFE POST KIDNEY DONATION



QUESTIONS?



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Your Live Kidney Donation Journey

Information Guide for Donors
in Newfoundland and Labrador



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Your body has 2 kidneys. Your kidneys work by removing fluid and unwanted wastes from your body.

Your body can work well with 1 kidney, and because of this, you can give the other kidney to someone else in need.

- Kidney donation is **giving** a kidney to another person in need.
- A **kidney donor** is someone who gives a kidney to another person who needs a kidney.
- A **kidney recipient** is someone who is given a kidney from the donor.

Kidney donation can be live or deceased

➔ Live donation is when a living person donates a kidney

➔ Deceased donation is when a kidney is donated by someone who passes away

There are 3 ways you can donate a kidney:

1. Compatible live kidney donation option
2. Paired-exchange option
3. Deceased donor option.

*Compatible live kidney donation is a **live** donation option

*Paired-exchange is a **live** donation option

*Deceased donor option is a **deceased** donation option

This information pamphlet will give you information on all 3 types of donation but most of the information will be on the live donation options.

Compatible Live Kidney Donation

What is Compatible Live Kidney Donation?

- **This is a live kidney donation option.**
- **It can only happen when a donor and recipient have matching blood types.**
- **If you know your blood type, a transplant coordinator can see if it matches the recipient's.**
- **You do not have to be related to the recipient to be a donor. You can also be a friend, someone who works with the recipient, family member, husband or wife.**
- **Medical tests need to be done to see if you are healthy enough to be a donor.**
- **Testing is organized by a transplant coordinator and sent to your family doctor to book appointments for you.**
- **The medical tests will 6 months to a year to complete and to get the test results back. The donation cannot occur until the testing is completed. The testing process will be discussed in detail later.**

(The Kidney Foundation, 2016)

Paired Exchange Option

Paired Exchange Option

- **Is a live donation option**
- **It can occur when a donor's blood type does not match the recipient.**
- **With this option, you cannot give a kidney to the recipient directly because your blood types do not match.**
- **Instead, you would give a kidney to another recipient who chose the paired-exchange option, as long as that person's donor is a match for your recipient. (It is like a swap or exchange)**
- **Testing takes the same amount of time as the other live option**
- **Testing is organized by a transplant coordinator and sent to your family doctor to book appointments for you.**
- **Wait-times for the donation to occur can be longer than compatible live donation. This depends on how quickly a match can be found.**

(Canadian Blood Services, 2016)

Deceased Kidney Donation

Deceased Donor Option

- **Is the only deceased donation option**
- **This option is when you choose to donate your kidneys when you pass away**
- **Your decision to donate is put in writing to make sure that family and hospital staff know that you want to be a donor**
- **Your kidney is given to a recipient on the transplant list who does not have a live donor, and is the best match for the kidney**
- **The average wait time for a recipient waiting for a deceased donor's kidney is 3-5 years**
- **Deceased donors do not need to see a transplant coordinator**

(The National Kidney Foundation, 2016)

For more information on deceased donation, contact organ procurement at 777-6600.

Kidney Donation in Newfoundland and Labrador

- In Newfoundland and Labrador, there are **2** transplant coordinators (one in St. John's and one in Corner Brook).
- To be a donor you need to get tests done to make sure you are healthy



What should I do if I want to be a donor?

- 1. First, tell the recipient you want to donate a kidney**
- 2. Next, call your family doctor to discuss donation and get your blood type checked.**
- 3. Call a transplant coordinator to discuss donation.**

The person you are giving the kidney to cannot call a coordinator for you. Live donation is a decision you must make yourself.

Coordinators contact information:
St. John's
709-777-3601
Corner Brook
709-637-5000 ext. 6190

Donation Location

- **Donors in Newfoundland and Labrador need to travel to Halifax, Nova Scotia to donate a kidney.**
- **Kidney donation cannot happen in Newfoundland and Labrador because there is no transplant surgeon.**
- **Travel time to Halifax, Nova Scotia is 1.5-2 hours by airplane**
- **You will be given full details on the hospital location and stay when you see a transplant coordinator.**
- **You will have to stay in Halifax for about a week but the stay could be longer depending on the surgery.**



Why Would I Not be Able to Donate?

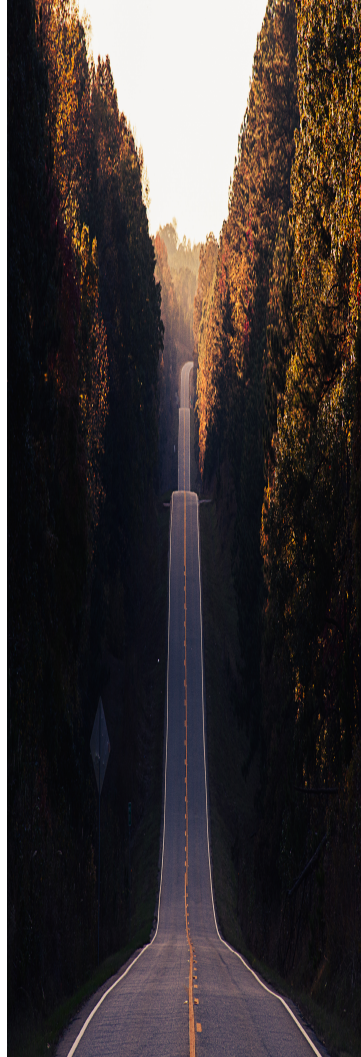
There are many medical conditions that would prevent a person from being able to donate



- **History of kidney stones**
- **History of kidney disease**
- **Actively seeing a kidney doctor**
- **High blood pressure**
- **History of heart disease**
- **Actively seeing a psychiatrist or psychologist.**
- **If you are pregnant, considering becoming pregnant, or breast-feeding.**
- **Actively using street drugs or abusing alcohol**
- **Diabetic or pre-diabetic**
- **Diagnosed with or previously diagnosed with cancer**
- **BMI greater than 35**

Your Kidney Donation Journey

After making contact with a coordinator, your live donation journey will begin. Here are some important points about the donation journey



- **Before you start any testing, you will be asked some questions about your health and lifestyle. This is to make sure you are in good health.**
- **After the questions, a transplant coordinators will send a list of required tests to your family doctor to arrange for you**
- **The transplant coordinator will look up all test results, and contact you with the results.**

If you DO NOT have a family doctor, you will be required to find one.

Donor Testing

What Medical Tests Needs to be done to be
a Live Kidney Donor?

