

Chapter 13

Health Literacy in the Development of Kidney Transplantation Programs in Low- and Middle- Income Countries

Jennie A. L. Jewitt-Harris
Transplant Links, UK

Andrew R. Ready
University Hospital Birmingham, UK

ABSTRACT

The need to introduce complex medical technologies in low- and middle-income countries (LMIC) is increasing, to improve quality of life and life expectancy. Despite improvements in medical infrastructure, many countries do not have the skills required to implement such technologies and need support from overseas organizations. Transplant Links (TLC) is a UK charity supporting the development of sustainable kidney transplant programs in LMIC countries. TLC's experience demonstrates health literacy challenges encountered in introducing a complex medical technology, of which transplantation is a good example. Such challenges were found to be wide-ranging, in a specialty already associated with low levels of health literacy. Nevertheless, such challenges need to be addressed and measures undertaken to improve the level of understanding of renal failure and transplantation by patients, families, health-care workers, and other stakeholders including politicians, healthcare managers, and the media. These measures may be transferable to the development of other complex medical technologies.

DOI: 10.4018/978-1-5225-4074-8.ch013

INTRODUCTION

There is an increasing need to introduce complex medical technologies in low and middle-income countries (LMIC). New technologies often bring significant improvements in survival and quality of life, but their introduction can create major challenges. Many countries who have previously been unable to develop such healthcare measures are now able to put in place the required infrastructure but do not necessarily have the accompanying specialist skills to implement them. Such development often relies on the support of volunteer specialist health professionals from other countries through partnerships and charitable organisations.

Health literacy is the degree to which individuals understand the new technology and its implications, and this often needs to be addressed for the introduction of a new medical technology to be successful. From the Health Minister tasked with supporting the development of a new facility, to the patient wanting to understand the treatment they are receiving, the health literacy requirements need to be tailored to address the specific needs of each group.

Success of a new treatment programme can rely on the development of an appropriate level of understanding for each group involved, and without this the new interventions may be at risk of failing, despite successful technical skill transfer. The experience of the Transplant Links (TLC) charity group in addressing health literacy challenges related to the introduction of kidney transplantation in LMIC countries, and the measures taken to overcome them, are described here as an example of those that may be encountered in the introduction of other complex medical interventions.

Renal Transplantation

The global burden of renal failure is enormous (Jha et al, 2013). Despite this, there is very little general understanding of what it means to have kidney failure, compared with the understanding of other chronic illnesses such as diabetes or cancer. In high-income countries, large kidney transplant programmes attempt to address the overwhelming need of end-stage kidney failure, although there is a constant shortage of organs. Attempts have been made to overcome this through the development of live-donor transplant programmes, and extension of criteria for acceptance of kidneys from deceased donors, in the knowledge that a kidney transplant offers better outcomes than dialysis, which is the only other alternative (Nieto, Inston, & Cockwell, 2016).

Renal transplantation is an example of a complex medical intervention which is now commonplace in many countries and offers clear clinical and financial advantages over peritoneal and haemodialysis. However, life on a kidney dialysis machine is expensive and open-ended. Quality of life is poor, with most patients on haemodialysis requiring three sessions per week for four hours at a time for the rest of their lives. Patients often describe it as existing rather than living. The financial burden of the treatment in LMIC countries frequently has to be taken on by the patients and their families, with many patients succumbing to their condition when their funds run out. Often, access to such services for children is non-existent, meaning that many young patients simply die. In many such countries with a public health service, healthcare managers are increasingly concerned about the financial burden of dialysis, and the escalating need for more facilities to be made available (Muller, 2016). The concern is intensified as the global incidence of renal failure and its risk factors such as diabetes and hypertension continue to rise, and are more prevalent in African and Caribbean communities (Bamgboye, 2006). Many countries are

therefore reviewing kidney transplantation as a route to cost-effectively improving quality of life, life expectancy and the burden on the health service.

The introduction of ethical live donor kidney transplantation has created opportunities for kidney transplantation services in many countries. This is particularly so in places where a deceased donor programme would be culturally unacceptable and/or logistically too challenging and where the legal infrastructure may prohibit it without complicated and lengthy legal amendments. Live donor transplantation also creates an opportunity to develop technical skills required for kidney transplantation because the surgery is planned, allowing advanced planning for personnel who wish to be in attendance. With support of specialist overseas colleagues through Transplant Links (TLC), these skills can be developed through long-term partnerships and mentoring, and offer the potential to pave the way for development of a deceased donor programme at a later stage (Ready, Nath, Milford, Adu, & Jewitt-Harris, 2016).

