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DOCTORAL SCHOOL OF APPLIED COGNITIVE PSYCHOLOGY

**FORMATIVE RESEARCH FOR A SOCIAL MARKETING CAMPAIGN
TO PROMOTE POSTMORTEM ORGAN DONATION**

Extended summary of the Ph.D. Thesis

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CHAPTER I. INTRODUCTION

1.1. General aspects about organ donation and transplantation

Due to the technological and medical progress, organ transplantation has become an effective and routine procedure for patients with end-stage organ failure (i.e. without other treatment options in most of the cases) (Ganikos, 2010). Currently, a single deceased organ donor can potentially save the life of nine patients on the waiting list for organ transplantation and dramatically improve more than fifty lives with donated tissues. Simultaneously, successful transplantation can indirectly improve the quality of life of recipients' families and friends (Ivarsson, Ekmeahag & Sjöberg, 2014; Bergkvist, Larsen, Johansson, Mattsson, & Fossum, 2018). Furthermore, evidence showed that transplantation's positive impact extends beyond recipients and their families, having the potential to help the deceased donor's loved ones in the mourning process (Manuel, Solberg, & MacDonald, 2014).

1.2. The organ shortage problem

The demand for organ transplantation is continuously growing worldwide due to increased organ failure cases and improvements in transplantation success rates and post-transplant health outcomes (Abouna, 2008). However, there are not enough organs available for transplantation to meet this demand, which led to a global organ shortage crisis (Abouna, 2008). Indeed, with the considerable progress in transplantation surgery and immunosuppressive medication, organ shortage is recognised as the most critical problem of the transplantation field now (Schnitzler et al., 2005; Alashek, Ehtuish, Elhabashi, Emberish, & Mishra, 2009).

Several clinical and psychosocial factors contribute to organ shortage, such as: not all patients in brain death are eligible donors; some potential eligible brain dead donors are missed because of inadequate medical care; some are not reported fast enough or at all for organ procurement; there is no knowledge concerning the patient's medical history or organ donation decision; their family cannot be contacted in time to give the consent or family refuses to consent (Ganikos, 2010). Another more distal factor that exacerbates the organ donation shortage is people's reluctance, in general, to register as donors, although many have a positive attitude towards organ donation (Morgan, Harrison, Chewning, Davis, & Dicorcia, 2007; Morgan, Stephenson, Harrison, Afifi, & Long, 2008; Alsalem, Thaichon, & Weaven 2020). Being registered as a donor can, though, give family members the possibility to find about the deceased's wish, easing their consent decision (Falomir-Pichastor et al., 2013). Earlier studies reported that previous discussions with the deceased person about organ donation decision represent an important determinant of next-of-kin intention to consent (Siminoff, Gordon, Hewlett, & Arnold 2001; Nijkamp, Hollestelle, Zeegers, Van den Borne, & Reubsæet, 2008) and actual consent (Sirois, Sears, & Marhefka, 2005; Falomir-Pichastor et al., 2013). Considering all the above, organ shortage is partly due to the missed attempt to change many potential donors into actual ones rather than the shortage of potential donors (Matesanz & Miranda, 2002).

1.2.1. Possible solutions to the global organ shortage problem

To resolve the global organ shortage crisis there were several proposed possible solutions, such as (1) the development of educational programs for medical staff and the general public concerning the necessity and advantages of organ donation; (2) the utilisation of marginal/extended criteria donors; (3) the utilisation of donors in cardiac death; (4) the introduction of opt-

out system; (5) the implementation of paired organ donation; (6) the acceptance of a compensated gifting system for deceased donor's family and living donors; (7) the acceptance of living unrelated donors (from altruistic reasons) for anonymous recipients; (8) using more living donors; (9) implementing the system of controlled financial benefit for a donor (Abouna, 2008).

From the strategies mentioned above, the introduction of the opt-out system received particular attention from the press, politicians, lawmakers and social marketers (Arshad, Anderson, & Sharif, 2019). Inspired by the Spanish model of organ donation, which became a reference point for other countries, Spain being the world leader in deceased organ donation for more than 20 years, several countries have adopted an opt-out system. It is considered that setting the organ donation as the default option could reduce the people's discrepancy between intention and action towards organ donation (Johnson & Goldste, 2003). Another argument is that the opt-out system could influence people to consider organ donation as a natural choice, a norm (Davidai, Gilovich, & Ross, 2012). The opt-out system also received some criticism, especially of its ethical nature (Shanmugarajah, Villani, Madariaga, Shalhoub, & Michel, 2014).

According to Arshad and his colleagues (2019), healthcare professionals should develop strategies meant to overcome the general public' cognitive barriers or their lack of interest regarding organ donation in order to increase organ donation rates, instead of debating between opt-out and opt-in systems. From their point of view, attitudinal change represents the key to success.

Moreover, for reducing the differences between organ demand and supply between countries, it is particularly important to contextualise the understanding of the impact of organ donation attitudes on the intention to donate organs, respectively the donor registration behaviour in different populations (Alsalem et al., 2020). Currently, most studies that assessed the

determinants of organ donation attitudes and intentions were conducted in the Americas (45%), followed by Europe with 26% (most of them located in Western Europe), Asia (22%), Australia (6%) and Africa (1.14%) (Alsalem et al., 2020). Therefore, the generalisability of the knowledge may be limited to other countries. Organ donation context of each country is shaped by the health system, the religious and legislative context, cultural particularities and social representations from the respective country (Alsalem et al., 2020). Thus, culturally-based insight-oriented studies represent a prerequisite for developing suitable, insightful and achievable promotion campaigns for a target population (Brennan, Binney, Parker, Aleti, & Nguyen 2014).

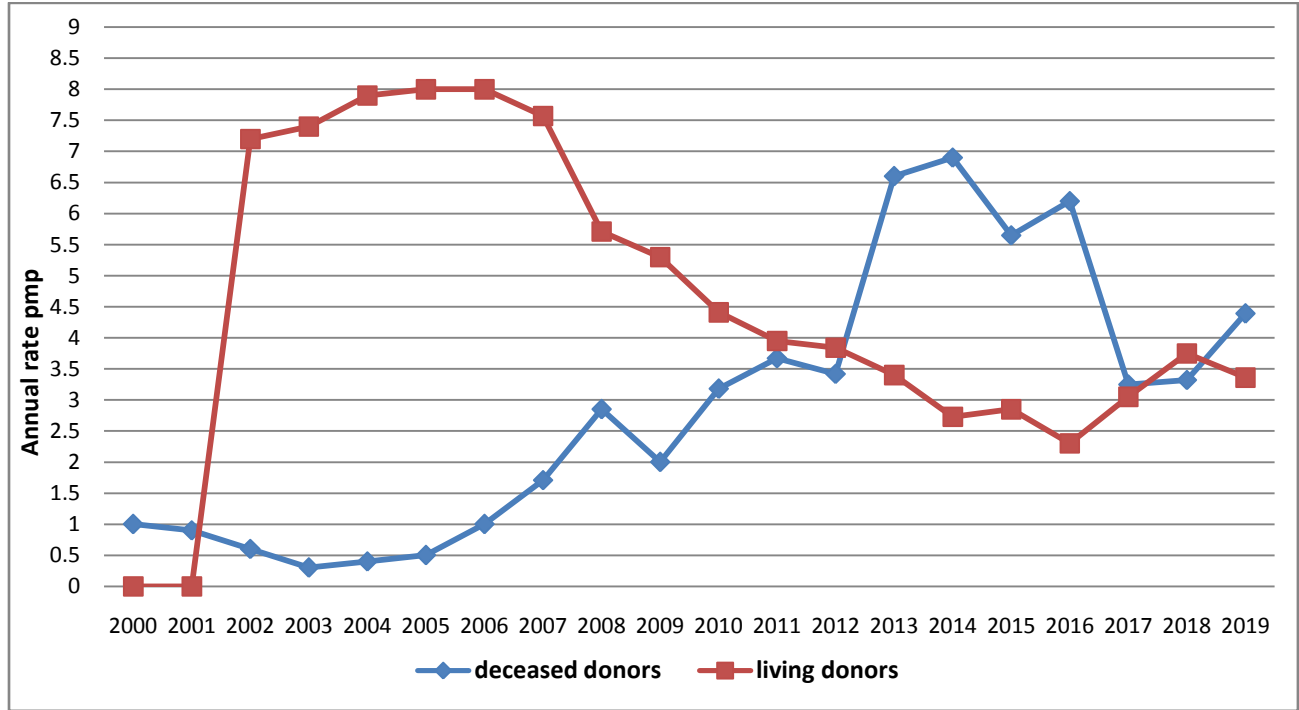
1.3. Organ donation and transplantation in Romania

As we have seen in Figure 1.2., Romania ranks currently at the bottom of the European hierarchy of deceased organ donor rates. The situation is not much different neither for the living donor rate (Domínguez-Gil, 2020). Figure 1.3. presents the evolution of organ donor rates (both deceased and living organ donors) in Romania over the last 20 years. Concerning the deceased organ donation, at the moment, Romania accepts only brain death donors, not donors after circulatory death. Romania currently has an opt-in legislative system.

