

# Micro-Cultural Differences in Switzerland: The Effectiveness of Targeted Promotional Messages in the Field of Organ Donation

A dissertation presented by  
**Anke Dunkel**

Supervised by  
**Prof. Peter J. Schulz**

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## **Board**

Prof. Peter J. Schulz (Università della Svizzera italiana)

Prof. Kent Nakamoto (Virginia Polytechnic Institute and State University)

Prof. Dr. med. Sebastiano Martinoli (Università di Basilea / Clinica Luganese  
Moncucco e San Rocco)



## **ABSTRACT**

Public information campaigns have played an important role in increasing awareness of organ donation and the need for more organ donors. In a recent study, it was found that awareness and knowledge, regarding organ donation, represented only two of several factors in people's decisions to engage in organ donation-related behaviors (Schulz et al., 2006). In addition, it was noted that the three main language groups in Switzerland differ substantially with respect to the influential factors in their organ donation decisions. A plethora of studies have examined cultural differences in health-related behavior. Existing studies tend to examine wide cultural differences or racial subcultures in the United States. This study aims at examining the role of cultural micro-variation, building on the previous study of organ donation in Switzerland. More specifically, the proposed research seeks to test the implications of these cultural differences as they relate to the design of targeted promotional campaigns for pro-social behavior. The study also applies communication theory concepts in the design of effective, targeted communication strategies to promote organ donation as an important example of health-related pro-social behavior. The study will test the effectiveness of differentiated communication messages within a small, very diverse country.



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# 1 Introduction

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In modern medicine, organ donation is one of the few topics to have such high public interest. It always involves more than one person, namely the donor and the patient's relatives, as well as the receiver, his/her support system, and an entire body of hospital staff.

The possibility of transplanting an organ into another person has been thought of as a "miracle" (Sharp, 1995) or a "miraculous procedure" (Plough, 1986). Today it can even still be considered as such given that for many people it is the only possible treatment to escape premature death. The other side is the continual increase in need for organ donors. Evans calls it the "Achilles' heel" of transplantation medicine (Evans, 1998). Many people are not "aware that during our lifetime we and our families might be as much potential organ receivers as organ donors" (Cantarovich, 2005). Langone & Helderman think of the increasing demand for transplanted organs as transplantation medicine being "a victim of its own success" (Langone & Helderman, 2003).

It is known that overall, the population supports transplantation medicine to a great extent and sees its benefits rather than its disadvantages. Still, only a few people commit to organ donation by registering as donors or by signing a donor card. Many attempts have been launched by politicians, opinion leaders, and health campaigners to close the gap between the number of needed and available organs.

"Campaigns seeking to promote communication between family members about organ donation must simultaneously seek to increase knowledge, debunk myths, and bolster positive attitudes about organ donation" (Morgan & Miller, 2001).

Organ donation is a difficult topic to communicate. This is because its a) a topic related to death and thus not easy to approach, b) its allocation is a difficult, ethical issue to be addressed, and c) it is an altruistic, pro-social behavior which is beyond one's own life. All of these issues make it difficult to draw attention while obtaining permission for organ donation. Therefore, a thorough and well-designed communication strategy is so crucial for the field.

The aim of the here presented monograph is to focus on ways to close the existing gap between the increasing waiting list and available donors by means of communication. In doing this, the research focuses on a very specific cultural background: including three geographically and culturally distinct groups. There have been many studies examining organ donation attitudes, perceptions, and behavior in cross-cultural contexts. However, only very few examine micro-cultural differences, as Schulz and fellow researchers did in their research, studying micro-cultural differences in Switzerland (Schulz, Nakamoto, Brinberg, & Haes, 2006). Studying micro-cultural differences means studying differences within one country, Switzerland, divided in three main language regions<sup>1</sup>. There is no doubt that the three language groups differ culturally, an assumption that will be discussed more in detail later in the research. Since Switzerland, in the European benchmark, shows very low donor rates per million of population, although the country recently changed its transplantation legislation and launched several big communication campaigns to promote organ donation, donor rates have stagnated at a relatively low level.

Campaigns in the last years were made with a “one size fits all” approach, translating the slogans simply from one language to the other using the same message content and message framing. The question then arose, if it would be more efficient to target the organ donation campaign to the specific attitudinal patterns of each language group, in regard to organ donation.

Results were also expected to be consequently applicable, not only to organ donation campaigning but also to other fields of health communication in Switzerland and other multilingual countries.

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<sup>1</sup> Officially, there are four official languages, but the latter is spoken by only 0.5% of the population and for socio-economic reasons will be neglected in the following study.

Dürrenmatt said once:

“Switzerland is not a small nation, but a federal assembly of small nations. There is nothing like THE Swiss, or THE Swiss nation, but there are German speaking Swiss, French speaking Swiss, Italian speaking Swiss, and leftovers of Romansch speaking Swiss.” (Dürrenmatt, 1998, p. 198)

[11]Original in German.

This given, with the further developed and examined findings, the standpoint will be from a social marketing and health communication perspective: “There is no such thing as targeting the general public” (Weinreich, 1999, p. 5). The hermeneutic approach of this monograph will be to better understand each group and examine possibilities to target Swiss Germans, Swiss French, and Swiss Italians better according to their particularities, especially in the field of organ donation. History, stereotypes, and existing research will be reported without attempting to replicate, confirm, or refute them. However, they will be taken as additional resources to develop the research hypothesis, interpret the results, and draw reasonable conclusions for the field of organ donation.

Doing this might open the way for similar future research in other fields, be it in marketing, health communication, or future organ donation campaigns.

The following monograph examines the effectiveness of targeted promotional messages in the field of organ donation in Switzerland. To do so, it is most crucial to place Switzerland in an international and European context. Therefore, the second chapter after the introduction is going to give a general overview about organ donation in the world, in the European Union, and how Swiss Constitutional and legal bodies deal with transplantation medicine. This is important to set out possibilities of intervention within the field of health communication to potentially increase the number of organ donors after death over a longer period of time.

Consequently, the third chapter will focus on cultural particularities in Switzerland, why the country is considered micro-cultural, and what the empirical evidences are to consider it as such.

When designing such a complex study as this one, it is most crucial to know the existing literature about organ donation behavior. A plethora of literature about attitudes in the field of organ donation, organ donation behavior, and cultural influences exists. Organ donation is a highly visible, accessible, and socially relevant topic. The here presented literature does not claim to be systemic, although it tried to give an overview about all relevant topics to the field. State of the art organ donation literature and topics conclude with the most crucial study upon which this project evolved. It was granted financing for three years from the Swiss National Science Foundation, about Knowledge and Attitudes of Swiss towards organ donation by Schulz et al. in 2006. Their research findings will be shortly laid out to consequently deduct the research question and hypothesis of this monograph (in Chapter 5).

Chapter 6 will then describe the methodology with which the research question was approached, and explain the quasi-experimental design. Chapter 7, will present an overall description of the sample characteristics and some preliminary analysis. While Chapter 8 summarizes the used measures and built up indices, main results will be presented in Chapter 9. This will be followed by a discussion and the limitations of the study in Chapter 10.

Before starting with the first chapter on organ donation in Europe and Switzerland, a few mentions to the reader shall be made. These are in order to avoid sensitivities among possible Swiss readers and give a guideline to the reader who is not familiar with the particularities of Swiss culture.



### ***Technical Foreword or Guidelines to the Reader***

Dealing with four languages posed a challenge for the writing up of this monograph. English, the language of this monograph, and the mother tongues of the three main linguistic groups in Switzerland (German, French, and Italian) are all part of the everyday life in Switzerland and are part of this one research project. Additionally, the aim was to equally master scientific, linguistic, and readability expectations while trying to be politically correct. Therefore, the following section will clarify some intentional decisions made when writing. These are to avoid possible resentment.

#### *Listing of / Referring to the Linguistic Groups*

For practical reasons of readability, in the following these three language groups will always be named according to the number of population they represent. This was a pragmatic choice to avoid confusion. This choice is neither discriminatory nor judgmental. It was purely based on statistical facts provided by the Federal Bureau for Statistics (Bundesamt für Statistik, 2011) and the official brochure explaining the political system of Switzerland (Schweizerische Eidgenossenschaft, 2011).

#### *Dealing with Stereotypes and the Author's Dissociation of the Latter*

The author of the here presented monograph is declining any responsibility for any prejudices or stereotypes mentioned and not susceptible to provoked misunderstandings. All of the mentioned “supposedly true” attributes for Swiss Germans, Swiss French, or Swiss Italians were taken from existing literature, mostly written by Swiss authors and/or taken from scientific literature.

The scope of this monograph is **not** to judge whether these findings (attributes or stereotypes) are true or false. However, some of them are referred to, to develop the research topic, justify the research questions (which is **not** to confirm or decline existing stereotype research), and lead to the hypothesis examined.

### *Translation of Quotes*

For readability reasons, the author of this monograph freely translated all quotes in the following monograph. The challenge of translating special terms adequately into English without losing the fine underlying meaning lead to the decision that all quotes that were translated into English from a foreign language are listed in the Annex A, in their original form. Original quotes can be found in German, French, or Italian. Whenever a quote was translated into English, it is marked with a number in brackets, for instance [1].

### *Frequency Table*

The questionnaire was part of a project funded by the Swiss National Science foundation, which contained more research questions than treated in this dissertation. These issues will be addressed in separate papers. However, the full frequency table is available upon request to the author, for the interested reader.

## **2 Organ Donation in Europe and Switzerland**

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## **2.1 Organ Donation History**

### **2.1.1 Transplantation in Mythology**

The transplantation of organs has a long history in human mythology (Bundesamt für Gesundheit). One of the first documents where transplantation can be found, stems from Hindu mythology (12<sup>th</sup> century B.C.). It explains how god Ganesha's life was saved as a child when his cutoff head was replaced with an elephant head (Dimmit & van Buitenen, 1978, p. 185). Also in China, scripts from the 3<sup>rd</sup> century B.C. describe experiments with exchanging hearts by the legendary Pien Ch'iao (Kahan, 1988). In Christian mythology, transplanting body parts can also be found. One example is when Jesus sticks a cutoff ear back onto a punished servant. Furthermore, the legend of the twins, St. Cosmas and St. Damian, who supposedly transplanted a leg from a deceased black man to a white man in need of a new leg (Keller, 1984). Today, transplantation medicine is not a "myth" anymore and throughout the last century has become a "treatment of choice".

### **2.1.2 From Failed Experiments to a "Treatment of Choice"**

The first experiments with organ transplantation were conducted as far back as the 18th century (Schooley Mitchell; UNOS, 2011a). A long time passed with a lot of failures and throwbacks, until 1954 when Joseph Murray and David Hume recorded the first successful kidney transplant at Brigham Hospital in Boston, USA. Almost 8 years later, the kidney of a deceased donor was transplanted for the first time (Donate Life. New York Organ Donor Network). In the upcoming years, medical success grew step by step until it became possible to also transplant lungs, pancreas, livers, and hearts (idem). In 1998, for the first time a hand was successfully transplanted, in 2005 a partial face transplant succeed and in 2010 the world's first full-face transplantation was accomplished.

The big laid out milestones of transplantation medicine show that during the last 50 years medical breakthroughs continued to improve the conditions for organ

transplantation. This was aided by the fast development and improvement of immunosuppressive drugs that continuously helped to increase the success of transplantation; meaning increased time of living for the transplanted patients (Schooley Mitchell).

In Switzerland, the first transplantations were successfully conducted by the Swiss surgeon and pioneer of Swiss transplantation medicine, Theodor Kocher. Already in 1883, he successfully transplanted thyroid tissues for the first time. The first kidney was transplanted in Switzerland in 1960. The big breakthrough discovery was of the immunosuppressive Cyclosporin in Basel in the 1970's. However, it was only in the 1980's that transplantation medicine was established in Switzerland. This resulted in six transplantation centers all over the country today: Zürich, Basel, Genf, Lausanne, Bern, and St. Gallen (Bundesamt für Gesundheit; Swisstransplant).

Since the 1970's, the increasingly fast improvement of transplantation medicine and immunosuppressives resulted in organ transplantation not only being a treatment of last resort. In the 1980's, transplantation medicine eventually developed to a standard procedure. In 1989, the 100,000<sup>th</sup> kidney was successfully transplanted worldwide. Up to today, over 470,000 kidneys, 74,000 livers, 54,000 hearts and 10,000 lungs have been transplanted worldwide, which is a great success for modern medicine (Bundesamt für Gesundheit).

However, the tremendous success from the medical standpoint creates a constant increase in organ demand while the organ supply stagnates (Bundesamt für Gesundheit). Therefore the "transplantation medicine became a victim of its own success" (Langone & Helderman, 2003).

## 2.2 Organ Donation and the World Health Organization (WHO)

According to WHO, data kidney transplants are carried out in 91 countries today. In 2005, approximately 66,000 kidneys, 21,000 liver and 6,000 heart transplants were performed (Shimazono, 2007). The WHO deals with organ donation under the topic *Ethics and Health*. In 1991, for the first time, WHO published guiding principles to emphasize voluntary donation, non-commercialization, a preference for cadaveric over living donation and for genetically related over non-related donors (World Health Organization, 2011). The WHO guiding principles on human cell, tissue, and organ transplantation contain eleven principles followed by additional detailed commentary on each principle (World Health Organization, 2009). The eleven principles contain recommendations for the following: (1) consent of the deceased person to transplant, (2) the role of physicians in the transplantation procedure, (3) the preference of “genetically, legally, or emotionally related” living donation, (4) transplantation from minors, (5) prohibition of commercialization, (6) publicly promoting organ donation, (7) compensation of physicians, (8) compensation of health care facilities, (9) allocation, (10) safety, efficacy, and quality of transplantation, and (11) transparency (idem).

Another organization that published guidelines for organ and tissue transplantation is the World Medical Association (WMA). In 2000, the 52nd WMA General Assembly in Edinburgh, Scotland adopted the WMA statement on human organ donation and transplantation. In 2006, it was revised by the 57<sup>th</sup> WMA General Assembly in Pilanesberg, South Africa and published on the WMA website. It contains topics such as professional obligations of physicians, social aspects of organ procurement, institutional and individual aspects, cadaveric organ donation, free and informed decision making about organ donation, the definition of death, organ allocation, and research about organ donation (World Medical Association, 2000).

### 2.3 Organ Donation in North America

A national transplantation association, in addition to the efforts of the respective health departments of the governments, organizes organ donation in most countries. In North America, for example, the Canadian Association of Transplantation (<http://www.transplant.ca/>), the United Network for Organ Sharing (UNOS, <http://www.unos.org/>), and the scientific registry of transplant recipients (<http://www.ustransplant.org/>) provide information about success rates of transplanted patients. The state association, Donate Life (<http://www.organdonor.gov/>), provides official information and further links about the topic of organ donation and transplantation.

In March 2011, the United States counted 72,151 patients on the active waiting lists. From January 2010 to December 2011, 28,664 transplants could be performed with the help of 14,505 donors (UNOS, 2011b).

### 2.4 Organ Donation in Europe

Also in Europe, the “steadily growing success of organ transplantation” is hampered by the lack of available organs (Schütt, 2002). Schütt, in his 2002 article, summarized 25 years of organ donation in Europe. Today, almost 10 years later, the situation has not changed much. Transplantation medicine is still progressing, becoming more and more an ordinary treatment. Therefore waiting lists are increasing, and donors are becoming scarce (idem). Organ donation is regulated differently in each country by the respective national laws. Some have opt-in systems such as Denmark, Germany, Greece, Great Britain, Netherlands, and Switzerland. While others have opt-out systems such as Belgium, Finland, France<sup>2</sup>, Italy, Luxembourg, Norway, Austria, Portugal, Sweden<sup>2</sup>, Slovenia, Spain, Czech Republic, and Hungary (Bundesamt für Gesundheit; Schütt, 2002).

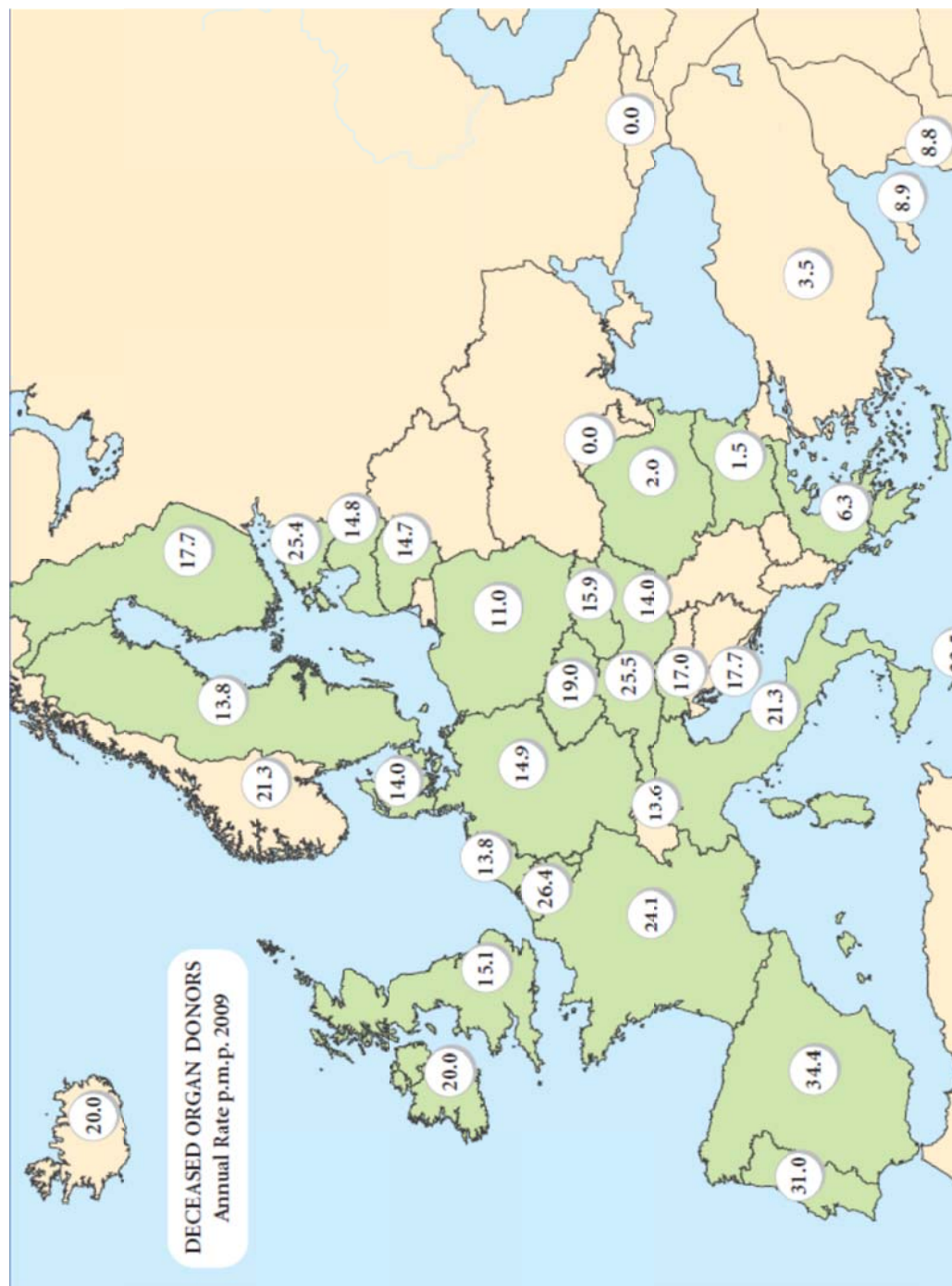
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<sup>2</sup> France and Sweden have an “information system”: relatives are informed about the ongoing procedure and if they do not veto it within a certain time period, the transplantation will happen.



In an opt-in legislation, organs from a deceased patient may be explanted in the case where a patient gave his agreement before passing away. In most countries with an opt-in legislation, an adjusted model is in place, allowing the relatives to decide about the explantation if the wish of the deceased is unknown. In an opt-out legislation, explantation is legally allowed if the deceased patient did not declare a contrary wish during his lifetime. The adjusted model would allow relatives to object such a decision (Schütt, 2002). The advantages and disadvantages of the respective systems shall be further discussed in the literature review.

It is noteworthy that even though a couple of European countries have donation rates between 20 and 30 donors per million of population (p.m.p.) (Council of Europe, 2010), donation rates in most European countries have remained stable since the 1990's (Schütt, 2002). Only Spain however, shows a noticeable increase in organ donation with a respectable 34.4 donors p.m.p. (Council of Europe, 2010). The Council of Europe provided an overview in figure 1 of the deceased organ donation rates from within Europe.



**Figure 1:** *Deceased Organ Donors. Annual Rate p.m.p. 2009.* [Source: Council of Europe. International Figures on Donation and Transplantation – 2009 (Council of Europe, 2010)]

#### 2.4.1 The Spanish Role Model

“Spain is the only example in the world of continuous improvement in cadaveric organ donation registered in a large country during more than 10 years” (Matesanz, 2004)

The great success of the Spanish Kingdom increasing its deceased donor rates to a record number of 34.4 donors p.m.p. gave way to a plethora of scientific research and analysis of the Spanish transplantation “model” or system. The Spanish *Organización Nacional de Trasplantes* (ONT, <http://www.ont.es/Paginas/default.aspx>) took several steps to improve the organization of transplantation medicine in the country. For instance, they increased the number of hospital staff involved directly or indirectly with the identification of organ donors. Every hospital performing transplantations had to assign a so called “transplantation coordinator”. Additionally, a standardized training program (TPM) became mandatory for all hospital staff involved in transplantation issues (Schütt, 2002). As a result, the numerous measures at the structural and organizational levels increased the number of available donors “exponentially” (idem). Also, Matesanz came to the same result in his analysis of factors that influence the development of an organ donation program. According to him, the great success of the Spanish model is primarily due to the structural changes. These changes include the introduction of a systematic death tracking in hospitals, creating a positive social atmosphere, improving relationship management with mass media, and “adequate economic reimbursement of the hospitals” (Matesanz, 2004). Italy, who is trying to apply the Spanish model as much as possible with regard to their own preexisting structures, could increase its donor rates per million of population significantly as well (idem).

### **2.4.2 Crucial Aspects to be Considered when Talking about Organ Donation**

Since different countries have different legal settings, not all measures taken in Spain can be adapted directly in all countries. Therefore other measures and interventions are needed. In the following, five main points of interest for most European countries will be laid out. However, they will be discussed in detail with the help of recent organ donation literature in the organ donation literature review.

Schütt (2002), as well as several other surveys like the Gallup survey 1992 (Gallup, 1993), repeatedly show that in all European countries the mainstream population has a positive attitude towards organ donation. Still however, none of the European countries can actually report a sufficient supply of donor organs. This results in a steady increase in the waiting lists.

According to Schütt (Schütt, 2002), the gap between the generally positive attitude and the refusal rate when the actual decision of donating a deceased relative's organ is made, is caused by a lack of signed donor cards. For instance, only 7-10% of Germans in favor of organ donation carry such a card (idem). The ambiguous role of the donor card or rather its effectiveness will be further discussed in subsequent chapters.

To improve attitudes towards organ donation and transplantation medicine, as well as to promote the importance of communication of one's own wish, many European countries initiated extensive national organ donation campaigns. Germany, France, Italy, the Scandinavian countries, the Netherlands, and also Switzerland have all launched such campaigns. Most of the campaigns emphasize that after having made up one's mind, it is crucial to communicate the decision either by signing a donor card or letting family members know.

While some countries focused on donor card initiatives to promote communication about organ donation within the family, other countries such as Sweden, the Netherlands, Denmark, Belgium, and Austria set up national organ donor registries to render access of donor information to hospital staff easier. In Belgium and Austria, who both have an opt-out system, registries serve to check whether a person explicitly expressed their wish not to donate their organs (Schütt, 2002). Although these registers seem to be an acceptable alternative to the donor card, Schütt has identified problems regarding their completeness, veracity issues, cost, and confidentiality (idem).

Research did not show a clear superiority of one or the other system. However, it appeared that Belgium and Austria, by changing from an opt-in to an opt-out system, could increase their donor rates (Michielsen, 1996). Compared to their neighbors, Germany and the Netherlands, they perform much better in terms of donors per million of population (Schütt, 2002).

In most countries, with registers or not, opt-in or opt-out systems, eventually next-of-kin are approached, informed, and asked for consent; even though legally the will of the deceased is binding (Schulz, van Ackere, Hartung, & Dunkel, 2011; Schütt, 2002). Schulz et al. conducted interviews with intensive care unit (ICU) staff and showed that before taking the risk of negative publicity, most ICU doctors would not proceed with the explantation if a close family member is completely opposed to it (idem). Negative publicity could include a polemic report run in a national tabloid, which in turn would damage the ICU's reputation and the progress of transplantation medicine. Almost half (46%) of all Europeans would refuse to donate a deceased relative's organs when asked according to the Eurobarometer 2007 survey (European Commission, May 2007). Interestingly, especially in Scandinavian countries where trust in the health care system is particularly strong (European Commission & DG Sanco, 2011), the refusal rate is much lower than in other countries. This again underlines the relevance of structural issues as seen before when sketching out the Spanish system.

Therefore the role of hospital staff is crucial in approaching families about the death of their family member and requesting for organ donation (Blok et al., 1999). A lot of research has been conducted on this topic in the past few years, and will be further detailed in the following chapters. Based on the realization of the hospital staff's important role in the decision procedure of organ donation within ICU's, the European Donor Hospital Education Programme (EDHEP) was launched in 1995. Its purpose was to train critical care staff appropriately to deal with deceased organ donation situations. This is not only difficult for them, but as research has shown, they are not comfortable in approaching the next-of-kin for organ donation. Therefore, the program consists of an educational package spread throughout a worldwide network, including standardized "train the trainers" courses (Blok et al., 1999).

### **2.4.3 The EU Governance of Organ Donation**

Switzerland, although being in the center of Europe, is not part of the European Union but has several bilateral agreements with the EU. One of these bilateral packages includes public health issues. For that reason, and the interdependence of European countries in finding matching organs and/or recipients, policies on the EU level are and will be relevant, to a certain extent, in Switzerland. Therefore, the EU governance of organ donation and transplantation shall be laid out briefly in this section, mainly referring to the article of Farrell (2010) entitled "Adding value? EU governance of organ donation and transplantation" (Farrell, 2010).

The treaty of Amsterdam, enforced since 1999, establishes competences for the European governing body to adopt "minimum harmonization measures". These measures set up quality and safety standards for actions related to blood, tissue, and organs (Farrell, 2010).

Since 1999, a plethora of governance initiatives followed. Additionally, the European Union sponsored several scientific conferences to thoroughly examine issues involving organ donation and transplantation (idem). As a result, European

Parliament and the Council of the European Union adopted the following proposal from the European Commission on March 31<sup>st</sup>, 2004: *“Directive on setting standards of quality and safety for the donation, procurement, testing, processing, preservation, storage and distribution of human tissues and cells”* (European Parliament, 2004).

As a consequence, the European Union sponsored and launched several empirical and scientific research projects. They also extended the consultation process with experts and stakeholders to identify further areas of concern and need for policy action (Farrell, 2010). In 2007, the European Commission published another communication with proposals for an action plan. This communication was accompanied by an impact assessment, as it is common practice in these cases. It provided details to the proposed plan, gave the intended launch of the Open Method of Coordination<sup>3</sup> (OMC), and identified common objectives to all stakeholders and parties of interest (Farrell, 2010).

The feedback from European Parliament and Council, as well as from national experts and stakeholders, for the initial action plan was mostly positive. However it stressed the urgent need to closely collaborate with all member states and especially avoid creating additional administrative burden, which could eventually decrease the number of potential donors. In consequence, the European Commission published a 6-year action plan covering several policy issues such as sharing best practices, models, and expertise. But it also included an EU wide risk regulation regime to establish basic quality and safety requirements, reduce risks for donors and recipients, and cross-border exchange for organs. Furthermore, three main challenges were defined in the action plan: increase organ availability, enhance efficiency and accessibility of transplantation systems, and improve quality and safety of organs (Farrell, 2010).

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<sup>3</sup> The OMC is a form of EU soft law which is not legally binding but aims at spreading best practices among member states (Borras & Jacobsson, 2004). For further information about the procedure consult:

<http://www.eurofound.europa.eu/areas/industrialrelations/dictionary/definitions/OPENMETHODOFCOORDINATION.htm>

The “*Action Plan on Organ Donation and Transplantation (2009-2015): Strengthened cooperation between member states*” foresees ten priority actions: transplant donor coordinators, quality improvement programs for organ donation, promote exchange of best practices, improve knowledge and skills of health professionals and patient support groups for organ transplantation, facilitate the identification of organ donors across Europe and cross-border donation in Europe, enhance efficiency of transplant systems, EU wide agreements on various aspects of transplant medicine, exchange of organs for urgent patients and difficult to treat patients, create registers facilitating the evaluation of post-transplant results, and create a common accreditation system for organ donation/procurement and transplantation programs (European Commission, 2008).

### **2.4.4 Eurotransplant, Scandiatransplant and Other**

Eurotransplant (<http://www.eurotransplant.org/>) is a transnational, non-profit organization including six European member states (Austria, Belgium, Croatia (non-EU state), Germany, Luxembourg, the Netherlands, and Slovenia). According to the information provided on the Eurotransplant website, the organization coordinates transplantation centers in regions that have more than 119 million inhabitants. The reasoning for a European or “international collaborative framework” (Eurotransplant) organization only covering 6 of 27 EU member states and only 6 of more than 40 on the European continent, is unclear. It also could not be further researched, neither with the help of scientific literature nor by contacting the organization itself.

Scandiatransplant (<http://www.scandiatransplant.org/>) is a counterpart of Eurotransplant. It is an organ exchange organization covering 24 million inhabitants in Iceland, Norway, Sweden, Finland, and Denmark (Grunnet et al., 2001). Additionally, all eleven national Nordic transplant centers cooperate under the roof of Scandiatransplant, with its headquarters in Aarhus, Denmark. Details about waiting lists and other information about its five member-states can be downloaded on their website.



All the other countries have their own respective organ transplantation organization with different scopes and tasks. Some examples are the Belgian Transplantation Society (<http://www.transplant.be/>), die Deutsche Stiftung Organtransplantation (<http://www.organspende.de/>), l' Agence de la biomédecine <http://www.efg.sante.fr/>), UK Transplant (<http://www.uktransplant.org.uk/ukt/default.jsp>), l' Associazione Italiana Donatori Organi (<http://www.aido.it/>), and etc.

### 2.4.5 Donor Action

*Donor Action* (DA) is an international initiative launched by Eurotransplant that aims at supporting ICUs in improving donation procedures (Schütt, 2002; Wight, Cohen, Roels, & Miranda, 2000). *Donor Action* also conducts surveys, collecting data from participating hospitals. This data has retrospective and prospective information in order to identify donors in hospitals, but also provides data on hospital staff's attitudes towards organ donation. The biggest challenge of this survey is to find hospital staff willing to invest time in a retrospective analysis of hospital records on deceased patients (idem). Wight calls it a "quality assurance program", diagnosing areas of weaknesses in donation practice (Schütt, 2002). Data from the *Donor Action* program is also available for Swiss hospitals and managed by the Swiss Foundation to Support Organ Donation (FSOD, <http://www.fsod.ch/Home.aspx>).

### 2.4.6 Conclusion for Switzerland and Relevance for this Monograph

Switzerland, with its 13.6 donors p.m.p., ranks as one of the last among its Western European neighbors. This stresses the relevance of organ donation in Switzerland and the need to take action: be it on a structural, legal, and organizational level or on a public discourse and communication level. The European benchmark, including other countries, might help to identify areas susceptible for change and improvement of the organ transplantation system in Switzerland.

This monograph has a particular focus on possibilities to increase the effectiveness of the communication of organ donation. Therefore, the structural and legal conditions in the Helvetic Republic will be briefly laid out to help understanding the way Swiss transplantation medicine is organized. However, they will not be discussed from a legal standpoint.

To increase donor rates, solely communication tactics will not be enough. A thorough benchmark, as proposed by the European Commission Action Plan 2009-2015, is most likely needed.

Still, one important element of public health topics is that people are often not aware of the importance of a topic. To make people aware, they need information. This information is mostly provided by federal and/or private institutions but needs to be communicated to the public.

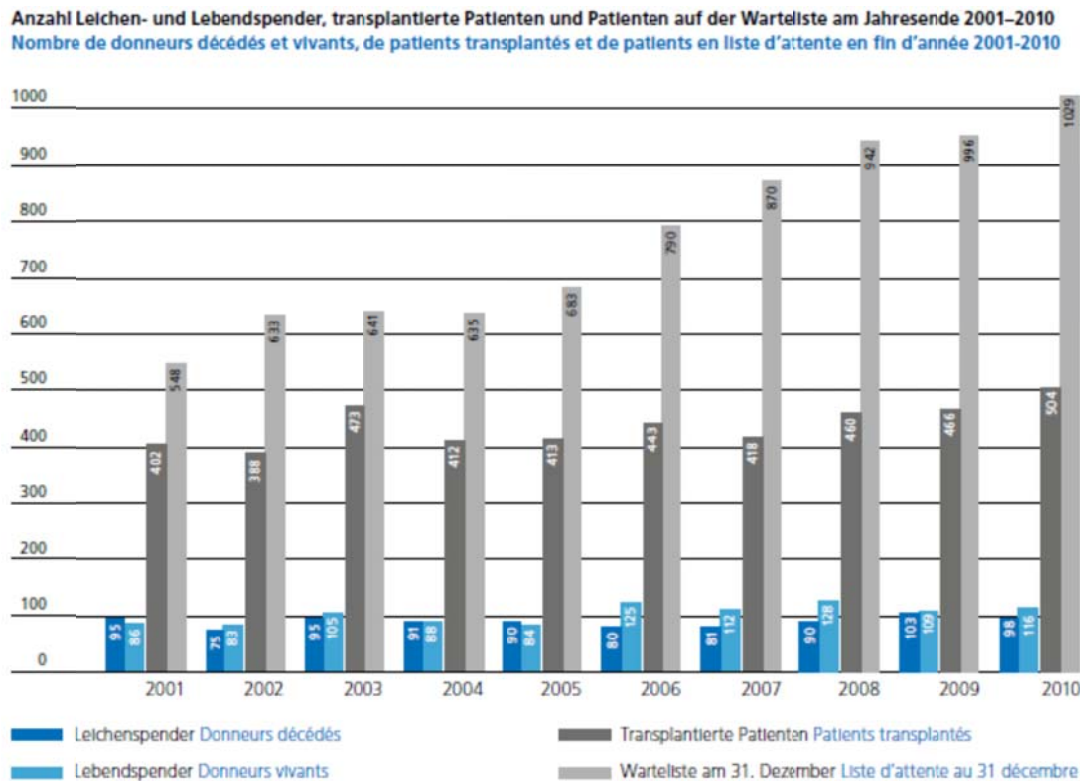
How organ donation could be communicated better in Switzerland is the main scope of this dissertation. To answer this question, it is important to a) understand how organ donation and transplantation is organized in Switzerland and b) why Switzerland is a so-called *Sonderfall*, or special case when it comes to communicating public health issues.

## **2.5 Organ Donation in Switzerland**

### **2.5.1 The Evolution of the Number of Organ Donors in Switzerland**

By the end of 2010 (December 31, 2010), 1,029 patients were on the waiting list for an organ in Switzerland. 504 transplantations were performed during the year of 2010 thanks to 98 deceased organ donors and 116 living organ donors (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011b). As shown in Figure 2, the number of people on the waiting list is increasing continuously year by year and the number of donated organs is stagnating. With a rate of 12.6 donors per million of population, Switzerland's rates are even worse than the European benchmark, including previous years. The 2010 Swisstransplant annual report frames this evolution in a positive way. It stresses the net increase of 21% of deceased donors since 2007, but does not reflect reality. The net donor rate, with 98 deceased donors in 2010, is almost the same as the rate 10 years ago, with 95 deceased donors in 2001. Thus, all public efforts within the last 10 years, from 2001 to 2010, to increase organ donation in Switzerland only resulted in a net increase of three donors.

## 2 Organ Donation in Europe and Switzerland



**Figure 2<sup>4</sup>:** Evolution of the Number of Living and Cadaveric Organ Donation and the Waiting List between 2001-2010. Source: (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011b)

### 2.5.2 The Waiting List in 2010

The average waiting time for an organ transplantation patient on the waiting list in Switzerland varies according to the organ needed. For a heart transplant, the average waiting time in 2010 was 210 days, for a lung 301 days, for a liver 182 days, and even 851 days for a kidney. The latter is especially due to an enormous increase of people in need of a kidney (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011b).

In 2010, 59 patients died while waiting for organ.

<sup>4</sup> Dark Blue: dead donors; Light Blue: living donors; Dark Grey: transplanted patients; Light grey: waiting list 31.12. 2010

### **2.5.3 Organ “Export and Import”**

As shown before, many European countries collaborate when it comes to organ donation. Exchanging organs between European transplantation organizations is a common practice and increases the success of finding the most suitable recipient for an organ or the most suitable organ for the right recipient. These exchanges are authorized and regulated by national laws and regulations.

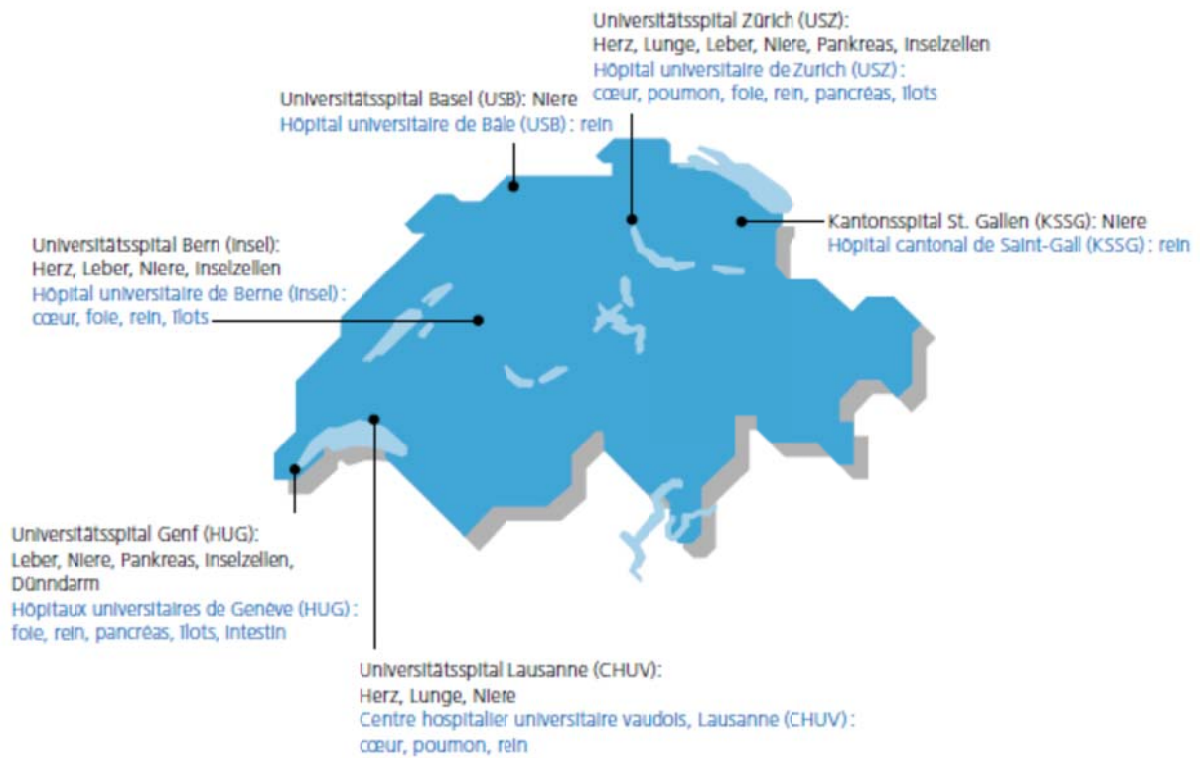
In 2010, 18 organs were “imported” to Switzerland and 19 organs, for which no suitable recipient could be found in Switzerland, were “exported”. This was the first time in five years that Switzerland exported more organs than it imported (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011b).

### **2.5.4 Transplantation Centers in Switzerland**

In Switzerland, there are six transplantation centers that perform organ transplantations: Lausanne, Geneva, Bern, Basel, Zurich, and St. Gallen (Figure 3). Identified potential donors from other hospitals are either transported to these transplantation centers or the respective explantation team goes/flies to the hospital that has an identified donor and performs the explantation on the spot.

## 2 Organ Donation in Europe and Switzerland

### Die Transplantationszentren der Schweiz Les centres de transplantation en Suisse



**Figure 3: Transplantation Centers in Switzerland** – Source Graph: (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011a)

### 2.5.5 The Role of the Federal Health Department

Art. 61 of the transplantation law assigns the duty of informing the public to the federal and cantonal administrations (Die Bundesversammlung der Schweizerischen Eidgenossenschaft, 2007). The duty of the administration is of an informative nature, not a promoting one. The law clearly defines the contents of what the population needs to be informed on, which explains how the official campaign is designed. In an interview with the federal-level responsible of the organ donation campaign, it was stated that the campaign only has an informative/educational purpose and does not strive to convince people. On its website, the BAG (Federal Department of Health) is even more precise, pointing out its aims and messages: (Bundesamt für Gesundheit, 2011b)

“The Swiss population has to be fully and neutrally informed about the transplantation law and made aware about sources of information about the topic.” (Bundesamt für Gesundheit, 2011b)

The Swiss population needs to know that the BAG provides “neutral, factual, correct, and complete information” (idem).

A federal health department official, stressed several times during an interview that the promotion of organ donation and arguing in favor is not part of the “information duty” of the state. It is therefore left to Swisstransplant and other (semi) private and non-profit organizations in the field to promote organ donation. The state’s duty is to inform citizens about the possibility to donate, making sure citizens know that this decision is a free and individual choice (as precised in art. 61 of the transplantation law (Die Bundesversammlung der Schweizerischen Eidgenossenschaft, 2007).

This separation of roles is an important detail in understanding why previous campaigns were designed in such a way (the campaigns themselves will be a shortly discussed in a later section).

### 2.5.6 The Role of Swisstransplant

On their website, Swisstransplant describes its role as the following:

*“Swisstransplant is the Swiss national office in charge of allocating organs to recipients in accordance with Swiss law. We work at a national level to organize and coordinate all activities related to organ allocation and also cooperate with similar organizations outside of Switzerland. We are also responsible in Switzerland for maintaining the waiting list of organ recipients and for creating relevant statistics.*

*The National Committee for Organ Donation (CNDO) came about in early 2009 through integration of the Swiss Foundation for Organ Donation (FSOD). It is dedicated to promoting organ and tissue donation in Switzerland.”*

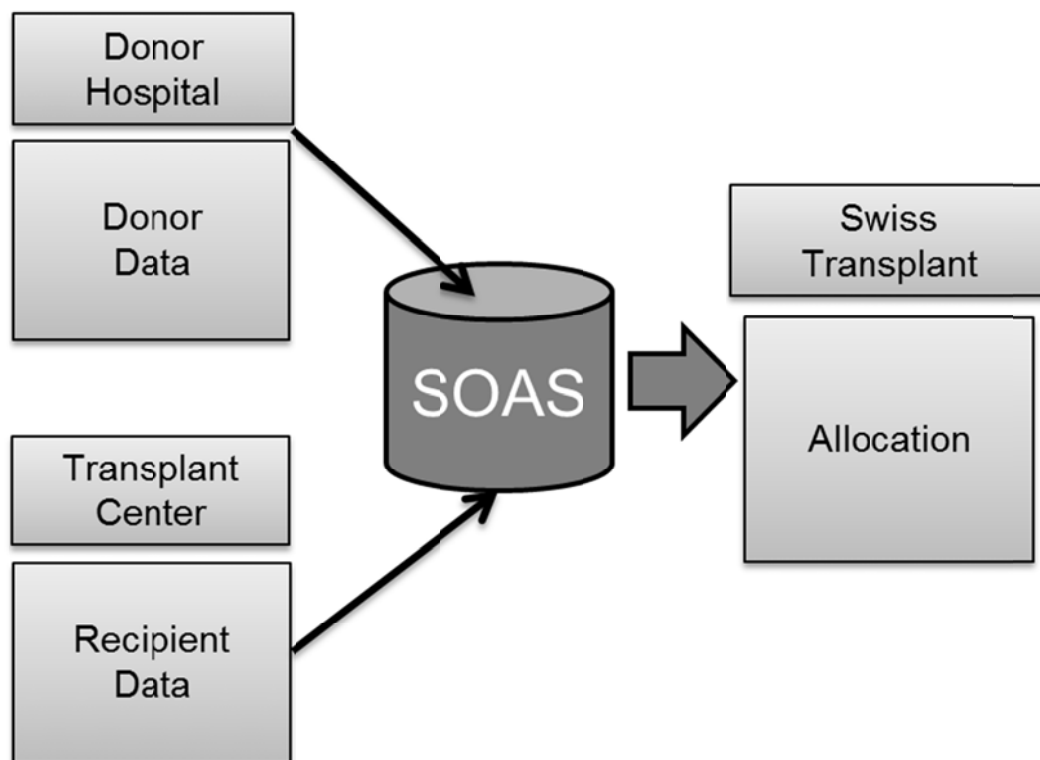
(Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011a)

Swisstransplant therefore plays a crucial role in the organ allocation, coordination, and communication process. Whenever an explantation/transplantation takes place, Swisstransplant is the central institution coordinating all necessary actions. It ensures that the law and medical guidelines of defining brain death, provided by the Swiss Academy of Medical Sciences, are applied correctly (SAMW).

The allocation of organs to patients on waiting lists is determined through criteria set by “medical professionals working in the area of transplantation, in cooperation with the Swiss Federal Office of Public Health” (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011a). The Organ Allocation ordinance, deliberated by the Federal Department of Home Affairs, determines patients’ acceptance and placement on the waiting list. They set priorities of patients according to medical urgency, Swiss residency, medical benefit, and waiting time (idem).



The final allocation of an available organ is made through an objective internet-based computer system, providing Swisstransplant with the medical data of the donor organ and eligible recipients. The computer program, SOAS, then matches the data and sends Swisstransplant the information. Swisstransplant will then eventually allocate the organ to a waiting patient (idem). An overview of this process is shown in Figure 4.



**Figure 4:** The Swiss Organ Allocation System (SOAS). Source: Swisstransplant (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011a)

Along with Swisstransplant, there are a plethora of small associations promoting organ donation and offering support to relatives and patients. A list of them can be found on the Swisstransplant website (<http://www.swisstransplant.org/l4/links-associations-health-donor-recipient-organ.php>). Swisstransplant coordinates the

activities of all associations active in the field of organ donation, by inviting stakeholders once a year to an annual meeting.

### **2.6 The Legal Framework for Organ Donation in Switzerland**

Transplantation is a procedure in transferring organs, tissues, or cells from one person to another. In the last century, the procedure has been medically improved and therefore, has more and more become a treatment of choice. Fighting diseases with new cells, tissues, or even organs not only allows better treatment for patients, but also saves lives. Through the improvement of transplantation medicine, legal and ethical issues become more and more important, and the need to discuss them at the State level increases (Kalitzkus, 2009).

In Switzerland, these issues are addressed in the Federal Constitution and under the transplantation law. The law further details the legal framework of organ and tissue donation in the Helvetic Republic.

#### **2.6.1 The Federal Constitution**

In 1999, both the Swiss people and the council of state clearly voted in favor of an amendment of the Swiss National Constitution; and thus the new article 119a. The article defines the responsibilities of the Swiss State in the domain. Section one of article 119a states that the federal state rules in the domain of organ, cell, and tissue transplantation. The federal state guarantees human dignity, the protection of the individual, and the protection of health. Section two gives the power to the federal state to define the rules for a fair organ allocation procedure and section three rules out any possibility for an organ market. It states that organ, cell, and tissue donation is free of charge and human organ trafficking is illegal (Bundesamt für Gesundheit, 2011b).

### **2.6.2 The New Transplantation Law 2007**

In addition to the transplantation article 119a of the Federal Constitution, national law further details the legal framework of organ donation in Switzerland. The Swiss transplantation law was voted in 2004, and the new version consequently was enforced on July 1, 2007 (Die Bundesversammlung der Schweizerischen Eidgenossenschaft, 2007).

It defines the circumstances under which organs, cells, and tissues can be explanted. Every explantation needs approval, organ allocation is organized by an independent national allocation service (Swisstransplant) to avoid discrimination, and organ trafficking is strictly prohibited. Furthermore, the law defines criteria for death, living donation, xenotransplantation, and research in the field of organ donation (idem).

The most relevant part of the 2004 transplantation law (applying to the scope and needs of this dissertation) is section 2, covering the laws on organ donation after death. Article 8 will be summarized and the entire law can be downloaded from the official transplantation website<sup>5</sup>.

Article 8 of the Swiss transplantation law defines the conditions for organ explantation after death (Die Bundesversammlung der Schweizerischen Eidgenossenschaft, 2007). Thus it rules that organs, cells, or tissues can be explanted from a deceased person only if the person agreed before his/her death and if death has been declared. If no certified approval or denial to donate from the deceased person can be found, the relatives closest to the deceased have to be consulted whether a declaration about the willingness to donate is known. If no declaration is known by the relatives, it is then up to the relatives to decide if the organs, cells, or tissues can be retrieved. Relatives are bound to respect the presumptive will of the deceased person. If close relatives do not exist or cannot be found, explantation is not allowed. The will of the deceased person takes priority over the will of the relatives. If it can be proved that the deceased person told a

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<sup>5</sup> <http://www.bag.admin.ch/transplantation/00694/index.html?lang=de>

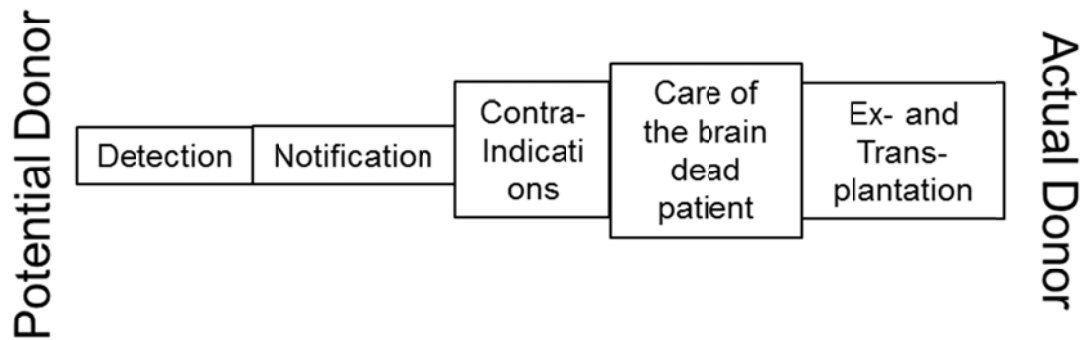
trusted third party about his/her decision to donate or not, this wish then takes priority over the will of the relatives. Once a person fulfills their 16th year of life, he/she is eligible to declare his/her wish to donate organs after death. The federal council is in charge of the definition of the closest relatives (Die Bundesversammlung der Schweizerischen Eidgenossenschaft, 2007).

The content of the transplantation law, as well as the official information on the website of the federal health department, have been used for the assessment of knowledge, as well as the design of the experimental intervention of the study. This will be further explored in the method section.

### **2.7 The Organ Donation Procedure and Intervention Possibilities**

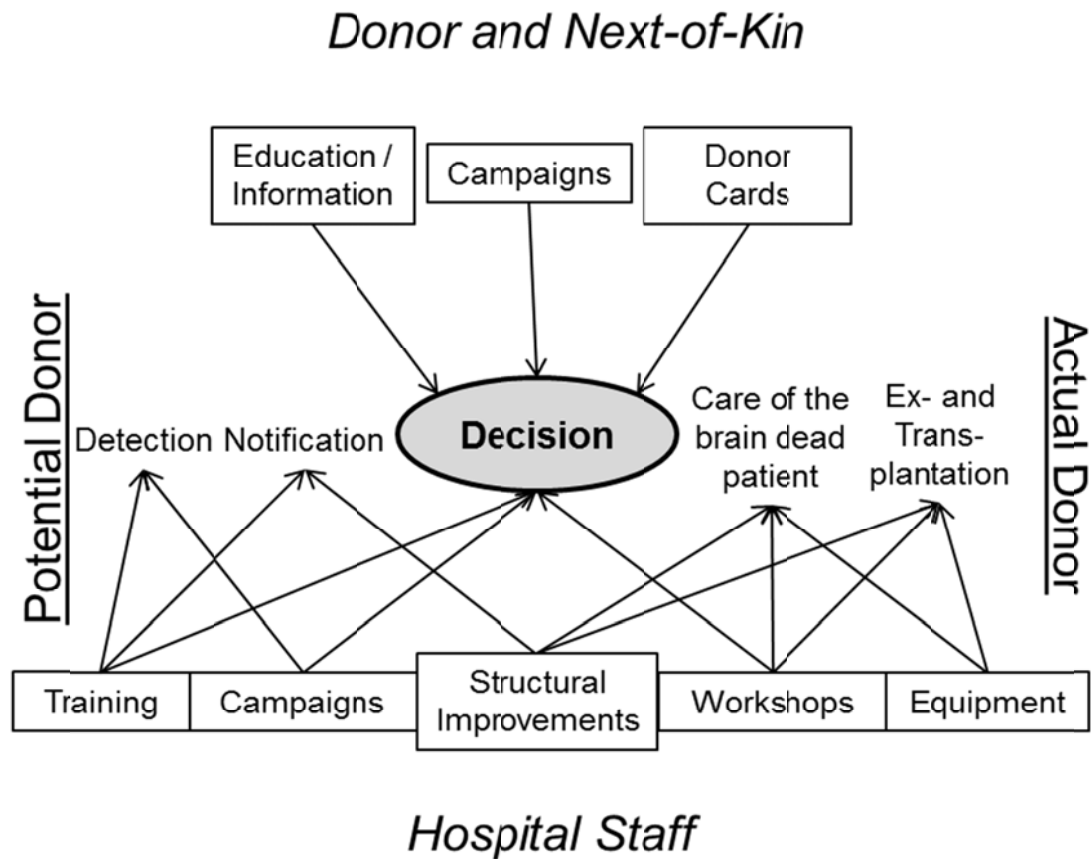
There are two different forms of organ donation: living donation and cadaveric donation. In Germany it is said that a living donor can only donate to a close relative, however, in Switzerland this is not the case (BZgA, 2008). In the following thesis, the focus will be on donation after death, also called cadaveric organ donation. Thus, the irrelevant legal and structural framework for living donation will not be further laid out. Only the organ donation procedure for cadaveric donation will be laid out. It will be done to detect intervention possibilities and point out the need for better communication of the topic to the public. This will eventually prepare people better for the process that they will face when asked about organ donation.

In Figure 5 the organ donation process is summarized as a model:



**Figure 5:** Adapted model of the organ donation process after Gold et al. 2001 (Gold, Schulz, & Koch, 2001)

The model shows the different steps from a medical point of view. First, a potential donor needs to be identified. Once that happens, transplantation coordinators are informed and Swisstransplant is notified and becomes in charge of the subsequent course of events. In the meanwhile, medical tests are run and the deceased body is taken care of to keep the organs intact. After an ok from Swisstransplant, the transplantation team will proceed with the explantation, and in consequence, the organs will be transported to the assigned recipient. However, the model only shows the process from a medical perspective. An important element is missing, namely the clarification whether the potential donor is “willing” to donate or not. In Switzerland, whether the donor card is found or not, relatives will be consulted about the ongoing process. Together with the medical staff, the decision whether to proceed or not will be taken. The following model, from Gold et al. including the decision step, shows points of action that could possibly have a positive impact on the explantation decision.



**Figure 6:** Adapted model of the intervention possibilities in the organ donation process to increase the number of successful donations, after Gold et al. 2001 (Gold et al., 2001)

Although Gold et al. designed the model for the organ donation procedure in Germany, it can be used to describe the Swiss organ donation system as well. There are two levels of possible intervention to distinguish: on one hand the hospital and its staff, and on the other the potential donor and his/her family.

Looking at the hospital and the medical staff, the intervention possibilities for improvement occur at several steps. One possible intervention would be at the initial training level, especially of intensive care staff who are always involved in the donation procedure (Gerli, 2011; Gold et al., 2001). Better training would impact the detection of potential donors, as well as the notification procedure and the decision

to proceed or not with the explantation. A campaign promoting a positive attitude within the hospital could have the ability to improve the detection of potential donors as well as the decision. From a technical point of view, structural improvements in terms of logistics, organization, technical workshops, and better equipment might increase the success of the whole process (Gold et al., 2001). There is a lot of scientific research about the role of the hospital staff in the organ donation process. This will be summarized briefly in the following literature review and sketch a more complete picture. However, the research itself of this monograph will focus on the upper part of Figure 6. In Switzerland, it is either the donor themselves (by signing a card or communicating their wish to donate) or their relatives who decide on continuing with the explantation. The challenge of social scientists is to understand the underlying processes behind the decision to donate or not (psychology) and try to find possibilities to enhance positive outcomes (health communication).

From the donor and next-of-kin viewpoint, it is mostly important that they are well informed and also perceive it as such. For instance, potential donors (all people thinking about signing a donor card or communicating their willingness to donate) believe it is important to have access to information they might need. This information includes the organs and tissues transplanted in Switzerland, the definition of brain death, the role of the donor card, and more. In Switzerland, all this information can be downloaded on the website of the national organ transplantation association *Swisstransplant*. They provide a glossary of all relevant topics to help make one's own decision or answer to doubts and questions anybody might have regarding the topic of organ donation (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011b).

To provide the population with the necessary information, the Swiss government, as most governments did, launched a large scale communication campaign after the 2007 law came into force (Bundesamt für Gesundheit, 2011a). Looking at the

Swisstransplant 2010 annual report, the effects of the last three years of campaigning on the actual donor rates are questionable<sup>6</sup> (see section 2.5.1).

The last element in Figure 6, with a point of possible intervention from the patient, is the donor card. Since there is no organ donor registry in Switzerland, the only way of consenting to donate one's organs after death is to sign a donor card or tell to the family. More precisely, the transplantation law lays out that organs, cells, or tissues can be retrieved only upon approval, including the deceased person having documented his/her will. Their will can be documented on a donor card, testament, assigning a third person of trust to take the decision. However if no declaration can be found, relatives decide about a possible explantation. If no declaration can be found and relatives cannot be contacted in time, explantation is prohibited (Die Bundesversammlung der Schweizerischen Eidgenossenschaft, 2007).

The pivotal role of the donor card is that it is legally binding and helps relatives make the difficult choice in a highly stressful situation of shock and sorrow (Kalitzkus, 2009). Still, the net effect of the donor card is limited. Interviews with heads of intensive care units in several transplantation centers in Switzerland have shown this to be true (Schulz et al., 2011). Schulz et al. 2011 interviewed 9 heads of intensive care units in Switzerland and stressed the importance of the donor card as a "vehicle" for communication within the family. Although found in only 5% of the reported cases, donor cards tremendously eased the family's decision at the hospital<sup>7</sup>. Additionally, it makes people think and talk about the topic. Having thought about organ donation before it was "time" significantly improved the possibility of a

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<sup>6</sup> It is important to bear in mind that the campaigns between 2007-2010 were launched by the federal health department, which was given the mandate by the new transplantation law of 2007 to "inform", not convince the citizen to donate (see article 61 *Information of the Public* of the Transplantationsgesetz, (Die Bundesversammlung der Schweizerischen Eidgenossenschaft, 2007)). At this point, the author of this monograph does not aim at judging the effectiveness of the campaigns in terms of "informing the citizen" but wants to stress, that in terms of actual donors, no significant changes can be observed (Bundesamt für Gesundheit, 2011a).