Health Literacy and Renal Transplantation

Despite the huge and expanding burden of renal failure, the level of health literacy related to it and transplantation is poor in countries with advanced facilities to treat it (Dageforde, & Cavanaugh, 2013), creating a significant challenge in addressing it in countries that don't have those facilities but need to develop an understanding to progress.

Transplant Links (TLC) is a UK registered charitable organisation whose goal is the development of ethical, sustainable kidney transplantation programmes in LMIC countries (Transplant Links Community, 2017). The skill transfer required to achieve this takes place through partnership with each country over several years until sustainability is reached.

Figure 1. Surgical teaching in transplantation in the Caribbean (©2016, A Jewitt-Harris, used with permission)



Health Literacy in the Development of Kidney Transplantation Programs

TLC has developed over ten years' experience in supporting the development of kidney transplant centres in Africa, Asia and the Caribbean (Ready et al, 2016). TLC has a small management team with a large group of volunteer specialist healthcare professionals who give up their time to work with partner countries over several years to support the development of transplant programmes. Volunteers include transplant surgeons, nephrologists, nurses, anaesthetists, operating theatre technicians and other associated specialties as required. A bespoke approach is taken to the support of each partner country to align with their specific development needs. Addressing the health literacy issues in each TLC partner country is fundamental to the success of the project at a variety of levels.

TLC surgical volunteer teams are often needed to undertake live-donor transplants within the partner countries, supported by operating theatre specialists and transplant nephrologists and nurses. Through repeated visits long-term skill development is supported so that demonstration of skills is eventually replaced by mentoring and support. Key programmes supported by TLC have included Trinidad and Tobago, Ghana, Nigeria, Nepal, Kenya, Jamaica, and Barbados. Each partner country approached TLC with a view to setting up a national transplant service, and developing the infrastructure required, and to obtain the advice, support and specialist skill transfer needed to make this possible. The first country to be supported by TLC was Trinidad and Tobago where the programme is operating independently and over 160 transplants have now been carried out (firstly live donor, then more recently also deceased donor), and support from TLC is now only needed for the more complicated and paediatric cases (Ready et al, 2016).

The stakeholders in any radical change in medical practice are wide-ranging and all require consideration regarding improving health literacy. When the TLC project began, it was assumed that the necessity for health literacy development would principally apply to patients and potential donors but it quickly became apparent that a much broader approach to addressing health literacy concerns was required for developing programmes to succeed and be sustained.

In all TLC partner countries, the challenges are many and varied ranging from political, to managerial, financial, institutional, logistical, medical, cultural and educational. The latter presents challenges at several levels. Health literacy relating to transplantation may be poor not only for patients and their potential live donors and their families but potentially also for the supporting healthcare staff, hospital management, local media and healthcare politicians. The groundwork needed to address this is pivotal, by both the TLC team and partner colleagues before transplants can be planned. Challenges are increased by the influence of local cultural understandings and customs, which in the field of transplantation can be significant and multi-layered. The myths and misunderstandings that are common in the UK in transplantation are usually supplemented in TLC partner countries and hindered by the lack of long-term media coverage and education on the subject. This finding is not surprising given the lack of previous availability of the specialty but does create a challenging starting point, where incorrect assumptions about pre-existing levels of knowledge may create further challenges. In some countries, for example, TLC has been surprised to learn that renal failure is regarded as the work of a demon, and patients have reported that they have been rejected by family members to avoid the effects of the demon.

Lack of transplantation health literacy in associated medical professions in partner countries is addressed through direct contact, teaching and mentoring by the TLC team. Volunteer transplant professionals are tasked with educating their peers in each country and supporting them in dealing with the transplant-specific health literacy needs of colleagues, patients, and families.

Addressing the transplantation health literacy of patients and potential donors has been challenging, as myths and misunderstandings in transplantation are common worldwide, and limited health literacy is already known to be common in kidney patients (Demian, Shapiro, & Thornton, 2016). Transplant recipients with low health literacy have been found to have higher creatinine levels (Gordon, & Wolf, 2009), indicative of a poorer outcome. The need to overcome this is vital given the importance of immunosuppression (anti-rejection medicine) adherence, essential to prevent rejection of the transplanted organ and known to be influenced by health literacy. In transplantation, the understanding of the donor, recipient and their families can affect the path of events and dictate the outcome of the transplant.

