



Universiteit Utrecht

The importance of anonymity in post-donation contact

A moral analysis of international blood stem cell donation

Eline Schiks

4302575



Thesis MA Applied Ethics

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Supervisor: Dr. M.A van den Hoven

In collaboration with WMDA

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Written by: **Eline Schiks**
4302575

Master Applied Ethics
Utrecht University
June 2015

Supervisor:
Dr. M. van den Hoven
Ethics Institute

Second reader:
Drs. C.J. Kessler
Ethics Institute

In collaboration with WMDA:
L. Foeken, *Executive Director WMDA*
M. Fechter, *Medical Director Eurodonor Foundation*

Preface

This thesis will conclude my master program in Applied Ethics at University Utrecht. My enthusiasm for donation and especially blood stem cell donation was sparked during my internship, in which I was accidentally introduced to this topic. Besides an interest in blood stem cell donation, ethical issues that arise between different cultures intrigues me. I hoped to combine these two topics in my thesis. I called Lydia Foeken, executive director of the WMDA and she told me that there was discussion in and between registries regarding post-donation donor-recipient contact. I was enthusiastic from the beginning, she offered me the opportunity to write about this topic and my supervisor, Dr. Mariette van den Hoven, approved. Let's start!

Now, a couple of months later, I am finished - thankful for getting the opportunity to write this thesis. The interesting topic and the enthusiasm of the registries and stakeholders made writing this thesis an interesting challenge. I want to thank all the participants of my survey and interviewees, with a special thanks to Melanie Buetow and Lynne Snediker from the National Marrow Donor Program. I loved our inspiring conversations on the telephone.

I want to thank Lydia Foeken and Mirjam Fechter for offering me their contacts, means and ideas to enable me to work on this topic. Your enthusiasm and willingness to help was motivating.

Also a word of thanks to the second reader of my thesis, Drs. Carla Kessler. Thank you for taking time to read my thesis. Last, but definitely not least, I want to thank my supervisor Dr. Mariette van den Hoven for her critical view, advice and comments.

Eline Schiks,

June, 2015

Summary

In this study I used the network model, a reflective equilibrium method, to gain insight in the moral importance of anonymity in post-blood stem cell donation contact. A survey and interviews provided insight in the considerations of the professionals working on the registries. These considerations were analyzed and evaluated by means of literature on moral principles and reference to the facts. This study concludes that the moral importance anonymity stems from the strong personal connection of two strangers in an unequal relationship – the donor and the recipient. Mainly due to this unequal relationship, allowing them to meet includes a chance on negative consequences or even harm. On the other hand, one wants to enable the recipient to express his gratitude and validate the donor's commitment. Yet, these are not the only relevant considerations. Professionals also refer to considerations on voluntariness of a possible subsequent donation, the value of informed consent, justice between donors and using these meetings as PR to recruit new donors. The moral analysis shows that considerations of the professionals might not be taken that strict, lightly or should be investigated further to see the moral relevance of it.

List of abbreviations and glossary

Glossary	
Anonymous contact	Contact between donor and recipient in which exchange of identifying information is not allowed. For example, via a letter which will be checked by the registry.
Direct contact	Contact in which donor and recipient can meet and exchange personal information. They are allowed to communicate without interference of the registry.
Registry	An organization that is coordinating the contact between the donor (donation blood stem cells) and the transplant centre (hospital where the patient will be transplanted)
List of abbreviations	
BMDW	Bone Marrow Donors Worldwide – international database in which information on the HLA-phenotypes of donors all over the world are stored and made available for search.
IC	Informed Consent – informed, voluntary and decisional-capacitated consent (Eyal, 2012). Informed consent has to be given multiple times throughout the blood stem cell donation procedure, e.g. to give permission to save personal data and store the genetic material, at the moment of donation and when the identity is disclosed to donor or recipient.
NMDP	National Marrow Donor Program- Be The Match Registry – the largest blood stem cell donor registry in the world located in the United States of America.
NM	Network Model – specific variant of RE
RE	Reflective Equilibrium – method of ethical reflection
WMDA	World Marrow Donor Association – a voluntary organization of representatives of blood stem cell registries, cord blood banks and other organizations and individuals with an interest in blood stem cell transplantation.

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1. Introduction

Blood stem cell transplantation is a relatively new treatment to cure life-threatening hematologic diseases (Boo et al., 2011). For this transplantation adult volunteer (unrelated) donors donate blood stem cells that are transfused into a patient. A close HLA-match (Human Leukocyte Antigen) between donor and patient is necessary for a successful transplantation. If there is a mismatch in the HLA phenotype, the immune system of the patient rejects the stem cells (Boo et al., 2011). Given that the successfulness of the transplantation depends on certain similarities in the DNA, one would expect that the biggest chance to find a suitable donor is within the family. However, the chance of a match with a family member is just 30 to 35% (Boo et al., 2011). Blood stem cell banks (registries) have therefore been set up to list volunteers who are, if required, willing to donate blood stem cells. In 1988 Eurodonor established a database in which the HLA-phenotypes of blood stem cell donors all over the world are shown – Bone Marrow Donors Worldwide (BMDW). By means of this global database, physicians can search for a potential match all over the world. In 2014 nearly 50% of the blood stem cell donations were provided for a patient living in another country. Global cooperation for the exchange of blood stem cells is challenging, since it involves practical as well as ethical issues. The World Marrow Donor Association (WMDA) works towards standardization by developing standards and guidelines for the international exchange of blood stem cells. Presently, the WMDA encounters questions concerning the anonymity of donor and recipient after the transplantation. Some registries allow post donation donor-recipient contact, while other registries only allow anonymous contact or no contact at all. Since blood stem cells are exchanged all over the world, registries are confronted with the policy of other registries. In order to enable registries to inform donors and recipients correctly about the policy of the other registry, and thereby the procedure that will be applicable for them, it is important that registries have a well-defined policy on post-donation contact. Insight in the moral aspects of (revealing) anonymity is necessary to develop this policy. Yet, there is no insight in or overview of the moral implications on holding or revealing anonymity.

This study is about the morally relevant aspects of anonymity in the post-donation process. The focus is on the question how registries should evaluate the moral arguments in this debate, in order to come up with their own, well-considered policy.

1.1 Background

The creation of a worldwide database – BMDW – led to the establishment of the WMDA in 1994. The WMDA aims to increase the quality of blood stem cells and to facilitate international exchange. It is an association of registries and cord blood banks, which provides a forum for discussion of issues regarding international blood stem cell donation. This can consist of logistics, quality control, ethics, finances, information technology and registry accreditation (WMDA, n.d.¹).

The mission of the WMDA is to foster: *‘international collaboration to facilitate the exchange of high quality blood stem cells for clinical transplantation worldwide and to promote the interests of donors’*. (WMDA, n.d.¹). Their vision is to work: *‘towards the goal that high-quality and secure blood stem cell products are available for all patients worldwide while maintaining the health and welfare of the blood stem cell donors’* (WMDA, n.d.¹). In both the mission and the vision safety and interest of the donor is stressed.

The WMDA formulates standards and guidelines for blood stem cell registries and cord blood registries. Nowadays 73 donor registries and 158 cord blood banks are member of the WMDA (WMDA, n.d.²). Twenty-one organizations are accredited, which means that they fulfill the WMDA standards (WMDA, 2014). The WMDA standards include regulation on the safety of blood and on the voluntariness of blood stem cell donors.

1.2 Problem statement, research question and aim

The confidentiality of the donor and recipient is an important part of the first phase of the transplantation process and needs to be taken into account by the registries and transplant physicians. Donor and recipient have to remain anonymous before transplantation to ensure a voluntary choice of the donor. The registries have to develop their own policy on post-donation contact between donors and recipient. Some registries allow direct contact between donor and recipient, which means that donor and recipient get to know each other’s identity after a defined time frame and are able to communicate without inference of the registry. Other registries allow donor and recipient to have anonymous contact, which means that they are allowed to send each other a letter/card, in which identifying information will be checked and edited. Some registries also allow donor and recipient to exchange gifts of limited value.

The policies conflict when the recipient is transplanted in a transplant centre from a registry in which direct post-donation contact is allowed receives blood stem cells from a donor from a registry in which direct contact afterwards is not allowed, or vice versa. It is desirable to inform the donor before donation on which post-donation procedure is applicable in his case to prevent that he will develop false expectations. Therefore, the WMDA aims for openness of post-donation policies. In 2010, the WMDA already asked registries to *‘carefully consider their policies’* regarding confidentiality of donor and recipient in the whole process (Shaw et al., 2010, p. 833). This advice had to ensure that each donor has the free and unbiased ability to decide whether to donate or not. Yet, more aspects are relevant in the discussion on revealing anonymity after donation or not. Insight in these morally relevant aspects of anonymity is necessary to enable the professionals working at the registries to consider their policy. The aim of this research is to give insight in these moral aspects. The central research question in this study is: *What is the moral importance of anonymity in post-donation contact*

in blood stem cell donation? This question will be answered by providing and analyzing the moral considerations of the professionals working at the registries.