The Romanian Transplantation System activity was marked by several irregularities and scandals that drew the media's attention in the last years. Some of the most salient negative topics were: accusations of lack of transparency concerning criteria for organ allocation; violations in using public funds; irregularities regarding the accreditation and functioning of certain transplant centres; irregularities found in the administration of the National Transplant Register; a transplant surgeon accused of fraud and forming an organised crime group.

Figure 1.

Organ donor rates evolution in Romania between 2000 and 2019



Note: Data for producing this chart were extracted from The International Registry of Organ Donation and Transplantation [IRODaT] (2020)

There is a lack of information concerning Romanians' knowledge, attitudes and practices towards organ donation and their determinant factors. To our knowledge, there is only one research on this topic on the Romanian population, conducted by Holman, Karner-Huțuleac and Ioan (2013). The study focused on individuals' willingness to consent for next-of-kin organ donation and its determinant factors. Therefore, more studies are needed to identify the barriers and facilitators of organ donation in the Romanian context in order to develop and implement effective and culturally tailored social change interventions.

1.4. Theoretical frameworks

1.4.1. Social Marketing Model

Although the studies on organ donation promotion campaigns do not explicitly mention the social marketing model as a theoretical framework, the campaigns' analysis indicates that social marketing principles were often successfully applied when these were developed and implemented (Harrison, Morgan, & Chewning, 2008; Alsalem et al., 2020).

Social marketing is defined as *"a process that applies marketing principles and techniques to create, communicate and deliver value in order to influence target audience behaviours that benefit society as well as the target audience"* (Cheng, Kotler, & Lee, 2010, p. 2). Therefore, social marketing programmes' main goal is changing the behaviour rather than changing beliefs or increasing awareness towards a certain social problem (Alsalem et al., 2020).

The principal concepts borrowed by the social marketing model from commercial marketing are: (1) the notion of exchange, (2) the segmentation of audience, (3) the competition, (4) the marketing mix (product, price, place and promotion), (5) the orientation to consumer and (6) the continual monitoring (Grier & Bryant, 2005).

The social marketing process is continuous and iterative. It comprises six steps/ phases: (1) the initial planning; (2) the formative research; (3) the development of marketing strategy; (4) the development and pretesting of the programme's activities and materials; (5) the implementation of the programme; and (6) the monitoring and evaluation of the programme during and after its implementation (Grier & Bryant, 2005).

1.4.2. The social marketing of organ donation

Public health professionals have integrated social marketing principles to organ donation campaigns, including consumer orientation, audience segmentation, the four Ps, design, pretesting and evaluation of the programmes and the promoting messages (Harrison et al., 2008). Most of these campaigns were based on social-cognitive models that consider the organ donation decision reflects a rational decision-making process (Alsalem et al., 2020). The most prominent theory in organ donation research is the Theory of Reasoned Action (TRA, Fishbein, & Ajzen, 1975, Alsalem et al., 2020). Accordingly, organ donation campaigns generally focused on attitudes, knowledge, social norms, control beliefs and behavioural intention to influence organ donation behaviours (e.g., donor registration, family discussion about organ donation) (Harrison et al., 2008). These variables were used in the audience segmentation and the marketing plan's development (Harrison et al., 2008).

Compared with other health behaviours targeted by social marketing and the social-cognitive change models, postmortem organ donation decision represents a unique situation. Firstly, it implies a high and uncommon cost for adopting a health behaviour, respectively confronting fear and the perspective of one's own death (Prottas, 1983). Contemplating the postmortem organ donation idea automatically involves thinking about one's death. This is not easy, especially since talking about death is still almost taboo in most cultures (Prottas, 1983). Secondly, the benefits for the deceased donor or deceased donor's family are not so clear and tangible as for other health behaviours promoted by social marketing programmes. Thirdly, postmortem organ donation is a complex social issue with deep cultural roots. Therefore, the strategies for promoting organ donation behaviours need to extend beyond the individuals and consider the social system and the culture where the behaviours happen (Alsalem et al., 2020).

1.4.3. Development of the Social Marketing Model based on Social Representations Theory

A limitation of the Social Marketing Model is that it usually treats the public opinion change and the attitudinal change as being determined by the same process (Lauri, 2008). However, social change, aimed by social marketers, cannot be equalised with individual attitude changing (Lauri, 2008). Social change requires both a change in individuals' attitudes and a change in public opinion and societal beliefs (Lauri, 2015). Hence, social marketers should focus on attitudes as well as public opinion in their research. They need to study how the target consumers make sense of the proposed change at both levels, individual one (i.e., how the change will impact the individuals' private lives) and societal one (i.e., how the change will be perceived by the public) (Lauri, 2015).

To overcome this limitation, Lauri (2008, 2015) proposed adopting the Social Representation Theory as a conceptual framework for the Social Marketing Model. The Theory of Social Representations, first introduced by Serge Moscovici (1961), represents a flexible theoretical framework that allows us to understand how people and groups of people elaborate, communicate and modify their social reality (Rateau, Moliner, Guimelli, & Abric, 2011). Social representations refer to lay theories that people form and use to comprehend and explain their world; their purpose is to make something unfamiliar, familiar (Moscovici, 1984). Unfamiliar is also the organ donation and transplantation phenomenon for most people, not many having direct experience with it (Morgan, 2009). Thus, according to Lauri (2008), the Social Representations Theory represents an ideal framework for the social marketing of organ donation. Lauri (2015) states that to change public opinion, social marketers must begin with understanding the social representations that the public has regarding the respective social issue. In this direction, she

proposed four improvements/ changes of social marketing theory based on the social representations (Lauri, 2008; Lauri, 2015), namely:

1. The proposed social change should be based on social representations.
2. The formative research should be realised with a methodology of social nature.
3. Target groups should be determined based on social representations.
4. Social marketers should employ group strategies to produce change.

The integrative model of social marketing and social representations was applied in a national organ donation campaign conducted in Malta in 1996. All campaign's elements were developed based on the Maltese social representations of organ donation gathered during formative research (it included media analysis, survey, interview and focus group methods) (Lauri & Lauri, 2005). The follow-up evaluation indicated that the campaign was successful, increasing the number of people registered as organ donors and creating more favourable attitudes towards organ donation in the population (Lauri, 2006; Lauri, 2008).

CHAPTER II: RESEARCH OBJECTIVES AND GENERAL METHODOLOGY

The present thesis is guided by the Social Marketing Model based on Social Representations Theory, an integrative model proposed by Lauri (2008; 2015). Social marketing framework emphasis the crucial role of formative research to develop an understanding of the target public, their perception regarding the behaviour intended to change and its associated barriers and facilitators. One of the assumptions of social marketing is that for changing the audience behaviours, the change agents need first to understand why individuals behave in a certain way (Fishbein et al., 2001). Therefore, the primary goal of the thesis was to collect, through a formative research process, data that could be used to design effective, culturally suitable organ donation promotion campaigns for the Romanian public.