At the outset, TLC team members attempted to identify common misunderstandings in kidney transplant patients and donors in the UK and expected these to be similar, or possibly increased, in countries where transplantation is not part of daily life. These misunderstandings were uncovered through conversations with British patients and their donors and with transplant coordinators and consultant nephrologists and transplant surgeons. They frequently encounter misunderstandings through their daily work, and these provided a starting point to address the specific health literacy need overseas.

Several themes emerged that were frequently encountered. A commonly reported basic misunderstanding relates to poor knowledge of anatomy and even the number of kidneys that are normally present. Patients and donors are often not aware that it is normal to have two kidneys and that a person can function normally with one. Without this basic knowledge, people cannot identify themselves as potential live donors or recipients. Where the kidneys are located within the body, how they connect to the bladder and what they do seems poorly understood. Those with kidney disease often don't realise that the old diseased kidneys are usually left in place and that the transplanted kidney is placed in the groin rather than near the other diseased kidneys. This can totally alter their perception of what the surgery will involve.

With regards to an understanding of the transplant process, misunderstandings relating to matching a donor kidney with a recipient are common. There is often surprise that donors do not have to be the same gender, or be genetically related. The early concept that a close match was mandatory for a transplant to take place is still widely thought of as relevant today (and is possibly confused by the use of a matching system to allocate organs through the deceased donation system).

The benefits of transplantation are often not well understood. The fact that life expectancy, morbidity, and quality of life are all improved through transplantation is often not apparent to patients and their relatives, who may perceive the risk of a transplant as being greater. They are also often unaware that anti-rejection medicine must be taken for the life of the kidney, and that without it, rejection can happen at any time. Rejection is often perceived to be an all-or-nothing situation that only occurs immediately post-transplant, and depends on whether the body will "accept" or "reject" the kidney. While rejection is more common in the early phase after transplantation, it is an issue in the longer-term. This fact is frequently poorly understood as is the recognition that the long-term use of anti-rejection medicines (known as immunosuppressants) is something of a pharmaceutical juggling act; therapeutic drugs being maintained to avoid rejection while avoiding over-immunosuppression and the risk of infection or cancer.

Potential live donors are frequently unaware that they can return to a normal healthy life after donating a kidney, can have a family as normal and will not need lifelong medication. The TLC team have even experienced cases in partner countries where the donor thought they would have to go on dialysis (and in the event of a parent donating to their child, have been willing to do so). Both patients and potential donors are also sometimes unaware that a kidney transplanted from a live donor has a greater chance of working well than a kidney from a deceased donor.

Health Literacy in the Development of Kidney Transplantation Programs

These are complicated concepts and the need for the patient and the donor to engage with them is essential for the success of the transplant. A potential transplant recipient must understand the delicate balance of their immunosuppressive medication, and the need for the levels of the medication to remain within a therapeutic window, for the transplant to be successful and for side effects to be minimised. Even an understanding of the timing of the blood tests to check the levels of the anti-rejection medicine is necessary for these tests to be meaningful in the management of their dosing.

In the UK, the general concepts around organ donation and transplantation have been present in popular media for decades. These have included campaigns for organ donation on high profile television programmes such as “That’s Life” to storylines in soap operas, such as “Coronation Street” that involve key characters needing a kidney for transplantation. Despite stories about transplantation becoming part of normal life in the UK, health literacy relating to the subject remains sparse and often confusing. Addressing this in partner countries where transplantation has never been part of everyday experience is even more challenging, but crucial to the success of the project. It is very different from many other developing surgical technologies, where the success of a new procedure may rely entirely on the skill transfer to the local surgeon, and the patient may indeed know no or very little difference in the technique used. With transplantation, there is a political, ethical, medical, logistical, surgical and consequently educational minefield to cross.