Not only moral considerations are important by questioning the desirability of revealing anonymity. Small registries might not have the resources to check all the letters and as a result, anonymous contact is not feasible for their registry to handle with due care. Not revealing identity does not imply that donors and recipients will not be able to meet each other. Several network sites have been set up to find each other (Mamond et al., 2012; Annema et al., 2015).

2. Methodology

Integration of empirical data in a reflective equilibrium (RE) method - the Network Model (NM) - was used to gain more insight in the moral importance of anonymity in post-donation contact in blood stem cell donation. RE was developed by John Rawls who argued that justified ethical beliefs are a harmony or balance between ethical judgments, principles, background and theories (Arras, 2006). Several versions of RE-models have been developed since then. In the NM as RE-method, moral principles are used to explain, organize and extend the moral intuitions on the case (Arras, 2010). In this study, empirical data about practice-internal norms were included into this deliberation process. Adding empirical data to a RE method is gaining popularity in bioethics (de Vries & van Leeuwen, 2010).

2.1 Network model

Van Willigenburg and Heeger developed the NM as a version of RE. Van Delden and van Thiel (1998) describe this method as a triangle of ‘moral intuitions’, ‘moral principles’ and ‘morally relevant facts’ (*See Figure 1*). The NM was chosen as method for this study for multiple reasons, which are all derived from van Delden and van Thiel (1998) and van der Burg and van Willigenburg (1998), namely:

- 1) The NM has a practical orientation. It aims to figure out what is the best thing to do.
- 2) The NM tries to cohere different standpoints.
- 3) The NM is open to theory and practice, which creates the possibility to give in-depth insight in the moral problem. It creates a dialogue between theory and practice.

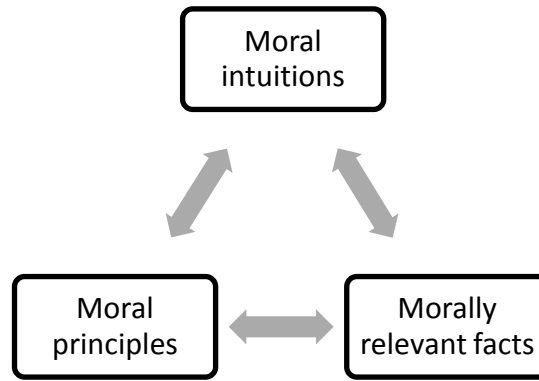


Figure 1: The 'Network Model' by van Delden and van Thiel (1998)

2.2 Empirical data

The NM model has the possibility to include empirical data about the moral norms of people working in the field. Several philosophers (e.g. van Delden & van Thiel (1998); de Vries & van Leeuwen (2010); Leget, Borry & de Vries (2009)) argue for inclusion the moral intuitions of third persons into a RE. Addition of these data is an answer to several critiques on bioethics, such as that bioethics would be too abstract, too general or too far removed from practice (de Vries & van Leeuwen, 2010). Empirical data about moral intuitions entails the experiences and moral intuitions of people working in the field. Van Delden and van Thiel (1998) refer to these data as practice-internal norms, whereas de Vries and van Leeuwen (2010) call these data third person moral experiences. There are several reasons to include practice-internal norms into this study, namely;

- 1) Inclusion of practice-internal norms enriches moral reasoning since it shows different factors of the problem. The researcher would not be able to come up with all these factors herself, since she is not working on the field of blood stem cell transplantation. It would be hard to oversee all these factors otherwise (van Delden & van Thiel, 1998; de Vries & van Leeuwen, 2010).
- 2) Integrating practice-internal norms into this study gives insight in the practical problems that policy on post-donation donor-recipient contact encounters. The practice-internal norms entail 'practical wisdom', the so-called 'phronesis' (van Delden & van Thiel, 1998; de Vries & van Leeuwen, 2010).
- 3) Staying close to practice during the research increases the chance of implementation, since it connects ethics with the practice of daily life (van Delden & van Thiel, 1998; de Vries & van Leeuwen, 2010).

These practice-internal norms can be included into a NM in different ways. Van Delden and Thiel use empirical data as an addition to their own moral thinking, whereas de Vries and van Leeuwen assume it to be the basis of a RE (van den Hoven & Kole, 2015). In this study, the method of de Vries and van Leeuwen was used, in which the moral experiences and intuitions of the professionals create the

starting point for the thinking process of the researcher. How these practice-internal norms are measured and weighed in this study is explained in *Chapter 2.4*. I will firstly elaborate on the choice to implement moral principles in this study.

2.3 Mid-level principles

The choice to implement ‘moral principles’ instead of ‘moral theory’ needs some justification. Some versions of the NM choose to use highbrow ethical theory or general background theories as an element of the NM. A Kantian or utilitarian theory can be considered as highbrow theory. Arras (2010) wrote extensively on the use of high theory on bioethics. There are three reasons why mid-level principles were chosen for this study, namely;

- 1) The first reason not to include high theory is the absence of consensus on which theory should be used. If there would be agreement on which theory to use, there would probably be a discussion about which version of that particular theory to use (e.g. rule utilitarianism or act utilitarianism?) (Arras, 2010).
- 2) Arras (2010) points out that ethical theory is too abstract to provide the answers necessary for practical implication. High theory in bioethics lacks to give any concrete guidance, since the field is too complex to describe with just one theory. One theory can give different options on how to act. O’Neill (2009) observes that specification of theory leads to too specific guidance, which makes them inapplicable for cases that are still unsolved.
- 3) Beauchamp (2007) explains the importance of principles in bioethics. Principles can be relatively easy be understood by people who are not specifically working in the field of bioethics, but had other kinds of professional training. Principles are used and recognized by people working in practice.

Using moral principles instead of high theory does not imply that no theory at all was used. The strength of mid-level principles is their start to reason from practice and analyze the moral implications of certain relevant concepts (Arras, 2010). Theories were used for the analysis of these concepts.

The principles of Beauchamp and Childress (2009) were chosen as leading moral principles. This is (internationally) the most used framework in the bioethics and is also used in the WMDA Ethics Working Group. This fits the aim to stay as close to practice as possible.

2.4 Steps in the process

As inspired by the explanation of van Delden and van Thiel (2014), this research was done in four steps. In this paragraph, the four steps that were taken in this study are explained.

- 1) Gaining insight in the morally relevant facts.
- 2) Gaining insight in the considerations of the professionals working on the registries.
- 3) Categorize these considerations.
- 4) Use moral principles to evaluate the considerations.

Step 1 – Morally relevant facts

The morally relevant facts of this study consisted of: 1) an overview of the WMDA member registries; 2) insight in the current policies of the registries and 3) factual information about e.g. the chance on request for a subsequent donor after a certain timeframe.

The WMDA provided an overview of her registry members including the number of adult volunteer donors registered. A survey was conducted among WMDA registry members to investigate the current policies and underlying considerations. (*The underlying considerations are described in the next paragraph*). This survey can be found in the *Appendix*. The survey was sent to 73 WMDA member blood stem cell registries. Twenty-eight WMDA member blood stem cell registries completed the survey. The National Marrow Donor Program/Be the Match (NMDP) from United States provided their document on the policies regarding post-donation donor- recipient contact of several registries.

Information on the process in general, such as the average timeframe between first and possible subsequent donation, was gained by a literature search.

It was planned to include results from evaluations of registries in this part, but none of the registries included in this research has evaluated their policy yet.

Step 2 - Moral intuitions – Survey and interviews

Moral intuitions refer to the practice internal norms. These norms were operationalized as all arguments, considerations, intuitions, norms and experiences that were mentioned by the participants. From now on, these five elements will be referred to as considerations. A survey was conducted to find out what considerations the professionals have regarding this topic (*This is the same survey for inquiry on the policies*). In this step, I only made an inventory of these considerations and did not evaluate the policies.

Interesting findings of the survey could lead to an invitation for an (telephonic or digital) interview with the main aim to clarify the policy and considerations behind that policy.

Two respondents did not answer the open questions and did not give insight in their moral intuitions. As a result, 26 surveys were used for this part of the research. Several respondents also sent me an overview in which they described problematic cases.

Seven interviews were conducted to get more insight in the considerations. I preferred to interview one professional from a registry that prohibited all contact between donor and recipient, but this was impossible to arrange. *Table 1* provides an overview of the interviewees and why they are chosen.