1. **Blood work to check your blood type (A, B, O, or AB) and to check to see if your genetics match the recipients**
2. **Two blood pressure readings, a height, and weight (body mass index must be below 35).**
3. **Two 24 hour urine samples & two other urine samples**
4. **Blood work to check your kidneys, liver function, blood levels, cholesterol, and to check for infections**
5. **Glucose tolerance test to check for diabetes (you will need to fast, get blood work, and drink a sugar solution).**
6. **Chest x-ray and EKG (tracing of your heart)**
7. **Renal ultrasound and Cat scan of abdomen (These appointments can take up to a few months to get booked).**
8. **Stool samples to check for blood (if over the age of 50)**
9. **See a heart doctor (if over the age of 50)**
10. **Meet with a social worker**
11. **A check-up with a nephrologist to check your health and review all of the testing that has been completed. (This is done last).**

After all testing is complete, results will be sent to Halifax to be seen by a transplant surgeon.

(Nova Scotia Health Authority, 2015)

Forms and Questionnaires to Complete

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MOTP (Multi-Organ Transplant Program) Form

- All donors need to sign a MOTP consent form that discusses your information being put in a private computer program for research, and educational purposes.
- Your name will not be identified and kept private.

Important Facts about Giving a Kidney

- Transplant coordinators will discuss the risks of kidney donation with you. This is your chance to ask questions.
- It is very important that you pay full attention when being educated on the risks about giving a kidney.

Questionnaires

- There are two questionnaires that ask you about your health and lifestyle.
- The first questionnaire is done the first time you call a coordinator. The second one is completed once the medical testing begins.

Donor Disclosure Form

- Donating should be something you want to do not something you have to do.
- This form needs to be signed to make sure that you understand that you should not feel pressured into donating kidney, and that donating a kidney is something that you truly want to do.

Financial Information

How will Kidney Donation Impact my Job and Finances?



- **Kidney transplant is surgery and you will need to take off 6-8 weeks from work until you feel better and healed.**
- **You should speak to your workplace about sick leave and if it is possible (Nova Scotia Health Authority, 2015).**
- **All transplants in Newfoundland and Labrador occur in Halifax, Nova Scotia.**
- **You will be responsible for the costs for flights and places to stay while in Halifax, but you will get the money back at a later date.**
- **Getting the money back will take time to happen and will involve filling out forms.**
- **A social work assistant can help you with the forms.**
- **You should meet with a social work assistant to discuss the costs involved with live kidney donation**

The social work assistant with the transplant program in Newfoundland and Labrador can be reached at 777-3623

Important Contact Information and Links



**Transplant Coordinator
Waterford Hospital, St. John's,
Newfoundland
777-3601**

**Transplant Coordinator
Corner Brook, Newfoundland
709-637-5000 ext. 6190**

sherisheppard@westernhealth.nl.ca

**Online information is available as a live kidney
donation education module and can be found at
<https://eportfolio.mun.ca/livekidneydonation>**

Information sessions are also
available and dates will be posted on
the online education module.

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Photo

Acknowledgements

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Live Kidney Donation

Information Guide for Health
Professionals in Newfoundland
and Labrador



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Memorial University School of Nursing.**

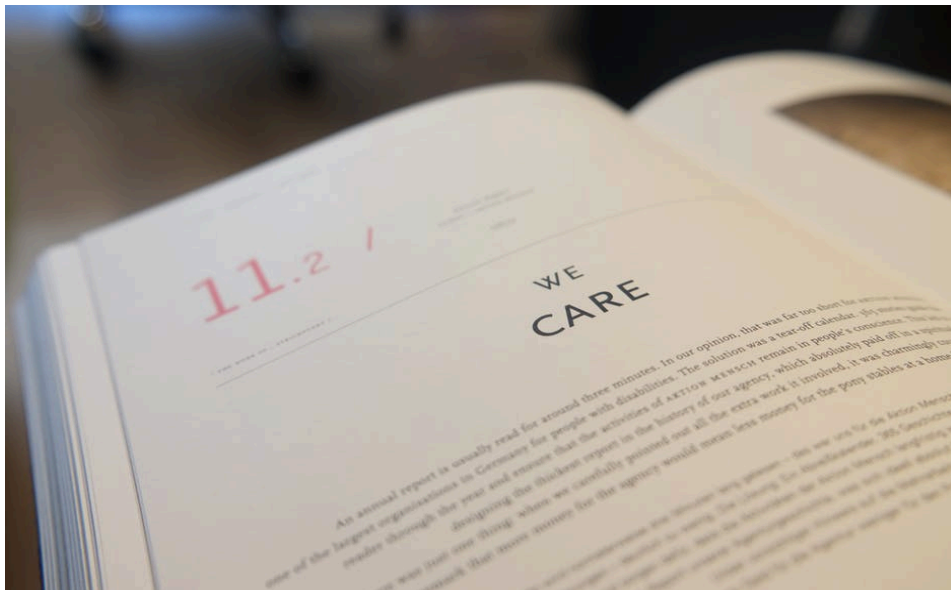
Why Educate on Kidney Donation?

There are three kidney donation options:

- Deceased Donor
- Compatible Live Donation
- Paired-Exchange

This pamphlet will act as a guide for health professionals to answer general questions. A transplant coordinator will discuss everything in detail with patients as their kidney donation journey progresses.

Currently, there are 2 transplant coordinators in NL: one in St. John's and one in Corner Brook. Due to the geography of NL, it is not possible for donors to have an in person visit with a coordinator each time they have questions or are inquiring about donating in general. In dialysis units, families of patients often attend the sessions with them, and many end up becoming donors. You may encounter these potential donors on a daily basis, and they may require your support or have some clarification questions.



Kidney Donation Options

There are three kidney donation options:

1. Deceased Kidney Donation
2. Compatible Live Donation
3. Paired Exchange Option

Compatible Live Kidney Donation

This live kidney donation option occurs when both the donor and recipient have compatible blood types and tissue typing. Therefore, the donor can give directly to the recipient. To be a compatible live kidney donor, the donor does not have to be a blood relative to the recipient, but is often a friend, co-worker, family member, or spouse. Testing involved takes 6 months to a year, and once completed, the transplant can be scheduled. The testing and eligibility criteria will be discussed in detail later.

(The Kidney Foundation, 2016)

Paired-exchange Option

The Living Donor Paired Exchange option also known as the “paired exchange” option is chosen when a donor has an incompatible blood type with the intended recipient. This means that the donor cannot give a kidney to that recipient directly. Instead, by choosing the paired exchange option, the donor agrees to give a kidney to a recipient anywhere in Canada, as long as that person’s donor is a match for their recipient. Testing takes the same amount of time as the other live option, but wait-times can be longer depending on how quickly a match can be found.

(Canadian Blood Services, 2016)

Deceased Donor Option

Occurs when a donor makes the decision to donate his or her organs to an anonymous person at time of death. This decision has to be made in advance and put in writing. Once the person dies, the organ would be given to the person on the transplant list that is the best match for the organ.