Addressing Health Literacy Needs

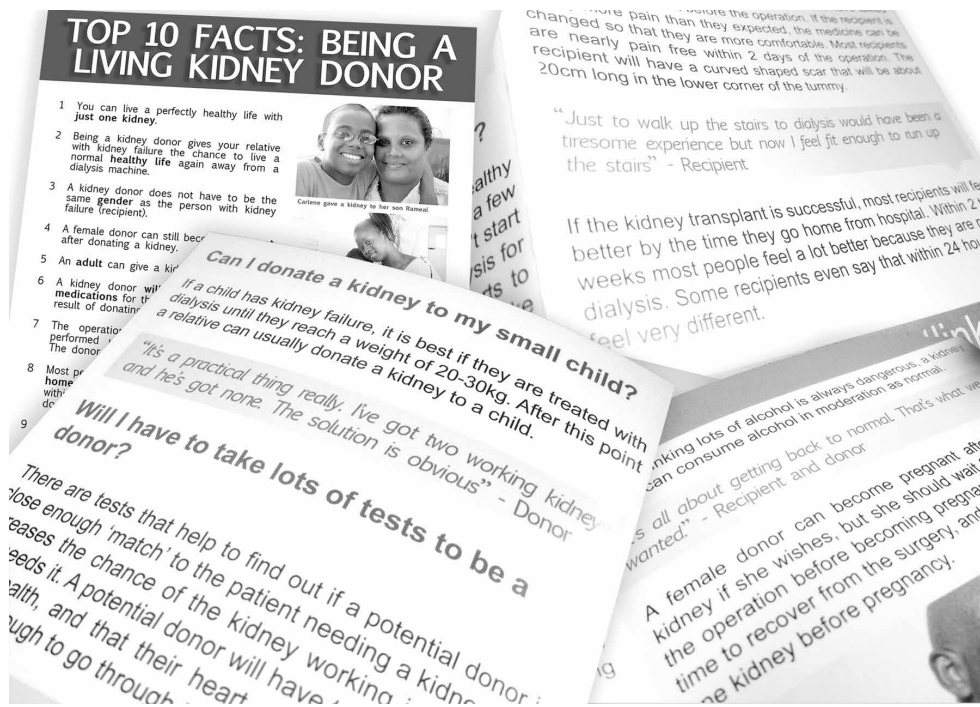
Health literacy is a positive predictor of transplant outcomes (Kazley, Hund, Simpson, Chavin, & Baliga, 2015). It is important in kidney transplantation for many reasons in addition to the adherence to medications which prevent graft loss. It is also crucial for understanding symptoms of rejection and infection, how to care for a transplant (cardiovascular risk, hydration, diabetes, blood pressure), successful pregnancy outcomes and how to live well with a transplant.

For TLC, the starting point in addressing the need for patient and donor education was a review of materials already available for patients and donors in the UK and to then make appropriate adaptations. However, the lack of availability of general educational materials that were not institution or nation-specific created the need from the outset for the development of new educational items for potential recipients and donors, family members and parents of paediatric patients. New materials were developed incorporating the feedback and input of local doctors and nurses from partner countries, paying attention to frequently asked questions by local patients and relatives.

The TLC educational materials are in a constant state of development, incorporating unexpected questions, and adjusting to respond to cultural and regional differences, and use of language. Posters for dialysis centres have been very useful, aimed at patients and their relatives, dispelling specific local myths about being a donor. Information leaflets (in print and online) outlining the steps before, during and after transplantation have been developed and adjusted to each country’s specific needs.

The role of the nurses cannot be underestimated in the long-term development of an educational relationship with the patients, their donors, and families. Teaching seminars with nursing staff have been a core part of the TLC programme, ensuring their full understanding, and of the common misunderstandings and concerns of patients. Demian et al. (2016) describe health literacy in transplantation as a modifiable risk factor with educational interventions as crucial in addressing risks. The TLC experience is that the relationship with nurses is key to the delivery of such interventions.

Figure 2. Transplant Links educational materials for patients, donors, and families



The challenge is increased by other culturally related factors such as patients' relationships with doctors. In the UK, questions from patients to doctors are frequent and encouraged, but in some TLC partner countries, there is a culturally embedded greater reluctance to ask, despite great care being taken to create the space to do so. In one example, in Nigeria, a young man was donating a kidney to his sibling. He listened carefully to the surgeon's unambiguous account of what would happen in the operation. It was not till afterwards that he plucked up the courage to ask "will I be asleep?". It was a stark reminder of the information that is taken for granted as understood, and the need to place information clearly in context. The assumption that everyone would understand that they will be under anaesthetic for the operation, in this case, could have created significant distress for the potential donor, and may even put them off coming forward, without such misunderstandings being addressed.