<sup>7</sup> As noted before, the donor card - by law - is equivalent to a testament. However, the interviews Schulz et al. ran with the heads of intensive care units showed that fearing bad press and public relations, doctors would rather not proceed with the explantation if the relatives refuse their approval: even though a donor card has been found.



favorable decision for organ donation, as several authors could show in their research (Schulz et al., 2011; Skumanich & Kintsfather, 1996). The donor card allows the owner to choose whether they want to be a donor or not, and if accepting to be a donor, the person can restrict their decision to specific organs (or exclude some organs or tissues). Additionally, there is space to put the name and address of a person of trust who is authorized to make the decision in the case of death.

Even though Schulz et al. showed that the donor card is not found very often, potentially due to the circumstance or because it got lost, research has shown that it makes people think and talk about the topic (Radecki & Jaccard, 1997; Radecki & Jaccard, 1999; Skumanich & Kintsfather, 1996).

Therefore, the fact of having signed a donor card will be considered in the following study as a proxy for organ donation behavior.

### **2.8 Campaigns to Promote Organ Donation in Switzerland**

Since coming into force, the new law made the BAG launch different campaigns each year. They were all designed the exact same way for the three main official language groups.

The first campaign had the aim to accompany the new law and inform the people. Therefore, and even though often criticized for the lack of creativity, it only contained the paragraph 8 of the Transplantation law that the will of the deceased person primes the will of the relative. As Schulz et al. in their 2011 article, *Factors intervening in family decision to consent to organ donation by a brain dead relative: Evidence from a survey in Swiss transplantation centers* (Schulz et al., 2011) showed, this is de facto not true. Doctors are very reluctant to proceed with organ explanation when relatives do not consent.

In later campaigns the decision was to focus the campaign (in the following) more on signing the card and communicating wishes to the family.

The 2008/2009 campaign asked citizens to inform themselves and make a decision. Again, the campaign was an exact translation of the slogan in all three languages. The slogans shown on the posters in three languages were *I decide myself, I know what I want*, and *Does somebody know what you want?*.

The 2010 campaign focused on the fact that it is in everybody's personal responsibility to make a decision and communicate it. This could be done by either signing a donor card or talking to family and relatives about one's own will. Once a person is dead, he/she cannot make this decision anymore. Thus it can only be done during the one's lifetime. Often empty donor cards are enclosed with the ads to increase the probability of signing a card. The poster campaign showed individuals of different age groups with a donor card in the hand saying *I have it in my hands* (Bundesamt für Gesundheit, 2011b).

### **2.9 Relevance for the Topic and Deduction of the Research Question**

As shown in the previous chapters, the organ donation campaigns are always shown the same in all three language regions. Since Schulz et al. 2006 (Schulz et al., 2006) showed substantial differences among the language groups, in their analysis of Swiss people's knowledge and attitude about organ donation, the adaptation of the campaign to the different language groups is sensible.

In the following thesis, it will be examined which elements a future campaign should contain to increase thoughts about the topic, decision making, and communication of that decision by signing a donor card or talking to their families or trustworthy person.

This leads to the topic of the following thesis about the effectiveness of targeted promotional messages in Switzerland. Thus the research question is, whether or not it is worthwhile to adapt the organ donation campaign to the specific characteristics of the three language groups.

The exact hypothesis and method will be presented later in the methodology chapter. Before doing that, an excursus about Swiss culture and why the linguistic regions show potential different characteristics and attitudes will be presented. In the second step, a summary of the health communication literature about adapting health messages to different audiences will be explored and lead to the research question and theoretical background from which the hypothesis will be drawn upon.



## **3 Switzerland – A micro Culturally Diverse Country?**

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The following sections will give some historical background to understand where differences among the language groups come from, eventually leading to the presented research question.

Still, the reader shall bear in mind that this is not a monograph about Swiss history nor about the (re-) definition of “culture”. However, it is considered crucial to have a rough understanding of why Switzerland is the way it is and where differences among the linguistic regions come from. This will help in understanding the designed hypothesis, as well as the conclusions drawn in the discussion. Therefore, in the following chapter, the notion of culture shall be first clarified, then Swiss history and culture will shortly be examined. It will show that Switzerland is not the culturally homogeneous country one would expect, but a peaceful co-existence of the different groups.

Here one of Switzerland’s most famous German-speaking writers, *Friedrich Dürrenmatt*, shall be quoted another time with a text passage of his book titled *My Switzerland*, summarizing all his pieces about his *Heimat* (home country):

“That many of what is said and thought in other countries about us, is simply not true, so for instance the living together of people with different mother tongues: They do not live together, but one next to the other” (Dürrenmatt, 1998, p. 189, free translation) [1] Original in German.

Therefore, the different heterogeneous groups need and want to be addressed differently: the challenge is to understand *how*. This will be the object of the following study after a short excursion about culture, Switzerland and “*Swissness*”.

### 3.1 The Notion of Culture

In most of the cross-cultural literature in the field of social sciences the terms *culture*, *culturally*, *cultural differences* are used in different contexts and settings. As mentioned before, several attempts have been taken to define culture in the past. Originally understanding cultures was an exclusive topic of ethnology scientists. Therefore to provide the reader with the right frame or mindset, before starting, a short excursion in ethnology shall be made.

There are several approaches in the history of ethnology research to address the topic of culture: the evolutionary approach, the holistic approach and the hermeneutic approach (Wicker, 2003). The evolutionary approach classifies culture according to the three stages of “wild”, “barbarize”, and “civilization” (Adam Ferguson or Lewis Henry Morgan)<sup>8</sup>. The holistic approach claims that culture is a higher instance comprising values, norms, rules, strategies shared, used and applied in the everyday life of people living in one society. Thus cultures show specific structures throughout all the different layers of a society. The holistic approach tries to quantify culture (Dubois 1961, Gladwin and Sarason 1953, Wallace 1952 or George Peter Murdock 1949, founder of the *Human Relation Area Files* (HRAF) (Wicker, 2003). The many failures in measuring culture as a quantitative concept lead to the hermeneutic approach of the concept *culture*. The hermeneutic approach does not try anymore to define culture. It is not anymore considered as a holistic system, which was a complete change in paradigm (idem). According to this approach, cultures are grids of interests/meaning (*Bedeutungsnetze*), created by human beings (Geertz 1993). The ethnologist therefore needs to read these grids, understand and interpret them. Measuring culture within this paradigm does not make sense (Wicker, 2003). This has been shown by most recent research, as Hofstede did with his organizational study in 2001 (Hofstede, 2001), who according to Wicker did not manage to “measure” culture as such, but just to statistically reproduce an image that already Hegel, Marx

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<sup>8</sup> This is a summarized and very simplified excursion on ethnological research origins in the field of culture.



and other philosophers of the 19<sup>th</sup> century draw from the occident and orient. However, these numbers do not tell us, how cultures are functioning from within: they prove existing differences but do not explain them (Wicker, 2003).

The following monograph tries to apply a hermeneutic approach. The aim is to understand cultural differences but not to a) redefine the notion of culture nor b) to measure it. The quantitative approach has been chosen not to quantify or measure or define culture, but exclusively to answer the question whether culturally targeted promotional messages in the field of organ donation would be effective – culture being an underlying concept of cultural differences, but not the main focus of this research.

#### **3.2 *Sonderfall* Switzerland**

Some authors call the living together in Switzerland of different “peoples” (Joye, Busset, & Schuler, 1992), language communities and religions on such a little territory the “Helvetic Miracle” (i.e. Siegfried 1969 or Rougemont 1970 in (Joye et al., 1992)). Many others “just” speak of it as *Sonderfall* (special case).

“Switzerland, born from the common wish of people of different mother tongue and different cultures to be united for good or for evil.” (Ribeaud, 2010) [5]

This sentence freely translated from the very last paragraph of Ribeaud’s book about language diversity in Switzerland, gives a good summary of what makes Switzerland a *Sonderfall*. This particularity is also inscribed in the Constitution of the Helvetic Republic:

The Swiss Federal Constitution defines in its Art. 4, 18 and 70 the role of the different languages spoken in the country. In the following they are freely translated:

**“Art. 4 National Languages:** The national languages are German, French, Italian and Romansch”<sup>9</sup> (Bundesverfassung der Schweizerischen Eidgenossenschaft, 1999)

**Art. 18 Liberty of Languages:** The liberty of languages is guaranteed. (Bundesverfassung der Schweizerischen Eidgenossenschaft, 1999)

**Art. 70 Languages:**

<sup>1</sup> The official languages of the federal State are German, French, and Italian. In issues involving directly people with Romansch as mother tongue, the latter becomes official language in the matter.” (Bundesverfassung der Schweizerischen Eidgenossenschaft, 1999)

Pascal Couchepin, at this time part of the federal government, said in 2005: “Today, nobody can anymore imagine a Switzerland not being Quattro-lingual. The treasure of our country is that we think in several languages.” (Ribeaud, 2010) [4]

However this is not a modern nor a new vision. It is deeply embedded in Swiss culture and thinking. In the second half of the century, every young man entering the military got as a present *Il libro del soldato* (The book of the soldier) in his mother tongue. The book stresses strongly the advantages for the individual and politics and positive aspects of the four national languages<sup>10</sup> (Merz & Bachmann, 1959, p. 51-52) [7].

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<sup>9</sup> Free translation of the German version of the Constitution.

<sup>10</sup> Detailed quote in Annex A *Original Quotes* [7]

### 3.3 Swissness – What is so Swiss about Switzerland: A Short Excuse into Swiss History<sup>11 12</sup>

Switzerland was originally a German speaking creation. From 1291 to 1789 the confederation of states was exclusively German speaking. When the canton Fribourg, the first French-speaking majority canton, joined the Confederation in 1481, the political pressure of Bern was so strong, that the patricians even Germanized their names. This was even the case after the conquest of another French-speaking canton, Vaud in 1536. Between 1513 and 1789 the only officially recognized language was German, even though it grew from the original three cantons to thirteen in 1789.

The French Revolution in 1789 brought the multilingualism of Switzerland. The French army and ideas beat German hegemony. Napoleon created the Helvetic Republic in 1798 with a central state, equality of citizens in front of the law, and strong executive powers. Additionally, the equality of the languages was recognized. For five years, Switzerland was a modern, centralized, pluri-lingual state. All attempts to divide the country because of language or culture claims could be resisted upon.

From 1798 on, all laws and decrees of the government were published in the official journal, in both German and French. Protocols of parliament sessions were translated to both languages and two interpreters were allowed during parliament sessions. This allowed for simultaneous German-French and French-German translations. In 1789, representatives of Ticino were also allowed for the first time in parliament. Following the example of their Swiss French compatriots, who

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<sup>11</sup> This chapter follows the logic of Ribeaud's chapter *La politique des langues* (Ribeaud, 2010, p. 187-192) combining and completing the freely translated and summarized evolution of Swiss history with elements of Reinhardt's *Geschichte der Schweiz* (Reinhardt, 2010), the official publication *La confederazione in breve* (Schweizerische Eidgenossenschaft), and the English speaking publication *Conflict and Compromise in Multilingual Societies. Switzerland* (McRae, 1983), in this section the before named authors will not be quoted separately unless a direct quote is used.

<sup>12</sup> The section does not claim completeness from an historic point of view, but wants to deliver a short overview to the reader, allowing for a better understanding of the underlying historical facts that might lead to some of the particularities of a Quattro-lingual country.

succeeded in making French a federal language, they would as well start to claim the translation of official documents in Italian.

The claim of Swiss German members of parliament that German is the mother tongue of the Helvetic Republic made the Swiss French so upset, that they would support the claims of their Italian speaking compatriots in introducing a third official language. As a consequence, since the Constitution claimed equality of languages, and with the French tripartite motto: *Liberté, Égalité, Fraternité*, both chambers voted in favor of the introduction of Italian as third official language. This was enforced on September 20, 1798.

Reinhardt, a professor of Swiss history, summarized it as follows<sup>13</sup>:

“This was when from 1798 on, out of the self-chosen confederation of different people, a new politicized concept of the nation was born: Switzerland as nation of disposition (*Gesinnung*), allowing for bridges between people, languages, and cultures with the commitment of liberty, justice, and civil equality” (Reinhardt, 2010, p. 95) [6] Original in German.

Interestingly, the new trilingualism “fruit” of the French Revolution, and part of Napoleon’s heritage, was contrary to the French idea of a centralized state. Still, and paradoxically, it was the origin of the modern multi-lingual and multi-cultural federal structure of the Helvetic Republic. The latter denomination was a result of the multi-lingualism. For simplicity reasons and to avoid language quarrels, the name of the state was engraved in Latin, *Confoederatio Helvetica* on the national currency. It is also the inscription above the entrance hall to the *Bundeshaus* (seat of the Parliament). The abbreviation CH, the official country code, today is a well-known *brand* all over the world.

It is also the shortest summary of *Swissness* that can be found: four<sup>14</sup> different languages/cultures, three geographically distinct regions, and one common Latin denomination: *CH*.

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<sup>13</sup> If language skills are sufficient, the German original quote in Annex A is strongly recommended.

One might conclude that after such a long time of living among each other in peace, justice, and equality, differences between the groups equaled out with passing time. However, still in the 21<sup>st</sup> century, the differences are an integral part of Swiss culture. This is not only shown by research (Läge, Marx, & Sträuli, 2000; McRae, 1983), but also in tour guides (Küng, 2008), exhibitions (Flütsch, 2006), media coverage, and everyday life (i.e. Merz & Bachmann, 1959). Some of the most famous quarrels between Swiss Germans and Swiss French will be laid out in the following sections. It will provide a better understanding of the “heterogeneity within the homogeneity”.

#### **3.4 Language differences = Cultural differences?**

Some critical researcher might claim that language differences are not automatically cultural differences. This thesis will avoid an excursus into the plethora of existing definitions of what culture is (see i.e., Kroeber & Kluckhohn, 1952). There is no common sense or agreement in science about the definition of culture and its related terms. McRae uses within five pages of his book on multilingualism in Switzerland, all the following terms almost interchangeably (McRae, 1983): “subcultural diversities” (p. 105), “races” (p. 106), “Swiss cultural diversity” (p. 108), “Swiss subcultures” (p. 108), “linguistic identity” (p. 108), “ethnic personality” (p. 108), “intergroup differences” (p. 109), and “linguistic and cultural co-existence” (p. 110).

The following sections do not aim to (re) invent a (new) definition of culture, but are meant to give some examples and explanations of Swiss public discourse. The purpose is to underline and prove that talking about cultural differences is indeed justified in the Swiss context. Why these differences are classified *micro*-cultural will be etymologically derived in the last section of this chapter.

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<sup>14</sup> The reader may be indulgent that the historical part of the Romantsch is neglected at this point. It is done to avoid a long and detailed excursion into Swiss history within the research frame of this monograph.

#### 3.4.1 The Röstigraben (Potato-Ditch): Myth or Fact in “Everyday Life”

The term *Röstigraben* describes differences, mostly in statistical and voting behavior, between the German and French speaking Swiss citizens.

“Linguistic regions, however, are only a statistical concept in Switzerland, having no administrative or legal consequences” as McRae correctly<sup>15</sup> summarizes in his book about Switzerland’s multilingual society (McRae, 1983, p. 55). In the following, an example of this statistical evidence is reported.

##### 3.4.1.1 The Statistical Röstigraben (Potato-Ditch)

In Laurent Flütsch’s exposition (catalogue) Rideau de Rösti – Röstigraben, a study of the M.I.S. Trend Lausanne, an independent Swiss market, opinion, and social research institute, shows main cleavages among the two groups. Swiss Germans and Swiss French vote differently in terms of gender quota (46.8% Swiss Germans vs. 29.7% Swiss French in favor), a more repressive drug policy (38.8% Swiss Germans vs. 29.7% Swiss French in favor), the decision to introduce the Euro (54.4% Swiss Germans vs. 27.7% Swiss French against), or work ethics (43.6% Swiss Germans vs. 60% Swiss French to work less hours) (Flütsch, 2006).

One of the most interesting polls, revealing such a clear cut in voters opinions, was the question whether Switzerland should join the European Economic Area (EEA) in 1992. Overall, the Swiss population voted against the Swiss accession to the EEA. Interestingly however, was that there was a very tight decision. There were clear differences in voting behavior between the different linguistic regions (Läge et al., 2000). While the French speaking West was strongly supportive of an accession to

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<sup>15</sup> It is written “correctly” because the Swiss Constitution does not define language regions as such, nor their borders. It foresees the “liberty of languages” and defines it as the official and national languages, but not where exactly, geographically spoken, they are supposed to be applied ( Bundesverfassung der Schweizerischen Eidgenossenschaft, 1999). Still, speaking of three main language regions, it is common among the population in science, literature, and media.

the EEA, the German speaking part of the country (with the exception of the big cities Bern, Zürich, and Basel) mostly voted against it (idem).

#### **3.4.1.2 The Röstigraben (Potato-Ditch) in Scientific Research**

Whenever a vote is decided along the language cleavage line, the Swiss French feel heteronymous, and get upset with their Swiss German “rulers”, for whom they have a variety of negative nicknames (Küng, 2008). Swiss Germans on the other hand do not have any negative nicknames for their Swiss French compatriots. (Küng, 2008) Quite the contrary, overall they show a lot of sympathy for French Swiss, as Fischer and Trier show in their study of the perception and self-perception of the Swiss (Fischer & Trier, 1962). The same study showed that only every 7<sup>th</sup> Swiss German citizen considers the Swiss French part as *abroad (Ausland)*, while every 4<sup>th</sup> Swiss French believes the same of the Swiss German part (idem).

Fischer and Trier also found that Swiss French describe their German-speaking compatriots as: strong, edgy, harsh, healthy, serious, diligent, and heavy. Funnily, the Swiss Germans confirmed that with their ratings of self-perception. Swiss French on the other hand are labeled by Swiss Germans as warm, light, happy, fast, funny, and relaxed. Interestingly the positive image of Swiss Germans towards their compatriots does not seem to be mutual (Küng, 2008). This might be due to the fact that, contrary to Swiss French and Swiss Italians, Swiss Germans are very reluctant to speak high German (standard German instead of dialect) to their compatriots. This makes it almost impossible for the French or Italian speaking Swiss to understand what the others are saying, even making the effort to apply the German they learned in school (Küng, 2008; Ribeaud, 2010; Büchi, 2000).

#### 3.4.1.3 *The Röstigraben according to Friedrich Dürrenmatt*

According to the before already nominated Swiss writer Dürrenmatt, the *Röstigraben*, or the differences between Swiss Germans and Swiss French do indeed exist. Dürrenmatt explains this difference with history: for Swiss Germans, the Helvetic Republic is originally *German*. The Swiss history has many German aspects, with Wilhelm Tell, the founding regions (all of the German speaking), and the “glorious” battles. The Swiss French cantons (regions) joined the Republic for religious reasons, thus being the reason why today they are part of Switzerland and not France. In consequence, the relationship of the Swiss French citizen with the federal state is less mystic and nationalistic compared to the Swiss Germans (Dürrenmatt, 1998, p. 115-116).

Additionally, the relationship with their “big” neighbors is much different. While the Swiss Germans are very proud of distinguishing themselves from what they ironically call “big canton” (Germany), by avoiding to speak standard German, but dialect instead; the Swiss French suffer a feeling of inferiority towards the French. This is mostly reflected, according to Dürrenmatt, in a feeling and/or behavior of superiority towards the ordinary dialect speaking Swiss German (Dürrenmatt, 1998, p. 116).

The geographic distance, combined with the language barrier, lead to a lack of dialogue among the groups. Dürrenmatt goes even further, saying that this dialogue is due to a lack of mutual interest caused by a different understanding/perception of one’s own national identity (*Heimatgefühl*) (Dürrenmatt, 1998, p. 200) [12] Original in

German.



### 3.4.2 *L'Italianità – “Liberi e Svizzeri” (Free and Swiss)*

Having joined the Helvetic Republic as a new canton in 1803, under the motto *Free and Swiss*, Ticino is the main, but not the only, geographical region of the Italian speaking Switzerland. There are four more valleys that are a part of the *Italianità* in a neighboring German-speaking canton. Altogether they represent 6.5% of the Swiss population (Reinhardt, 2010) and (Ribeaud, 2010).

As Ribeaud summarized it, it is not just a new language and culture, but also a way of living and a state of being that characterizes the Italian speaking population (Ribeaud, 2010) [2]<sup>Original in French</sup>. However, it would be an insult for Ticino Swiss to be called Italian, even though an intense economic and personal relationship exists with the neighboring Italian region Lombardy (Lurati, 1992).

The men of Ticino contributed in an important way to the Swiss national cultural heritage. Their artists and handcrafters brought new things to Switzerland, as well as painters, architects (Botta), sculptures, plasterers, writers, and economists (Ribeaud, 2010). The other two language regions are, however, not often aware of the role the *Italianità* played in common Swiss heritage. Giuseppe Motta, former member of the Swiss government, 1911-1940, once said:

“Ticino without Switzerland would lose its importance; Switzerland without Ticino, would see mutilated its ideal of a federal State” (Ribeaud, 2010, p. 256) [3]<sup>Original in French</sup>.

The question is whether differences between the Swiss Italians and their compatriots are as visible and strong as between Swiss Germans and Swiss French. Thus whether there is applicability to the *Röstigraben* also a so-called *Polentagraben*<sup>16</sup>.

Dürmüller, in 1997, states that although the term *Polentagraben* (polenta-ditch) itself might be known among Swiss citizens, the tensions between the North and South or

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<sup>16</sup> *Polenta* is a very typical dish south of the Alps. It is very common in Ticino, the Italian speaking part of Switzerland, as well as in Lombardy, the north of Italy.

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the West and South are by far not as intense as they are between North and West (Dürmüller, 1997). According to Dürmüller, this is due to a) that one fifth of the Italian speaking community, at one point of their careers lived in another language region, and b) that Swiss Italians are more open to learn the other national languages. They start early on in school with French and continue with German studies in high school (idem) [8]Original in French.

Still, the “lower degree” of the so-called “tensions” does not mean that there are no cultural differences. This has been repeatedly underlined as an integral part and strength of Swiss culture. Beginning with high Swiss officials in the very early 20 century, for instance in Philipp Etter’s Federal Council, to present day, noticing the spiritual heritage of the Swiss confederation. This strongly defends the diversity of the citizens by underlining their strong bind in one common union (Chollet, 2006) [9]Original in French.

Peter Bichsel, a popular and famous author in Switzerland, wrote a summary in his book, *Des Schweizern Schweiz*, as follows:

“I am glad that they are with us: the Swiss Italians, Swiss French, and Romansch. Together we can help us mutually to avoid becoming “typical” (Bichsel, 1997, p. 24) [10]Original in German.

In the following sections, some scientific literature will be presented and try to grasp this phenomenon, from a scientific view, of *diversity in unity (or unity in diversity?* as said in Froidevaux’s article about Swiss pluralism (Froidevaux, 1997)) in the Swiss culture.

### **3.4.3 Early Research about Cultural Differences in Switzerland: Group Characteristics and Stereotypes<sup>17</sup>**

Already early literature in the 1950's studied differences between Swiss French and Swiss Germans (Siegfried, 1950). Siegfried, in his early 1950's book, already classified Swiss Germans as "orderly, practical, little give to abstractions, capable of intense commitment to work, scrupulously honest, blunt and plain spoken, solid implacable in the application of rules". Swiss French on the other hand, are described as "more oriented towards general principles and abstractions, more emotional, more eloquent, more dynamic, but also serious, practical, and apt in administration" (McRae, 1983, p. 93).

Other literature gathered by McRae, and summarized in his 1983 monograph, confirmed these first findings and completed this picture (McRae, 1983). According to them: Swiss Germans are serious, industrious, reliable, cautious, and traditionalist; while Swiss French are considered less driving, less vigorous, more superficial, more individualistic, warmer in personality, more tolerant, and more open to new ideas (McRae, 1983).

An early scientific study, conducted by Fischer & Trier in 1962, analyzed, with the help of Osgood's profile method (Osgood & Tannenbaum, 1957), the relationship between Swiss Germans and Swiss French from a socio-psychological view point, comparing hetero-stereotypes (Fischer & Trier, 1962). Fischer & Trier thus did not only look at what Swiss French think about Swiss Germans and vice versa, but they also analyzed whether their self-picture matched the stereotypes from the other group. Interestingly, most of them did match (idem) and continued to do so in later studies (i.e. Frei et al. 1983 in (Kreis, 1992)).

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<sup>17</sup> It shall be underlined that none of the below mentioned stereotypes are invented by the author of this monograph, nor may they be judged true or false by the latter. This section is simply summarizing existing literature.

### 3.5 Homogenous vs. Heterogeneous or “just” Micro-Diverse Switzerland?

#### 3.5.1 From Homogeneous to Heterogeneous and from Macro to Micro: an Etymologic Excuse

Why talk about *homogenous* and *heterogeneous* in the context of this monograph? The two terms are important to distinguish and will help clarify and define the notion of “micro diversity”, as used by Schulz et al. in the 2006 study (Schulz et al., 2006). Google-ing the term “cultural micro diversity”, their article appears in the second and third position. By adding *Switzerland* to the search term, the only hits containing all four search words are related to their 2006 article. The others contain only the terms micro-diversity, culture, or Switzerland. Therefore, it shall be clarified in this section what exactly the understanding of a homogeneous or heterogeneous country is and why this leads to the classification of Switzerland as a culturally, micro-diverse country. Collins’ thesaurus (Collins, 2003) gives the following definitions for the two antonyms:

“**heterogeneous** *adjective* = **varied**, assorted, contrary, contrasted, different, disparate, dissimilar, divergent, diverse, diversified” , etc... (Collins, 2003, p. 345)

“**homogeneous** *adjective* = **uniform**, akin, alike, analogous, cognate, comparable, consistent, identical, kindred, similar, unvarying” (Collins, 2003, p. 349).

Switzerland, a modern and stable democracy embedded within the European Union, might seem to somebody from “outside” as a very uniform, consistent country like its neighbors. Also, that Switzerland is without any major political issues, compared to other countries such as Belgium or Lebanon (Joye et al., 1992).

However it will be shown in the following sections that looking from “within” the country, there is nothing fitting Collins’ thesaurus’ definitions of *homogeneous*. Switzerland has four official languages (German, French, Italian, and Romansch), three main geographical areas, and topographically distinct language regions that create an immense amount of variety, contrast, difference, and diversity. To what extent this diversity is *macro* or *micro*, shall be discussed in the following sections.

Collins' thesaurus does not provide any definition for the prefix **macro** nor **micro**. Online dictionaries were consulted providing the following explanations: **Macro**, from the Greek word *makròs*, is defined as “large, long or great in size or duration” (dictionary.com). **Micro**, from the Greek word *mikròs*, is defined as “very small in comparison with others of its kind (*microcassette*; *microlith*), too small to be seen by the unaided eye (*microfossil*; *microorganism*), localized, restricted in scope or area (*microburst*; *microhabitat*), (of a discipline) focusing on a restricted area (*microeconomic*), containing or dealing with texts that require enlargement to be read (*microfilm*; *microreader*)...” (dictionary.com).

Whether cultural differences can be classified **micro-differences** or **macro-differences**, this strongly depends on the reference groups. The before discussed short excursion about *Swissness*<sup>18</sup> (Swiss culture), explained that all elements of the before quoted definition of **micro-** are met; mainly from a non-Swiss perspective<sup>19</sup>.

Being all Europeans<sup>20</sup>, and additionally all citizens of the same Western European country, differences between the inhabitants might seem “very small” (dictionary.com) and thus negligible. This is especially brought into light considering the stability and peacefulness with which these groups live together (or next to each other according to Dürrenmatt (Dürrenmatt, 1998)), and looking at other regions, i.e. the Balkan, to which the Swiss situation is not comparable at all (Ribeaud, 2010).

Thus, differences might indeed be “too small to be seen by the unaided eye” (Collins, 2003) of a non-Swiss. Especially since they are very “local” and “restricted in scope or area” (idem), being the three main language regions of Switzerland. Additionally, the analysis of the differences is “focused on a restricted area” or discipline, thus culture<sup>21</sup>. Finally, the topic of cultural diversity in such a restricted area requires “enlargement” (idem) to be detected, which is last part of the before mentioned definition.

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<sup>18</sup> Definition and origin in (Eidgenössisches Institut für Geistiges Eigentum) and (Feige et al., 2008).

<sup>19</sup> Most probably also from a Swiss perspective, but this shall not be a topic at this point.

<sup>20</sup> The term *European* here is used referring to the continent of Europe, not to the European Union.

<sup>21</sup> Why language is considered an appropriate proxy-measure for culture will be developed later.

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In consequence, and in accordance with Schulz et al.'s 2006 publication entitled: *More than nation and knowledge: Cultural micro-diversity and organ donation in Switzerland* (Schulz et al., 2006), Switzerland will be treated as a heterogeneous and culturally micro-diverse country.

#### **3.5.2 Conclusion: Switzerland – A Micro Culturally Diverse Country!**

While most studies looking at cultural differences did so between different ethnic groups in one country or between two countries (Guadagnoli, McNamara et al., 1999; Kopfman, Smith, Morrison, Massi, & Yoo, 2002; Morgan, Mayblin, & Jones, 2008; Morgan & Cannon, 2003; Rubens, 1996; Siminoff, Burant, & Youngner, 2004; Spigner, Weaver, Cardenas, & Allen, 2002), none of those studies looked at micro-cultural differences between one and the same ethnic group, with the same religion and the same historical background, but basically differing in mother tongue and linguistic location. Schulz et al. (2006) did so, but have been the only ones to try to explain health behavior by micro-cultural differences within one and the same country so far (Schulz et al., 2006).

In the previous sections it has been clarified that a) Switzerland seen from inside is a heterogeneous country, b) that existing differences can be called micro, and c) those differences commonly and in existing research are named and defined as "cultural". To sum up, the etymological examination of what heterogeneous/homogeneous and micro/macro exactly mean, the question still remains whether the so-called micro-differences can be considered cultural. In the following monograph, differences in behaviors and attitudinal patterns will be considered "cultural" even though there has been no scientific reflection upon the appropriateness of the term when analyzing Switzerland and its four-lingual citizens. A justification for the use of the term has been given in the previous sections.

### **3.6 Empirical Research about Behavioral Differences among Language Groups in Switzerland**

Not only is it historically proven (see section 3.3) that differences between language groups exist, (in mentality, habits, and attitudes), but also empirical research recently produced evidence of several differences in behavior and attitudes among the three main language regions in Switzerland. There are empirical findings that suggest differences between the language regions not only when it comes to political attitudes, voting behavior (i.e. Dorn, Fischer, Kirchgässner, & Sousa-Poza, 2008; Fischer & Trier, 1962; Läge et al., 2000; Renaud, 1998), or different scientific approaches in communication sciences (i.e. Jarren, 2000; Probst & Lepori, 2007; Saxer, 2005), but also to different health beliefs and behavior (Bisig et al., 2003; Bisig & Gutzwiller, 2004; Bopp & Gutzwiller, 1999; Faeh, Minder, Gutzwiller, & Bopp, 2009; Mosimann & Cepleanu, 1997; Schulz et al., 2006; Wang & Schmid, 2007).

In the north of Switzerland people speak German, in the west, French, and south of the Alps, Italian. Together with the Romansch, making up only 0.5 % of the population and living in the east, they all have a common goal: living together peacefully under a common roof of democracy. This does not mean that there are no tensions among the different groups, something that has been proven by several researchers throughout the last 30 years (Fischer & Trier, 1962; Grieder, 1938; Vallotton, 1938) and discussed in detail previously. Weilenmann, in the early 20th century, went so far as to speak of the spiritual exchange of three cultural nations (Weilenmann, 1925). In their stereotyping, researchers as the already mentioned Fischer & Trier found in 1962 a strong attachment of the French speaking Swiss to the neighboring France. The Swiss Germans however, did not feel the same strong ties with the neighboring Germany. However, both still feel more Swiss than French or German, despite their difference in language (Fischer & Trier, 1962).

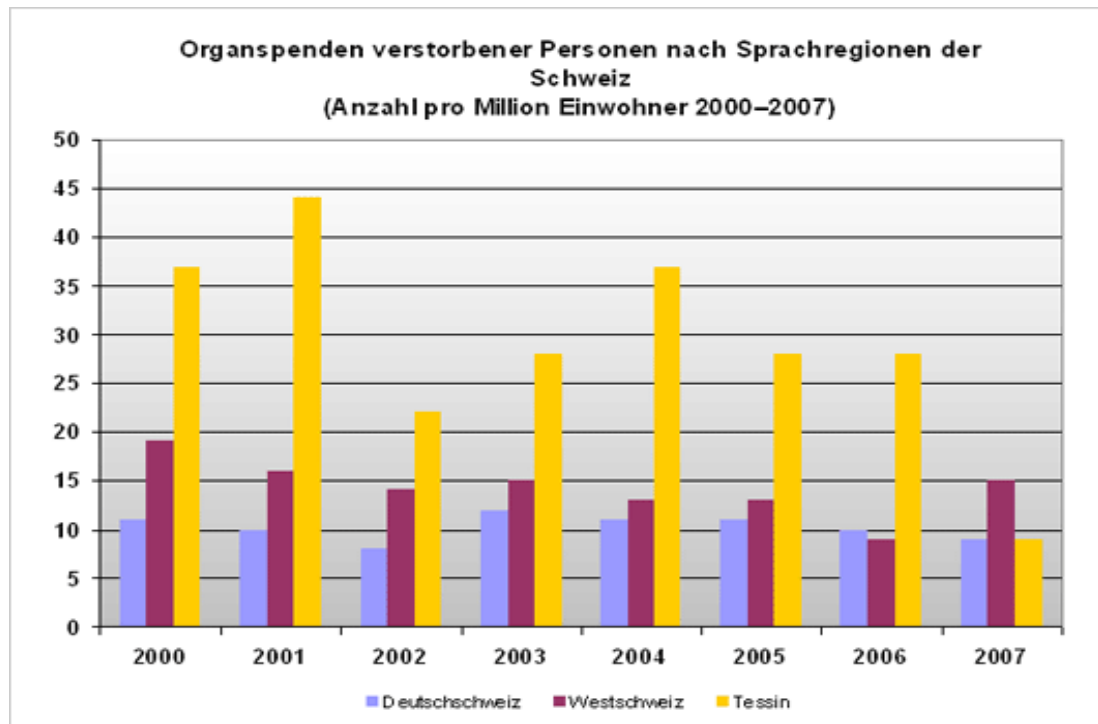
These differences are most interesting for (health) communication research. Early psychology research stated that the way people perceive the world and their environment depends very much on their respective group involvement and integration (Hofstätter, 1949; Hofstätter, 1990). Using this as starting point, the

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health communication researcher needs to understand what are these differences in group perceptions.

Empirical research in Switzerland has shown that not only group perception (Fischer & Trier, 1962) but also contemporary (health) behavior differs among the language borders within Switzerland. This was shown by Schulz and his fellow researchers in their organ donation research; for instance Schulz et al. (2006) (Schulz et al., 2006), Bisig (2003) (Bisig et al., 2003), or by the Swiss health survey (Schweizerische Eidgenossenschaft, Bundesamt für Statistik, 2007). A glimpse at the figures of the Federal Statistics Office of the Helvetic Republic also gives interesting insights. Since 1992, the Federal Statistics Office conducted the Swiss Health Survey every other year, not only asking for current illnesses and health statuses, but also including questions about attitudes towards health, life-style, customs, and health related behavior (Schweizerische Eidgenossenschaft, Bundesamt für Statistik, 2007). The results of the Swiss Health Survey show that there are indeed behavioral and cultural differences within the field of health. While Swiss French, for instance, do not pay as much attention to healthy eating as their compatriots, Swiss Germans found it much less important to freely choose the doctor they go to. Swiss Italians have fewer experiences with marijuana than the other language groups (idem). Other differences have been found in the field of organ donation. The Federal Statistics Office published a graph (Bundesamt für Gesundheit, 2009) showing that there are big differences among the donor rates in the three main language regions of Switzerland (see figure below).





**Figure 7** The number of organ donors per million of population by language group: blue bar= Swiss Germans, red bar = Swiss French, yellow bar = Swiss Italians. Source: Bundesamt für Gesundheit <http://www.bag.admin.ch/transplantation/00692/index.html?lang=de>[02.06.2009].

Figure 7 shows, that compared to the Swiss German and Swiss French speaking groups the number of cadaveric donors per million of population among Italian speaking Swiss is much higher.

To examine where these behavioral differences came from, especially the ones in the field of organ donation, Schulz and his research fellows conducted a survey in 2006 about the knowledge and attitude of the Swiss population towards organ donation. The results were striking. They proved differences among the linguistic regions, which the authors called micro-cultural differences (Schulz et al., 2006). Wang & Schmid ran another study showing such micro-cultural differences among the language regions about health literacy in Switzerland, published in 2007. Wang & Schmid illustrated that the biggest differences between information processing and health related decisions existed with the Italian speaking Swiss (Wang &

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Schmid, 2007). Among them, the low comprehension skills of written health messages and problems with doctor-patient relationships rendered health decisions problematic. Language skills were most developed among Swiss Germans, also their interest in their own health state. French speaking Swiss on the other hand, were the worst in understanding information from their general practitioner and not so interested in self-medication for minor illnesses. Interestingly, empirical surveys ran by the former Centre for Applied Research in Communication and Health (ARCHE) from the Institute of Communication and Health Lugano for Health Promotion Switzerland showed that Swiss French attributed much more responsibility to state institutions in the health field than Swiss Italians or Swiss Germans (Frisch & Schulz, 2009). Regional differences also existed when it came to effective measures on fighting obesity (Ehmig & Faustinelli, 2008).

After having discussed extensively the historic and cultural background of the country Switzerland, in the following literature review existing organ donation search shall be reviewed to draw a hopefully complete picture of intervening factors when it comes to communicate a topic as difficult as organ donation.

## **4 Literature Review: From Adapting Health Messages to Messaging Organ Donation (in Switzerland)**

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## 4.1 Organ Donation in Social Sciences Research

The following chapter is a review of existing literature about organ donation. Lots of research in social sciences has been conducted in the field of organ donation for many years. The following literature review does not aim for completeness nor is it a systematic review. Databases such as *Pubmed*<sup>22</sup> have been searched for key words such as organ donation, targeting health messages, culture, etc. Different domains of research have been detected that will be briefly laid out in the following chapter. It will give an excellent overview on the relevant topics that are crucial when trying to understand a complex topic such as organ donation. In the following, different research results are presented that directly or indirectly create a complete picture of the organ donation landscape. Divided into six big sections, the different aspects will be presented to help understand the complexity of the topic. The excursion through organ donation literature looks at the chronic lack of organ donors from different angles. It also will show points of analysis most relevant to the topic and eventually draw conclusions for an effective campaign, especially in such a culturally diverse country like Switzerland.

The first section will discuss ethical issues about organ donation. It will show that research has adopted a systematic approach, studying mainly economic and political aspects of transplantation medicine, as well as legal and institutional aspects of organ donation, including the crucial role of hospital staff and family members in the organ donation procedure. After exploring the general transplantation medicine framework, research about behavioral patterns will be introduced. It will explore why people donate or not and what makes their behavior engage or not with organ donation. Most of the researches include psychological components and/or (health-) behavioral models. Given that the main focus of this dissertation is the effectiveness of specific campaigns in a micro-cultural environment, organ donation research, including cultural components, will be

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<sup>22</sup> Pubmed is the U.S. National Library of Medicine, comprising of more than 20 million citations for biomedical literature, scientific journals, and online books (<http://www.ncbi.nlm.nih.gov/pubmed/>). It is a useful tool to detect relevant literature for health related topics such as organ donation.

consequently presented. Since successful campaigning includes designing effective health messages, relevant research about health and organ donation communication will be laid out. It will conclude in a short summary of Schulz et al.'s study (2006) on micro-cultural differences in the field of organ donation in Switzerland and will be the base on which the following study is designed.

## **4.2 Research about Increasing the Donor Pool**

### **4.2.1 Organ Donation and Ethics**

Organ donation, transplantation medicine, and ethics have been topics that are strongly related to each other. Lots of discussion has taken place, especially in medical sciences about the definition of death and brain death, which is not a big topic anymore today (Bernat, 2009). There are also other topics, however, death is linked so closely to organ donation and ethical discussions. Some discussion relate to approaching families in grief and sorrow with an organ donation request (Truog, 2008), or about altruism (Blondeau, Godin, Gagnéa, & Martineau, 2004).

In the following, some studies, including ethical aspects, will be examined more closely. They are considered to be extremely relevant in understanding the delicateness of organ donation and why it is so difficult to communicate a topic involving death, grieve, and sorrow. Since moral norm is a strong predictor for intention, especially for altruistic behaviors such as organ donation, several authors tried to discuss ethical constructs such as autonomy, beneficence, justice, and others (Blondeau et al., 2004).

Another field of research discussing ethical issues in the organ donation process, is the role of clinicians and organ procurement organizations such as Swisstransplant, Scandiatransplant, and others (Truog, 2008). Medical staff in opt-in systems is exposed to conflicting ethical obligations: the commitment towards the patient and his/her family, the commitment to society in the willingness to convince the family to donate the deceased one's organs, all while being "fully transparent, fair, and evenhanded" (idem). The hospital staff itself might not be convinced of its

“commitment to the society”, and therefore has been the subject of many scientific studies. A summary of the arising topics and issues from recent research will be given in the following sections of this chapter. This problem has also been further discussed by Hoeyer and Jensen in a recent article titled *Organ donation and the ethics of muddling through* (Hoeyer & Jensen, 2011). Hoeyer and Jensen emphasize that in intensive care units, organ donation conversations, in regards to ethics, cannot be conducted with rational decision trees. Every situation is unique and general rules would not be applied efficiently or caringly (idem). The topic is already a particularly delicate one to discuss with relatives of a deceased patient; death is not an easy topic by itself nor is the medical term brain death. The patient, whose functioning is carried out by medical machines, does not seem to be dead since he/she is still breathing and still has a warm body (Kalitzkus, 2009). The technical definition of brain death is the irreversible cessation of all clinical brain functions. This is particularly difficult to communicate to people, more importantly relatives, although the concept is well recognized internationally and common practice throughout the world (Bernat, 2009). The “bio-philosophical basis”, as Bernat calls it, of brain death is the definition of death as “the irreversible loss of the critical functions of the organism as a whole.” It could also be said as “the irreversible cessation of all clinical functions of the brain” (idem). Although internationally applied and has become common practice, there is some academic discourse from within medical circles about the exact definition of brain death. That is why Bernat’s article is entitled *Contemporary Controversies in the Definition of Death* (idem). This ongoing discussion and technical character of the topic might not only lead to confusion among lay person/relatives but also among hospital staff (i.e. nurses) (for details on the discussion view Bernat’s article) (Bernat, 2009). The topic is mentioned here because it is an important issue in organ donation communication and might also become a barrier in the decision process of relatives, which will be discussed later on. To sum up, even though in medical circles it might pose an issue for discussion, brain death is a worldwide accepted, applied, and used indicator for the end of a patient’s life in hospitals.

From a campaigning perspective, the role of ethics is the most crucial. Communicating organ donation practices to the greater public is only possible because there is a general consensus that it has positive aspects on society (Gallup, 1993). A medical treatment is ethically accepted in society; therefore it is even possible to approach people through campaign messages. The underlying positive assumptions that link organ donation to the virtues of altruism and charity create a large potential to reach people through communication; therefore, effective communication is highly important.

#### **4.2.2 Religion<sup>23</sup>**

Another “institutional” argument often brought forward (especially by lay people) is the role of religion in the organ donation process. Although all major religions support organ donation and transplantation medicine, religion can interestingly still impact the behavioral outcome of donating or not. A couple of researchers examined this phenomenon more closely.

Religion should not be an issue in the decision of organ donation since all major religious leaders declared organ donation to be in line with their existing religious rules (Akgün, Tokalak, & Erdal, 2002; Bacigalupo, Huerta, & Montefusco-Siegmund, 2007; Flores, Perez, Thambo, Valdivieso, & Grupo de Estudios sobre Muerte Encefalica, de las Sociedades Chilenas de Nefrologia y de Trasplante, 2004; Waissmann, 1996). Not only studies in Western, Christian countries, proved this, but also a study published by Akgün from Baskent University, Ankara, Turkey, concluded that “studies performed in various Islamic countries have shown that organ donation during life and after death is well accepted by Muslims” (Akgün et al., 2002).

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<sup>23</sup> For detailed information about which religions support organ donation and which consult the following summary table  
<http://www.donatelife.gov.au/Media/docs/Organ%20donation%20and%20your%20religion-243f32ec-aedf-4f91-8590-d35a6cfae2d8-1.PDF> (Australian Organ and Tissue Authority, 2009)



While the catholic church, under Pius XII, was reluctant about the diagnosis of brain death, Pope John Paul II recognized the medical criteria for death and underlined that if rigorously applied, it does not conflict with “essential elements of a sound anthropology” or canon law (idem). Jewish law also recognizes the ethical value of transplantation medicine. The Islamic code of medical ethics also identifies it, emphasizing that organ donation is a benefit to society as a whole (Bacigalupo et al., 2007; Flores et al., 2004).

Existing research shows that although religious opinion leaders favor organ donation, followers occasionally have doubts about organ donation and the compatibility of their beliefs with organ donation (Morgan & Miller, 2002). Morgan et al. (2002), for instance, could detect some concerns from Christians about having or not having all their body parts (body integrity) at the time of resurrection (idem). Therefore, although almost all religious leaders encourage their members to donate, convincing knowledge about organ donation, being in line with the respective canon law, is needed to decrease insecurity towards organ donation. Morgan et al., and also Cantarovich later on, suggested to include religious leaders in health campaigns, and especially organ donation messaging (Cantarovich, 2005; Morgan & Miller, 2002).

This would make the campaign stronger because even though organ donation is supported by all major religions, survey participants often cite religious views as a reason for not donating (Sander & Miller, 2005). Sander and Miller found that especially African and Hispanics, compared to Caucasian<sup>24</sup> Americans, name religious arguments for not donating, although there are no documented conflicts between organ donation and these cultures (idem). This might be a hint that religious views are a pretext for other underlying reasons to refuse donation that participants do not generally feel comfortable talking about.

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<sup>24</sup> “Caucasian” is the term U.S. researchers, as well as the U.S. census, use in their publications interchangeably for *White* Americans (S. S. Lee, Mountain, & Koenig, 2001; U.S. Census Bureau, 2010).

Some researchers even hypothesized that religious people are more prone to donate than non-religious people. Ryckman studied the hypothesis of Allport (1966) that intrinsic religiosity lead to a higher willingness to donate than extrinsic religiosity <sup>25</sup>. Ryckman however, could not detect any of such a difference whatsoever in his study. He found intrinsic religiosity was unrelated to the willingness to engage in organ donation behavior. However, Ryckman discovered participants classified as living their religion extrinsically, but having a strong social orientation, were more willing to donate than others (Ryckman, van den Borne, & Thornton, 2004). Ryckman's findings, together with the research findings on altruism and pro-social behavior, lead to the assumption that it is rather the social network and altruistic character traits of a person that make them more probable to engage in organ donation or not. This was found more so than being religious or not.

Stephenson's results in 2008 also indicate that religious and subjective norms were not predicting factors of the willingness to donate (Stephenson et al., 2008). However Cantarovich's recommendation, emphasized in his 2005 publication about the attitudes of major religious groups, states that the need to involve religious groups in promoting organ donation behavior might be an important factor to overcome existing barriers of organ donation. It could also promote a positive attitude towards transplantation medicine, even though canon law or the position of the religious leader may not be as clear to all followers (Cantarovich, 2005). Recently, the publication of Oliver et al.'s article about organ donation, transplantation, and religion confirmed the need to address religious issues in patient decisions on organ donation because "religious concerns play a significant role, much more often than clinicians and transplant teams believe" (Oliver, Woywodt, Ahmed, & Saif, 2011).

To conclude, the topic of religion reveals two faces of the same coin. From a canon law perspective, the positions are clear in all major religions. Members of religious

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<sup>25</sup> According to Allport (1967), intrinsic oriented people "consider their religious beliefs as ends in themselves. They live in terms of these beliefs, loving and caring for others", extrinsic oriented people "tend to use their religion for self-serving and ulterior motives, such as comfort and protection, friendship, status, or social support."

groups might not be aware of those positions and use religion as a pretext for underlying concerns that they do not want to talk about or simply do not dare to mention in hospital settings; feeling uncomfortable towards the medical doctors and staff (Oliver et al., 2011). Therefore, including religious and belief leaders in communications about organ donation, as suggested by Cantarovich and Morgan & Miller, should be considered for future campaign/promoting actions (Cantarovich, 2005; Morgan & Miller, 2002).

#### **4.2.3 Politico-Economic Aspects of Organ Donation**

Although commonly considered as an altruistic act and an act of charity, authors from a politico-economic perspective have also discussed organ donation and its related markets. Those reflections, even though existing laws in most countries prohibit a free organ donation market, Switzerland included, are relevant contributions in showing the limited action in the field. They also emphasize the role of communication even more, making people think and, consequently, decide to go with their positive attitude and sign a donor card, for instance.

Also in Switzerland, along with other countries where transplantation medicine is an established treatment for organ failure, organ donation is treated based on altruism in the traditional “gift-of-life” approach. This principle can be found in the Swiss Federal Constitution, as well as in the Swiss transplantation law. Both prohibit organ trafficking or financially remunerated trading. While the market approach for organ donation is unacceptable for the Helvetic Republic, Delmonico et al.’s suggestions (2002) for ethically acceptable compensation possibilities could be discussed from a legal standpoint.

Several authors have thought from an ethical, legal, and economical point of view about turning to an “organ donation market”, from an economic perspective, and leaving the “gift discourse” behind (Barnett, Blair, & Kaserman, 1992; Dickens, 1994; Guttman & Guttman, 1993; Kaserman, 2002; Levine, 2000; Radcliffe-Richards et al., 1998; Stempsey, 2000; Zutlevics, 2001). The mentioned list of authors show it is

always a reoccurring suggestion to meet the continuously increasing organ shortage. Also, Schweda and Schicktanz in their 2009 article about *Public ideas and values concerning the commercialization of organ donation in four European countries*, discussed with eight focus groups the role of European values and ideas in their consideration of financial incentives for organ donation (Schweda & Schicktanz, 2009). The results clearly showed a vast difference for living and cadaveric organ donation. While most participants thought the commercialization of living donation was unacceptable, there were more people willing to consider the commercialization of post mortem donation. However, the latter strongly depended on the relationship of the participants to their own body. For some people, a dead body loses its utility value to the deceased person, thus a market approach seemed to be more justified (idem). Another author who intensively discussed the topic was Obermann. In 1998, he published a whole article similar to the title of this section: "Some politico-economic aspects of organ shortage in transplantation medicine" (Obermann, 1998). In the article, Obermann lays out the different approaches to fill the gap of available organs. A possible approach, from the medical perspective, would be to enlarge the donor pool by allowing for non-heart beating organ donation. Another more societal approach, could be to develop "local" transplantation activity, promoting donation within a specific region and addressing the regional sense of affiliation.

Obermann laid out economic approaches, such as financial incentives, as well (Obermann, 1998). Byrne and Thompson as did so in their 2001 published article entitled *A positive analysis of financial incentives for cadaveric organ donation* (Byrne & Thompson, 2001). From an economic point of view, organ donation as its own "market" could make sense. Obermann also discussed the "interference between (financial) incentives and altruism" (Obermann, 1998). Altogether he stays very skeptical about linking the topic of money to the deceased human body. He comes to the conclusion that "although payment of unrelated living suppliers can theoretically be justified and may have some advantages, the public notions seem to be far too controversial for implementation" (idem).

Other authors focused on finding solutions to ethically acceptable incentives. The research group around Delmonico, which published an article in 2002 about possible solutions, studied these possibilities apart from payment methods (*Ethical incentives — not payment — for organ donation*) (Delmonico et al., 2002). Delmonico et al. discussed solutions to encourage organ donation such as a ceremony awarding a donor medal of honor, reimbursement for funeral expenses, organ exchanges between living donor relatives (those who want to give to their beloved but cannot for medical reasons), paid medical leave from work for (living) organ donation, facilitating access to an organ for people who previously gave one, or donor life insurance in case something happens during the donation surgery (living) (Delmonico et al., 2002). Delmonico's suggestions so far have not been taken into account in public discourse in Switzerland and further legal examination is needed to know whether they would be in line with existing law and the Swiss federal Constitution. So far, in Switzerland, the non-market approach is clearly supported by stakeholders in the field.

#### 4.2.4 Opt-in vs. Opt-Out<sup>26</sup>

There are two common legal frameworks that regulate organ donation in a country: the informed consent system or opt-in, and the presumed consent system or opt-out. Many researchers have tried to evaluate and judge whether one is superior to the other.

Since July 2007, Switzerland's new law clearly establishes an informed consent, thus an opt-in model. Therefore, from the current situation, a switch to presumed consent is not foreseen. The intervention possibilities to increase organ donation behavior are legally limited. They lay in the a) structural and organizational improvement of the procedure and b) in communicating the topic better to the Swiss

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<sup>26</sup> Reminder: in "opt-in" systems, people have to actively agree to organ donation during life time, otherwise their relatives are asked for approval by the hospital staff, in "opt-out" or alternatively called "presumed consent" systems, by default everybody is a potential organ donor unless he/she registers or declares a contrary will.

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population to increase awareness, set a positive frame, and build trust in the medical procedure.

In the early 1990's, researchers were already interested in comparing the performance of opt-in and opt-out systems (Mehlman, 1991; Roels, Vanrenterghem, Waer, Gruwez, & Michielsen, 1990; Spital, 1992). Looking at the Council of Europe map, showing the 2010 donor rates per million of population (see Figure 1, p. 38), one pattern is striking regardless of all research done in the field. Countries with some form of an opt-out system (Belgium, Finland, France, Norway, Austria, Portugal, Spain, and the Czech Republic) all have higher donor rates than opt-in countries (such as Denmark, Germany, Great Britain, The Netherlands, and Switzerland). In Belgium for instance, the total number of available organs increased by 140% when changing from an opt-in to an opt-out system (Roels et al., 1990).

In 1996, Paul Michielsen drew a balance ten years after Belgium's change from an opt-in (informed consent) to an opt-out (presumed consent) system (Michielsen, 1996). Michielsen stressed that the opt-out system respects the will of the deceased person much more than other systems. Any time a potential donor is detected in a Belgian hospital, the medical staff consults the central registry to see whether the person registered his or her will. If not, the deceased person has accepted to be a potential donor by default. According to Michielsen, the opt-out system thereby frees the next-of-kin from having to make a decision and from any responsibility. According to Michielsen, the presumed consent law (opt-out) is not only a relief for relatives, but also for the intensive care unit medical staff. In an informed consent system (opt-in), they have the delicate duty of approaching the relatives in grief to ask for their consent to organ donation. From the patient's view, the new presumed consent (opt-out) laws "responsibility is now put on the doctors". From the doctors perspective, the responsibility is no longer on them, but on the law. Doctors do not feel responsible for the "society" anymore and can focus solely on the care of the patient and the family (Michielsen, 1996).

The previously mentioned article on politico-economic aspects of organ shortage by Obermann, raises the issue of opt-in vs. opt-out systems. In favor of an opt-out

system, Obermann expresses that “if the majority within a society is in favor of organ transplantation (...) it seems appropriate to consider a change of existing rules in order to facilitate organ donation” (Obermann, 1998). Obermann considers it a paradox that the majority of people favor organ donation but do not want to donate themselves. Therefore, he comes to the conclusion that the mandatory state approach is an appropriate one. It (the opt-out system) “gives adequate notion of minority protection and allows individual decision making” (idem).

While other authors also looking at the economic impact and analyzing the actual increase in donation rates strongly favor the default option (Johnson & Goldstein, 2003), some fervently argue in favor of the informed consent (opt-in) system. Clark agreed in 2003 with his article: *To be or not to be a donor: a person's right of informed consent* (Clark, 2003). Clark, contrary to Michielsen and Obermann, is convinced that from an ethical and social perspective, the opt-in system, based on altruism and voluntarism, is the only option that respects the individual's right to decide autonomously (Clark, 2003). In scientific literature, arguments in favor and against both systems were only discussed by a few authors, and came to a conclusion that the literature is more favorable for an informed consent system. Randhawa et al. conducted interviews with representatives from all different stakeholder groups involved in organ donation, such as different religions and minority groups, and showed that in Great Britain, for instance, faith leaders are more supportive for the existing opt-in system. Apparently the interview partners recognized the shortcomings of the current system but still saw room for improvement within the legal setting and were generally against a legislation switch to a presumed consent (opt-out) option (Randhawa, Brocklehurst, Pateman, Kinsella, & Parry, 2010). Even though faith and belief opinion leaders in the UK favor the status quo opt-in system, an “organ donation task force” was called in to examine the possibility of introducing a presumed consent law. This resulted in a first draft of the *Organ Donation (Presumed Consent) Bill of 2009* (Cherkassky, 2010). The decision to do so was justified by statistical and empirical evidence, which does not leave much room for doubt.

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In 2006, Abadie and Gay published the results of their study in the *Journal of Health Economics*, looking at the effect of presumed consent laws in 22 countries over a 10-year period (Abadie & Gay, 2006). Controlling several potential factors affecting organ donation rates in the different countries, Abadie and Gay concluded that the presumed consent legislation “has a positive and sizeable effect on organ donation rates” (idem).

Two years later, another study by Mossialos et al. (2008) examined the effect of organ donation legislation, with evidence from a European survey, on individuals’ willingness to donate their own or their relative’s organs. Mossialos and his research group again confirmed that presumed consent organ donation policy positively affects actual organ donor rates (Mossialos, Costa-Font, & Rudisill, 2008).

From an ethical standpoint, there has recently been an interesting discussion in the *Journal of Medical Ethics* about the claim of “normative consent” by Saunders (Saunders, 2010). Saunders makes the arguable statement that refusing to donate one’s organs is “morally wrong” and therefore considers an opt-out system legitimate. The state authorities take the “morally right” decision instead, allowing the individual to stick with its “morally wrong” decision (Saunders, 2011). At this point it shall not be discussed what is right or wrong, but Saunders brings forward one important element that has been discussed before. This is the problem of not knowing exactly what the deceased person would have wanted. In this respect, his argument seems pertinent that an “opt-out system, ... spares the worries as to what the deceased would actually have wanted” (Saunders, 2010). Criticized by colleagues for his “totalitarian approach”, he again underlined in a vindication of the before mentioned article, published in the same journal in early 2011, that an opt-out system is not “totalitarian” because individuals have the right to opt-out if they wish to do so (Saunders, 2011). Overcoming the polemics of the discussion and considering the fact that all organ donation surveys in the last 20 years revealed that the majority of people are in favor of organ donation and transplantation medicine, there seems to be an underlying consensus about the morality and altruistic character of organ donation.