The average wait time for a person waiting for a deceased donor’s kidney is at least 3 years. It can be longer depending on the person’s blood type, and the number of organs that come available to the transplant center

(The National Kidney Foundation, 2016).

This information pamphlet will focus on the live donation options: Compatible Live Kidney Donation and Paired-Exchange

Kidney Donation in Newfoundland and Labrador

The transplant coordinators are responsible for organizing all testing for donors. They will send a list of required tests to the donor's family doctor. There are **NO** transplant surgeons in the province. Therefore, although donation testing occurs in Newfoundland and Labrador, the actual kidney donations occur in Halifax, Nova Scotia.

It is important to educate donors on the importance of making an informed decision on donation. They should not feel forced or coerced into donating. If they are interested in the live kidney donation process, they need to get in contact with their family doctor to get their blood type checked and discuss donation. After seeing their family doctor, then a transplant coordinator should be contacted. Interest needs to be expressed by the donor directly, and cannot be voiced by another health professional or the recipient.

Contact information for the transplant coordinators in Newfoundland and Labrador:

**Marion Coffey- St. John's
709-777-3601 or marion.coffey@easternhealth.ca**

**Sheri Sheppard- Corner Brook
709-637-5000 ext. 6190 or
sherisheppard@westernhealth.nl.ca**

Exclusion Criteria

Reasons why a person would not be eligible to be a donor

There are specific exclusion criteria for the live donation options that would prevent a person from being able to donate. You should familiarize yourself with the criteria as many donors have questions on this topic



- **History of kidney stones**
- **History of kidney disease**
- **Actively seeing a nephrologist**
- **High blood pressure (if under the age of 50). If over the age of 50, you can be taking one non-combination blood pressure drug. This can be discussed further with a transplant coordinator.**
- **History of heart disease**
- **Actively seeing a psychiatrist or psychologist.**
- **If you are pregnant, considering becoming pregnant, or lactating.**
- **Actively abusing street drugs or alcohol**
- **Diabetic or pre-diabetic**
- **Diagnosed with or previously diagnosed with cancer**
- **BMI greater than 35**

Required Testing

There is a specific list of required testing that all live kidney donors need to complete in order to donate

All testing is completed in this order unless otherwise specified

Blood work to determine blood type and tissue typing (If the blood type or tissue typing does not match, you can consider the paired-exchange option or otherwise would be unable to donate).



Two blood pressure readings, a height and weight (body mass index must be below 35).



Two 24 hour urine samples & two urinalysis 1 week apart



Blood work to test kidney function, liver function, cholesterol, and serology



Glucose tolerance test to check for diabetes



Chest x-ray and EKG



Required Testing

Continued

Renal ultrasound and CT scan of abdomen (These appointments can take up to a few months to get booked).



Stools for occult blood (if over the age of 50)



See a cardiologist (if over the age of 50)



Meet with a social worker



History and physical with a nephrologist to check your overall health and review all testing that has been completed. (This is done last).

After all testing is complete, all results will be sent to Halifax for review and acceptance by a transplant surgeon

(Nova Scotia Health Authority, 2015)

Information on Consent Forms and Questionnaires

On occasion, it may not be geographically possible for a donor to travel to St. Johns or Corner Brook to sign consent forms that are required for the live kidney donation process. In these instances, a copy of the forms may be sent to another health professional to either give a copy to the donor in their area or be present when the transplant coordinator discusses the forms.

The forms can then be sent back to the coordinator with the donor's signature.

A brief overview of the consent forms and questionnaires will be outlined in this information pamphlet.



MOTP (Multi-Organ Transplant Program) Form

- The MOTP program for Atlantic Canada, provides Atlantic Canadians with information on transplant services and statistics (MOTP, 2016).
- All donors are to complete an MOTP consent form consenting to their information being privately kept in a database for research, educational, and statistical purposes.
- The donor's name will not be identified and kept confidential.

Important Facts about Giving a Kidney

- Transplant coordinators will also read and discuss the risks of kidney donation with all donors

- This is a good opportunity for donors to ask questions

Questionnaires

- There are two questionnaires that ask donors about their health and lifestyle.
- The first questionnaire is done the first time donors call a coordinator. The second one is completed once the medical testing begins.

Donor Disclosure Form

- A donor should feel completely confident in the decision to donate
- This form needs to be signed to make sure that the donor understands that he or she should not feel pressured into donating kidney.

(Capital Health 2012; Nova Scotia Health Authority, 2015)

Financial Concerns

Who should donors contact for financial concerns about



- **Kidney donation will require donors to take off 6-8 weeks from manual work to recover. Kidney donors must consider whether or not this timeframe will impact their job security or impact financial budgets and plans (Nova Scotia Health Authority, 2015).**
- **All transplants in Newfoundland and Labrador occur in Halifax, Nova Scotia. Although flights and accommodations will get reimbursed post-transplant, the costs will need to be paid up front by the donor. The reimbursement process takes time and will involve paper work and government approval.**
- **Potential kidney donors should meet with a social work assistant to discuss the financial concerns.**

The social work assistant involved with the transplant program in Newfoundland and Labrador is Susan Galway. She can be reached at 777-3623 or susan.galway@easternhealth.ca

Important Contact Information and Links



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**Marion Coffey- Transplant Coordinator
Waterford Hospital, St. John's, Newfoundland
777-3601 or marion.coffey@easternhealth.ca**

**Sherri Sheppard- Transplant Coordinator
Corner Brook, Newfoundland
709-637-5000 ext. 6190 or
sherisheppard@westernhealth.nl.ca**

**Online information is available as a live kidney
donation education module and can be found at
<https://eportfolio.mun.ca/ddd077/>**

Information sessions are also available and
dates will be posted on the online education
module.

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Appendix C4

Online Education Module

The module can be found online at <https://eportfolio.mun.ca/ddd077/>

This appendix consists of screen shots to demonstrate the module's layout and content

Live Kidney Donation

An education module for living kidney donors, recipients, and healthcare professionals in Newfoundland and Labrador

An Introduction to the Online Module

Objectives

Table of Contents

Section 1: Overview of Kidney Donation

->Background on kidney donation

->Facts on Kidney Transplant and Donation

->Summary of the deceased kidney donation option

-> Overview of Live Kidney Donation Options

->Compatible Live Kidney Donor Option

->The Living Donor Paired-Exchange Option

Section 2: Information on Donation Location & Transplant Coordinators for Newfoundland and Labrador

-> Donation Location

->Transplant Coordinators in Newfoundland and Labrador

Section 3: The Kidney Donation Process in Newfoundland and

An Introduction to the Online Module

Welcome to this online module focusing on live kidney donation. The online module is designed to increase knowledge on kidney donation, specifically live kidney donation options.