Table 1: Overview of the interviews

Interview	Reason	Aim of the interview
Be the Match, NMDP – United States Zentrales Knochenmarkspender-Register Deutschland – Germany	These registries together cover 52,9 % of all donors of the BMDW, both allow direct contact	More insight in the current policy and considerations behind that policy
Bone Marrow Donor Program – Singapore	Interesting: socio-economic factors were relevant .Other culture	More insight in the current policy, the considerations behind that procedure and possible other norms and values
Armenia Bone Marrow Donor Registry - Armenia	Non-western culture and extensive elaboration on the topic. Provided document with negative experiences.	More insight in the current policy, the considerations behind that policy and possible other norms and values
Europdonor – the Netherlands	Practical reasons. They allow anonymous contact.	More insight in the current policy and considerations behind that policy.
WMDA Ethics Working Group	Chair of the working group responsible for recommendation document of the WMDA (2006)	Insight in the discussion that was held within this working group

Step 3 - Categorization

In this step, the considerations were categorized. Firstly, the considerations were categorized on where it was a consideration for: contact in general, direct contact or against direct contact. Within these three categories, I categorized on basis of the content of the considerations, the assumptions underneath the considerations and the moral principles of Beauchamp and Childress (2009).

Step 4 - Evaluation and weighing of the considerations

A general literature study aimed to gain insight in the principles relevant in this debate. Beauchamp and Childress' work (2009) was not considered to be superior, since this does not guide us through the weighing and balancing of principles. The databases of 'Google Scholar', 'PubMed' and 'Philosopher's Index' were used to gain more information on the principles. Search term as 'harm',

'beneficence' and 'voluntariness' were used in combination with a specific search on donation. From there on, the 'snowball method' was used.

The aim of the research was to give insight in the credibility of certain considerations. In the moral analysis the considerations were evaluated, weighed and compared to the other considerations.

2.5 Discussion of the method

Several methods are used on the field of bioethics. In this paragraph I want to respond to some critiques on the RE and explain why I think this method fits this research the most.

RE/NM is criticized for the assumption that one can go from 'is' to 'ought', while current practice does not imply that it is also the most desirable situation (van Delden & van Thiel, 1998). Leget, Borry and de Vries (2009) describe different ways of how empirical data and normative reasoning could be related. One of their suggestions is the 'critical applied ethicist'. This account makes the 'is'/'ought' discussion less relevant. It tests the considerations, which is the input for developing a moral theory. This study does not aim to come up with a moral theory, but the considerations were used as input and tested on basis of existing theories on the relevant principles. The 'is'/'ought' discussion is therefore not relevant in this study.

The RE/NM method is also criticized for the reason there is only one thinker involved: the researcher. This increases the risk on bias or self-justification. Inclusion of moral intuitions of third persons softens the critique and increases the credibility of this method, yet does not lift the argument of the researcher-bias completely. The method requires, according to van Thiel and van Delden (2014): 1) an open, reasonable attitude of the researcher (see also: de Vries & van Leeuwen, 2010). 2) a clear description of the researcher's way of reasoning and 3) ability of the researcher to adjust her beliefs. This study fulfills these requirements.

The RE/NM-method provides a way in which the arguments, considerations, experiences and intuitions can be shared, challenged, accepted or adjusted (van Thiel & van Delden, 2014). This method is considered to be appropriate for this research, for the going back and forth between the elements.

3. Morally relevant facts

Ethics cannot be done without knowing the facts (van Thiel and van Delden, 1998). Therefore, this chapter firstly describes some relevant facts about blood stem cell donation . In the second paragraph, I will give an overview of registries post-donation policies. The third paragraph entails some examples of policies as an illustration.

3.1 Relevant statistics and facts

In the 2006 WMDA recommendation, the authors state that 75% of the donor/recipient pairs will not be able have direct contact. This is based on the current policies and the percentage of recipients that dies within one year after the transplantation.

In case a subsequent donation is required this will take place within one year after the first donation for 75% of the cases (personal announcement; chair of the WMDA Ethics Working Group, 2015). An estimated percentage of 9-11% of the subsequent donations takes place more than two years after the initial donation. For all transplantations this means that in 2% of all donations a subsequent donation is required after more than one year. This calculation is based on the statistics of the registries. From those statistics, the chance on a subsequent donation after two years could not be calculated.

Another relevant fact mentioned in the interview and in the literature, is that once a donor and recipient have each other's contact details, they are able to communicate with each other without interference of the registries. The registry loses authority and control over it (Mamode et al, 2013). This can have undesirable consequences. An example of such a consequence was mentioned during one of the interviews. A relatively poor donor had not been on vacation for the past three years. The wealthy recipient felt sorry for the donor, since he had saved his life, but was not able to go on vacation. The recipient therefore offered the donor a cruise on the Median Sea. The registry (accidently) noticed this and was able to prevent it from occurring. This does not have to be common practice, but it is in conflict with regulations that require the donation is an unpaid gift.¹

3.2 International overview of policies

The NMDP document and the survey provided insight in the current policies. In *Figure 2* a map of the world is presented, on which the policies of the registries are visualized. Some countries have more registries, which have different policies regarding post-donation donor-recipient contact. In that case the registry with the biggest number of donors listed is displayed, since it can be assumed that this registry will also have more donations.

Figure 2 shows that most registries allow direct contact. European countries seem to be more reluctant about the allowance of direct contact. This map also shows that the biggest countries mostly allow direct contact, while in the smaller countries direct contact is often not allowed. This might show the influence of practical restrictions. The amount of registries that allows direct contact is no indication of the number of transplantations, nor about the amount of disclosures of identity. Based on the total number of donors registered in the global database BMDW, over 65% of all adult volunteer donors worldwide are registered in the registries from Unites States, Germany and Brazil. These registries

¹ It can be questioned whether this offering of a vacation is problematic. This example aimed to illustrate the out-of-control position of the registries.

allow direct contact. This study does not provide insight in the number of blood stem cell transplantations and disclosures of contact, since the focus is on the quality of the considerations and not on specific statistics. This chapter aimed to give a brief insight in the policies and how they are spread over the world.

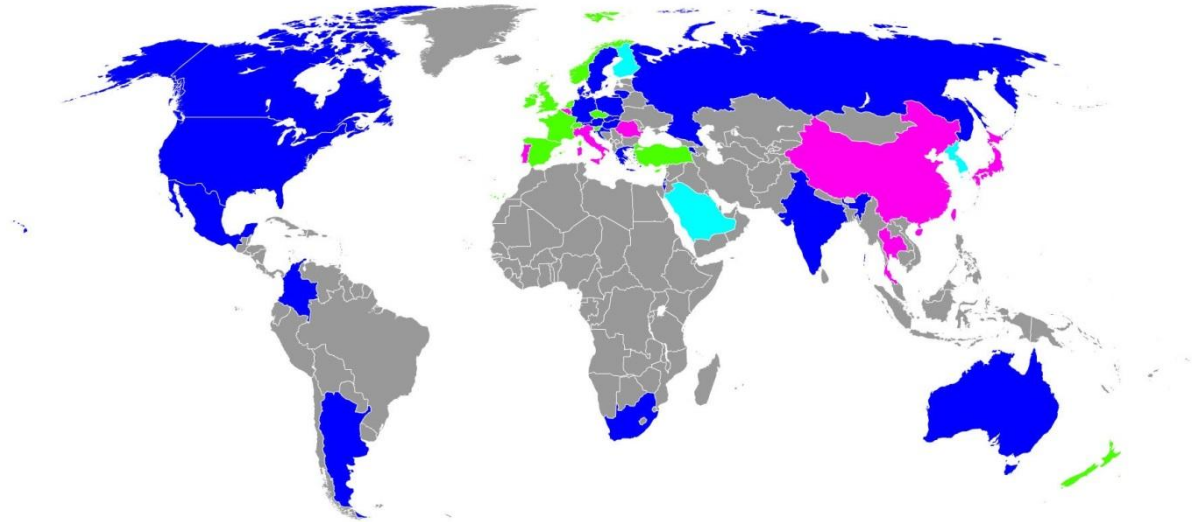


Figure 2: World map. Dark Blue: direct contact allowed. Purple: only exchange of gifts and anonymous contact allowed. Green: Only anonymous contact allowed. Light Blue: no contact allowed. Grey: No data available.