Formative research is a process that informs the development of effective behaviour change programmes by gaining an understanding of the local context where the behaviours happen and the barriers and facilitators of the behaviour (Cunningham-Erves et al., 2020). The main aim of formative research is to study and integrate the culture of the target population in order to ensure the cultural sensitivity of the programmes (Glanz, Rimer, & Viswanath, 2008). It involves using qualitative and quantitative collecting data methods to develop a comprehensive profile of what motivates different audience segments. This profile is then employed for marketing the product (the benefits of behaviour) (Prestin & Pearce, 2010).

Taking all this into account, the present thesis consists of seven chapters organized around the four studies of preproduction (formative) research that we have conducted. Each study is self-contained, targeting a certain goal. However, the studies are related and together advance cumulative knowledge regarding the organ donation topic in the Romanian context.

The first goal of our research was **to explore the content of Romanian online media related to organ donation** (Chapter III- **Study 1**). To achieve this goal, we conducted a content analysis study.

Second, we aimed **to get indications of the knowledge, beliefs, attitudes and practices of Romanian general public related to postmortem organ donation and to identify the determinants of the attitudes and behavioural outcomes towards postmortem organ donation**, using a cross-sectional research design (Chapter IV- **Study 2**).

Our third aim was **to explore the social representations of the organ donation held by first-year Romanian students** (Chapter V- **Study 3**). The study was based on the structural approach of social representations, using the Hierarchical Evocation method. For a better understanding of the phenomenon, we explored separately the meanings that students associate with "organ donation", "organ transplantation" and "organ donors". Another objective of this study was to assess students' practices and knowledge towards organ donation and identify the most used sources of information on organ donation.

Next, we focused on the experience of postmortem organ donation from the transplant recipients' point of view in order to understand the whole picture of the phenomenon. Thus, the fourth aim was **to explore how individuals experience life with a transplanted kidney from a deceased donor** (Chapter VI- **Study 4**). In this study, in-depth semi-structured interviews were conducted and analysed using the Interpretive Phenomenological Analysis approach.

The last chapter (Chapter VII) summarises the main findings, discusses the thesis's contributions, acknowledges the limitations, and reflects on possible directions for future research.

CHAPTER III. Study 1: Organ Donation in Romanian Online Media: a content analysis

Introduction

Research findings in the organ donation field show that most people generally have favorable attitudes toward organ donation (Morgan & Miller, 2002; Morgan et al., 2008; Tian, 2010). However, there is a significant gap between attitudes and behaviors, the positive attitudes are not reflecting in donor registration or consent for next-of-kin organ donation (Morgan et al., 2008; Falomir-Pichastor et al., 2013; Siegel et al., 2014). This made researchers ask how the general public form their opinion about organ donation. In many studies, the most used and influential information source about organ donation reported by people is the mass media (Morgan et al., 2005; Feeley & Servoss, 2005; Feeley & Vincent, 2007; Quick et al., 2007). This is not surprising considering the fact that not many people have personal experience with the organ donation and transplantation process; organ donation represents a good example of "second-hand reality" (Morgan et al., 2007).

Social representation theory (SRT, Moscovici, 1984) asserts that the information from mass media about a new or mysterious phenomenon to which few people have direct access, as organ donation, is the first step in creating social representations and forming public opinion about that phenomenon (Flick, 1998; Moscovici, 1998). SRT provides an ideal framework for understanding the joined role of mass media, interpersonal communication and individuals cognitions in shaping behaviors (Morgan, 2009). Thus, most social representations researches generally start by examining the content and the nature of information from the media about the phenomenon (Moscovici & Hewstone, 1983). Therefore, analyzing media coverage of organ donation may give insight into how people's social representations about organ donation were

formed. Also, it may help better understand the discrepancy between people's attitudes, intentions and behaviors towards organ donation.

Present Study

The purpose of the present study is to explore the content of Romanian online media related to organ donation. We opted to focus on online media because its content and quality of the information might differ from that of traditional media. Since the advent of the Internet and especially Web 2.0, the media arena changed dramatically. Today, online media represents one of the top sources of news, reaching a huge audience. Web 2.0 allows everyone to share their opinions about any news or topic and even create their own content (Kamel Boulos & Wheeler, 2007). As a consequence, this allows fake news to appear and spread much faster than in traditional media. Moreover, Web 2.0 also changed the field of health communication and health campaigns (Tian, 2010). The Internet became the main source of health-related information for an increasing number of people (Nazir & Soroya, 2021). For instance, Prestin et al. (2015) found that, once online, approximately 70% of people use the Internet as their first source for seeking health-related information.

Identifying online media content about organ donation to which Romanians have access could give us insight into how the public's attitudes toward organ donation were shaped, the sources of their reluctance and fears regarding organ donation. Moreover, this study could help us better understand the macro-social factors (i.e., political, legal, religious, demographic, socio-cultural, economic) related to organ donation in Romania from the point of view of both stakeholders and the public. This double analysis of the macro-social environment is an essential step in developing effective organ donation campaigns (Lauri, 2008).

Our main research questions are: (a) What is the valence of materials toward organ donation?, (b) Does the valence of materials differ by the media outlet, the proximity of story or year of publication?, (c) What organ donation topics are more likely to be prominently featured in Romanian online media? (d) How is the distribution of the materials by topic over the years?

Method

Search strategy and data collection

Using Google search engine, we searched with “organ donation” term for media reports published online between October 2012 and October 2019 in the Romanian language. The rationale for selecting this time interval was to capture the period when organ donation started to receive media attention following the Ministerial Order of November 2012 regarding founding of the Romanian National Registry of organ donors, tissues and cells and the legislative proposal of implementing the electronic health card and introducing the organ donation option on it.

We opted for Google search because this is the most popular search engine in Romania, with a market share of 97.53% in 2020 (StatCounter, 2021). Hence, it allows us the selection of the most readily accessible information sources about organ donation for Romanians. We chose to include for data analysis the first 20 pages generated by Google. The search was made semestrial, between February 2016 and November 2019.

The following online materials were considered eligible: newspapers, magazines, informational websites, videos and blog pages. The informational websites category included: health-related websites, law-related websites, religious websites, websites of different public institutes and non-governmental associations. The "video" category included local and national TV news, debate-type shows, interviews and documentaries about organ donation streamed on

Romanian online TV stations (we included also the ones in a foreign language with Romanian subtitles), videos with messages/ campaigns promoting organ donation.

We excluded the materials from the following categories: (1) were duplications (N=38); (2) contained less than one paragraph about organ donation and transplantation (N=9); (3) were not in Romanian language (N=5); (4) were posted on online discussion forums (N=7); (5) the links could not be accessed anymore (N=6); (6) the publication date did not appear (N=8). After removing these 73 items, our sample consisted of 313 materials.

Coding plan

The coding instrument contained a set of codes used in previous media content analysis research (Feeley & Vincent, 2007; Quick et al., 2009; Feeley et al., 2016) and codes established by the authors after the independent examination of a subsample of 60 materials (drawn randomly from the final sample). The coding categories were: (1) year of publication, (2) media outlet, (3) type of material, (4) the valence of the material, (5) the topic of material, (6) the proximity of the story. Regarding the coding of the type of material, it was a decision based on the overall nature of the article. The topic of the material category allowed the assigning of more than one code. It was measured dichotomously (namely, the topic appears vs. the topic does not appear) for providing a more nuanced analysis of the organ donation online content.

Procedure

Copies of the online materials were saved in a Word document for being analyzed. The video materials were previously transcribed verbatim by the first author and included in the analysis. Each material was coded manually using a pen and paper approach. The analysis was conducted by two independent coders (namely, the first author and another coder) and audited by

the second author, an experienced qualitative researcher. The inter-coder reliability was calculated and the Cohen's kappa coefficients ranged between .81 and 1 for all variables. The differences in coding were reviewed and discussed with the second author.

Data analysis

The unit of analysis was each whole material (article) published online. The materials were analyzed mainly for their manifest content. However, we also considered the latent content for the materials that used a rhetorical or ironic tone, easily detectable by the reader. All statistics were performed using IBM SPSS Version 21.0.

Results

General characteristics of the sample

Three hundred and thirteen materials were included in the final analysis of the study. Table 2 presents the general characteristics of the sample.