To sum up, the main tenor of the argumentation, statistical, empirical, and also ethical research favors an opt-out or presumed consent model. The following are always recurring arguments: Firstly, evidence has shown that countries who changed from an opt-in to an opt-out system have increased their donor rates. Secondly, research has shown that overall; countries with opt-out models have higher donor rates than countries with opt-in models. Thirdly, from an ethical standpoint, the opt-out system would respect the will of the deceased patient better (Cherkassky, 2010; Michielsen, 1996; Obermann, 1998). Fourthly, the opt-out system would relieve the medical staff from the burden of feeling responsible for “society” and from approaching the relatives when they are in a state of shock, grief, and emotional stress (Saunders, 2010; Saunders, 2011) And finally, an argument that has been mentioned before, morally. The majority of society is in favor of organ donation, which theoretically neutralizes any reproach of state totalitarianism, especially when looking at the European benchmark. Many countries have shown with their organ donation legislation in that an opt-out system is compatible with modern democracies (Gallup, 1993).

Swiss law foresees an informed consent approach. Since there is no central registry where people can sign up for or against organ donation, the only way to commit to organ donation behavior consists of two possibilities: either by signing the organ donor card, or by communicating their wish to their next-of-kin, or both. Since communication within the family is more difficult than it sounds (topic discussed in a later section), the donor card plays a decisive role in the donation process. Some researchers tried to explore the role of the donor card, which will be laid out in the following section.

#### **4.2.5 The Role of the Donor Card**

Although research has shown the relevance of the donor card in enhancing family communication and making people commit to a certain behavior (Prottas, 1983; Skumanich & Kintsfather, 1996), in Switzerland, the donor card is found in less than 5% of the cases, Schulz et al. (2011) proved this through interviews with heads of intensive units throughout Switzerland (Schulz et al., 2011). However, the fact that explantation might not take place without family consent, even if the donor card is reported (Schulz et al. 2011), gives the donor card a specific role, to enhance family communication, which showed to be most crucial in the final decision moment.

Signing a donor card is a commitment that proves a person thought about the topic and made up his/her mind of their own will. If this eventually leads to a discussion with the family will be analyzed in a separate analysis from this monograph.

The role of the donor card is not to act as a last will and thus testament, but much more as a “vehicle” of communication and to push people to think about the topic. The idea is not new at all and has already been expressed in the early 1980’s by Jeffrey Prottas. He stated that “the most concrete and perhaps productive aim ought to be to motivate people to express their wishes to their families. Indeed, the major argument for donor cards rests on this and not on their status as wills” (Prottas, 1983). Thirteen years later, Skumanich and Kintsfather (1996) were examining an article on the persuasive effects of promoting the donor card and came to the conclusion that “due to the present critical shortage of donor organs available for transplantation, effective communication strategies are necessary to heighten public commitment to donation. The promotion of organ donor card-signing may be a successful vehicle in the achievement of this goal” (Skumanich & Kintsfather, 1996). Skumanich and Kintsfather emphasize the pivotal role of the donor card and argue that signing a donor card promotes discussion as well as awareness within the family. The donor card requires the signature of two witnesses, preferably from the family members (*idem*). In Switzerland however, the donor card does not require signatures of any family member, although it allows for indication of a person of trust. This is one who decides on the matter donation after death.

Having the donor card signed by two family members, as suggested in Skumanich and Kintsfather's article (*idem*), seems to be an efficient way to enhance family discussion, which – as discussed before – is so crucial in the final moment of decision.

Morgan and Miller (2001) however, stayed skeptical in respect to the assumption of Skumanich and Kintsfather, saying that “simply signing a donor card will stimulate family discussion” (Morgan & Miller, 2001). In their sample, of the 40% of respondents who signed a donor card, 86.5% also had discussed the topic with family members (*idem*). This confirms the claim that the donor card serves as vehicle for communication about and for donation.

#### **4.2.6 Estimating the Number of Potential Donors**

To identify possible points of intervention, other than legal issues that are difficult to change, some researchers were interested in the institutional framework of organ donation to detect possibilities for improvement and eventually increase the number of available organs. An institutional approach to analyze the scarcity of sources of available organs would have to be a detailed analysis of the hospital records.

To estimate the possible effect of communication campaigns and persuasion, several researches have been conducted to estimate the potentiality of increasing donors by analyzing intensive care unit records from the past. They would then be used to identify how many potential donors have been lost and why (Miranda, Fernandez Lucas, & Matesanz, 1997; Ohm, Brase, Meyer-Moldenhauer, & Wagner, 2001; Sheehy et al., 2003).

Miranda, Fernandez, & Matesanz, in 1997, stated that there is a need to run precise retrospective analysis for each hospital separately to locate possible problems and detect local potential to improve the structural environment for organ donation. Miranda et al. detected that there are important differences between hospitals, in respect to minimal standards in the organ donation procedure. This happens among different hospitals within Spain and in the US. As shown by Gold's model of

intervention possibilities from the staff's side (Figure 6), the first stage in which potential donors get "lost" is when diagnosing a patient's brain death and considering him as a potential donor. Miranda et al. therefore called for a better donor detection program to increase available organs (Miranda et al., 1997).

A similar study was conducted by Ohm, Brase, Meyer-Moldenhauer & Wagner in northern Germany in 2001. In 1998, they analyzed the medical records of deceased patients from 16 different intensive care units in the Hamburg region for their eligibility to organ explantation. As a result, Ohm et al. detected 51 potential organ donors who could have provided 70 more organs if the detection procedure was improved; meaning an increase of transplanted organs of 134% (Ohm et al., 2001).

A third example comes from Sheehy et al. (2003) whose ambition was to estimate the number of potential organ donors in the United States. Sheehy and her research group studied the composition of the national brain-dead donor pool during a three-year period. They searched for reasons for organ donor refusals and eventually suggested ways to increase the organ donation rate in the United States. For Sheehy's group, the lack of donors was more important than the detection problem noticed earlier by Miranda or Ohm. However, Sheehy's group came to the conclusion that the main reason for the lack of donors, was a lack of consent to request the deceased one's organs from family members. Furthermore, they noticed that potential and actual donors are more concentrated in larger hospitals. Therefore, especially in the large-scale hospitals, the process of obtaining consent from family members to increase the number of recovered organs needs to improve (Sheehy et al., 2003). Still, Sheehy et al. come to the conclusion that the performance, in term of organ donation of each hospital, should be evaluated through a comparison of the number of actual donors to potential donors. This would allow an intervention targeted at the specific hospitals in terms of better detection and finalization of potential donation. Results could also be used to improve campaign planning and other public interventions. They could be on a structural, educational/training level for hospital staff, or for the hospital's internal communication initiative to promote a positive attitude towards organ donation among the hospital staff.

#### **4.2.7 The Role of the Hospital Staff (Intensive Care Unit)**

The role of the hospital staff under an informed consent or opt-in legal framework is obvious: it is the hospital staff's duty to ask the next-of-kin for their consent for organ donation of a deceased patient. Thus, the role of hospital staff in the decision process for or against organ donation has been researched and discussed thoroughly for a long time. Jasper, for instance, wrote an articles in the early 1990's titled: *Organ donation terminology: Are we communicating life or death* (Jasper, Harris, Lee, & Miller, 1991). In it, Jasper underlines the particular importance of making technical terms understandable, such as brain dead or life support. It is important in the communication process between medical professionals and family members of a deceased patient, showing in an experimental simulation that misunderstandings occur often in conversations between the two parties (idem).

Lopez-Navidad, Domingo, and Caballero (1997) went so far as to state that "the loss of potential organ donors is not usually due to the laws regulating the process or to the population's attitudes in different countries... [but the] main problem is found within the hospital, that is the organization and qualifications of all those health care workers involved in the organ procurement process" (Lopez-Navidad, Domingo, & Caballero, 1997). In the following years, many of these studies were conducted in different hospital settings, all coming to the same conclusion: the attitude towards organ donation of hospital staff, the internal organization of the hospital, and the training of hospital staff to approach family members of a deceased patient appropriately, all matter in the decision process in favor or against organ donation (Spielman & Verhulst, 1996).

In the late 90's for instance, Linyear & Tartaglia's (1999) article: *Family communication coordination: A program to increase organ donation* discusses the best ways to make an organ donation request. They concluded that the most important elements are the private setting of the conversation and the "decoupling" of functions between the doctor in charge of the patients care and the person who requests the donation, particularly nurses (Linyear & Tartaglia, 1999). Sque, Payne

& Vlachonikolis' (1999). In their article about *Cadaveric donor transplantation: nurses' attitudes, knowledge and behavior*, Sque et al. recognize the crucial role of nurses' awareness, knowledge, and attitude towards organ donation. They found that nurses, especially, occasionally share their ambivalent attitudes towards the topics and have their own fears in regard to the decision about organ donation (Sque, Payne, & Vlachonikolis, 1999). A little later, Sanner brings up another aspect that is different from the hospital staff's attitude towards organ donation. Namely that laypersons sometimes have "pseudo-scientific, irrational, magical, and false ideas" about the body and death and do not see the "body-as-machine", as some physician might do. In her article, *Cadaveric donor transplantation: nurses' attitudes, knowledge and behavior*, Sanner speaks of a certain "deafness" of physicians. This "deafness" tends to be towards special and often trivial concerns that relatives might not even dare to mention because they are either ashamed or not able to formulate them (Sanner, 2001). Martinez et al. concluded in their 2001 article, *Organ donation and family decision-making within the Spanish donation system*, that two efforts need to be done to reduce organ shortage: promote a positive attitude towards organ donation and improve training of the health professionals involved (Martinez et al., 2001). Frutos et al. (2002) came back to the "key role" of the family interview with medical staff in their article entitled: *Family refusal in organ donation: Analysis of three patterns*. Frutos et al. came to a similar conclusion as their predecessors, namely that the way physicians approach the family is the "key moment" in the decision process for or against donation (Frutos, Ruiz, Requena, & Daga, 2002). This conclusion was also confirmed by Brazilian researchers who stated a year later that the knowledge, and especially the positive attitude of hospital staff, are fundamental when communicating information about organ donation (Amaral, Roza, Galvao, Jardim, & Medina-Pestana, 2002). Williams et al. also found this to be true in their 2003 article, *The physician's role in discussing organ donation with families* (Williams et al., 2003).

Blok et al. launched another interesting research in 2004. They investigated the effects of trainings offered by the European Donor Hospital Education Program, on the self-efficacy of hospital staff (nurses and physicians) in approaching relatives to

ask for consent to organ donation of a deceased patient (Blok et al., 2004). Arnold on the other hand, focused on the challenge of explaining brain death and its neurological criteria to family members of a deceased patient. This was a research that was in line with Blok et al. (2004) (Arnold, 2005). Another publication, Sque, Long and Payne's (2005) *Key factors influencing families' decision-making*, also dealt with this area of research. They identified three relevant key issues. The first issue was the training of health care professionals in how to approach relatives and what contents need to be discussed. The second was the guarantee for good care and smooth communication processes within the hospital structures, which eventually leads to the third, the need to encourage family discussion about organ donation before approaching the situation where they have to make such an important decision (Sque, Long, & Payne, 2005).

Frutos et al. also published an article in 2005 comparing donating and non-donating families to each other and the reasons for non-donating behavior. Again, they concluded that "family interview is a fundamental step in the process of organ donation" and that other variables related to the patient, relatives, and the attitudes towards organ donation, the hospital staff plays a crucial role in the decision for or against donation (Frutos et al., 2005). Brown et al.'s (2010) main finding in their article about the *Barriers to obtaining family consent for potential organ donors* was that transplantation coordinators approaching family members earlier might increase consent rates (Brown et al., 2010). Saviozzi et al. (2011), published the most recent article, dealing again with the *Refusal to donate after brain death*. They came to the same conclusion as other researchers, that "the presence of experienced, committed health care personnel is necessary to reduce refusal rates and increase the available organ donor pool" (Saviozzi, Bozzi, De Simone, & Filipponi, 2011).

A particularly relevant research in this domain was published in 2006 by Frates, Bohrer & Thomas (Frates, Bohrer, & Thomas, 2006). In their article, published in the *Journal of Health Communication* entitled *Promoting organ donation to Hispanics: The role of the media and medicine*, Frates et al. (2006) suggested measures to promote organ donation behavior among Hispanics. They were similar to the measures suggested by Schulz et al. (2006) to promote organ donation among

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Swiss Italians (Schulz et al., 2006). They namely involved including healthcare professionals in the community in the educational and promotional process, since they are particularly well-positioned to do so (Frates et al., 2006). Actions suggested by Frates et al. included in-service training, including cultural sensitivity, to all levels of staff that have direct patient contact, providing literature about organ donation to physician offices and clinics, and encouraging general practitioners as well as hospital staff, to give information and mention the topic to patients (idem). Another suggestion that Frates et al. made is to include the question about the willingness to donate in the initial health assessment. Here one could incorporate information about the discussion of organ transplantation and donation in the medical records of each patient (Frates et al., 2006). While the latter suggestion is again more of a structural nature, the idea of including general practitioners and other health professionals in the communication process on organ donation also came up when Schulz et al. suggested strategies to promote organ donation among southern Swiss. This idea of involving primary care physicians in the communication process came up again in 2010. Two researchers published an article with the same title: *Primary care physicians' attitudes and practices regarding discussing organ donation with their patients* (Randall, 2010; Thornton, Curtis, & Allen, 2010). Thornton notes that only few primary care physicians report having discussed organ donation with their patients. Hence, involving primary care physicians in the promotion of organ donation seems to be a new and promising path. The intervention possibility, within a fixed legal framework, foresees an opt-in/informed consent model.

Kesselring, Kainz, and Kiss published another original research in 2007 about the *Traumatic memories of relatives regarding brain death, request for organ donation and interactions with professionals in the ICU*. It underlined the role of the hospital staff and the decision process within the hospital from the perspective of the relatives approached for organ donation, including their memories (Kesselring, Kainz, & Kiss, 2007).

Truog, in his 2008 article in the New England Journal of Medicine entitled *Consent for organ donation – balancing conflicting ethical obligations*, described the informed



consent process within the hospital as a well-adjusted discussion of the available options. The consent approach includes thorough counseling for the next-of-kin of a deceased patient. This is so the family feels comfortable in making a reflected decision that is “best for themselves” (Truog, 2008). Truog also discussed the “presumptive approach for organ donation” under which the transplantation coordinators are advised to introduce themselves to the family members as “grief counselors” without disclosing their dual role. This is mainly to console the next-of-kin, but also to promote organ donation behavior as “the right thing to do” (idem).

This approach might be questionable from an ethical point of view. Still, one might argue that it all depends on the situation. As mentioned before, the article by Hoeyer and Jensen (2011) said that there is not one single rational tree to stick to in an intensive care unit, but there are several ways to approach a family. Approaching the family has different possibilities. Their success definitely depends on the attitude of the medical staff toward the topic and the procedure itself.

While so far presented research analyzed intervention points from the hospital’s perspective, the research examined in the following section rather focuses on the family perspective.

#### **4.2.8 The Role of the Family of the Deceased in the Decision Process**

One of the main articles summarizing all the different aspects that play a crucial role in the family, is Radecki & Jaccard's article *Psychological Aspects of Organ Donation: A Critical Review and Synthesis of Individual and Next-of-Kin Donation Decisions*. It was published at the end of the 1990's and summarized all the existing research so far, examining factors influencing family decisions in favor or against organ donation (Radecki & Jaccard, 1997).

The role of the family in the decision process on proceeding with the explantation or not has been shown to be most relevant in recently published research. Even though by law, opt-in or opt-out, the deceased patient's expressed wish prevails, research has shown that to avoid emotional distress in presumed (den Hartogh, 2011) or informed consent (Schulz et al., 2011) systems, the next-of-kin almost always has the final word on explantation (Loewy, 2000). Therefore, stressing the need to discuss the topic of organ donation with family members and to communicate one's will to somebody is the most crucial aspect for organ donation campaign planers.

Discussing the role of the staff in the organ donation process already came close to the topic of the role of the family in their decision whether to proceed or not with an explantation. Since Swiss law, and all other opt-in models, foresees family consent in the case that no donor card is found, the family has the burden of making the final decision. It is most common that the next-of-kin has the last word in the decision, and is a universal feature of the existing systems of post-mortal organ procurement (den Hartogh, 2011). This is hard for the relatives, and as Hartogh emphasizes, it "demands a greater sacrifice from the next of kin than from the donor". In a situation of shock and sorrow over the death of a family member, they have to agree if they want to send their loved one to the operating theatre, even though they do not seem to be dead (den Hartogh, 2011).

The topic of family consent has been well researched in the past decade. Several authors have shown that next to other obstacles, family consent is the key barrier to increasing organ donor rates. Approximately half of the potential donors refuse

consent to donation. This has been a continuously recurring finding over the past decade (Gortmaker et al., 1996; Guadagnoli, McNamara et al., 1999; Robbins et al., 2001). Frutos et al. (2005) summarized it in their article, comparing donating and non-donating families to each other as follows:

“The family interview to determine the wishes of the deceased during life about organ donation is not only a legal requirement, it is also the stage at which most potential donors are lost. Minimizing these losses necessitates awareness of all the variables involved in the family interview” (Frutos et al., 2005).

To explore reasons for refusal rates among family members, in 1998 Burroughs et al., surveyed 225 family members after having been approached for organ donation and whether they regretted their decision or not. Burroughs et al. (1998) could detect three layers of the analysis: participants who donated vs. those who did not, participants who post-hoc were still satisfied with their decision and those who were not, and participants who would donate again and those who would not (Burroughs, Hong, Kappel, & Freedman, 1998). While “formal education, being married, volunteerism, signing donor cards, and having personal conversations about donation” predicted donation, satisfaction with the decision to donate was predicted based on comfort and confidence during the decision-making process, familiarity with the medical center, and the understanding of the concept of brain death (idem). Burrough’s results again stress the importance of the medical staff, as discussed before, but also drew the conclusion that “people should be encouraged not only to sign donor cards, but to have discussions with family about their wishes.” Also that “individuals should be encouraged to seek the help of family and friends during the decision” (idem) since it will be up to them to eventually give consent. For these people, it helps to know what the deceased would have wanted and decided for him/her-self (Guadagnoli, E. 1999). Siminoff and Chillag (1999) formulated their findings more drastically, saying that “the true gift comes from the family” (Siminoff & Chillag, 1999). While the “gift” discourse is intensively discussed as well (i.e. Kuczewski, 2002), Lauritzen et al. also speak of the “tyranny of gift” (Lauritzen, McClure, Smith, & Trew, 2001). However, this shall not be further discussed at this

point. Siminoff et al., two years later, published an article about *Factors influencing families' consent for donation of solid organs for transplantation* (Siminoff, Gordon, Hewlett, & Arnold, 2001). It revealed that family and patient socio-demographic variables especially ethnicity, age, and cause of death, as well as prior knowledge of the patient's wish, play a significant role in the decision process to donate a family members' organs (Siminoff et al., 2001). Family discussions, especially about organ donation, as well as families' closeness to the transplant coordinators were found more likely to donate (idem).

Frutos and fellow researchers also published articles in 2002 and 2005 about family refusals to organ donation in Spain and their reasoning. In the 2002 article, *Family refusal in organ donation: Analysis of three patterns study in Spain*, Frutos et al. stressed that the "the family interview is a key moment in the process of converting a potential donor into a real donor" (Frutos et al., 2002). According to them, there are two decisive elements for a positive decision outcome: the deceased's attitude towards organ donation, if known, and the families' attitude towards organ donation, if the deceased's wish is unknown (idem). Also, Sque et al. (2005) tried to identify ways to ease the decision-making about donation for relatives (Sque et al., 2005). Relevant factors in the decision making process were the knowledge of the deceased patient's wish, the (positive) attitude of the decision makers (the family) towards organ donation, the chance to give meaning to death, and the perceived quality of hospital care (idem). All these elements have already been discussed so far. Families who especially refused to donate the organs of their loved ones reported having the impression that "not enough had been done to save the deceased". Interestingly however, most of the interviewed families did not complain about being approached by hospital staff for organ donation. Overall, families agreed that it was right for health professionals raise the topic (idem).

In 2009, Simpkin, Robertson, Barber and Young published a systematic review about the modifiable factors influencing relatives' decisions to offer organ donation. They were: the information discussed during the request, perceived quality of care of donor, understanding of brain stem death, timing of the request, setting in which

the request was made, and the approach and expertise of the person making the request (Simpkin, Robertson, Barber, & Young, 2009).

In the last three years, a few more studies confirmed these results, proving that attitudes and beliefs of families are critically influencing people's intention to donate, impacting the donor rates significantly (Jones, Reis, & Andrews, 2009). Anker and Feeley, in their 2010 published article about family refusals, traced the problem of family refusals back to four categories: the deceased patient's wish, structural barriers, negative belief systems, and lack of public education (Anker & Feeley, 2010). Interestingly, recent articles also raised the topic of ethical minorities, which consented less often to organ donation than the average general population (Anker & Feeley, 2010; Brown et al., 2010; Jacoby & Jaccard, 2010). Before discussing the role of the ethical background more in detail, research about behavioral patterns that help explain and understand organ donation behavior shall be presented. This will be done before discussing cultural aspects because most of the organ donation studies, including cultural comparisons, rely on findings from research about behavioral patterns.

### **4.3 State of the Art: Research Organ Donation (non-) Behavior**

#### **4.3.1 Organ Donation as Pro-Social Behavior (Altruism and Community Orientation)**

"Altruism in the context of organ donation, is often narrowly defined as an absence of monetary exchange and commercialization...Altruism plays a central role in transplantation and the promotion of organ donation. However, the concept has multiple meanings for transplant physicians" (Fortin, Dion-Labrie, Hebert, & Doucet, 2010).

During the last 20 years of organ donation research, from the research of the early 90's up to today, there is general consensus about altruism impacting organ donation behavior (Cleveland, 1975; Horton & Horton, 1990; Kopfman & Smith,

1996; Morgan & Miller, 2001; Sanner, 1994; Skumanich & Kintsfather, 1996; Stevens, 1998). Skumanich and Kintsfather, or Horton and Horton, related positive attitudes and commitment to organ donation to humanitarian and altruistic values (Mostafa, 2010). While Cleveland (1975) suggested altruism is a major psychological underpinning for organ donation behavior, Belk and Austin (1986) found that materialism was negatively related to the willingness to donate organs after death. This confirms the previous and relates to existing findings that altruism is an important determinant of organ donation behavior (Belk & Austin, 1986; Mostafa, 2010).

Prottas (1983) relates altruism to the moment the decision occurs to engage in organ donation behavior. More specifically, before the procedure occurs but after a beloved died and the family members must make a decision in favor or against organ donation. Motivations for families to approve organ retrieval from a deceased relative can vary. Prottas forenames the following: altruism, realizing the deceased one's wishes, wishing to mitigate death, wishing to "rehabilitate" the dead by a socially approved act and more (Prottas, 1983). His main point is that it is much easier to act according to altruistic reasoning when people are not dealing with sudden death, shock, bereavement, and grief, but rather make the decision before the situation occurs (idem). The main problem with deciding about organ donation is that "people are asked to decide to donate their organs at a time when it is their wish and expectation that they will never have the opportunity" to do so (idem).

Sharp (1995) looks at the topic of altruism from a more anthropological perspective (Sharp, 1995). According to Sharp, donors and recipients are confused by the concept of altruism. Giving one's relative's organs is eventually not as selfless as it seems, most people act with the underlying assumption of grief relief by helping somebody and acting in an altruistic way (idem). While this might create cognitive dissonance for the people making the decision to donate, by signing a donor card during lifetime or giving consent to donation for a deceased relative, generally "altruistic behavior fosters social cohesion and social exchange" (Batten, 1990). Horton and Skumanich also relate organ donation behavior to altruism, positive attitudes, and commitment to donation by linking the behavior to humanitarian

values such as helpfulness or being loving. This came out of Rokeach's value survey identifying 18 of them (Horton & Horton, 1991; Rokeach, 1973; Skumanich & Kintsfather, 1996).

Although families of deceased patients may regard organ donation as a way of giving meaning to death or hoping to get other emotional support and/or satisfaction of the altruistic act of donating (Sharp, 1995; Siminoff & Chillag, 1999), Skumanich and Kintsfather (1996) emphasize that "although altruistic helping may produce feelings of personal satisfaction or relief, personal gain is regarded as a by-product of the behavior rather than an end goal" (Skumanich & Kintsfather, 1996). According to several authors, it is especially the construct of empathic arousal that motivates altruistic behavior (Batson & Powell, 2003; Dovidio, 1984; Skumanich & Kintsfather, 1996). Skumanich and Kintsfather (1996) consider empathy arousal as the "catalyst" for involvement, especially in the context of organ donation. In their model of persuasion effects of the donor card, Skumanich and Kintsfather hypothesize that empathy and involvement "have a direct effect on attitude toward donation, which, in turn, has a direct effect on the behavioral intention to pledge organs by signing a donor card" (Skumanich & Kintsfather, 1996).

Empirically, altruism is a difficult concept to measure in a uniform way since it is comprised of so many different traits and depends on each individual and the situational reasoning. However, people who are considered to be altruistic generally are broad-minded, cheerful, helpful, courageous, truthful (Horton & Horton, 1991; Kopfman & Smith, 1996), caring, compassionate, empathetic (Skumanich & Kintsfather, 1996), and try to ease suffering (Sanner, 1994; Stevens, 1998). These, and other dimensions of altruism, are usually used to study the relationship between altruism and the willingness to donate; as also done by Morgan and Miller (2001) (Morgan & Miller, 2001).

In line with existing research, emphasizing the importance of empathy and involvement, Singh et al. (2002) brought forward an interesting hypothesis: "that information about potential organ recipients would increase the viewer's willingness to donate a next-of-kin's organs and their own willingness to become an organ

donor” (Singh, Katz, Beauchamp, & Hannon, 2002). The results of their experimental intervention supported this hypothesis. The experimental group received information about potential recipients and was more willing to donate a next-of-kin’s organ than the control group (*idem*). Thus, the conclusion drawn was that including information about potential donor recipients might increase the willingness to donate next-of-kin’s organs. In Switzerland, in other opt-in systems as well, donors and recipients are strictly and legally separated. To avoid emotional distress on both sides, donor relatives in Switzerland will never know who got the donated organ, nor will recipients know the family of the donor. Therefore, Singh’s suggestion can only be realized to a certain extent. Public campaigns could include special arguments showing the feelings and situations of potential, imaginary receivers. Giving details directly to the family deciding about organ donation for their recently passed away beloved about the potential organ receiver, is legally excluded.

Recently, Blanca et al. (2007) tried to analyze the psychological profile of organ donors and non-donors by examining variables such as pro-social behavior, constructive thinking, and different dimensions of the big-five personality trait inventory (Blanca, Rando, Frutos, & Lopez-Montiel, 2007). Blanca et al. showed that non-donors indeed have lower scores in pro-social behavior than donors and they tend to show more prejudices. Interestingly, this group also shows lower degrees of empathy and willingness to cooperate. This was just to name a view of the characteristics Blanca et al. results attributed to donors and non-donors (*idem*).

Public campaigns in the United States especially were using the argument of altruism by their “gift discourse” (Shaw, 2010). However, more than eliciting altruism, the gift discourse in public campaigning was used to distinguish the donation from a commercial act and avoid the impression of commoditization of the body. Gift rhetoric is used to transmit a positive image of donation as being a “noble and morally worthy act” (*idem*). Shaw also discussed the suggestion of Sque et al. (2008) of using the term of sacrifice. This opened up a new dimension of understanding the experience of donating and non-donating to the next-of-kin (Shaw, 2010; Sque, Long, Payne, & Allardyce, 2008). Although Shaw sees some



“merit” in this approach by increasing comprehension of the complexity of the decision process, they concluded that the term “sacrifice” would be “too harsh to use publicly and is unlikely to promote positive views of organ donation” (Shaw, 2010).

#### **4.3.2 General Attitude all Over the World**

“Theoretically speaking organ donation is an interesting health communication issue because overall, global attitudes are extremely positive, and yet behavior does not appear to have followed such positive attitudes” (Morgan & Miller, 2002)

This quote is supported heavily by evidence in existing organ donation research. When talking about the attitude of the general public towards organ donation, research results from the last 20-30 years again and again reported one consistent result: when asked about their general opinion on organ donation, participants all over the world mostly favored transplantation medicine (Farsides, 2000). Looking at special professional groups who are relevant in promoting a positive image of organ donation to the public, as for instance journalists, Martinez-Alarcon et al. could confirm the prevailing favorable general opinion towards transplantation medicine (Martinez-Alarcon et al., 2011).

The positive general attitude towards transplantation medicine is one side of the coin. The other side is the number of wide spread myths and believes associated with organ donation in society (Cox, 1986; Kopfman, Smith, Yun, & Hodges, 1998; Lenehan, 1986). These mistakenly accepted myths and fables about organ donation, from a large part of the population, became obstacles to organ donation behavior where an underlying consensus in favor of transplantation medicine existed (Sanner, 1994; Sanner, Hedman, & Tufveson, 1995). This paradox is further described by Sanner, Hedman and Tufveson (1995) who tried to unveil myths in campaigns, focusing on educating people about realities of organ donation medicine and research (Sanner et al., 1995).

Over the years, a lot of research has been done to define the role of knowledge towards organ donation, its impact on attitudes, the role of religion, and the effect of a certain “ick-factor”. A detailed summary about the results of this research will be found in the following sections.

#### **4.3.3 Components Predicting the Intention to Donate and to Sign a Card**

“Information about the relationship of attitudes, values, knowledge, and actual behavior among adults is needed if targeted communication campaigns promoting organ donation are to succeed” (Morgan & Miller, 2002)

A lot of research has been done in this respect that will be laid out in the following, including the variables Morgan & Miller mentioned in the above quote. It was taken from their (2002) article *Communicating About Gifts of Life: The Effect of Knowledge, Attitudes, and Altruism on Behavior and Behavioral Intentions Regarding Organ Donation*.

#### **4.3.4 State of the Art: Predicting the Intention to Donate**

Several researchers have tried to define predictors of the intention to engage in organ donation behavior. It is the most crucial in understanding the underlying processes of people’s decision and to consequently design effect measures to improve the outcome for society (Horton & Horton, 1991; Kopfman & Smith, 1996; Morgan & Miller, 2002).

Radecki & Jaccard (1997) in their *Critical review and synthesis of individual and next-of-kin donation decisions* pointed out the most relevant psychological aspects explaining organ donation behavior. An example is for instance decision confidence, organ donation knowledge, or perceived decision importance (Radecki & Jaccard, 1997).

The most common reasons for not donating organs were, according to a 2008 study by Morgan et al., mistrust in hospital staff, doctors, and the allocation system on one hand, and the belief in a black market for organs on the other. Another highly ranked reason was that the receiving person does not “deserve” the “gift” (Morgan, Harrison, Afifi, Long, & Stephenson, 2008). The most common reasons for donating, according to Morgan et al.’s (2008) findings, were based on religion or the desire to help other people in need (idem) (see section about altruism).

Denvir and Pomerantz (2009) explored the argument of fearing worse treatment or “less-than-optimal-care” by hospital staff more in detail (Denvir & Pomerantz, 2009). Interestingly, especially minority groups in society fear less-than-optimal care. This is related to the organ donation procedure (Morgan et al., 2008; Morgan, Miller, & Arasaratnam, 2003), which most probably is related to the existing myths about organ donation in society (Cox, 1986; Kopfman et al., 1998; Lenehan, 1986) and mistrust in the existing legal system (i.e. Coelho et al., 2007; Frates et al., 2006).

Morgan and Miller titled their 2002 article *Communicating About Gifts of Life: The Effect of Knowledge, Attitudes, and Altruism on Behavior and Behavioral Intentions Regarding Organ Donation* (Morgan & Miller, 2002). In the following sections, existing literature about the role of attitude and religion will be reviewed. Finally, the “ick-factor” and the difficulty of the topic of death, related with the topic of organ donation, will be discussed. As Sanner discussed in her 2001 article, these topics’ relevance are most probably underestimated since they conclude irrational arguments (Sanner, 2001).

#### 4.3.4.1 *Attitude*

West & Turner define attitude as “the manner in which an actor positions himself or herself relative to others” (West & Turner, 2007). One of the most famous and quoted publications on attitudes was from Ajzen & Fishbein in 1980 about *Understanding Attitudes and Predicting Social Behavior* (Ajzen & Fishbein, 1980). Fiske & Taylor, a couple of years later in 1984, even emphasized that attitudes have always been accorded “star status in social explanations of human behavior by lay people and professionals alike” (Fiske & Taylor, 1984). Attitude is a crucial element in most health behavioral theories: in the Theory of Reasoned Action, the Theory of Planned Behavior, or the Integrated Behavioral Model. Here *attitude* is a decisive factor in predicting behavioral outcome (Glanz, Rimer, & Viswanath, 2008).

Also, attitudes towards organ donation have been studied for a long time in psychology and social sciences (Farsides, 2000). Attitudes are mostly studied together with the influence of knowledge (next section) (i.e. Albright et al., 2005) and how they are linked to behavior (i.e. signed cards) or behavioral willingness (i.e. intent to sign card) (Horton & Horton, 1991; Horton & Horton, 1990; Horton, 1991; Kopfman & Smith, 1996; Morgan & Miller, 2001; Smith, Kopfman, Massi Lindsey, Yoo, & Morrison, 2004).

An especially interesting article about attitudes in organ donation behavior is by Sanner, published in *Social Science & Medicine* in 2001 with the title *Exchanging spare parts or becoming a new person? People's attitudes toward receiving and donating organs* (Sanner, 2001). In this study, Sanner studies the public's feelings about donating organs on one hand and about receiving organs on the other. Sanner found seven typical attitudes, summarized in the following: (1) the willingness to receive and to give, (2) willingness to receive but not to give, (3) willingness neither to receive nor to give: organ donation is against nature (we try to do things we shouldn't), (4) willingness neither to receive nor to give: influencing organ (change of attitude with organ from somebody else), (5) willingness neither to receive nor to give: reincarnated body (views on reincarnation and direct resurrection of the earthly body), (6) mixed feelings initially to receive, willingness to

give preferably to family members, (7) the body image or the feeling of uncertainty concerning the perception of the body image if a transplantation was performed (a plastic thing would feel unnatural). Out of this, one can differentiate two concepts of the body: for some it is like a machine and thus exchanging parts seems natural. Others think that the extrinsic organs would influence the new hosting body (Sanner, 2001).

The most common conclusion in studies about organ donation attitude is that knowledge is correlated to a positive attitude towards organ donation. This relationship is mostly presented as a causal relationship although a positive attitude could predict the same interest in the topic and consequently lead to higher knowledge scores. Still, mainstream organ donation attitude research confirms that knowledge predicts a positive attitude towards organ donation and organ donation behavior. The 2001 study of Gross et al. among Swiss Italian military recruits also found these results (Gross, Martinoli, Spagnoli, Badia, & Malacrida, 2001). The survey was conducted over a 10-year period to observe changes in attitude over time; that eventually did not occur. This finding is in line with the stability of the net number of donated organs in Switzerland between 2001 and 2011 (see Figure 2). While 61% of young Swiss soldiers would donate their organs in case of brain death, 13% said they would refuse and 26% had not made up their mind yet. When asked what they would decide for a deceased relative, half of the participants said they would agree to explantation. The fact that 80% of the participants said they felt they were not well informed, confirms existing research about the relationship between knowledge and attitude towards organ donation (Gross et al., 2001; Jacob Arriola, Robinson, Perryman, & Thompson, 2008).

#### **4.3.4.2 Knowledge**

Horton & Horton in the early 90's studied the role of knowledge in college students to predict organ donation behavior in more detail (Horton & Horton, 1990). Horton and Horton could relate knowledge to having signed a donor card, attitudes toward organ donation, and the willingness to donate the own or a relative's organs (idem). One year later, the two researchers again published an article about intervening factors in the decision on organ donation. By testing two different models, Horton and Horton could relate the fact that having a donor card one obtained certain values and factual knowledge about organ donation, including attitude and willingness constructs. In a second step, the researchers extended the model by the variables attitude towards death, prior blood donation, and age of the participant (Horton & Horton, 1991).

Also, Radecki and Jaccard in their organ donation literature review in 1997, came to the conclusion, that overall, studies show homogeneously that "consent decisions are primarily influenced by prior knowledge of the deceased individual's wishes" (Radecki & Jaccard, 1997). As already stressed in the previous section there is one main tenor on organ donation research all over the world:

*Knowledge is related to attitude toward donation as well as to proxy measures for intention to donate* (DeJong et al., 1998; Ford & Smith, 1991; Horton & Horton, 1991; Horton & Horton, 1990; Jacob Arriola et al., 2008; Morgan & Miller, 2002; Radecki & Jaccard, 1997; Sanner, 1994; Weber, Martin, & Corrigan, 2006).

Misinformation about organ donation or the previously mentioned existing myths are especially crucial barriers to an individual's decision making about donating organs or not. In particular, non-donors were most confused on the definition of brain death, religious standpoints in regard to organ donation, ethical concerns, and the financial burden responsibility, thus a lack of factual knowledge (Horton & Horton, 1990; Sanner, 1994; Morgan & Miller, 2002, Weber, Martin, & Corrigan, 2006). Schulz et al. (2006) also found that knowledge significantly predicted organ donation behavior. Interestingly, this was only true for one of the samples: Swiss Germans but not for Swiss Italians (Schulz et al., 2006). Other researchers recently expressed an overall

doubt about the 'predictive role' of knowledge (Brug, van Vugt, van den Borne, Brouwers, & van Hooff, 2000; Morgan, Miller, & Arasaratnam, 2002; Morgan & Miller, 2002; Weber et al., 2006).

In 2008, Morgan et al. looked at the rationality of the organ donation decision and whether the latter are guided by facts or rather emotions/feelings (Morgan, Stephenson, Harrison, Afifi, & Long, 2008). Morgan et al. had a sample at their disposal, counting 4,426 participants. Contrary to their previous study in 2002 where they showed significant knowledge differences between donors and non-donors (Morgan & Miller, 2002), the 2008 researchers showed that "cognitive-based factors", such as knowledge about the donation procedure, were significantly less impacting on the decision than "non-cognitive variables such as the desire to maintain bodily integrity". It was also thought that signing a donor card might "jinx" the owner of the donor card or even risk minor medical treatment (Morgan, Stephenson et al., 2008).

Interestingly, Morgan and Miller were neither the first nor the only researchers who claimed a slight doubt on the effectiveness in terms of knowledge on the willingness to donate. In 2000, Brug et al. studied *Predictors of willingness to register as an organ donor among Dutch adolescents*. Contrary to existing research, they were not able to report a significant relationship between knowledge about organ donation and the willingness to register (Brug et al., 2000). Neither did Weber et al. in 2006 who claimed extremely low effect sizes in previous research, supporting the idea that knowledge is linked to consent to organ donation (Weber et al., 2006). Weber also refers to the Morgan and Miller study (Morgan & Miller, 2002), mentioned before, underlining that even though significant, the effect of the knowledge variable accounted only for less than 3% of the variance in the outcome variable intention to sign a donor card (idem).

These results support the introductory skepticism about the causal direction of the relationship between knowledge and attitude. This argument becomes particularly relevant when looking at the results of the here presented study, where the lack of an effect for knowledge was striking.

#### **4.3.4.3 *The “Ick” Factor and the Challenge to Deal with the Topic of Death***

The topic of organ donation is not easy to approach: death is a prerequisite of organ transplantation (Bredehorn, Langer, Eichhorst, Bormke, & Wachsmuth, 2002). Additionally, organ donation in most countries where organ trafficking or commoditizing is prohibited is considered an altruistic behavior. It does not benefit or reward the behaving person him or herself, because “altruistic” behavior comes from the dead. The topic of death is a very delicate issue for most people in Western societies. Social denial of death is still avoided in present society (idem). Organ donation, and thus death, are typically considered threatening topics related to anxiety (Kopfman et al., 1998), the fear of the end-of-life, and the insecure question about the “what’s next” (Horton & Horton, 1990). Already in 1983, Prottas tried to capture why marketing organ donation was so particularly challenging (Prottas, 1983). In his article he notes that the topic of death is almost a taboo and reactions to the word were usually very strong. Getting young healthy people to talk and think about death is especially a challenge (Prottas, 1983). Although empirically, young people are the most in favor to organ donation (maybe also because death is so far away from their imagination, that being in favor to organ donation is easier). Prottas found out that organ donation and the related topic of death were such sensitive issues that organ donation campaigns completely avoided mentioning the word “death”. This was because its primary effect evoked fear, which was contrary to the wish of transferring a positive image of transplantation medicine. Campaigners preferably want to evoke positive thoughts and outcomes of their position, and push people to reflect on their own death. Additionally, to the sensitive issue of the topic of death, Prottas lays out another challenge in communicating the necessity of making a decision to the population: the spatial distance. “People are asked to decide to donate their organs at a time when it is their wish and expectation that they will never have the opportunity” (Prottas, 1983).

From the physicians and hospital staffs’ viewpoint, it is difficult to convey the message of death and at the same time ask for organ donation consent (Bredehorn et al., 2002). Overall, whether it is from the patient or the hospital staff’s perspective, it is well acknowledged among researchers that the topic of organ donation and the



related death make people feel uncomfortable (Weber et al., 2006). This was a phenomena or rather triviality which very convincingly helps in understanding why people avoid thinking and discussing organ donation, but must eventually “make up their mind” about a decision to donate or not after they die.

A most recently published article from Kirshbaum, with the revealing title *Talking about death and dying: must we really?*, studies the willingness of the British public and health care staff to talk about death and dying. They observed an impressively strong avoidance behavior between both groups. Such behavior impedes effective decision-making, effective coping, preparation for death, and organ donation behavior (Kirshbaum, 2011).

In addition to the fear of death and the anxiety level the topic evokes in many people, a certain “ick-factor” towards the topic come into play and generates ambiguous and wrong fantasies in people’s mind (Sherman, Sherman, Smith, & Rickert-Wilbur, 2001). Sherman et al. studied the disgust sensitivity and attitudes toward organ donation among African-American college students (2001). Sherman found that the higher participants rated on disgust sensitivity, the less positive was their attitude towards organ donation and the lower their intention was to engage in organ donation behavior; such as signing a card or communicating their wish to the family (idem).

Also, O’Carroll et al. identified the so-called “ick-factor”, a fundamental reaction of disgust towards the topic and related imaginations. This was a crucial emotional barrier to organ donation behavior (O’Carroll, Foster, McGeechan, Sandford, & Ferguson, 2011). In O’Carroll’s study, recently published in *Health Psychology*, the “ick-factor” was the only variable that could significantly distinguish donors from non-donors. Traditional rational-cognitive variables such as knowledge, attitude, and subjective norm failed to do so. This was a finding that was most interesting in terms of public health measures and the organ donation campaign. Health campaign planners have to take this strongly into consideration. Negative affect attitudes are crucial barriers to organ donation behavior (idem) and it might be worth it to address

them and go beyond the traditional “informative” approach to increase factual knowledge among the population.

#### **4.4 The Dependent Variables in Empirical Research Studying Organ Donation Behavior Outcome**

##### **4.4.1 The Intention to Donate**

Almost all existing studies in the field of organ donation studied the intention to donate posthumously as one possible outcome measure (Feeley & Servoss, 2005). Additionally, as already mentioned, several attitude items were assessed to find possible proxies for organ donation behavior. Horton & Horton (Horton & Horton, 1991), Kopfman & Smith (Kopfman & Smith, 1996) or Morgan & Miller (Morgan & Miller, 2001) also did this research. Others studied the *influence of prior thought and intent on the memorability and persuasiveness of organ donation message strategies* (Smith, Morrison, Kopfman, & Ford, 1994).

In 1996 Skumanich and Kintsfather designed a causal model of persuasion effects based on the elaboration likelihood model of Petty and Cacioppo (Petty & Cacioppo, 1986). They wanted to detect evidence of the motivation to sign a donor card, after having read a certain message type. Signing a donor card was a major outcome variable in their model since it concluded the intention to donate with a clear written commitment (Skumanich & Kintsfather, 1996).

In her 1996 article, Kopfman also studied the intent to donate and the differences between people who are in favor of organ donation and high intent to donate but did not decided to commit, by signing a donor card for instance (Kopfman & Smith, 1996).

Other studies also examined reasons for people to sign donor cards, eventually identifying points of intervention for future campaigns. For instance, Dundes and Streiff also did so in their 1999 article about the crisis in organ donation (Dundes &

Streiff, 1999), Radecki and Jaccard (Radecki & Jaccard, 1997; Radecki & Jaccard, 1999) and also the earlier study of Horton & Horton Horton (Horton & Horton, 1991).

The intention to donate is a good indicator of what people might decide for a deceased next-of-kin in the hospital when asked for it by medical staff. Therefore however, it is important to know what the rest of the family members think about the topic, so the wish of the dead patient can be respected. Thus, communicating the intention to donate is important for family members in case the worst-case situation of a (sudden) death occurs on one hand, but on the other hand also a personal commitment to organ donation possibly influences the final decision. Therefore, many research studies also measured the intention to communicate one's own will to family members.

#### **4.4.2 The Intention to Communicate**

There is a plethora of research about the importance of the discussion of organ donation with the relatives and next-of-kin (Burroughs et al., 1998; DeJong et al., 1998; DeJong & Drachman, 1995; Radecki & Jaccard, 1997; Riether & Mahler, 1995; Rosel, Frutos, Blanca, & Ruiz, 1999; Siminoff, Arnold, & Hewlett, 2001; Smith et al., 2004; Smith, Massi Lindsey, Kopfman, Yoo, & Morrison, 2008; Verble & Worth, 2000; Verble et al., 2002).

The importance of the intention to communicate one's wish to donate or not to the family or a person of trust has already partly been discussed before: in the section about the role of the family members in the organ donation process. The Gallup survey, conducted throughout Europe in the beginning of the 1990's, revealed that 93% of survey participants would donate deceased relatives organs if they had expressed their wish to donate during their lifetime. If this wish is unknown, the approval rate would drop from 93% to 47%. Considering the fact that people in general have a positive attitude towards organ donation, the crucial role of talking to the family becomes even more apparent (Smith et al., 2004).

Already ten years ago, Morgan and Miller, as a result of their survey, drew the conclusion that the quality of the discussion between the potential donor and his/her family depends on the ability of each person to address vital issues regarding donation (Morgan & Miller, 2001). Morgan and Millers article, titled *Beyond the organ donor card: The effect of knowledge, attitudes, and values on willingness to communicate about organ donation to family members*, gives a good summary of the relevant factors that make people communicate their wish to relatives or not (Morgan & Miller, 2001).

Jeffres et al. (2008) also studied *Communication as a predictor of willingness to donate one's organs* and found out that while controlling attitude and demographics, people communicating with others about organ donation were generally more willing to donate and generally had a more positive attitude towards organ donation (Jeffres, Carroll, Rubenking, & Amschlinger, 2008). Again, the causal relationship might be questioned: whether people with a positive attitude towards organ donation find it easier to talk about, or whether talking about organ donation increases positive attitudes. The latter interpretation seems a little far-fetched especially considering the literature discussed in the section before about avoidance of difficult topics and the "ick-factor" of organ donation. Even though communicating the difficult topic might also lead to a decrease in negative feelings, which is cause and which is effect, needs to be further examined.

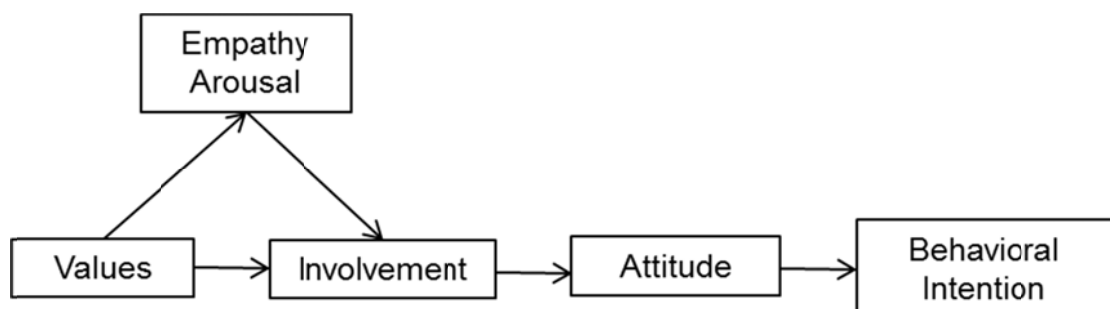
Whatsoever, the relevance of family communication to increase final donor rates is undoubted in scientific literature and engaging family discussion has been explored in numerous ways (Afifi et al., 2006; Atkins, Davis, Holtzman, Durand, & Decker, 2003; Morgan, 2004). The latter represents a particularly big challenge for organ donation campaigners. Morgan discovered in her 2004 study that only half of all people in favor of donating their organs after death were also willing to discuss their thoughts about organ donation with family members (Guadagnoli et al., 1999; Morgan, 2004). These findings were similar among samples with Dutch adolescents (Reubsaet, Brug, van den Borne, & van Hooff, 2001) or Afro-Americans in the United States (Morgan, 2004). This indicated that the ethnic or racial background of participants does not really matter: family discussion about the topic of organ

donation and death is a) difficult and b) the most crucial in increasing donor rates because it forces people to make up their minds. Therefore interventions targeted at the different stages of commitment are needed to make people think about the topic, commit to a certain behavior, and eventually communicate this commitment to their families and friends (Guadagnoli et al., 1999). This was also the conclusion of Smith et al. (2008) after analyzing predictors of engagement in family discussion about organ donation: “practitioners should design messages that argue explicitly for family discussion” (Smith et al., 2008).

## 4.5 Attempts to Apply existing Health Theories to Organ Donation

### 4.5.1 Skumanich & Kintsfather (1996) – Empathy and Involvement

In the middle of the 1990’s, Kintsfather and Skumanich tried to test a causal model of persuasion effects based on the elaboration likelihood model of persuasion effects of Petty and Cacioppo (Petty & Cacioppo, 1986; Skumanich & Kintsfather, 1996). Thus, Skumanich and Kintsfather tested a model including values, empathy arousal, and issue involvement. The model (Figure 8) was found to be significant.



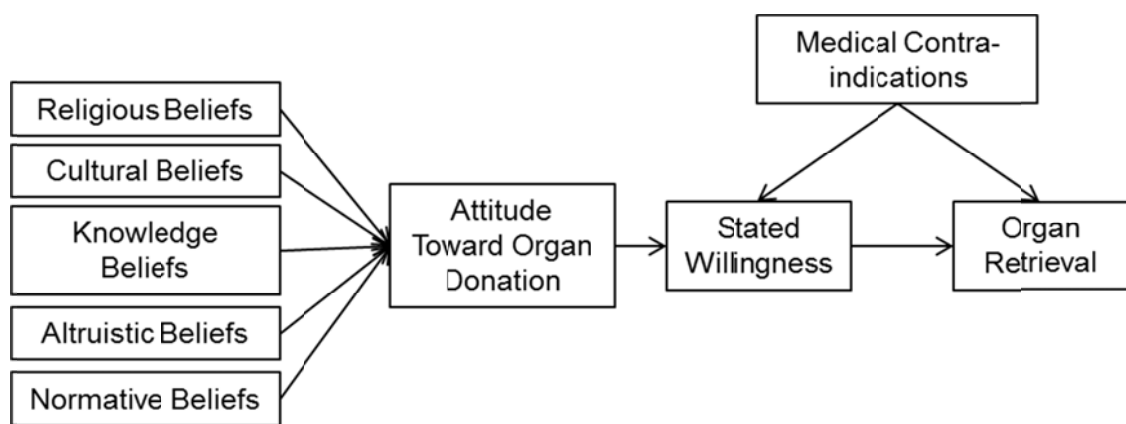
**Figure 8:** Causal model of response to organ donor card appeals after Skumanich & Kintsfather (Skumanich & Kintsfather, 1996).

As already shortly discussed in previous sections, Petty and Cacioppo's elaboration likelihood model (Petty & Cacioppo, 1986) being taken by Skumanich and Kintsfather showed involvement as a central factor in dealing with a certain topic, here organ donation. According to the elaboration likelihood model (ELM), in the process of attitude building, the subjective and intrinsic relationship towards the object/topic plays a crucial role. Depending on the degree of involvement, information is processed differently. People strongly involved in a certain topic evaluate the actual quality of the arguments more. This phenomenon is also called the *central route of persuasion* (Petty & Cacioppo, 1986). According to the assumptions, it is the central processing of arguments that eventually leads to a change in attitude and actual behavior. People with higher involvement are also more informed or interested in looking for additional information on a certain topic. On the contrary, people with low involvement scores perceive information only periphery (*peripheral route*). For this group of people, the quality of arguments counts less than, for instance, attractiveness of the sender of the information. For these people, it is difficult to predict actual behavior. Therefore, Skumanich and Kintsfather reason on the assumption that people who are involved show a more central processing route and thus show a more positive and persistent attitude towards organ donation. Furthermore, they emphasize the role of empathy as a result of knowing somebody somehow involved with organ donation. The fact of knowing somebody in distress is an effective cue of inciting helping behavior and thus altruistic behavior (Skumanich & Kintsfather, 1996). The decision of signing a donor card is considered to be a high involvement situation (Ford & Smith, 1991; Horton & Horton, 1990; Horton, 1991; Petty & Cacioppo, 1986; Skumanich & Kintsfather, 1996). Therefore, to summarize it in Skumanich and Kintsfather's words:

“Arousal of empathy is a result of an encounter with someone in distress- **either in person or via media effort** – is an effective cue for expressing helping behavior; an empathy arousal cue is effective in evoking heightened concern about donation” (Skumanich & Kintsfather, 1996)

#### 4.5.2 Radecki & Jaccard (1997) – Modeling Organ Donation Behavior

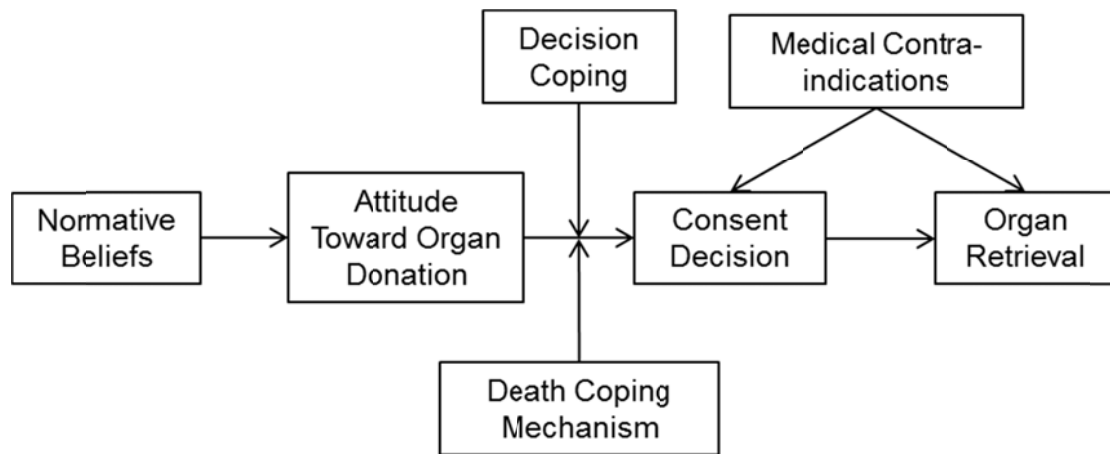
Radecki and Jaccard (1997) proposed three different models to analyze the underlying reasons for the discrepancy between attitudes and intentions, including several social psychological theories and constructs. The first model they suggested concerns the individual's decision to donate organs posthumously and looks at the following:



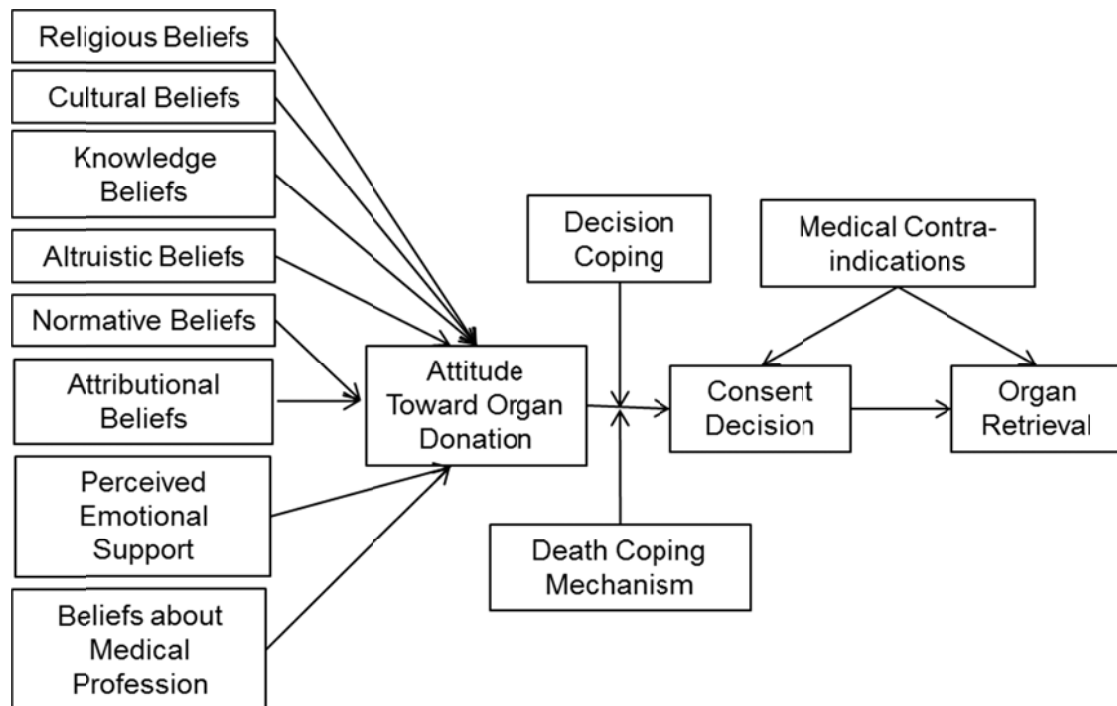
**Figure 9:** *Modeling Individual Decisions to Organ Donation after Death after Radecki & Jaccard (Radecki & Jaccard, 1997).*

The other two models Radecki and Jaccard suggested in their 1997 article were about the family consent decision on organ retrieval of the deceased patient. The two models differ because of the two situations: a) when the deceased's intention to donate or not is known (Figure 10) and b) when the deceased's intention to donate is unknown (Figure 11).

4 Literature Review: From Adapting Health Messages to Messaging Organ Donation  
(in Switzerland)



**Figure 10:** Modeling Next-of-Kin Consent when Decision of the Deceased Patient is Known (Radecki & Jaccard, 1997).



**Figure 11:** Modeling Next-of-Kin Consent when Decision of the Deceased Patient is not Known (Radecki & Jaccard, 1997).



To explain reasons for the discrepancy between attitudes and intentions, Radecki and Jaccard suggested applying various other social psychological constructs, such as cognitive dissonance theory and attribution theory. Furthermore, they claimed “the application of balance theory to willingness to donate and self-perception theory as it impacts the willingness to identify oneself as an organ donor and establish a “donor identity” (Radecki & Jaccard, 1997).

Since none of the before mentioned models will be tested in the following research, they will not be further discussed. For details, the reader should refer to Radecki and Jaccard’s article *Psychological Aspects of Organ Donation: A Critical Review and Synthesis of Individual and Next-of-Kin Donation Decisions* (Radecki & Jaccard, 1997).