3.3 Description of the policy

There are different ways to formalize the policy on allowance of direct contact and anonymous contact. This paragraph describes some differences in the policies. All registries take the similar first step. The donor subscribes at the registry and when a donor is a potential match, the registry will contact the donor and request the donor to donate. The regulations regarding post-donation contact will be introduced to the donor during one of the ‘informed consent’ sessions.² Since these first steps of the procedure are not relevant for the discussion on post-donation contact, the description of the policies beneath do not include this first stage.

In *Table 2* provides an overview of several policies, including some –known – characteristics of these policies.³ Probably, not all differences between the policies are mentioned in this table, since some were unknown on basis of this study.

² Registries often have multiple ‘informed consent’-sessions. Most registries are required to get additional consent for each step; joining the registry, providing a sample, allowing a sample to be tested, research requests, consent for physical exams and blood testing, consent on day of donation, consent for multiple donations or additional products. They have to sign a consent for each specific action that is taking place.

³ This is not a complete list of WMDA member registries. The registries in this table were participants of the survey and/or were at the list of the NMDP.

Table 2: Overview of the policies

Country	Policy	Characteristics of policy (from survey/interview/NMDP)
Korea, Finland, Saudi-Arabia	No contact	<i>Unknown</i>
Switzerland, the Netherlands, Ireland	Anonymous	Just one letter allowed
France, Spain, Cyprus, New Zealand, Czech Republic, Norway, Turkey, Slovenia, United Kingdom (WBMDR)	Anonymous	<i>Unknown</i>
Japan, Italy, Romania, Belgium, China (CMDP), Portugal, Taiwan, Thailand	Exchange of gifts (anonymous)	<i>Unknown</i>
Sweden, Hong Kong, Denmark, Argentina, Greece, Hungary, India, Israel, Mexico, Slovakia	Direct contact – 12 months	<i>Unknown</i>
United States	Direct contact – 12 months	Anonymous written contact first is encouraged.
Singapore	Direct contact – 12 months	Contact initiated by the registry. Donor and recipient first have to meet, after meeting they are allowed to exchange personal data. Oral permission is sufficient.
Armenia, Colombia	Direct contact - 12 months	Discouraged
Lithuania, Croatia, Poland, Canada, United Kingdom (BBMR)	Direct contact – 24 months	<i>Unknown</i>
Germany	Direct contact – 24 months	Anonymous written contact first is encouraged.
Australia	Direct contact – 24 months	Discouraged
Russia (Karelian)	Direct contact – 36 months	<i>Unknown</i>
South Africa	Direct contact – 60 months	Donor, recipient, registries and physicians have to agree.

		Recipient has to be clinically well.
Austria	Direct contact – 60 months	Discouraged

This table shows some morally relevant differences. For example, in Singapore oral consent suffices to meet your donor/recipient, while most other registries require at least written consent. This difference has legal and moral implications. Signing a form may rise more awareness of the fact that you are consenting to something relevant. Another example of a morally relevant difference is the requirement or encouragement to have anonymous contact beforehand or not. Having anonymous contact before can have significant implications for the expectations of donor and recipient. It is important that donor and recipient have realistic expectations (*See chapter 5.4*).

To offer an impression of the policies to establish either anonymous or direct contact, I will give some detailed descriptions of the policies.

Anonymous contact

In the Netherlands only anonymous contact - and no exchange of gifts - is allowed. Donors are informed about the regulations on donor-recipient contact during the informed consent session before donation. The donor is informed about age and sex of the recipient directly after donation if he wants to. He is allowed to contact Eurodonor half a year after the transplantation to receive information about the current condition of the recipient. The donor and recipient can send one anonymous letter to each other. Personal information that could lead to the identification of the other will be removed from the letter by the registry. It is the responsibility of the transplantation center to inform the recipient about the possibility to send an anonymous letter to the donor. Eurodonor does not actively ask for the letter.

Direct contact

Table 3 provides an overview of some policies from registries that allow direct contact. This table gives insight in possible varieties within these policies.

Table 3: Different in policies that allow direct contact

	Informed about possibility for direct contact	Moment of disclosure of identity	Criteria	Conditions
United States	Pre-transplant-education session	12 months	IC from both parties. Encouraged to have anonymous contact beforehand	Delivery of personal data or public meeting
Germany	During donation procedure	24 months	IC from both parties. Encouraged to have anonymous contact beforehand	Delivery of personal data or public meeting
Singapore	Request is sent to them after 12 months	Pair will meet at the donor centre in a ‘relaxed’ atmosphere, free to exchange personal data	Oral consent from both parties No big socio/economic differences	See each other before they have had any contact

3.4 Discussion of the empirical research

This empirical research (i.e. the survey, interviews and literature search) aimed to give insight in the morally relevant facts. Twenty-eight WMDA member registries responded on the survey and another 19 policies of WMDA member registries were described in the NMDP document. In total, the policy from 47 of the 65 registries were included in this part of the study. As a result, it was not possible to give an overview of all registries worldwide. Since the aim of this part of the research was to give insight in different policies, this is not problematic. It gives a representative overview of the policies worldwide, since it covers 64% of the registries.

I received contradicting information on some policies, which already shows that there is no clarity on the policies. For example, a respondent answered that their registry did not allow any contact, while later on in the survey the respondent explained that donor/recipient were allowed to send each other one anonymous letter. Another example is a respondent who answered that direct contact was not allowed in their registry, but the attached policy showed it was allowed. An explanation for this contradicting information might be that the question was not clearly asked. In case of contradicting information I choose: 1) received policy, 2) survey and 3) NMDP document. The survey fulfilled its aim in the extent that it gave insight in the policies and in the differences in procedures between two policies that for example allow direct contact.

4. Considerations

Insight in the different considerations concerning the importance of confidentiality between donor and recipient of stakeholders is gained in three ways; 1) the survey, 2) additional interviews and 3) the 2006 WMDA Ethics Working Group document. This chapter provides an overview of the considerations.

The considerations are categorized. The categories were made by the researcher, who searched for common arguments. Some categories were easy to find and easily restricted, while some are more open, e.g. the category on harm. In the next paragraphs, the numbers behind the categories show the amount this consideration is mentioned in the survey. Some quotes from the surveys and/or interviews are included to give an impression of the kind of considerations that fell under that category.

Firstly, I will describe the considerations in favor of contact in general. In the second paragraph the considerations against direct contact will be given. The last paragraph entails the considerations which were given on why direct contact should be allowed.

4.1 Considerations in favor of contact in general

There seems to be a general agreement that contact, either anonymous or direct, should be allowed. Only one registry that participated in this study does not allow any contact. The considerations in favor of contact in general fell under three categories.

1. Donor and recipient should be able to express gratitude / feel a connection (17)

'The donor and patient become blood relative and they want to thanks each other.'

'We consider that it is important for both parties to have the opportunity to meet if they both agree to share information'

2. Contact has a positive influence on the recipient's mental health (1)

'We believe that patient's morale would affect positively and also it may help him clinging life'.

3. The donor is entitled to see what he committed to (interview)

These considerations might in a more extreme extent also count as consideration in favor of direct contact.

4.2 Considerations against direct contact

Several considerations were given against the allowance of direct contact. Considerations that refer to the requirement to fulfill the national law were not included in this analysis, since these do not give insight in the underlying considerations. The other considerations were divided into six categories.

These considerations were mostly provided by professionals working on registries that only allow anonymous contact and/or the exchange of small gifts.

1. The registry should protect the donor and recipient against a harm or a burden (17 + WMDA recommendation 2006).⁴
 - *'Donors may not be in a situation to deal with the death of the patient if they become close contacts.'*
 - *'... donors request money or other favors to patients'*
 - *'... sometimes lowered expectations of what would transpire from meeting your donor/recipient. Sometimes the relationship is not as close as they expected'* (Protection for disappointment)
 - *'There is a potential for the recipient and their family to be burdened by a donor who becomes overly attached'*
2. The registry should not allow that the voluntary character of a subsequent donation is jeopardized (4 + WMDA recommendation 2006)⁵
 - *'If the patient requires a second donation or donation of a kidney the pressure is immense if they know each other.'*
3. It is not able to establish direct contact for practical reasons (1 + interview + WMDA recommendation 2006).
 - *'A contact would require resources to guide and follow up; our duty is to protect and maintain donor integrity.'*
4. The nature of donation does not include such contact (2)
 - *'The entire initiative is based on anonymity; similar to blood donation'*
5. Negative publicity regarding those donor-patient meetings can have an adverse effect on the amount of donors (WMDA recommendation document, 2006).
6. Allowing direct contact discriminates between donors, since some donors will not get the chance to meet their recipient (interview).

4.3 Considerations in favor of direct contact

Professionals from registries in which direct contact is allowed provided two counter arguments on the considerations that are mentioned in the previous paragraph.