Table 2

General characteristics of the sample

Variable	N	%
Year of publication		
2012*	24	7.7
2013	34	10.9
2014	46	14.7
2015	39	12.5
2016	54	17.3
2017	34	10.9
2018	59	18.8
2019*	23	7.3
Media outlet		

Newspaper	206	65.8
Magazine	20	6.4
Website	53	16.9
Video	14	4.5
Blog	20	6.4
Type of material		
Informative	247	78.9
Interview	28	8.9
Argumentative	35	11.2
Discussion	3	1
Proximity of the story		
National	126	40.3
Local	117	37.4
International	70	22.4

Note: N=313 material for each variable; *the search for 2012 and 2019 was not realised for the entire year.

We briefly present the main findings:

1. In terms of valence, our analysis indicated that most of the materials were positive (57.2%), 14.1% were neutral, 12.5% were negative, and 16.3% were mixed.
2. Regarding the relation between the valence of materials and media outlet, the results indicated a tendency for blogs to represent organ donation more negatively. The majority of these negative materials were, in fact, extremely negative, depicting organ donation frighteningly and sensationally.
3. As for the relation between the valence and the proximity of the story, the analysis indicated that local stories about organ donation were more positive in nature.
4. In terms of the valence of the materials over the years, our analysis indicated some variations. In 2014 and 2017, organ donation coverage was more negative than in the other years. The negative coverage from 2014 coincided with the distribution of

electronic health cards in the population, which was supposed to include the organ donation option. In 2017, it seems that some scandals and irregularities within the organ donation and transplantation system made the organ donation topic more salient to the public negatively.

5. In terms of topic of materials, the analysis indicated that materials about promotion, information about organ donation and system were the categories that occurred most frequently, followed by events, policy and legal categories.
6. With respect to the distribution of the materials by topic over the years, our findings indicated that in the landmark years for the Romanian Organ Donation and Transplantation System, the policy, system or legal categories were most prevalent. These materials depicted more national or international stories and were published more in media outlets with national coverage. In the years without major political actions in this domain, the stories related to promotion, events and information occurred most frequently. Conversely, these were more likely to present local stories and to be published in local coverage media.
7. In terms of accuracy of the information, although we did not have a specific aim to analyse it, we found materials with obviously inaccurate and misinforming content (e.g., fake news about organ traffic cases, utilisation of clinical death or coma terms instead of brain death).
8. Moreover, the analysis revealed that online coverage of organ donation subject was modest over time.

9. Based on our analysis and corroborating the findings with organ donation statistics, it is presumptive to say that were moments when the Romanian media influenced the national organ donation legislative measures and public attitudes towards organ donation.

Discussions

Given Romania's organ shortage crisis, media coverage surrounding organ donation is of particular interest. This research provides an overview of organ donation representation in the Romanian online media. Using this approach offered us the opportunity to understand better the experience of an Internet user that is interested in the organ donation phenomenon. It provides us with a complex picture of the variety of messages, sometimes contrasting, that is covered online and, at the same time, a possible explanation for the different representations of organ donation of the general public. The analysis results give us a glimpse into how media may shape people's opinion about organ donation. However, the research method allows only a speculative answer regarding this relationship. Future studies require experimental methods to examine the impact of exposure to different materials and organ donation frames. The analysis also contributes to understanding the Romanian organ donation macro-social environment, having a valuable insight of formative research.

**CHAPTER IV. STUDY 2: KNOWLEDGE, ATTITUDES AND PRACTICES
REGARDING POSTMORTEM ORGAN DONATION AMONG ROMANIAN ADULT
POPULATION**

4.1. Introduction

There is a dearth of information about the factors that influence Romanians attitudes, willingness and practices toward organ donation. To our knowledge, only one study was conducted on this topic in Romania (Holman, et al., 2013). However, this study focused only on the willingness to give next-of-kin consent and its determinant factors. Also, the survey was conducted more than eight years ago and solely in one city of Romania. Hence, more research is needed to gain a better understanding of the factors influencing organ donation decision in the Romanian context as a means to develop culturally suitable social change solutions.

4.2. The present study

Constructs from the extended version of the Organ Donation Model (ODM) provided the main theoretical framework of the current study (Morgan et al., 2008). Traditional cognitive-based variables (namely, knowledge, attitudes, subjective norms), mass media and interpersonal sources of information about donation and non-cognitive variables (namely, ick, jinx, bodily integrity, medical mistrust and perceived benefits) were all taken into account. Additionally, we examined several significant organ donation determinants less studied from the current literature, such as self-efficacy (Anker, Feeley & Kim, 2010), religiosity and religious norms towards organ donation (Stephenson, Morgan, Roberts-Perez, Harrison, Afifi & Long, 2008; Wakefield et al., 2010), communication apprehension about death (Carmack & DeGroot, 2018). Considering

Romanians' cultural and religious background, we believed that it is relevant to explore these influences. The study's dependent variables were: actual donation registration behaviour, intention to register, willingness to donate organs postmortem, discussion and willingness to discuss organ donation intention with significant persons and willingness to give next-of-kin consent.

The main purpose of this study was (1) to get indications of the knowledge, beliefs, attitudes and practices of Romanian general public related to postmortem organ donation and (2) to identify the determinants of the attitudes and behavioural outcomes towards postmortem organ donation. The specific aims were as follows:

1. to assess the knowledge, beliefs, attitudes and practices toward deceased organ donation among the adult population in Romania;
2. to identify the most used and most influential sources of information on organ donation among the adult population in Romania;
3. to assess the willingness to give next-of-kin consent among Romanian adults in both situations of knowing and not knowing the deceased's wishes;
4. to assess willingness to discuss with the family members/ significant persons about postmortem organ donation wishes, the awareness about family's organ donation wishes and the perceived barriers for discussing;
5. to examine the differences between donors and non-donors (i.e., those who registered as organ donors or not) in terms of demographics, knowledge, affective attitudes and perceived social norms;
6. to assess the willingness to donate organs postmortem among adult population in Romania and to analyse its determinants;

7. to assess the intention to register as organ donor among Romanian adult population and to identify its determinants;
8. to identify the underlying factors of affective attitudes towards postmortem organ donation among Romanian adult population.

4.3. Method

Between June and September 2016, an online cross-sectional survey was carried out using a convenience sampling method (N=1205). The eligibility criteria were a) age over 18 years and b) native Romanian speaker. We used descriptive statistics, ANOVA, *Kruskal-Wallis test*, the Chi-square test, hierarchical multiple regression, multinomial logistic regression and Structural Equation Modeling to analyse data.

4.4. Results

A total of 1207 individuals completed the survey, but data of two participants were eliminated from analysis because were under 18 years. Out of the 1205 respondents, 910 were females and 295 males. The age range was between 18 and 72 years, with a mean of 27.05 years (standard deviation (SD)= 8.194 years). Other socio-demographic characteristics of the participants are presented in Table 4.1.

Table 4.1.

The socio-demographic characteristics of the participants

	No. (%)
Gender	
Male	295 (24.5%)
Female	910 (75.5%)
Age	

18-35	1036 (86%)
36- 55	155 (12.9%)
56+	14 (1.1%)
Religious self-identity	
Orthodox	883 (73.3%)
Roman Catholic	39 (3.2%)
Greek Catholic	30 (2.5%)
Protestant	48 (4%)
Neo-protestant	36 (3%)
No religion	153(12.7%)
Others	15 (1.3%)
Ethnicity	
Romanian	1166 (96.8%)
Hungarian	32 (2.7%)
Others	5 (0.4%)
Last graduated school	
General school	6 (0.5%)
High school	436 (36.2%)
Post-secondary	25 (2.1%)
Faculty	363 (30.1%)
Master	347 (28.8%)
Doctorate	28 (2.3%)
Marital status	
Single	436 (36.2%)
in a relationship	489 (40.6%)
married	260 (21.6%)
Divorced	17 (1.4%)
Widowed	3 (0.2%)
Self-assessed economic status	
Low	49 (4.1%)
medium-low	171 (14.2%)
Medium	630 (52.3%)
medium-high	277 (23%)
Increased	78 (6.5%)
Average monthly income	
under 900 RON	60 (5%)
900-1800 RON	269 (22.3%)
1800-2700 RON	298 (24.7%)

2700-3600 RON	208 (17.3%)
over 3600 RON	370 (30.7%)
Place of residence	
Urban	1073 (89%)
Rural	132 (11%)
Work/ studies in medical field	
No	1043 (86.6%)
Yes	162 (13.4%)

Next, we will briefly outline the principal findings:

1. Although most of the respondents have overall positive attitudes towards organ donation (namely, 83.6% would be willing to donate organs postmortem), their support is not reflecting in the intention to become a donor (only 37.4% reported their intention to register) or in the actual registration (14.9% reported that are already registered as donors). Moreover, the analysis indicated that 20.1% of participants were unsure about their intention to register, and 31.8% did not think about it.
2. Regarding the determinants of the willingness to donate organs postmortem, the following factors were statistically significant from the variables tested: bodily integrity, the jinx factor, the ick factor, medical mistrust, perceived benefits, self-efficacy and religious norms.
3. With regard to intention to register as an organ donor, the analysis showed that from the factors included in the model, only willingness to donate, affective attitudes, perceived benefits and subjective norms significantly predicted whether someone intended or not to register as an organ donor.

