



RESEARCH ARTICLE

UTILIZING A HEALTH BEHAVIOR APPROACH TO ENCOURAGE ORGAN DONATION IN LATIN AMERICA: INSIGHTS FROM A CASE STUDY IN CHILE

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ARTICLE DETAILS

Article History:

Received 17 July 2023
Revised 21 August 2023
Accepted 23 September 2023
Available online 26 September 2023

ABSTRACT

Organ transplantation presents a promising opportunity to enhance quality of life and extend life expectancy in patients with end-stage chronic organ failure. Although the societal benefits of transplantation are clear, the shortage of organs donated in Latin America poses a significant barrier to accessing this life-saving treatment, resulting in high waitlist mortality rates and prolonged time on the waitlist. To address the problem of organ donation hesitancy, we thoroughly analyzed the behavioral factors by applying concepts from the Socioecological Model, the PRECEDE/PROCEED framework, and Health Behavior Theories. We identified various personal, interpersonal, and community factors that may explain low donation rates and hinder the effectiveness of current strategies, highlighting the lack of information, the spread of myths about donation, the emotional burden for families, and the lack of sufficient human and technical resources. We propose a 10-step evidence-based intervention recommendation that involves focusing on increasing donation rates in the population, improving knowledge about donation and its process, preparing health professionals, developing strategies to promote donation with a focus on the young adult population, implementing specialized teams in transplants and the massification of preservation technologies. In summary, developing countries or countries with low organ donation rates must design evidence-based public policies. This article provides readily accessible information for the public, decision makers and relevant stakeholders.

KEYWORDS

Transplant, organ donation, health behavior.

1. INTRODUCTION

Organ transplantation can improve life quality and life expectancy in multiple organ types (Grinyo, 2013). Conversely, without suitable organ donors, waiting time for patients with end-stage organ failure increases, waitlist mortality increases, and surgical outcomes deteriorate (Martinez, 2019; Van der Doef, 2018; Contreras et al., 2020). During 2020 Chile only had 141 donors for 17.5 million habitants, constituting a reported rate of 7.4 donors per million, one of the lowest in the Latin American region and far from world leaders in organ donation like Spain (Arshad et al., 2019). The explanation of low organ donation rates varies from country to country and is inherently multifactorial and complex. Preconceived negative beliefs about organ donation seem to be the most commonly identified cause, but there is a lack of knowledge about the causes of these beliefs (Mekkodathil et al., 2020). The socioecological model (SEM) is a model to explain health behavior from an individual to a societal level, and it has been used extensively in fields such as gun violence (The Social-Ecological Model, 2021). The PRECEDE/PROCEED model is a framework that describes the phases to analyze a health problem and design interventions. It was developed in 1970 by Lawrence Green and consists of a combined acronym: PRECEDE (predisposing, reinforcing, enabling, causes, educational diagnosis, and evaluation) and PROCEED (policy, regulatory, organizational, constructs in educational and environmental development) (Porter, 2016). The model has been systematically applied to various health problems such as injury prevention, road traffic safety, and quality of life promotion (Howat et al., 1997; Omidi et al., 2016; Azar et al., 2017). Regarding health behavior, several theories attempt to

systematically explain behavior in population. There are no published analyses of health behavior factors involved in organ donation.

2. METHODS

We developed a stepwise approach to identify evidence-based interventions for increasing the number of organ donors in Chile. First, we provided a general description of the problem of low organ donation rates in Chile. Next, we used a socioecological model (SEM) to analyze the situation further, considering various factors that affect organ donation rates, including individual, interpersonal, organizational, community, and societal factors. We then conducted a PRECEDE/PROCEED analysis, a planning model used in health promotion, to identify important factors influencing behavior change related to organ donation. Lastly, we used the health behavior theories to identify key concepts that could be used to design effective interventions to increase organ donation rates in Chile. Based on our assessment, we then provided evidence-based recommendations for increasing organ donation rates. These recommendations will inform the development of future interventions to increase the number of organ donors in Chile and, due to external validity, most of Latin America.

2.1 Factors that Cause Low Organ Donation Rates in Chile

2.1.1 Public's Lack of Understanding about Brain Death

Chilean legislation mandates that cadaveric donations can only be made by individuals diagnosed with brain death, which accounts for just 2% of

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10.26480/jhcdc.02.2023.62.66

all reported deaths worldwide (Aboubakr and Alameda, 2021). Unfortunately, this trend is also evident in Latin America, where no country allows organ donation following circulatory death. The challenge, however, lies in the general population's little understanding of brain death (Shah et al., 2015). This makes it difficult for families to consent to organ donation when their loved ones appear alive in intensive care units. This lack of awareness is especially problematic in low- and middle-income areas comprising most of Chile's population (de Andrade, 2015). Without adequate education and knowledge of complex medical concepts such as end-of-life decision-making and brain death, it can be challenging for individuals to comprehend and make informed decisions about organ donation.