1. When donors and recipients are informed about the potential benefits and risks of disclosure of personal information, the registry does protect them enough (3).
 - *'...each party understands and accepts the obligations and risks of direct contact'*

⁴ This category includes all negative experiences of donors and recipients. Most respondents were too general in their answers, so making more specific categories was not possible.

⁵ Actively mentioned, thus not as an answer from question of the survey.

2. To prevent jeopardizing of the voluntariness of a subsequent donations, registries set a required timeframe before identity is disclosed. The chance on a subsequent donation diminishes in time. Furthermore, donors are informed about the possibility of a request for a subsequent donation (5).
 - *'I do not think it is a problem when you secure written informed consent beforehand and that you make sure to inform donor/patient that they have the right to say no'*

Two additional considerations were given in favor of direct contact.

1. Meetings between donor and recipient can be used as marketing to recruit new donors (4)
 - *'It encourages other people to become a donor; it has emotional influence on people'*
2. Not allowing direct contact lowers donor commitment. (1 + interview)
 - *'I believe it (not allowing direct contact, red.) creates a disconnect to the process and lowers donations commitment'*

4.4 Discussion of the empirical research

The overview of the considerations is limited in some ways. First of all, I did not include the considerations and experiences of the donors and recipients. I focused on the perspective of the registries, since the aim of this research is to give insight in the moral arguments regarding anonymity to enable them to develop a well-considered policy.

The results of the survey and interviews show that – without application of any theory – some principles are used: 1) 'Do good' for the donor and recipient, 2) Protect the donor and recipient from harm, 3) Aiming to get as many donors as possible, to be able to help more patients and 4) Stay focused on the nature of donation.

These principles seem to arise from the considerations that come from practice. In the next chapter, I will do a moral analysis to evaluate and weigh the considerations.

5. Moral analysis

The previous chapters gave an overview of the policies and underlying considerations concerning post-donation donor-recipient contact. The most professionals working on this field seem to agree about the desirability for a follow-up for the donor and that donor and recipient should have at least one chance to express their gratitude to each other. The professionals do not agree about the desirability of disclosure of identity, which is the focus of this study. The aim of this research is to

analyze the current considerations that support the policies of the registries. In this chapter, I analyzed these considerations in three ways, namely by:

- 1) Explicating the assumptions (and the consequences of those assumptions).
- 2) Drawing analogies with other kinds of donation.

Switzer, Dew, Butterworth, Simmons and Schimmel (1997) hold that analogies can be drawn between all kinds of living donation, since this all entails medical voluntarism. Some differences have to be mentioned: Blood stem cell donation and organ donation both require a medical procedure and donation to a specific patient, while blood donation is less invasive and impersonal.

When donating blood stem cells, the body makes new ones, while with organ donation you 'lost' your organ.

- 3) Connecting them to the principles of Beauchamp and Childress (2009).

I will connect and weigh the considerations of the professionals to see how they relate to each other. The considerations refer to two levels. I start with the considerations related to the individual donor or recipient, after which I will give some considerations related to the registry or society as a whole.

5.1 The nature of donation – donor's entitlement

The entitlement of the donors to meet their recipient can be analyzed by questioning the nature of donation. The WMDA requires that the donation should be voluntary, unpaid and free of coercion. The donor has to be willing to donate blood stem cells for any patient in need. In this paragraph I will describe three perspectives one can hold on the nature of donation, since this can provide insight in the donor's entitlement in the discussion on post-donation contact. People might have different ideas on the nature of donation, without explicitly stating so. One respondent on the survey referred to what he considered to be nature of donation. The description of these natures of donation hopefully increases the awareness about the importance of making up your mind for these implicit thoughts.

Altruistic account

Altruism in donation is often considered to be the necessary condition to make the donation justifiable, especially in organ donation. According to Moorlock, Ives and Draper (2013) this is problematic, since there is no clear definition or conception of altruism. Altruism can refer to the action or to the motivation for that action. In the discussion on the nature of donation, the motivational part is most relevant, yet even for the motivational part multiple definitions and accounts are possible. Miller defines altruism as: *'behavior that is intended to meet the needs of others, where there is no immediate self-interested reason to help, and where there is no institutional requirement that one should (p.136)'*. (Miller in: Moorlock, Ives and Draper, 2013). This definition highlights that, when donation is considered to be altruistic, the donor rejects any personal benefit from the donation, even a sense of 'feeling good' is not sought. The donation is purely other-regarding.

If one holds that the nature of donation is altruistic (as in the above-mentioned definition), the question for direct contact – or even contact at all – seems unnecessary and possibly even unreasonable from the perspective of the donor. Anonymity, and remaining anonymous after donation, can be seen as a characteristic and thereby as a proof of an altruistic act (Ferguson, Farrel and Lawrence, 2008). The donor donated his blood stem cells to help the recipient. From an altruistic nature of donation, it would not be necessary – even contradictory - for the donor to ask for direct contact with the recipient, since the characteristic of altruistic gift is to expect nothing in return, not even the gratitude and words of thanks from the recipient.

Donation as act of two-sided benevolence

Another account, based on another interpretation of altruism, is still voluntary, but not longer altruistic as in the sense described above. The difference with altruism concerns the motives of the donor; if a donor does have an interest for the self-rewarding feelings after donation, we better use the notion of ‘two sided benevolence’. Den Hartogh (2003) argues that pure altruism – as described in Millers’ definition - does not exist. Motives are always mingled with ego-centric motives, such as the pleasurable feeling afterwards. I will call this account ‘two-sided benevolence’, since donor and recipient both benefit.

Several studies were conducted to find out the real motivation for people to donate. These studies seem to show that the two-sided benevolence account fits practice the most. For example, Switzer et al. (1997) confirm that donors donate for ego-centric reasons. The reasons most mentioned for contact after blood stem cell donation were: exchange-related motives (increasing the chance of surviving for the patient), idealized helping motives, normative motives, positive feeling motives, empathy related motives and past-experience motives (Switzer et al., 1997). These motivations are also found in case of blood donation: Ferguson, Farrell and Lawrence (2008) argue that most blood donors do not donate for altruistic reasons, but also for personal reward. This means that both donor and recipient gain from it, which makes it an act of two-sided benevolence.

When the personal benefit for donors to donate is considered to be a legitimate part of donation, the argument for contact from the donor’s perspective is stronger than when an altruistic account is hold. It may not be sufficient to allow direct contact, but this account acknowledges and allows that donors also donate for their own benefit. The meeting with their recipient can contribute to this feeling of personal reward.

Donation as moral duty

Govert den Hartogh, a Dutch philosopher, tried to give a new impulse to the discussion on donation (den Hartogh, 2003). He argued that donation of bodily material has to be seen as a moral duty of the members of a society instead of as an altruistic gift. Healthy people are able to donate their blood stem cells and some people need these blood stem cells. On one day, the healthy ‘potential’ donor might be

the one that needs those blood stem cells. Therefore one can establish a kind of ‘association’ in order to give the opportunity to save the other person’s life by making a ‘pool’ of people who are able to donate. Everyone – even you if you become ill - profits from existence of such an ‘association’, and therefore one should contribute to it as well. This ‘pool’ should be created by society, and it is your duty as a member of the society to donate (den Hartogh, 2003). Snelling (2014) also argues that blood donation needs to be seen as an obligation, since the wrongness of free-riding implicates that everyone should contribute to a system they also benefit from.

This account of donation, which is very much in favor of donation is different than the other two accounts, since people are more or less considered to be obliged to donate for the society. In this account, the idea of benevolence is expected to be a moral duty, not a free choice of agents. Therefore it might be better to consider this an act of reciprocity and not of benevolence. An implication of this perspective might be that the claim for the donor to have contact with the recipient becomes weaker. If it is your moral duty to donate, there is possibly no incentive for a follow-up.

On the other hand, despite the fact that benevolence for the specific recipient is not the main motive to donate in this account, benevolence can be relevant from the perspective of the registry. It is considered be the donor’s moral duty to donate, yet this does not imply that the donor has no concerns about or feel a connection with the recipient. Considering donation as a moral duty has no direct consequences for how the donor should feel about the recipient and the donation, nor on whether he is allowed to have self-rewarding feelings afterwards. I think it is justified to hold that, despite the fact the donation is considered to be a moral duty, the donor should be allowed to have anonymous or direct contact with the recipient, since he might feel a connection with them (*See chapter 5.2*). I think the account of donation as moral duty does not offer sufficient arguments to rule out entitlement for donors to meet their recipient.

Which account?

In the previous paragraphs multiple perspectives on the nature of donation are shown. It is important to be aware and critical on the implicit thoughts of the nature of donation, since it influences – unconsciously – the arguments on post-donation contact, at least for the appeal of donors on contact with their recipient.