4. In terms of registration as an organ donor, only age, medical background, self-assessed level of knowledge, perceived social norms and the non-cognitive factors significantly discriminated between the registration groups.
5. The principal sources of information about organ donation for our respondents were the media ones, particularly films, TV shows/ documentaries and news. The most often utilised interpersonal information sources were talks with friends, followed by talks with relatives. Concerning the perceived influence of all these sources, TV shows/ documentaries ranked first, then films and news.
6. Regarding discussions about their intention/ wish related to organ donation with significant others, our analysis revealed that 58% of participants did not have this conversation. However, 59.4% of them reported that they would be willing, respectively very willing to discuss it.
7. For attitudes toward next-of-kin consent, our results indicated that, in the scenario of not knowing the next of kin wish, 33.6% of respondents would be likely and 21.7% very likely to consent. Still, in the scenario of knowing that next-of-kin expressed the wish to be a donor, 17.1% of participants reported that they would be likely, respectively very likely to consent (74.7%).

4.5. Discussions

The main purpose of this study was to gain an understanding of the knowledge, beliefs, attitudes and practices of Romanian general public related to postmortem organ donation and to identify the determinants of the attitudes and behavioural outcomes towards postmortem organ donation. To our knowledge, this is the most extensive study conducted in Romania on this topic, the first theory-driven study to assess (1) predictors of both willingness to donate organs

postmortem and intention to register as a donor, (2) the differences between donors and non-donors, (3) the discussions with family about organ donation and the perceived barriers for discussions and (4) the underlying factors of non-cognitive variables towards postmortem organ donation among Romanian adult population. It provides valuable insights into formative research for organ donation promotion interventions in the Romanian context. Findings are especially relevant at present when Romanians seem to be more reluctant than in the past to organ donation, reflected in the decreasing annual deceased organ donors rate (NTA, 2019).

Our study confirms the value of the extended ODM model and the crucial influence of affective, visceral reactions in relation to organ donation attitudes and behaviours. Deceased organ donation barriers and motivations are deep, complex and multifaceted. For an efficient social change, it is necessary to study the interaction between the cognitive and non-cognitive factors. It is important to not underestimate the role of superstitious beliefs, myths, "gut feelings", personal interpretation of religious precepts, misconceptions, local beliefs and social representation, folk customs and beliefs surrounding death and funerals when it comes to organ donation understanding. Future work is required to explore in-depth these aspects in the Romanian context in order to gain insights about how we can target them in culturally-appropriate organ donation campaigns. This study gives us a broad picture of what Romanians know, think, feel and practice related to postmortem organ donation, providing valuable insights of formative research.

CHAPTER V. STUDY 3: SOCIAL REPRESENTATIONS OF ORGAN DONATION AMONG ROMANIAN STUDENTS: A STRUCTURAL APPROACH

Introduction

Many studies in organ donation literature were conducted on university and college students samples. Beyond the fact that it is easier to recruit and motivate them to participate, Feeley (2007) states that are other more important reasons for targeting students in the organ donation research. Firstly, they meet the demographic profile of those more in favour to register as organ donors (namely, younger and with a higher socioeconomic status). Secondly, they are clinically healthier, but also more prone to engage in risk behaviours, and this make them more likely to become potential eligible donors. Thirdly, students tend to be more open to new information and knowledge. Also, they may become opinion leaders in their field after graduation and may shape other people perspectives (Feeley, 2007).

A meta-analytic review of communication campaigns for promoting organ donation found that is still not clear what factors or activities are more efficient than others in promoting organ donation (Feeley & Moon, 2009). One of the study's recommendation was to use, when possible, the interpersonal methods because these *"reassure individuals' decision to donate, provide the means to pledge one's donation wishes, and communicate the normative nature of altruism within a community"* (Feeley & Moon, 2009, p. 71). Morgan (2010) also emphasis that the campaigns, especially the university-based campaigns or worksite ones, that contain interpersonal contact with prepared staff and volunteers are more efficient than interventions delivered only through mass media channels.

Lauri (2008) argues that for changing public opinion through a campaign, the social market agents must consider people's social representations and attempt to work at this level rather than individual attitudes level. She also states that target-population segmentation for a campaign would be more efficient if based on social representations rather than on other characteristics, like socio-demographic characteristics or lifestyle. In a social campaign, the most effective segmentation methods are those that capture most clear the differences in the behaviour of the target group (Kotler and Roberto, 1989). Members of a group with the same socio-demographics and lifestyle, can still have different social representations on a topic (Lauri, 2008). Therefore, cannot be considered a homogeneous group when developing a social marketing campaign.

Since the appearance of the Theory of Social Representations were developed different approaches for studying them (e.g., anthropological, discursive, socio-dynamic, structural approaches) (Lo Monaco, Piermattéo, Rateau et. Tavani, 2017). The structural approach (also referred as the "central core theory" or "central nucleus theory") represents one of the main developments of the social representations theory (Molnier & Abric, 2015; Garnier, 2015; Lo Monaco et al., 2017). This approach it is based on the assumption that a social representation is hierarchized and organised in a dual system: a central system and a peripheral system (Abric, 1993).

The central system, also known as central core, contains a limited number of elements, which are consensual among the group (define the homogeneity of the group). Also, the central core is linked to the collective memory and the history of the group, it is coherent, stable, rigid, change resistant and not sensitive to the immediate context (Abric, 1993; Rateau, Moliner, Guimelli et., Abric, 2011; Dany, Urdapilleta & Lo Monaco, 2015). In terms of expression, it is

considered that central elements are abstract, unconditional/ non-negotiable and constitute elements of definition (Molnier & Abric, 2015).

The peripheral system includes many elements, that are flexible, it tolerates contradictions and the heterogeneity of the group, it is sensitive to immediate context and changes over time (Rateau et al., 2011; Dany et al., 2015; Molnier & Abric, 2015). The peripheral elements express specific cases, concrete and contextualised elements, which people associate conditionally with the object of representation (Molnier & Abric, 2015).

The present study

Understanding students' social representations of organ donation provides valuable insights into designing effective, culturally-appropriate university-based campaigns for promoting organ donation. The purpose of this study was to explore the social representations of the organ donation held by first-year Romanian students using the structural approach of social representations theory. For a better understanding of the phenomenon, we explored separately the meanings that students associate with "organ donation", "organ transplantation" and "organ donors". Also, we aimed to assess students' practices and knowledge toward organ donation and identify the most used sources of information on organ donation.

Method

The study was based on the structural approach of social representations theory, using the Hierarchical Evocation method (Abric, 2012). Between October and December 2017, an online cross-sectional survey was carried out using a convenience sampling method (N=325 students, 228 females, m=19.4 years). The questionnaire consisted of three sections, namely:

(1) Hierarchical Evocation Tasks. Below, we present an example of how the task was formulated in the questionnaire. It was composed identically for organ transplantation and organ donor.

Please write the first four words/expressions that come spontaneously to your mind when thinking about "organ donation". Write them in the order in which they came to your mind.

Answer A:

Answer B:

Answer C:

Answer D:

Now, please order the above-mentioned words/expressions from the most important (1) to the least important (4), having in mind the link with "organ donation".