The transplant literacy of healthcare professionals associated with the introduction of a new programme must also be addressed at many levels to ensure that the process is successful. What might initially be seen as a minor procedural matter, such as the request to have ice available in the operating theatre, is soon recognised as vital when it becomes clear that it is needed to preserve the kidney between the donor and recipient operations, and failure to do so may forever affect the performance of that kidney.

The excitement created by the first transplant in a country is usually encouragement for learning in advance of the procedure, but it is often only 'in the doing' that learning happens. A stark example was during Ghana's first ever transplant, where a young man received a kidney from his sibling. The operating theatre nurse had prepared for weeks for the operations, and her professionalism and capability was outstanding. It was not until the recipient operation was carried out though, and the donated kidney was presented to the surgeon, that the nurse realised what a transplant actually meant and exclaimed: "but only Jesus Christ himself can do that!". While this amused all, and lightened the atmosphere, it illus-

Health Literacy in the Development of Kidney Transplantation Programs

Figure 3. Ghana's first ever transplant (©2008, J Jewitt-Harris)



trated how transplantation in many countries is so outside of the normal that it takes time to filter into the everyday of even the healthcare professionals involved, and that there is a conceptual and education hurdle to overcome before it does.

Cultural differences in communications may create additional barriers to improving local health literacy. In countries such as Ghana, it is well known that communications are often indirect and there is a reluctance to give feedback that may be considered negative in any way by its recipient. Silence is common if there is discomfort about a question that has been asked or concern that the answer will not be the one that is desired. This makes producing information leaflets difficult, as the feedback of patients and nurses is crucial in developing materials that are informative and meaningful, and that use accessible language. When producing draft educational materials for local adaptation, feedback was often difficult to obtain, even though the draft needed to be adapted to make it locally useable. This is an interesting challenge. In these situations, the TLC team often seek the assistance of local healthcare workers many of who have spent time training or working in the UK. Such personnel are often more comfortable with giving “negative” feedback (despite assurance that it is not regarded as negative) as well as imparting their understanding of how the information would be interpreted locally, and could be best adapted.

In contrast, in Jamaica, feedback is more direct, and comments on the very British phraseology in some of the draft materials was useful to make changes that communicate clearly with local patients and have a feeling of local relevance. Other cultural differences in Jamaica impacted on the relationships developed with local healthcare professionals, and the subsequent development of useful materials. For example, the formality of addressing colleagues in Jamaican hospitals was not something the TLC volunteers had anticipated, and the use of first names may not be appropriate, and possibly even be offensive, if used too early in a professional relationship. Building of relationships is fundamental to improving health literacy and all other aspects of the projects in all TLC partner countries. Assumptions made about the way to

behave created challenges, and attention to cultural differences in behaviour, etiquette, philosophy for life, and ways of living have had to be understood in both directions for progress to be made and literacy to be improved. Religious and spiritual considerations may also be important in some countries, as well as an understanding of other local concerns such as the role of witchcraft in developing renal failure, and the use of spiritual healing and herbal medicines.

Use of images or photographs within the educational materials is also culturally embedded. Different meanings can be taken from images, and working with local staff, particularly the nurses, who develop the closest relationships with the patients and donors, was essential to try to ensure the most useful, acceptable and informative images were incorporated into educational materials. Smiling for the camera is not always regarded as a positive thing, and in some instances, may be seen as unprofessional. Similarly, hand gestures in photographs often have different meanings in different cultures.

The lack of health literacy in kidney transplantation also needs addressing beyond medical professionals and patients. Detailed summaries of the field of kidney transplantation, and its benefits over dialysis must also be provided to healthcare managers and politicians, and lengthy conversations have often been required to elaborate on the intricacies which are broad ranging and essential for an understanding of the value and challenges of developing a programme.

Health literacy development beyond the hospital is challenging. The introduction of complex medical technologies requires support at governmental level. The support of Health Ministers as well as regional and local healthcare management has been essential to the success of developing transplant programmes, and local financing of the projects, and requires a significant investment in time in the early stages of a new project. Health Ministers and their colleagues sometimes have a background in healthcare but this is not always the case, and it has often been important to ensure that they receive the information about a proposed transplantation project in a clear and detailed way, making no assumptions. The TLC team has found that it is preferable to furnish the local doctors with the proposal documents and encourage them to adapt them as they feel appropriate and present them to politicians, with the stated full support of TLC, as opposed to TLC sending them directly.