2.1.2 Unexpected Death in Young Individuals and Its Impact on Their Families

The sudden death of a young individual can be a daunting situation for their family members as they are bombarded with a plethora of information. As a result, organ donation communication is often unsuccessful. Furthermore, due to the reluctance to accept the improbable occurrence of unintentional injury resulting in death, their family members usually do not engage in significant discussions the issues like organ donation.

2.1.3 Addressing the Absence of End-of-Life Conversations within Families

Despite the lack of information about advanced care directives in healthy adults, existing literature shows that end-of-life discussions are uncommon, even among young adults with severe illnesses and cancer (Hiscock et al., 2017; Ngwenya, 2017). Studies indicate that these discussions rarely occur. That being said, most data suggest that adolescents and young adults are willing to choose and document their preferred medical treatment for end-of-life situations if allowed to do so (Wiener, 2012).

2.1.4 The Public's Suspicions Regarding the Organ Retrieval Process

There is a widespread misunderstanding about the organ donation process at multiple levels. Consequently, people in the community often believe that healthcare workers will not do everything they can to save patients and may intentionally cause their death to become organ donors. Although Chile's universal donor law was passed in 1996, this misconception likely led four million people to unregister from the

universal donor registry as of 2021 (Lang and Hugo, 2016). Among those remaining in the registry, only 47% of families ultimately follow through with the organ donation process.

2.1.5 Public's Beliefs about Income Inequality's Impact on the Organ Waitlist

In countries with universal healthcare systems, individuals belonging to high socioeconomic groups are often favored for referrals, work-ups, and transplants (Zhang et al., 2018). Despite a lack of empirical evidence, those from underprivileged backgrounds in Chile may have concerns regarding equal access to transplants. This is because of highly mediatic transplants in family members of politicians (Ghorbani, 2011).

2.1.6 Limited Effectiveness of Media Strategies in Promoting Organ Donation

According to the CDC, unintentional injury is the primary cause of death among individuals aged 1 to 44 years old. Despite improvements in road traffic safety and trauma care, there are still significant disparities in exposure to trauma between high-income and low-income countries. Additionally, younger and more vulnerable populations exhibit substantial differences in risk-taking behaviors (Payne et al., 2017). Traumatic brain injury remains a leading cause of worldwide brain death, further highlighting the importance of identifying people with the highest risk of diagnosis (Machado, 2010). Young adults engaging in risky behavior in low or middle-income countries may be a particularly vulnerable population and potentially suitable candidates for organ donation (Payne et al., 2017).

Targeting young adults may yield the highest efficacy for interventions promoting organ donation. This demographic is often more receptive to behavior change than older adults, making them a prime target for health behavior interventions (Zanjani et al., 2006; Vale et al., 2020). A successful example of this approach was observed in 2017 when a TV campaign featuring influential Chileans was implemented specifically for young adults, resulting in a record number of transplants.

2.2 The Socioecological Model for Explaining Low Organ Donation Rates in Chile

Using the socioecological model of behavior change (SEM), we developed a comprehensive list of problems that could be addressed at all community levels, as seen in Table 1 (Golden and Earp, 2012; The Social-Ecological Model, 2021).

Table 1: Socioecological Model of Organ Donation in Chile.	
SEM Level	Public Health Problem
Intrapersonal	- There is a common belief that consenting to organ donation for oneself or a loved one can negatively impact their chances of receiving curative treatment.
Interpersonal	- Many families avoid discussing end-of-life conversations, causing potential distress for all parties involved if an unexpected death occurs.
Community	<p>General population</p> <ul style="list-style-type: none"> - Although a universal donor law in Chile exists, family members often retract presumed consent for organ donation of their loved ones. - In Latin American culture, grieving is a highly emotional process that can make decisions regarding organ donation for a loved one unbearable. - There is limited awareness about the frequency of organ failure, the advantages of organ transplantation, and how a low organ donation rate affects the likelihood of receiving an organ among the general public. <p>Societal popular beliefs that suggest that access to organ transplantation may be dependent on an individual's social status</p> <ul style="list-style-type: none"> - The act of refusing to donate organs has become increasingly normalized. <p>Healthcare workers</p> <ul style="list-style-type: none"> - The notification to organ procurement agencies about potential donors is often delayed. - There is contradictory information regarding transplant-related information to family members after hospital admission. - Healthcare workers are experiencing work overload, causing them to avoid the additional responsibility associated with potential donors.

Next, we analyzed the problem using a different framework.

2.3 PRECEDE-PROCEED Model to Tackle The Shortage of Organ Donation in Chile

The model structures the problem into predisposing, reinforcing, and enabling factors, as seen in Table 2. A complete detailed diagram of the model can be read in Addendum I.