Still, the three models give a perfect summary of summarized and laid out literature (mentioned above) although published already five years ago. The only factor recent research added to this model, was the “ick-factor” and its relevance, laid out by O’Carrol et al. (2011). This still needs to be further researched, to what extent it would be an additional factor on the beliefs side, or even overlap with some other factors.

Although Radecki and Jaccard’s models fully cover the discussed models, for reasons of completeness, other suggestions of applying existing health communication research and modeling to explain organ donation behavior will be shortly presented in the following.

#### **4.5.3 Robbins et al. (2001) and the Transtheoretical Model (TTM)**

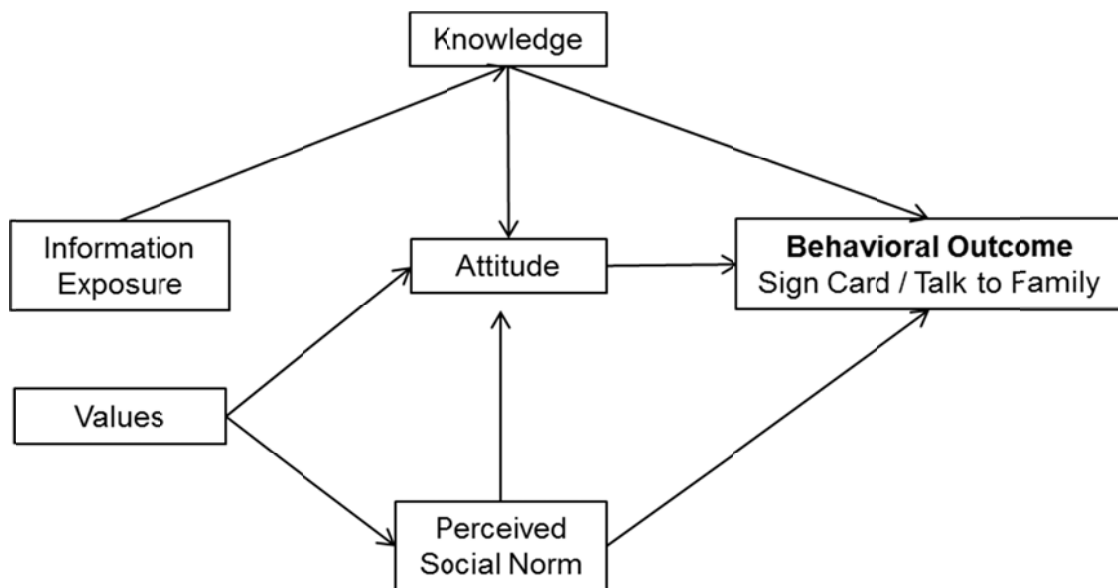
In 2001, Robbins et al. tried to model the “motivational readiness” of family members in their consent to organ donation of a deceased relative (Robbins et al., 2001). The researchers around Robbins chose the Transtheoretical Model (TTM) of behavior change as a theoretical framework, which basically says that behavior changes occur in a well-defined series of stages of change. Those stages are following: the

precontemplation stage (individuals are not ready to change, are unaware of the issue, generally underestimate the “benefits” and overestimate the “costs”), the contemplation stage (individuals start to think about taking action, advantages and disadvantages still being balanced), preparation stage (decided to take action, first small steps to achieve the goal), action (actively engage in behavior change), and maintenance stages (stick to new behavior and avoid relapse) (Prochaska & Velicer, 1997). As noticed by Robbins himself, the decision process for organ donation behavior differs from other health behaviors such as physical activity or smoking. Anyways, Robbins tried to extend the transtheoretical model to also explain cadaveric organ donation “by measuring two key model constructs in a sample of individuals who consented to or refused consent for organ donation of a brain dead family member” (Robbins et al., 2001). Robbins et al. were exclusively examining the precontemplation and the contemplation stages, thus not applying the transtheoretical model. They found out that people in these two stages are often “mis-served”. Robbins et al. claimed that there was an urgent need to match the communication approaches to the different stages of behavior that they are in:

“a stage-matched approach would highlight the key decisional factors in the donation consent process and tailor the intervention to the level readiness present in the family” (Robbins et al., 2001).

#### **4.5.4 Explaining Organ Donation Behavior with the Theory of Reasoned Action (TRA) and the Theory of Planned Behavior (TPB)**

Morgan, Miller and Arasaratnam (2002) developed the Organ Donor Model (ODM), which is an application of the Theory of Reasoned Action (TRA) (Morgan et al., 2002). The ODM combines variables such as attitude toward organ donation, perceived social norms, religious and moral values, sources of information, and general knowledge to predict signing behavior among participants (see Figure 12).



**Figure 12:** *The Organ Donation Model (ODM)* after Morgan, Miller & Arasaratnam (2002)  
(Morgan et al., 2002)

Results of the evaluation of their organ donor worksite project indicated that “participants who were exposed to educational messages about organ donor misconceptions were more likely to indicate that they were organ donors than those in the control condition” (Morgan et al., 2002).

Another attempt at applying the theory of reasoned action was conducted a few years later by Weber, Martin & Corrigan (2007). Apart from illustrating the usefulness of the theory to another health related behavior (Weber, Martin, & Corrigan, 2007), Weber et al. showed that people who signed a donor card had more positive attitudes towards donation and had stronger intentions of signing that card. While these results seem trivial and tautological, they showed the relevance of the opinion of reference groups that were most intriguing, especially for organ donation campaigners.

Just recently, Hyde and White (2010) published an article about whether organ donation communication decisions were reasoned or reactive by testing the applicability of the theory of planned behavior with the organ donor willingness

model. Differently said, the aim of the research was to explore whether people's decisions to donate were reasoned and/or social reaction pathways (Hyde & White, 2010). The researchers used an ambitious structural equation modeling approach. They came to the conclusion that decisions to communicate organ donation decisions were best explained by reasoned pathway, thus the theory of planned behavior turned out to be a parsimonious model. This was especially true for registering their wish to donate organs. The role of moral norm, self-identity, and prototypes were especially crucial in predicting discussion with the next-of-kin about organ donation decisions (idem).

Another attempt to approach organ donation behavior with a different theory was recently published by Kim, Shen & Morgan (2011). They tried to apply situational theory of problem solving (STOPS) to explain organ donation behavior (Kim, Shen, & Morgan, 2011). Kim et al. concluded that the identification of active subpopulations who are motivated to talk about organ donation seek out, select, and disseminate relevant information that would support health communicators to effectively increase awareness of the organ shortage. The STOPS helps to segment the population in meaningful subgroups and help improve strategic planning and practice of health campaigns (idem). The application of the STOPS to future organ donation campaigns in Switzerland might be a feasible solution, in line with existing law and thus be subject of further research.

#### **4.6 State of the Art: The Role of Cultural Differences in Organ Donation Research**

In the previous chapter, several aspects have been laid out, for instance psychosocial constructs that explain organ donation behavior. Those constructs could be categorized as intrinsic cues to organ donation. Others, such as the role of the hospital staff, society, and the next-of-kin could be categorized as extrinsic cues. So far only studies were presented, leaving out cultural or ethical components although some of researchers included them. To avoid confusion and show all different intervention points separately, in this literature review, the cultural

component shall be introduced only at this point. This will eventually lead to the research framework of the following study.

A large amount of research has been done involving cultural components to explain organ donation behavior, or rather to identify intervention possibilities to address certain ethnic groups better. In order to render (health) campaigns more efficient, knowing whether it is worth it or not to target health messages to (micro) culturally diverse groups is most important. However, before further examining the precise research question and the relevant study, a final excursion is needed into health messaging literature. As laid out by many researchers, adapting health and organ donation messages to specific subgroups seems to be an effective strategy to reach the different audiences better and thereby increase donor rates (Albright et al., 2005; Baughn, Auerbach, & Siminoff, 2010; Bresnahan et al., 2007; Cherkassky, 2010; Dodd-McCue & Tartaglia, 2007 et al.; Kopfman & Smith, 1996; Morgan et al., 2008; Morgan, Adams, Seed, & Jones, 2010a; Reddy et al., 2003; Schulz, 2006; Schulz et al., 2006; Siminoff, Lawrence, & Arnold, 2003; Siminoff, Burant, & Ibrahim, 2006; Wong, 2010a; Wong, 2010b; Wong, 2011).

“Health communication strategies are at the core of both mass media campaigns and public health interventions” (Devos-Comby & Salovey, 2002)

Therefore, the following chapter will lay out the possibilities proposed by existing research to adapt health messages, respectively organ donation messages, more efficiently to reach specific target groups.

In the United States, many researchers looked at the different organ donation behavioral patterns among different ethnic groups. Results showed differences among African-Americans, Asian-Americans, and Caucasian-Americans for instance (Guadagnoli, McNamara et al., 1999; Kopfman et al., 2002; Morgan et al., 2008; Morgan & Cannon, 2003; Rubens, 1996; Siminoff et al., 2004; Spigner et al., 2002).

The group around Siminoff, who regularly publishes articles on this topic, attempted several times to explain and understand differences in organ donation behavior among African-Americans (Siminoff et al., 2004; Siminoff & Arnold, 1999; Siminoff et

al., 2003; Siminoff et al., 2006). In their 1999 article, Siminoff et al. tried to capture why African-Americans donate less frequently than Caucasian (White) Americans, although in other aspects of life, African-American people are much more likely than other ethnic groups to volunteer in charitable activities. The main finding was that African-Americans mistrust the system much more than their Caucasian compatriots (Siminoff & Arnold, 1999). This finding could be replicated in Siminoff et al.'s 2003 study, comparing black and white family experiences and perceptions towards organ donation. The results showed that African-Americans showed a lower level of knowledge about their families' wishes, less favorable attitudes towards organ donation in general, and much less trust in the existing health care system. All of these elements were relevant in explaining why African-Americans were less likely to donate than other study participants (Siminoff et al., 2003). The results were relevant a couple of years later in 2006 when Siminoff et al. again confirmed that "African-Americans reported greater mistrust in the equity of the donation system and were more favorable about providing tangible benefits to donor families than white respondents" (Siminoff et al., 2006). Thus, after seven years, no improvement could be observed. This shows a need for public intervention to better target and address minority groups.

Guidry and Walker (1999) assessed cultural sensitivity in printed cancer material and detected that culture was a crucial variable because it affects the retention of transmitted information. To deliver effective health messages, informative material should be targeted toward African-Americans, including cultural sensitive visual messages (Guidry & Walker, 1999; Guadagnoli, McNamara et al., 1999).

Kopfman and fellow researchers (2002), based on the existing findings, showed that African-Americans were less likely to sign a donor card, showed less prior thought, and had weaker intentions to engage in organ donation behavior than Caucasians. They tested cognitive and affective reactions to organ donation messages and compared the two groups, resulting that they do not actually differ in reactions to a statistically based persuasive organ donation message. Although Kopfman et al. failed to detect differences in the perception of differences; they were able to propose suggestions on how to better approach African-Americans with

communication campaigns about organ donation. African-Americans, having less donor cards and lower levels of prior thought about organ donation than Caucasians, showed a slightly higher level of anxiety when reading the organ donation message. This anxiety, was not reflected in unfavorable thoughts or emotions however. Thus, they concluded that organ donation campaigners should focus on triggering favorable thoughts and positive emotions in African-Americans (Kopfman et al., 2002).

Another research group that intensively studied cultural differences in organ donation behavior was the Susan Morgan group. A dozen of articles, including the challenge to address racially/ethically different groups more accurately, were published in the last 10 years that will only briefly and partly be sketched out in the following (Afifi et al., 2006; Morgan, 2004; Morgan et al., 2008; Morgan, Adams, Seed, & Jones, 2010b; Morgan & Cannon, 2003; Morgan, 2006a; Morgan, 2006b; Morgan et al., 2003).

In the first study in 2003, Morgan et al. showed that although African-Americans differ significantly from Caucasian-Americans in attitude and knowledge items, the nature of the relationship between knowledge, attitudes, values, and behavior remained the same between the two groups. As result, they suggested that both groups needed to be addressed in campaigns; increasing knowledge and tackling common myths about transplantation medicine (Morgan et al., 2003). In a second step, they explored ways to close the knowledge gap among African-Americans by using more effective persuasion messages (Morgan & Cannon, 2003). African-Americans were especially concerned about inequitable organ allocation (favoring white and rich patients) and feared a higher medical bill. Interestingly, they were more willing to use the family as a source of information (idem). The latter phenomenon was further explored in a 2004 study about African-American's communication with family members about organ donation (Morgan, 2004). This time, Morgan et al. used the organ donation model laid out before to detect factors leading to family discussion among African-Americans. The 2006 study completed this series of exploring organ donation behavior among African-Americans by giving "specific recommendations for campaigns targeting African-American's willingness

to donate organs”. Again, they pointed out basic differences among Caucasian and African-Americans, this time on other cognitive variables such as uncertainty (Afifi et al., 2006; Morgan, 2006a). To explore the origin of these behavioral differences among ethnic groups, Morgan et al. recently ran a study in the United Kingdom where black Caribbean ethnic subgroups showed much weaker intentions to engage in organ donation behavior. The aim of the study was to detect whether the reluctant organ donation behavior could be traced back to organ donation attitudes and behavior in the country of origin, or whether it is a particular pattern among the ethnic minority groups in Great Britain. The findings revealed that in the country of origin, Barbados, favored cadaveric organ donation, while black Caribbean in southern London showed a high prevalence of negative attitudes. This supported the hypothesis that the negative attitudes towards deceased organ donation among minority groups is more a result of feeling disadvantaged in a high income country than inherent to the culture of origin (Morgan, Adams, Seed, & Jones, 2010a).

The research about African-American’s behavioral and attitudinal patterns, in regard to organ donation, are particularly important. This is because they show a much “greater disparity between the number of antigen-matched donors than other Americans”, meaning that African-American patients show better transplantation results when they receive organs from their own ethnical group (Rice & Tamburlin, 2004).

The amount of existing research on this topic is so vast, that in the following only a few selected studies will be reported. This will provide an idea of the multiplicity of studies that exist in the field.

Jacob et al. in 2005 and 2010 tried to identify attitudinal barriers to organ donation by studying African-American’s support for organ and tissue donation (Arriola, Robinson, Thompson, & Perryman, 2010; Jacob Arriola, Perryman, & Doldren, 2005). Davis et al. (2005) studied the importance of hospital care staff, including cultural components as well. One of their main conclusions was the emphasis of the serious need to improve African-American’s trust in medical care providers (Davis et al., 2005). Hall et al. (2007) additionally included measures of self-efficacy;



comprising constructs from the transtheoretical model, stages of change, and decisional balance theory, relating them to organ donation among an African-American college population (Hall et al., 2007). In the same year, Dodd-McCue and Tartaglia (2007) examined the differences in consent rates among African-American donors and non-donors and other ethical groups. Results were similar to the ones of their predecessors: there is need for more effective culturally sensitive intervention messages, targeted specifically to the particular characteristics and needs of African-Americans (Dodd-McCue & Tartaglia, 2007). Park et al., in 2009 found out that differences did not occur so much among ethnic groups but rather appeared as the strength of specific relationships between attitudes and intention. For instance, some relationships were stronger or weaker among a specific ethnic group (Park, Smith, & Yun, 2009) a finding that was also confirmed in Schulz et al.'s 2006 study. As mentioned previously, Schulz found relationships with different strengths for different language groups in Switzerland (Schulz et al., 2006). Others also tried to incorporate or test health behavioral models to explain the differences in the strength of relationships. Bresnahan et al. (2007) also compared the willingness of Americans, Koreans, and Japanese to register as organ donors using the theory of planned behavior and detecting differences in the effect of knowledge and perceived behavioral control (Bresnahan et al., 2007). Baughn et al., part of the research group around Smith, recently examined the (mis-) matching of transplantation coordinators and ethnic groups in 2010; analyzing empathy and affect between African-American transplantation coordinators and caucasian families and vice versa. While African transplantation coordinators showed more affect with African-American families, white transplantation coordinators observed the opposite. Cultural mistrust between coordinators and families was identified as a crucial element in increasing or decreasing positive attitudes towards organ donation among minority groups (Baughn et al., 2010). Salim et al. were also interested in the topic and studied *Contributing factors of willingness to donate organs in the Hispanic American population* and *The impact of race on organ donation rates in Southern California* (Salim et al., 2010; Salim, Schulman et al., 2010).

Another researcher very interested in this field is Wong. Wong recently published a couple of articles about cultural and religious factors and their impact on organ donation in different ethnic populations (Albright et al., 2005; Wong, 2010a; Wong, 2010b; Wong, 2011). Detected barriers to organ donation among Chinese, Indian, Malaysian, Filipino, or other groups was detected in focus groups, covering mostly topics that have also been researched in the U.S. (i.e. Sheehy et al., 2003), Asia (i.e. Reddy et al., 2003) or Europe (Akgün et al., 2002; i.e. Cherkassky, 2010; Schulz et al., 2006). For instance, religion, cultural myths, misperceptions, fear of disfigurement, fear of surgery, distrust of the medical system, or family approval were all researched. Results showed significant differences in relevance of certain topics to the different ethnic groups. Therefore, Wong also suggests to provide different populations with culture-specific information (Wong, 2010a). Additionally, “organ donation and transplantation organizations should work closely with community and religious organizations to address sociocultural barriers” (Albright et al., 2005; Wong, 2010b; Wong, 2011).

#### **4.7 Messaging Organ Donation**

As the previous chapters have shown, a great number of researchers have shown how to design and adapt health messages for different target audiences (Maibach & Cotton, 1995). Messages can be adapted in different ways: they can be adapted to the stage of behavioral change (Fishbein & Cappella, 2006; Lippke, Schwarzer, Ziegelmann, Scholz, & Schuz, 2010; Maibach & Cotton, 1995), to a specific audience (Austin, 1995; Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003; Slater, 1995), to certain psychological features, such as the use of statistical evidence vs. narratives (Feeley, Marshall, & Reinhart, 2006; Greene & Brinn, 2003; Kopfman et al., 1998), or fear appeals (Hale & Dillard, 1995) or positive affect (Cacioppo & Petty, 1989; Monahan, 1995).

To adapt and respectively target health communication, in this case organ donation communications, it is necessary to first understand the audience. Therefore, the

following sections will give an overview about existing research in audience segmentation, then focus on research about designing more effective of health messages, and finish with existing empirical evidence about messaging organ donation more successfully.

#### **4.7.1 Existing Research about Audience Segmentation**

It is widely accepted that the audience does not adapt to the campaign or information transmitted but the campaigners and health communicators need to adapt to the audience. Researchers in the 1980's knew that audience segmentation was necessary to render public communication efforts more effective. According to Weinreich, "there is no such thing as targeting the general public" (Weinreich, 1999, p. 5). However, intelligent audience segmentation does not necessarily lead to success. There are many other confounding variables, such as resources of the campaign, the quality of implementation, and others that all relate to success. Still, the lack of such careful segmentation is more than likely to hinder public (health) communication or education programs (Slater, 1995).

Slater, in her book's chapter of Maibach's manual about how to design health messages, uses the analogy of comparing the communication of health campaign planners to one within a family or a social network. Slater says that we are all continuously adapting to the communication styles of our family, friends, acquaintances, or colleagues. Whenever the interlocutor changes, people adapt their communication style. The communication style not only changes in content, but also in style, whether one addresses a superior, a spouse, or a salesperson. It also depends on the situational hierarchy, whether the communicating person is in the position of power or in the position of needing something. As Slater notes, "what is appropriate in one case will not, normally, be appropriate in another" (Slater, 1995, p. 186). The degree to which a person is able to adapt to a certain context determines the success rate in terms of achieving one's goals through communication. This is also valid for health campaigns. As previously presented

research shows, targeting health communication to specific audience segments is the most crucial for success.

For health message designers, it is crucial to carefully analyze the different audiences before addressing them. The challenge is knowing to what extent health communicators should segment their audiences and to what extent the message should be adapted. Is it enough to focus on country characteristics or should segmentation be more precise, going down to the ethnic, regional, linguistic, or even a personal level, e.g.?

Some researchers, such as Kreuter et al. (2003), closely examined the limits of culturally appropriate health communication strategies. They discussed different strategies such as targeting and tailoring and whether it would be practicable to make every health promotion program culturally appropriate for every possible subgroup (Kreuter et al., 2003, p. 134).

#### **4.7.1.1 Audience Segmentation in Health Communication – Learning from Marketing**

The challenge for health communicators is to define and decide to what extent audience segmentation is feasible and reasonable. To do this, it is worth looking at marketing literature. Even though health topics are not comparable to yogurt brands, and definitely need to be treated in a different way, the rationale for audience segmentation in functional or operational terms remains applicable. Grunig (1989), in his summary of the criteria for market segmentation, emphasized that “segments must be definable, mutually exclusive, measurable, accessible, pertinent to an organization’s mission, reachable with communication in an affordable way, and large enough to be substantial and to service economically” (Grunig, 1989, p. 203).

Later on, Slater (1995), based on Grunig’s principles, wrote that audience segments must be both, similar antecedent qualities that determine the health behavior in

question – knowledge, concerns, and motivations – and be reachable through similar media organizational or interpersonal channels (Slater, 1995, p. 187).

Most commonly, audience segmentation is done on a demographic level, distinguishing audiences by race, gender, ethnicity, income, or age. Slater stresses that such an approach is only reasonable if these variables are correlated with specific characteristics such as knowledge, constraints, motivations, and other cognitive variables that influence a certain health behavior (Slater, 1995). There is a trap though in demographic segmentation. Two 20-year-old Swiss Italian pupils, both in single parent households of upper middle class, living in a catholic urban community, may be extremely different in their character traits. While one is socially active, engaging in summer jobs and other activities, the other might prefer to hang out with friends, doing nothing and/or even abuse substances. Hence, although demographically “categorized equally”, the two individuals could not be more different one from each other. A solution to avoid this problem of demographic audience segmentation would be to take into account motivation or constraint variables that directly influence health behavior (Slater, 1995). This is particularly important when talking about such a difficult topic as organ donation.

Much research has been done in the field of social and cognitive psychology, as already analyzed in the previous sections. While Ajzen and Fishbein highlighted attitudinal beliefs and perceptions of relevant social norms in their behavioral model (Ajzen & Fishbein, 1980), others further included self-efficacy (Bandura, 1986; Strecher, DeVellis, Becker, & Rosenstock, 1986), salience of and involvement with health behavior (Chaffee & Roser; Grunig & Hunt, 1984), perceived preventability and costs of alternatives (Maiman & Becker), or other constraints regarding behavior (Slater, 1995).

Summing up, marketing and psychology literature strongly emphasizes the need for audience segmentation. Considering the apparent differences in organ donation behavior in different cultural groups, the need to account for cultural differences arises. Before going into detail about research taking cultural elements into account

when communicating health topics, different strategies to address different audience segments shall be shortly summarized.

#### **4.7.1.2 Strategies to Address Different Audience Segments**

Two of the most quoted and empirically researched strategies to address a specific audience segments are tailoring and targeting health messages. *Tailoring* includes all strategies that are *intended to reach one specific person* based on characteristics unique to that person, derived from a previous individual assessment (Kreuter, Farrell, Olevitch, & Brennan, 1999). *Targeting* does not have a mutually agreed upon definition (Kreuter & Skinner, 2000). While Pasick et al. (1996) suggested that the process of targeting is one of identifying a population subgroup for whom an intervention is developed (Pasick, D'Onfrio, & Otero-Sabogal, 1996), Rimal and Adkins (2001) literally spoke of "audience segmentation" and considered the process of targeting as a selection of appropriate channels to best reach a specific target group (Rimal & Adkins, 2001). Yet Kreuter and Skinner defined targeting as the use of "a single intervention approach for a defined population subgroup that takes into account characteristics shared by the subgroup's members" (Kreuter & Skinner, 2000). All of these approaches to the concept of targeting "implicitly assumed that there is sufficient homogeneity within the target population to justify using one common approach to reach all its members" (Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003).

To say it differently, tailoring is adapting (health messages) to individual characteristics while targeting means adapting to the characteristics of a specific group of the population. Therefore, one would tailor to individual needs and target to a specific audience segment. At the same time, Kreuter's definition of targeting makes it clear that to address a specific cultural group of the population with an adequate communication message, the more reasonable it would be to use the *targeting strategy*. This is "given that tailored communication programs are often neither cheap nor easy to build, an approach that matches individuals to generic

materials might maximize the fit of health messages while keeping costs lower” (Kreuter, Oswald, Bull, & Clark, 2000, p. 313).

This becomes even more apparent when communicating to a culturally heterogeneous society. While there is no universal definition of the term *culture*, its related terms have a general agreement that culture is “learned, shared, and transmitted from one generation to the next, and it can be seen in a group’s values, norms, practices, systems of meaning, ways of life, and other social regularities” (Betancourt & Lopez, 1993; Hughes, Seidman, & Williams, 1993; Kreuter et al., 2003; Orlandi, Landers, Weston, & Haley, 1990; Rohner, 1984).

#### **4.7.2 Existing Research: Targeting Health Messages**

Attempts to target messages to specific audiences have been made since the beginning of the 1990’s when Snyder and Rouse (1992) tested HIV messages and linked them to actual and perceived risk of the study participants. They suggested dividing the audience by their actual and by their perceived risk and gave specific recommendations for message design for four different target groups. This was not without emphasizing the need to pretest the messages for their appropriateness in the respective target groups (Snyder & Rouse, 1992).

Campbell et al. (2000) tested tailoring and targeting approaches within a worksite health promotion program to address multiple health behaviors among blue-collar women. Additionally, their aim was to closely examine the relationship between health risks, health behaviors, stages-of-change, and behavior change (Campbell et al., 2000). Others, as for instance Ryan et al. (2001), tried to quantify the effectiveness of the tailoring approach versus the effectiveness of the targeting approach (Ryan, Skinner, Farrell, & Champion, 2001). More studies in that same year studied the effectiveness of targeted interventions such as Schneider et al.’s study who tested the different messages in different cultural contexts. The study detected significant differences, especially among Anglo-Saxon and African-American women (Schneider et al., 2001). Reubsaet et al. (2001) published two

studies about determinants of organ donation behavior among Dutch adolescents and tested the effectiveness of tailored messages to specific characteristics, beliefs, and misconceptions of adolescents (Reubsaet et al., 2001; Reubsaet, van den Borne, Brug, Pruyn, & van Hooff, 2001). There has been a plethora of intervention studies testing tailored health message approaches that cannot all be listed at this point. For a few more examples, Reubsaet and colleagues further researched Dutch adolescents' organ donation attitudes, knowledge, and behaviors a couple of years later and came to a similar conclusion. This was namely that specific health-education messages tailored to students majoring in different disciplines or to people in various occupations increased their willingness to donate (Ryckman, van den Borne, Thornton, & Gold, 2005; R. Ryckman, Gold, Reubsaet, & Borne, 2009). One more example, Bellis et al. (2002), studied the effectiveness of tailored interventions among 41 African-Americans in preventing sexually transmitted diseases and recommended a strategy (Bellis, Grimley, & Alexander, 2002).

Collins and Zoch (2001) focused on the need to target the young, poor, and less educated, and not only via traditional mass media because this way did not always show to be the most efficient information channel to convey information. Instead, there might be other channels that allow pro-social messages to be conveyed to similar audiences (Collins & Zoch, 2001). This is also along the lines with research about the effects of involvement (Skumanich & Horton, 1991; Skumanich & Kintsfather, 1996). Still, Collins and Zoch advise that if mass media has to be used, "it may be necessary to rethink both the content and the intended receivers of such messages" (Collins & Zoch, 2001).

As a consequence, the research showed attitudinal and behavioral differences among ethnic groups in the United States. A couple of studies have been conducted in the last decade to test the effectiveness of targeting promotional health messages to ethnic minorities/groups (i.e. Devlin, Anderson, Hastings, & Macfadyen, 2005; Morgan & Cannon, 2003). Morgan and Cannon, for instance, (2003) tried to target organ donation messages at specific African-American concerns and found it to be an efficient strategy (Morgan & Cannon, 2003). In 2004, Guttman and Salmon related ethical issues in public health communication to eight different topics, among



them tailoring and targeting health messages to specific segments of the population (Guttman & Salmon, 2004), for instance families (Jones et al., 2009). Other researchers proved the effectiveness of targeted health messages recently for the effectiveness of tobacco product labeling (Devlin et al., 2005).

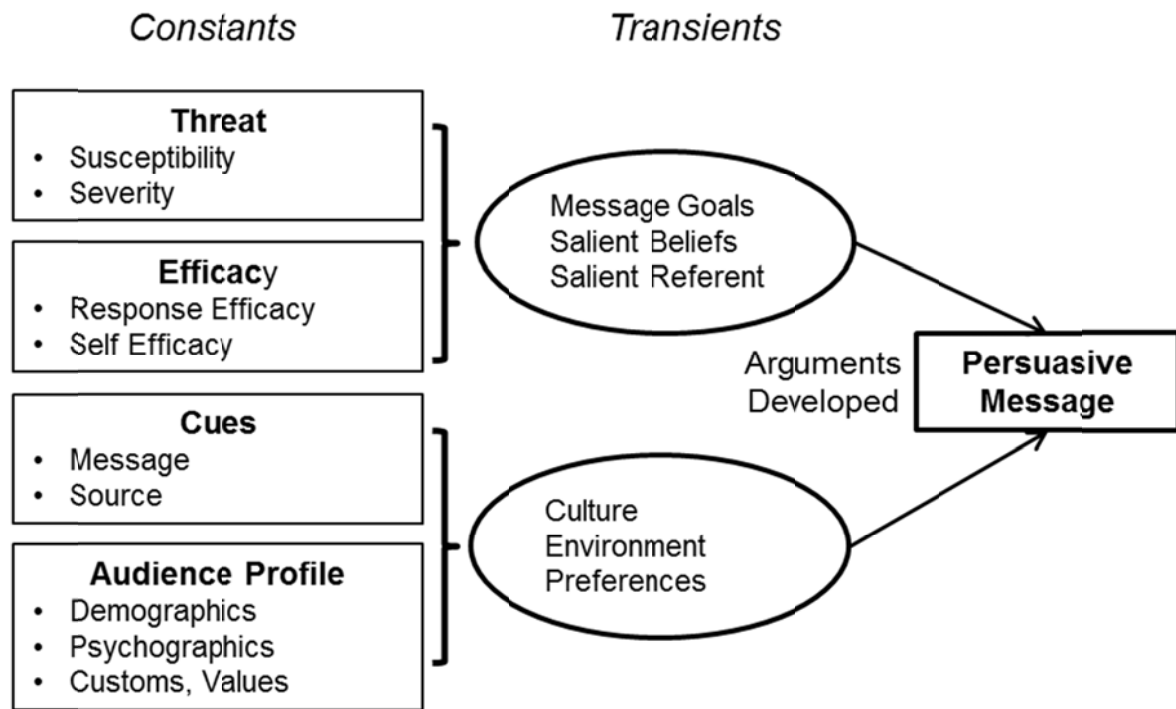
As a last example, Schneider's 2006 article, *Getting the biggest bang for your health education buck – Message framing and reducing health disparities*, summarized the role of health message framing in the general population and minority groups. Furthermore, the article discussed the impact of targeting health messages to group characteristics to increase persuasive messages (Schneider, 2006). The latter finding, together with everything reported before, will play a crucial role in the deduction of the following research hypothesis.

Before doing so, however, another excursus into different practical and empirical attempts to adapt and target messages will be further explored.

#### **4.7.3 State of the Art: Messaging in Health Communication**

##### **4.7.3.1 *The Persuasive Health Message (PHM) Framework***

The persuasive health message framework is a combination of theory of reasoned action (Fishbein & Ajzen, 1975), the elaboration likelihood model (Petty & Cacioppo, 1986), and protection motivation theory (Rogers, 1983). In the PHM, there are two categories of variables that need to be considered before designing a health message: First the group in rectangular boxes in Figure 13 consists of constant variables such as the perceived threat, self-efficacy of the target group, channel and source and traditional audience characteristics such as demographics, psychographics, or values. The second block of variables, classified as "transients", describe the factors that differ from one population to another (Witte, 1995). The so-called transients, or changeable components of the message, can be salient beliefs, salient referents, culture, environment, or message goals (idem). An overview of the PHM as Witte sketched out can be found in Figure 13.



**Figure 13:** *A Framework for Developing Culturally Specific Persuasive Health Messages* (Witte, 1995).

The figure shows that transient variables are divided into two groups. The group that is most relevant for this study is the one that includes culture as variable. Culture, environment, and preferences (lower oval box under *transient*, see Figure 13) are variables used to design a proper audience profile (Witte, 1995). To do so, source and message need to be considered. This is done to know which channels are available (environment) or are preferred (preferences) by a specific group of population (culture). The content of the information needs to be carefully determined, taking into account the audience profile (demographics, psychographics and customs) (idem). The theory of reasoned action, from Fishbein and Ajzen (Fishbein & Ajzen, 1975; M. Fishbein, 1981), lead to the conclusion that “the only way to effectively induce behavior change in a persuasive message is to change the underlying set of salient beliefs that are causing a specific behavior” (Witte, 1995).

Creating an effective persuasive health message after the PHM requires three basic steps. First information about the threat and efficacy or the recommended response must be gathered. Consequently, cultural and environmental characteristics need to be assessed to make an appropriate audience profile and detect relevant cues. Finally, the transient information for each of the constant components is used to design an effective message conveying a specific health behavior (idem).

#### **4.7.3.2 Using “Involvement” or “Empathy” in Health Messages**

One factor that appeared to be most relevant, as well in Petty & Cacioppo's elaboration likelihood model, as in Skumanich & Kintsfather's organ donation model, was the degree of involvement of each individual with a certain topic. Involvement and empathy are crucial elements in predicting organ donation behavior, especially because of the nature of the topic. Organ donation is strongly related to negatively related topics such as illness, death, and unfortunate events (Cacioppo & Petty, 1989; Petty & Cacioppo, 1986; Petty & Cacioppo, 1984; Skumanich & Horton, 1991; Skumanich & Kintsfather, 1996).

Thus involvement and empathy have to be taken into account when designing and targeting health messages to specific (ethnic) groups. They are even more important when dealing with delicate issues such as the death of a relative, and even more for organ donation. It is fact that in most Western countries, organ donation is seen as an altruistic act and an act of charity. This renders the importance of empathy and involvement arousal (as discussed previously) even higher.

Generating empathy arousal can be reached by showing similarities between the recipient of the message and the person (for instance in a media spot or on a poster campaign) transmitting the message (Cialdini, 1988; Duck, 1994; O'Keefe, 1990). In 2001, a research group around Bagozzi found an increase in willingness to donate bone marrow when potential donors believed the recipients would be of their own ethnic background (Bagozzi, Lee, & Van Loo, 2001). This finding also confirmed

early research from the mid-1950's from Hovland et al. (Hovland, Janis, & Kelley, 1953).

An interesting perspective put forward by Schulz et al. (2002) stated that considering the general support for organ donation in populations where donor rates stagnate, mass media campaigns do not seem to have the desired effect. According to the research group around Schulz, "mass media effects can hardly be further increased by campaigns" (Schulz, Gold, von dem Kneesebeck, & Koch, 2002). They emphasize the empirically proved link between involvement and actual behavior, claiming that only an "orchestra of coordinated strategies" will be effective in increasing donor rates on the long run (idem).

While empathy arousal, created by involvement, is one strategy to adapt health messages to different levels of "involved" health communication receivers, another strategy is to evoke positive affect and/or by refuting existing myths about a certain health behavior.

#### **4.7.3.3 *Positive Affect and Refutational Elements in Health Messages***

Raising positive affect is most crucial when communicating organ donation to the general public. Many scholars studied the role of affect in persuasion processes and found this to be true (Forgas, 2009). Already in 1985, McGuire confirmed "affect can play [an] important role in attitude change" (McGuire, 1985). There is a lot of research about the role of positive affect in health messages (Forgas, 2009; Glanz et al., 2008) and refuting common myths to achieve this goal, or rather avoid the namely negative reaction provoked by common myths. Only chosen articles from the vast range of existing research articles will be laid out in this section; chosen upon their relevance to the field of messaging organ donation, that will be further discussed in the next section.

The most relevant publication in this respect was published in 1984 by Winkel, who noted a “lack of effectiveness of positive appeals for donation” (Winkel, 1984). Therefore, he proposed the use of refutational messages.

Refutational messages are meant to refute existing myths about a certain health behavior; for instance in organ donation, the myth that a dead body has to be incinerated after explantation. The expected effect of refuting existing myths is to incorporate positive aspects of the specific health behavior, in this case organ donation. Information that refutes common negative misperceptions about transplantation medicine, and the whole organ donation process, was hypothesized to create a more positive affect than the control group who did not get the particular message (idem). Although Winkel did not find any significant differences between the groups (intervention and control group), the people whose willingness increased, the ones who had to read a message combining affect increased and myth refuting elements scored significantly higher than the control group. Therefore, he concluded that the combination of positive affect and refutational message would be the most effective (Winkel, 1984). Other researchers recently replicated and confirmed those results, combining the two aspects would be most effective in terms of outcome behavior (Ford & Smith, 1991; Skumanich & Horton, 1991).

Skumanich & Horton, as well as Ford & Smith (Ford & Smith, 1991; Skumanich & Horton, 1991), did similar experimental studies in 1991 and concluded that a combination message, including positive and fear-refutational elements, would be most effective. While organ donation research shows rather positive affects for fear-refutational health messages, lots of research has been conducted to assess the effect of actual fear appeals in health messages.

#### **4.7.3.4 *Fear Appeals in Health Messages***

Since the topic of organ donation itself raises uncertainty and negative emotions, because it is related to death (see previous discussions), the use of fear appeals in organ donation campaigning, using common sense, is not appropriate. The aim is to

convince people about the positive aspects of organ donation and tries to refute existing myths (see section before). The worst thing that could happen for transplantation medicine, from a public communication perspective, is negative media coverage, bringing up underlying fears in an otherwise positive organ donation mind setting. However, in this section, existing research about using fear appeals in health messages shall be shortly presented to give a complete picture about research that was done in the field of effective health messaging. This is even though, eventually, the use of fear appeals in organ donation messaging is practically excluded and has not been taken into account neither by organ donation scholars. All organ donation scholars examined were “fear refutational” messages (see section before).

According to Hale and Dillard, fear appeals are persuasive messages predicting harmful or social consequences of failure for respecting a certain health message recommendation (Hale & Dillard, 1995). Positive affect includes, as simple as the words say, all positive and pleasant emotions the message evokes to the receiver of a specific health recommendation (idem). Interestingly, fear appeals have been most commonly used in public communication campaigns. While the contrary is true for commercial advertising which focuses the messages “on the positive side of life” and try to avoid negative emotions related to their product (Batra, 1986; Thorson & Friestad, 1989).

Zajonc (1980) suggested for the first time that “affective judgments may be fairly independent of, and precede in time, the sorts of perceptual and cognitive operations commonly assumed to be the basis of these affective judgments” (Zajonc, 1980). This argumentation would be in line with before mentioned research about the “ick-factor” when processing organ donation. This so far has not been fully researched and needs to be explored further. Along with this argumentation, Monahan (1995) noted that positive affect renders an audience open minded and positively toward an issue or campaign under the motto “we feel, then we think” (Monahan, 1995). This was supported by other researchers, as for instance by Isen (1987), who came to the conclusion that “regardless of whether it is direct or indirect, positive affect has shown to encourage people to recall pleasant things, to

judge things positively, to make faster decisions, to be more benevolent toward others, and to be more compliant” (Isen, 1987). Monahan, in her book chapter titled *Thinking Positively. Using positive affect when designing health messages*, concluded that “positive affect can be used to stress the benefits of healthy behavior, to give individuals a sense of control, and to reduce anxiety or fear” (Monahan, 1995, p. 95). These results will be most relevant for attempts to adapt the organ donation campaign in Switzerland and render it more efficient.

#### **4.7.3.5 Statistical vs. Narrative Evidence**

Another strategy in adapting health messages that has been tested numerous times in the field of (health) communication is the effectiveness of statistical or narrative evidence. This topic is most crucial to the following quasi-experimental study, since it used both statistical and narrative elements during the experimental intervention.

Most studies of narrative versus statistical evidence test for the superiority of one or the other strategy. Before introducing some studies examining the effectiveness of narratives and statistical evidence, both strategies shall be shortly defined for better understanding. Allen et al., in their article comparing the persuasiveness of narrative and statistical evidence using meta-analysis (Allen et al., 2000), gave the following definitions for narrative and statistical evidence based messages. Statistical evidence based messages use quantitative information such as statistical data to support a certain conclusion; such as 90% of Mars citizens would donate their organs, would you? Narrative based messages on the other hand use stories to support a certain conclusion. The story, offering a vivid example of the problem, is presented in a narrative way that supports arguments in favor of a specific health behavior, as of instance organ donation (Allen & Preiss, 1997).

There is no common agreement whether one or the other strategy would be more effective in persuasive health messages. While some researchers, as for instance Green and Brinn (2003), Allen and Preiss (1997), or Kopfman et al. (1998), overall found slightly stronger effects for statistical messages, others such as Taylor and

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Thompson (1982), Reinard (1988), Weber, or Dunlop et al. (2008) suggested narratives being more effective than statistical information (Allen & Preiss, 1997; Dunlop, Wakefield, & Kashima, 2008; Greene & Brinn, 2003; Kopfman et al., 1998; Reinard, 1988; Taylor & Thompson, 1982; Weber et al., 2006).

In statistical messages, the operationalization is the most critical issue, since many covariates may intervene with the outcome: evidence quality, source credibility, quantity, base rate fallacy, etc. (Greene & Brinn, 2003). Interestingly, there are few studies combining statistical and narrative approaches for health messages. This was suggested by Allen et al. (2000), stressing the need “to consider the case where a message combines statistical and narrative evidence to determine if a combination of evidence is more effective than a single form of support” (Allen et al., 2000). It was also said by Green and Brinn (2003) that putting it “in conjunction, they may produce a broader range of effects than either alone” (Greene & Brinn, 2003). An issue that came up a few years before in a study of organ donation messages in the late 1990’s by Kopfman, Smith, Yun, and Hodges (1998) and Reynolds and Reynolds (2002) (Kopfman et al., 1998; Reynolds & Reynolds, 2002).

Overall, there is no controversy that the manner and extent of message processing by recipients matters (Aune & Reynolds, 1994; Petty & Cacioppo, 1984). While there are a few controversies about different forms of message processing (Eagly & Chaiken, 1993; Reynolds & Reynolds, 2002; Stiff, 1986), empirical results have shown that bombarding message receivers with statistics only would distract them from systematically processing presented evidence. This would therefore decrease the effectiveness of a certain health message (Reynolds & Reynolds, 2002).

All of these studies have been done without taking into account cultural variability. However there might be differences in expectations for forms of proof and statistical evidence in different cultural segments that could have an impact on the results of these studies. This has also been claimed by Allen & Preiss themselves in their 1997 publication, suggesting to “consider the impact of cultural variability as a basis for divergence in findings” (Allen & Preiss, 1997).



#### **4.7.4 State of the Art: Messaging Organ Donation**

A part from several studies testing different strategies to adapt health messages to different audiences or stages of changes, there is a couple of research about messaging health done in the specific field of organ donation, as coercively already indicated in the previous sections. In the following section research testing different health messaging strategies especially in the field of organ donation will be laid out. This is the basis upon which the here presented study will be built upon.

Already as early as in 1983, Prottas was looking at the possibility of treating organ donation as any other product being a subject to marketing attempts. According to Prottas organ donation can be considered as a “prestige product” since the utility of one’s organs after death is negligible. Thus, the organ donor is giving away something of no value and thereby gains status (Prottas, 1983). While the element of “gaining status” is questionable, Prottas also affirms that considering the delicate role the topic of death takes in Western societies, the spatial and psychological distance between the decision and the actual occurrence of organ donation, differentiate organ donation from other marketed products and therefore requires special strategies in message design (idem). However, coming back to the prominent role of audience segmentation and the importance of effective health messaging, Prottas considers audience segmentation totally “worthwhile”, seeing “enough salient differences among population groups in terms of attitudes and behavior” (idem).

Kopfmann et al. in the late 1998s explored cognitive and affective reactions to statistical evidence and narrative persuasive messages. The aim of the study was to analyze the origins of differences in persuasiveness for different message types. According to Kopfmann et al.’s results statistical evidence based messages produced more results in terms of all the cognitive reactions (positive and negative thoughts, message credibility, and message), while narratives produced significantly more results for all affective reactions (arousal of positive and negative emotions, anxiety) (Kopfman et al., 1998). Their results show that both statistical and narrative

based messages “can be effective persuasive tools” to communicate organ donation (idem).

These findings failed to be replicated in Feeley et al.’s study (Feeley et al., 2006) blaming Kopfman et al. (1998) for the applied methodology creating a bias in the results favoring the statistical message. In Feeley et al.’s study (2006) “narrative messages were evaluated more positively, seen as more causally relevant, and rated as more credible when compared to the actual messages” (Feeley et al., 2006). Although the study design was similar to the study design of Kopfman et al. findings were significant in the opposite direction than previously hypothesized (idem).

Another interesting article using psychological components to promote organ donation behavior is the one published by Farsides in 2000. Farsides wonders in his article with the title *Winning hearts and minds: Using psychology to promote voluntary organ donation* whether it is not an antagonism that in general people are favorable towards organ donation and research findings that suggest decisions about organ donation behavior are more affected by perceived negative than by perceived positive characteristics (Cacioppo & Gardner, 1993; Horton & Horton, 1990; Parisi & Katz, 1986; Skowronski, 1997). Farsides, in his research about psychological aspects in organ donation found that persuasion messages addressing concerns about negative aspects of organ donation seem to be more effective than messages focusing on the positive aspects only (Birkimer et al., 1994; Farsides, 2000; Ford & Smith, 1991) .

#### **4.7.5 State of the Art: Organ Donation Promotion and Campaigns**

##### **4.7.5.1 *Empirical Evidence from Organ Donation Campaigns***

Based on the vast amount of existing research in the field, many researchers tried to launch test campaigns for organ donation and assess their effectiveness. In the following, those attempts to test organ donation campaigns and the consequently drawn conclusions will be shortly reviewed. They provide useful ground for this research and open up possibilities to develop future organ donation campaigns.

Sanner et al. (1994 and 1995) for instance, in their previously mentioned study, conducted an organ donation awareness campaign that included mass media advertisement as well as interpersonal interventions. As a result, many people who initially were reluctant to signing an organ donor card eventually accepted and did so. However they only did so after light had been shed on common misperceptions (Sanner, 1994; Sanner et al., 1995).

Kopfman and Smith (1996) described, as a result of their study about understanding the audience in health communication, one preliminary phase of a possible organ donation campaign in which three target audiences were identified. Kopfman and Smith found out that low intent participants also had lower knowledge scores, were not very altruistic, and had high levels of anxiety towards signing a donor card. As a result, the two researchers concluded that “effective design of health campaigns depends on an accurate and through audience analysis”, and in consequence, created an appropriate targeting strategy (Kopfman & Smith, 1996). Apart from organ donation campaign studies, alternative approaches were empirically tested. Some examples are Weber and Napieralski, who in 1999 studied the effectiveness of lecturers to promote organ donation behavior (Weber & Napieralski, 1999) or Gassmann, Vorderer and Wirth who, in their 2003 study, evaluated the effectiveness of German TV entertainment programs to promote organ donation behavior (Gassmann, Vorderer, & Wirth, 2003).

Weber and Napieralski (1999), instead of testing traditional mass media campaign tools, chose to analyze the effects of providing public information about organ

donation through education by lectures. The evaluation of respective interventions demonstrated that the lecture format for providing information is an efficient tool to inspire confidence in the transplantation medicine and health professionals. Still, the lectures did not result in a change of the willingness to donate organs after death (Weber & Napieralski, 1999). In a second study, five years later, Weber et al. created and tested the effectiveness of persuasive messages advocating organ donation and stressing the success of humorous messages in the form of narratives instead of a “neutral in tone” or other, statistically based messages (Weber et al., 2006).

Gassmann et al. (2003), in their study about the persuasion capacity of popular TV shows to initiate organ donation behavior, confirmed that TV shows have potential to influence recipients in a positive way and to reflect upon on socially relevant topics. To support the argument, a former program director of a German TV chain was quoted saying “television can be relevant also in a trivial way” (Schradi, 1986). Meaning that if well done, TV has the potential to promote social relevant topics, social values, and positive behavioral patterns (Gassmann et al., 2003).

This reflection is partly confirmed by Conesa and research partners who studied the influence of different sources of information on attitude toward organ donation one year later (Conesa et al., 2004). They found that indeed the medium with the greatest incidence on the population was television, followed by radio and press. However, it was not the most effective outcome. In terms of outcomes, information provided by health professionals, public speeches, and discussions about organ donation with friends and family were much more effective (Conesa et al., 2004).

In a recent study by Silverman, published in 2007 in the Journal of Mass Communication Education, he discussed a case study teaching a PR campaign class to college students. He compared the effectiveness of a student designed PR campaign to the outcome measured by the increase in number of students who registered for organ donation. As a result, Silverman reported an increase of signed donor commitments from 18.5% to 52% (Silverman, 2007). The validity of the study is questionable though, since students might be more enthusiastic within a college

class and/or be biased by the wish to get an outstanding grade; linking the latter to a positive outcome of their study.

Feeley et al. adapted a similar approach in 2009 to test the effectiveness of a peer-to-peer campaign promoting organ donation among racially diverse college students. Feeley et al. relied on existing literature about ethnic disparities in organ donation behavior and consequently designed an intervention aimed at addressing students' fears and misconceptions on culturally diverse campuses. As Silverman observed, participation in the campaign class increased student's interest in transplantation medicine and organ donation. Additionally, it showed to be effective to increase donor registration among racially diverse groups (Feeley et al., 2009). Concerns about the validity of the conclusions were similar to the ones mentioned before in Silverman's study.

Another study from the same year studied the relationship of organ donation information exposure, to participants with attitudes, beliefs, and donation decisions to their next-of-kin (Rodrigue, Cornell, & Howard, 2009). Rodrigue, Cornell and Howard (2009) examined, on the basis of previous research, the relationship between information exposure and socio-psychological constructs, as well as behavioral outcomes. They concluded that a "continued development and implementation of public education campaigns for organ donation with an emphasis on repeated exposure over time" is needed (*idem*).

Concluding the presented literature so far, personal targeted interventions, including health professionals and concerned people; evoked involvement seemed to be the most effective in terms of outcome behavior. Such behaviors include signing a donor card or communicating one's wish about donate to their own family. Still, mass media provides a range of tools that can reach a large number of people with a relatively reasonable cost-efficiency calculation (Rodrigue et al., 2009; M. Sanner, 1994; Sanner et al., 1995; Wakefield, Loken, & Hornik, 2010). Wakefield, in 2010, reviewed outcomes of mass media campaigns in a variety of health related behaviors such as tobacco use, alcohol and drug consumption, heart disease risk factors, STDs, road safety, cancer screenings, child survival, and blood and organ

donation. They concluded that “mass media campaigns can indeed produce positive changes or prevent negative changes in health-related behaviors across large populations” (Wakefield et al., 2010).

#### **4.7.5.2 Concrete Advises for Organ Donation Campaigns Derived from Empirical Studies**

Several authors gave precise advice in their conclusions to organ donation campaign planners on how to improve the outcome of their messages. Martinez et al. (1995), for instance, suggested to present more real cases and emphasize the increased quality of life for organ recipients. Additionally, they underlined that “incentives [for] organ donation should be directed at reasons of solidarity and reciprocity”, thus emphasizing a more altruistic act in organ donation behavior. Also, the family discussion about organ donation needs to be promoted better. The procedures to obtain a donor card or to register as a donor clearly also needs to be explained better (Martinez, Martin, & Lopez, 1995).

Farsides (2000) concluded five precise recommendations for organ procurement organizations, authorities, and other health communicators. According to Farsides “Individuals’ donation wishes, where explicit, should be decisive, next-of-kin should witness donor decisions, mandated choice should replace voluntary ‘opting-in’, initial donation choices should be repeatedly re-evaluated, those involved in organ procurement should distance themselves from models where bodies are seen as machines or gardens, and embrace models where bodies are viewed as sacred extensions of the self” (Farsides, 2000).

Miller et al. (2007), in their article about psychological reactance and promotional health messages, suggested that the most important thing to be aware of is not using abstract language but rather concrete language. These messages receive more attention and are thus considered more important. They will also eventually generate more positive affect and positive assessments of the sources (Miller, Lane, Deatrick, Young, & Potts, 2007).

## 4.8 Conclusion and Bridge to the Conducted Research

Existing research has identified a plethora of variables, which open segmentation opportunities to health campaigners. The challenge of audience segmentation for the health campaigner is to find the optimal combination of similarities that best distinguish various groups (idem). Existing research however, focuses on macro-cultural differences. These differences are mostly between countries such as the US and Asian cultures, or different ethnicities such as Hispanics and Caucasian-Americans in the United States (i.e. Lee, Kim, & Chen, 2010, Park, Shin, & Yun, 2009). None of the behavioral models have been tested in a micro-cultural diverse environment as one can find it in Switzerland. Thus, to adapt health campaigns, in particular the organ donation campaign, effectively in Switzerland, cognitive constructs need to be examined first. This should be done to understand the underlying processes of different behaviors among the language groups in Switzerland. A first attempt to do so has been done by the research group Schulz et al., who did a survey among Swiss people about their knowledge and attitude toward organ donation. Since the results of this study are the foundation of the hypothesis in this research, Schulz et al.'s study from 2006 shall be summarized in more detail. Together with the previously mentioned organ donation and health messaging research, the relevance of Schulz et al.'s findings will be emphasized (Schulz et al., 2006).

### 4.8.1 Findings from the Organ Donation Attitude Survey in Switzerland (Schulz et al. 2006)<sup>27</sup>

The *Raising Awareness of Organ Donation in Switzerland* research project was divided into two consecutive projects. The first project aimed at detecting micro-cultural differences in Switzerland, examining knowledge, attitudes, and organ

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<sup>27</sup> The whole section relies on Schulz et al.'s 2006 study and therefore will not be quoted separately unless a direct quote from the original publication is used.

donation behavior. Having found differences among the language groups, a second project was launched to test whether targeting organ donation promotion messages at the linguistic groups in Switzerland would be effective. This will all be laid out in a later section. However, before passing to the actual study design, hypothesis, methodology, and results, it is necessary to look closer at the design, hypothesis, and results of the first study.

In Schulz et al.'s 2006 study about knowledge and attitudes towards organ donation among the Swiss language groups, 1,509 Swiss adults, drawn in a stratified random sample from all areas of the country, were asked to participate in a telephone survey. Results of the study showed that respondents varied widely in their views of and participation in organ donation behaviors. It was found however, that the three linguistic regions of the country formed "natural market segments". Schulz et al. referred to this in their article, in which one can exhibit systematic differences in response to organ donation and related behaviors. These differences could be predicted through different patterns of antecedent knowledge, beliefs, and attitudes. As shown in Table 1, objective knowledge regarding organ donation was highest among Swiss-Germans and lowest among Swiss-Italians. However, Swiss-Italians have a substantially higher rate of participation in organ donation. Among Swiss-Germans, negative emotions were highest, positive emotions lowest, and moral concerns were the most pronounced, relative to the other language groups. This suggests that awareness and knowledge, which had been identified in earlier studies as critical factors, do not tell the whole story.



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**Table 1** *Knowledge, Emotions, and Social Contacts Regarding Organ Donation (Mean Score)*

Item or Scale	Language Group			p-value
	German	French	Italian	
Objective Knowledge	8.82	7.77	7.30	<.001
Negative Emotions regarding signing Organ Donation Card	0.86	0.57	0.67	<.001
Positive Emotions regarding signing Organ Donation Card	2.29	2.75	2.72	<.001
Procedural Knowledge	.190	.327	.121	<.001
Closeness of Others with Organ Donation Card	-.239	.150	-.041	<.001
Contact with Others involved in Organ Donation (e.g., physicians)	0.63	0.81	1.12	<.001
Moral Concerns regarding Organ Donation	1.07	0.70	0.92	<.001

Source: Schulz (2007) unpublished document

The table shows the mean scores of different items such as knowledge, negative and positive emotions towards organ donation, knowing others with a donor card and/or involved in organ donation, knowing somebody who decided about organ donation or had to donate a relative's organs, knowing medical staff working in the field, and moral concerns.

Group comparisons showed that factors important to citizen decisions regarding organ donation vary substantially across the three language groups. Positive and negative affects were important for all three language groups. Knowing another person with an organ donor card had a positive effect, suggesting the importance of social networks. Moral concerns were significant for Swiss Germans and Swiss Italians but not for Swiss French. Objective knowledge was significant for Swiss Germans and Swiss French but not for Swiss Italians. Based on these results and

ancillary attitude and belief measures, it was argued by Schulz et al. (2006) that these differences are driven, at least in part, by different social identities.

While much research has been devoted to individual and family identities, and a lot of activity has been framed implicitly by the national identity, the previous analysis suggested the importance of regional and community factors. More specifically, the notion of a public good and peoples' responses to it can be defined at these multiple levels and in different regions.

Swiss Germans had many more negative emotions than Swiss French or Swiss Italians towards organ donation. Swiss Italians, on the other hand, were more often to know somebody, somehow involved in transplantation medicine. Social (local) contact appears to play an important role, especially for Swiss Italians. The Swiss French, in a middle ground, overall show few negative emotions and more positive emotions towards organ donation than their compatriots. Having seen with the Swiss Italian population, community orientation appears to play an important role. It seems that their decisions to engage in donation behaviors are driven by personal exposure and sense of community, more so than by a cognitive analysis and decision. They know significantly less about technical and procedural issues than their compatriots. Thus, Schulz et al.'s results would suggest that messages promoting the value of organ donation to the local community would increase acceptance among Swiss Italians, while for Swiss Germans information and knowledge oriented campaigns would have to a similar effect.

As in many other countries (Gallup Organization 1993; DeJong et al. 1999; Cosse and Weisenberger 2000; Siminoff et al. 1995), the Swiss population has largely positive views about organ donation. However, this sentiment has not yet led to subsequent behavioral commitment in the form of signed organ donor cards or communication of potential donors' wishes to family members. In order to increase commitments through a communication campaign, Schulz et al.'s analysis of the Swiss experience suggests that it is imperative to consider the differences among the three main language groups.

Mass media campaigns in Switzerland have been largely uniform across the country. There is no adaptation to the micro-cultural variation exhibited by respondents. As such, there is a need to apply communication and health communication theory, as well as social marketing concepts and results of organ donation research to the campaigns. This is the general problem of the design of targeted health communication campaigns, precisely organ donation programs.

#### **4.8.2 Justification for the Research of this Thesis**

Consistent with the literature on pro-social behavior, the results of Schulz et al.'s first survey in 2006 pointed to two broad classes of influence on a person's decision regarding organ donation. They are individual factors, such as knowledge and affective responses to the idea of organ donation, and social factors, like family and community motivations. The three language groups in Switzerland respond differently to these factors.

Concluding from these findings, and combining it with suggestions from health communication research, it seems the most appropriate way to target organ donation messages is to target each specific language group within Switzerland. This would be in line with Kreuter et al.'s advice that health communicators/campaigners do best when they adapt their strategies to the specific characteristics of a "group of the population starting with developing culturally appropriate strategies" (Kreuter et al., 2003). Or as Collins and Zoch suggest, if mass media has to be used, "it may be necessary to rethink both the content and the intended receivers of such messages" to be most effective (Collins & Zoch, 2001). In this case, the receivers of the message are the Swiss, who differ significantly on different levels from each other. They are not only geographically and linguistically differentiated but also on an organ donation behavioral and attitudinal level.