The purely altruistic account of donations is criticized quite often, especially due to the impossibility to donate for purely altruistic reasons. Several studies showed that the donor’s motivation almost always includes ego-centric reasons, such as gaining more self-esteem. This does not automatically imply that it is impossible to strive for an altruistic account. It is defensible to argue for an altruistic account of donation, while being aware that people also have ego-centric reasons. The common practice is not necessarily the way you want it to be. In defining policies, professionals at the registries can show that they strive for a specific account of donation. They could forbid post-donation contact,

since donors are not supposed to achieve personal gain for it, not even in a word of thanks from the recipient.

Accepting donation as a moral duty would be a radical change in current practice. This is not easy to imply, since a claim has been made on society and on individual citizens. The idea of voluntarism is common in society and it is questionable how this account is related to the voluntary character of a donation, since there is an appeal on donors. People will protest against this account, which should be taken into account for there is still a need of donors.

5.2 Expression of gratitude

The considerations in favor of contact in general refer to the connection that donor and recipient apparently have. This paragraph will discuss this connection and see whether the request for direct contact can be justified by it.

The first consideration was that donor and recipient should have the chance to express gratitude to each other. This consideration or other considerations referring to this gratitude were not given as argument for direct contact specifically. However, I think – and may also be the purpose of the respondents – that the registries aim to ‘do good’ for the donors and recipients and that they probably have multiple ideas about what is necessary to provide them the chance to express their gratitude. Is an anonymous letter sufficient, or is direct contact necessary?

One respondent mentioned a second consideration referring to benefit to the recipient: contact might have positive influence on his mental health. This is an empirical question. I will go into more depth in the positive mental effects of meeting one’s donor. But more research is necessary to find out the effects of this contact on the overall mental health of the recipient.

Two questions need to be addressed to analyze the connection between donor and recipient and their willingness to express gratitude. Firstly, whether the request for an expression of gratitude is justifiable from a moral point of view. Secondly, whether an anonymous letter is sufficient, or if disclosure of contact is necessary – or at least morally unproblematic – for this aim. The argument is analyzed by making an analogy with blood donation and organ donation.

Personal connection

“It was just pure emotion – like we had known each other for years. Larry had already called me his brother in his letters, and I really felt like that at the moment. I was indescribable and I hardly noticed that TV crews were filming us. After a few quick interviews, it was time to head to Lake Jackson to meet ‘mom and dad’. When we arrived, there was a large banner in front of the house that read, ‘Welcome home, John’. And that was exactly how I felt; like I had come home. I had hardly climbed out of the car when Larry’s mother, Christine, and father, Larry Senior, grabbed me in their arms (...) It was a wonderful moment”

Quote from: Sharing Life (2015), p. 92.

The quotation above illustrates an example of a donor and recipient that felt a very strong connection. They feel like they were brothers, and apparently, the whole family felt like they had a new member. I want to emphasize that this is an extreme example, and not all donor and recipient pairs do feel such a strong connection. In this paragraph, I will discuss this personal connection.

Every day, lots of people from all over the world donate and receive blood. PubMed, Google Scholar and Philosophy Index did not give any results on the discussion on anonymity in blood donation. It can therefore be assumed that this discussion does not exist, anonymity in blood donation seems to be an obvious characteristic. Donors do not feel the need know their recipient’s identity and vice versa. Why not? In both treatments donors offer a part of their body and both treatments are life-saving. However, some differences between those donations exist: blood donation has less impact on the physical condition of the donor, it is less time consuming and blood donation is more common, which might give rise to practical arguments. Another, probably important reason for the absence of this discussion is that blood stem cell donation feels more personal than blood donation. A blood donor is asked to donate if there is a shortage on a certain blood group. The donor donates blood and when a patient needs this blood, it will be transplanted. Blood stem cell donation has a different procedure. Donors are personally asked to donate when a match with an individual patient is found. This might give rise to feelings of personal connection between donor and recipient. This personal connection is considered to be important in moral dilemmas, as also shown in the trolley cases. In the trolley cases, one is able to save the life of five innocent people by offering the life of one person (see *Figure 3*). In the left situation, one can save five people by pulling the swift to divert the trolley on the side track, where the trolley will kill one person. In the right situation, one can stop the trolley by pushing a man over the bridge. This man will not survive. The result is the same, five people are saved by offering one. It turns out that people are more reluctant to push the man over the bridge. One explaining factor is that pushing the man over the bridge is more personal (Greene, Sommerville, Nystrom, Darley & Cohen, 2001). This personal connection might also explain a difference in blood stem cell donation and blood donation and feed the discussion about anonymity in blood stem cell donation.

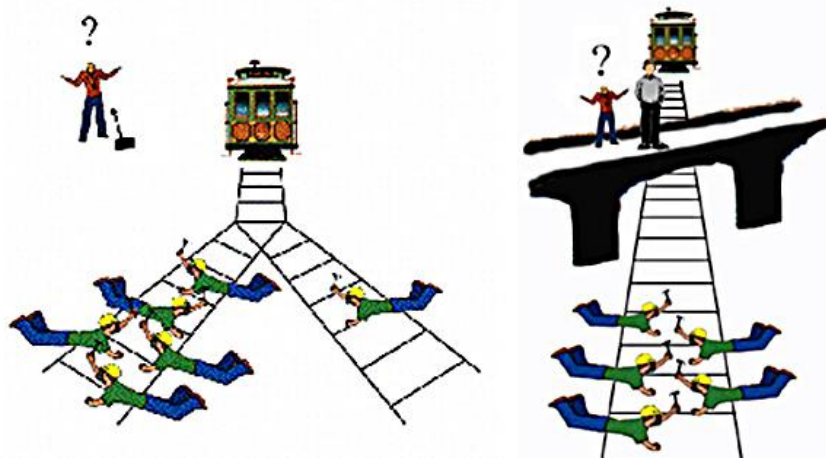


Figure 3: Trolley cases. Source: <http://sippingphilosophy.com/2014/03/12/the-trolley-problem/>

The ‘personal connection’-argument counts for the donor as well as the recipient. The donor donated specifically to the recipient, and the recipient knows someone took the effort to donate his blood stem cells to save his life. For this personal connection, donor and recipient might feel an urge to express their gratitude to their donor or recipient.

Analogy with organ donation

I will also draw an analogy between living organ donation and blood stem cell donation. Organ donors also donate their organ to someone specific. In organ donation the desirability for anonymity is also discussed. Research was conducted to find out people’s opinion on anonymity in organ donation. Some of these studies were conducted among recipients and concluded that the majority of recipients preferred to stay anonymous (e.g. Annema, op den Dries, van den Berg, Ranchor & Porte, 2015; Klerk, Zuidema, Kranenburg, IJzermans & Weimar, 2008; Dobbels et al., 2009). Ono et al. (2008) conducted a study among donors and recipients and concluded that both wish for direct contact. The considerations in this discussion are quite the same as in blood stem cell donation; the most important considerations for recipients not to meet is to prevent negative feelings (Dobbels et al., 2009) and the most important reason to meet is their willingness to express their gratitude. The donors want to know the recipient’s identity to be able to confirm the benefits of the donation (Ono et al., 2008). The arguments in the discussion on living organ donation seem to be limited to the question on whether donors and recipient should – despite the chance on negative consequences - have the freedom to decide whether they want to disclose their identity or not. Especially physicians refer to the emotional pressure and the possibility for a request for money as adverse consequences. This emphasizes the relevance of the harm-argument (which will be discussed in *Chapter 5.4*) and seems to correspond with the current discussion in blood stem cell donation. Professionals at the registry try to benefit the donor and recipient by the disclosure of identity, but this disclosure includes a risk on harm. The question is whether this risk on harm is justified. This question will be discussed in *Chapter 5.4*.

Some differences between organ donation and blood stem cell donation have to be expressed. The above-mentioned studies among recipients concluded that a feeling of guilt is a relevant factor. Patients with an alcoholic cirrhosis for example, realize their request to the donor may be a huge burden on them, while it can be considered their own mistake that they are ill now. Their life-style was of enormous impact on their disease. People with such a life-style related disease may be more reluctant to meet their donor, for they are afraid the donor will blame them. This is not relevant in the discussion on blood stem cell donation, since the diseases that can be treated or cured with a transplantation are not strongly related to life-style.

It's all in the word!