There are 7 sections included in this module that contain a number of important topics. Each section and topic is outlined in the table of contents.



Kidney donation is a new journey for a donor, and there are multiple pieces leading up to the actual donation date. This includes a lot of medical testing and appointments with healthcare professionals to ensure that donors are in good health. In the end, all of the pieces fit together, and a kidney donation can take place.

Giving a kidney is a kindhearted action that will have a major impact on the life of a person waiting for a kidney transplant. However, if you or someone you know is considering donating a kidney, it is important to be aware of the donation process, risks, and procedures involved. If the donor is unsure about the kidney donation process, it can stop at anytime

Please take the time to familiarize yourself with the content contained in this education module. This online module only acts as an education guide. The transplant coordinators are available to answer any additional questions along the way.

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Protected: Objectives

Objectives:

By the end of this online module, the learner will be able to:

- Identify the need for an online education module on live kidney donation for patients and healthcare professionals in Newfoundland and Labrador.
- Recognize the purpose of e-portfolio and how it can be used as an education tool
- Outline the barriers to live kidney donation in Newfoundland and Labrador
- Utilize the online education module when educating patients on kidney donation

The purpose of this online module is:

- To educate the general public, transplant candidates, and health care members on live kidney donation
- To provide a brief overview on kidney donation options
- To discuss eligibility criteria for the live kidney donation options
- To discuss required testing for the live kidney donation options
- To increase knowledge on the live kidney donation process in Newfoundland and Labrador
- To increase knowledge on the financial portion of live kidney donation
- To provide up to date contact information on transplant coordinators in Newfoundland and Labrador

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Protected: Section 1: Overview of Kidney Donation

Section 1 of the online module will provide an overview of kidney donation.

This section is discussed in 6 topics:

1. A background on kidney disease and what kidney donation is
2. Facts on kidney transplant and donation
3. A brief summary of the deceased kidney donation option
4. An overview of live kidney donation options
5. Compatible live kidney donation option
6. Living donor paired-exchange option



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Protected: → Background on kidney donation

People are born with 2 kidneys, but a person can live a normal life with 1 kidney.

Sometimes both kidneys stop working for medical reasons such as: high blood pressure, diabetes, and genetic conditions such as polycystic kidney disease.

Kidney donation is giving a kidney to another person whose kidneys have stopped working.

A *kidney donor* is someone who gives a kidney to another person who needs a kidney.

A *kidney recipient* is someone who is given a kidney from the donor.



Brief Background on Kidney Disease and donation

The kidney is one of the few organs that can be donated at either the end of life or from a living person (The Kidney Foundation of Canada, 2017).

Facts about the kidney

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Protected: → Facts on Kidney Transplant and Donation

Here are some interesting facts and statistics on kidney disease and the need for kidney donors

- Chronic Kidney Disease is currently on the rise in Canada. The number of Canadians requiring renal replacement therapy has tripled in the last 2 decades (The Kidney Foundation of Canada, 2016).
- 1 in 10 Canadians are diagnosed with Chronic Kidney Disease (The Kidney Foundation of Canada, 2017).
- An average of 15 people are diagnosed with Chronic Kidney Disease on a daily basis in Canada (The Kidney Foundation of Canada, 2017).
- The need for kidney transplants is 2.5 times higher than the number of donated kidneys that are available through deceased and live kidney donation (Canadian Institute of Health Information, 2016).
- The province of Newfoundland and Labrador has less kidney transplants occur on an annual basis compared to other Atlantic provinces (Multi-Organ Transplant Program, 2016).



From these facts, it is evident that there are an increasing number of people being diagnosed with chronic kidney disease. Therefore, the need for kidney donors are in greater demand then ever.

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Protected: → Summary of the deceased kidney donation option

Deceased Kidney Donation

Although the focus of this online education model is on live kidney donation options, deceased donation will be briefly discussed.

- Anyone can make the decision to be a deceased kidney donor. There are no specific tests that need to be completed.
- The deceased kidney donor option occurs when a person makes the decision that his or her kidneys will be donated to an anonymous person at time of death.
- The decision to be a deceased kidney donor has to be made in advance and put in writing. The decision to donate can be discussed with a family doctor or primary physician. The donor should also let family know his or her wishes on organ donation.
- Once the person passes away, the kidney is donated to a person on the transplant list that is the "best match" for the organ. This is determined through blood testing. The donor and recipient would need matching blood types.
- If the donor is not a good match for someone, the body could attack the donated kidney, this is known as rejection.
- The person is considered the "best match" for the organ when he or she has the least likely possibility of rejecting the donated kidney.

(The Kidney Foundation of Canada, 2017).



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Protected: → Overview of Live Kidney Donation Options

There are two live kidney donation options:

1. Compatible live kidney donation
2. Paired-exchange

The testing for both live donation options is the same, and takes 6 months to a year to complete. This could take longer depending on appointment wait-times, and how quickly a donor chooses to get the testing done.

(The testing will be discussed later in the online module)



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Protected: → Compatible Live Kidney Donor Option

What is the compatible live kidney donor option?

The compatible live kidney donation option can happen when both the donor and the recipient have compatible blood types (matching blood types) and tissue typing (match genetically). When the blood types and tissue typing match, there is a less chance that the recipient will reject the donor's kidney.

In this option, the donor can give **directly** to the recipient.

This donation option is the most desired of the three kidney donation options.

Recipients wanting a transplant may reach out to family and friends for interest in being kidney donors. To be a compatible live kidney donor, the donor **does not** have to be a blood relative. Donors are often friends, colleagues, family members, or a spouse.

(The Kidney Foundation of Canada, 2016)

When a person considers being a live kidney donor, he or she should talk to a family doctor, and get a blood test to determine his or her blood type.

Understanding Compatibility

To understand if your blood type is compatible or a match with the recipient, a blood test can be performed. The results usually take about a day to come back. Below is a short summary of blood type compatibility. A family doctor or a transplant coordinator can also review blood type compatibilities with the donor in greater detail once he or she has completed the blood test. For a summary of compatible blood types for kidney donation, see figure 1 below.

Figure 1: Blood Type Compatibilities

Blood type	Recipient	Donor
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Protected: →The Living Donor Paired-Exchange Option

What is the Living Donor Paired-Exchange Option?

The living donor paired-exchange option also known as the "paired-exchange" option or KPD, is a live kidney donation option. It is a program that is made possible by Canadian Blood Services and all transplant centres Canada wide. This option is chosen when a donor has an incompatible blood type, tissue typing, or antibodies with the intended recipient. If the donor is incompatible or not a match for the recipient, then the transplanted kidney could be rejected. Therefore, when choosing the paired-exchange option, the donor cannot give to the intended recipient directly (Canadian Blood Services, 2016).