#### 4 Literature Review: From Adapting Health Messages to Messaging Organ Donation (in Switzerland)

It would be especially interesting within the Swiss context to test whether linguistic differences reflect in the reception of statistical or narrative messages. Some first results, in this respect, have been presented in Schulz et al.'s study about organ donation in Switzerland in 2006. The same argument was valid for studies testing the efficiency of fear appeals vs. positive affect.

These studies suggested that campaigns could, and also should, be adapted to cultural differences. Such adaptations of health messages to broad cultural contexts have been conducted (e.g. Huerta & Macario, 1999). The question now is, whether similar adaptations would be valuable in a multi-linguistic country like Switzerland. If this is the case, one might consider understanding and defining smaller target groups, in other contexts, outside of Switzerland to reach as many people as possible.

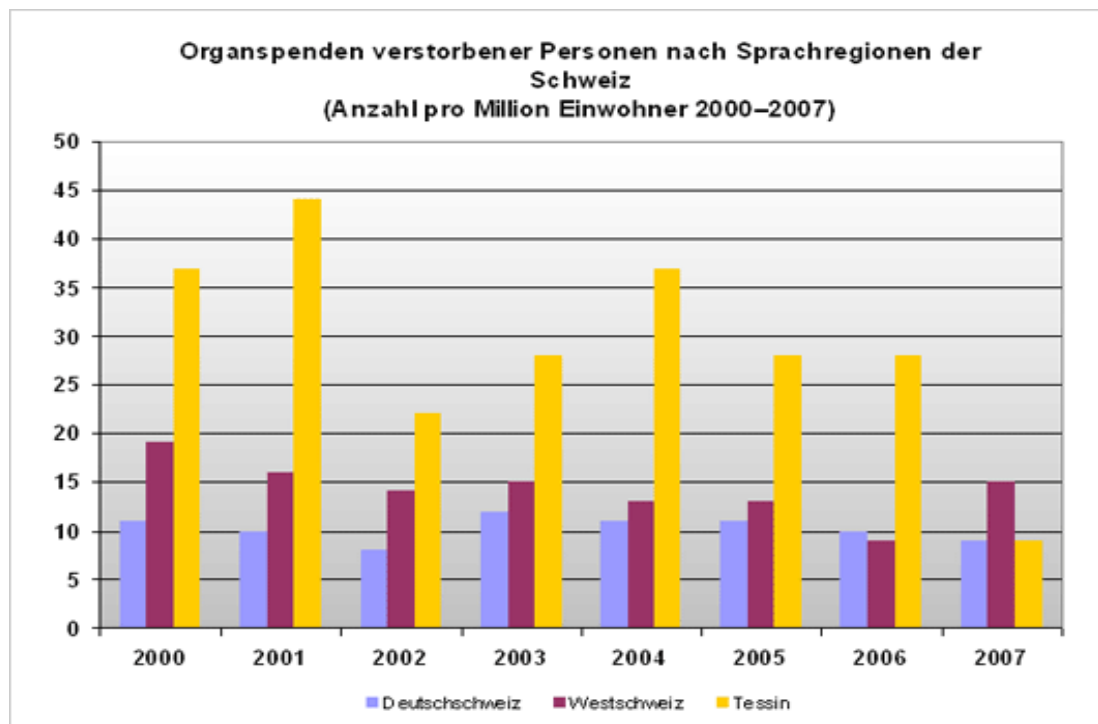
In the following, such a targeting approach will be adapted. The effectiveness of a targeted intervention in Switzerland, tested by quasi-experimental methodology, will be further laid out in the results section of this thesis.

## **5 Research Question**

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The number of organ donors in Switzerland over the past decades did not vary significantly (see Figure 14). Additionally, as seen previously, Switzerland is on the very bottom in the European benchmark when it comes to donors per million of population (Council of Europe, 2010). Campaigning in Switzerland has not concluded in a net increase in organ donor rates since 2001 (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011b). However, this picture is not the same all over Switzerland. As figures published by the Federal Health Department in 2009 show, there are important regional discrepancies in the number of donated organs per million of population:



**Figure 14:** The number of organ donors per million of population by language group: blue bar= Swiss Germans, red bar = Swiss French, yellow bar = Swiss Italians. Source: Bundesamt für Gesundheit <http://www.bag.admin.ch/transplantation/00692/index.html?lang=de>[02.06.2009].

The figure shows the donors per million of population between 2000 and 2007 divided by language region. Unfortunately, more recent reports published by Swisstransplant or the Federal Health Department or the Federal Statistics

Department do not provide any more numbers classified by language regions but only by hospitals. Nonetheless, at the moment of the design of the following study, this graph was a most crucial starting point for the entirety of the research conducted. It shows that over 10 years, the donor per million of population rate was significantly higher in the Italian speaking part of Switzerland (yellow bars) than in the other two language regions (blue = German speaking part, red = French speaking). The reasons for that have been explored by Schulz et al. (2006) in the study *More than nation and knowledge: Cultural micro-diversity and organ donation in Switzerland* (Schulz et al., 2006).

Having found significant differences among the language groups, in their knowledge and attitude toward organ donation, the consequent main investigation question is whether it would be effective to target health messages - specifically organ donation messages - to the different linguistic groups in Switzerland. Existing research of organ donation in Switzerland has shown that there are not only differences in donor rates, but also in knowledge and attitudes towards organ donation among the language regions (Schulz et al., 2006). This leads to the assumption that targeting campaigns to the specific needs and characteristics of each language group would be an effective approach to people about engaging in organ donation behavior<sup>28</sup>.

The aim of the study is to test whether the manipulation of a specific flyer has an influence on the perceptions and the feelings about that flyer and eventually on the intention to engage in organ donation behavior. According to Schulz et al.'s findings, it is expected that this relationship is different for each language group. It is also hypothesized that the community orientation of participants will differ for each language group. For instance, Swiss Italians would be expected to be more community oriented than Swiss Germans (Schulz et al., 2006), and thus be more open to the community oriented flyer. The effect of the flyer on the outcome variables will supposedly be different in each language group. Additionally, it was

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<sup>28</sup> Note that it is not so much about persuasion, but about making people aware and deciding what they want. Studies have shown that most people are generally in favor but have difficulties in deciding for themselves (European Commission, May 2007; Gallup, 1993).



also expected that attitude, personal organ donation experience, and knowledge about organ donation would differ in each language group. This would contribute differently to each of the region's willingness to engage in organ donation behavior.

## 5.1 Hypothesis

### 5.1.1 Language Differences in Attitudinal Components (Knowledge, Personal Experience, Community Orientation and Attitude) Towards Organ Donation and the Intention to Engage in Organ Donation Behavior

One of the results in Schulz et al.'s 2006 study was that "language groups differ in terms of knowledge, emotions, and social contacts regarding organ donation" (Schulz et al., 2006). On the previous study's finding, Swiss Italians scored significantly higher than the other two populations. The statement, *It is altruistic to donate one's organs*, had the outcome of: 87.5% Swiss Italians strongly agreeing, compared to 72.4% of the Swiss German population and 77.8% of the Swiss French population ( $p < .001$ ) (Schulz et al., 2006). Together with other findings, the researchers concluded that Swiss Italians "appear to be much more community oriented. Social and local contact appears to play an important role" (Schulz et al., 2006). This, together with the findings about knowledge and personal experience with organ donation, lead to the hypothesis that:

#### **H1: Swiss Germans differ from their compatriots because...**

- H1.1 Swiss German are more knowledgeable than Swiss French and Swiss Italians.
- H1.2 Swiss German are less community oriented than Swiss French and Swiss Italians.
- H1.3 Swiss German are less willing to donate their organs after death compared to Swiss French or Swiss Italians.

**H2: Swiss French differ from their compatriots because...**

- H2.1 Swiss French are overall well informed: less than Swiss Germans but more than Swiss Italians.
- H2.2 Swiss French are more community oriented than Swiss Germans.
- H2.3 Swiss French are generally in favor of donating organs after their death, being more positive towards the topic in general than Swiss Italians or Swiss Germans.

**H3: Swiss Italians differ from their compatriots because...**

- H3.1 Swiss Italian are generally not well informed about organ donation procedures. They show the weakest knowledge levels compared to the other two populations.
- H3.2 Swiss Italian show high levels in community orientation, higher than Swiss Germans and Swiss French.
- H3.3 Swiss Italian are generally in favor of donating their organs after death, more so than Swiss Germans. However, this is not reflected in the number of donor cards signed.

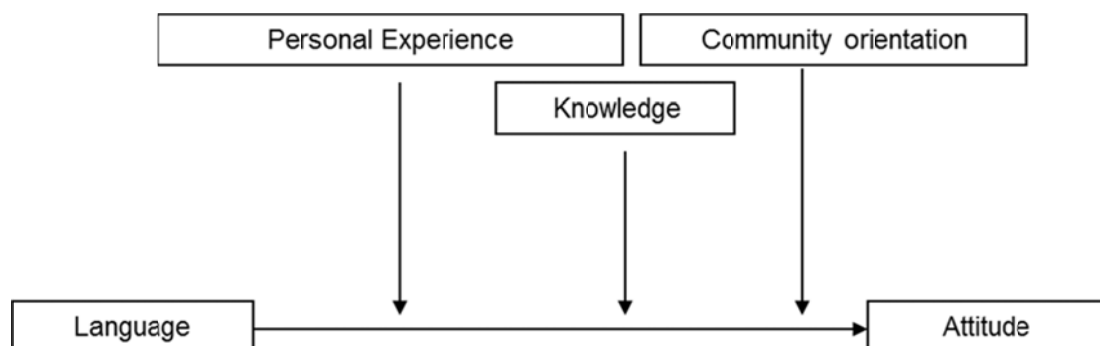
**5.1.2 The Effect of Personal Experience, Knowledge and Community Orientation on the Attitude Towards Organ Donation and the Intention to Engage in Organ Donation Behavior in the Three Language Groups**

Knowledge has been shown to be a crucial factor in creating a certain attitude, especially in the field of organ donation (Horton & Horton, 1991; Radecki & Jaccard, 1997; Radecki & Jaccard, 1999; Schulz et al., 2006 et al.). The previous organ donation study (Schulz et al., 2006) specifically showed that knowledge was more important for Swiss Germans than for Swiss Italians.

Skumanich & Kintsfather (1996) showed the importance of empathy and involvement in the decision to become an organ donor. "Empathy and involvement

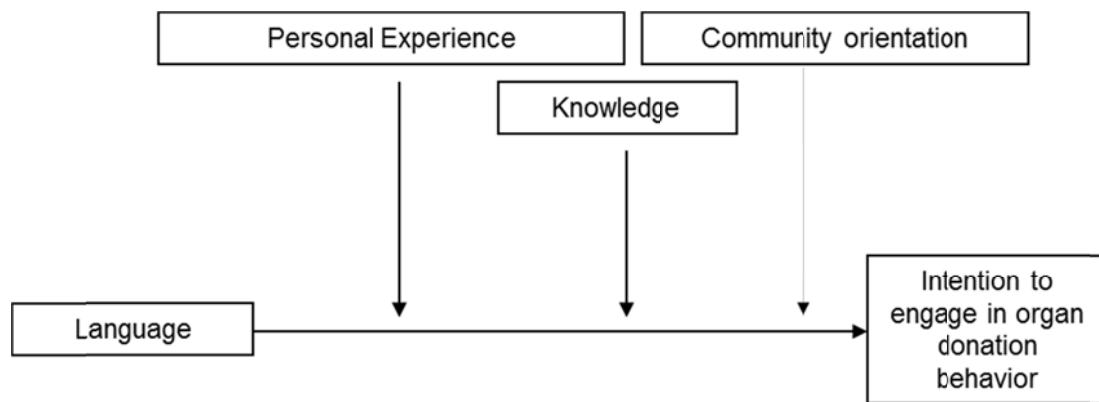
are hypothesized to have a direct effect on attitude toward donation, which, in turn, has a direct effect on the behavioral intention to pledge organs by signing a donor card" (Skumanich & Horton, 1991). Knowing a person and being strongly committed to one's social environment and community both may increase involvement and empathy (idem). Including the previous organ donation study, one could show different levels of "community orientation" among the linguistic regions (Schulz et al., 2006). Therefore in a second step, it was hypothesized that the attitude in each language group was moderated by the number of personal experiences in the field of organ donation, the knowledge level, and the community orientation of a person (see Figure 15 and 16).

**H4: Personal experience, knowledge and community orientation moderate the relationship on attitude in the three language groups.**



**Figure 15** Interaction models with language as focal independent variable and personal experience OR knowledge OR community orientation as moderator variable on the outcome variable attitude towards organ donation

**H5: Personal experience, knowledge and community orientation moderate the relationship on the intention to engage in organ donation behavior in the three language groups.**



**Figure 16:** *Interaction models with language as focal independent variable and personal experience OR knowledge OR community orientation as moderator variable on the outcome variable attitude towards organ donation*

### 5.1.3 The Influence of Mother Tongue on Cognitive and Affective Reactions to Different Organ Donation Flyers

The before presented literature about the necessity to target health messages to different ethnic groups, and the empirical evidence showing that differences among the language groups in Switzerland exist, even though they might not be called “ethical” or “cultural”, lead to the assumption that different message styles would arouse different cognitive and affective reactions among the participants of each language groups:

#### H6: Reactions to the flyer intervention among Swiss Germans

The Swiss German population, in the previous study, appeared to be the most private (individualistic) on the topic of organ donation (Schulz et al., 2006). They were the least likely to have strong connections to other people who signed an organ donor card or who were involved with organ donation. This is why Swiss Germans were expected to be less community oriented than the other two populations. Additionally, they exhibited a higher level of knowledge about organ donation. Thus the following hypotheses were generated:

- H6.1 Swiss Germans' cognitive and affective appreciation of the flyer is most positive for the objective flyer.
- H6.2 Swiss Germans will not appreciate the community oriented or emotional flyer and perceive it as rather imposing.

#### **H7: Reactions to the Flyer Intervention among Swiss French**

The Swiss French population, in the previous study, appeared to be more comfortable with the concept of organ donation and more sensitive to both social and individual factors. Consequently, a message aimed at raising awareness of the need and providing information about related behaviors, such as signing organ donor cards, was hypothesized to be effective. Swiss French's knowledge about organ donation was not predicting organ donation behavior in the previous study. Therefore, a community oriented or emotional positioned message arousing empathy and involvement (Cacioppo & Petty, 1989; Petty & Cacioppo, 1986; Skumanich & Horton, 1991) was hypothesized to be the most effective in impacting the willingness to engage in organ donation behavior.

- H7.1 Swiss French would give both the community oriented as well as the emotional flyer more positive ratings for cognitive and affective appreciation than for the objective flyer.
- H7.2 The objective flyer would provoke the least positive feelings of all flyers among Swiss French.

#### **H8: Reactions to the flyer intervention among Swiss Italians**

As noted above, the survey results suggested that, compared to Swiss German and Swiss French populations, the Swiss Italian population has a stronger (local) collectivistic orientation. In addition, this group exhibited a higher level of positive affect but also a higher level of moral concern about organ donation, both having significant effects on intention to engage in organ donation behavior. Still, this group exhibited the lowest level of objective knowledge. However, this knowledge had no significant effect on the intention to engage in organ donation behavior. As such, the following hypotheses were formulated:

H8.1 Because of their strong community orientation, a message stressing the value of organ donation to the local community, family, and friends (the community oriented flyer) would arouse most positive cognitive and affective appreciation ratings.

H8.2 For Swiss Italians the objective/informative message will evoke the least positive feelings compared to the other two flyers.

#### **5.1.4 The Role of Community Orientation in the Influence of Mother Tongue on Cognitive and Affective Reactions to Different Organ Donation Flyers**

Having seen several times that empathy arousal and the wish to help others is the most important factor in organ donation (Batson & Powell, 2003; Dovidio, 1984; Skumanich & Kintsfather, 1996), the next step is to consider whether the reactions to a specific flyer in each language group was moderated by the degree to which the participant knew other people involved or scored particularly high/low on community orientation items. These conclusions lead to the hypotheses 9 and 10:

**H9: The degree of community orientation moderates the reactions to the specific flyers.**

**H10: The moderating effect is different within each language group.**

#### **5.1.5 The overall Influence of the Flyer Manipulation on the Willingness to Engage in Organ Donation Behavior Among the Language Groups**

Finally, the question remained if any of the flyers had an impact on the actual willingness to engage in organ donation behavior of the participants. Based on previous findings it was thus hypothesized that:

**H11: The flyers impacted the outcome variables *Having signed a donor card since the first interview* and *Willingness to sign a donor card*.**

H11.1 Among Swiss Germans, the objective/informative flyer is most effective in making people engage in organ donation behavior.

H11.2 Among Swiss French, both the community oriented as well as the emotional flyer are most effective in making people engage in organ donation behavior.

H11.3 Among Swiss Italians, the community oriented flyer is most effective in making people engage in organ donation behavior.

## **5.2 Summary: The Overall Effect of the Flyers**

To sum up, according to the theory and the previous study, the flyer should have shown different effects on the perception within the three language groups in Switzerland. For example, it was expected that Swiss Italians would appreciate the community oriented flyer more than the informative/objective flyer. At the same time, Swiss Germans were expected to appreciate the informative/objective more than the others. Swiss French were expected to appreciate the emotional flyer the most, knowing already a lot about organ donation and mostly being in favor of it; even though they have lower donor rates per million of populations than Swiss Italians do (Schulz et al., 2006). So far, the hypotheses focused on the preferences of each language group. In the following they will be summarized by the message type.

H-M-1: An objective message will be more appreciated by the Swiss Germans than by the Swiss Italians and the Swiss French.

H-M-1: An objective message will be more effective in terms of behavioral outcome for Swiss Germans than for Swiss Italians and Swiss French.

H-M-2: An emotional message will be more appreciated by the Swiss French and Swiss Italians than by the Swiss Germans.

H-M-2: An emotional message will be more effective in terms of behavioral outcome for Swiss French and Swiss Italians than for Swiss Germans.

H-M-3: A community oriented message will be most appreciated by the Swiss Italians.

H-M-3: A community oriented message will be most effective in terms of behavioral outcome for Swiss Italians.



## **6 Methodology**

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## 6.1 Sampling

Shadish, Cook, & Thomas (2002), in their textbook about experimental and quasi-experimental designs, summarized the advantages of an experiment as the following:

“The strength of experimentation is its ability to illuminate causal inference. The weakness of experimentation is doubt about the extent to which that causal relationship generalizes” (Shadish, Cook, & Thomas, 2002, p. 18),

Experiments are usually very specific and highly localized. Shadish et al. pointed out that experiments are mostly conducted in specific settings with one specific treatment and all possible versions of it (Shadish et al., 2002). At this point, it is important to stress that in the presented experimental setting, it was deliberately decided not to test all the different intervention or treatment possibilities for economic and feasibility reasons. Only three specific treatment possibilities have been chosen as intervening factors. The three interventions will be specified and further detailed later on in this chapter. One of the main characteristics of an experiment is that the sample is drawn randomly. As already mentioned, for logistical and financial reasons, it was not possible to run the experiment entirely random, thus the following study is in the “quasi-experiment” category (Pedhazur & Schmelkin, 1991; Shadish et al., 2002).

The main problem with a quasi-experimental design is that it does not entirely reflect the population. Cronbach et al., in the early 1980's (Cronbach & et al., 1980), (Cronbach, 1982) emphasized that generalization in quasi-experiments is limited to a) the “domain about which the question is asked” and b) to the “units, treatments, variables, and settings not directly observed” (Cronbach, 1982). Under the second point *b*, it is especially important to underline that the aim of the quasi-experiment in this study was not primarily generalization, but to find out whether there are specific behavioral patterns for each language group. Furthermore, the study wanted to

eventually help find an appropriate approach in targeting health messages. The aim was not to draw general conclusions about all Swiss.

## 6.2 Factorial Design

The following study was run in the form of a 4x3 factorial quasi-experimental design as shown in table 2:

**Table 2** *Summary Factorial Design*

4x3 Factorial Design			
Message Type	Language Group		
	German	French	Italian
Informative	60	60	60
Emotional	60	60	60
Community Oriented	60	60	60
Control Group	20	20	20

Three different message types were developed and translated in French, German, and Italian. This resulted in nine different flyers, which were presented randomly<sup>29</sup> to the interviewees. 60 additional interviewees did not get any flyer at all, and instead received a shorter questionnaire, leaving out all questions about the appreciation of the flyer. These 60 control interviews were equally distributed among the three language groups.

Before running the interviews, flyers and questionnaires were pre-tested several times to avoid translation problems. The flyers were also tested to determine whether the flyer had the characteristics it was supposed to have.

<sup>29</sup> "At random" to a certain degree since Swiss French only got French flyers, Swiss Germans only German flyers, and Swiss Italians only Italian flyers

### 6.3 The Experimental Intervention: Developing Flyers and Questionnaires

In the following paragraphs, development and content of the experimental intervention, the flyer, and the questionnaire will be summarized in English. An overview of the questions per construct can be found in Annex B: *Synopsis of Questionnaire*. The full questionnaire, in the original languages German, French, and Italian will be provided upon request. Participants had to read one out of three different messages about organ donation or were randomly assigned to the control group and did not read any messages. The control group only had to read a shortened questionnaire, without any questions on the evaluation of the flyer.

#### 6.3.1 Operationalization of Message Types (Flyers)

To design the messages, several sources were consulted, one of them was the *Guide for Planning Public Awareness and Education Initiatives to Promote Organ and Tissue Donation* of the Canadian Council for Donation and Transplantation (The Canadian Council for Donation and Transplantation, 2005). Among other recommendations, the guide suggested to use testimonials from donors and their families, as well as assure a credible source to render the flyer effective. It also suggested that organ donation messages should remind people that the majority of individuals and opinion leaders are in favor of organ donation. Further, the guide recommended the use of emotional appeals focused on the humanitarian approach (idem). The previous research about communicating health topics, and especially organ donation, was taken into account when deciding about the content of the intervention.

To design the messages, different choices of manipulation had to be taken. A clear distinction between flyers was a challenging task. The messages about organ donation had to contain certain factual information and inherently emotional content. The most appropriate design would have been to create one message and

manipulate single wordings in a first step, then translate the messages to be as close to the original as possible. To be as realistic and authentic as possible, it was decided that it needed to be more flexible. The community oriented flyer and the emotional flyer were both emotional, although at a different degree, and contained minimal amounts of information about organ donation. The easiest to design, with a clear distinction to the other flyers, was the **informative flyer**. It was kept neutral and reported objectively, explaining facts and mentioning figures. The effects of the flyers were pre-tested. “Usability<sup>30</sup>” testing was applied to examine the effect the flyer had on the reader. The text messages were printed in a flyer format, pretending to come from an official but fictitious institution. The flyers were kept equal in design and pictures, meaning that the design and the pictures of all the flyers were identical for each version. The manipulation focused exclusively on the content and writing style. Three of the nine different flyers can be found in the Annex C.

**The emotional flyer** was written in a narrative way, telling a story about a family having to decide whether or not they should agree to donate the organs of their beloved deceased relative or not. It was supposed to be emotional and touching.

**The community oriented flyer** was aimed at stressing the importance of the family, the value “us”, the family, and the community by using specific vocabulary on purpose; implying these values such as “we”, “family”, “friends”, “neighbors”, “colleagues”, “us”, and etc.

None of the flyers directly asked readers to go sign a donor card, nor was any direct appeal found in any of the flyer versions. The back message on the flyer only described indications on how to become an organ donor. Still, this indication was kept general and did not directly ask the reader to participate.

The back of each flyer was identical: first, an explanation how one can become an organ donor and where to get a donor card was listed. Second, how to contact the fictitious organ donation association was also given. The name of the latter being

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<sup>30</sup> More information on usability testing can be found in the section about pre-testing flyers and questionnaires.

invented, the address, and phone number were real in case a participant wanted to seriously request further information<sup>31</sup>.

In the following, a summary of the flyer content is given in English for each version; the original pre-tested flyers in German, French, and Italian will be provided upon request.

### **6.3.2 The Operationalization of the Informative / Objective Flyer**

The informative flyer contained statistical and legal information about the organ donation process. The first paragraph stressed the increased need for organs in general. The second paragraph quoted numbers of waiting lists, how many people in Switzerland wait for an organ, how many transplants have been performed during the last year, and how many people died because they did not get a new organ in time. A third paragraph briefly explained the (new) Swiss transplantation law, in effect since July 2007, and its impact on the average citizen. The last three paragraphs aimed at clarifying common myths, for instance about the anonymity of the organ donor and organ receiver, allocation criteria for organs, or about the conditions to become an organ donor (age, etc.). The message style was kept neutral in emotions and purely explanatory.

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<sup>31</sup> Interviewers were asked to bring back all of the interview material. However, if participants wanted to keep the flyer, they were allowed to do so. None of the participants actually called the number indicated. It simply served to render the flyer more credible.

### **6.3.2.1 *The Operationalization of the Emotional Flyer***

The emotional flyer told the story of Julia, a young woman who died in a car accident, and her parents having to decide whether to donate her organs or not. The parents' reasoning was reported quoting thoughts and reasons why they eventually agreed to give away their just deceased daughter's organs. In parallel, the story of another young woman was told. This woman, will get a new kidney – not knowing if it is Julia's kidney or not. It shows that the fate and pain of one can turn out to be the happiness of the other. It is meant to underline the fact that death was turned into life and hope, without participants knowing who the "other" was. The message was designed to be highly emotional and was pre-tested for that in all three languages.

### **6.3.2.2 *The Operationalization of the Community Oriented Flyer***

The community oriented flyer started off with some general figures about organ donation in Switzerland. This was to show the relevance of the topic for the society as community, without using the word "community" explicitly throughout. In the second paragraph, the word "we" was introduced to involve the reader and create a feeling that the reader was part of what is happening. Additionally, the importance of the family and its role in the decision process was explained and stressed. Further on, words such as "everybody", "friends", "colleagues", "us", etc. were used more frequently. This was the only flyer that was slightly more assertive towards the end, claiming active discussion within the family. However, it did not ask people to give their organs; instead it stressed the importance to talk with family about the wish to donate organs or not, underlining that this should be feasible for everybody.



### 6.3.3 Operationalization of the Questionnaires<sup>32</sup>

The questionnaire, contrary to usual practice (Brace, 2008), contained some demographic questions in the very beginning. In his book about designing survey questionnaires, Brace underlines in the section *Sensitive Sections* that:

“If the interview is to include questions of a sensitive nature, then they should not be asked right at the beginning of the interview. Where the questionnaire is interviewer administered, this allows a relationship to be built between interviewer and respondent, so that the interviewer is more willing to disclose sensitive information” (Brace, 2008, p. 43).

Organ donation can be considered an overall sensitive issue; it touches the integrity of one’s own body and the topic of death. Therefore, a special sampling method was used, which will be explained more in detail in the *Sampling* section. It should be mentioned that interviewers knew the interviewees personally. Asking for personal data in the beginning was a way of positioning the interview situation, and at the same time delaying the more sensitive issues about the willingness to donate organs after death to the end of the first questionnaire. Still, staying in line with Brace’s recommendations, the question asking for the participant’s phone number to follow up was asked only at the very end of the first questionnaire. Personal information was put at the beginning of the questioning, therefore, detaching it from the most sensitive part, the phone number; rendering the claim of anonymity supposedly more credible.

The demographic item block at the beginning of the questionnaire asked for year of birth, gender, marital status, children, religion, education, profession, rural/urban setting, mother tongue, and whether the interviewed person is working in the health sector or not (see Synopsis of Questionnaire in Annex B).

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<sup>32</sup> In the following a summary of all constructs will be given. Further on, in the section *Measures* more details will be given how single items were summarized or indexed to proceed with during the analysis

#### **6.3.4 The Operationalization of “Language” and “Flyer”**

When preparing interviewer material, each questionnaire had a code at the very top of the page including the language of the questionnaire, the abbreviation of the version of the flyer, and an identification number. The code, consisting of 6 letters and 3 digits, was handwritten on the top of the first page of each questionnaire. Each interview file had different material for each group; for the experimental groups, two questionnaires and a flyer, for the control groups only a single questionnaire. Interviewers were neither instructed about the contained information in the code, nor did they know which flyer was contained in the file.

Interviewers were instructed to supervise that the experiment was run in the correct order. Pre-tests showed that interviewees had difficulties with the longer questions and the 7-point Likert-scales when read by the interviewer, therefore, the decision was taken to make them read and answer the questionnaire themselves.

By doing this, the role of the interviewer was reduced to supervising the sequence (first questionnaire, reading the flyer, and then the second questionnaire) controlling that interviewees would not go back to the first questionnaire after having read the flyer. Most importantly, this was to convey confidence by the simple fact of knowing the interviewee to a certain degree. By doing so, we were hoping to reduce social desirable answers and get as honest and sincere answers as possible.

##### **6.3.4.1 The Operationalization “Knowledge”**

Knowledge about organ donation was assessed with several questions similar to the ones used in Schulz et al.’s first study (2006). All of the items were nominal (right, wrong, I don’t know). Some of the measures were subjective, for instance: *Do you know what you have to do to make your organs available after death? If so, how?* (the latter was recoded into right/wrong) *Have you ever heard about organ donation? Do you feel informed about organ donation?*

Since merging subjective and objective knowledge did not make sense conceptually, the following analysis will concentrate on the objective measures<sup>33</sup>. These measures consisted of a 14-item knowledge scale. Each item was a statement about the organ donation procedure in Switzerland and participants had to say whether the statement was true, false or unknown.

For data entry, “no”s and “don’t know”s were both coded as wrong and true answers as correct. Eventually each person scored between 0, everything wrong and thus not knowing anything, and 14, everything correct and thus very well informed.

#### **6.3.4.2 The Operationalization of the Construct “Attitude”**

Attitude was measured with several items either on a 7- or 5-point Likert-scale: *Organ donation is a good thing to do, I can understand if some people might not want to give their organs after death, Thinking about organ donations scares me and makes me think of death, Would you agree to organ donation for a deceased relative who did not express his wish to donate or not before dying, and Would you agree to organ donation for a deceased relative who did express his wish to donate or not before dying* (Schulz et al., 2006). The questionnaire also assessed whether people would vote in favor or against a law introducing an opt-out<sup>34</sup> system in Switzerland. This item was not included in the analysis<sup>35</sup>.

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<sup>33</sup> Additional analysis including the relevance of subjective knowledge will be conducted and published separately.

<sup>34</sup> *Reminder.* Opt-out systems or presumed consent, are terms to describe the legislation of a country that classifies all citizens as potential donors in absence of an explicit opposing statement before death (Abadie & Gay, 2006).

<sup>35</sup> Additional analysis including these items will be conducted and published within a separate framework.

#### **6.3.4.3 The Operationalization of the Construct “Personal Experience”**

Schulz et al.’s study in 2006 showed that knowing people involved in the organ donation process predicts the willingness to engage in organ donation behavior, especially for Swiss Italians (Schulz et al., 2006). The question was asked again because it was hypothesized that the intensity of the network linked to organ donation was different in each language region. Therefore, the questionnaire contained three items measuring “personal experience”. The first two items have also been used by Feeley & Servoss in 2005 (Feeley & Servoss, 2005): *Do you personally know somebody who has received an organ or is waiting for one?* and *Do you personally know somebody who had to decide to give the organ of a deceased relative*. The third item was replicated from Schulz et al.’s study (Schulz et al., 2006) *Do you know any doctors or medical staff involved in organ donation?*.

#### **6.3.4.4 The Operationalization of the Construct “Community Orientation”**

Eight different items realized the concept of community orientation, consequently they were factor analyzed and put together into an index (see chapter *Preliminary Analysis*). The items were all measured on a 7-point Likert-scale going from 1 - *I totally disagree* to 7 - *I totally agree*. The items were formulated as the following: *My family is for me the most important*, *My friends are for me the most important*, *I get along alone very well and do not need others support*, *I like to have a lot of people around me*, *I like to spend time alone*, *I like to be socially active, i.e. for my community*, and *I know my neighbors very well and see them regularly*. These questions were all asked in the first set (wave 1). In the second set (wave 2), one single-question relating to community orientation was asked: *How important is organ donation for the community in your opinion?*.

#### **6.3.4.5 The Operationalization of the Construct “Perception of the Flyer”**

The perception of the flyer was assessed in a semantic differential like format. It was not exactly a semantic differential, but had a similar form using adjective 7-point Likert – scales. The scale had positive adjectives on one side and the negative (opposite) objectives on the other. Adjectives that were asked included *trustworthy*, *emotional*, *comprehensive*, *informative*, *credible*, *convincing*, *appealing*, *touching*, and *imposing* (see Annex D).

#### **6.3.4.6 The Operationalization of the Construct “Feelings about the Flyer”**

To assess the feelings about the flyer, again 7-point Likert-scales were used. This time making the participants rate whether they agree or do not agree with the suggested statement. Items asked included: *Reading the flyer I felt aggrieved*, *Reading the flyer I felt concerned*, *Reading the flyer I felt reassured*, *The flyer made me think about the topic*, *The flyer made me nervous*, *The flyer would be understandable for my friends*, and *The flyer gave me an overall good impression of the transplantation medicine*. In the follow up, we asked people whether they remembered the flyer they had read during the first wave, and if so, what exactly they remembered.

#### **6.3.4.7 The Operationalization of the Assessment of the “Willingness to Engage in Organ Donation Behavior”**

The intention to engage in organ donation behavior was assessed twice: during the first wave – the written questionnaire – and during the second wave – the telephone follow-up four weeks later. It is important to note, at this point, during the first wave, the items about the willingness to engage in organ donation behavior were assessed after the experimental intervention, meaning after the participants had read the flyer.

The intention to engage in organ donation behavior was assessed in both waves. It was done so with the following questions: *Would you agree to give your organs after death? (5-point scale in both waves)* *Do you have a donor card? (yes or no, filter question)* and *Would you sign a donor card? (5-point scale)* in the first wave, *dichotomous yes or no question* in the second wave.

The question *Do you have a donor card?* in the second wave was further extended to include *since when?* After data entry, the answers were re-coded in *had donor card before first interview* and *signed donor card between the two interviews*.

### **6.4 Translation and Pre-tests of Experimental Intervention (Flyers) and Questionnaire**

To avoid differences in the conceptual equivalence of the translation of the instruments and measures, an integrated method was used as Sidani et al. described in their article about *Cultural adaptation and translation of measures: An integrated method* (Sidani, Guruge, Miranda, Ford-Gilboe, & Varcoe, 2010). The experimental intervention, hence the flyers, were translated, back translated, and pre-tested several times to assure that they are linguistically appropriate and understood as they were supposed to be perceived.

#### **6.4.1 Translation...**

##### **6.4.1.1 ...Of the Flyer**

Flyers and questionnaires were all developed in German first. After having discussed and amended different forms of the flyer, three German flyer manipulated versions were finalized. Following, the German flyers were then given to Italian and French native speakers to translate.

After the first translation, flyers were again discussed with researchers of the respective mother tongue and amended accordingly. Thereafter, flyers were given back to native German speakers, knowing French or Italian, to back translate the flyer and compare it to the original and the translation, checking for differences.

As a result, researchers were faced with a decision. They could either translate the flyers as close as possible to the original content, but by doing this losing the authenticity of the flyer. This would, in consequence, also effect the parts of which mainly lied in the manipulation of the degree of the emotional content. Or they could allow for minimal changes and deviations in content in order to make the manipulation more authentic and credible. Eventually the researchers opted for the authenticity of the flyer and the similarity of emotionality in the manipulation.

Consequently, translators were instructed to focus on transmitting the “feeling” of the flyer. The proper transmission of the cognitive message was considered more important than a word-by-word translation of the content. That is why the flyers of the same manipulation, in the different languages, differ slightly in content and length.

#### **6.4.1.2 ...Of the Questionnaire(s)**

The questionnaire was first developed in German and then translated, back translated, discussed, and amended into Italian and French. The procedure was similar to the procedure of the flyer translation. For the questionnaire, the focus was much more on precise translation than for the flyers. This was to warrant comparability of the results among the language groups. After each pre-test of the flyer and questionnaire, mostly linguistic adaptations were carried out.

#### **6.4.2 Pre-tests**

Both flyers and questionnaires were pre-tested for usability (Nielsen, 2010) in the three language groups. This was done by asking the institutes research assistants

to pre-test their social networks at home, with neighbors, friends, friends of friends, etc. To pre-test the usability of the flyers and questionnaires, we also assessed the reaction of people being questioned by an acquaintance instead of a stranger.

The reactions reported by the research assistants supported the choice of our sampling method. *“I’m only do this because I know you”, “I’m only answering this question because I know you”* were two of the quotes reported.

The Canadian *Guide for Planning Public Awareness and Education Initiatives to Promote Organ and Tissue Donation* (The Canadian Council for Donation and Transplantation, 2005) suggested to include the following items when pre-testing messages which has been done during the usability tests of our flyer:

*“What is the main idea of the flyer? What did you particularly like? What did you dislike? Was anything offensive? If so, what? Were there any understanding problems? Language issues? Was there anything hard to believe?”* (The Canadian Council for Donation and Transplantation, 2005)

### **6.4.2.1 Pre-tests of the Flyer**

Flyers were tested during the design process and as an integral part of the questionnaires’ pre-tests; the flyer was also a part of the pre-tests. Research from Jakob Nielsen has shown that usability tests with no more than five people are enough to assess whether users, or in our case participants, have problems understanding, for instance with a manual or the flyer as an experimental intervention (Nielsen, 2010).

Nielsen, on his website, concluded his research: “The ultimate user experience is improved much more by three tests with [five] users than by a single test with 15 users” (idem). According to this, each flyer was tested for understanding and perception of emotion in each translated language. After five tests in each language and discussing changes thoroughly with native speakers, flyers were amended



accordingly. With this accomplished, flyers were, for a second time, showed to test-persons (different participants than before), asking them again to rate understandability, authenticity, and feelings the flyer evoked. Consequently, changes were again discussed with native speakers and flyers were adapted accordingly.

#### **6.4.2.2 *Pre-tests of the Questionnaires***

The procedure for pre-testing the questionnaire was similar to the procedure pre-testing the flyer manipulations. The questionnaire was pre-tested in each language with 5 to 10 people in a first step. As described before, interviews were run in the supposed setting, again with student interviewers. Interviewers were asked to note every single problem participants might have while answering the questionnaire and/or while reading the flyer. According to the reported comments, questionnaires and/or flyers were adapted and pre-tested a second time.

### **6.5 Sample**

The sample size was decided based on budgetary restrictions and the reasoning with the number of cells in the previously shown Table 2 (p. 184) of the factorial design. The idea was to have at least 50 people in each experimental group. To balance eventual dropouts, 10 participants were added to each cell, plus the control group. The sample then consisted of 60 participants, per language group. Altogether, this made 600 participants, 200 for each language group. It was intentional not to weigh participants according to the number of inhabitants in the respective language region. German Switzerland counts for approximately 64% of the Swiss population, French Switzerland for around 20% and the Italian part for around 6%. Since it was a quasi-experimental design, statistical feasibility was prioritized over representativeness.

## **6.6 Interviewer Training**

Interviewer trainings were run with approximately 50 student interviewers conducting between 10 and 20 interviews each. They were done in their social networks, at home, and where they went during school holiday.

Interviewers had to be Swiss and go to their hometowns on holiday to run the interviews within their social networks.

During the interviewer trainings, one in each language, students were told about the project in general, their role during the interview (passive but confidence transmitting), and the importance of not interfering. It was left up to the interviewee whether he/she would like to sign a donor card or not after the interviews. It was particularly stressed that the aim of the study was to understand people's motivations and not to convince anybody to donate his/her organs.

Additionally, interviewers were given requirements (quota sheets), where they had to control the age, gender, and whether the person had finished school with an A-level or not. This was to roughly control for education and avoid possible sampling bias (by interviewing students and their student friends only). Interviewers were additionally told not to focus on close family when doing the interviews, but to go into their large social networks and do interviews with neighbors, parents of friends, friends of friends, etc.

## **6.7 The Follow-Up – Survey**

At the end of the first study, participants were asked whether they agreed to participate in a five minute follow-up interview by telephone a month later. People who agreed to do so were asked to put their telephone number on an extra sheet. The interviewer would then put the questionnaire identity number next to the telephone number to be able to connect the interviews later on.

The telephone survey conducted a month later was a computer-assisted survey. Interviewers were read a questionnaire over the phone, and immediately filled in the answers on the computer-assisted questionnaire. Data from the online database *Dimensions* was eventually exported directly into PASW (SPSS) for data analysis.

The design and translation procedure for the telephone survey was equal to the one in the first wave. Interviewers native in German, French, or Italian were hired and trained before the actual survey started. Some of the interviewers were the same as in the first survey, some were not. The follow-up took place four weeks after the initial baseline interview.



## **7 Preliminary Analysis**

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### 7.1 Data cleaning, Merging Data basis, Recode Variables

One person did the data entry, (the author of this monograph). It was first done in Excel and eventually exported to PASW (SPSS). Before giving out the interview material to each interviewer, every questionnaire was given an identification number (*IDNO*) from 1 to 600. Additional structural information was coded with the variables *interviewer* (1-47), *date of the interview*, and the *code of the interview*. The latter contained information about the language of the interview, the code for the message it contained (abbreviated and understandable to neither interviewers nor interviewees), and the identification number.

The code of the interview was particularly important in merging the two datasets, since it contained the relevant information, that made the merging of both possible.

In a first step, the two datasets were merged with the help of Excel, and in a second step exported to PASW (SPSS). The final dataset was then screened for data cleaning and variables recoded.

## 7.2 Response Rate

The sampling method chosen and explained before (methodology chapter) provided us with unusually high response rates. Table 3 shows the overall response rate of both surveys. One interview is missing for the Swiss French participants because one of the interviewers did not return it back to us. The discrepancy between the number of conducted phone calls and the number of cases in the dataset were related to a merging problem, as explained at the end of the table.

**Table 3** *Data Collection and Response Rate*

	Swiss German	Swiss French	Swiss Italian	Total
<b>December 2008:</b>				
Number of Contacted People	200	200	200	100%
Number of Responses / Filled in Questionnaires	200	199	200	99.5%
<i>Response Rate (in Percent) of Written Survey</i>	99.5%			
<b>February 2009:</b>				
Number of Available Phone Numbers	184	182	153	519
Number of Answered Phone Calls	147	158	128	433
Number of Allocated Interviews	145	157	126	428*
<i>Response Rate (in Percent) of Telephone Survey</i>	80%	87%	84%	83%
<i>Response Rate (in Percent) of Allocated Interviews</i>	79%	87%	82%	82%

\* Because of errors in the entered codes, 5 interviews could not be clearly allocated to a first wave code. Therefore the decision has been taken to leave them out



### 7.3 Sample Description

In the first step, it was controlled whether participants filling in the questionnaire considered German, French, or Italian as their mother tongue. The results are shown in Table 4.

**Table 4** *Mother Tongue of the Participants*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Italian	1%	3%	88%	30%
German	96%	4%	7%	36%
French	1%	92%	2%	31%
Other	2%	1%	4%	2%
Missing	1%	1%	0%	1%
<i>TOTAL</i>	<i>101%</i>	<i>101%</i>	<i>101%</i>	<i>100%</i>

As the figures in Table 4 show, Swiss Germans, 96%, and Swiss French, 92%, considered German and French (the respective interview languages) as their mother tongue. Among the Swiss Italian participants, 12% indicated a different language than the interview language to be their mother tongue. A separate analysis was conducted on the outcome variables to test whether these 12% differed significantly from the Swiss Italians. The results were all non-significant, and thus the decision was made to leave all the participants in the sample.

In a second step, the sample was checked for differences in gender. Interviewers were asked to respect their quota sheets, avoiding a bias in gender, age, or education. Table 5 shows the gender count per language region, as well as the total. The chi-square was not significant. Therefore, men and women were equally distributed across the sample and subsamples (divided by language groups). This conforms to the data of the Swiss Federal Statistics Office (Bundesamt für Statistik), indicating on their website that per 100 women in the country, there are 96.8 men.

Thus the country is almost split in half, as reproduced also in the summary of our sample (see Table 5).

**Table 5** *Gender of the Participants*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Female	54%	51%	57%	53%
Male	46%	49%	43%	47%
<i>TOTAL</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>

$\chi^2(2, N=595) = .222; p=.895$

Thirdly, the sample distribution of age was looked at. The year of birth was coded as *age in years* and further divided in four age groups: *under 20*, *20-39*, *40-64*, and *65+*. The age groups were created to conform to the age groups displayed on the website of the Federal Statistics Bureau (BFS) of Switzerland. The summary of the sample description, according to age, is shown in Table 6.

**Table 6** *Age of the participants*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Under 20	2%	3%	1%	2%
20-39	35%	43%	47%	41%
40-64	49%	42%	35%	42%
65 +	15%	13%	18%	15%
<i>TOTAL</i>	<i>101%</i>	<i>101%</i>	<i>101%</i>	<i>100%</i>

$\chi^2(6, N=598) = 11.629; p=.071$

The reason why there are so few people under 20 is that interviewers were instructed to interview adults. By Swiss law, an adult is a person having had their 18th birthday. Although after their 16th birthday, a person may already decide about his/her willingness to donate (Svisstransplant, Schweizerische Nationale Stiftung für Organspende und Transplantation, 2011a).

Although interviewers were provided with quota sheets to meet specific age group criteria, the data shows some bias in age per language group. While the represented age groups for Swiss French are very similar to the overall average, the Swiss German sample contained significantly more participants between 20-39 years old and the Swiss Italian sample significantly more participants between 40 and 64 years old.

Since it was hypothesized that subsample community orientation was a specific characteristic and might be related to the importance of the family, participants were also asked for their marital status. This meant whether they live with somebody, have children or not, and if so how many.

The summaries of the three variables are shown in Table 7, 8, and 9.

**Table 7** *Marital Status of the Participants*

	Swiss German <i>N</i> =200	Swiss French <i>N</i> =199	Swiss Italian <i>N</i> =200	Total <i>N</i> =599
Single	35%	40%	42%	39%
Married or living together	45%	50%	39%	44%
Divorced or living separated	13%	5%	12%	10%
Widow	7%	6%	8%	7%
No response	1%	0%	0%	0.2%
<b><i>TOTAL</i></b>	<b>101%</b>	<b>101%</b>	<b>101%</b>	<b>100.2%</b>

$$\chi^2(8, N=597) = 13.854; p=.086$$

Table 7 shows that there are no significant differences between the languages groups for the marital status. The amount of people married, living together, divorce

or living separated differs slightly from one group to the other but without producing an overall significant chi-square. Still Swiss French in this sample seem to almost never divorce, being either single or married and living together.

The next table (table 8) shows whether participants had children or not.

**Table 8** *Children of the Participants*

	Swiss German <i>N</i> =200	Swiss French <i>N</i> =199	Swiss Italian <i>N</i> =200	Total <i>N</i> =599
Yes	60%	55%	50%	55%
No	40%	45%	50%	45%
<i>TOTAL</i>	100%	100%	100%	100%

$$\chi^2 (2, N= 597) = 4.236; p=.120$$

Table 8 shows that in this sample, significantly more Swiss Germans have children than Swiss Italians. However, as shown in the next table (Table 9), Swiss Germans have fewer children on average than the other language groups.

**Table 9** *Number of Children per Participant*

	Swiss German <i>N</i> =120	Swiss French <i>N</i> =109	Swiss Italian <i>N</i> =99
Minimum	1	1	1
Maximum	5	7	5
Mean	2.11**	2.45	2.25

Language regressed on Number of children, significant difference between Swiss Germans and Swiss French with a beta coefficient of  $B = -.339$ ,  $t(322) = -2.953$ ,  $p < .01$

Language regions also differed in religion. This is historically known and documented by the Federal Statistics Office. The experiment sample approximately meets the data reported by the BFS (Bundesamt für Statistik). While the German speaking part is more Protestant, the Italian speaking part is more Catholic (see Table 10). Still, one should be reminded that most world religions favor organ donation (Swisstransplant, Schweizerische Nationale Stiftung für Organspende und

Transplantation, 2011a). Secondly, in 2006, Schulz et al. could not detect any effect of religion in predicting organ donation behavior in Switzerland (Schulz et al., 2006).

**Table 10** *Religion of the Participants*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Catholic	36%	70%	69%	58%
Protestant	41%	18%	11%	23%
Muslim	0.5%	0.5%	0.5%	1.5%
Jewish	0.5%	0%	0.5%	0.3%
Other	3%	0.5%	1%	2%
Laic or Non Active	19%	11%	18%	16%
<i>TOTAL</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>	<i>100.08%</i>

$\chi^2(10, N=599) = 79.29; p < .001$

In the following, the level of education of the different subsamples is examined. Table 11 shows the differences in the level of education of the different subsamples.

**Table 11** *Education of the Participants*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Obligatory School	13%	9%	16%	13%
Vocational Training (without high school degree)	25%	34%	25%	28%
Gymnasium / High School	16%	16%	23%	18%
University of Applied Sciences (Fachhochschule)	18%	14%	12%	14%
University Degree	29%	23%	23%	25%
Other	0%	4%	1%	2%
No school at all	0%	0%	0.5%	0.2%
<i>TOTAL</i>	<i>101%</i>	<i>100%</i>	<i>100.5%</i>	<i>100.2%</i>

$\chi^2(12, N=599) = 31.004; p < .01$

Table 11 mainly shows differences in the amount of people who finished school with a high school degree and participants who did a vocational training, which seems to occur particularly often among Swiss French participants. For the analysis Education of Participants was used as covariate to control for.

Table 12 describes the differences in professions of the participants. Unfortunately, most of the participants did not pay attention to the additional specification of who earns the most in the household. Many people marked the other category and specified they were a student, housewife, or pensioner. Thus the results of this question cannot be interpreted properly and cannot serve as a test of differences in social class. To indicate social class standing, the level of education would be a better indicator.

**Table 12** *Professional Activity of the Person who Earns most in the Household*

	Swiss German <i>N</i> =200	Swiss French <i>N</i> =199	Swiss Italian <i>N</i> =200	Total <i>N</i> =599
Worker	6%	4%	17%	9%
Employee or Functionary in Lower Position	25%	37%	29%	30%
Employee or Functionary in Higher Position	32%	34%	17%	28%
Employee or Functionary in Leading Position	9%	10%	9%	9%
Small Enterprises or Farmers without Employees	6%	3%	6%	5%
Company with Employees or Freelancers	17%	9%	8%	11%
Other	1%	2%	2%	2%
Student	2%	0%	8%	3%
Housewife	3%	0%	3%	2%
Pensioner	0%	2%	3%	2%
<i>TOTAL</i>	<i>101%</i>	<i>101%</i>	<i>102%</i>	<i>101%</i>

$\chi^2(18, N=599) = 79.984; p < .001$

Table 13 describes the rural/urban setting where participants came from.

**Table 13** *People's self-judgment of their rural / urban environment*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Agglomeration	17%	25%	40%	27%
City / Town	34%	38%	34%	35%
Country Side	48%	36%	26%	37%
Don't know	1%	1%	0.5%	1%
<i>TOTAL</i>	<i>100%</i>	<i>100%</i>	<i>100.5%</i>	<i>100%</i>

$\chi^2(6, N=599) = 34.285; p < .001$

While Swiss Italians came significantly more often from the agglomerations, Swiss French and Swiss Germans were more often from the countryside. As a last point, participants were cross-checked if they were working in the health sector and if so, where. The results are shown in Table 14.

**Table 14** *Participants working in the health sector*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Yes	12%	12%	8%	11%
No	89%	88%	92%	89%
<i>TOTAL</i>	<i>100%</i>	<i>100%</i>	<i>100.5%</i>	<i>100%</i>

Cross tab analysis showed a Pearson chi-square, which was not significant. Thus the sample contained the same amount of people working in a health-related field in all three language groups. On average 11% of the sample does work in the health sector.

## 7.4 Manipulation Checks

The manipulation check was evaluated with items included in the semantic differential, like item block. The first table (Table 15) shows as a reminder another overview on the number of flyers, of each type, given to each language group.

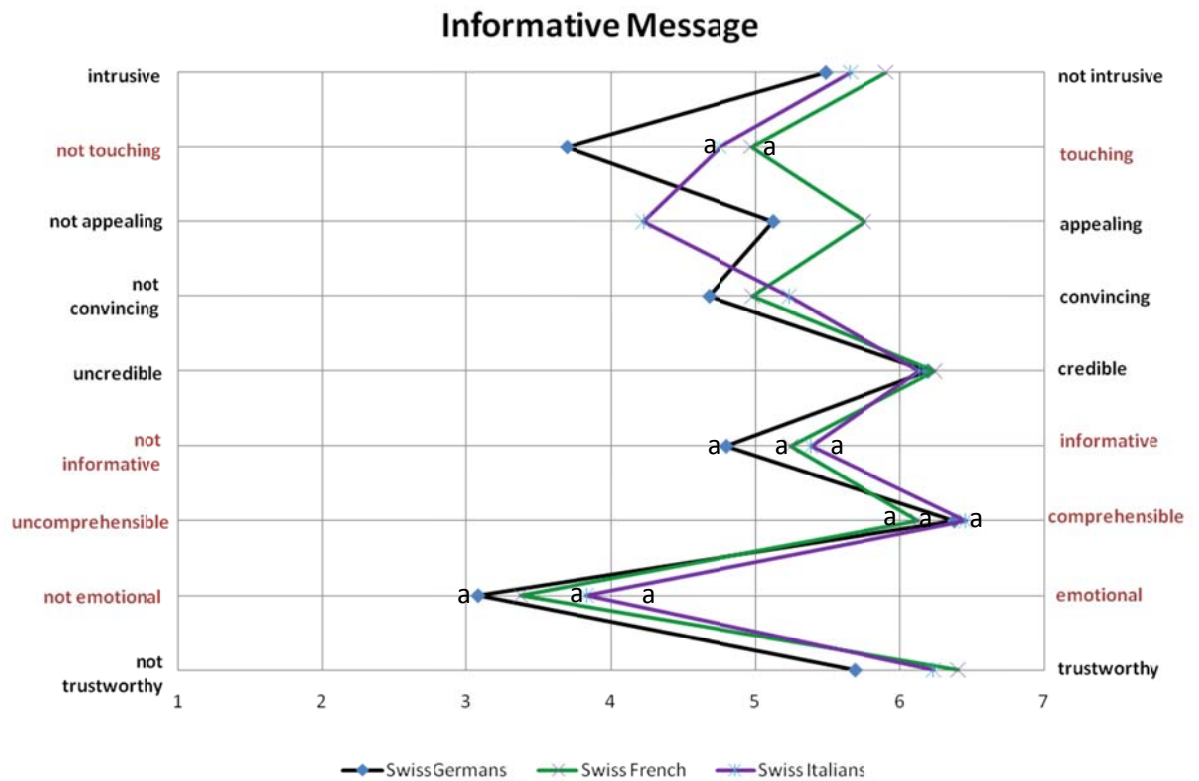
**Table 15** *Overview of the flyer versions that have been handed out.*

	Swiss German	Swiss French	Swiss Italian	Total
Informative/Objective Flyer	60	59	60	179
Emotional Flyer	60	60	59	179
Community Oriented Flyer	60	60	61	181
Control group (without Flyer)	20	20	20	60
<i>Total</i>	<i>200</i>	<i>199</i>	<i>200</i>	<i>599</i>

The following graphs show the manipulation check for each flyer separately. The items in red (touching, informative, comprehensible, and emotional) were those items used for the manipulation check. All items were expected to be comprehensible. The informative flyer was rated highly informative and scored lower on items such as touching and emotional.



Figure 17 shows the ratings for informative/objective kept flyer.

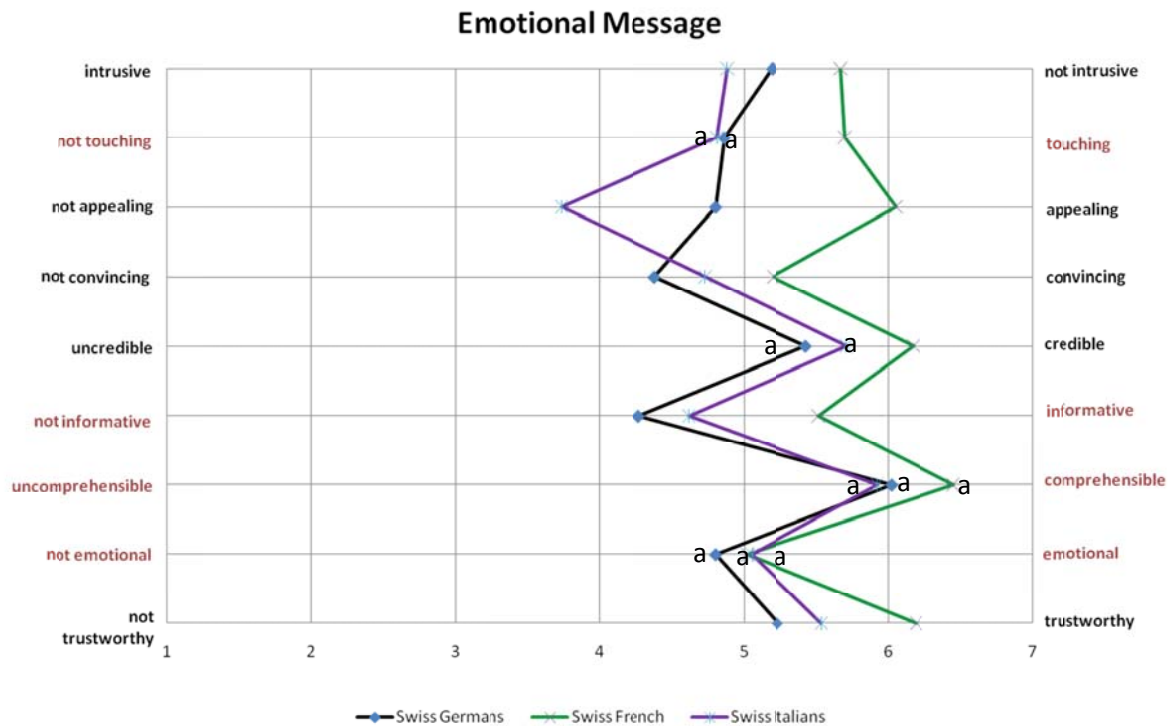


**Figure 17:** *Ratings per Language Group for the Informative Flyer.* **Note.** Means that do not share subscripts differ at  $p < .05$  in the Tukey honestly significant difference comparison.

As expected, all flyers were equally high rated on the item comprehensible. This means that participants did not have any problems understanding the content. Most of the participants did not find the informative flyer very emotional, meaning that the manipulation succeeded. Still, the mean for touching indicated that Swiss French and Swiss Italians, on average, found the informative flyer also touching. This is possible considering the precarious topic of organ donation and death (Bacigalupo et al., 2007; Serani-Merlo, 2007). In consequence, thinking about death might be considered touching to many people - an interpretation that needs to be proven by further research. Interestingly, Swiss Germans were the only subsample that had a

mean lower than 4 on the item touching, and thus do not seem to find the informational flyer touching, compared to the other two subsamples.

Figure 18 shows the manipulation check for the emotional message.