Well written articles about the work of TLC and transplantation, in newspapers and magazines, have often been beneficial supplementary materials to append to proposal documents. The work of a good journalist is invaluable in getting the concepts across in a clear and concise way. TLC documents are frequently prepared by doctors who, despite best efforts and intentions, are notorious for using medical language and assuming knowledge. Any good relevant articles written by journalists will have the benefit of clarifying as well as endorsing the goals of the project and achieving the goal of enhancing the transplant literacy of the decision makers. In all cases, there is no substitute for the development of good relationships with policy makers to support health literacy, and in all countries, the progress of TLC projects has been enhanced where this has been possible, and misunderstandings are readily addressed.

The health literacy of sponsors of charitable projects including the TLC programmes equally needs attention. Sponsorship is increasingly difficult to secure - and sustain - and the development of an understanding of the field of transplantation for key decision makers is crucial to this. Sponsors may not be just financial but also political, managerial or charitable including patient groups. All sponsors need to understand from the outset that the very positive long-term goal of a national sustainable kidney transplant programme may have some negative hurdles along the way such as transplants not working, being cancelled, or being delayed. These are all normal occurrences in any transplant programme, but may need managing and careful communication to maintain relationships, engagement and long-term support.

Ethics and Health Literacy

Health literacy in the context of transplantation extends to an understanding of the ethical framework in which a transplant can take place. The ethical understandings and assumptions around organ donation are complicated and deeply embedded in local culture. The rigour with which concerns relating to organ trafficking are upheld in the UK is often not matched elsewhere. On one occasion, a senior ministerial official who was very supportive of the development of an ethical kidney transplant programme in his country, asked as we were leaving a meeting “where can I buy a kidney for my friend?”. While this seemed to be an extraordinary and inappropriate question to the TLC team, it was seemingly asked in complete innocence, and with surprise at the TLC team’s response.

In some partner countries, the legal and ethical framework for transplantation requires development so that live donor transplantation can proceed. In these situations, again, the need to develop materials (presentations, documents, and films) pitched at the right level for the audience are essential for addressing the health literacy needs of those involved. In the UK, live-donor transplantation takes place under the framework of the Human Tissue Act 2004, and the guidelines for this are often used in partner countries to develop a framework for a committee approach to ensuring the ethical process is maintained. Committee members may include patients, legal representatives, and other non-medical professionals, all of whom will be required to take on an advanced level of understanding of the subject to make appropriate and impactful decisions.

A crucial aspect of the ethical and health literacy challenge is the need to ensure the full understanding of the donor who is undergoing an operation for the benefit of the health of another person. It is even more important that they understand the implications when they are putting themselves at risk for the interests of another. The donor goes through many steps to ensure that they are healthy and to minimise the risk to them, as well as to optimise the chances of success of the transplant. Informed consent of the donor is crucial, and opportunities for asking questions and raising concerns must be created. The committee approach to ethical donation is a further opportunity for donors to raise their concerns, away from the pressures inherent in the pre-transplant assessment process. The TLC team impresses upon everyone involved in the many steps of the process that the understanding of the donor is mandatory, and as in the UK, the opportunity to ask questions and to withdraw from donation remains open.

The Patient’s Voice

In all aspects of health literacy relating to kidney transplantation and the introduction of any new complex medical treatment, the voice of the patients is paramount. There is no better advocate, or more convincing influencer and educator, than a patient who can put across their experience to others. This can take place in many situations, from a press conference to a conversation with a fellow patient in an outpatients department, and opportunities to encourage and nurture it are welcomed.

In Jamaican newspapers, the voice of the patients who were the first to have successful transplants as part of the TLC project was a significant step in improving health literacy about kidney transplantation at the same time as gaining political support for the project.