To participate in the paired-exchange live kidney donation option, the kidney donor does not have to be a blood relative. The donor can be a friend, family member, co-worker, etc. The donor would also have to complete all of the same testing as a donor in the compatible live kidney donation option.

How the Process Works

- By choosing the paired-exchange option, the donor consents to giving a kidney to a recipient anywhere in Canada, as long as that person's donor is a match for their recipient. It is essentially a "swap."
- Pairing donors and recipients occur in match cycles. Match cycles occur three times per year and the pairs are determined by a computer generated system.
- Once the testing is complete, the wait-time for donation varies due to the mix of blood types and available donors and recipients in the match cycles. If a donor matches with another pair, both pairs will be notified and the surgeries will occur at the same time.
- Both kidneys will be taken from the donors first and then transplanted into the recipients

A clarification flow chart for the paired-exchange option is found in Figure 2

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Section 2: Information on Donation Location & Transplant Coordinators for Newfoundland and Labrador

Section 2 of the online module will provide information on where the live donation takes place for Newfoundlanders and Labradorians. The section will also focus on the role of the transplant coordinators.

This section is discussed in 2 topics:

1. Donation Location
2. Transplant Coordinators in Newfoundland and Labrador



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Protected: -> Donation Location

All required testing to be a live kidney donor occurs in Newfoundland and Labrador. However, there are no kidney transplant surgeons working in the province. Therefore, no transplants occur in Newfoundland and Labrador. Both recipients and donors are required to travel to Halifax, Nova Scotia, for the donation and transplant surgery to take place. In some cases, if a donor is participating in the paired-exchange option, the donor may be required to travel to further transplant centres within Canada depending on where matching pairs are located. This will be discussed in detail with a transplant coordinator as the donation process progresses.

- Travel to Halifax takes 1.5-2 hours by flight
- Flights will be arranged in advance, but the donor should not book a flight until advised by a transplant coordinator.



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→ Eligibility and Evaluation

Protected: →Transplant Coordinators in Newfoundland and Labrador

Transplant Coordinators

Kidney donation is a new journey or transition in the donor's life. There is a lot of information to be informed about, and health care professionals need to ensure that donors are in optimal health prior to donating.

There are 2 transplant coordinators who are responsible for organizing the required tests that need to be completed for live kidney donors in Newfoundland and Labrador. They also provide education to donors and are available to answer any questions that donors may have. They will be in direct contact with all donors during their live kidney donation journey. One coordinator is located in St. Johns, Newfoundland and the other is located in Corner Brook, Newfoundland. The coordinator that the donor contacts will depend on his or her geographical area.

Before contacting a coordinator, the donor should be in contact with a family doctor to discuss the intent to donate and to get a blood type checked.

Once the donor has discussed live kidney donation and gets his or her blood type checked through a family doctor, the donor should contact one of the two coordinators if interested in donating a kidney.

Contact Information

St. John's Coordinator (Responsible for donor testing for all of St. Johns, the Avalon, Clarenville, Burin Peninsula, Central Newfoundland, Northern Peninsula, all of Labrador).

Marion Coffey, BN RN cNeph

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Protected: Section 3: The Kidney Donation Process in Newfoundland and Labrador

Section 3 of the online module discusses the kidney donation process in Newfoundland and Labrador.

This section is discussed in 4 topics:

1. Eligibility and exclusion criteria for live kidney donors
2. Required testing for live kidney donors
3. Consent forms for live kidney donors
4. Sequence of required testing



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Protected: →Eligibility and Exclusion Criteria for Live Kidney Donors (Who can be a kidney donor?)

This section of the topic is very important because transplant coordinators get numerous questions from potential donors wondering if they are healthy enough and suitable to donate. By providing information on this topic, more frequently asked questions can be answered here instead of having to directly get in contact with a coordinator.

- Once donors contact a family doctor and receive blood work to test their blood types, they are then ready to contact one of the two transplant coordinators (the contact information for the coordinators has been provided in a previous section of the online module).
- Upon contacting a coordinator, the kidney donation journey will begin.
- Eligibility Criteria will be the first topic discussed between the transplant coordinator and the donor. Eligibility is who can be a kidney donor. This is determined through your medical history, blood type, and your current health.
- It was outlined earlier that live kidney donors can be friends, family member, co-workers, spouses, and even acquaintances. However, there is exclusion criteria or a number of health conditions that would prevent someone from being a kidney donor. To be a kidney donor, the person must be in optimal health before an organ would be removed from his or her body.
- Living kidney donors must also be over the age of 18. No one under the age of 18 will be considered for donation because the donor would not be permitted to make the decision without a guardian or substitute decision maker. To be a donor, the person needs to be able to make an informed decision on whether or not he or she want to be a kidney donor. This decision needs to be made by the donor without a substitute decision maker.

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Protected: ->Required
Testing for Live Kidney
Donors

After ensuring that the donor meets the eligibility criteria, the kidney donation process will begin, and the coordinator will discuss a number of tests that are required to ensure that the donor is in optimal health to give a kidney.

- The list of tests will be faxed by the transplant coordinator to the donor's family doctor, who will arrange the testing. Therefore, it is important to for the donor to see a family doctor prior to contacting a coordinator.
- If the donor does not have a family doctor, he or she will need to start seeing one. A list of family physicians in Newfoundland and Labrador can be located on the College of Physicians and Surgeons website or a transplant coordinator can assist the donor with finding a doctor in their area.

A link to the college of physicians can be found below:

[Link to College of Physicians and Surgeons](#)

- The only tests that will be arranged by the coordinators and not the family doctors will be the renal ultrasound and CT Scan. These tests will be discussed in detail later.
- Once tests are complete, the coordinator will review results and discuss results with a Nephrologist.
- If a donor has an abnormal test result or the Nephrologist feels that any results are a risk to the donor's own health, he or she may be asked to repeat the test, get sent to a specialist for further assessment, or the donation testing could end (Nova Scotia Health Authority, 2015).

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Protected: → Consent Forms for Live Kidney Donors

Along with the tests described in the previous section of the online module, there are a number of consent forms and paperwork that needs to be completed prior to being accepted as a kidney donor. A brief summary of the consent forms are discussed below.

Donor Disclosure Form: The donor will be expected to sign a donor disclosure form that acknowledges that he or she understands that kidney donation cannot occur for financial exchange or as a result of coercion or force (Nova Scotia Health Authority, 2015).

