

Chapter 15

Health Literacy: The Way Forward to Increase the Rates of Deceased Organ Donation

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ABSTRACT

Organ shortage is a worldwide persisting problem, as patients on waiting lists increase while actual donors cannot meet the demand for organs. Cultural and religious concerns, gaps of information, lack of medical procedure awareness and of understanding transplant-related terminology are some reasons why people refuse to donate organs. The medical, ethical, social, cultural, religious aspects of deceased organ donation (DOD) bring out the need for a systematic agenda of lifelong learning public awareness raising and health literacy on this issue. This chapter presents findings of a comparative research project in three European countries about how people learn about DOD and their suggestions for systematically promoting health literacy. A total sample of 1309 medical students, renal patients, and hospital administrative staff participated in a survey regarding attitudes, knowledge, sources of information, and communication about DOD. In addition, 51 participants took part in focus groups elaborating on their experiences and suggestions regarding health literacy about DOD.

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INTRODUCTION

The concept of health literacy has evolved by leaps and bounds during the last years. The range of definitions and conceptual frameworks have expanded considerably more than the first notion of HL, as it was presented by Simmons in 1974, which focused on health education on schools. Multiple researchers and organizations explore various issues of health literacy, such as knowledge and understanding regarding specific health issues, antecedents, prevalence, health promotion, disease prevention, and promotion of well-being.

How does health literacy work? Efforts to answer this question include smaller and larger scale projects. Literacy skills are essential for understanding health information, yet the 1992 National Adult Literacy Survey (NALS) in the United States found that 90 million Americans have limited literacy skills, which entails difficulty understanding information in complex texts, such as informed consent forms (Institute of Medicine, 2004). The 2003 NALS showed that the health literacy skills of 14% of the respondents were below a basic level, 22% were at a basic level, 53% were at intermediate, while 12% were at proficient level. According to the European Health Literacy Survey (Sørensen et al, 2013) found that about 47% fall into the categories of low and inadequate health literacy. In the UK, Rowlands et al (2014) found that 43-61% of the population have levels of low health literacy.

More specifically, patients with limited health literacy may have difficulty understanding key concepts and terms about their condition. A survey in 11 countries (Cajita et al, 2017) with 1365 patients suffering from heart conditions, showed that 33% of the overall participants had inadequate health literacy. Although the health literacy levels varied between the countries, lower educational levels were generally associated with lower health literacy levels. An Australian cross-sectional study (Lambert et al, 2015) with 366 patients with chronic kidney disease either at predialysis, or dialysis, and with transplanted patients explored and compared their health literacy needs using the Health Literacy Management Scale (HeLMS). According to their results, about 25% of patients on dialysis or having received a transplant have difficulties understanding health information. Transplanted patients seem to have the highest proportion of health literacy needs, while about 40% of all the patients in the study have difficulties with their attitudes towards health. Another study (Gordon & Wolf, 2009) focusing on the knowledge deficits of patients who underwent kidney transplant showed that they had limited knowledge regarding graft survival and the risk of adverse outcomes. The majority of these recipients (81%) had difficulty to understand one or more common terms used in transplants, such as sensitization, blood urea nitrogen, and urethra, while about 25% of the participants had poor understanding of terms, such as immunosuppression and toxicity.

Other problematic areas for patients with limited health literacy skills seem to be their attitudes towards their disease, adherence to medication, and self-management. According to Miller's (2016) meta-analysis of studies about patient populations with chronic conditions, medication compliance needs less health literacy skills than complex treatment management behaviors. In addition, health literacy interventions had a positive impact on patients' treatment compliance by 16% in comparison to patients who had not attended such interventions. Among the most effective interventions were found to be the use of audio-visual and online educational materials, web-based applications, handouts, and social support resources. Another study (Demian et al, 2016) in Canada explored the health literacy skills of 96 patients using the Health Literacy Questionnaire, as well as their compliance to medication. Transplant patients who scored lower on the health literacy scale also showed less adherence to immunosuppressant medications. Another area in need of health literacy efforts is end-of-life care and decision-making. Brach et al (2012)

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