Within a newspaper article was a quote that demonstrated a clear understanding of kidney failure and the benefits of transplantation. It stated,

Figure 4. Good media coverage as a source of helpful health information



“One of three patients who received kidney transplants last year, Shaneik Lawson, expressed appreciation for the programme and stressed the need for its continuation to help others like her get a second chance at living a normal life, free of the stress of multiple dialysis treatments every week for the rest of their lives” (Pickering. 2014)

Journalists in all countries have been supported through the proactive provision of detailed press releases from TLC in association with partner hospitals outlining the project and providing supporting background material to avoid assumptions and misunderstandings where possible and increasing the chances that the outcome is appropriately informative as well as of public interest. Appearances on television and radio have also supported the development of public understanding. This is usually most effective when local patients and doctors are interviewed, but has also been usefully supported by TLC team members in some circumstances where a third party voice adds to the strength of the messages. A wife who successfully donated a kidney to her husband, in an interview said: “There’s nothing I love more than to hear the sound of my husband peeing with my kidney”. In one sentence, she conveyed so much about the role of the donor, the reality of a successful outcome, and the fact that genetically unrelated, across gender donation is possible.

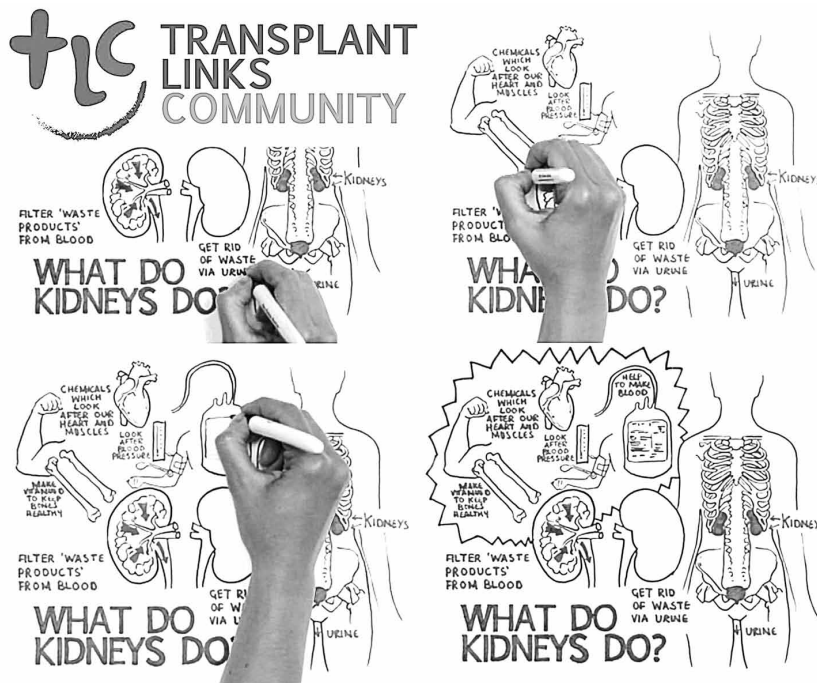
Health Literacy in the Development of Kidney Transplantation Programs

Patient groups have a powerful collective voice and are a great asset in supporting the development of educational materials for future patients and donors. TLC have sought the assistance of patients and donors in maintaining the ongoing development of materials through asking them about their experience, and clarifying what they did or didn't know or expect, what they wish they had known before the procedure, and what information might help future patients and donors. The materials developed for patients and donors can also be beneficial for giving an insight to those who are involved in the system and may need their understanding of the field to be enhanced. These individuals may include administrators, volunteers, and ethics committee members.

Many additional approaches have been taken by the TLC team to broaden the understanding of transplantation for all involved. These have included online articles and interviews in the forms of diaries, videos and newsletters, each adding a different angle to create engagement with the project, and increase understanding.

The TLC experience across a variety of countries and cultures has resulted in development of teaching materials for a variety of audiences, continually adapted to the needs of each partner country. The potential to partner with local media, as well as the use of new technologies presents opportunities to create accessible materials to continue to improve health literacy in this and other medical fields. The development of new technologies is expected to make a significant difference to the way in which TLC can improve health literacy in kidney transplantation with its partner countries. Novel ways of illustrating complex technologies, apps, animations, podcasts and videos are increasingly more able to be accessed across the globe, and offer real opportunities to improve health literacy in this field, particularly now that mobile phones are so widely available in many partner countries.

Figure 5. Transplant Links educational video explaining how the kidney works



CONCLUSION

In summary, the success of the introduction of new complex medical interventions relies not just on the transfer of medical skills, but also on careful attention to the health literacy of all those involved in the process. The TLC experience demonstrates some of the challenges and the actions taken to address them, and the need to remain constantly vigilant and open minded about the unexpected, as well as constantly mindful of the role of culture and experience in creating an environment receptive to a new technology. In assessing the potential to support the introduction of new technologies, consideration must be given to health literacy concerns from the outset, and to the time, effort and expense required to investigate, address and maintain these factors.