Another explanation for the wish to express gratitude (and probably the feeling of a personal connection) could be the word: 'stem cells'. During this research, I talked with a lot of people about 'blood stem cell donation'. Several people told me that 'stem cells' are more special to donate than blood. The word makes them feel like one donates something special. Those stem cells are considered to refer back to the 'origin' of your body. It might be interesting to see how these people react when the word would be changed in 'bone marrow transplantation' and whether this influences the connection the donor and recipient apparently feel. This different word use is not taken into account in this study. Research to the difference in word-use is necessary to investigate the impact.

Is direct contact necessary?

The relevant question in this discussion is to what extent the need to express gratitude for the donor and recipient can be fulfilled by means of a letter. This letter gives the recipient the opportunity to talk about his experience and express his thankfulness. In the quote on the right one expresses this desire to express their gratitude personally, and hopes that the letter is enough to show their gratitude. People would agree that this expression is easier and more sincere by meeting each other in person. Other considerations have to be taken into account to see whether it is justified to allow donor and recipient to meet. In the next paragraph, I will first weigh the perspective of donor and recipient and include some considerations about the cross-cultural aspect of this problem. Thereafter I will discuss and analyze the other considerations of the professionals.

'I would have like to visit you and thank you in person, but since this is not allowed, I hope you will not feel disappointed that I am sending you my gratitude this way'

Quote from: Sharing Life (2015), p. 70.

5.3 Weighing of perspectives

In the previous paragraphs I showed some considerations concerning the donor's and recipient's entitlement to request for disclosure of identity. In this paragraph I will discuss how these considerations are related to each other and to the registry's responsibility. This relation is relevant for the discussion on which policy should be leading in case of conflicting policies.

Since this study focuses on considerations from professionals working in the registries, it is important to see how the considerations concerning entitlement should be weighed. The main task of the registries is to facilitate the exchange of blood stem cells in order to treat patients. The professionals want the blood stem cell transplantation to be a positive experience for donor and recipient. They want to ‘do good’ by informing donors about successfulness of the transplantation and to giving recipients the opportunity to express gratitude. It is assumed that this enables donor and recipient to satisfactorily close the procedure and possibly build a relationship.

For registries it is legitimate to consider who is more entitled to request disclosure of identity. As shown in *Chapter 5.1*, the donor’s entitlement depends partly on the nature of donation one strives from. Yet, some additional considerations regarding this entitlement can be given. The donor requests for direct contact out of curiosity, probably, for he wants to know how the recipient is doing and confirm his help. He is not the ill person whose life is saved. He identifies himself as a donor and this meeting would fit his identity and therefore he should be allowed to meet this recipient. Yet, even if donation is considered to be important for someone’s identity, the meeting would be a confirmation of his identity and not the formation of the identity as a donor, since he is already a donor. I am somewhat reluctant to hold that confirmation of identity, curiosity and a need to know whether the transplantation was successful are sufficient reasons to justify the donor’s request for revealing the anonymity. The need to know whether the transplantation was successful can be fulfilled by a follow-up. The donor acted praiseworthy by offering a part of this body to save someone’s life, but – especially for the unequal relationship – this might not imply that he is entitled to know the recipient’s identity. When the donor refuses to donate since he is not allowed to meet the recipient, one can doubt whether this is a suitable donor. What makes it so important for him to get to know the recipient’s identity? This extreme desire to know the recipient’s identity, even so strong that he would rather let the patient die than donate and not be able to meet him, can indicate the wrong motives to donate (e.g. easy victim for blackmailing). It is therefore questionable whether it is desirable to have donors with such an extreme wish to reveal anonymity. A follow-up and an anonymous letter should probably suffice for the donors’ closure of this act.

The donor’s entitlement differs from the recipient’s entitlement. The recipient is a patient, whose life is saved. He has been ill for a long time and is cured now. This has a bigger emotional impact than donating your blood stem cells. The recipient knows of the asymmetry in the relation with his donor and may feel an urge to thank him, in order to show how grateful he is for receiving this second chance. People do not like to be in an unequal relationship (Vonk, 2007) and the recipient may be willing to equalize this relationship as much as possible. A letter would not be sufficient for the recipient. He might feel that he has to do more to equalize this relationship. This argument can justify a recipient’s request on direct contact with the donor, since then he will be able to show how thankful

he is. It can therefore be argued that the entitlement of the recipient to request contact is bigger than the donor's entitlement.

Cross-cultural differences

The conceived difference in entitlement between donor and recipient for direct contact has implications for the cross-cultural exchange. When donor and recipient are connected to registries with different policies regarding blood stem cell donation, which policy should be leading?

Multiple moral principles and considerations are relevant in this discussion. How these principles and considerations are weighed partly depends on culture. This can also be concluded when different studies are compared. Ono et al. (2008) concluded that 82% of the recipients and 60% of the donors preferred to have direct contact. Their study was conducted in Brazil, where direct contact after blood stem cell transplantation is already allowed. The studies that concluded that the majority of recipients was against revealing anonymity were conducted in Belgium and in the Netherlands, in which direct contact is not allowed. These differences may already show that culture holds their own public morality and the policy is adjusted to this morality. The studies might function as a self-fulfilling prophecy.

Acknowledging culture's relevance does not solve the problem. A common ground has to be found since blood stem cells are exchanged worldwide. The current regulation is that the most restricting policy is the leading policy; probably for juridical reasons. It is therefore not automatically the most morally justified solution. Another option could be to discuss the considerations case by case in order to find an appropriate solution for that specific donor/recipient pair (this would also lead to contradicting statements, for one can argue that this should be made possible for every pair, from the standpoint of justice). Given the above-mentioned arguments, one can also consider to make the policy of the recipient's registry the leading one. For the focus of this study is on the moral importance of anonymity, I will not deepen this discussion here.

5.4 The risk of harm

The risk of harm is the most common – and probably most important – consideration against direct contact. The principle of non-maleficence, prevention of harm, is often mentioned as an important part of an ethical theory. Beauchamp and Childress (2009) acknowledge most ethical theories recognize the importance of non-maleficence.

In this paragraph, I will first give examples of what harm in this context entails and relate this to theory. Secondly, I will connect these examples and the theory to the principles of beneficence and autonomy.

Examples of harm

The answers on the survey were not specific on what harm entails, yet the documents that respondents added to the survey gave more insight. I also used the studies on anonymity in organ donation to become more familiar with what harm in this field entails. *Table 4* provides some examples/categories of harm which can be inflicted on donor or recipient when identity is disclosed.

Table 4: Possible harm inflicted to donor and recipient by disclosure

Donor	Recipient
Positive meaning of donation destroyed when meeting is not going well (Dobbels et al., 2009)	Positive meaning of donation destroyed when meeting is not going well (Dobbels et al., 2009)
Possibility of ‘psychological rejection’: idealization of recipient (e.g. survey; Mamode et al., 2013)	Possibility of ‘psychological rejection’: idealization of donor (e.g. survey; Mamode et al., 2013)
Emotional involvement; not able to handle (e.g. survey; registries)	Emotional involvement; not able to handle (e.g. survey; registries)
Feeling of guilt in case of unsuccessful transplantation (e.g. survey; Mamode et al., 2013) <i>Also by follow-up on recipient</i>	
Unwanted attention (e.g. survey; Mamode et al., 2013)	Unwanted attention (e.g. survey; Mamode et al., 2013)
Disappointment when the recipient does not agree (registry)	Feel obliged to consent to this contact and to maintain this contact, to prevent them looking ungrateful (Dobbels et al., 2009)
Request for money, e.g. due to big socio-economic differences (e.g. registry)	Request for money, e.g. due to big socio-economic differences (e.g. registry)

All these examples of harm in the table refer to mental harm and most of them arise from the unequal relationship donor and recipient are in. This table entails to the risk of harm when donor and recipient meet each other, but this does not imply that allowing only anonymous contact, exchange of gifts or no contact at all, excludes the risk of harm. Donors and recipients can also be harmed when contact is prohibited. An example of this harm is for donors, they might have issues closing the procedure and keep worrying about the recipient. Another example from the perspective of the recipient, is that he feels that he is not able to thank the donor sufficiently. Not allowing this means that the donor and recipient do not have a choice. When direct contact is allowed after consent of both donor and recipient, the option is offered and they are free to choose. The prevention on harm is thus broader than only looking at harm in case of disclosure of identity.

Beauchamp and Childress (2009) offer a conception of harm in which they focus on physical harm. I will discuss a broader account of harm, which is explained by e.g. Kloocksiem (2012).