1.

2.

3.

4.

(2) Organ donation scale. Within this part, we investigated the self-assessed level of knowledge about organ donation, personal experience with organ donation and transplantation, the actual donation registration behaviour, intention to register as an organ donor, willingness to donate organs postmortem and sources of information about organ donation.

(3) Demographic data. This included items referring to age, gender and religion.

Data analysis

Following the method advanced by Abric (2003) for analyzing hierarchical evocations, in the first step, we conducted a lexical analysis for each of the three corpora of associations (i.e.,

the associations produced by sample based on the stimulus terms "organ donation"/ "organ transplantation"/ "organ donor") for reducing data. In each case, we organised the 1300 words/ expressions into semantic categories. The categorization was made individually by the first author and another research colleague. After the separate categorization process, the results were compared and the differences in categorization or interpretation were discussed until an agreement was reached. The words/ expressions belonged to the categories with a very low frequency (less than 10 words) were excluded from the analysis at this point. In the second step, we carried out a hierarchical evocations analysis in order to obtain the structure of the social representations.

Figure 5.1.

The four zones of the hierarchical structure of associations

		Average Importance (AEI)	
		High (<2.5)	Low (>2.5)
Frequency	High	Central zone	First peripheral
	Low	Contrasted elements	Second peripheral

Results

Our analysis conducted on 325 students revealed the following findings:

1. The majority of students had, in general, positive social representations of organ donation. Organ donation was seen as an act of kindness, help and a new chance for life.

2. The words life, help, saving/ saviour were common to all three social representations' central core, qualifying as potential central elements of the core.
3. Based on observed evocations, it is presumptive to say that media influenced students' understanding of organ donation. The words and expressions "(give) life", "saving", "help", "(a new/ second) chance", "making good", "love", "be a hero" are common in the messages promoted by organ donation campaigns.
4. The analysis of the contrasted and peripheral elements also revealed that some participants have certain concerns, doubts and fears in relation to organ donation, especially about organ trafficking, brain death diagnosis, and potential abuses made by doctors. However, these elements were not found for "organ donor" stimulus.
5. In terms of registration as an organ donor, 98.5% of participants declared they did not register.
6. As regards willingness to donate, 82% of students declared that they would want to donate organs postmortem. However, concerning the intention to register, the analysis revealed that 7.5% of respondents do not intend, 23.4% are intending, 15.9% are not sure, and 53.3% did not think about this until now.
7. The primary sources of information reported by respondents were the media ones. The internet was the most used channel of information, followed by TV.

Discussions

To our knowledge, this is the first study of this type conducted in Romania on organ donation topic. It provides valuable insights into how to design and conduct culturally-appropriate, locally-embedded university-based campaigns for promoting organ donation. Organ

donation and transplantation represents a complex issue of both suffering and hope that causes strong feelings and thoughts in society. Previous researches showed that people hold many misconceptions, superstitions, fears, "gut feelings", conflicting beliefs towards organ donation (Morgan et al., 2008; Newton, 2011; O'carroll et al., 2011). These reactions are often rooted in religious beliefs, local beliefs surrounding death, funerals and afterlife, representations of their own body or personal experience with health system. Therefore, for social change it is necessary that social market agents to understand these deeply rooted attitudes and the lay theories that people create to explain organ donation (Lauri, 2009). Thus, the Social Representation theory can provide an ideal framework for organ donation promotion campaigns.

Our findings indicate that Romanians students' social representations of organ donation are generally positive. Organ donation is seen as an act of kindness and help for those in need, a new chance for life. The words life, help, saving/saviour, are common to all three social representations' central core, qualifying as potential central elements of the core. Despite the suffering and the pain caused by the death of a loved one, central to people's understanding of organ donation is the possibility for doing a good deed and save the lives of those without other chance. The words and expressions evoked by participants may reflect the influence that media has on shaping people's understanding of organ donation. The words "(give) life", "saving", "help", "(a new/ second) chance", "making good", "love", "be a hero" are the most used ones in the messages promoted by organ donation campaigns.

Although our study indicated almost a unanimous agreement that organ donation is a good deed, analysing the contrasted and peripheral elements we can see that from participants evocations arise also some concerns, especially regarding various illegalities in organ donation and transplantation field, such as human organ trafficking, concerns regarding brain death

diagnosis, the potential abuses made by doctors, patients discrimination based on money. Interestingly, these elements were found just for organ donation and organ transplantation stimulus; in the cases of organ donor representations none of these ideas were mentioned. This result may reinforce the idea that the participants perceive organ donation as a noble and kind act and suggest that our participants concerns and doubts regarding organ donation are mainly rooted in the medical system mistrust. At the same time, these could be the effect of negative sensationalized media portrayals of organ donation and transplantation.

This study gives us a broad picture of social representations of organ donation among the Romanian students, providing insights of formative research. For instance, in a future organ donation campaign addressed to students, we could use the words/ expressions evocated in this study for designing the messages/ materials from the campaign. We could also segment the groups of intervention and tailor the messages for each group based on participants evocations about organ donation and transplant. However, for developing more effective campaigns, it is necessary that this study to be corroborated with an in-depth exploration study of the social representations of organ donation among Romanian students.

CHAPTER VI. STUDY 4: THE EXPERIENCES OF LIVING WITH A TRANSPLANTED KIDNEY FROM A DECEASED DONOR

Introduction

Kidney transplantation is considered an optimal treatment option for patients with End-Stage Kidney Disease (ESKD) (Tonelli et al., 2011; Nielsen, Clemensen, Bistrup, & Agerskov, 2019; Chong, Kim, Kim, & Lee, 2016). Existing evidence points out that successful transplantation has a better long-term survival rate, provides a higher quality of life (QoL) and it is more cost-effective compared with dialysis (Tonelli et al., 2011; Kaballo et al., 2018; Chong et al., 2016). However, post-transplant life involves numerous medical and psychosocial challenges for patients such as: the need to adhere to permanent immunosuppressive therapy and a new lifestyle, confronting comorbidities, an increased malignancy risk, pronounced side effects, fear of infections or graft rejection, coping with uncertainty and social reintegration (Kamran, 2014; Schulz & Kroencke, 2015).

The present study

The present study aims to explore how individuals experience life with a transplanted kidney from a deceased donor. Findings can improve quality of care and prepare recipients for living with a kidney transplant. Understanding individuals' challenges and needs after transplantation is a prerequisite for a holistic approach to care and for developing effective patient education and self-management programs.

Methods

Design

Interpretive Phenomenological Analysis (IPA) was considered the most appropriate method for this study as its primary purpose is to explore and understand in depth the way people make sense of their experiences (Smith & Osborn, 2008).

Participants

The 8 participants were recruited during the 4th Edition of Summer school for patients with chronic kidney failure, organised by the Romanian Transplant Recipients Association. The first author joined the event and received permission to present her study, recruit potential participants for interview and conduct participant observation. The inclusion criteria were: over the age of 18 years, Romanian native speaker, self-reported stable graft function, at least one year since transplantation, dialysis before transplantation, having the first transplant and receiving the graft from a deceased donor.

Table 6.1.

Socio-demographic characteristics of participants

Pseudonym	Age	Gender	Duration of dialysis	Calls for transplant	Years since transplant surgery	Marital status	Employment status	Religion
Sebi	29	Male	1 year	two	1	single	ill-health retirement	Orthodox Christian
Sofia	31	female	2 years	two	5	in a relationship	ill-health retirement	Orthodox Christian

Ana	30	female	9 years	six	2	married	ill-health retirement	Orthodox Christian
Oliver	32	Male	2 years	two	12	married	ill-health retirement	Orthodox Christian
David	37	Male	1 year	two	1	divorced	ill-health retirement	Orthodox Christian
George	54	Male	3 years	two	8	married	employed	Orthodox Christian
Adi	64	male	4 years	two	4	in a relationship	retired	Orthodox Christian
Ema	33	female	2 years	four	6	single	ill-health retirement	Orthodox Christian

Results

Three main themes emerged from the data and each one presents a certain level/ aspect of the post-transplant experiences: An inner struggle to find a new normality (personal level); Me and the others (relational level); and Only between me, my donor and God (spiritual level). However, this delimitation is an artificial one, as the three themes are interrelated. We outline the main findings:

1. The analysis revealed that patients expected post-transplant life to mean returning to their lost normality, disrupted by dialysis. However, post-transplant life was described by participants rather as an ongoing inner struggle to find or negotiate a new normality.
2. Confronting the idea of their own death, the permanent uncertainty and the prospect of losing their freedom seemed to influence recipients to focus on living in the present.
3. The "me and the others" theme illustrates the impact of relationships on the participants' coping with the transplantation experience, as well as the impact of this experience on relationships. It appears that supporting family members represented an essential

resource for patients' adaptation. However, most participants found it difficult to express their thoughts and emotions with their loved ones, each one stating that "someone normal" (i.e. healthy) cannot understand them. Findings revealed a feeling of inadequacy experienced by recipients in relation to others, which seems to have led to other psychological problems in some cases, such as fear of rejection or involvement, reluctance to accept other people's support and ambivalence concerning emotional expression.