Preliminary Questionnaire: This questionnaire was mentioned earlier in the online module. When the donor first contacts the transplant coordinator, the preliminary questionnaire will be completed to ensure that eligibility criteria is met and the donor can proceed with testing (Nova Scotia Health Authority, 2015).

Medical Lifestyle Questionnaire: The medical lifestyle questionnaire takes about 30-45 minutes to complete. It must be done over the phone or in person with a coordinator. This questionnaire goes into greater detail than the preliminary questionnaire. The questionnaire focuses on family history, family doctor, travel, past relationships, past surgeries, and obtains information on the donor's overall lifestyle (Nova Scotia Health Authority, 2015).

30-day Questionnaire: The 30-day questionnaire is a shorter version of the medical lifestyle questionnaire, and is completed within 30 days of when the donation will take place. The transplant coordinator will not complete this questionnaire until a date for the kidney donation is set (Nova Scotia Health Authority, 2015).

Multi-Organ Transplant (MOTP) Consent Form: The MOTP program for Atlantic Canada, provides Atlantic Canadians with information on transplant services and statistics (MOTP, 2016). All donors are to complete an MOTP consent form to consent or decline to their information being privately kept in a database for research, educational, and statistical purposes. The donor's name will not be identified and will be kept confidential. Instead, donors are given an

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Protected: → Sequence of Required Testing

If at any time during the work-up the donor is not considered to be in optimal health, the kidney donor work-up will end.

The sequence of the kidney donor work-up is as follows:

1. **Preliminary questionnaire:** The eligibility criteria, blood type, and medical history will be discussed through a preliminary questionnaire. This is completed before any other testing.
2. **Blood Work to get blood type:** If blood work is not completed prior to contacting a coordinator, blood work will need to be completed to determine the blood type.
3. **Tissue Typing:** A blood work slip will be given to the donor by the coordinator to get tissue typing (genetic test) done. This blood work is sent to Halifax and will take 2-3 weeks to return to the coordinator. Other tests will not be started until both the blood type and tissue typing results are back and reviewed.
4. **Serology:** This is a blood test to check for pathogens or infections such as: HIV, Hepatitis, Varicella, Syphilis, Zika Virus, Epstein Barr Virus, and cytomegalovirus. This is completed on all potential donors to ensure that no harmful diseases or infection are transmitted to the recipient when the kidney is transplanted.
5. **Blood Pressure, Height, & Weight:** 2 blood pressure readings, a height and a weight are required (this is to ensure that the donor does not have high blood pressure and that his or her body mass index is less than 35) If the blood pressure reading is high, the donor may require 24 hour blood pressure monitoring. This monitoring requires the donor to wear a monitor for 24 hours and the monitor gets an average reading of the person's blood pressure for a whole day.
6. **24 Hour Urine and Urinalysis:** Two 24 urine samples and two urinalysis are required. (The 2 separate 24 hour urine samples and urinalysis samples need to be collected a week apart). The 24 hour urine sample will be collected at home for 24 hours. The urine collection usually starts early morning. The first sample is discarded and then all other urine samples will be collected until the next day at the same time that the person started the previous day. The donor will then be expected to bring the sample to the nearest hospital. At the hospital, the donor

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Protected: Section 4: The Donor Surgery

Section 4 of the online module focuses on details of the transplant surgery.

This section will be discussed in 4 topics:

1. Information on the kidney retrieval
2. Donation recovery time
3. Life post kidney donation
4. Admission letter and when to book flights



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Protected: → Information on the Kidney Retrieval

The transplant surgery can take place two ways:

1. Open nephrectomy
2. Laparoscopic surgery.

- For donors in Newfoundland and Labrador and in the Atlantic Provinces, laparoscopic surgery is usually done due to its' many benefits
- The surgeon can determine which surgery is right for the donor by viewing the CT scan and Ultrasound reports.

(Nova Scotia Health Authority, 2015).

How are the surgeries different?

- Laparoscopic nephrectomy is an operation that occurs when the surgeon makes some small incisions in the donor's abdomen (belly) and then utilizes a camera to view the kidney and take the kidney out of the donor's body (Gupta, Raina, & Kumar, 2005).
- The open nephrectomy usually has a longer recovery time than laparoscopic surgery. This is because it involves a larger incision to take the kidney out of the donor's body. (Gupta et al., 2005).

Benefits of laparoscopic surgery:

1. Less invasive surgery due to the smaller incision and duration and results in decreased hospital stays
2. Donors experience decreased pain post-surgery than after having an open nephrectomy
3. More cosmetically appealing for donors since the cut is very small and there is usually less scarring than when donors have an open nephrectomy
4. Decreased risk of infection and post-surgery complications when done laparoscopically

(Gupta et al., 2005)

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Protected: ->Donation Recovery Time

Since donation involves a surgery, being educated on recovery time is very important. Without this education donors may not give themselves the proper amount of time to heal. Below are a list of important points to consider with regards to live donation recovery time.

- The donor will be in hospital for approximately 3 days if the surgery is done laparoscopically
- The hospital stay will be a week or longer for an open nephrectomy.
- The health professionals at the hospital will educate donors on the signs of infection at the surgical site. Infection can cause redness, swelling, tenderness, and yellow or brown drainage where the surgery took place. The donor should be checking for any of these signs, and let a health professional know if they appear.
- It will take approximately 6-12 weeks before the donor will be able to perform manual labour. Manual labour involves lifting, pulling, straining, and being on your feet. The donor needs to give the body time to heal in order to prevent complications.
- If the donor's occupation requires manual labour, he or she will not be able to go back to work until the 6-12 weeks are over.
- For office workers, the donor can return to work in 4-6 weeks. This depends on recovery and healing time. The donor will still not be able to do any heavy lifting, pulling, or straining.
- Once the recovery time is over, most people return to their normal routines and live life as before. If complications arise, leave from work and restrictions on activities could take longer.
- Remember that everyone heals and gets back into their routines at different paces. No two people are alike. It is important that donors get back into a normal routine within their own limits. They should not push themselves to go back to work if they are not feeling back to normal.

(Nova Scotia Health Authority, 2015)

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Protected: → Life post Kidney Donation

Upon returning to Newfoundland and Labrador, donors will no longer be followed by the transplant coordinator or Nephrologist that they met with prior to when the donation took place.

- Most kidney donors live normal lives post-donation. Once the donor has recovered, most people go about living life as they have in the past.
- It is the donor's responsibility however, to meet with a family doctor for an annual check-up or if any issues arise.
- Unless issues arise or the donor is otherwise advised, the donor will not be responsible to travel to Halifax for any further appointments or assessments.
- Donors need to keep their own health in mind and follow healthy practices to maintain a healthy lifestyle (healthy eating, exercise, and rest).