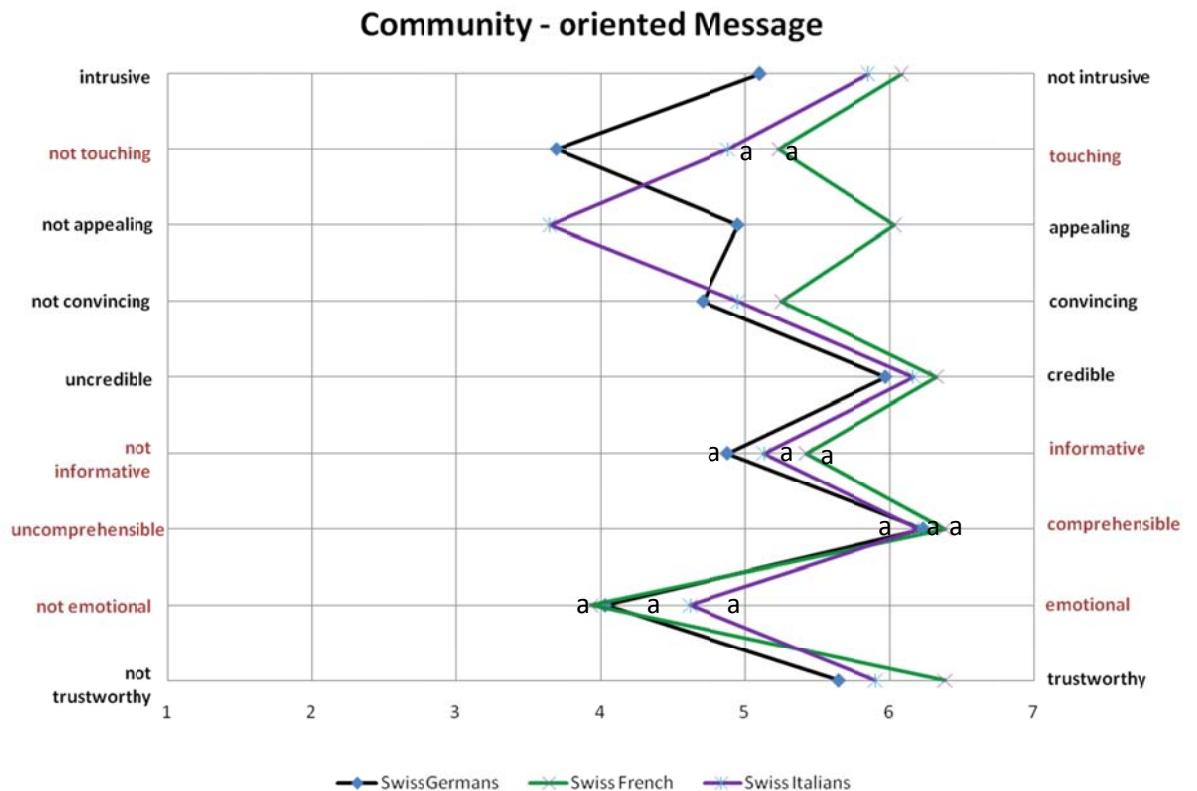


**Figure 18:** Ratings per Language Group for the Emotional Flyer. **Note.** Means that do not share subscripts differ at  $p < .05$  in the Tukey honestly significant difference comparison.

The emotional flyer was mostly comprehensible. The mean ratings for emotional and touching were above 4 in all language groups. This result is one that could be expected from an emotional flyer. This again confirms the effectiveness of the manipulation. Still, the flyer was overall assessed as informative. This was not exactly the intention of the manipulation, but is an acceptable side effect because some informative elements were consciously included in the flyer to make it appear more authentic (see chapter about flyer manipulation). While Swiss Germans and

Swiss Italians assessed the flyer as moderately informative, Swiss French found it much more informative.

Figure 19 shows the results for the community oriented message type.



**Figure 19:** Ratings per Language Group for the Community oriented Flyer. **Note.** Means that do not share subscripts differ at  $p < .05$  in the Tukey honestly significant difference comparison

Pleasingly, the community oriented flyer was also judged as comprehensible by all three language groups. This flyer was also assessed as *informative*. Surprisingly, when comparing the means for *informative* between all three flyers, all three flyers scored between almost 5 and 6. This again might be due to the fact that for practical reasons, a minimum amount of information about the organ donation procedure was provided to create an authentic “story” or message. This should not be a problem

given that additional mean comparisons<sup>36</sup> of the item *emotional* confirmed that, indeed, the informational flyer was much less *emotional* and hence confirmed the aim of the manipulation. It showed that, as intended, the informational flyer/message was assessed less *emotional* than the community oriented flyer, and the community flyer was assessed less *emotional* than the emotional flyer.

### 7.5 Attrition

#### 7.5.1 Simple Descriptive Analysis

Of the 599 overall participants, 428 (71.5%) also eventually participated in the post-test a couple of weeks later. Thus, 171 (28.5%) dropped out, either not willing to participate after the survey was over, or not answering their phone in February; hence the attrition rate of 28.5%.

#### 7.5.2 Identifying Different Patterns of Attrition

In the following, specific patterns of the non-response rate were checked for any specific language group, message, or other demographic variable.

Firstly, the impact of coming from a specific language group was checked with the willingness to participate in the second survey or not. To do this, dummy variables within the languages (German, French, and Italian) were regressed on the dummy variable attrition (0=the participant did not answer the second questionnaire 1=the participant did answer the follow-up questionnaire).

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<sup>36</sup> The graphs comparing the means of each flyer within each language group are attached in Annex D. This is to facilitate readability at this point and to avoid confusion.

**Table 16** Attrition by Language Group (Actual Counts)

	Language of the Interview			Total <i>N</i> = 599
	Swiss German <i>N</i> = 200	Swiss French <i>N</i> = 199	Swiss Italian <i>N</i> = 200	
Written and Telephone Survey	145	157	126	428
Written Questionnaire Only	55	42	74	171
Significance	ac*	ab***	b***c*	

a= Comparison between Swiss Germans and Swiss French ( $B = -.065$ ,  $t(598) = -1.451$ ,  $p = .147$ )

b= Comparison between Swiss French and Swiss Italians ( $B = .162$ ,  $t(598) = 3.61$ ,  $p < .001$ )

c= Comparison between Swiss Germans and Swiss Italians ( $B = .097$ ,  $t(598) = 2.16$ ,  $p < .05$ )

Concluding the table, the Swiss Italian attrition rate was significantly higher than the attrition rate of the other two language groups. There was no significant difference between Swiss French and Swiss Germans.

In a second step, it was analyzed if gender had an effect on attrition:

**Table 17** Attrition by Gender (Actual Counts)

	Gender		Total
	Male	Female	
Written and Telephone Survey	193	232	425
Written Questionnaire Only	89	81	170
<i>Total</i>	282	313	595

Regressions with dummies and analysis of variance results indicated that gender did not have a significant impact on the attrition rate.

Thirdly, the impact of age on attrition was examined. The results showed that the older the participants were, the less willing they were to participate in the second survey. The summarized PASW crosstab with chi-square is shown in Table 18.

**Table 18** Attrition by Age (Actual Counts)

	Age Group				Total
	Under 20	20-39	40-64	65+	
Written Questionnaire	0	58	71	42	171
Written and Telephone Survey	11	189	180	47	427
<i>Adjusted Residual for pre- and post-test</i>	<i>2.1</i>	<i>2.3</i>	<i>0.1</i>	<i>-4.2</i>	
<i>Total</i>	<i>11</i>	<i>247</i>	<i>251</i>	<i>89</i>	<i>598</i>

$\chi^2 (3, N= 599) = 22.653; p<.001$

A similar result was achieved when regressing age as scale variable (coded in years living) on attrition ( $B = -.004, t(597) = -3.586, p<.001$ ).

To sum up, the younger the people were, the more willing they were to participate in the second survey. Finally, it was analyzed whether having read any particular message had an effect on attrition. The results are shown in Table 19:

**Table 19** Attrition by Flyer

		Experimental Intervention			
		Informational Flyer	Emotional Flyer	Community Oriented Flyer	Control Group without Flyer
Written Questionnaire	Count	51	36	57	27
	Expected Count	51.1	51.1	51.7	17.1
	<i>Adjusted Residual</i>	<i>.0</i>	<i>-3.0</i>	<i>1.0</i>	<i>3.0</i>
Written and Telephone Survey	Count	128	143	124	33
	Expected Count	127.9	127.9	129.3	42.9
	<i>Adjusted Residual</i>	<i>.0</i>	<i>3.0</i>	<i>-1.0</i>	<i>-3.0</i>

$\chi^2 (3, N= 599) = 14.976; p<.01$

The table (19) shows that people who did not receive a flyer dropped out more often and did not want to participate in the second survey. However, people who received the emotional flyer were much more likely to participate in the second survey.

This effect occurs especially among Swiss Italians. Running the analysis for the three language groups separately, it is the only group where receiving a flyer was significantly predicting another participation in the second wave. Table 20 shows the results for Swiss Italians only, since for the other two groups the Chi-Squares were not significant.

**Table 20** Attrition by Flyer for Swiss Italians

		Experimental Intervention			
		Informational Flyer	Emotional Flyer	Community Oriented Flyer	Control Group without Flyer
Written Questionnaire	Count	18	16	17	13
	Expected Count	22.2	21.8	22.6	7.4
	<i>Adjusted Residual</i>	-1.3	-1.9	1.4	2.4
Written and Telephone Survey	Count	42	43	34	7
	Expected Count	37.8	37.2	38.4	12.6
	<i>Adjusted Residual</i>	1.3	1.9	1.4	-2.7

$$\chi^2 (3, N=200) = 11.840; p=.008$$





## **8 Measures**

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## 8.1 Personal Experience

*Personal Experience* was measured by three different terms. All three terms were categorical with two choices: yes or no. The questions were taken from Feeley & Servoss (Feeley & Servoss, 2005) and Schulz et al. (Schulz et al., 2006), and have been treated separately in the analysis. A summary of the first frequency results, per language region, is given Table 21 to 23.

**Table 21** *Do you personally know somebody who has received an organ or is waiting for an organ?*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Yes, I do know a person who has received or is waiting for an organ transplantation.	26%	41%	29%	32%
No, I do not know such a person.	74%	59%	71%	68%
<i>TOTAL</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>

$$\chi^2 (2, N = 599) = 11.875; p < .05$$

Underscore = less than expected answers in the cell

**Bold = more than expected answers in the cell**

**Table 22** *Do you personally know somebody who's family had to decide whether or not to give the organs of a deceased relative?*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Yes, I do know a person who has received or is waiting for an organ transplantation.	6%	10%	8%	8%
No, I do not know such a person.	95%	90%	92%	92%
<i>TOTAL</i>	<i>101%</i>	<i>100%</i>	<i>100%</i>	<i>100%</i>

$$\chi^2; p > .05$$

**Table 23** *Do you know any doctors or medical staff dealing with organ donation?*

	Swiss German <i>N</i> =200	Swiss French <i>N</i> =199	Swiss Italian <i>N</i> =200	Total <i>N</i> =599
Yes, I know personally such a person.	6%	3%	6%	5%
Yes, I know such a person through other people.	5%	4%	6%	5%
Yes, I know such a person from the media.	16%	11%	13%	13%
No, I do not know such a person.	74%	83%	76%	78%
<i>TOTAL</i>	<i>101%</i>	<i>101%</i>	<i>101%</i>	<i>101%</i>

$\chi^2$ ;  $p > .05$

At first glance, Tables 21 to 23 show that there were only slight differences among the language groups of people knowing a person to have received an organ. However, in the following analysis, the three items are treated separately.

If respondents answered *yes* in item 21 or 22, they were also asked to specify if the person they know was a friend, acquaintance, colleague, or part of their own family. Respondents in item 23 had four choices to choose from:

- *Yes, I know personally such a person*
- *Yes, I know such a person through other people*
- *Yes, I know such a person from the media*
- *No, I do not know such a person*

The question was reproduced from Schulz et al.'s study in 2006 (Schulz et al., 2006). However, to answer the before developed research question, it will not be further analyzed in this chapter, but shall be an object of separate examination.

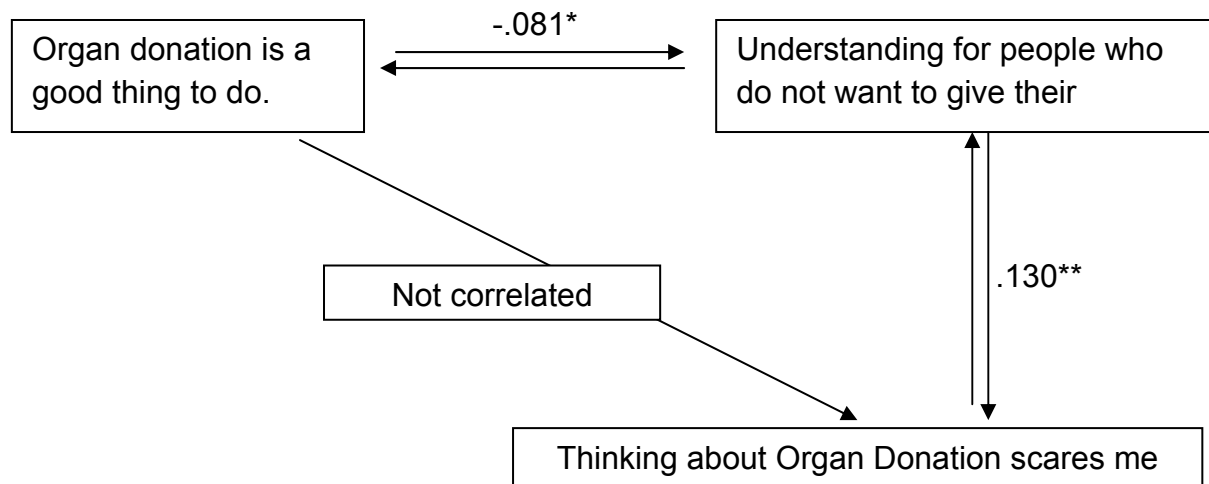
## 8.2 Attitude towards Organ Donation

Attitude was measured in the first wave with six items and in the second wave with two open questions. However, the latter is not going to be analyzed within this dissertation since it is not part of the hypothesized model. The two open questions, however, covering the main argument in favor or against organ donation, could eventually serve for a qualitative analysis. It could also help interpret where people see problems in the organ donation procedure.

Items in the first wave covered two levels: the general attitude towards organ donation (*Organ donation is a good thing to do, I can understand if people do not want to donate their organs, Thinking about organ donation scares me*) and what has been called the personal attitude toward organ donation.

The general attitude has been measured on a 7-point Likert type scale (1 *I totally disagree*, 7 *I totally agree*). The personal attitude was measured in two steps. In a first step, five answer categories were given (*Yes, I would, Yes probably, I don't know, No, probably not, and No, I would not [give my assent]*). In the second step, participants were asked on a 7-point Likert type scale how confident they were in answering the above question.

The correlation matrix of the general attitude showed that not all three items were correlated, which makes sense conceptually. A person who considers organ donation to be something good, might be less understanding towards people with a different opinion but still be scared when thinking about the practical implications of the topic. A summary of the correlation matrix is modeled in Figure 20, where “+” and “-” stand for a positive or negative correlation and \*\* equals a significance level of  $p < .01$ .



**Figure 20:** *Inter-Correlations between the Attitude Items.*

A factor analysis of the general attitude items came up with only one factor. However, considering the correlation table, it does not make sense conceptually to create an attitude index because two of the three variables were not correlated. Thus, for the analysis of the construct attitude, all items were kept separate.

### 8.3 Knowledge

Knowledge was sought after in a block of 14 statements. Participants had to read each statement and say whether they considered the statement true, false, or did not know. After data entry, the 14 items were re-coded in a dichotomous variable where 1 was the correct answer and 0 was the wrong answer. Both *I don't know* and wrong answers were coded together as *not knowing*.

The entire item block can be found in the synopsis of the questionnaire in Annex B.

After close examination, two items were eliminated from the analysis for ambiguity reasons. One item was eliminated because the answer had a true and a false dimension, making it difficult for participants to answer the question correctly. The other was eliminated because the response rate for Swiss Germans was extremely high while for Swiss Italians it was extremely low. This, on one hand, indicates a possible translation problem and on the other, was not coherent with the results of the other items.

Consequently, knowledge items were grouped into four categories of formative knowledge indices, summing up the right amount of answers.

The first knowledge category was *Procedural Knowledge*, comprising the following three items:

- After donation, the body must be burned and a normal funeral is not possible anymore. (wrong)
- Five years after receiving a donor organ, one can get to know the donor's family. (wrong)
- Organ donors can decide to whom they want to give their organs. (wrong)

Table 24 summarizes the frequency of the knowledge index *Procedural Knowledge*:

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	200	1.73	1.03	1.58	1.87
French	198*	2.06	0.97	1.92	2.19
Italian	200	1.50	1.03	1.35	1.64

*Note.* \*One interviewer apparently flipped over the knowledge page, this page remained as the only one empty.

The second knowledge category was *Medical/Technical Knowledge*, comprising of the following four items (see summary in Table 25):

- One can become a donor only at a certain age. (wrong)
- Organs can be taken if the heart has stopped beating. (wrong)
- Organs can be taken only after at least two independent doctors have confirmed the death. (right)
- Organs can be taken only if there is no doubt that the person is brain dead. (right)

**Table 25** *Index: Sum of Medical/Technical Knowledge Items (4)*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	200	2.13	1.20	1.96	2.30
French	198*	1.92	1.08	1.77	2.08
Italian	200	2.03	1.07	1.88	2.17

*Note.* \*One interviewer apparently flipped over the knowledge page, this page remained as the only one empty.

The third knowledge category was *Donor Card Knowledge*, comprising of three items (Table 26):

- Signing a donor card is binding for at least three months. (wrong)
- Before signing a donor card, one has to do a medical examination. (wrong)
- Once a donor card is signed, one will be registered into a central database. (wrong)



**Table 26** Index: Sum of Donor Card Knowledge Items (3)

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	200	1.18	1.08	1.02	1.33
French	198*	1.64	1.11	1.49	1.80
Italian	200	0.83	0.91	0.70	0.96

*Note.* \*One interviewer apparently flipped over the knowledge page, this page remained as the only one empty.

The fourth and last knowledge category was the *Relevance to Society Knowledge*, comprising of only two items (see summary Table 27):

- The transplantation of a heart, lung, liver, or kidney is usual practice in modern medicine. (right)
- Anybody who needs an organ in Switzerland receives one. (wrong)

**Table 27** Index: Sum of Relevance to Society Knowledge Items (2)

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	200	1.64	0.61	1.55	1.72
French	198*	1.61	0.58	1.53	1.69
Italian	200	1.32	0.71	1.22	1.41

*Note.* \*One interviewer apparently flipped over the knowledge page, this page remained as the only one empty.

## 8.4 Community Orientation

The concept *community orientation* was adapted from a form of Morgan and Miller's (Morgan & Miller, 2002) altruism scale, with a stronger focus on the family and community. It has been measured by seven items in the first wave and one item in the second. Since the first seven items were asked before the intervention, and the last item after the intervention, it was decided to separate the latter for further analysis. Thus why in the following it will not appear anymore and analysis will concentrate on the seven items only. All items were measured with a 7-point Likert type scale (1 = *I totally disagree* 7 = *I totally agree*).

Items asked for before the experimental intervention, were the following:

**Table 28** *My family is the most important thing in my life.*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	199	6.38	1.17	6.12	6.54
French	197	6.31	1.18	6.15	6.48
Italian	200	6.56	0.85	6.44	6.68

**Table 29** *My friends are the most important thing in my life.*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	199	5.13	1.64	4.90	5.36
French	197	5.38	1.42	5.18	5.58
Italian	200	5.22	1.51	5.01	5.43

**Table 30** *I get along alone and do not need anybody else to support me.*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	199	3.57	2.06	3.29	3.86
French	197	2.71	1.79	2.46	2.96
Italian	200	3.79	1.98	3.51	4.06

**Table 31** *I like to have many people around me.*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	199	4.90	1.64	4.67	5.13
French	198	4.92	1.49	4.72	5.13
Italian	200	5.00	1.63	4.77	5.23

**Table 32** *I like to be on my own.*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	199	4.36	1.67	4.12	4.59
French	198	4.21	1.79	3.96	4.46
Italian	200	4.38	1.79	4.13	4.63

**Table 33** *I like to do charity/be socially active.*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	200	4.06	1.88	3.79	4.32
French	197	4.25	2.00	3.97	4.53
Italian	200	4.33	1.81	4.07	4.58

**Table 34** *I know my neighbors very well.*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	200	4.62	1.77	4.37	4.86
French	197	4.52	1.93	4.25	4.79
Italian	200	4.52	1.97	4.24	4.79

An exploratory factory analysis with a Varimax rotation was run to reduce the seven items to fewer dimensions. Initially, the factorability of the seven items was examined. Several well-recognized criteria for the factorability of a correlation were used. Firstly, four of the seven items correlated with at least .3 to at least one other item, suggesting reasonable factorability. Secondly, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .541, which was slightly above the suggested KMO level of .5 in order to proceed with a factor analysis. The Bartlett's test of sphericity was significant ( $\chi^2$  (21)=359,13,  $p<.001$ ), supporting the hypothesis that the correlation matrix is not an identity matrix. Finally, the communalities were all above .3 (table 35), except for the item *My family is the most important in my life*; further confirming that each item shared some common variance with other items. Since the item *My family is the most important in my life* had a much lower communality level than the other items (see Table 36), with almost no variance in the answers and thus a non-normal distribution, it was decided to drop this item from the analysis.

**Table 35** *Communalities Community Orientation*

	Extraction
My family is the most important factor in my life	.293
My friends are most important in my life	.835
I get along alone and do not need anybody else to support me	.579
I like to have many people around	.631
I like to be on my own	.701
I like to do charity/be socially active	.504
I know my neighbors very well	.675

The maximum likelihood analysis is highly recommended in Ostello & Osborne's article (Costello & Osborne, 2005). They quote Fabrigar, Wegener, MacCallum, and Strahan (1999) saying that the maximum likelihood method would be the best, allowing "for the computation of a wide range of indexes of the goodness of fit of the model [and] permits statistical significance testing of factor loadings and correlations among factors and the computation of confidence intervals" (Costello & Osborne, 2005). Having run both, the classical default option of PASW, the principal component of extraction, still seemed to give more coherent results. Therefore, the following results are based on a principal component analysis to identify and compute composite community orientation scores with some underlying factors.

The initial eigen values showed the extraction of seven factors. The first factor explained 26% of the variance, the second 18%, and the third 16%. The result of the factor analysis is summarized in the rotated component matrix of Table 36:

**Table 36** *Rotated Component Matrix Community Orientation Items*

	Component		
	1	2	3
I know my neighbors very well	.816		
I like to do charity /be socially active	.708		
My family is the most important factor in my life	.525		
My friends are most important in my life		.910	
I like to have many people around		.677	
I like to be on my own			.820
I get along alone and do not need anybody else to support me			.741

Although the factor analysis suggested the existence of three underlying factors, it was decided to keep only two items, excluding the item *My family is the most important factor in my life* for the before explicated reasons.

Factor three was dropped since it is – conceptually – the exact opposite of factor two. A person who likes to be alone, most probably does not like to be with many people; as does a person getting along well alone, probably does not need any friends.

Therefore, composite scores, in the following called *indices*, were calculated for two factors based on the mean of the included items. These items had their primary loadings in the respective factor. The two factors were named 1) Community Index Social, a person who likes to be in company of others (including the items *My friends are most important to me* and *I like to have many people around*) and 2) Community Index Commitment towards society (including the items *I like to do charity/be socially active* and *I know my neighbors very well*).

Internal consistency for each scale was examined using Cronbach's alpha. The alphas were moderate and almost low: .532 for *Community Index Commitment* (two items) and .51 for *Community Index Social* (two items). Eliminating or adding more items could not have achieved substantial increases in alpha for any of the scales.

The descriptive statistics, split up by language group for the two community orientation factors (N=599), can be found in Table 37 and 38.

**Table 37** *Index Community Index Commitment (towards society)*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	200	4.34	1.52	4.12	4.55
French	199	4.39	1.57	4.17	4.61
Italian	200	4.42	1.62	4.19	4.65
<b>Total</b>	<b>599</b>	<b>4.38</b>	<b>1.57</b>	<b>4.25</b>	<b>4.51</b>

**Table 38** *Index Community Index Social (like to be in company)*

	N	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	200	5.02	1.36	4.83	5.21
French	198	5.15	1.16	4.99	5.31
Italian	200	5.11	1.30	4.93	5.29
<b>Total</b>	<b>599</b>	<b>5.09</b>	<b>1.28</b>	<b>4.99</b>	<b>5.20</b>

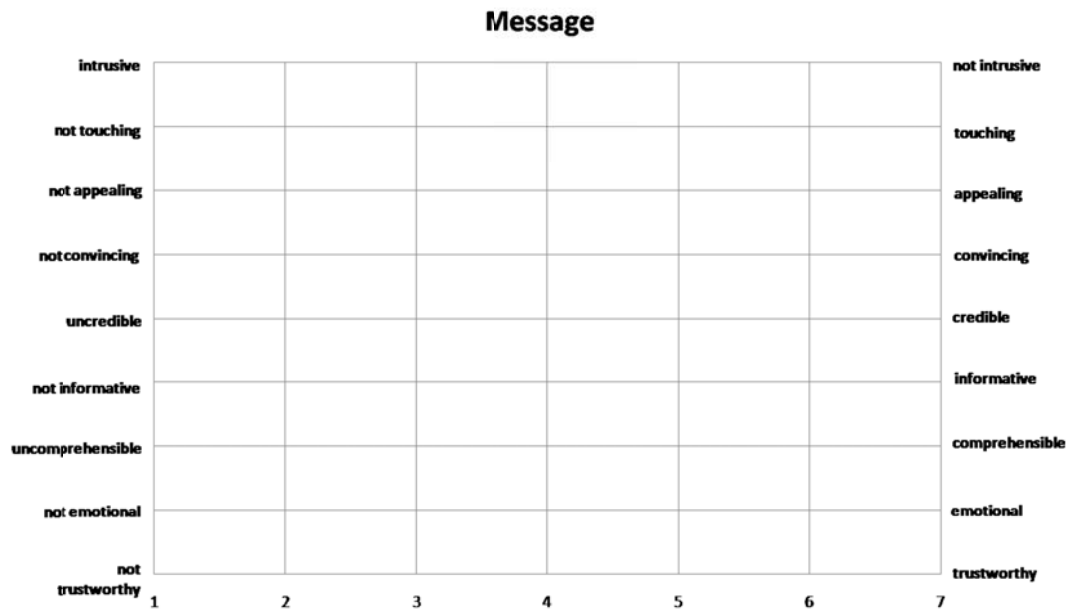
The Levene's test for homogeneity of variances was not significant, meaning the two factors met the for the analysis required criteria of homogeneity of variances. The simple ANOVA test on language and community orientation (index 1 and 2) was not significant either, suggesting that community orientation does not vary by language group.

## 8.5 The Operationalization of the Construct “Perception of the Flyer”

After reading a randomly assigned flyer, participants were presented with a block of items to evaluate how they perceived the experimental intervention. To evaluate the perception of the flyer, a semantic differential type scale was applied. According to Heise (Heise, 1970) the “semantic differential (SD) measures people's reactions to stimulus words and concepts in terms of ratings on bipolar scales defined with contrasting adjectives at each end” (Heise, 1970, p. 235). While the original Osgood scale goes from 3 to 0 and then up to 3 again, this study decided to stick with the 7-point Likert type scale to be consistent with the rest of the questionnaire and render the answering process easier. In Osgood's original scale, 0 equals *neutral* while in the 7-point scale the equivalent is *point 4*. The scale points were not assigned any label in this study. The end points were only labeled with the respective adjective (see Figure 21<sup>37</sup>). Items were chosen based on the message credibility scale used by Smith et al. in their 2004 study (Smith et al., 2004).

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<sup>37</sup> In the original questionnaire, positive and negative items were inverted. The item *intrusive* was recoded after data entry so 1 was always the negative ratings and 7 the positive ratings.



**Figure 21** *Template to test the appreciation of the flyer including items to cross-check the intervention manipulation.*

According to Heise (idem), the bipolar adjective, if adapted, is also usable for “persons from any culture”. The traditional semantic differential was designed to reduce affective reactions towards a specific object or concept to three dimensions, labeled Evaluation, Potency, and Activity (EPA). These dimensions have been verified and replicated in a notable variety of studies. As Heise (1970) summarizes, the EPA ratings have been obtained for hundreds of word concepts, stories and poems, social roles and stereotypes, colors, sounds, shapes, and for individual people.

In Switzerland, Fischer & Trier used the SD from Osgood et al. in 1962 for a socio-psychological study of the perception of the self and other among Swiss German and Swiss French citizens. While Fischer & Trier applied the Osgood et al. SD in its original design, this study is only using an adaption of the scale. This is because the aim was not to measure affect itself, but to what extent the message made people think and/or consequently change their attitude and behavior. Therefore, the scale



was used a) for an additional manipulation check and b) to test which message style might be more appreciated by which language group.

To be able to model the perception of the flyer together with the other constructs, it was necessary to reduce the nine items to two or more dimensions. To this end, an exploratory factor analysis has been conducted.

Initially, the factorability of the nine items were examined. The same criteria for the factorability of a correlation were used. Firstly, nine of the nine items correlated at least .3 to at least one other item, suggesting reasonable factorability. Secondly, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .805, which is well above the KMO level suggested to proceed with a factor analysis. The Bartlett's test of sphericity was significant ( $\chi^2(36)=1336,82$ ,  $p<001$ ), supporting that the correlation matrix is not an identity matrix.

Maximum likelihood analysis was used, for the before detailed reasons, with the oblique rotation matrix *direct oblimin* (PASW) to extract the factors.

The initial *Eigen* values showed the extraction of nine factors. The first factor explained 39% of the variance and the second 15%.

**Table 39** *Structure Matrix Perception of The Flyer*

	Factor	
	1	2
Trustworthy	.730	
Emotional		
Comprehensible	.594	
Informational	.488	-.618
Credible	.828	
Convincing	.567	-.857
Appealing	.554	
Touching	.343	-.354
Not Intrusive	.483	

Since the output of the factor analysis was neither conceptually consistent with a principal component estimate nor with a maximum likelihood estimate, the factor analysis was dropped. Instead, two formative indices have been constructed from a conceptual perspective.

The first index summarized the evaluative adjectives *credible*, *trustworthy*, *informative*, and *convincing* under the label *Cognitive Perception* of the flyer. The second index was created with the label *Affective Perception* including the ratings of the items *appealing*, *touching*, and *not intrusive*.

Internal consistency for each of the scales was examined using Cronbach's alpha. The alpha for the index *Cognitive Perception* was relatively high, with .76. This is not surprising considering that the structural matrix correlated eight out of nine items. The alpha for the index *Affective Perception* of the flyer was moderately low, with a value of .46. However, conscious of this statistical weakness, the decision was made to continue the analysis. It seemed more reasonable to group cognitive reactions to the flyer, such as credibility or trustworthiness, on the one hand and affective reactions, such as appealing, touching or intrusive, on the other hand.

## 8.6 The Operationalization of the Construct “Feelings about Organ Donation Evoked by the Flyer”

The feelings evoked by the flyer, in addition to the assessment by adjectives, were measured with seven items on a 7-point Likert type scale (1 = *I totally disagree*, 7 = *I totally agree*). Items were chosen based on the anxiety scale used by Smith et al. in their 2004 study (Smith et al., 2004).

An exploratory factory analysis with a Varimax rotation was run to reduce the seven items to fewer dimensions. Initially, the factorability of the seven items was examined. The same criterion as before for the factorability of a correlation was used. Firstly, seven of the seven items correlated at least .3 to at least one other item, suggesting reasonable factorability. Secondly, the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy was .55, which is again slightly above the suggested KMO level of .5 to proceed with a factor analysis. The Bartlett's test of sphericity was significant ( $\chi^2$  (21)=791,32,  $p<001$ ), supporting the hypothesis that the correlation matrix is not an identity matrix. Finally, the communalities were all above .3, further confirming that each item shared some common variance with other items (Table 40).

**Table 40** *Communalities Feelings About the Flyer*

	Extraction
While reading the flyer, I felt aggressed.	.736
While reading the flyer, I was worried.	.817
The flyer made me appeased.	.510
The flyer put OD in a positive light	.742
The flyer made me pensive/thoughtful.	.852
The flyer made me nervous.	.721
The flyer would be understandable also for friends and family.	.607

Also, after running both an explorative factor analysis with orthogonal axis as well as a free moving axis (oblimin), it was decided that this item should stick with the principal component extraction with a Varimax rotation.

The initial *Eigen* values showed the extraction of seven factors. The first factor explained 29% of the variance, the second 26%, and the third 16%. The result of the factor analysis is summarized in the rotated component matrix of Table 41:

**Table 41** *Rotated Component Matrix*

	Component		
	1	2	3
While reading the flyer, I felt aggressed.		,490	,698
While reading the flyer, I was worried.			,897
The flyer made me appeased.	,692		
The flyer put OD in a positive light	,847		
The flyer made me pensive/thoughtful.		-,878	
The flyer made me nervous.		,752	
The flyer would be understandable also for friends and family.	,742		

When exploring the data with different combinations of inclusion of items, the decision was made to exclude the item *While reading the flyer, I was worried*. Consequently, the rotated component matrix only suggested two factors with loadings higher than .6. The new matrix was changed to look like Table 42:

**Table 42** *Rotated Component Matrix*

	Component	
	1	2
The flyer put OD in a positive light	.855	
The flyer made me appeased.	.723	
The flyer would be understandable also for friends and family.	.675	
The flyer made me nervous.		.839
While reading the flyer, I felt aggressed.		.785
The flyer made me pensive/thoughtful.		-0.64

Before calculating composite scores, the item *The flyer made me pensive* (1 = *I totally disagree*, 7 = *I totally agree*) was inverted. Therefore on the new scale, 1 would mean that the flyer made the person pensive and 7 that the person's emotional condition had not changed because of the flyer. Since the factor analysis showed such high factor loadings; with the negative emotions *aggressed* and

*nervous*, not thinking about organ donation, or being indifferent towards the topic, these were included in the same index as negative feelings.

The composite scores, again called *indices*, were calculated for two factors based on the mean of the included items, which had their primary loadings on the respective factor. The two factors were named:

1) Index (Flyer Positive): The flyer generated positive feelings, including items provoking positive feelings in the participants such as *The flyer put organ donation in a positive light*, *The flyer made me appeased*, and *The flyer would be understandable also for my friends and my family*.

2) Index (Flyer Negative): The flyer made participants nervous, including the items *The flyer made me nervous*, *While reading the flyer I felt aggressed*, and *The flyer made me pensive*.

Internal consistency for each of the scales was examined using Cronbach's alpha. The alphas were moderately high: .649 for *Index Flyer Negative* (3 items) and .637 for *Index Flyer Positive* (3 items). Eliminating or adding more items could not have achieved substantial increases in alpha for any of the scales.

The descriptive statistics split up by language group for the two flyer indices (factors) (N=540<sup>38</sup>) can be found in Table 43 and 44.

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<sup>38</sup> The N here is different from before because the control group did not get a flyer to read. Therefore, did also not have the part of the questionnaire asking about their perception or feelings of the flyer.

**Table 43** *Index: The Flyer Generated Positive Feelings (Index Positive)*

	<i>N</i> <sup>39</sup>	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	178	5,01	1,23	4,82	5,19
French	176	5,47	1,14	5,30	5,64
Italian	180	4,66	1,45	4,44	4,87

**Table 44** *Index: The Flyer Made the Participants Nervous (Index Nervous)*

	<i>N</i> <sup>39</sup>	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	178	2,43	0,95	2,29	2,57
French	176	2,34	1,07	2,18	2,50
Italian	180	5,25	1,09	5,09	5,41

### 8.7 The Operationalization of the Construct “Intention to donate” (Written Questionnaire)

The intention to donate one’s organs after death was measured with two items on a 5-point scale: 1 = no, 2 = probably not, 3 = I don’t know, 4 = probably yes, and 5 = yes.

The questions were: *Would you agree to donate your organs after death?* and *Would you sign a donor card?* Additionally, the questionnaire assessed whether people already had a donor card (yes/no) and whether they had thought about

<sup>39</sup> The *N* here is different from before because the control group (60 participants) did not get a flyer to read. Therefore, did also not have the part of the questionnaire asking about their perception or feelings of the flyer.

organ donation before (yes/no). Only the first two questions were used to assess the intent to donate.

**Table 45** *Would you agree to organ donation after your death?*

	<i>N</i>	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	196	3.87	1.28	3.69	4.05
French	195	4.21	1.08	4.05	4.36
Italian	200	3.89	1.31	3.70	4.07

**Table 46** *Would you sign a donor card?*

	<i>N</i>	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	166	3.43	1.23	3.25	3.62
French	129	3.66	1.21	3.45	3.87
Italian	174	3.49	1.32	3.29	3.69

## 8.8 The Operationalization of the Construct “Intention to donate” (Telephone Survey)

The same question as in wave one was asked again in wave two, measuring the willingness to sign a donor card in the future on a 5-point Likert-type scale.

**Table 47** *Would you sign a donor card?*

	<i>N</i>	Mean	SD	95%-Confidence Interval	
				Lower Bound	Upper Bound
German	143	3.87	1.290	3.65	4.08
French	155	4.26	1.161	4.07	4.44
Italian	126	4.09	1.180	3.88	4.30

The second question on signing a donor card was dichotomous, and respondents in the telephone had the choice of answering *yes* or *no*. A summary is shown in Table 48.

**Table 48** *Summary: Would you sign a donor card? - Written and Telephone Survey Compared*

	Swiss German		Swiss French		Swiss Italian	
	Written n=166 %	Telephone n=68 %	Written n=129 %	Telephone n=66 %	Written n=174 %	Telephone n=67 %
Yes, I would sign a donor card.	20	<b>53</b>	27	<b>46</b>	28	<b>81</b>
Yes, probably.	34	♦	36	♦	28	♦
I don't know.	29	♦	21	♦	24	♦
No, probably not.	5	♦	6	♦	8	♦
No, I would not sign a donor card.	13	<b>47</b>	9	<b>55</b>	13	<b>19</b>
<i>TOTAL</i>	<i>101</i>	<i>100</i>	<i>99</i>	<i>101</i>	<i>101</i>	<i>100</i>

## 8.9 The Operationalization of the Construct “Behavior” (Wave Two)

The variable measuring the actual outcome, *Behavior*, is categorical and summarized in Table 49 (*Have you gotten a donor card since the first interview? (yes/no)*).



**Table 49** *Summary Behavior in Wave 1 and 2*

	Swiss German		Swiss French		Swiss Italian	
	Written	Telephone	Written	Telephone	Written	Telephone
	n=200	n=144	n=199	n=157	n=200	n=125
	%	%	%	%	%	%
Yes, I have a donor card (had it before the 1st interview).	14	21	33	37	13	18
Yes, I have a donor card (received since the last interview).	♦	13	♦	12	♦	17
No, I do not have a donor card.	86	66	68	52	87	65
<i>TOTAL</i>	<i>100</i>	<i>100</i>	<i>101</i>	<i>101</i>	<i>100</i>	<i>100</i>

♦ Question has not been asked during the interview.



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## 9.1 Patterns in Organ Donation “Thinking” among Language Groups

As starting point, the items were analyzed separately. A basic frequency table was produced for every item of the pre- and post-test. Language groups reported frequencies and first significance tests were run to see whether there were major differences on single items according to language group.

### 9.1.1 Willingness and Intentions to Donate Organs after Death by Language Group

Before analyzing the willingness, intention, and signing of a donor card by language group, Table 50 shows how many participants already had a donor card during the first interview and how many participants signed one in between the two interviews. Showing the respective increase in total donors card from the first to the second interview.

**Table 50.** *Possession of a Donor Card by the Participants of the First Wave.*

	Swiss German <i>N=195</i>	Swiss French <i>N=194</i>	Swiss Italian <i>N=200</i>	Total <i>N=589</i>
Yes, have donor card.	<u>14%</u>	<b>33%</b>	<u>13%</u>	20%
No, don't have donor card.	<b>86%</b>	<u>68%</u>	<b>87%</b>	80%

$\chi^2$  (2, N = 589) = 29.012;  $p=.000$

Underscore = adjusted residual < 1.96

**Bold= adjusted residual > 1.96**

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Table 50 shows that compared to Swiss Germans and Swiss Italians, Swiss French were much more likely to have already signed a donor card before the first interview took place.

In the following, behavioral patterns will be assessed and summarized further under the name *intention to engage in organ donation behavior*. This includes the willingness to donate and sign a donor card during the first and the second wave.

Univariate ANOVA, with language as the fixed factor and the three outcome variables (willingness to donate wave one, willingness to sign a card wave one, and willingness to donate wave two) as dependent variables, show differences in the intention to engage in organ donation behavior among the language groups in a separate analysis.

The means for the willingness to donate in wave one significantly differed among the language groups,  $F(2, 589) = 4.696$ ,  $p = .009$ . Tukey post-hoc comparisons of the language groups indicate that Swiss French ( $M = 4.21$ , 95% CI [4.05, 4.36]) are significantly more likely to be willing to donate their organs after death than Swiss Germans ( $M = 3.87$ , 95% CI [3.69, 4.05]),  $p = .018$  or Swiss Italians ( $M = 3.89$ , 95% CI [3.70, 4.07]),  $p = .027$ . However, Swiss Germans and Swiss Italians do not differ in the willingness to donate ( $p = .989$ ).

Consequently, participants were asked how sure they were in giving an answer to the latter question. This question was also tested for group differences, which were shown to be significant:  $F(2, 589) = 6.143$ ,  $p = .002$ . Interestingly, Swiss Italians ( $M = 5.98$ , 95% CI [5.77, 6.19]) were much more confident in answering the question about their willingness to donate than Swiss Germans were ( $M = 5.37$ , 95% CI [5.31, 5.61]),  $p = .001$ . All other comparisons produced by the Tukey post-hoc analysis showed to be not significant at an  $\alpha$ -level of  $p < .05$ .

The overall test for the comparison was not significant for the variable *Willingness to sign a donor card*  $F(2, 469) = 1.226$ ,  $p = .294$ . The Tukey post-hoc comparison confirmed the overall statistics, leading to the conclusion that in each language

region the same amount of people would potentially sign a donor card as in the other regions.

The question about the willingness to donate or not was repeated in the second wave. It showed an overall significant F-statistic as well,  $F(2, 424) = 3.876$ ,  $p = .021$ . Again, as in the first wave, Tukey post-hoc comparisons showed that Swiss French ( $M = 4.28$ , 95% CI [4.07, 4.44]) were significantly more likely to be willing to donate their organs after death than Swiss Germans ( $M = 3.87$ , 95% CI [3.65, 4.08]),  $p = .016$ . However, the contrast between Swiss French ( $M = 4.28$ , 95% CI [4.07, 4.44]) and Swiss Italians ( $M = 4.09$ , 95% CI [3.88, 4.30]) was not significant, neither was the one opposing Swiss Italians to Swiss Germans. A summary of these results is shown in Table 51.

**Table 51.** Mean scores of Participants on Intention to Engage in Organ Donation Behavior.

		Swiss Germans	Swiss French	Swiss Italians
<i>Number of participants</i>	<i>N</i>			
1. Willingness to donate (wave1)	591	3.87 <sub>a</sub> [3.69, 4.05]	4.21 [4.05, 4.36]	3.89 <sub>a</sub> [3.70, 4.07]
1a. How secure were you giving the answer	591	5.37 <sub>a</sub> [5.31, 5.61]	5.66 <sub>ab</sub> [5.38, 5.94]	5.98 <sub>b</sub> [5.77, 6.19]
2. Willingness to sign card (wave1)	469	3.43 <sub>a</sub> [3.25, 3.62]	3.66 <sub>a</sub> [3.45, 3.87]	3.49 <sub>a</sub> [3.29, 3.69]
3. Willingness to donate (wave2)	424	3.87 <sub>a</sub> [3.65, 4.08]	4.28 <sub>b</sub> [4.07, 4.44]	4.09 <sub>ab</sub> [3.88, 4.30]

*Note.* Values for 1, 2 and 3 are mean scores on a 5-item scale (1 = no, 1 = probably not, 2 = don't know, 3 = probably yes, 4 = yes). Values for 1a are mean scores on a 7-item scale (1 = not sure at all, 7 = totally sure). Numbers in brackets are 95% confidence intervals of the means. Means that do not share subscripts differ at  $p < .05$  in the Tukey honestly significant difference comparison.

Additionally, it was examined whether there were differences among the language groups in the willingness to sign a card (second wave) and actually having signed a donor card after the first interview. Results of the chi-square test are shown in Table 52 and 53.

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**Table 52.** *Possession of a Donor Card by the Participants of the Second Wave.*

	Swiss German <i>N=144</i>	Swiss French <i>N=157</i>	Swiss Italian <i>N=125</i>	Total <i>N=426</i>
Participants <b>not</b> having a donor card after the second wave	66%	<u>52%</u>	65%	60%
Participant who had already a donor card before the first interview.	21%	<b>37%</b>	<u>18%</u>	26%
Participant who signed donor card after the first interview.	13%	12%	<b>17%</b>	14%

$$\chi^2 (4, N = 426) = 16.104; p=.003$$

Underscore = adjusted residual < 1.96

**Bold = adjusted residual > 1.96**

Table 53 shows that Swiss French had donor cards more often in the first wave than the other two language groups. Still, there were no significant differences between the three language groups in the number of people who signed a donor card between the interviews and only when looking at those who did not have a donor card in the first wave. Therefore, in all three language groups, approximately the same number of people signed a donor card after the first interview. However, this does not tell the whole truth: table 53 also shows the increase in organ donor cards per language group, which eventually shows significant differences among the language groups.



**Table 53.** *Increase in Signed Donor Cards of Participants in First and Second Wave.*

	Swiss German <i>N=49</i>	Swiss French <i>N=76</i>	Swiss Italian <i>N=44</i>	Total <i>N=169</i>
Participant had already a donor card during the first interview.	30 (61%)	<b>58 (76%)</b>	<u>23 (52%)</u>	111 (66%)
Participant signed donor card after the first interview.	19 (39%)	<u>18 (24%)</u>	<b>21 (48%)</b>	58 (34%)
<i>Increase in Donor Cards</i>	63%	31%	91%	52%

$$\chi^2 (2, N = 169) = 7.754; p=.021$$

Underscore = adjusted residual < 1.96

**Bold = adjusted residual > 1.96**

Only looking at the net number of signed donor cards (in brackets), as said before, as many Swiss Germans signed a donor card as Swiss French or Swiss Italians did. Only looking at the percentages, one might get the impression that Swiss Italians signed a donor card after the first interview significantly more often than Swiss Germans or Swiss French. However, saying there were no differences would, again, not tell the whole story either. Looking at the increase in organ donor cards between the two waves, there were overall over 50% more signed donor cards than before the interview. While among Swiss French, the increase in donor cards was about 30%, for Swiss Germans an increase of 60% could be observed, and even a 90% increase among Swiss Italians.

The more positive attitude among Swiss Italians could also be observed with the question about the future willingness to sign a card. Results are summarized in Table 54, showing the willingness to sign a donor card for those who did not do so when asked in the second interview. About 45% of the Swiss Italian participants and only 25% of the Swiss French citizens said yes. This is explainable considering that Swiss French already had a donor card in the first wave much more often than expected.

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**Table 54.** *Would You Sign a Donor Card? (Wave 2) (All participants not having signed a card in wave 2 yet)*

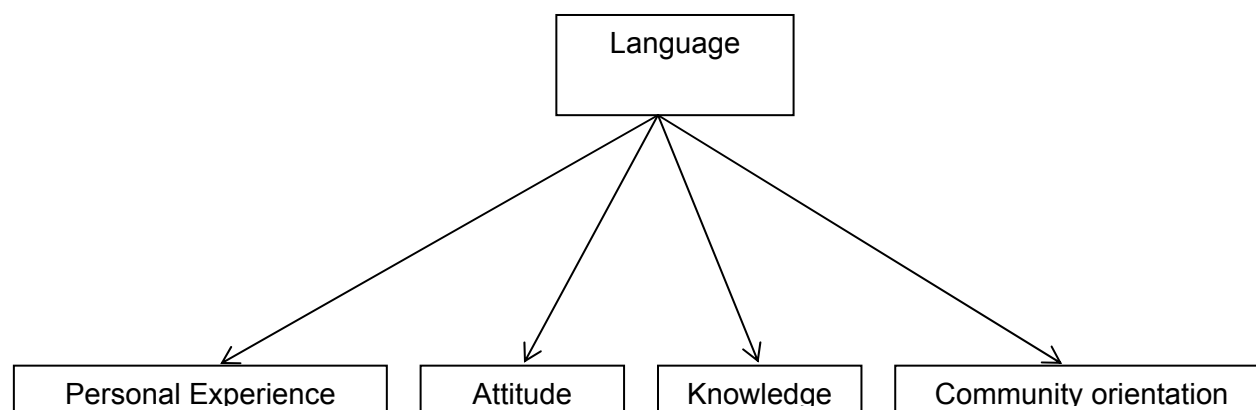
	Swiss German <i>N</i> =68	Swiss French <i>N</i> =66	Swiss Italian <i>N</i> =66	Total <i>N</i> =200
Yes, I would.	53%	<u>46%</u>	<b>81%</b>	60%
No, I would not.	47%	<b>55%</b>	<u>19%</u>	40%

$\chi^2 (2, N = 200) = 18.470; p < .001$

Underscore = adjusted residual < 1.96

**Bold = adjusted residual > 1.96**

### 9.1.2 Attitudinal Components of Organ Donation Thinking



**Figure 22:** *Linguistic differences in organ donation behavior and community orientation of the participants*

In a first step, it was important to examine whether participants differed on particular items according to their adherence to a specific language group. In the following, it will be examined whether key items such as personal experience, attitude towards

organ donation, knowledge, and community orientation were significantly different across the language groups.

### 9.1.2.1 *Personal Experience*

Table 55 shows the summary of people who know somebody who has received or is waiting for an organ. In the table, Swiss French know of such a person significantly more often than Swiss Germans and Swiss Italians do.

**Table 55.** *Do You Personally Know Somebody Who Has Received an Organ or Is Waiting for an Organ.*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=599</i>
Yes, I do know a person who has received or is waiting for an organ transplantation.	<u>26%</u>	<b>41%</b>	29%	32%
No, I do not know such a person.	<b>74%</b>	<u>59%</u>	71%	68%

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$$\chi^2 (2, N = 599) = 11.875; p = .003$$

Underscore = adjusted residual < 1.96

**Bold = adjusted residual > 1.96**

Table 56 shows the percentage of participants in each language group who knew somebody or a family that had to decide about organ donation for a deceased relative. The same tendency could be observed as before. However, the difference between the language groups was not strong enough to render the chi-square significant.

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**Table 56.** *Do You Personally Know Somebody Whose Family Had to Decide about Organ Donation of a Deceased Family Member.*

	Swiss German <i>N=200</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=200</i>	Total <i>N=597</i>
Yes, I do know such a person.	6%	10%	8%	8%
No, I do not know such a person.	95%	90%	92%	92%

$\chi^2 > .05$

The last relevant question to control for people being involved (emotionally involved) in the organ donation procedure was whether they knew any medical staff working with organ donation. Table 57 shows the percentages for each language group, they were not significantly different.

**Table 57** *Do You Know any Doctors or Medical Staff Dealing With Organ Donation?*

	Swiss German <i>N=198</i>	Swiss French <i>N=199</i>	Swiss Italian <i>N=197</i>	Total <i>N=594</i>
Yes, I know personally such a person.	6%	3%	6%	5%
Yes, I know such a person through other people.	5%	4%	6%	5%
Yes, I know such a person from the media.	16%	11%	13%	13%
No, I do not know such a person.	74%	83%	76%	78%

$\chi^2 > .05$

### 9.1.2.2 Attitude

Univariate ANOVA was used to test for differences on each of the items mentioned in Table 58. Means differed significantly among the language groups for the item *Organ donation is a good thing to do*,  $F(2, 596) = 6.67$ ,  $p = .001$ . Tukey post-hoc comparisons of the three groups indicated that Swiss French ( $M = 6.58$ , 95% CI [6.44, 6.72]) gave significantly higher ratings on the 7-point scale than Swiss Germans ( $M = 6.13$ , 95% CI [5.93, 6.33]),  $p = .001$ . Comparisons between Swiss Italians ( $M = 6.36$ , 95% CI [6.19, 6.54]) and the other two groups were not statistically significant at  $p < .05$ .

For the second item, *I can understand if somebody does not want to donate his organs after death*, means differed significantly among the language groups,  $F(2, 596) = 3.176$ ,  $p = .042$ . Tukey post-hoc comparisons of the three groups indicated that Swiss French ( $M = 5.69$ , 95% CI [5.46, 5.91]) gave significantly higher ratings on the 7-point scale than Swiss Italians ( $M = 5.25$ , 95% CI [4.96, 5.53]),  $p = .047$ . Comparisons between Swiss Germans ( $M = 5.6$ , 95% CI [5.34, 5.87]) and the other two groups were not statistically significant at  $p < .05$ .

For the third item, *Organ donation scares me*, means did not differ significantly among the language groups,  $F(2, 597) = .938$ ,  $p = .392$ . Tukey post-hoc comparisons of the three groups were still run for explorative reasons, and confirmed the overall test. Neither Swiss French ( $M = 2.66$ , 95% CI [2.38, 2.94]), Swiss Italians ( $M = 2.79$ , 95% CI [2.50, 3.07]), nor Swiss Germans ( $M = 2.52$ , 95% CI [2.27, 2.76]) differed from each other on this item at an  $\alpha$ -level of  $p < .05$ .

Means differed significantly among the language groups for the fourth item, *Would you agree to donate the organs of a deceased relative who did not express to do so or not before dying?*,  $F(2, 596) = 9.827$ ,  $p = .000$ . Tukey post-hoc comparisons of the three groups indicated that Swiss French ( $M = 3.41$ , 95% CI [3.21, 3.61]) gave significantly higher ratings on the 7-point scale than Swiss Italians ( $M = 3.07$ , 95% CI [2.88, 3.26]),  $p = .042$  and Swiss Germans ( $M = 2.79$ , 95% CI [2.59, 2.99]),  $p =$

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.000. Comparisons between Swiss Germans and Swiss Italians were not statistically significant at  $p < .05$ .

**Table 58.** Summary of Group Comparisons. Attitude Towards Organ Donation.

	Swiss Germans	Swiss French	Swiss Italians
<i>N</i>	200	199	200
1. Organ Donation is a good thing to do.	6.13 <sub>a</sub> [5.93, 6.33]	6.58 <sub>b</sub> [6.44, 6.72]	6.36 <sub>ab</sub> [6.19, 6.54]
2. I can understand if somebody does not want to donate his organs after death.	5.60 <sub>ab</sub> [5.34, 5.87]	5.69 <sub>a</sub> [5.46, 5.91]	5.25 <sub>b</sub> [4.96, 5.53]
3. Thinking about organ donation scares me.	2.52 <sub>a</sub> [2.27, 2.76]	2.66 <sub>a</sub> [2.38, 2.94]	2.78 <sub>a</sub> [2.50, 3.07]
4. Would you agree to donate the organs of a deceased relative who did not express to do so or not before dying?	2.79 <sub>a</sub> [2.59, 2.99]	3.41 [3.21, 3.61]	3.07 <sub>a</sub> [2.88, 3.26]

*Note.* Values are mean scores on a 7-point scale (1 = *I totally disagree*, 7 = *I totally agree* for items 1-3 and 1 = *no*, 2 = *probably not*, 3 = *don't know*, 4 = *probably yes*, 5 = *yes* for item 4). Numbers in brackets are 95% confidence intervals of the means. Means that do not share subscripts differ at  $p < .05$  in the Tukey honestly significant difference comparison.

### 9.1.2.3 Knowledge

Table 59 shows the overall summary of means and standard deviations for each knowledge category. At the first glance, means show that overall; Swiss Italians seem to know much less about organ donation than the other two groups. This confirms what Schulz et al. found out in their 2006 survey, stating that Swiss Italians barely know anything about the organ donation procedure. To test if differences varied significantly among the language groups, Univariate ANOVAs were again used as a test method for each of the items mentioned in Table 59.

For *procedural knowledge*, means differed significantly among the language groups,  $F(2, 598) = 15.498$ ,  $p = .000$ . Tukey post-hoc comparisons of the three groups indicated that Swiss French ( $M = 2.06$ , 95% CI [1.92, 2.19]) gave the right answer significantly more often than Swiss Germans ( $M = 1.73$ , 95% CI [1.58, 1.87]),  $p =$

.003 and Swiss Italians ( $M = 1.50$ , 95% CI [1.35, 1.64])  $p = .000$ . Comparisons between Swiss Italians and Swiss Germans were not statistically significant at  $p < .05$ .

For *medical/technical knowledge*, means did not differ significantly among the language groups,  $F(2, 598) = 1.682$ ,  $p = .187$ . Tukey post-hoc comparisons of the three groups were still run for explorative reasons and confirmed the overall test. Neither Swiss French ( $M = 1.92$ , 95% CI [1.77, 2.08]), Swiss Italians ( $M = 2.03$ , 95% CI [1.88, 2.17]), nor Swiss Germans ( $M = 2.13$ , 95% CI [1.96, 2.30]) differed from each other on this item at an  $\alpha$ -level of  $p < .05$ .

For the item *knowledge about the donor card*, means differed significantly among the language groups,  $F(2, 598) = 30.634$ ,  $p = .000$ . Tukey post-hoc comparisons of the three groups indicated that Swiss French ( $M = 1.64$ , 95% CI [1.49, 1.80]) gave the right answer significantly more often than Swiss Germans ( $M = 1.18$ , 95% CI [1.02, 1.33]),  $p = .000$  and Swiss Italians ( $M = .83$ , 95% CI [0.70, 0.96])  $p = .000$ . Also, comparisons between Swiss Italians and Swiss Germans were statistically significant at  $p = .003$ .

For *knowledge about the relevance of organ donation for society*, means differed significantly among the language groups,  $F(2, 598) = 15.592$ ,  $p = .000$ . Tukey post-hoc comparisons of the three groups indicated that Swiss Italians ( $M = 1.32$ , 95% CI [1.23, 1.41]) gave the right answer significantly less often than Swiss Germans ( $M = 1.46$ , 95% CI [1.56, 1.72]),  $p = .000$  and Swiss French ( $M = 1.61$ , 95% CI [1.53, 1.69])  $p = .000$ . Comparisons between Swiss French and Swiss Germans were not statistically significant at  $p < .05$ . Table 59 summarizes the results:

## 9 Results

**Table 59.** Summary of Group Comparisons. Knowledge About Organ Donation.

	Swiss Germans	Swiss French	Swiss Italians
1. Procedural Knowledge (4)	1.73 <sub>a</sub> [1.56, 1.87]	2.06 [1.92, 2.19]	1.50 <sub>a</sub> [1.35, 1.64]
2. Medical / Technical Knowledge (5)	2.13 <sub>a</sub> [1.96, 2.30]	1.92 <sub>a</sub> [1.77, 2.08]	2.03 <sub>a</sub> [1.88, 2.17]
3. Knowledge about the Donor Card (4)	1.18 [1.02, 1.33]	1.64 [1.49, 1.80]	0.83 [0.70, 0.96]
4. Knowledge about the relevance for society (3)	1.64 <sub>a</sub> [1.56, 1.72]	1.61 <sub>a</sub> [1.53, 1.69]	1.32 [1.23, 1.41]

*Note.* Values are mean scores on a 3 to 5 - item scale specified in brackets ( ) (0 = no correct answer, 1 = 1 correct answer, 2 = 2 correct answers, 3 = 3 correct answers, 4 = 4 correct answers, 5 = 5 correct answers). Numbers in brackets [ ] are 95% confidence intervals of the means. Means that do not share subscripts differ at  $p < .05$  in the Tukey honestly significant difference comparison.