4. Our findings indicated that meeting other patients with a kidney transplant helped recipients to achieve a sense of normality in their post-transplant life.
5. The theme "Only between me, my donor and God" discusses the spiritual aspect of the post-transplant experiences. Spirituality appeared as the main route to participants' resilience.
6. The analysis revealed that all recipients followed the Romanians traditions for remembering of the dead for their donors. According to the recipients' stories, these rituals were beneficial, helping them to make sense of their bond with the donor, to cope with the emotional conflict of living because of someone's death and to manifest their gratitude in a meaningful way.
7. Another important spiritual connection was with God. Faith in God has been the participants' fundamental system of meaning and stability during the transplantation experiences, especially in moments of fear of death or the unknown, in those of loneliness and misunderstanding.

8. From analysis also emerged some possible adverse effects of religious coping strategies, such as the anxiety of being judged and punished by God. Participants felt indebted and guilty for not being grateful enough for God's "gift of life".

Discussions

This study revealed how recipients of a kidney transplant from a deceased donor coped with post-transplant life, namely by struggling to find a new normality, seeking support from others and from God. Results show that patients expected post-transplant life to mean returning to their lost normality, disrupted by dialysis. This is consistent with studies that explored the experiences of waiting for a kidney transplant, where the transplant was represented as "the light at the end of the tunnel", freedom from dialysis and the return to their life before it (Burns et al., 2017; Yngman-Uhlin, Fogelberg, & Uhlin, 2016). The media metaphors concerning transplantation such as "the gift of life" or "a new chance" suggest the end of health problems without acknowledging its potential difficulties and may contribute to recipients' false expectations (Waldron, Malpus, Shearing, Sanchez, & Murray, 2017).

Findings highlight the need for patient education programs after kidney transplantation. Greater attention should be paid to interpersonal coping processes and the idea that transplantation is not just a personal crisis. Additionally, healthcare professionals should facilitate the patients' access to patients' groups. These may improve the adjustment and social integration following transplantation, normalising recipients' experiences and reducing feelings of isolation (Lonargáin et al. 2017). Results show how the participants' transplantation experiences are shaped by certain cultural, religious and spiritual beliefs, indicating the importance of a holistic nursing approach (Strandberg, Ovhed, Borgquist, & Wilhelmsson,

2007). Furthermore, findings could help professionals assist the recipients in making sense of their bond with the deceased donor and integrating the new organ in their identity. Similarly, these could contribute to developing grief counselling protocols for the donors' families. Understanding recipients' experiences and feelings could help the donors' families in their search for meaning and acceptance of the donor's death and their donation decision.

The experience of receiving a kidney from a deceased donor represents a complex psychological challenge for recipients. Living with a transplant represents an inner struggle to find a new normality rather than returning to an envisioned lost normality. Most of the recipients' suffering came from relational challenges concerning their post-transplant life. However, the transplantation experience helped recipients gain better knowledge of how to live their life. The study highlights how recipients try to make sense of their bond with the deceased donor, how they cope with emotional conflicts rising from receiving a kidney from a deceased donor and how they integrate aspects concerning the deceased donor into their identity during the post-transplant experience. The study is unique as it shows the spiritual dimension of the transplantation experience and how the recipients' views on transplantation and organ donation are shaped by their religious and cultural background.

CHAPTER VII. GENERAL DISCUSSION AND CONCLUSIONS

This thesis aimed to provide insight into determinants of organ donation attitudes and behavioural outcomes in an effort to place the formative research foundation that will assist in developing targeted organ donation campaigns. Based on the Social Marketing and Social Representations theoretical framework, we sought to understand the Romanian adults' knowledge, beliefs, attitudes, social representations and behaviours towards postmortem organ donation with the aim to design effective, culturally appropriate organ donation promotion messages in the future. We treated this subject in four studies that addressed some knowledge gaps in the literature and responded to several critical questions regarding the Romanian organ donation context. In the next section, we discuss the most important contributions of the present thesis. Further, acknowledge the limitations and offer some future research directions and concluding remarks.

The first study of the thesis focused on exploring the content of Romanian online media related to organ donation. In terms of contributions, this study adds to the literature that investigated organ donation media coverage in the United States (Feeley & Vincent, 2007; Morgan et al., 2007; Quick et al., 2009; Tian, 2010; Feeley et al., 2016;) and Australia (Maloney & Walker, 2000). By including different media outlets materials in our analysis, we had access to a more complex picture of various messages, sometimes contrasting, covered online. Focusing specifically on the content from Google web pages related to organ donation allowed us to better understand an Internet user's experience interested in the organ donation phenomenon that actively seeks information about it. This study brings valuable insight into formative research. It helps us better understand the Romanian organ donation macro-social environment from the

point of view of both stakeholders and the general public. This double analysis is an essential step in developing effective organ donation campaigns (Lauri, 2008). Therefore, the present findings are critical in understanding organ donation representations and communication practices and may constitute the first action towards intervention. Regarding methodological contributions, based on prior research, we designed a more comprehensive coding scheme. Using adapted taxonomies from other studies for certain variables allows us to compare how organ donation is represented in Romania versus other countries.

Study 2 aimed to give insights into adult Romanians' knowledge, beliefs, attitudes and practices related to postmortem organ donation and to identify the psychosocial determinants of their attitudes and behavioural outcomes towards postmortem organ donation. In terms of original contributions, to our knowledge, this is the most extensive study conducted in Romania regarding postmortem organ donation topic, the first theory-driven study to assess, in one setting, (1) predictors of both willingness to donate organs postmortem and intention to register as a donor, (2) the differences between donors and non-donors, (3) the discussions with family about organ donation and the perceived barriers for discussions and (4) the underlying factors of non-cognitive variables towards postmortem organ donation among Romanian adult population. The results are particularly relevant now when Romanians seem to be more reluctant to organ donation than in the past based on the decreased deceased organ donors rate. By investigating the predictors of intention to register as a donor (not only to donate organs in general) and the family discussions about intention, respectively the perceived barriers associated with discussing, the present study addressed some important knowledge gaps in the organ donation literature (Alsalem et al., 2020). Furthermore, the study examined the inclusion of additional factors to the ODM model, such as self-efficacy, religiosity, religious norms towards organ donation,

communication apprehension about death. These factors received little attention until now in the existing literature on organ donation. Our findings confirm the value of the extended ODM model and emphasise that the non-cognitive factors, visceral reactions have a bigger impact than the traditional socio-cognitive factors regarding organ donation outcomes. Hence, these factors must be studied and targeted more in future interventions. Moreover, the study responds to previous requests that highlighted the pressing need to contextualise the understanding of organ donation influences among different socio-cultural environments (Alsalem et al., 2020). Thus, this study has important implications in terms of developing culturally appropriate organ donation interventions for Romanians.

The purpose of **Study 3** was to explore the social representations of the organ donation held by first-year Romanian students to gain insights into designing effective, culturally appropriate university-based campaigns for promoting organ donation. In terms of original contributions, to our knowledge, this is the first study from Romania employing this type of method on organ donation topic. It gives us a broad picture of social representations of organ donation among the Romanian students, providing insights of formative research for crafting culturally, locally embedded organ donation campaigns for students. The findings from this study and the previous one regarding the high percentage of respondents who are not sure about their intention to register as donors or did not think about it highlight the need for making organ donation more salient. In this way, people will have the opportunity to form a decision about it.