(Nova Scotia Health Authority, 2015)



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Protected: → Admission Letter and When to Book Flights

Donors often wonder when the best time is to book a flight?



- Once the health professionals in Halifax make the final decision that the kidney donation can take place, the donor will receive an admission letter. The admission letter will contain the date of the kidney donation/transplant surgery.
- Both the donor and the recipient will need to travel to Halifax at the same time for pre-admission and to meet the transplant team. This is usually the day before the scheduled surgery. Therefore, the admission letters will state the same date.
- Although both the donor and recipient are involved with the transplant, the donor has full control on whether or not the transplant can occur on the recommended date (Halifax puts forward).
- In most instances, the coordinator in Halifax will call the coordinator in Newfoundland and Labrador with a potential transplant date. The coordinator in Newfoundland and Labrador, will then contact the donor to ensure that date works for him or her. If it does not, another date can be considered.
- The recipient is not notified until the donor agrees on a transplant date.
- Flights should not be booked until the admission letter is received and the transplant date is decided on. This is because any potential dates

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Protected: Section 5: Financial Information for Live Kidney Donors

Section 5 of the online module will focus on financial information

Many donors have questions on what financial costs are associated with kidney donation, the reimbursement plan, and who to contact for more information. Here is some key points to remember when taking finances into consideration on the live kidney donation journey.

- To be a kidney donor, the person will be undergoing one of the two surgeries discussed in the previous section of the online module: open nephrectomy or laparoscopic. The surgery will prevent the donor from performing manual labour for 6-12 weeks or until the donor is recovered post-surgery (Nova Scotia Health Authority, 2015). Not every job pays sick benefits and this could leave the donor without normal income for the period of time that he or she will be off of work.
- Kidney donors will need to discuss leave from work with their employers and consider how the donation process will impact leave balances at work as well as income and budget. Donors will be attending appointments, getting testing completed, and then taking time to travel to Halifax for the donation to take place.
- Donors will be expected to pay for flights to and from Halifax themselves and this will not be arranged by the transplant team. Donors are also responsible for accommodation costs if they choose to go to Halifax prior to admission or if a family member escorts them and requires a place to stay.
- Donors may also be required to take a cab to and from the hospital back to the airport. It is important to set aside \$60 each way for a cab ride.

However, expenses can be claimed. There are government forms that need to be filled out and approved for the reimbursement process. This may take time to occur.

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Protected: Section 6: Information Specific for Healthcare Professionals

Section 6 of the online module gives some specific education to healthcare professionals outside of the transplant team.

This section will be discussed in 4 topics:

1. Information on the need for education on kidney donation
2. Consent forms and questionnaires
3. Educating donors on the importance of the family doctor in the donation process
4. How to gain more access to education on live kidney donation



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Protected: → The Need for Education on Kidney Donation

Why do healthcare professionals outside of the transplant team need education on live kidney donation?

Due to the fact that there are only 2 transplant coordinators in Newfoundland and Labrador, and the geographical restraints of the province (long distances for some potential donors to meet with a coordinator), healthcare professionals outside of the transplant team may receive questions on kidney donation. These questions could be from potential donors and recipients who might be considering pursuing a live kidney donor.

The transplant coordinators in Newfoundland and Labrador have not had a prepared information session, pamphlet to distribute, or online module as a guide in the past. Many healthcare professionals have voiced the need to have further information. This online module should be the biggest aid in providing the information that is desired. It will also be updated as policies and procedures change.

There has also been 2 pamphlets, and an information session created to give health care professionals the chance at gaining continuing competence on live kidney donation. One pamphlet is for patients while the other is specifically for healthcare professionals. These pamphlets will be distributed to healthcare centers province-wide.

Please note: Healthcare professionals outside of the transplant team are not expected to complete any of a kidney donor's testing or discuss any forms, consents, or in depth information. However, they may need to be present for the signing of consent forms or receive questions on eligibility and contact information for coordinators. If you are a healthcare provider and require further information or clarity on the live kidney donation process, both transplant coordinators can be contacted from Monday to Friday to address your concerns or questions.

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Protected: → What to do With Donor Consent Forms and Questionnaires

On occasion, it may not be geographically possible for a donor to travel to St. Johns or Corner Brook to sign consent forms that are required for the live kidney donation process. In these instances, a copy of the forms may be sent or faxed to another health professional to either give a copy to the donor in their area or be present when the transplant coordinator discusses the forms.

The forms can then be sent back to the coordinator with the donor's signature.

Healthcare professionals outside of the transplant team are not required to discuss the forms and consents themselves.

Any healthcare professional who is unsure about the consent forms or requires further information, please contact one of the coordinators to discuss the forms in greater detail.



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Protected: ->Educating Donors on the Importance of Having a Family Doctor

Many donors will inquire on how to go about the donation process and if he or she would be a suitable donor. Therefore, it is important to discuss the need for a family doctor.

Throughout the online module, there has been a lot of emphasis on the family doctor's role in ordering the tests that the transplant coordinators organize and request. Without a family doctor, donors would not get their requested testing completed in a timely manner. Both transplant coordinators are registered nurses who are not permitted to order testing. Therefore, having a family doctor prior to beginning the donation process would be an asset for all potential donors.

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Protected: -> How to Gain more Access to Education on Live Kidney Donation

Anyone desiring more education on live kidney donation or have specific questions, there are a number of resources that they can avail of:

1. Contact the St. John's or Corner Brook Coordinator
2. Attend an Information Session (the sessions will be held by a healthcare professional with experience in the transplant program. Check back to the online module for updated dates and times for the information sessions. A copy of the powerpoint presentation used for the information session is available on this module in the closing remarks section.
3. There is also an information pamphlet that will be available province wide to provide quick access to information on live kidney donation. A copy of this pamphlet is also found in the closing remarks section of this online module.

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Protected: Section 7: Closing Remarks

Section 7 is the closing remarks.

This final section of the online module will include 4 topics:

1. Additional Resources
2. Photo Acknowledgements
3. References
4. Dates for Information Sessions

If you have any questions regarding the content in the module, please do not hesitate to contact a transplant coordinator for additional information.



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Protected: ->Summary of Additional Education Resources

Information sessions are available check back to this online module for dates and locations

->The link to the presentation for the information session is located below:

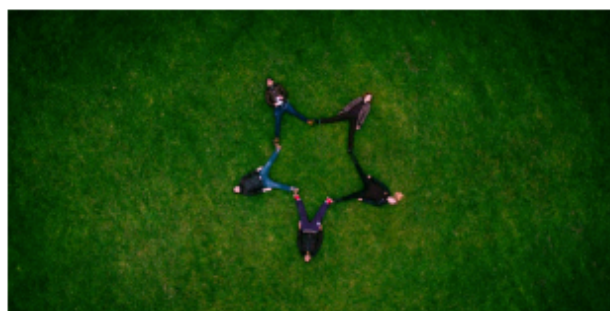
[Presentation for live kidney donors updated for online module June 2017](#)

->Pamphlet- Your Live Kidney Donation Journey (Pamphlet designed for donors, recipients, and their families). This pamphlet will be available in dialysis units, and health centers across Newfoundland and Labrador. You can also get a copy of the pamphlet from a transplant coordinator.