Later on, the impact of specific knowledge will be analyzed relating to the intention to engage in organ donation behavior.

### 9.1.2.4 Community Orientation

According to Schulz et al.'s results (Schulz et al., 2006) one might expect that Latin cultures, such as the Swiss French and Swiss Italian ones, would show significantly higher means on one or another community dimension. This effect did not appear when running Univariate ANOVAs with language as factor and the two indices of community orientation as dependent variables. Both ANOVA F-tests were way over the suggested  $\alpha$  level of .05. For the *community index social*, the F-test was  $F(2,595) = .512$ ,  $p = .599$  and for *community index commitment*  $F(2,596) = .149$ ,  $p = .862$ . If community orientation had a different impact on the perception of the flyer, or on the intention to engage in organ donation behavior within each language group, will be analyzed later in more detail.

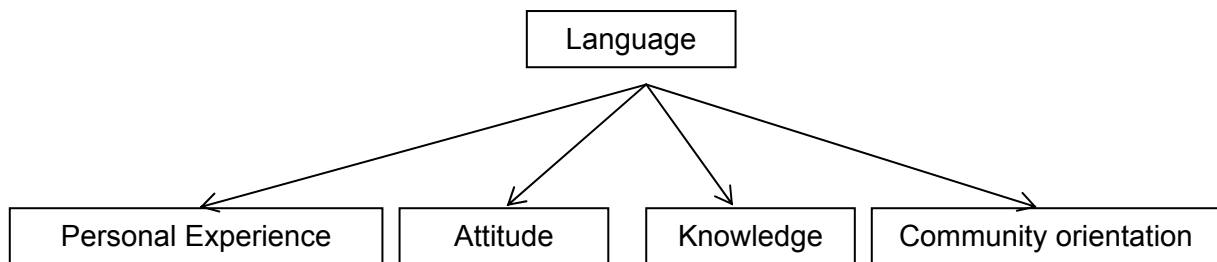


### 9.1.3 Summary Attitudinal Components of Organ Donation Thinking and Intention to Engage in Organ Donation Behavior by Linguistic Region

#### *Intention to Engage in Organ Donation Behavior*

Swiss French not only had donor cards significantly more often, but also were significantly more willing to donate organs than Swiss Germans or Swiss Italians (see Table 51). Interestingly however, Swiss Italians were the most confident in their answer compared to the other two groups. The willingness to sign a card did not significantly differ among the linguistic groups. Looking again at the willingness to donate in wave two, Swiss French were still more willing to donate than Swiss Germans but not more than Swiss Italians. This result indicated that the interview and/or the intervention helped raise awareness among Swiss Italians. However, the number of signed cards among those who did not previously have a donor card, was relatively the same among the language groups. **Swiss French** already had a donor card during the first interview significantly more often than expected. **Swiss Italians** and **Swiss Germans** signed as many donor cards in between the interviews as their French-speaking compatriots, but attained a significantly higher increase in donor cards than Swiss French. In line with that result, of those who did not have a donor card in wave two, **Swiss Italians** were willing to sign a card significantly more often, while **Swiss French** were willing to sign a card significantly less often. This might be due to the fact that a) Swiss French purposely do not have a donor card and b) hint that Swiss French are not generally more in favor of donation, but are simply more aware of the topic and thus made up their mind more consciously.

### *Attitudinal Components in Organ Donation Thinking*



**Figure 23:** *Linguistic differences in organ donation thinking (attitude), personal experience, knowledge, and community orientation of the participants.*

*Personal Experience, three items: a) knowing somebody who has received an organ, b) knowing the family who decided about the organ donation of a deceased relative, and c) knowing a doctor/medical staff who deals with organ donation.*

Swiss French know a person who received or is waiting for an organ significantly more often than their compatriots.

*Attitude, three items: a) organ donation is a good thing to do, b) understanding people who do not want to give their organs, and c) thinking about organ donation scares me.*

Swiss Germans are overall slightly less in favor of organ donation than Swiss Italians and Swiss French. Swiss Italians are the least tolerant group towards people who do not want to donate their organs. Overall, the majority of people are not scared (with a maximum mean score of 3 on a 7-point Likert-scale) when thinking about organ donation. Swiss Germans are the least likely to give organs of a deceased relative if his/her wish was unknown. Swiss French are the most likely to do so.

*Knowledge, four indices: a) procedural knowledge, b) medical/technical knowledge, c) knowledge about the donor card, and d) knowledge about the relevance for the society.*

Swiss French have more procedural knowledge, as well as knowledge about the donor card than both Swiss Germans and Swiss Italians. Overall, medical/technical knowledge is not very high. Swiss French and Swiss Germans are equally aware of the relevance of the topic but also much more so than Swiss Italians.

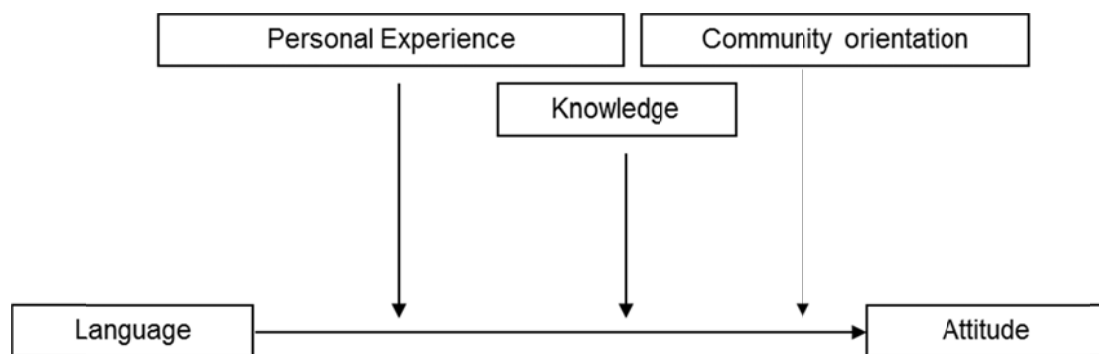
*Community Orientation, two indices: a) community orientation: social relations and b) community orientation social commitment.*

There were no differences in community orientation among the language groups, which is contrary to one of our main hypotheses. In the following, the community orientation in each language group will be still analyzed. This will be done to seek if it had different impacts on the perception of the flyers and the intention to engage in organ donation behavior.

## 9.2 The Effect of Personal Experience, Knowledge and Community Orientation On Attitude and Intention to Engage in Organ Donation Behavior

### 9.2.1 The Effect of Personal Experience, Knowledge and Community Orientation on Attitude Towards Organ Donation

After analyzing whether the language groups differed based on specific characteristics, the second step is to examine whether these particular patterns had a moderating effect on the attitude towards organ donation.



**Figure 24:** Summary of the Interaction Models with language as focal independent variable and Personal Experience, Knowledge or Community Orientation as moderator variables on the outcome variable attitude towards organ donation.

Analyses were conducted separately, meaning that altogether 27 different interaction models were tested: Language x Personal Experience (3 items) x Attitude (3 items) = 9 interaction models, Language Knowledge (4 items) x Attitude (3 items) = 12 interaction models, and Language x Community Orientation (2 items) x Attitude (3 items) = 6 interaction analyses. Altogether, nine plus twelve plus six

equals a total of 27 interaction analyses. In the following, only significant results will be reported for simplicity and readability reasons<sup>40</sup>.

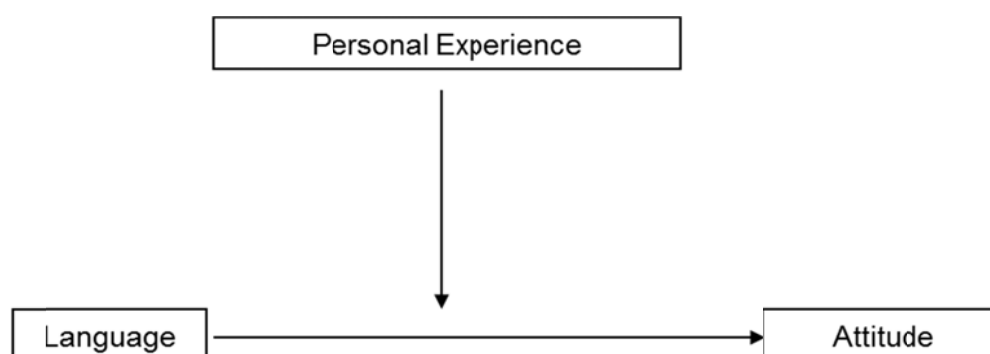
The community orientation indices were not significantly correlated with the knowledge indices, thus multicollinearity issues were excluded. The community orientation index: *social relations* did not correlate with personal experience, but the community orientation index: *social commitment* did so. Reasoning for so as to why would need further analysis and discussion. Some of the knowledge items were highly correlated with some of the personal experience items. This seems to be logical: knowing people who have received an organ or had decided about donation for a third person, predicts their level of knowledge on the topic. Here, multicollinearity is an issue again. However, it is not considered essential in the further analysis because the aim of this chapter is to identify relevant elements within each language group when processing information on organ donation. It is not to what extent, but due only to knowledge or personal experience. Thus, a correlation of both is consciously tolerated in the following.

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<sup>40</sup> *Note.* Each interaction analysis has been run separately. Hierarchical regression including the 27 combinations stepwise and block wise has been conducted but did not contribute any relevant results and is therefore not reported.

### 9.2.1.1 Does the Personal Experience of a Participants with Organ Donation have a Different Impact on the Attitude in Each Language Region?

The first analysis focused on whether knowing somebody involved in the organ donation process moderates their attitude, in each language group.



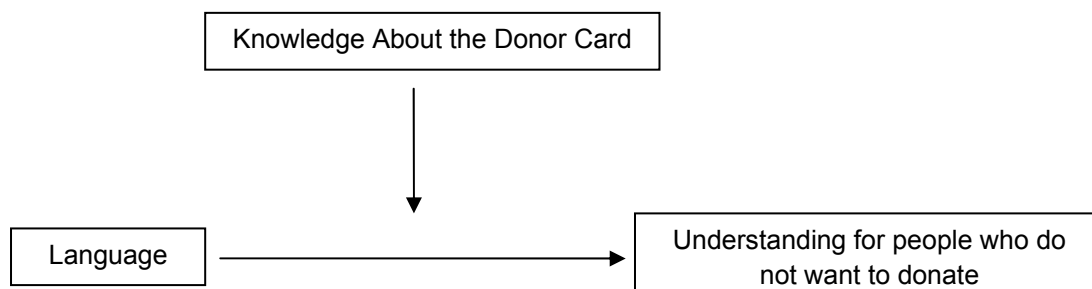
**Figure 25:** Interaction model with language as focal independent variable and personal experience as moderator variable on the outcome variable attitude towards organ donation.

Altogether, 12 models were tested. *Personal experience* was the overall summarized variable, whether participants knew anybody who had to deal with organ donation (1 = yes, 2 = no) but also with single items, testing the interaction for each item separately (knowing medical staff involved in transplantation, knowing family who decided about a deceased relative's organ donation, and knowing a family where somebody received an organ). The dependent variables were *organ donation is a good thing to do*, *thinking about organ donation scares me*, and *understanding for people who do not want to donate*. Interaction analysis showed that none of the product terms were significant.

Whether a person has or not had *personal experience* (with other people) in the organ donation procedure, this does not have an impact on their attitude towards organ donation in any of the linguistic regions.

### 9.2.1.2 Does the Knowledge of Participants about Organ Donation and the Procedures Behind Have a Different Impact on the Attitude in Each Language Region?

To test for the moderating effect of knowledge on the relationship of language and attitude interaction, analyses have been conducted for each attitude dimension (*Organ donation is a good thing to do*, *Organ donation scares me*, *Understanding for people who do not want to donate*, and *Assent to organ donation of a deceased relative whose wish to donate was unknown*) and each knowledge dimension (*Procedural knowledge*, *Medical/Technical Knowledge*, *Knowledge about the donor card*, and *Social relevance*) separately. Thus, (4x4) 16 interaction models were tested. Still, only one product term was significant. The product term language and knowledge about the donor card on the attitude dimension, *Understanding for people who do not want to donate* shown in Figure 26 and Table 60.



**Figure 26:** *Interaction Model with language as focal independent variable and Knowledge about the card as moderator variable on the outcome variable “Understanding for people who do not want to donate”*

## 9 Results

**Table 60.** *Regression Analysis Comparing Swiss French and Swiss Italians to Swiss Germans on the dependent variable understanding for people who do not want to donate potentially moderated by the knowledge about the donor card of the participants*

	B	SE	$\beta$	t	Sig.
<i>Constant</i>	5.479	.192		28.483	.000
Swiss French Dummy	.592	.303	.150	1.955	.051
Swiss Italian Dummy	.042	.262	.011	.161	.872
Knowledge about donor card	.106	.121	.062	.874	.383
PT French x Know	-.333	.169	-.180	-1.976	<b>.049</b>
PT Italian x Know	-.439	.188	-.155	-2.332	<b>.020</b>

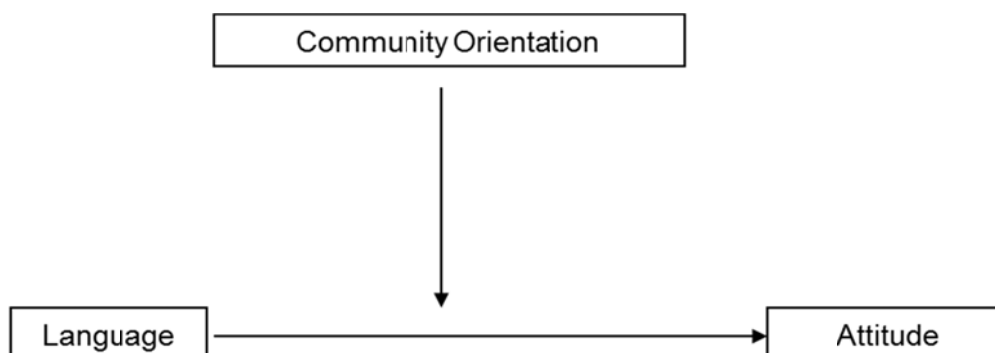
*Note.* PT = product term, **significant PT in bold**,  $R^2 = .027$ ,  $F(5,589) = 3.314$ ,  $p = .006$

Table 60 indicates that the Swiss French and the Swiss Italians who knew more about the donor card and the way it functions, had, on average, a lower understanding for people who do not want to donate. Their understanding was lower than Swiss Germans. This result stresses the importance for people to know exactly what having a donor card means and does not mean, especially in the Swiss French and Swiss Italian speaking parts of Switzerland.



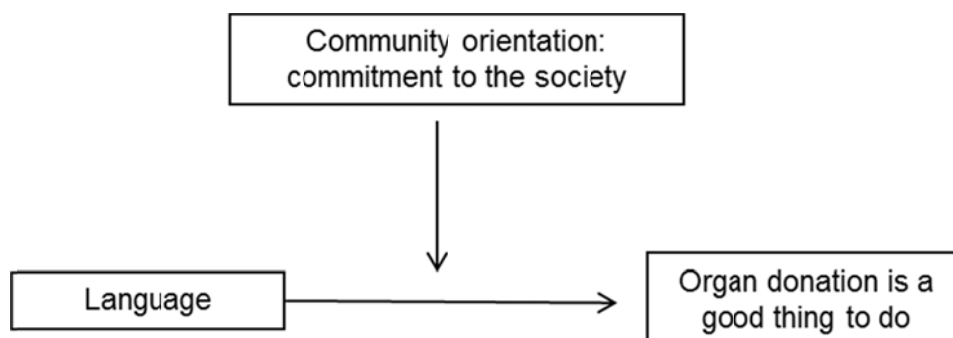
### 9.2.1.3 Test for Interaction: Language – Community Orientation – Attitude

Figure 27 shows the interaction analysis with language as an independent variable and community orientation, *social* (and *commitment to others*), as a moderator variable; run for each of the four dependent variables for attitude.



**Figure 27:** Interaction Model with language as focal independent variable and Community Orientation as moderator variable on the outcome variable Attitude.

For community orientation: *social activity*, none of the interaction terms were significant and therefore not reported. In the following, only the models that showed significant interaction terms will be reported.



**Figure 28:** Interaction Model with language as focal independent variable and Community Orientation: Commitment to the Society as moderator variable on the outcome variable “Organ donation is a good thing to do”.

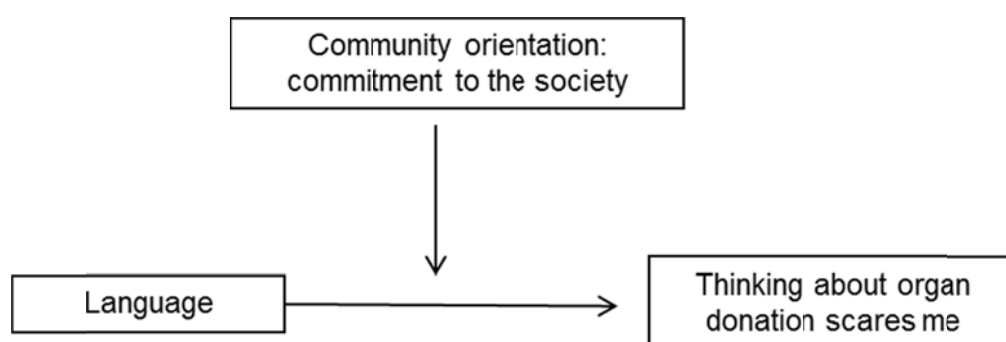
## 9 Results

**Table 61.** Regression Analysis comparing Swiss Germans and Swiss French to Swiss Italians on the dependent variable *organ donation is a good thing to do* moderated by the commitment to the community of the participants.

	B	SE	$\beta$	t	Sig.
Constant	5.842	.253		23.068	.000
Swiss German Dummy	.034	.365	.013	.093	.926
Swiss French Dummy	.990	.362	.377	2.734	.006
Community Orientation: Social Commitment	.120	.054	.151	2.213	.027
PT German x Soc Commitment	-.061	.079	-.109	-.774	.440
PT French x Soc Commitment	-.179	.077	-.327	-2.308	<b>.021</b>

Note. PT = product term, **significant PT in bold**,  $R^2 = .033$ ,  $F(5,590) = 4.017$ ,  $p = .001$

Table 61 shows that Swiss French who like to be socially active, score lower on average in the attitude item *organ donation is a good thing to do* than Swiss Italians. This might be an indicator that for Swiss Italians, being socially active is a better indicator to a positive attitude towards organ donation than for Swiss French.



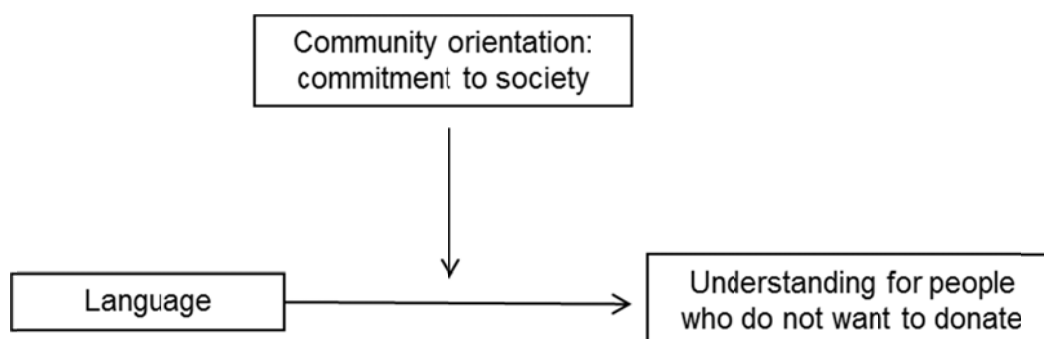
**Figure 29:** Interaction Model with language as the focal independent variable and Community Orientation: Commitment to the Society as moderator variable on the outcome variable "Organ donation scares me".

**Table 62 .** *Regression Analysis Comparing Swiss Germans and Swiss French to Swiss Italians on the dependent variable thinking about organ donation scares me moderated by the commitment to the community of the participants.*

	B	SE	$\beta$	t	Sig.
<i>Constant</i>	2.188	.401		5.458	.000
Swiss German Dummy	.961	.579	.232	1.660	.097
Swiss French Dummy	.035	.574	.009	.062	.951
Community Orientation: social commitment	.137	.085	.110	1.610	.108
PT German x Soc commitment	-.283	.125	-.323	-2.270	<b>.024</b>
PT French x Soc commitment	-.041	.123	-.047	-.333	.739

*Note.* PT = product term, **significant PT in bold**,  $R^2 = .014$ ,  $F(5,591) = 1.675$ ,  $p = .139$

Table 62 shows that on average, Swiss Germans who engage in social activities are less scared about organ donation than Swiss Italians and Swiss French ( $B = -.242$ ,  $p = .056$ ).



**Figure 30:** *Interaction Model with language as the focal independent variable and Community Orientation: Commitment to the Society as moderator variable on the outcome variable “Understanding for people who do not want to donate”.*

## 9 Results

**Table 63.** Regression Analysis Comparing Swiss Germans and Swiss French to Swiss Italians on the dependent variable understanding for people who do not want to donate potentially moderated by the commitment to the community of the participants.

	B	SE	$\beta$	t	Sig.
Constant	5.784	.380		15.212	.000
Swiss German Dummy	-.192	.549	-.049	-.350	.727
Swiss French Dummy	-.892	.545	-.227	-1.638	.102
Community Orientation: social commitment	-.123	.081	-.104	-1.516	.130
PT German x Soc commitment	.125	.118	.150	1.060	.290
PT French x Soc commitment	.304	.116	.371	2.613	<b>.009</b>

Note. PT = product term, **significant PT in bold**,  $R^2 = .022$ ,  $F(5,590) = 2.709$ ,  $p = .020$

Table 63 shows that Swiss French participants who are socially engaged are, on average, more understanding towards people who do not want to donate than Swiss Italians are.

### 9.2.2 The Effect of Personal Experience, Knowledge and Community Orientation on the Intention to Engage in Organ Donation Behavior (Wave One)

For the ease of readability, a reminder that the *Intention to engage in organ donation behavior* in wave one was comprised of two dependent variables:

- Willingness to donate organs after death (wave one)
- Willingness to sign donor card (wave one)

### 9.2.2.1 *The Role of Personal Experience with People Involved in the Organ Donation Procedure on the Intention to Engage in Organ Donation Behavior (Wave One) in Each Language Group*

To test whether knowing someone involved in the organ donation procedure had an impact on the behavior within each group, the personal experience dummy was regressed on the two outcome variables separately for each subsample.

Regression coefficients were significant for both dependent variables, only within the Swiss French subsample. Thus, for the Swiss French, the fact of knowing someone, either a doctor, a person who received an organ, or someone who decided to donate a relatives organs or not predicted the willingness to donate organs after death with a  $B=.357$   $t(194) = 2.296$ ,  $p=.023$ ,  $R^2 = .027$ . This also showed a marginal effect on the willingness to sign a donor card with  $B=.394$ ,  $t(128) = 1.818$ ,  $p=.071$ ,  $R^2 = .025$ .

### 9.2.2.2 *The Role of Knowledge on the Intention to Engage in Organ Donation Behavior (Wave One) in Each Language Group*

To test whether one of the knowledge categories (*procedural, medical, about the donor card, or the relevance for society*) impacted the intention to engage in organ donation behavior, all four knowledge categories were regressed on the two outcome variables *Willingness to donate* and *Willingness to sign a donor card* separately for each linguistic region.

Results showed that **procedural knowledge** played a significant role only among Swiss Germans. This was predicted with a  $B=.197$ ,  $t(195) = 2.234$ ,  $p=.027$ ,  $R^2 = .025$ , and showed the willingness to donate but not the willingness to sign a card.

For **technical/medical knowledge**, results were more complex and are therefore summarized in Table 64.

## 9 Results

**Table 64.** *Medical / Technical Knowledge Regressed on Willingness to engage in organ donation behavior.*

	B	SE	$\beta$	t	Sig.	$R^2$
<i>Willingness to donate after death</i>						
Swiss German (200)	.167	.075	.157	2.209	<b>.028</b>	.025
Swiss French (199)	.129	.071	.130	1.816	<b>.071</b>	.017
Swiss Italian (200)	.157	.087	.128	1.811	<b>.072</b>	.016
<i>Willingness to sign donor card*</i>						
Swiss German (165)	.062	.080	.060	.770	.442	.004
Swiss French (127)	.030	.104	.025	.285	.776	.001
Swiss Italian (173)	.172	.096	.135	1.793	<b>.075</b>	.018

\*Filter Question: only participants who did not have a donor card yet

The results showed again that technical/medical knowledge seems to play a crucial role for Swiss Germans. However, the results are not the same for both outcome variables, leaving room for interpretation about Swiss Germans reluctance towards signing the donor card itself.

Results also revealed that knowledge about the donor card was the most important factor in participants' willingness to engage in organ donation behavior. Results are summarized in Table 65.

**Table 65.** *Knowledge About The Donor Card Regressed on Willingness to Engage in Organ Donation Behavior.*

	B	SE	$\beta$	t	Sig.	$R^2$
<i>Willingness to donate after death</i>						
Swiss German (200)	.310	.082	.261	3.771	.000	.068
Swiss French (199)	.292	.067	.300	4.356	.000	.090
Swiss Italian (200)	.378	.099	.262	3.818	.000	.069
<i>Willingness to sign donor card*</i>						
Swiss German (165)	.130	.101	.100	1.284	.201	.010
Swiss French (127)	.061	.107	.051	.573	.568	.003
Swiss Italian (173)	.278	.123	.169	2.255	.025	.029

\*Filter Question: only participants who did not have a donor card yet.

Again, the same pattern as before can be observed. While the knowledge about the donor card has a big effect on the willingness to donate for all three linguistic groups, it only predicts the willingness to sign the card among Swiss Italians.

Finally, the social relevance knowledge category was examined. There was only one significant result on the outcome variable *Willingness to donate organs after death*. Among Swiss French, the more participants were aware of the lack of organ donors and the relevance of the topic in general, the more willing they were to donate their organs after death ( $B=.425$ ,  $t(193) = 3.227$ ,  $p=.001$ ,  $R^2 = .017$ ). Still, knowledge did not have an impact on the willingness to sign a card.

### 9.2.2.3 *The Role of Community Orientation on the Intention to Engage in Organ Donation Behavior (Wave One) in Each Language Group*

When testing the direct effect of the two community orientation indices on the two outcome variables *Willingness to donate* and *Willingness to sign a donor card* with simple linear regression analysis, three out of four regression equations were highly significant. The effect of social relations ( $B=.171$ ,  $t(589) = 4,330$ ,  $p=.000$ ,  $R^2=.031$ ) and social commitment ( $B=.029$ ,  $t(590) = .908$ ,  $p=.365$ ,  $R^2=.001$ ) on *Willingness to donate* and the effect of social relations  $B=.178$ ,  $t(468) = 4,129$ ,  $p=.000$ ,  $R^2=.035$ ) and social commitment ( $B=.080$ ,  $t(468) = 2,180$ ,  $p=.030$ ,  $R^2=.010$ ) on the willingness to sign a donor card. Thus, one can conclude that the community orientation of the participant has an impact on its willingness to engage in organ donation behavior. Still, the question is whether this relationship differs in each language group.

Consequently, the analysis was repeated for each language group separately to see whether there were differences on the effect of community orientation within each language group. The results are shown in Table 66 and Table 67.

**Table 66.** *Community Orientation: Social Relations Regressed on Willingness to Engage in Organ Donation Behavior Within Each Language Group.*

	B	SE	$\beta$	t	Sig.	$R^2$
<i>Willingness to donate organs after death</i>						
Swiss German (200)	.105	.067	.112	1.575	.117	.013
Swiss French (199)	.176	.068	.185	2.605	<b>.010</b>	.034
Swiss Italian (200)	.227	.070	.224	3.239	<b>.001</b>	.050
<i>Willingness to sign a donor card*</i>						
Swiss German (165)	.088	.069	.098	1.264	.208	.010
Swiss French (127)	.244	.082	.256	2.982	<b>.003</b>	.065
Swiss Italian (173)	.225	.074	.225	3.027	<b>.003</b>	.051

\*Filter Question: only participants who did not have a donor card yet.



**Table 67.** *Community Orientation: Social Commitment Regressed on Willingness to Engage in Organ Donation Behavior Within Each Language Group.*

	B	SE	$\beta$	t	Sig.	$R^2$
<i>Willingness to donate organs after death</i>						
Swiss German (200)	.107	.060	.128	1.804	<b>.073</b>	.017
Swiss French (199)	-.042	.049	-.061	-.851	.396	.004
Swiss Italian (200)	.026	.058	.032	.455	.650	.001
<i>Willingness to sign a donor card*</i>						
Swiss German (165)	.104	.060	.134	1.736	<b>.084</b>	.018
Swiss French (127)	.009	.067	.012	.137	.892	.000
Swiss Italian (173)	.108	.065	.125	1.651	.100	.016

\*Filter Question: only participants who did not have a donor card yet.

Table 66 and 67 show that the degree of social commitment, for instance activities in the local community, does not predict the organ donation behavior in either of the language groups. Only a slight tendency can be seen among Swiss Germans. They tend to be more inclined to donate their organs after death or sign a donor card if they were involved in community activities. Interesting differences can be seen for the other community index: social relations (Table 66). Swiss French and Swiss Italians' intention to engage in organ donation behavior is stronger if the person likes to be in the company of others and rates the importance of family and friends higher. This effect has a different outcome among Swiss Germans (see Table 67). This finding confirms the original hypothesis that community orientation plays a crucial role in processing organ donation information and decisions. Why the community oriented flyer did not work better with the Swiss French and Swiss Italians anyhow will be covered in the discussion chapter.

### **9.2.3 Summary of the Effect of Personal Experience, Knowledge and Community Orientation on the Attitude Towards Organ Donation and the Intention to Engage in Organ Donation Behavior**

#### *Summary of the Effect of Personal Experience, Knowledge and Community Orientation on the Attitude Towards Organ Donation*

As seen in the chapter, personal experience influences the attitude of participants. However, further analysis showed that this influence was not different depending on the linguistic group adherence of participants.

The attitude of participants in each language group was not impacted by their social activities, but if participants were committed to their neighbors and society in general a more positive attitude was observed. For instance, Swiss Germans, being socially committed, showed less fear of organ donation as a topic than socially committed Swiss French or Swiss Italians. On the other hand, Swiss French, scoring high on social commitment, showed more understanding for people who do not want to donate compared to Swiss Italians. Finally, Swiss Italians, also scoring high on social commitment, were more likely to find organ donation a good thing to do than Swiss French.

#### *Summary of the Effect of Personal Experience, Knowledge and Community Orientation on the Willingness to Engage in Organ Donation Behavior*

#### **Personal Experience with People Involved in the Organ Donation Process**

Only among Swiss French participants did knowing someone who had a personal experience with organ donation have an impact on the willingness to donate; and only a marginal influence on the willingness to sign a donor card.

## Knowledge about Organ Donation

Overall, knowledge appeared to have an impact on the willingness to donate but barely on the willingness to sign a card, this leaves room for interpretation as to why this could be. Interestingly, the relevance of a specific kind of knowledge towards the intention to engage in organ donation behavior seemed to be different when looking at the linguistic groups separately (summary results Table 68 and 69). Note that for all three language groups, knowledge about the donor card was the most crucial in predicting the willingness to donate organs after death.

### *Swiss Germans*

Within the Swiss German group, technical knowledge such as procedural knowledge, medical/technical knowledge, and knowledge about the donor card was especially crucial in predicting their willingness to donate or not, confirming Schulz et al.'s results from 2006. The proper judgment on the relevance to society did not predict the willingness to donate however. Still, none of the knowledge items predicted the willingness to commit to donation though a signed donor card.

### *Swiss French*

Within the Swiss French participants, the high importance of knowledge about the donor card, the  $\alpha$ -level for medical/technical knowledge, was marginally significant (see Table 68); and the conscience about the relevance for society revealed to be a predictor for the willingness to donate organs after death as well. While Swiss French and Swiss Germans' willingness to sign a card could not be predicted by any of the knowledge items, it could be done for Swiss Italians.

### *Swiss Italians*

As shown in Table 69, Swiss Italians do not care about procedural knowledge in their decision to donate their organs or not after death. While medical/technical knowledge predicts both their willingness to donate, as well as their willingness to sign a card, it can only be seen at a marginal  $\alpha$ -level of  $p < .1$ . However, knowledge about the donor card predicted both at a significant  $\alpha$ -level of  $p < .05$ .

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**Table 68.** *Regression Models Predicting the Willingness to Donate Organs After Death by Knowledge Category.*

	Language group Swiss Germans			Swiss French			Swiss Italians		
Number of observations	200			199			200		
Predictor	Coefficient	p-Value	R <sup>2</sup>	Coefficient	p-Value	R <sup>2</sup>	Coefficient	p-Value	R <sup>2</sup>
Procedural Knowledge	0.197	0.027	.025	0.114	ns	ns	0.120	ns	ns
Medical / Technical Knowledge	0.167	0.028	.025	0.129	0.071	.017	0.157	0.072	.016
Knowledge about Donor Card	0.310	0.000	.068	0.292	0.000	.090	0.378	0.000	.069
Knowledge about Social Relevance	0.055	ns	ns	0.334	0.042	.035	0.109	ns	ns

Note. ns = non-significant

**Table 69.** *Regression Models Predicting the Willingness to Sign a Donor Card by Knowledge Category.*

	Language group Swiss Germans			Swiss French			Swiss Italians		
Number of observations*	165			127			173		
Predictor	Coefficient	p-Value	R <sup>2</sup>	Coefficient	p-Value	R <sup>2</sup>	Coefficient	p-Value	R <sup>2</sup>
Procedural Knowledge	0.077	ns	ns	0.077	ns	ns	0.013	ns	ns
Medical / Technical Knowledge	0.062	ns	ns	0.030	ns	ns	0.172	0.075	.018
Knowledge about Donor Card	0.130	ns	ns	0.061	ns	ns	0.278	0.025	.029
Knowledge about Social Relevance	0.091	ns	ns	0.256	ns	ns	0.031	ns	ns

## Community Orientation

As hypothesized, the community orientation of participants predicted their willingness to differently engage in organ donation behavior according to their language region.

### *Swiss Germans*

*Social commitment* (people involved in charity and their neighborhood) was only marginally significant at an  $\alpha$ -level of  $p < .1$ . This predicted the willingness to donate after death, as well as the willingness to sign a donor card among Swiss Germans. The community orientation index *social relations* (participant likes to be around others and friends are the most important) seemed to be much more relevant for the other two groups.

### *Swiss French and Swiss Italians*

For both groups, knowing a lot of people and being around them significantly predicted not only their willingness to donate after death, but also their willingness to sign a donor card. This again is an indicator that, especially for Swiss Germans, willingness to donate does not by far mean willingness to sign a donor card. There is a large threshold between both, which will be further reflected upon in the discussion part.

### **9.3 The Influence of Mother Tongue on Cognitive and Affective Reactions to Different Organ Donation Flyers**

#### **9.3.1 The Influence of Mother Tongue on Feelings (Affective) Provoked by the Flyer Manipulation**

##### **9.3.1.1 *The Overall Effect of the Flyer on “Feelings about Organ Donation Evoked by the Flyer”***

Univariate ANOVA, with the flyer as the fixed factor and *positive feelings* in a first step followed by *negative feelings* in a second step as dependent variables, showed that means for feelings did not differ significantly for the different flyer interventions,  $F(2, 534) = .852$ ,  $p = .427$  for *positive feelings* and  $F(2, 534) = .855$ ,  $p = .426$  for *negative feelings*.

##### **9.3.1.2 *Does the Flyer Evoke Different Feelings in the Different Linguistic Regions ?***

To test whether there were differences among the linguistic groups, the same analysis was repeated for each subsample (linguistic region) separately. This was to test for possible differences within each experimental group.

When looking at the negative feelings the flyers evoked in the participants, the overall F-statistic remained not significant for each linguistic group. The positive feelings provoked by the flyer in each linguistic region were marginally significant for Swiss Italians only in the F-statistics  $F(2, 180) = 2.861$ ,  $p = .060$ . Tukey post-hoc comparisons of the flyer versions further showed that within only the Italian group, the informative flyer ( $M = 5.02$ , 95% CI [4.70, 5.34]) generated (marginally significant) more positive feelings about organ donation than the community oriented flyer ( $M = 4.44$ , 95% CI [4.06, 4.82]),  $p = .071$ .

### 9.3.2 The Influence of Mother Tongue on the Perception (Cognitive and Affective) Provoked by the Flyer Manipulation

#### 9.3.2.1 *The Overall Effect of the Flyer on “Perception of the Flyer”*

Univariate ANOVA with the flyer as the fixed factor and *cognitive appreciation* (trustworthy, informative, convincing, and credible) of the flyer in a first step followed by *affective appreciation* (appealing, touching, and not intrusive) of the flyer in a second step as the dependent variables, shows that the means for the perception of the flyers did not differ significantly among flyers:  $F(2, 539) = .027$ ,  $p = .973$  for the *affective appreciation of the flyer* but did significantly differ for the *cognitive appreciation of the flyer*,  $F(2, 538) = 4.006$ ,  $p = .019$ . Tukey post-hoc comparisons of the three flyers' means indicated that the informative flyer ( $M = 5.59$ , 95% CI [5.42, 5.77]) was rated significantly more trustworthy and credible than the emotional flyer ( $M = 5.25$ , 95% CI [5.04, 5.46]),  $p = .028$ . Also, the community oriented flyer ( $M = 5.56$ , 95% CI [5.38, 5.73]) was rated more credible than the emotional flyer, even though only at a marginal  $\alpha$ -level of  $p = .056$ . Comparisons between the community oriented flyer and the informational flyer were not statistically significant at  $p < .05$ . In the following, the same analysis was repeated for each linguistic region separately.

#### 9.3.2.2 *Does the Flyer Generate Different Perceptions in the Different Linguistic Regions?*

As before, the analysis on the feelings evoked by the flyer was repeated for each language group separately to test for possible differences within each experimental group. For the *affective appreciation*, none of the group comparisons showed to have a significant  $\alpha$ -level. However, differences appeared for the *cognitive appreciation*. While for Swiss Germans and Swiss French there were no differences in the perception of the flyer, Swiss Italians rated the informative flyer significantly more often as trustworthy, credible, and convincing ( $M = 5.75$ , 95% CI [5.46, 6.04]) than the emotional flyer ( $M = 5.14$ , 95% CI [4.76, 5.53]),  $p = .034$ . For the

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community oriented flyer, ratings ( $M = 5.53$ , 95% CI [5.20, 5.86]) did not significantly differ at an  $\alpha$ -level of  $p < .05$  from the other flyer versions.

These results did not confirm what was expected in the hypothesis. The observed tendency was even contrary to what was expected: namely that Swiss Italians tended to rate the informative flyer as more trustworthy and credible. The question now is, whether this result was also reflected in the number of donor cards signed between the first and the second interview; the results have shown that it did not.

### 9.3.3 Summary of the Influence of Mother Tongue on Cognitive and Affective Reactions to Different Organ Donation Flyers

#### *The Influence of Mother Tongue on Feelings Provoked by the Flyer Manipulation*

The overall highly non-significant F-statistics indicated that there was no overall effect of the flyer manipulation on the feelings it provoked. For the *negative feelings*, this result was confirmed when looking at the language groups separately. For the *positive feelings*, a marginal trend among **Swiss Italians** could be observed, namely that the informative flyer was generating more positive feelings than the community oriented flyer.

#### *The Influence of Mother Tongue on the Perception of the Flyer Manipulation*

Results were more interesting when looking at the immediate perception of the flyer. When looking at the overall effect, the *affective appreciation* was not influenced by the flyer manipulation, while the *cognitive appreciation* was. Overall, the informative flyer and the community flyer were both rated more credible and trustworthy than the emotional flyer.

When looking at the three language groups separately, the flyer manipulation still did not have any significant impact on the way people rated its *affective appreciation*. However, for the *cognitive appreciation*, **Swiss Italians** rated the informative flyer significantly more often as trustworthy, credible, and convincing,



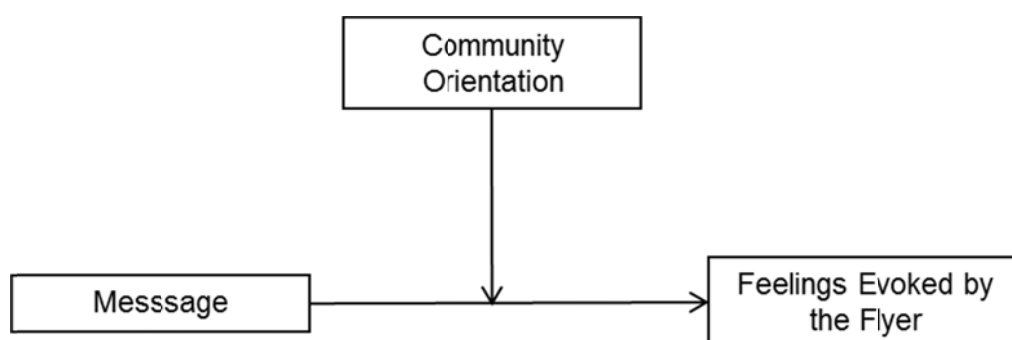
more so than the emotional flyer. Even though the perception of the flyer did not differ at a significant  $\alpha$ -level from the other flyers, one result is striking. If differences showed to be significant, **Swiss Italians** showed a slight preference for the informative flyer compared to other flyers.

## 9.4 Does Community Orientation Affect the Feelings and Perceptions of Participants about the Flyer and Organ Donation?

### 9.4.1 The Role of Community Orientation in Participants Feelings about Organ Donation after Having read one of the Flyer Manipulations

#### 9.4.1.1 *The Overall Impact of Community Orientation: Is Community Orientation Moderating the Effect of the Flyer on the Feelings it Evoked*

To test whether the effect of the flyer on feelings about organ donation was moderated by participants' community orientation, four models were examined. Two models, with the two community orientation indices as the moderator variables on positive feelings generated by the flyer as outcome variable, and two models with negative feelings as outcome variables. The idea is summarized in Figure 31.



**Figure 31:** *Interaction Model with Message as focal independent variable and Community Orientation as moderator variable on the outcome variable “Feelings evoked by the flyer”*

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In the following, only significant results will be reported. Knowing many people and having many social relationships did not impact the feelings the flyer evoked, neither positively nor negatively.

For the community orientation index *social commitment*, some results were significant of which only the significant ones are summarized in Table 70.

**Table 70.** *Interaction Analysis Comparing the Effect of the Different Message Types on the Dependent Variable Positive Feelings Generated by the Flyer depending on the social commitment of the participants.*

	B	SE	$\beta$	t	Sig.
<i>Constant</i>	4.861	.281		17.322	.000
Informative Message Dummy	-.692	.402	-.247	-1.719	.086
Emotional Message Dummy	-.920	.400	-.328	-2.299	.022
Community Orientation: Social Commitment	.034	.060	.040	.558	.577
PT Info x Soc Comm	.193	.087	.324	2.215	<b>.027</b>
PT Emo x Soc Comm	.205	.086	.347	2.374	<b>.018</b>

*Note.* PT = product term, **significant PT in bold**,  $R^2 = .054$ ,  $F(5,533) = 5.982$ ,  $p = .000$ .  
The reference group in the above table is the community oriented flyer.

Table 70 shows that participants with a higher score on the social commitment index, reading the informational flyer or the emotional flyer, showed, on average, positive feelings about organ donation significantly more often than people who read the community oriented flyer. The comparison between participants reading the informational flyer and the emotional flyer was not significant and is therefore not reported.

#### 9.4.1.2 *Testing for Community Orientation as Moderator in the Linguistic Regions*

When running the interaction analysis for all four models separately in each linguistic group, the influence of community orientation varies significantly from one group to the other. Results for community orientation regressed on positive feelings evoked by the flyer are summarized in Table 71.

Table 71 shows that in none of the three language groups, did knowing many people and liking to be around friends moderate the impact of the flyer on the positive feelings it evoked. Being committed to others, helping, and doing charity moderated the effect of the flyer among Swiss Germans and Swiss Italians, although not among Swiss French. The product terms in Table 71 show for instance, that among Swiss Germans, people with a higher community orientation: *social commitment* found that the informative and emotional flyer evoked positive ratings significantly more often than the community oriented flyer did. This indicates that the latter was not very well perceived by Swiss Germans.<sup>41</sup>

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<sup>41</sup> The regression equation comparing the informative flyer to the emotional flyer was not significant and is therefore not reported.

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**Table 71.** *Community Orientation Regressed on Positive Feelings Evoked by the Flyer and by language group.*

	B	SE	$\beta$	t	Sig.
<i>Community Orientation: Social Relations</i>					
<b>Swiss German</b>					<b>ns</b>
<b>Swiss French</b>					<b>ns</b>
<b>Swiss Italian</b>					<b>ns</b>
<i>Community Orientation: Social Commitment</i>					
<b>Swiss German</b>	$R^2 = .091$				
<i>Constant</i>	5.314	.448		11.854	.000
Dummy Informative Flyer	-1.366	.659	-.527	-2.072	.040
Dummy Emotional Flyer	-1.835	.646	-.708	-2.841	.005
Community Orientation: Social Commitment	-.060	.100	-.074	-.597	.551
PT Community Orientation x Dummy Info*	.311	.146	.560	2.135	<b>.034</b>
PT Community Orientation x Dummy Emo*	.391	.142	.716	2.759	<b>.006</b>
<b>Swiss French</b>					ns
<b>Swiss Italian</b>	$R^2 = .083$				
<i>Constant</i>	4.491	.514		8.738	.000
Dummy Informative Flyer	-.930	.757	-.303	-1.229	.221
Dummy Emotional Flyer	-.681	.732	-.221	-.930	.354
Community Orientation: Social Commitment	-.012	.109	-.014	-.112	.911
PT Community Orientation x Dummy Info*	.333	.159	.535	2.092	<b>.038</b>
PT Community Orientation x Dummy Emo*	.178	.158	.272	1.128	.261

*Note.* \* Reference Group: community oriented flyer. PT = product term

Table 71 further shows that also for Swiss Italians people with a strong community orientation social commitment showed more positive reactions to the informative than to the community oriented flyer.<sup>42</sup>

<sup>42</sup> As before the comparison between the informative and the emotional flyer is not reported since it was not significant.

The same analysis has been repeated with the negative feelings evoked by the flyer and is summarized in table 72.

**Table 72.** *Community Orientation Regressed on Negative Feelings Evoked by the Flyer and by language group.*

	B	SE	$\beta$	t	Sig.
<i>Community Orientation: Social Relations</i>					
<b>Swiss German</b>	$R^2 = .06$				
<i>Constant</i>	1.992	.426		4.678	.000
Dummy Informative Flyer	1.711	.619	.851	2.764	.006
Dummy Community Flyer	.951	.716	.469	1.327	.186
Community Orientation: Social Relations	.080	.079	.114	1.013	.313
PT Community Orientation x Dummy Info*	-.344	.119	-.890	-2.905	<b>.004</b>
PT Community Orientation x Dummy Comm*	-.173	.137	-.444	-1.262	.209
<b>Swiss French</b>					<b>ns</b>
<b>Swiss Italian</b>					<b>ns</b>
<i>Community Orientation: Social Commitment</i>					
<b>Swiss German</b>					<b>ns</b>
<b>Swiss French</b>					<b>ns</b>
<b>Swiss Italian</b>	$R^2 = .039$				
<i>Constant</i>	4.545	.426		10.657	.000
Dummy Community Flyer	.780	.581	.340	1.342	.181
Dummy Emotional Flyer	.694	.585	.300	1.187	.237
Community Orientation: Social Commitment	.192	.089	.286	2.164	.032
PT Community Orientation x Dummy Comm**	-.217	.122	-.459	-1.779	<b>.077</b>
PT Community Orientation x Dummy Emo**	-.218	.125	-.442	-1.744	<b>.083</b>

*Note.* \* Reference Group: emotional flyer. \*\* Reference Group: informative flyer.  
PT = product term

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Table 72 shows that while for Swiss Germans community orientation: *social relations* seemed to moderate the negative perception of the flyer, for Swiss Italians it was rather the community orientation: *social commitment* index. Among Swiss Germans, knowing many people lead to less negative ratings with the informative flyer than the emotional flyer; indicating that for Swiss Germans, community orientation is not necessarily related to a stronger appreciation of the community oriented flyer, or differently formulated, does not reduce their appreciation for the informative flyer.

The product terms in Table 72 show that Swiss Italians, being socially committed, tended to rate the community oriented and emotional flyer less negative than the informative flyer<sup>43</sup>. Still, the p-levels are closer to .1 than to .05. At this point, it is important to keep in mind that the informative flyer still evoked significantly more positive feelings among Swiss Italians, with an  $\alpha$ -level of  $p < .05$ . Especially keeping in mind that positive emotions lead to more positive health outcomes, which has been shown repeatedly in health communication research (Monahan, 1995).

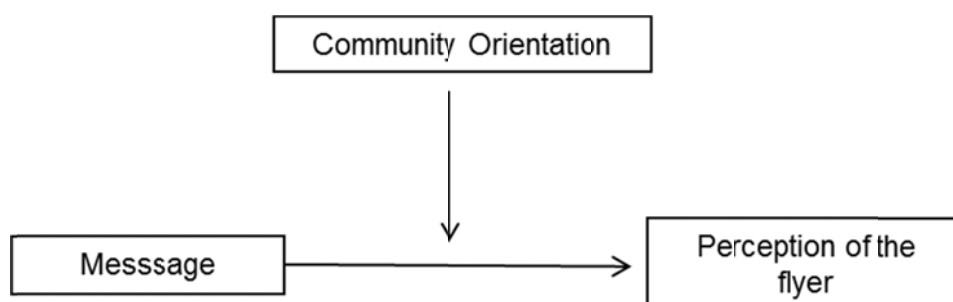
### **9.4.2 The Role of Community Orientation in Participants Perception of the Flyer**

#### **9.4.2.1 *The Overall Impact of Community Orientation: is Community Orientation Moderating the Effect of the Flyer on the Perception of It?***

To test whether the effect of the flyer was moderated by the community orientation of the participants, again, four models were examined. Two with *community orientation: social activity* as the moderator, in a first step *affective perception of the flyer* as outcome variable and secondly the *cognitive perception of the flyer* as outcome variable, as shown in Figure 32. Two more were also done with *community orientation: commitment to society* as potential moderating variable shown in Figure 32.

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<sup>43</sup> As before, unreported comparisons were not significant.



**Figure 32:** Interaction Model with Message as focal independent variable and Community Orientation as moderator variable on the outcome variable “Perception of the flyer”.

**Table 73.** Interaction Analysis Comparing the Effect of the Different Message Types on the Dependent Variable Affective Perception of the Flyer Depending on the Social Relations of the Participants

	B	SE	$\beta$	t	Sig.
Constant	5.069	.343		14.780	.000
Informative Message Dummy	-1.025	.516	-.386	-1.985	.048
Community Message Dummy	-.721	.552	-.272	-1.305	.192
Community Orientation: social relations	.003	.066	.003	.044	.965
PT Info x Soc relations	.197	.099	.394	1.998	<b>.046</b>
PT Comm x Soc relations	.134	.105	.268	1.271	.204

Note. PT = product term, **significant PT in bold**,  $R^2 = .019$ ,  $F(5,532) = 2.034$ ,  $p = .072$   
Reference Group: informative flyer

The table shows only marginally significant results. The overall F-test was not significant and only one of the three tested product terms (Table1 only shows two of them) showed an  $\alpha$ -level slightly below  $p = .05$ . Still, it is important to notice that participants who indicated that their family and friends were important to them, rated the informative flyer, on average, slightly more appealing than the emotional flyer.

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For the community orientation: *social activity*, none of the product terms showed to be significant, indicating that whether participants were social or not would not affect the effect the flyer had on finding the latter trustworthy, credible, or informative.

In a next step, it was tested whether community orientation: *commitment to the society* moderated the effect the message had on its affective perception. Results are shown in Table 74.

**Table 74.** *Interaction Analysis Comparing the Effect of the Different Message Types on the Dependent Variable Affective Perception of the Flyer Depending on the Social Commitment of the Participants*

	B	SE	$\beta$	t	Sig.
<i>Constant</i>	5.287	.271		19.519	.000
Informative Message Dummy	-.825	.388	-.311	-2.126	.034
Emotional Message Dummy	-.552	.387	-.208	-1.427	.154
Community Orientation: Social Commitment	-.053	.058	-.066	-.912	.362
PT Info x Soc Commitment	.191	.084	.340	2.277	<b>.023</b>
PT Emo x Soc Commitment	.133	.083	.238	1.598	.111

Note. PT = product term, **significant PT in bold**,  $R^2 = .015$ ,  $F(5,533) = 1.579$ ,  $p = .164$

Table 74 shows that participants who scored higher on social commitment, having read the informational flyer, rated, on average, the flyer significantly more appealing than participants who got to read the community oriented flyer. All the other comparisons were not significant. The reason why this is reported in so much detail is that together with Table 70 (first table in this chapter), contrary to our hypothesis, it shows that participants to whom the community is more important did not like the messages where these values were put forward.

In a last step, an interaction analysis was run for commitment to the society as the moderator variable, message as the focal independent variable, and cognitive perception as the dependent variable. Still, none of the product terms were significant, indicating that whether participants were committed to the community or



not, would not affect the effect the flyer had on finding the latter trustworthy, credible, or informative.

Again, the analysis was repeated for each linguistic group separately to test for possible differences.

#### **9.4.2.2 *The Impact of Community Orientation: Is Community Orientation Moderating the Effect of the Flyer on the Perception of it in the Different Linguistic Regions?***

Table 75 shows the results for the interaction analysis, with message as the focal independent variable, community orientation as the moderator variable, and cognitive perception (trustworthy, credible, informative, and convincing) as the dependent variable run separately for each language group.

A moderating effect could only be observed for Swiss Germans and Swiss French. While Swiss French, knowing many people and liking to be around them, rated the community oriented flyer as significantly less credible and less convincing than the emotional flyer, this effect was inverted for the Swiss Germans. Swiss Germans, knowing more people, tended to rate the community oriented flyer as well as the informative flyer more credible than the emotional flyer.

Interestingly, neither for Swiss Germans nor for Swiss Italians was the community index: *social commitment* moderated as convincing or credible in the rating of the flyer. Only among Swiss French was it that the more active participants were in their local community, the less likely they were to rate the community flyer as convincing, compared to the emotional flyer.

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**Table 75.** *Community Orientation Regressed on Cognitive Perception of the Flyer and by language group.*

	B	SE	$\beta$	t	Sig.
<i>Community Orientation: Social Relations</i>					
<b>Swiss German</b>	$R^2 = .073$				
<i>Constant</i>	5.936	.578		10.264	.000
Dummy Informative Flyer	-.973	.841	-.353	-1.157	.249
Dummy Community Oriented Flyer	-2.115	.960	-.766	-2.203	.029
Community Orientation: Social Relations	-.215	.108	-.223	-1.997	.047
PT Community Orientation x Dummy Info*	.287	.161	.541	1.784	<b>.076</b>
PT Community Orientation x Dummy Comm*	.508	.184	.957	2.761	<b>.006</b>
<b>Swiss French</b>	$R^2 = .039$				
<i>Constant</i>	4.739	.589		8.041	.000
Dummy Informative Flyer	.212	.948	.089	.224	.823
Dummy Community oriented Flyer	1.885	.954	.790	1.976	.050
Community Orientation: Social Relations	.207	.114	.210	1.809	.072
PT Community Orientation x Dummy Info*	-.061	.180	-.138	-.338	.736
PT Community Orientation x Dummy Comm*	-.357	.180	-.813	-1.979	<b>.049</b>
<b>Swiss Italian</b>	<b>ns</b>				
<i>Community Orientation: Social Commitment</i>					
<b>Swiss German</b>	<b>ns</b>				
<b>Swiss French</b>	$R^2 = .032$				
<i>Constant</i>	4.960	.437		11.349	.000
Dummy Informative Flyer	.484	.599	.203	.808	.420
Dummy Community Oriented Flyer	1.279	.619	.538	2.068	.040
Community Orientation: Social Commitment	.185	.094	.261	1.971	.050
PT Community Orientation x Dummy Info*	-.119	.132	-.228	-.904	.367
PT Community Orientation x Dummy Comm*	-.272	.131	-.562	-2.073	<b>.040</b>
<b>Swiss Italian</b>	<b>ns</b>				

*Note.* \* Reference Group: emotional flyer . PT = product term

**Table 76.** *Community Orientation Regressed on Affective Perception of the Flyer and by language group.*

	B	SE	$\beta$	t	Sig.
<i>Community Orientation: Social Relations</i>					
<b>Swiss German</b>	$R^2 = .088$				
<i>Constant</i>	5.868	.499		11.753	.000
Dummy Informative Flyer	-1.797	.726	-.748	-2.476	.014
Dummy Community Oriented Flyer	-3.105	.829	-1.293	-3.748	.000
Community Orientation: Social Relations	-.175	.093	-.209	-1.883	.061
PT Community Orientation x Dummy Info*	.318	.139	.688	2.287	<b>.023</b>
PT Community Orientation x Dummy Comm*	.541	.159	1.172	3.408	<b>.001</b>
<b>Swiss French</b>					<b>ns</b>
<b>Swiss Italian</b>					<b>ns</b>
<i>Community Orientation: Social Commitment</i>					
<b>Swiss German</b>	$R^2 = .068$				
<i>Constant</i>	4.901	.419		11.700	.000
Dummy Informative Flyer	-1.264	.616	-.526	-2.051	.042
Dummy Emotional Flyer	-.480	.604	-.200	-.795	.428
Community Orientation: Social Relations	-.071	.093	-.095	-.765	.445
PT Community Orientation x Dummy Info*	.334	.136	.648	2.457	<b>.015</b>
PT Community Orientation x Dummy Emo*	.196	.132	.387	1.483	.140
<b>Swiss French</b>					<b>ns</b>
<b>Swiss Italian</b>	$R^2 = .054$				
<i>Constant</i>	4.015	.493		8.146	.000
Dummy Emotional Flyer	.682	.676	.253	1.010	.314
Dummy Community Oriented Flyer	1.436	.672	.537	2.138	.034
Community Orientation: Social Relations	.189	.103	.241	1.841	.067
PT Community Orientation x Dummy Emo**	-.248	.144	-.431	-1.717	<b>.088</b>
PT Community Orientation x Dummy Comm**	-.340	.141	-.616	-2.406	<b>.017</b>

*Note.* \* Reference Group: community oriented flyer. \*\* Reference Group: informative flyer.  
PT = product term

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While for Swiss French and Swiss Italians, the community orientation: *social relations* did not moderate their affective appreciation of the flyer, however, for Swiss Germans it did. Swiss Germans, having more interpersonal relationships and enjoying them more, rated the informative, as well as the community oriented flyer as appealing, touching, and not intrusive, compared to the emotional flyer. This indicates that Swiss Germans appreciated the emotional flyer the least. This conclusion is again confirmed when looking at the second half of the table, showing that Swiss Germans who are more committed to their local community appreciate the informative flyer more than the community oriented flyer.

