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, healthcare 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

Related Content