Modifying behavior and addressing societal issues can significantly benefit the shortage of organ donors, ultimately reducing the risk of death or extensive wait times for those in need of transplants. To achieve this, our proposed intervention is designed to encompass educational initiatives and policy reform. Educational endeavors will be aimed at the community,

healthcare professionals, and school-age children. Meanwhile, policy adjustments to expand donor eligibility criteria, streamline referral processes, and foster widespread access to innovative organ preservation technologies can further augment the effectiveness of our intervention.

2.4 Health Behavior Theories (HBT) to Address Organ Donation Shortage in Chile

Although systemic institutional problems might influence the number of potential donors that are identified and consented, applying constructs from health behavior theories can target specific behaviors at the individual level.

We selected four constructs for the organ donation problem using different health behavior theories (Table 3).

Table 2: Predisposing, Reinforcing and Enabling Factors for Lack of Organ Donation in Chile

Predisposing factors	Reinforcing factors	Enabling factors
A devastating diagnosis such as brain death in a previous individual impairs decision-making regarding organ donation in their family members.	Media attention can promote awareness about the need for organ donation and transplantation, potentially leading to increased donor registration and organ availability	There is a limited public awareness about organ donation and its life-saving benefits.
Fear among families about the healthcare system not providing the best care to become potential organ donors.	Advocacy and community outreach efforts can promote greater awareness and understanding of the issues related to organ donation and transplantation, including addressing disparities in access to care or bias in the allocation process	Lack of trust in the medical profession and concerns about the fairness of organ allocation processes.
The need for a transplant during one's lifetime is seen as unlikely.	Ethical and legal frameworks for organ allocation processes exist to help ensure fairness and transparency in the distribution of organs, though challenges and controversies may arise in individual cases.	Fear of premature death or disfigurement, including myths about how organ donation affects funeral arrangements or physical appearance.
		Inadequate support and information for families of potential donors during a traumatic event
		Religious or cultural beliefs that discourage or prohibit organ donation

Table 3: Proposed Health Behavior Theories Applied to Organ Donation in Chile.

Construct	HBT Source	Rationale	Example
Perceived barriers	Health Belief Model	A common belief among people that agreeing to donate organs may result in them not receiving aggressive medical treatment when it is required.	"If I become an organ donor, they will not try to save my life in the hospital."
Perceived susceptibility	Health Belief Model	People think diseases requiring organ transplantation are very uncommon and might never need a transplant.	"Why would I need a transplant? What difference does it make if I am not a donor?"
Experiential attitude	Integrated Behavior Model	Family members experience a profound sense of fulfillment when they opt to donate the organs of a loved one. This stems from the belief that their cherished family member will continue living through the lives of those who receive their organs, and a sense of generosity knowing that they have made a positive impact on the lives of those in need.	"My brother donated organs and helped eight people. He is a hero."
Environmental Constraints	Integrated Behavior Model	Peer pressure to refuse organ donation from extended family members and friends. The lack of appropriate infrastructure for quiet conversation with family members in hospitals contributes.	"Why should I be an organ donor if no one else is?" "I was asked to donate my son's organs and I was asked in a hallway. They didn't even know his name."

2.5 Improving the Organ Donation Rate through 10 Evidence-Based Interventions

2.5.1 Reducing Public Skepticism Towards Organ Donation System by Dispelling Myths

The most common reason for unwillingness to donate organs is mistrust. Mistrust could be addressed by transparent statistics on organ donation and media campaigns focused on the simplicity of the waitlist and that everyone will receive the same care, regardless if organ donation is being considered or not. Ensuring that everyone on the waitlist has equal organ allocation is also an important aspect of this communication.

2.5.2 Fostering Altruism as A Positive Societal Trait, Particularly With Regards To Organ Donation.

With a collective effort to promote organ donors as heroes and acknowledge the generosity of the families of donors, coupled with detailed reports on how the organs were used, we can establish a profound sense of respect for the donors and their loved ones. Over time, this could begin to shift societal perception and elevate organ donation to the status of an important virtue.

2.5.3 Highlighting the event of transplantation on recipients' lives.

Although organ transplantation has the potential to greatly improve the

quality of life of those who need it, many individuals are not aware of the different types of organs that can be transplanted or the challenges that patients on the waiting list face. To address this knowledge gap, media campaigns can highlight the experiences of young transplant recipients and showcase their remarkable transformations before and after receiving organ transplants. This approach can help raise awareness about the importance of organ donation and encourage more people to become donors.

2.5.4 Facilitating End-Of-Life Conversations Within Families To Promote Organ Donation.

Having discussions about end-of-life plans and expressing the desire to become an organ donor is a crucial component of addressing organ donation issue among young people. These conversations become considerably easier with family members once they have previously contemplated the hypothetical event of an unexpected demise or injury.