Interestingly, Swiss Italians, who are committed to the local community, rated the emotional and community oriented flyer less appealing than the informative flyer. This finding is conform to the before presented results but contrary to the previously developed hypothesis.

### **9.4.3 Summary: The Role of Community Orientation in Perception of the Flyer and Feelings it Evoked.**

#### *The Role of Community Orientation on the Feelings Evoked by the Flyer*

In the overall sample, only the community orientation index *social commitment* moderated the effect of the flyer on the feelings it evoked. Overall, participants who did more charity claimed to have more positive feelings after reading the informative or the emotional flyer than after reading the community oriented flyer.

Looking at the different language groups, the picture looked slightly different. Although, the overall result was that participants, community oriented or not, generally preferred the informative flyer over the others. An overview of the detected significant results can be found in Table 77.

**Table 77.** *Summary of the Interaction Models with Message as Focal Independent Variable, Community Orientation as Moderator and Feelings or Perceptions as Dependent Variable*

	Cognitive Perception		Affective Perception		Positive Feelings		Negative Feelings	
	<i>Social Relations</i>	<i>Social Commitment</i>	<i>Social Relations</i>	<i>Social Commitment</i>	<i>Social Relations</i>	<i>Social Commitment</i>	<i>Social Relations</i>	<i>Social Commitment</i>
<b>Swiss Germans</b>	<b>+</b>	<b>ns</b>	<b>+</b>	<b>+</b>	<b>ns</b>	<b>+</b>	<b>+</b>	<b>ns</b>
<b>Swiss French</b>	<b>+</b>	<b>+</b>	<b>ns</b>	<b>ns</b>	<b>ns</b>	<b>ns</b>	<b>ns</b>	<b>ns</b>
<b>Swiss Italians</b>	<b>ns</b>	<b>ns</b>	<b>ns</b>	<b>+</b>	<b>ns</b>	<b>+</b>	<b>ns</b>	<b>+</b>

*Note.* + = community orientation is moderating the effect of the flyer. ns = community orientation is not moderating the effect of the flyer (the direction is not indicated in the table since it depends on the message type which is not indicated in this table)



### ***Positive Feelings***

#### Testing for Community Orientation: Social Relations as Moderator Variable

For none of the linguistic groups did the community orientation index *social relations* (the fact of knowing people and liking to be around friends etc.) significantly moderate the feelings evoked by a specific flyer manipulation.

#### Testing for Community Orientation: Social Commitment as Moderator Variable

Among **Swiss Germans**, participants who were committed to the local community by doing charity etc., the informative, as well as the emotional message, evoked significantly more positive feelings than the community oriented flyer.

While for **Swiss French** the community orientation index *social commitment* did not affect the feelings that were evoked by a specific flyer, **Swiss Italians**, with a high social commitment, tended to be significantly more stimulated, in a positive way, by the informative flyer than by the community oriented flyer.

### ***Negative Feelings***

#### Testing for Community Orientation: Social Relations as Moderator Variable

While for **Swiss French** and **Swiss Italians** the community orientation *social relations* did not impact negative feelings that a single flyer evoked, it did for **Swiss Germans**. For the latter, the more community oriented they were, the less negative ratings they would give for the informative flyer compared to the emotional flyer.

#### Testing for Community Orientation: Social Commitment as Moderator Variable

The community orientation index *social commitment* did not impact **Swiss Germans** or **Swiss French's** negative perception of the flyer while it did for **Swiss Italians**. The latter, showing more social commitment, tended to rate the community oriented as well as the emotional flyer slightly less negative than the informative flyer.

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### *The Role of Community Orientation on the Perception of the Flyer*

The overall analysis showed that the community orientation index *social relations* was moderating the effect of the flyer on its affective appreciation (perception). The community orientation index *social commitment* did so with cognitive appreciation (perception) of the flyer.

Overall, the more participants that were involved in charity activities, the more likely they were to rate the informative flyer convincing and trustworthy, compared to the community oriented flyer. The higher participants were rated on the community index *social relations*, the more likely they were to rate the informative flyer as appealing, touching, and not intrusive, compared to the emotional message.

### ***Cognitive Perception***

#### Testing for Community Orientation: Social Relations as Moderator Variable

**Swiss German** participants with high ratings on the community orientation index *social relations* rated the informative and the community oriented flyer as much more credible and convincing than the emotional flyer. **Swiss French**, however, with a high rating on *social relations*, rated the community oriented flyer significantly less credible and convincing than the emotional flyer, indicating a slight preference for the emotional flyer. **Swiss Italians'** social relations did not impact their cognitive appreciation of the flyers.

#### Testing for Community Orientation: Social Commitment as Moderator Variable

**Swiss Germans** and **Swiss Italians'** cognitive appreciation was not influenced by their social commitment to the community. **Swiss French** however, with a higher commitment to the local community, tended to rate the community oriented flyer as less credible and less convincing than the emotional flyer.



### ***Affective Perception***

#### Testing for Community Orientation: Social Relations as Moderator Variable

**Swiss Germans**, with a high score on the *social relations* index, tended to rate the informative and the community oriented flyer as more appealing and less intrusive than the emotional flyer. For **Swiss French and Swiss Italians**, the *social relation* index did not affect the outcome.

#### Testing for Community Orientation: Social Commitment as moderator variable

While for **Swiss French** the community orientation index *social commitment* did not have any effect on the outcome, it did for **Swiss Germans** and **Swiss Italians**. **Swiss Germans**, with a high rating on the *social relations* index, rated the informative flyer as more appealing and less intrusive than the emotional flyer. Also, Swiss Germans with a higher *social commitment* score rated the informative flyer as significantly more appealing than the community oriented flyer. **Swiss Italians**, with a higher *social commitment* score, found both the emotional and the community oriented flyer less appealing and more intrusive than the informative oriented flyer.

## **9.5 Targeting the Organ Donation Campaign: Did the Flyer Manipulation Impact the Intention to Engage in Organ Donation Behavior?**

### **9.5.1 The Overall Effect of the Flyer on the Intention to Engage in Organ Donation Behavior**

Univariate ANOVA with the flyer as the fixed factor and *Willingness to donate* (1 = no, 2 = probably not, 3 = don't know, 4 = probably yes, 5 = yes) in a first step followed by *Willingness to sign a card* (1 = no, 2 = probably not, 3 = don't know, 4 = probably yes, 5 = yes) in a second step as the dependent variables showed that means on the outcome variables did not differ significantly for the different flyer

## 9 Results

manipulations. This was also found for the control group,  $F(3, 591) = .275$ ,  $p = .843$  for *Willingness to donate organs after death* and  $F(3, 469) = 1.036$ ,  $p = .376$  for *Willingness to sign a donor card*.

Additionally, the same analysis was run for the three outcome variables of the second wave: *Willingness to donate* (1 = no, 2 = probably not, 3 = don't know, 4 = probably yes, 5 = yes), *Signed a donor card since the first interview* (dummy coded 1 = yes, 0 = no), and *Would you sign a donor card* (dummy coded 1 = yes, 0 = no). All of them were highly non-significant and therefore F-tests were not reported anymore. As before, to see whether there were "hidden" effects within each linguistic subsample, the analysis was repeated for the three subsamples.<sup>44</sup>

### 9.5.2 The Effect of the Flyer on the Willingness to Engage in Organ Donation Behavior in the Different Linguistic Regions

For all five dependent variables in Chapter 9.5.1, Univariate ANOVA's were repeated in the three language subsamples. All the F-tests were far beyond a significant  $\alpha$ -level of  $p < .05$  and therefore will not be reported.

### 9.5.3 Test for Mediation: Flyer – Feelings about Organ Donation – Intention to Engage in Organ Donation Behavior

It was hypothesized that the effect of the flyer would be mediated by the feelings it evoked. Thus, the next step was to test whether the participants' evoked feelings mediated their intent to engage in organ donation behavior. To establish mediation, the four steps suggested by Baron & Kenny (1986) were followed. The first step is whether the initial variable is correlated with the outcome variable. Wave one's

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<sup>44</sup> Additionally covariates such as gender, education, attitude, community orientation and knowledge were controlled for, but without effect on the significance level of the outcome variables.

*Willingness to donate*, *Willingness to sign a card*, and *willingness to donate*, and wave two's *willingness to sign a card*, and *having signed a card* were used as dependent variables in separate regression equations. The dummy variables for the different messages as independent variables, as Baron & Kenny suggested, were also used. The results confirmed the previous findings that none of the results were close to being significant at an  $\alpha$  – level of  $p < .05$ . In consequence, mediation could be excluded.

#### **9.5.4 Test for Mediation: Flyer – Perception of flyer – Intention to Engage in Organ Donation Behavior**

As in 9.5.3, the basic assumption of mediation of the independent and dependent variables being correlated was violated, including the mediation *Flyer – Perception of the flyer – Intention to engage in organ donation behavior*.

#### **9.5.5 Summary: The Impact of the Flyer Manipulation on the Willingness to Engage in Organ Donation Behavior**

Overall, the flyer did not directly impact the willingness to engage in organ donation behavior. Contrary to all hypotheses, results remained highly non-significant when testing for the impact of the flyer in the three different language groups.



## **10 Discussion and Limitations**



## 10.1 Discussion

### 10.1.1 Attitudinal Components and Intention to Engage in Organ Donation Behavior

In terms of attitude and knowledge of the participants of the different language groups, the results of Schulz et al.'s (2006) previous study could be confirmed. Swiss French are most positive towards organ donation, Swiss Italians show wide knowledge gaps, and Swiss Germans know a lot but are very reluctant to sign a donor card. However, while in Schulz et al.'s study Swiss Germans seemed to be overall most knowledgeable, this time Swiss French were also found to be very knowledgeable. Although none of the participants knew a lot about medical or technical details, at least Swiss Germans and Swiss French are aware of the relevance of the topic for the society. Interestingly, Swiss Italians did not seem to be aware of the relevance of the topic for the society. Even though public information campaigns from the last three years, initiated by the federal health office, were launched at the same time and run equally as often throughout the country, it seemed that Swiss Italians did not grasp the importance and impact for the society. The fact that Swiss French knew somebody who received or is waiting for a donor organ significantly more often might explain that they knew generally more about the procedure and the topic.

Swiss Germans were willing to donate their organs significantly less often compared to the Swiss French. This result confirmed earlier findings, for instance from Schulz et al. (Schulz et al., 2006) or the official statistics about actual donor rates in the language regions (Bundesamt für Gesundheit, 2009). What could have been shown in this study is that Swiss Germans especially have a big threshold between the declared willingness to donate and the willingness to sign a card. Reasoning could be a high fear that they would receive inferior medical treatment. This has been shown to be a commonly listed argument against organ donation commitments in organ donation literature (Denvir & Pomerantz, 2009; Morgan et al., 2008; Morgan, Stephenson et al., 2008). It was also an important issue for Swiss Germans in Schulz et al.'s previous study in 2006. One item with crucial significant differences

( $p < .001$ ) was *Organ donors must fear inferior treatment, because doctors wait for their organs*. While 17.6% of Swiss Germans thought this was the most relevant issue, only for 8.3% of the Swiss Italians thought so (Schulz et al., 2006).

Thinking about organ donation did not scare the majority, the mean score in all three groups was around 3, thus the middle and lower part of the 7-point Likert-type scale. Whether the previously discussed “ick-factor” or the fear of death had an impact on organ donation behavior or not, was not assessed in this survey.

An interesting result was the number of donor cards signed between the two interviews:

**Table 78.** *Increase in Signed Donor Cards of Participants in First and Second Wave.*

	Swiss German <i>N</i> =49	Swiss French <i>N</i> =76	Swiss Italian <i>N</i> =44	Total <i>N</i> =169
Participant had already a donor card during the first interview.	61%(30)	<b>76%(58)</b>	<u>52%(23)</u>	66%(111)
Participant signed donor card after the first interview.	39%(19)	<u>24%(18)</u>	<b>48%(21)</b>	34%(58)
<i>Increase in Donor Cards</i>	63%	31%	91%	52%

$$\chi^2 (2, N = 169) = 7.754; p = .021$$

Underscore = adjusted residual < 1.96

**Bold = adjusted residual > 1.96**

As discussed before, Swiss Italians had 90% more donor cards after the survey than before. Also, the intervention for Swiss Germans had a relatively high effect with a 60% increase in signed donor cards. Swiss French from the very beginning had more donor cards, but Swiss Germans and Swiss Italians need more incentives to think about the topic. The survey however, did not control for social desirability differences among the language groups.



### **10.1.2 The Role of Personal Experience, Knowledge and Community Orientation**

#### **10.1.2.1 *Personal Experience***

From knowing people who had to go through organ donation before or possibly medical staff, also predicted a more positive attitude towards organ donation. This relation was the same in all three language groups.

Only among Swiss French knowing somebody who received or is waiting for an organ, and thus being a little involved oneself, did have a positive effect on a) the willingness to donate and also b) the willingness to sign a card. Thus, using empathy in their campaign could be an effective tool. This must be carefully pretested though among a test population; the here designed community oriented flyer did not have the desired positive reactions among Swiss French.

#### **10.1.2.2 *Knowledge***

During the 2007/2008 campaign every household was sent an information sheet with a donor card included. The procedure was the same for all of Switzerland. Still, the level of knowledge about the donor card was especially low for Swiss Italians. For all three language groups, knowledge about the donor card was significantly predicting the willingness to donate. However, only for Swiss Italians did it also predict the willingness to sign a card.

An interesting phenomenon revealed by this survey was that when Swiss Germans and Swiss French declared a willingness to donate, that did not necessarily result in a consequent willingness to sign a donor card, while this was the case for the Swiss Italians. This might be an indicator, that to raise awareness and eventually enhance organ donation behavior among Swiss Italians, it might be enough to increase exposure and explain the role of the donor card particularly. This should be done also because they are generally more in favor of donating their organs after death.

Knowledge about the donor card specifically predicted the willingness to donate for all three language groups; while it predicted the willingness to sign a card only for Swiss Italians. This lead to the conclusion that a) for Swiss Germans and Swiss French knowing about the donor card does not necessarily make them sign it, but b) it still predicts their willingness to donate. For Swiss Italians however, it is enough to simply improve the communication about the role and the significance of the donor card, as well as how to get one, to make them make up their minds and sign a card.

For Swiss Germans especially, technical/medical knowledge turned out to be crucial in predicting the willingness to donate. There seemed to be an important threshold between the willingness to donate and the willingness to sign the card, especially among Swiss Germans. The reasons are still concealed. Future organ donation research in Switzerland might clarify why Swiss Germans have a bigger issue with signing a donor card.

The conclusion one might draw from these results is that instead of trying to make Swiss Germans sign a card, which for unexplained reasons are not willing to do so, it would be more effective to create a message emphasizing the importance of a) making a decision and b) telling the family about that decision.

After the here presented survey, official campaigns in 2009 stressed the importance of communication with the family. Bringing together Schulz et al.'s (2006) results that knowledge predicts organ donation behavior among Swiss Germans and the here shown reluctance to sign a card, future campaigns for Swiss Germans might be more effective if the reasons to communicate with the family are stressed. Results have shown that Swiss Germans value information, so informing them on the reasons why they should communicate their own wish to donate or not after death could raise their awareness of the topic. This would also go together with the stereotype about Swiss Germans seeing themselves as knowledgeable, rational, and correct (Fischer & Trier, 1962). So, instead of telling Swiss Germans things they already know, a more emotional approach, stressing the importance of communication with peers might be the best approach to increase awareness, resulting in the communication of once own willingness to donate or not. This would

still be in line with the existing campaign and the claim of the government that its duty is not to convince but to “inform” the citizen (Bundesamt für Gesundheit, 2011a).

Swiss Italians on the other hand, need more information to become aware of the relevance to society and the actual lack of donors. Apparently, existing campaigns explaining the law, the 2007/2008 campaign, did not succeed in doing so. They did not reach Swiss Italians. An option might be, again referring to Schulz et al.’s (2006) findings, namely that personal communication is more effective with Swiss Italians by enhancing awareness of medical staff and bring up the topic directly at general practitioners or pharmacies for instance. But also by planning a poster campaign to wrap relevant information in with the local authorities, a local celebrity, or just locals who would be explaining it to each other. The here presented study clearly showed Swiss Italians want information, but after one and a half years of campaigning (the survey was conducted 1.5 years after the 2007 campaign was launched), they did not know a lot more than in Schulz et al.’s 2006 study, and thus, the strategy did not work out. This clearly shows that there is an urgent need to better target the different populations.

### 10.1.2.3 *Community Orientation*

Contrary to the hypothesis, Swiss Italians did not show a higher community orientation as previous research suggested (Schulz et al., 2006).

Interestingly, being active in the local community and liking to do charity had a small effect on the positive attitude towards organ donation among Swiss Germans but not for the other two groups. Swiss French participants who were socially committed were, on average, more understanding than Swiss Italians towards people who do not want to donate. Reasons for that need to be further investigated to provide more insight on why some Swiss French do not donate. Another reason is because they show an overall positive attitude towards organ donation, which also resulted in a high number of people having a donor card. Unfortunately this study did not grasp the underlying factors for Swiss French reasoning and behavior. However, it would be most interesting to investigate these since this and Schulz et al.'s study showed that there are differences in a) attitudes and b) behavioral outcomes among the language groups. The reasons still remain concealed however.

Another interesting result was that whether a person likes to be in company, and rates the importance of the family and friends higher, has a stronger effect on the intention to engage in organ donation behavior among Swiss French and Swiss Italians than among Swiss Germans, both for willingness and to sign a card.

This finding confirms the original hypothesis that community orientation plays a crucial role in processing organ donation information and decisions. Why the community flyer eventually did not work better with the Swiss French and Swiss Italians is another question. It could be due to either a false assumption, namely that community oriented people also appreciate a community oriented flyer (which could not be confirmed by this study) or that the supposedly community oriented flyer was not well enough designed and adapted to these people. The question is whether people who already are highly social and have strong relationships with others, need to be targeted at all by the campaign. They are already very positive towards the topic and willing to donate and sign donor cards.

### 10.1.3 Cognitive and Affective Reactions to the Organ Donation Flyer

The aforementioned need to provide Swiss Italians with better and more information is also confirmed by a slight preference for the informative flyer.

This was the only significant result when examining the effects of the flyer on the outcome variables. None of the other language groups showed a clear preference for any of the flyers. The reasons for that shall be discussed later on in the *Limitation* section.

### 10.1.4 The Role of Community Orientation in the Perception of the Flyer and Feelings it evoked

The fact that even Swiss Italians, with a higher social commitment, doing charity etc., showed a tendency to prefer the informative flyer, confirms the –contrary to our hypothesis– before mentioned suggestion of the need for more but also better presented information among Swiss Italians.

For Swiss Germans, being active in their local community, the community oriented flyer was least appreciated, meaning that the informative and the emotional flyer evoked significantly more positive emotions. This confirms the perviously mentioned doubt, that community orientation does not necessarily lead to a stronger appreciation of a community oriented flyer or alternatively the flyer was badly designed. For Swiss Germans, having many social relations, the informative flyer evoked less negative emotions than the emotional flyer. A similar pattern could be observed with Swiss Italians, who are active in their local community; the informative flyer evoked much less negative emotions than the other two flyers. This again stresses the need for more and better information for Swiss Italians. However, Swiss Germans, being more social, still prefer the informative flyer to the emotional flyer.

**Overall, the hypothesis that community orientation (either knowing many people or being active in the local community<sup>45</sup>) leads to a preference of the community oriented flyer has been proven wrong. Whenever a relationship between community orientation and a preference for a specific flyer could be observed, it was a preference for the informative flyer first, emotional flyer second, and community flyer last. This did not change when looking at each linguistic group's data separately.**

#### **10.1.5 The Impact of the Flyer on the Willingness to Engage in Organ Donation Behavior**

There was no direct effect of the flyer on the willingness to donate or to sign a card, neither in the first wave nor in the following telephone survey in any of the language groups. Possible reasons for that will be discussed in the section *Limitations of the Study*.

Although the flyers did not show any effect in predicting organ donation behavior, it is most relevant to evaluate how the flyers were perceived. The latter is of crucial relevance because to be able to raise awareness, an ad must be seen and processed. As shown above in the presented survey, the information campaign following the introduction of the new transplantation law in 2007 did not render the population any more informed than before. Especially not the Swiss Italians, who apparently did not process the provided information although they needed and wanted it. Swiss Germans on the other hand, remembered the information provided but were still reluctant to discuss the topic or to commit to any specific behavior. For the first group, a thorough design and pre-test of organ donation campaigns should help transmit better information to Swiss Italians. For the latter, a positive frame increasing involvement, empathy (Petty & Cacioppo, 1986; Petty & Cacioppo, 1984; Skumanich & Horton, 1991; Skumanich & Kintsfather, 1996), and stressing the

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<sup>45</sup> Multicollinearity between the two indices exists but is not further discussed because the the analysis was run within a simple linear regression model and not within a multiple regression model.

impact for the family in a hospital setting might be more successful. This is also shown through existing literature about designing health messages, for instance in Monahan's contribution about using positive affect when designing health messages (Monahan, 1995).

Even though, a lack of the flyer's effect could be observed, still doing an interview about organ donation led to an increase in signed donor cards of 91% among Swiss Italians (see Table 54). The question is whether this can be explained by a stronger social desirability effect among Swiss Italians from doing the interview with a person in their own social network, or that, as suggested before, for Swiss Italians, the personal approach is much more efficient.

Another secondary effect that could be observed, although the flyers did not have the desired effect on the outcome variables and thus the intention to engage in organ donation behavior, it did have an effect on the participation rate in the second wave. Overall, having read an intervention flyer significantly predicted the participation, also in the follow up. This effect, when splitting the file and running the analysis for the three language groups separately, disappeared for Swiss Germans and Swiss French and increased for Swiss Italians. Among the Swiss Italians, especially participants who read the emotional flyer, participation was predicted in the follow up survey. Therefore, one can conclude although the flyer did not have the expected outcome on the willingness to engage in organ donation behavior, there were differences in the perception of different flyer interventions and differences in consequent behavior (see attrition analysis section 7.5). Reasons for the lack of effect in actual outcome will be discussed in the follow section *Limitations of the Study*.





## 10.2 Limitations

Some methodological issues of this research can be noted; particularly, some of the concepts such as attitude or community orientation may seem vague. In future research, the item scales might be completed and amended and a more thorough definition of *community orientation* could be defined.

The introduction of the new law in 2007, and the awareness-raising activities done by the Swiss government and organ donation associations such as Swisstransplant, could be seen as a validity issue impeding experimental intervention. Communications with officials of the federal department in charge of the organ donation campaign confirmed that during this research study period, no actions (hanging posters, internet adds, or sending information to households) were taken. Thus, there is no risk that between first and second wave (telephone survey) additional public action was taken that would impede the presented results.

From a methodological viewpoint the extremely low R squares might be intriguing. On the one hand this is due to the way of the analysis. All analyses were run separately to be able to clearly distinguish all, also small, effects. Analyzing more variables in a more complex model, for instance in a structural equation framework, running the model as a whole, and taking into account various covariates in the same time automatically increases the R square. However, after numerous preliminary analyses, the more intuitive way was opted for, parceling out the analysis of running them separately. This was a pragmatic decision to ease the interpretation for the reader. Another explanation is because of the extreme complexity of the cognitive and affective processing within the process of attitude forming and decision making. This is particularly true for social sciences. Moderator effects were especially difficult to detect because already R squares of 0.01, which would be as much as explaining 1% of the total variance, “should be considered important” (McClelland & Judd, 1993, p. 377). McClelland and Judd also referred to Champoux, Peters (1987) and Chaplin (1991) who reviewed much of the existing

social science literature and concluded that most of the field study interactions typically account for not more than 1% to 3 % of the variance (idem).

A most striking result of this study was the extremely low effect of the flyers on the outcome variables; favoring organ donation and the willingness to sign a donor card. The possible reasons, from a methodological viewpoint, shall be discussed more in detail. The lack of a clear effect could be explained by several methodological reasons of which some shall be listed in the following.

The first question is, whether one small intervention, during a half hour interview, could be strong enough to change a person's attitude towards organ donation. At this point, one might refrain from claiming to be able to change the mind of somebody. For future studies it might be more valuable to test whether the intervention/flyer could raise awareness and make people think about the topic. This might be a better indicator for the effectiveness of the intervention than the actual behavior or attitude. In the field of organ donation, which is so closely related to death, people tend to avoid thinking about the topic overall (see section about the "ick"-factor and the role of death).

Another explanation might be in the design of the experimental intervention. Each participant only rated one message. Maybe allowing them to rate their preferences, reading all three of the flyers and comparing them one to one, might produce stronger effects in the appreciation of the different flyer approaches.

Furthermore, the flyer manipulation itself might also have been problematic. For reasons explained in the methodology section, there was no clear distinction between a) form of the message (narrative vs. statistical) and b) content (information or story). While one message was statistical and the other two narratives, all of them contained some information. This mixture of message types within messages, not comparing them directly within each participant, might render a clear statistical distinction in consequence difficult.

Finally, one inherent characteristic of an experiment is, as Shadish and Thomas pointed out that experiments are mostly conducted in specific settings with one specific treatment and all possible versions of it (Shadish et al., 2002). For several reasons it was decided not to test all. The main challenge was to a) talk about organ donation, an emotional topic by defaults, without being emotional, b) tell a story about organ donation without providing any information, and c) create a credible and trustworthy flyer for each case. Thus, reflected but arbitrary decisions were made based on previous literature and research. Consequently, not all possibilities were tested, which might be an impeding element in finding crucial differences.

Another element is whether the hypotheses were built upon false assumptions from the beginning. Even if the common stereotype of Swiss Italians being more community oriented and seeing the family and friends as a larger role was true, this might not necessarily lead to a greater appreciation of a community oriented flyer. The same is true for the Swiss Germans: even if knowledge within Swiss Germans predicts organ donation behavior, as seen in Schulz et al.'s study 2006 (Schulz et al., 2006), this does not necessarily mean that they need even more information. Apparently, knowing significantly more than their other compatriots, Swiss German's willingness to engage in organ donation behavior or not, is not significantly higher, independent of their knowledge.

### **10.3 Conclusion, Practical Implications and Need for Future Research**

#### **10.3.1 Practical Implications for Targeting the Organ Donation Campaign in Switzerland**

Since organ donation in Switzerland highly relies on altruism and the voluntary engagement of people and their relatives, public communication becomes even more important. It should provide the population with relevant information on one hand, but also promote a positive image of organ transplantation medicine, its breakthroughs, and its advantages. It should also unveil existing myths and increase confidence in the medical institutions as well as in the structure and organization of the field. This is crucial in establishing a positive image of Swiss transplantation medicine.

Health communication therefore is one of the main and most crucial tools in achieving these goals. To find the right communication strategy, it is important to understand how target audiences process information and then find an effective way to communicate the relevant information. By doing this, the strategy should create a positive attitude by conveying trust to donors, receivers, and the respective families on a difficult topic related to illness and death.

Additionally, to Skumanich & Kintsfather's advise, to create messages "that arouse empathy, and ask on the donor card to make it witnessed by two family members on the card itself" (Skumanich & Kintsfather, 1996) more suggestions based on the previously presented results for future organ donation campaigns shall be given in the following.

##### **10.3.1.1 *Swiss Germans***

An organ donation campaign targeting Swiss Germans should particularly raise the awareness of social relevance and the lack of donors to arouse empathy. Additionally, raising the awareness about the positive emotional outcomes from communicating one's own wish to relatives who will then have to decide about

explantation, in a very stressful moment of grief and sorrow, seems to be a promising strategy. Furthermore, there is no need to provide more information about the law, the donor card or else given that overall, Swiss Germans are well informed. Since Swiss Germans are so reluctant to sign a card, although willing to donate, the importance of talking with the family (and/or friends) about the topic should be further stressed (as already done by the 2010 official campaign<sup>46</sup>). When using a community or an emotional approach, one needs to be careful as an over imposing community approach creates an instructing effect, which Swiss Germans tend to depreciate. Stressing the role of the donor card as vehicle for communication however might be effective. It should underline its main aim is not to tell doctors about one's own wish, but their own family and relatives who will eventually have to make the decision.

#### **10.3.1.2 *Swiss French***

Swiss French revealed to be the group most difficult to target. They a) already know so much about the topic, b) are very positive towards the topic, and c) already have more donor cards than all other groups.

Swiss French are already positive and knowledgeable; making them a little mystery. The presented study did not succeed in understanding the Swiss French audience better, while further research, possibly with qualitative interviews, focus groups, or observations is urgently needed and could understand them better. Further research is also needed to examine the reasons why Swiss French who do not sign donor cards and do not want to give their organs. Once analyzed, this might help to find a way to adapt the communication message to the French speaking population.

However, some indications drawn from the few revelations detected in the presented study shall be given. Thus, an organ donation campaign targeting Swiss French might be more effective if it used empathy in the campaign; although this

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<sup>46</sup> Further research might now evaluate the effects of the 2010 campaign, assessing how many people told family members or friends about their wish to donate or not since the latest official campaign.

should be carefully pretested among a test population. The here designed community oriented or emotional flyer did not have the desired positive reactions among Swiss French.

### **10.3.1.3 *Swiss Italians***

An organ donation campaign targeting Swiss Italians should stress the relevance of the donor card, especially since knowledge about the donor card predicted actual behavior in signing a card. They should be told more precisely what the donor card is for, the implications, that one does not need to do a medical exam, where and how they can get it, ect. Swiss Italians, contrary to Swiss Germans, do not seem to need reasons on why they should talk to their family, but rather **indications how** to talk to them.

However, it turned out that providing information might still be of use. There is still need to carefully design this information. Apparently, putting law paragraphs on posters or sending the new laws by mail to each household was not very effective in informing the Italian speaking population. There is need for information but there is especially a need for improving the communication of this information.

Additionally, what Schulz et al. (2006) already suggested once, involving doctors and pharmacists to provide information might be more effective than a poster campaign for Swiss Italians.

### **10.3.2 Implications for the field of health communication**

Knowing this and combining it with other findings, for instance about personality traits in the linguistic regions (Dunkel & Zurbriggen, 2011), these findings could not only be used to improve the organ donation public communication but also other campaigns in other domains. Understanding the existing differences is highly crucial

in obtaining optimal results in the communication of health related issues in Switzerland. Simple translations often create misunderstandings or lead to the complete avoidance of the information provided. This happened in the 2007 poster campaign with the Italian speaking population, which still manifests very low levels of knowledge about the topic.

### **10.3.3 Future Research**

A big weakness of this study is that it does not really grasp the reasons of a specific behavior in each language group. Differences might be explained by a) common stereotypes or even by b) the stereotype research about the linguistic groups in Switzerland. The lack of exact measures grasping the psychological reasoning behind the decisions to donate or not is a pertinent point of criticism. Testing existing models, such as the health belief model (Glanz et al., 2008), the theory of reasoned action, or its extended version the theory of planned behavior (Ajzen & Fishbein, 1980; M. Fishbein & Ajzen, 1975), and including cultural differences would reveal some of these psychological aspects better. This could lead to eventually understanding why Swiss Germans, Swiss French, and Swiss Italians reason and act so differently.

A more complex study, testing personality traits in the different language regions, might provide interesting insights into behavioral differences. In the Swiss Household Panel, a representative survey among the Swiss population repeated every year, the short version of the big five inventory was sought out. An analysis of the dataset (Dunkel & Zurbruggen, 2011) showed that the language regions differ on three dimensions: extraversion, openness, and agreeableness. A full assessment of the long versions of the big five inventory (neuroticism, conscientiousness, extraversion, openness, and agreeableness), in relation to health topics, might provide more detailed information about the differences in reasoning, processing of information, and decision making among the three linguistic groups. More studies to

show that differences exist are not needed, but studies that define these differences and explain them.

Another possible solution, additional to the personality trait measurement, might be to run focus groups in the three language regions to grasp the differences in reasoning organ donation decisions. This seemed to reveal important and promising outcomes in recent research, as for instance in Arriola et al.'s study (Jacob Arriola et al., 2005) who did focus groups among African Americans to “improve the development of effective culturally sensitive intervention messages targeting the African-American community.” Another is Devlin et al.'s study (Devlin et al., 2005), who conducted focus groups in seven European countries to examine the potential to “provide targeted and personally relevant messages” (idem).

Eventually, this study could show again that there are indeed attitudinal and behavioral differences among the Swiss; more precisely among the linguistically and geographically distinct Swiss. However, it failed to provide explanations for the specific behaviors.

What remains apparent is Wong's suggestion to provide different populations with culture specific information (Wong, 2010a). To better target these population segments, they need to first get a thorough psychological profile, which will need future research.



## **11 Bibliography**

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Micro-Cultural Differences in Switzerland:  
The Effectiveness of Targeted Promotional Messages in  
the Field of Organ Donation

Anke Dunkel

**ANNEX**



## **ANNEX A – ORIGINAL QUOTES**

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- [1] „dass schliesslich vieles von dem nicht stimmt, weswegen uns das Ausland bestaunt, das Miteinanderleben von Menschen verschiedener Sprachen etwa: Sie leben nicht miteinander, sie leben nebeneinander.“ (Dürrenmatt, Friedrich 1998, p. 189)
- [2] « Ce n'est pas seulement une langue et une culture, mais aussi une manière de vivre et un état d'esprit qui caractérisent la Suisse italienne » (Ribeaud, José 2010, p. 234)
- [3] « Le Tessin sans la Suisse perdrait tout son importance ; la Suisse sans le Tessin, cela reviendrait à mutiler l'idéal de l'État confédéré. » (Ribeaud, José 2010, p. 256)
- [4] « Aujourd'hui, personne ne peut plus imaginer une Suisse qui ne serait pas quadrilingue. La richesse de notre pays, c'est de penser en plusieurs langues » (Ribeaud, José 2010, p. 273)
- [5] « La Suisse, née de la volonté de peuples aux langues et cultures différentes d'unir leur destin pour le meilleur et pour le pire... » (Ribeaud, José 2010, p. 273)
- [6] „so hatte sich ab 1798 aus derselben Matrix des erwählten Volkes ein neues, politisiertes Konzept der Nation herausgeformt: die Schweiz als Gesinnungsnation, die Unterschiede der Völkerschaften, Sprachen und Kulturen, überbrückte und deren Zusammenhalt das Bekenntnis zu Freiheit, Recht und staatsbürgerlicher Gleichheit bildete“ (Reinhardt, Volker 2010, p. 95)
- [7] “La pluralità delle lingue può essere talvolta fastidiosa; essa rallenta le comunicazioni tra centro e periferia, tra governo e popolo, appesantisce l'amministrazione e la fa più costosa, ritarda la comunione spirituale tra cittadini d'uno stesso Stato. ... Data la diversità delle lingue, è certo difficile spiegare agli Svizzeri le stesse cose, ma è assai più difficile scatenare in essi delle passioni; è quindi un vantaggio per la ragione, cioè per una politica di tranquilla persuasione e di problemi concreti. Inoltre, la diversità delle lingue è un rimedio contro il nazionalismo razzistico e contro la forma più pericolosa del nazionalismo, che è il nazionalismo culturale, ed è una conferma dell'idea di Giuseppe Mazzini, intesa a un concetto politico e morale di nazione, che si inverte non già su presupposti materiali (stirpe, sangue, lingua) ma sugli argomenti dello spirito: la volontà, la storia vissuta e sofferta insieme. Benché per stirpe, per caratteri e per lingue diversi, lo svizzero di Lugano, quello di Disentis, quello di Basilea e quello di Ginevra si sentono legati insieme dalla volontà e dalla storia (che è poi ancora una prova di continua volontà), cioè da un vincolo spirituale più impegnativo di qualsiasi somiglianza fisica.” (Merz, Riccardo 1959, p. 52)
- [8] « Il reste néanmoins que, si on ne peut parler de fossé entre allemand et italien ou français et italien, c'est que les Suisses du sud, se montrent plus ouverts vis-à-vis des autres régions linguistiques et davantage disposés à apprendre l'une et l'autre langue. On connaît certes en



Suisse l'expression « Polentagraben », fossé de la polenta, manifestement forgée à l'imitation de l'expression « Röstigraben », et bien entendu, les Tessinois montrent aussi une certaine aversion face aux groupes linguistiques plus importants ; mais en comparaison des relations entre Alémaniques et « Welches » [Swiss French], ces attitudes n'ont qu'un effet insignifiant sur la communication linguistique entre les différents groups »

- [9] « L'une des expressions les plus claires de cette synthèse boiteuse se trouve dans le message du Conseil fédéral sur la patrimoine spirituel de la confédération, rédigé par Philipp Etter en 1938. On y retrouve à la fois une apologie de la diversité des cultures qui forment la Suisse et une affirmation de sa profonde unité, en mêlant dans un joyeux syncrétisme les influences de Ramuz, Reynold, Gotthelf, et d'autres encore. » (Chollet, Antoine 2006, p.137)
- [10] „Ich freue mich darüber, dass sie mit dabei sind, die Tessiner, die Welschen, die Romanen. Wir können uns gegenseitig daran hindern, typisch zu werden“ (Bichsel, Peter 1997, p. 24)
- [11] „Die Schweiz ist nicht ein Kleinstaat, sondern ein Bund von Kleinstaaten. Es gibt ja auch nicht Schweizer, d.h. es gibt nicht eine schweizerische Nation, sondern es gibt Deutschschweizer, Welschschweizer, Tessiner und Reste von Rätoromanen“ (Dürrenmatt, Friedrich 1998, p. 198)"
- [12] „Die Schweiz ist interessant als Kunstgebilde, als ein Zusammenleben von Menschen, von denen ein jeder ein ganz anderes Heimatgefühl hat, eine andere Sprache. Ein Welschschweizer denkt an den Genfersee oder an den Neuenburgersee oder das Waadtlandt, er hat ein anderes Heimatgefühl als der Ostschweizer. Es gibt verschiedene Heimaten. Die Schweiz ist ein Mutterland und nicht ein Vaterland.“ (Dürrenmatt, Friedrich 1998, p. 200)
- [13] „Fernsehen kann auch auf triviale Weise wesentlich sein“ (Schradi, J. 1986)

## **ANNEX B –Synopsis of the Questionnaire**

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Anke Dunkel

# **Raising Awareness of Organ Donation (II). The Effectiveness of Targeted Promotional Messages.**

Synopsis of Questionnaire

Lugano, May 2011

## Explanation of Synopsis:

The below following synopsis contains all questions that have been asked in the December 2008 written questionnaire and in the January/February 2009 following telephone survey to a sample of Swiss from German, French and Italian speaking regions in Switzerland. The questions are grouped thematically and follow the same structure as the frequency table book.

The numbers in each cell refer to the item number (question) in the questionnaire.

The sign ♦ indicates, that this particular question has not been asked in the respective wave.

A *P* means that the question has been asked pre-intervention, meaning before participants read the experimental intervention/flyer.

**Social-demographic Variables:**

	First Wave 2008/2009	Telephone Survey 2009	Scale
Language of the interview	<b>Included in Code</b>	<b>1</b>	Nominal
Year of Birth	<b>1</b>	♦	Scale
Gender	<b>2</b>	♦	Nominal
Marital Status	<b>3</b>	♦	Nominal
Children	<b>4</b>	♦	Scale
Religion	<b>5</b>	♦	Nominal
Education	<b>6</b>	♦	Nominal
Profession	<b>7</b>	♦	Nominal
Urban/Rural Setting	<b>8</b>	♦	Nominal
Mother Tongue	<b>9</b>	♦	Nominal
At the moment working in health sector	<b>10</b>	♦	Nominal

## Knowledge about Organ Donation:

	First Wave 2008/2009	Telephone Survey 2009	Scale
Do you know what you have to do to make your organs available after your death?	<b>11</b>	♦	Nominal
Have you ever heard of a donor card?	<b>12</b>	♦	Yes/No
14 Knowledge Items / right-wrong	<b>13</b>	♦	Right, Wrong, Don't know
Do you feel informed about organ donation?	<b>15</b>	♦	Yes/No
Did you look for more information about organ donation?	♦	<b>6, 6a</b>	Yes/No

## Attitudes towards Organ Donation:

	First Wave 2008/2009	Telephone Survey 2009	Scale
Organ Donation is a good thing.	14	♦	Scale 1-7
I can understand that some people might not want to give their organs after death.	14	♦	Scale 1-7
Thinking about organ donation scares me and makes me think about death.	14	♦	Scale 1-7
Would you agree to organ donation for a deceased relative who did not express his wish to donate or not before dying?	16	10	Scale 1-5
Would you agree to organ donation for a deceased relative who expressed his wish to donate before dying?	17	♦	Scale 1-5
Would you vote in favor of a law introducing an opt-out system?	18	♦	Yes/No
What is in your opinion the main argument in favor of organ donation?	♦	14,16	open
What is in your opinion the main argument against organ donation?	♦	14,16	open



**Willingness to donate organs after own death:**

	First Wave 2008/2009	Telephone Survey 2009	Scale
Would you agree to give your organs after death?	<b>P25</b>	<b>7</b>	1-6
Do you have a donor card?	<b>P26</b>	<b>8</b>	Yes/No
Did you ever think about signing a donor card?	<b>P27</b>	<b>8b</b>	Yes/No
Would you sign a donor card?	<b>P28</b>	<b>8c</b>	1-5
Did you think about organ donation since the first interview?	<b>♦</b>	<b>1</b>	Yes/No

**Personal Experiences:**

	First Wave 2008/2009	Telephone Survey 2009	Scale
Do you personally know somebody who has received an organ or is waiting for an organ?	<b>19.1,19.2</b>	♦	Yes/No
Do you personally know somebody who's family had to decide whether or not to give the organs of a deceased relative?	<b>20.1,20.2</b>	♦	Yes/No
Do you know doctors dealing with organ donation?	<b>21</b>	♦	1-4

**Factors to indicate „community-orientation”:**

	First Wave 2008/2009	Telephone Survey 2009	Scale
My family is for me most important.	<b>22</b>	♦	1-7
My friends are for me most important.	<b>22</b>	♦	1-7
I get along alone very well and do not need others support.	<b>22</b>	♦	1-7
I like to have a lot of people around me.	<b>22</b>	♦	1-7
I like to spend time alone.	<b>22</b>	♦	1-7
I like to be socially active, i.e. for my community.	<b>22</b>	♦	1-7
I know my neighbors quiet well and see them regularly.	<b>22</b>	♦	1-7
In your opinion how important is organ donation for the community?	♦	<b>11</b>	1-7

### The willingness to communicate the wish to donate or not its organs after death:

	First Wave 2008/2009	Telephone Survey 2009	Scale
I find it difficult/easy to talk with my family about organ donation.	<b>22</b>	♦	1-7
I find it difficult/easy to tell my family whether or not I would like to give my organs after death.	<b>22</b>	♦	1-7
I will soon tell my family whether or not I would like to give my organs after death.	<b>22</b>	♦	1-7
I would not like to tell my family whether or not I would like to give my organs after death.	<b>22</b>	♦	1-7
I would ask a family member to witness my signature of the donor card.	<b>22</b>	♦	1-7
Did you discuss the topic within your family?	♦	<b>2</b>	Yes/No
Did you communicate your wish to donate or not to your family?	♦	<b>3</b>	Yes/No
Do you know whether your family members would like to donate or not their organs after death?	♦	<b>4, 4a</b>	Yes/No
Did you discuss the topic with your friends?	♦	<b>5</b>	Yes/No

## Appreciation of the Flyer:

	First Wave 2008/2009	Telephone Survey 2009	Scale
Trustworthy, Emotional, Comprehensive, Informative, Credible, Convincing, Appealing, Touching, Imposing	<b>P23</b>	♦	1-7
Reading the flyer I felt aggressed.	<b>P24</b>	♦	1-7
Reading the flyer I felt concerned.	<b>P24</b>	♦	1-7
Reading the flyer I felt reassured.	<b>P24</b>	♦	1-7
The flyer made me think about the topic.	<b>P24</b>	♦	1-7
The flyer made me nervous.	<b>P24</b>	♦	1-7
The flyer would be understandable for my friends.	<b>P24</b>	♦	1-7
The flyer gave me an overall good impression of the transplantation medicine.	<b>P24</b>	♦	1-7
Do you remember the flyer you had to read during the first interview?	♦	<b>12, 13</b>	Yes/No

## **ANNEX C – FLYER INTERVENTION**

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## Wie kann man Organspender werden?

- Organspenderausweis beim **Arzt** oder **Apotheker erfragen**, ausfüllen, bei sich tragen und dies der Familie mitteilen.
- Organspenderausweis im Internet runterladen z.B. auf der Seite von Swisstranplant: **www.swisstranplant.org**, ausfüllen, bei sich tragen und dies der Familie mitteilen.
- **Der Familie** den Wunsch nach dem Tod seine Organe zu spenden mitteilen.

Organe spenden - Leben schenken e.V.

Via Giuseppe Buffi 13, 6900 Lugano  
Tel.: 0586664486  
Fax: 0586664647  
[www.leben.schenken.ch](http://www.leben.schenken.ch)

Organe spenden-  
Leben schenken



# Organspende in Zahlen und Fakten

In den letzten 10 Jahren hat die Transplantationsmedizin grosse Fortschritte gemacht. Die Nachfrage nach Organen ist folglich rasch angestiegen. Heute fehlen in der Schweiz nach wie vor Organspender. Im Folgenden erhalten Sie einige Zusatzinformationen zum Thema Organspende.

**STATISTIK** Im letzten Jahr haben nur 418 Menschen ein Organ erhalten. 1371 Personen befanden sich 2007 auf der Warteliste. 50 Personen sind gestorben, weil sie nicht rechtzeitig ein Spenderorgan erhalten haben. Die Wahrscheinlichkeit, eines Tages Organspender zu werden, ist sehr viel geringer als die, eines Tages selbst ein Organ zu benötigen.

**GESETZ** Nach Schweizer Recht kann nur derjenige Spender werden, der einer Spende zu Lebzeiten zugestimmt hat (z.B. Organspendeausweis), oder dessen Familie einer Spende zustimmt. Kann die Familie nicht kontaktiert werden und der verstorbene Patient hat keinen Spenderausweis, dürfen keine Organe entnommen werden. Organspende ist kostenfrei sowohl für Spender als auch für Empfänger. Der Handel mit Organen ist verboten. Der Besitzer des Ausweises kann jederzeit seine Meinung ändern.

**ANONYMITÄT** Es gibt kein zentrales Register, das eine Liste mit Organspendern



führt. Sofern kein Ausweis gefunden wird, wird die Familie befragt. Organspende ist anonym. Auch die Empfänger können mit der Spenderfamilie nicht in Kontakt treten.

**ORGANVERTEILUNG** Die Empfänger der Organe sind auf einer Warteliste. Es gibt keine Vorzugsbehandlung für reiche und berühmte Patienten. Die Auswahl des Empfängers erfolgt nach Warteliste und medizinischen Kriterien.

**MEDIZINISCHE VORAUSSETZUNG** Es gibt KEINE Altersgrenze für Organspende. Die Untersuchung, ob ein verstorbener Patient Spender werden kann, erfolgt erst NACH der Diagnose seines Todes. Manche Menschen befürchten, dass sie mit Spenderausweis schlechter behandelt werden. Das ist nachweislich nicht der Fall.

## Wie kann man Organspender werden?

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- Organspenderausweis im Internet runterladen z.B. auf der Seite von Swisstransplant: **www.swisstranplant.org**, ausfüllen, bei sich tragen und dies der Familie mitteilen.
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Organe spenden-  
Leben schenken

# Warten auf ein Organ- eine schwere Zeit

Julia liebte es auszugehen, war immer gut gelaunt und ihr Lachen so herzlich und ansteckend. Als die 22-jährige an den Folgen eines schweren Verkehrsunfalls stirbt, geben Ihre Eltern ihre Organe zur Transplantation frei.

Sie war auf dem Rückweg aus dem Urlaub, als sie die Kontrolle über ihr Auto verlor und im Strassengraben liegen blieb. Noch an der Unfallstelle sinkt sie in ein tiefes Koma. Nach einigen Tagen gestehen sich Ärzte, Krankenschwestern und Eltern ein: Julia geht es nicht besser. Es geht ihr schlechter.

Aber wie kann der Entscheid, seinem Kind, das Aschlafend vor einem liegt, Organe zu entnehmen, getroffen werden? „Es war für uns eine Schocksituation“, sagt ihr Vater, „in der wir einfach überfordert waren. Meine Frau und ich waren beide völlig aufgelöst und total überfordert mit der Frage nach der Organspende. Letztendlich haben wir uns dafür entschieden, weil wir gespürt haben, dass Julia nicht mehr bei uns war. Ich erinnere mich an ihre zarten, warmen Hände. Es waren die gleichen warmen Hände, als sie schon von uns gegangen war. Aber es waren nicht mehr Julias Hände. Besser gesagt: es waren nicht mehr die Hände unsere lebenden Julia. Verstehen Sie? Es ist nichts, was man wissenschaftlich beschreiben kann, aber wir waren uns trotzdem sicher, dass Julia nicht mehr bei uns war.“

Vor der Operation bekommt Julia noch einmal Besuch von ihren Eltern. Dann wird sie in den



Operationssaal gerollt. Ihre Nieren schenken zwei anderen Menschen neue Hoffnung. Hoffnung auf ein normales Leben. Einige Tage später nehmen Familie und Freunde bei der Beerdigung endgültig Abschied von Julia.

Gleichzeitig wird die 35-jährige Sabine per Helikopter in die Transplantationsklinik geflogen. Auch sie hat Tränen in den Augen, denn für sie hat sich soeben ein Hoffnungsschimmer gezeigt: Nach drei Jahren Wartezeit und regelmässiger Dialyse soll sie heute eine neue Niere bekommen. Sie weint: aus Angst, Freude und Erleichterung.

Seither sind mehr als 20 Jahre vergangen. Heute ist sie Gross-mutter und geniesst die Zeit mit ihren Enkelkindern in vollen Zügen. Von der Krankheit keine Spur mehr. Nur die Pillen erinnern sie zweimal am Tag daran, dass ihr Leben etwas anders verlaufen ist, als das der meisten Menschen.

Vielleicht Dank Julia! Und Dank ihren Eltern!

## Wie kann man Organspender werden?

- Organspenderausweis beim **Arzt** oder **Apotheker erfragen**, ausfüllen, bei sich tragen und dies der Familie mitteilen.
- Organspenderausweis aus dem Internet runterladen, z.B. auf der Seite von Swiss-transplant: **www.swisstranplant.org**, ausfüllen, bei sich tragen und dies der Familie mitteilen.
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Organe spenden-  
Leben schenken

# Warten auf ein Organ, das kann uns alle treffen

Obwohl viele von uns Schweizern die Organspendemedizin befürworten, sterben jährlich zahlreiche Mitbürger, während sie auf ein Organ warten. 2007 waren 1371 Patienten auf der Warteliste. Nur 418 haben ein Spenderorgan erhalten.

Diese Zahlen überraschen, denn Umfragen zeigen, dass die grosse Mehrheit der Schweizer generell für Organspende ist. Allerdings ist Organspende auch kein Thema, worüber wir gerne sprechen. Dabei ist das Gespräch mit der Familie sehr wichtig. Denn wird bei unserem Tod kein Organspendeausweis gefunden, so ist das medizinische Personal verpflichtet, die Familie um Zustimmung zu einer Organspende zu bitten. Das ist nicht leicht, denn die Angehörigen sind in einem Zustand des Schocks und der Trauer. Haben sie vorher innerhalb der Familie das Thema Organspende schon einmal angesprochen, so fällt den Verwandten der Entschluss dafür oder dagegen oft leichter, weil sie bewusst im Interesse des Verstorbenen entscheiden können.

Oft durchleben die Betroffenen eine lange Zeit der Qual bis sich ein geeigneter Spender findet. Die Durchschnittswartezeit für eine Niere beträgt zwischen 5 und 8 Jahren. Wenn man mit Freunden und Bekannten spricht, stellt man oft fest, dass nicht wenige von ihnen sich schon einmal mit dem Thema Organspende beschäftigt haben. Viele haben sogar schon einen Spenderausweis



bzw. eine wohlüberlegte Meinung, ob sie spenden möchten oder nicht. Jeder könnte einmal in die Situation kommen, in der er oder eine nahestehende Person auf eine Organspende angewiesen ist. Jene unter uns, die einer Organspende nach ihrem Tod zugestimmt haben, helfen auf diese Weise zahlreichen Betroffenen und deren Familien. Möglicherweise zählen einige von den geretteten Patienten sogar zu ihren Freunden, Nachbarn oder Arbeitskollegen.

Organspende ist in der modernen Medizin keine Ausnahme mehr. Die Transplantationsmedizin hat sich in den letzten Jahren stark weiter entwickelt, worin der Grund für den Anstieg der Nachfrage nach Organen liegt. Viele von uns schätzen diese Entwicklung in der Medizin, da sie vielen Mitmenschen ein neues Leben schenkt. Es mangelt weder an Mitgefühl noch an Solidarität und doch reden wir nur selten über unseren Wunsch, Organe zu spenden oder nicht. Das können wir ändern, indem wir mit unserer Familie und unseren Freunden darüber sprechen.

## **ANNEX D - SEMANTIC DIFFERENTIAL TYPE GRAPHS**

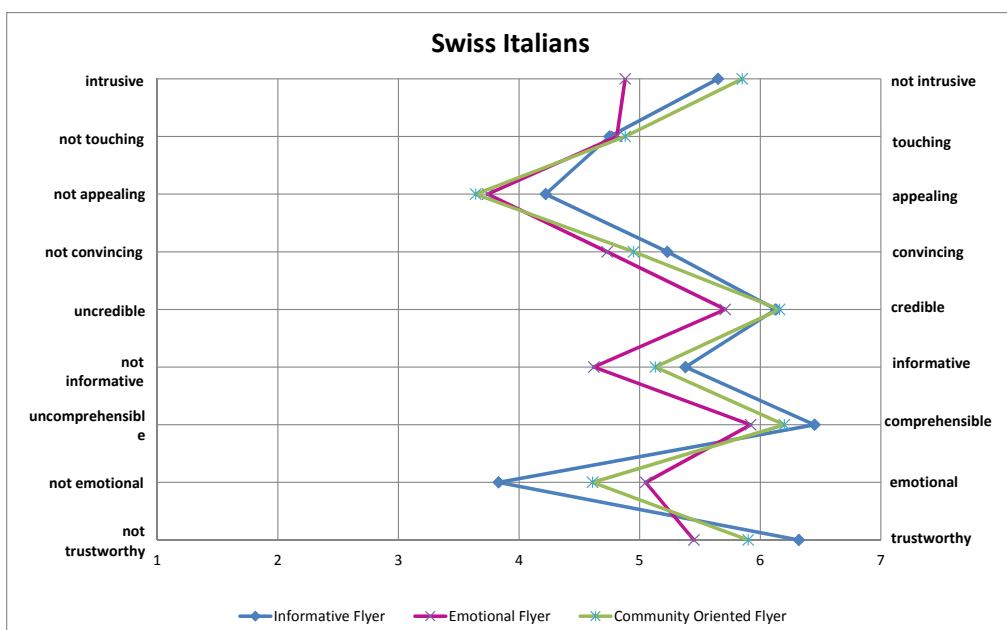
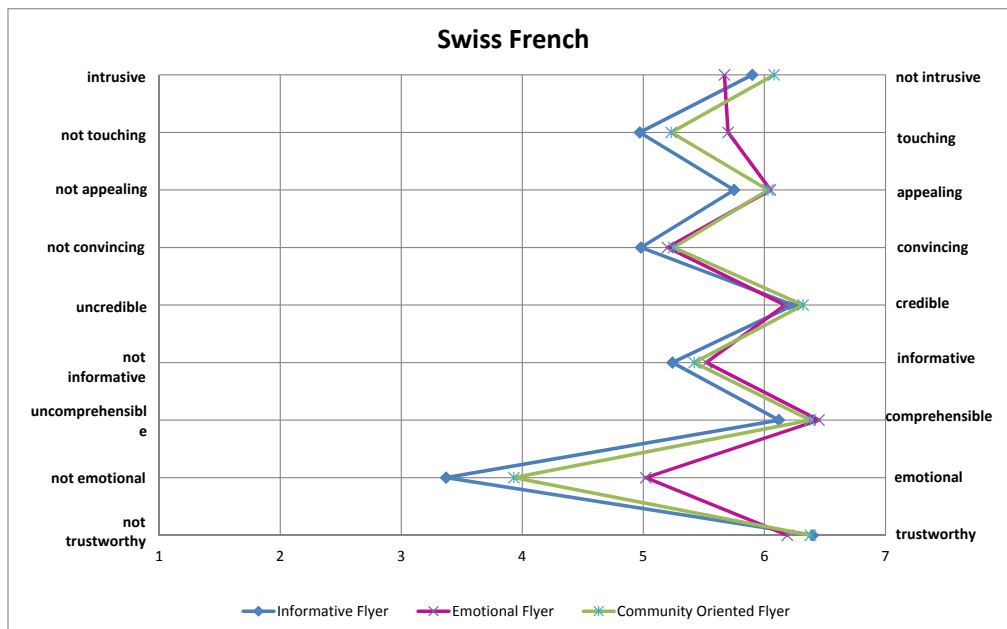
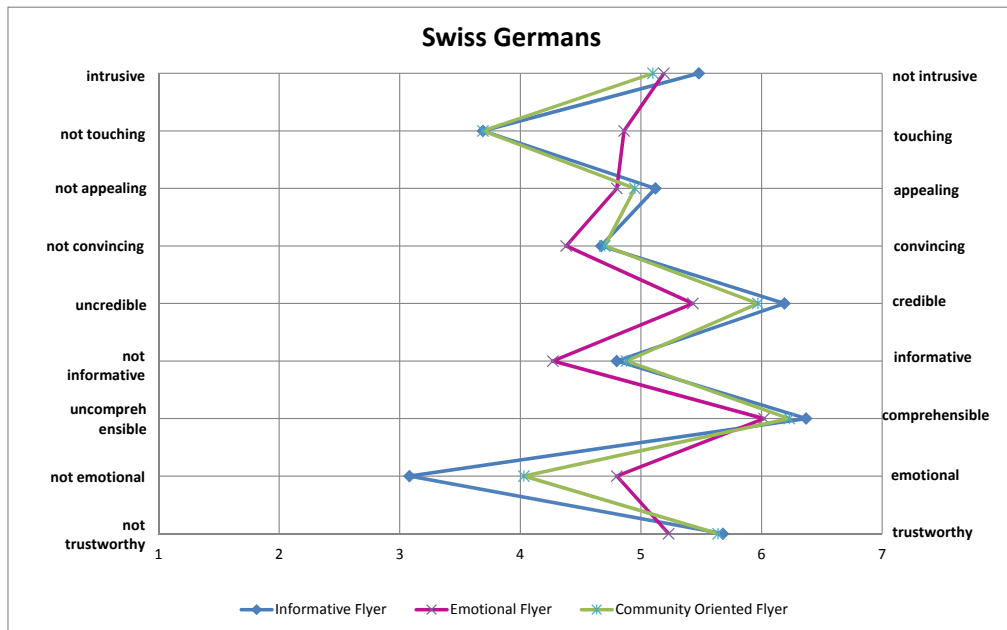
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**(Appreciation of the Flyer)**





## Appreciation of the Flyer by Language Group





### Appreciation of the Flyer by Message Type