The introduction of complex medical technologies in LMIC countries is a growing challenge. Infrastructure development in many countries whose GDP is increasing and whose access to healthcare is improving is often not matched by skill development across the range of healthcare professionals to provide complex services. The challenges are manifold and include addressing the level of health literacy of patients, their families, and of the many tiers of involvement within the community as well as within hospital management and healthcare professionals. The success of a new technology relies on skill and knowledge transfer to the professionals involved, supplemented by an awareness and willingness to seek out and address health literacy issues.

Transplant Links experience in dealing with health literacy challenges as part of the introduction of kidney transplantation provides an example of the many difficulties that may be anticipated with similar programmes. However, it also illustrates approaches through which they may be addressed and particularly the need to work with the material that is available and accessible and the need to constantly adapt this to meet local requirements. Above all, it illustrates the pivotal reliance on team working and communication between all involved.

ACKNOWLEDGMENT

With thanks to Aimee Jewitt-Harris and Laura Ludman for assistance with text, photography and the management of TLC; and to all TLC volunteers who have given their time to support this work and share their knowledge and skills. Please visit www.transplantlinks.org for further information.

REFERENCES

- Bamgboye, E. (2006). End-stage renal disease in sub-saharan Africa. *Ethnicity and Disease*, 16, S2-5–S2-9
- Dageforde, L., & Cavanaugh, K. (2013). Health Literacy: Emerging Evidence and Applications in Kidney Disease Care. *Advances in Chronic Kidney Disease*, 20(4), 311-319.
- Demian, M., Shapiro, R., & Thornton, W. (2016). An observational study of health literacy and medication adherence in adult kidney transplant recipients. *Clinical Kidney Journal*, 9(6), 858–865. doi:10.1093/ckjfw076 PMID:27994867

Health Literacy in the Development of Kidney Transplantation Programs

Gordon, E.J., & Wolf, M.S. (2009). Health literacy skills of kidney transplant recipients. *Progress in Transplantation*, 19(1), 25-34.

Jha, V., Garcia-Garcia, G., Iseki, K., Li, Z., Naicker, S., Plattner, B., ... Yang, C. W. (2013). Chronic kidney disease: Global dimension and perspectives. *Lancet*, 382(9888), 260–272. doi:10.1016/S0140-6736(13)60687-X PMID:23727169

Kazley, A., Hund, J., Simpson, K., Chavin, K., & Baliga, P. (2015). Health literacy and kidney transplant outcomes. *Progress in Transplantation*, 25(1), 85-90.

Muller, E. (2016). Transplantation in Africa – an overview. *Clinical Nephrology*, 86(13), 90-95.

Nieto, T., Inston, N., & Cockwell, P. (2016). Renal transplantation in adults. *British Medical Journal*, 355, i6158. doi:10.1136/bmj.i6158 PMID:27903494

Pickering, C. (2014). Ferguson to implement kidney transplant policy. *WiredJa Online News*. Retrieved from <http://www.wiredja.com/sci-tech-health/health/kidney-transplant-policy-coming>

Ready, R., Nath, J., Milford, D., Adu, D., & Jewitt-Harris, J. (2016). Establishing sustainable kidney transplantation programmes in developing world countries: A 10-year experience. *Kidney International*, 90(5), 916–920. doi:10.1016/j.kint.2016.08.024 PMID:27742191

Transplant Links Community. (2017). Retrieved from <http://www.transplantlinks.org>

KEY TERMS AND DEFINITIONS

Deceased Donor: A person who has died and whose organs are to be donated for transplantation.

Dialysis: A procedure for treating kidney failure through connection to a blood filtration machine.

Kidney Transplantation: The process of removal of a kidney from one person with normal kidney function and implanting into another to treat their kidney failure.

Live-Donor Transplant: The removal of one kidney from a healthy live person to donate to another person to treat their kidney failure.

Renal Failure: Cessation of the normal functioning of kidneys.

Skill Transfer: Sharing of specialist knowledge and procedures.

Stakeholders: Those with a vested interest in a project or activity.

Sustainable: With the potential to be independently maintained over a long period of time.