2.5.5 Utilizing Media Campaigns Targeted at Young Adults to Raise Awareness and Encourage Donation.

By utilizing epidemiologic data, media campaigns can be strategically directed towards individuals who are more likely to become organ donors, specifically the younger population. By tailoring campaigns to this demographic group, there is a greater potential for a measurable increase in donor rates over time.

2.5.6 Enhancing Healthcare Worker Education to Better Support Organ Donation and Transplantation.

The current healthcare worker education curriculums are heterogenous and may lack of focus on transplant education, leading to a disheartening number of healthcare providers holding similar misconceptions to the general public. There is a critical need for improving educational content to address this issue and to incorporate transplantation into continued education for those healthcare workers already practicing.

2.5.7 Developing specialized transplant staff to improve overall patient experience.

Specialized transplant staff is an essential component in improving the overall patient experience for family members. The transplant process can be incredibly overwhelming, complicated, and emotionally exhausting. Having staff members with extensive knowledge and expertise in the transplant field can make all the difference in providing support, guidance, and education that family members need to navigate the transplant process successfully.

2.5.8 Diversifying Donor Recruitment Methods to Expand The Donor Pool And Increase Donation Rates.

Promoting living organ donation, allowing geographically remote hospitals to successfully donate, improving access to facilitate the diagnosis of brain death and changing laws to allow donation after circulatory are some methods that could be used for expanding the donor pool.

2.5.9 Implementing Infrastructure That Provides Space for Important Conversations And Grieving.

Hospitals are known for their hectic and crowded atmospheres, often leaving little room for privacy and comfortable communication. As a result, difficult conversations between healthcare personnel and families of patients may occur hastily and in inconvenient settings, such as hallways. By providing dedicated spaces for grieving and discussions, hospitals can ease stress for family members and facilitate the important process of organ donation for their loved ones.

2.5.10 Increasing Access to Organ Preservation Technologies for All Recipients, Irrespective of Their Insurance.

Various advanced technologies, including ex-vivo lung perfusion long and specialized cooling systems, have been developed to enhance the utilization of marginal organs (Divithotawela, 2019; Campo-Canaveral de la Cruz, 2023). However, the availability and affordability of these technologies is not uniform, which can ultimately undermine their potential benefits. Thus, improving access to these innovative methods can help to expand the donor pool and thereby benefit a larger population.

3. DISCUSSION

The paper discusses the issue of low organ donation rates in Latin America, using Chile as a case example. We used a stepwise approach using the Socioecological Model, the PRECEDE-PROCEED model and Health Behavior Theories to analyze to identify important factors influencing behavior related to organ donation. The utility of the PRECEDE/PROCEED strategy in the context of organ donation has been proposed by other authors to improve organ donation programs (Tantisattamo and Kalantar-Zadeh, 2023). Health professionals have mainly been used as promotion agents, focusing less on mass media campaigns and on healthcare education (Bas-Sarmiento et al., 2023). Although healthcare workers are essential in educating the public, data suggests that the negative to proceed with organ donation primarily focuses on the public's intentions, attitudes, and inaction (Robitaille et al., 2021). Some best-performing campaigns have concentrated on reciprocal altruism ("if you would get a transplant, then you should be an organ donor as well") (O'Carroll et al., 2017). Altruism as a virtue has also been identified as a successful predictor of behavior (Tusche et al., 2016).

A key factor identified in any social marketing campaign has been timing. The intervention's timing must be appropriate and hopefully channeled at specific population segments (Robitaille et al., 2021). Also, messages must be delivered in short and attractive formats, focusing on narratives or stories more than isolated information (Caplan, 2016; Frank et al., 2015). With our analysis we were able to identify several factors that may cause low organ donation rates, such as the public's lack of understanding about brain death, unexpected death in young individuals and its impact on their families, absence of end-of-life conversations within families, the public's suspicions regarding the organ retrieval process, public beliefs about

income inequality's impact on the organ waitlist, and the limited effectiveness of media strategies in promoting organ donation. To promote organ donation, Chile and Latin America may need to focus on dispelling myths about organ donation, fostering altruism as a positive societal trait, facilitating end-of-life conversations within families, utilizing media campaigns targeted at reciprocity in young adults, enhancing healthcare worker education, developing specialized transplant staff, diversifying donor recruitment methods, implementing infrastructure that provides space for meaningful conversations and grieving, and increasing access to organ preservation technologies for all recipients, irrespective of their insurance.

ACKNOWLEDGEMENTS

Blake Reilly and Ryan Kennedy from the Program Planning for Health Behavior Change course from the Master of Public Health Program at the Johns Hopkins Bloomberg School of Public Health.

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