[Information Pamphlet for Live Kidney Donors- June 2017 for online module](#)

->Pamphlet- Live Kidney Donation: Information guide for health professionals (Pamphlet designed for healthcare professionals). This pamphlet will be available at all dialysis centers across Newfoundland and Labrador.

[Information Pamphlet for health professionals- Updated June 2017.](#)



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Protected: ->Photo Acknowledgements

Below are a summary of acknowledgements for all photos contained in this online learning module. All photos were obtained from <https://www.pexels.com/> and attribution was not required.

Photo of airplane, Josh Sorenson, 2015, Pexels, <https://images.pexels.com/photos/59519/pexels-photo-59519.jpeg?w=940&h=650&auto=compress&cs=tinysrgb>

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Protected: ->References

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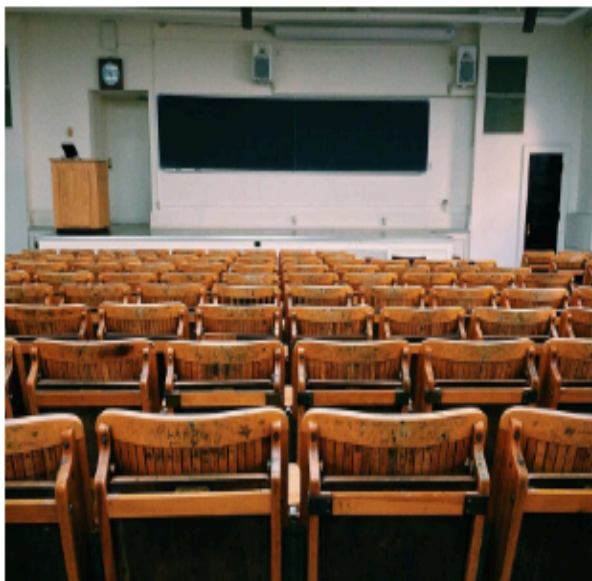
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Protected: -> Updated Dates for Information Sessions on Live Kidney Donation

Check back to this online module for a list of dates for information sessions



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Protected: Evaluation Survey

Evaluation of online module

Please choose the response that best indicates how you felt about the online education module on live kidney donation.

The answers to these questions will help us improve how to make your learning experience better.

1. The online education module on live kidney donation, was easily accessible

Strongly Agree ☐ Agree ☐ Neither Agree or Disagree ☐ Disagree ☐ Strongly Disagree ☐

2. The online education module on live kidney donation was easy to navigate through

Strongly Agree ☐ Agree ☐ Neither Agree or Disagree ☐ Disagree ☐ Strongly Disagree ☐

3. The content contained in the online education module was easy to understand

Strongly Agree ☐ Agree ☐ Neither Agree or Disagree ☐ Disagree ☐ Strongly Disagree ☐

4. The online education module on live kidney donation contained enough information to meet my learning needs

Strongly Agree ☐ Agree ☐ Neither Agree or Disagree ☐ Disagree ☐ Strongly Disagree ☐

5. The online education module on live kidney donation, provided adequate information on the live kidney donation process

Strongly Agree ☐ Agree ☐ Neither Agree or Disagree ☐ Disagree ☐ Strongly Disagree ☐

Appendix D

Permissions

NSHA pamphlet -- Giving a Kidney #0654

Baldwin, Daisy Hi Lara, Thank-you very much for getting back to me, I will be sure to use the attributi... 5/15/2017

Pamphlets [pamphlets@nshealth.ca]

   **Actions** ▾

To: Baldwin, Daisy

Inbox

Monday, May 15, 2017 9:38 AM

- You replied on 5/15/2017 1:37 PM.

Hello Daisy,

Thanks for your recent request to adapt the NSHA pamphlet, Giving a Kidney (2015) for your local patient population. I did not hear back from my contacts about any need to update the 2015 content at this time. As you're likely aware, the current version of the pamphlet can be found here: <http://www.cdha.nshealth.ca/patientinformation/nshealthnet/0654.pdf>

All of our nephrology pamphlets are listed together here: <http://library.nshealth.ca/Pamphlets/WQ>

In case any others are useful to you. You can also check our library catalogue (<http://libcat.nshealth.ca/>) and search any keyword for all patient pamphlets in our collection.

We updated Writing to Your Donor Family (#1212) just in April which isn't listed under nephrology because it's more general than that, but may be of interest to you: <http://www.cdha.nshealth.ca/patientinformation/nshealthnet/1212.pdf>

When adapting this pamphlet, 0654 Giving a Kidney, please include this attribution statement:

Adapted with permission from Nova Scotia Health Authority © 2015.

Thank you for getting in touch about this. Have a great week!

Lara

Baldwin, Daisy*Sent Items*

Thursday, May 18, 2017 9:59 AM

Hi Dallas,

Thank-you for getting back to me. Just to make sure that I understand, if I acknowledge the photos came from Pexels on my education resources, that should cover me correct? I will not have to email them for permission since that is clearly stated, correct?

Also, did you look into Microsoft Clip Art? Should I acknowledge those pictures as well?

Daisy

Clairmont, Dallas*Inbox*

Thursday, May 18, 2017 9:21 AM

Good morning Daisy,

I have reviewed the Pexels site and their photo license does clearly state that all photos on this site are free for any personal and commercial purpose without seeking permission. However, even though they state that attribution is not required, standard academic practice requires us to provide acknowledgement.

Hope this helps.

Dallas

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Memorial University of Newfoundland
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Clairmont, Dallas**To:** Baldwin, Daisy**Actions** ▾*Inbox*

Thursday, May 18, 2017 12:34 PM

Hi Daisy,

I would source it as follows: identifier, photographer, date, Pexels, url. [Example: child wearing hat, Nick Karvounis, 2015, Pexels, <https://www.pexels.com/photo/grayscale-photography-of-kid-s-wearing-hat-63941/>].

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Dallas

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Memorial University of Newfoundland
G.A. Hickman Building | Room ED 2000M
St. John's, Newfoundland, Canada A1B 3X8
T [709 864 7578](tel:7098647578) | F [709 864 6783](tel:7098646783)
<https://citl.mun.ca/>
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