In order to develop effective campaigns for postmortem organ donation is essential to understand the whole picture of the phenomenon. Therefore, in **Study 4**, we changed the register and focused on the experience of organ donation from the recipients' point of view. Specifically,

the study aimed to explore the experience of kidney recipients from a deceased donor throughout the transplant process.

In terms of original contributions, to our knowledge, this study is the first of this type conducted in Romania. Understanding recipients' challenges and their needs in the transplant process it is a prerequisite for developing effective patient education programmes after kidney transplantation. Results show how the participants' transplantation experiences are shaped by certain cultural, religious and spiritual beliefs, indicating the importance of a holistic nursing approach. Also, the study highlights how recipients try to make sense of their bond with the deceased donor, how they cope with emotional conflicts rising from receiving a kidney from a deceased donor and how they integrate aspects concerning the deceased donor into their identity during the post-transplant experience. These findings could help professionals assist the recipients in making sense of their bond with the deceased donor and integrating the new organ in their identity. Moreover, these could contribute to developing grief counselling protocols for the donors' families. Not least, these findings are very relevant for the social marketing of postmortem organ organ donation. The study is unique as it shows the spiritual dimension of the transplantation experience and how the recipients' views on transplantation and organ donation are shaped by their religious and cultural background.

To sum up, the type of change advocated in an organ donation campaign does not give pleasure to people. It usually involves asking people to think about one's own death, talk about death and make a massive sacrifice without tangible benefits for themselves or their significant others (Prottas, 1983). Therefore, changing opinions and behaviours on such a complex issue as postmortem organ donation requires that social marketing agents understand the deeply culturally rooted attitudes and beliefs of the general public. Social campaigns often fail because these employ too much of a

scientific/ theoretical approach and ignore the "lay theories" surrounding the issue (Lauri, 2008). Thus, the present thesis, structured as a pre-campaign formative research based on Social Representation theoretical framework, aimed, through the first three studies taken together, to understand the perceptions, beliefs, social representations and practices which the target audience has of the organ donation issue; to understand as much as possible about the target audience in relation to this social issue. The last study of the thesis, exploring the transplant recipients' experience, was also extremely important for obtaining a complete picture of the organ donation social marketing environment.

The studies included in the present thesis have some limitations. In our view, one important limitation of the thesis is using only the "organ donation" searching term to identify the online media content in Study 1 (Chapter 3). We decided for this approach because we wanted particularly to access the content to which an individual is exposed when is actively seeking out information about organ donation. Another limitation of the thesis is using a convenience sample in study 2 and 3 (Chapter 4 and 5). This limits the generalisability of findings and could exacerbate the selection bias. A third limitation is using a single-item or two items measures to assess factors of interest (e.g., social norms, religious norms towards organ donation, communication apprehension about death, self-efficacy) to reduce the length of the questionnaire (study 2). It would be beneficial to refine the measures of these constructs to gain a better and more nuanced understanding of their influences. An important limitation of study 3 is inherent to the Hierarchical Evocation method, which can only address the hypotheses of centrality and cannot diagnose the structure of a social representation. However, we acknowledged this limitation and interpreted with caution the results. Another limitation is the retrospective nature of transplant recipients' stories in study 4 (Chapter 6). Recipients' subsequent experience and their current state could impact how well they recall the past experiences and

feelings. Future studies should use IPA prospective longitudinal approach to overcome this limitation. Related to study 4, a potential limitation concerns the homogeneity principle. The age of participants ranged between 29 and 64 years, the time since transplantation varied between 1 and 12 years, and the dialysis period was between 1 and nine years. However, overall the convergence in participants' experience was strong. Moreover, we consider that potential differences between cases add depth to the analysis, illustrating the complexity of transplantation experiences.

Notwithstanding these limitations, the results of this thesis offer important guidelines for a future campaign and invite further research in this regard. Next, we will present the main lessons learned from the formative research process.

- From the results of the first study, corroborated with the results from Study 2 and 3, emerged that media techniques as well as interpersonal and group techniques are important to disseminate organ donation promotional messages and produce a change in public opinion.
- The modest media coverage of the topic highlights the need to make organ donation more salient to the general public. For instance, we consider that a 20/ 30 seconds spot about organ donation disseminated on Radio and TV posts will make the organ donation topic more salient to the public, inviting people to think about their stance regarding it and discuss with the significant others their views.
- Also, the media analysis revealed the need for a better communication between authorities and media and for more accurate information regarding the entire organ donation process.

- The survey results, congruent with the literature, indicated that young people with a higher socioeconomic status were more in favour of organ donation. This suggests that the students' community would be most accessible, suitable and with the best results for implementing a more targeted organ donation campaign. Moreover, a university-based campaign would allow better integration of interpersonal and group strategies of the social marketing program.
- The analysis of the results from Study 2 and 3 revealed that although many people are in favour of organ donation and willing to donate organs postmortem, they are sceptical or uncomfortable about registering as organ donors. Therefore, the campaign should promote discussing organ donation wishes/ decision with significant others as being equally important as register as an organ donor. Also this suggests that a future campaign should focus on the population segment with positive attitudes toward organ donation rather than try to change/ convince people against organ donation.
- We consider that is important not to persuade people too aggressively to register as organ donors. Instead, we can offer them accurate information about the organ donation and transplantation system, respectively about organ procurement process, making things more transparent and reducing their fear and doubts regarding organ donation in this way. For instance, it is essential that people find: how could register as donors because there were so many changes that is not clear for many; how is administrated the Organ Donor Registered because the news from last years about it raised several concerns; what is the legislation for organ donation and transplantation; that the donors' families are still consulted and their consent matters even when the patient was register as a donor; what means brain death and how is this diagnosis established; how are chosen the possible

transplant recipients; what happens from the moment the family is giving permission for organ procurement until burial;

- The analysis of the survey also revealed that non-cognitive, affective factors are critical determinants of attitudes and behavioural outcomes towards organ donation. Therefore, it is crucial that a campaign not ignore these aspects and approach them openly. For instance, the change agents should include discussions regarding medical mistrust, people's fears of medical abuses in this field, invite the participants to tell about the organ donation stories that they read/ hear; debunk the myths that circulate about these. Also, it is important to consider and sensitively address the superstitions that people may hold regarding organ donation and their beliefs related to the importance of bodily integrity for the funeral.
- The word associations for organ donation phenomenon identified in Study 3 should be used to design campaign messages and slogans for target audience. It is important that the campaign metaphors to be consonant with audience' representations about organ donation. Using people's words and expressions would reinforce the positive representations about organ donation.
- Also, the result regarding "organ donor" representations from Study 3 (i.e., the associations for this term did not reveal concerns, doubts and fears as for "organ donation" and "organ transplantation" terms) suggests that the campaign should focus on what are people's perceptions of organ donors, what is in their perception the profile of an organ donor. The positive perceptions of organ donors could increase people's willingness to register as organ donors through the cognitive dissonance path.

- The campaign could also include testimonials of transplant recipients regarding their experiences through transplantation process. In this way, general public could have the whole picture of the organ donation phenomenon. Depicting the positive aspects of postmortem organ donation (such as saving lives, the hope raised from a tragedy, the meaningful bond between recipient and deceased donor, donors' family consolation) could reinforce people's positive representations about organ donation and reduce their reluctance or ambivalence regarding it.
- Another message that the campaign should include is that the Orthodox Church and the other main religions do not oppose organ donation. Moreover, these see organ donation, as long as it is done for altruistic reasons, as an act of love and kindness worthy of praise.

To conclude, this thesis offers unique and necessary insights regarding postmortem organ donation in the Romanian context. Also, it contributes to the broader literature on organ donation, addressing some important knowledge gaps. Both the quantitative and qualitative findings of the thesis have important implications of formative research for developing future culturally appropriate organ donation campaigns. However, in order to reduce people' reluctance towards organ donation and increase the organ donor registration rate, there is a need to rigorously develop and evaluate interventions, strategies and persuasive messages that are most effective for producing a change in different population segments.

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