The counterfactual account

The most intuitive definition of harm is that harm is inflicted when someone is worse off than he would be without the action (Kloocksiem, 2012; Shiffrin, 2012). Kloocksiem (2012) defends the counterfactual account - the intuitive account which states that harm is inflicted when someone is worse off than he should have been when identity was not disclosed. Harm is considered to be close to benefit. This can be illustrated by a linear line, see *Figure 4*. The black dot is the current situation. If the action causes someone to be positioned on the red line, he is worse off than he would have been without the action and harm is inflicted. When one is positioned on the green line, after the action, one is better off.⁶



Figure 4: Counterfactual account of harm

This theory can be applied to disclosure of identity in blood stem cell donation. The middle of the line in *Figure 4* is the situation of the donor/recipient before the disclosure of identity. The intention of the disclosure is to position the person on the green line, which means he will be better off by meeting his donor/recipient, e.g. since due to the ability to express gratitude. Yet, there is a risk the person will be worse off and be positioned on the red line. The person is harmed according to the counterfactual comparative account. This shows the interplay between benefitting and harming someone and is the most general idea of what harming and benefitting entails. An example is that donor and recipient are allowed to meet, since the recipient want to express gratitude and the donor was committed and curious about how the recipient was doing. It seems an action of benevolence to allow those people to meet each other. Yet, it is possible that either one of them is disappointed when the relationship is realized in a personal meeting rather than fantasized prior to meeting. This effect is a risk of the meeting, and could be considered as harm.

Different impact of harm

Harm can be inflicted in different extents, which also can be seen in the examples/categories in *Table 4*. One can question to what extent disappointment, idealization and emotional involvement can be considered as harm. Certain donors and recipients may perfectly be able to deal with this situation and

⁶ This comparison is not as straight forwarded as it is formulated here. There is a discussion on what has to be considered as the 'current situation'. An illustrative example is the child that is drowning in the pond and by one's attempt to save him, you break the child's arm. Therefore, he is worse off than he was before he fell in the pond, but better off than when he drowned.

would not consider this as harm. In human life, one encounters several disappointments and disillusion. This does not per se have to be considered as harm.

Harm can be categorized on the different extents. For example in Table 4, the upper two can be considered as harm to a lesser extent than the following four. The upper two (i.e. idealization and positive meaning destroyed) are 'just' negative feelings focused on the (thoughts of) person himself. The later four (i.e. emotional involvement, guilt, disappointment/feel obliged and unwanted attention) can be considered as more harm, since they impact the relationship between donor and recipient. It therefore can lead to even more harm. The request for money may be considered as extreme harm. This is just an example of how these examples of harm can be categorized. Of course, the impact on someone's life differs per person. One would feel the emotional involvement and not be able to handle with the death of the recipient, while the other also feels an emotional involvement, but can work this out for himself. For each category one should be critical on the extent it can be considered as harmful for the donor or recipient. Requirements can be set to include these negative feelings in the category of real harm. Such a requirement might be that the donor or recipient has to ask for support by a psychologist.

The disclosure of identity intends to start a relationship between two strangers. The disadvantage of this relationship is that it holds an asymmetry from the beginning, which has its consequences. As social psychologists (e.g. Vonk, 2007) acknowledged, this unequal relation is undesirable for both parties. It can be concluded that this unequal start might therefore increase the chance of negative feelings. These feelings can have adverse consequences, since people will be looking for manners to equalize that relationship (Vonc, 2007), for example by an extreme dependent attitude from the recipient, or an arrogant one from the donor, in which he feels justified to interfere with the recipient's lifestyle.

In relation to this unequal relationship, social justice is mentioned as a relevant factor. Blood stem cell transplantation is a life-saving treatment. The donor saved the life of the recipient. If the donor and recipient have a different SES, the recipient might feel obliged to do something in return for the donor; if the donor is relatively poor and the recipient rich, the unequal relationship leads to a bigger chance to develop an undesirable relationship. This argument is even more important in countries in which different levels of SES are common. If this argument is just used on an individual level, one can wonder how this then relates to the argument about justice. It seems unfair that the decision on donor and recipient to meetings depend on their SES.

This paragraph shows that different extents of harm and that there are multiple factors that explain this harm, but an argument for the risk of harm is hard to make in this discussion. No empirical data on harm in this context is available, since no study is undertaken to find out how this contact develops and registries do not evaluate their policies yet. Registries loose donor and recipient after identity is

revealed. This data is necessary to get an overview of how donors/recipient experience the adverse consequences and what the quantity and severity of the (possible) harm is. This can be helpful in taking a stance in relation to this argument. The aim of this paragraph was to show that one has to remain critical on what is considered to be harm.

Autonomy vs. harm

In the survey and interviews professionals referred to the informed consent procedure that donor and recipient have to go through before identity is disclosed. In this procedure the risk of harm is mentioned and explained. The consent that follows from this procedure is considered to be sufficient to justify the exposure of donor and recipient to this risk. In this paragraph I will question whether informed consent is sufficient to justify this harm. Professionals want to protect their donors and recipients against harm. But when donors and recipients signed an informed consent, this harm suddenly becomes justified? It is legitimate to wonder whether this is really the case (Shiffrin, 2012). This argument shows that the respondents value the autonomy of donor and recipient to a great extent. Donors and recipients should have the freedom to decide whether they want to meet, and if they want to take the risk of harm, it is their choice and this should be respected.

This focus and value to autonomy can also be found in another argument: the argument on paternalism. In the literature regarding anonymity in organ donation, it is often argued that it is paternalistic to forbid contact (e.g. Mamode et al., 2013). Acting paternalistic towards Y is defined as interfering with the liberty or autonomy of Y without consent of Y for the reason that it will improve or prevent to diminish the welfare of Y (Dworkin, 2011). This idea is applicable in this case. When registries do not allow direct contact, people cannot choose to disclose identity, while they were never asked about which policy they preferred. The registries do not allow this disclosure since they want to prevent harm or a diminished welfare to the donor or recipient.

By making paternalism an argument against allowing this direct contact, one assumes that autonomy is more important as principle than the principle of non-maleficence or beneficence (Beauchamp & Childress, 2009). The assumption is also prevalent in the reference to informed consent. Paternalism and informed consent are used as a sufficient argument to allow direct contact between donor and recipient. I think this assumption needs further justification. The principles of non-maleficence, benevolence and autonomy have to be in harmony. For example, one can infringe autonomy in different extents. Forbidding someone to go to college is infringement on a different extent than forbidding him to park his car across the street. Nys (2008) also observes these different 'levels' of autonomy, and uses these levels as an argument for the justification of the so-called paternalism. On a scale of infringement on autonomy, one can question what impact forbidding them to meet has. I already argued that this infringement may be experienced differently for donor and recipient. As already argued for in this paragraph, the same scale can be made for harm. These questions do not

have an overall answer, but questioning and being critical on the extent in which these principles are presumed to be threatened, is necessary. Reference to the informed consent procedure or paternalism is therefore not sufficient as an argument against direct contact and additional arguments are necessary.

5.5 Voluntariness of the donor for a subsequent donation

Voluntariness is by Beauchamp and Childress (2009) considered as one important element of an autonomous choice. In the survey, professionals from the registries argue that if donor and recipient have already met each other and there is a request for a subsequent donation or organ, the voluntarily character of the donation is jeopardized. This argument is recognized and taken into account by the development of the policies. Direct contact is only allowed after a certain timeframe. This timeframe differs between registries from one till five years. One year after the first transplantation, the chance on a subsequent donation is 2% (*see Chapter 3.1*). In the survey, respondents refer to the necessary informed consent before the disclosure of identity. This informed consent includes information on the chance for a subsequent donation. Donors who want to meet their recipients are thus aware of the possibility to donate a second time. If it is expected that the recipient will need a subsequent donation and the required timeframe is near, the policies of most registries require postponement of the disclosure of identity.

Several professionals argue that it is impossible to make a voluntary decision if the donor already met the recipient. Yet, there is no definition of requirement a donor has to fulfill in order to make a voluntary decision (den Hartogh, 2008). Professionals in the field hold that the donor might feel pressure, a feeling that they do not have a choice when they are asked to donate a second time. Without this subsequent donation, the recipient will probably die. For now, it is assumed that the recipient or recipient's family will not coerce the donor to donate. When coercion is involved, a real threat is involved and the voluntariness of the donation is definitely undermined. This can also happen and is a valid argument, but not the kind I will discuss in more depth. I want to discuss whether the voluntariness is undermined if the donor knows the recipient's identity and the recipient the donor's, without any coercion of the recipient (or his family).

Internal pressure

Govert den Hartogh (2008) wrote a chapter on voluntariness by living donations. His chapter will be used to reflect and evaluate the given argument. Den Hartogh (2008) argues that one should be less concerned about voluntariness in cases of moral necessity. Feeling an internal pressure or an obligation to donate without any external claim is an example of a feeling of moral necessity.

This moral necessity stems from the overriding will and rational consideration to save someone's life. This argument probably overrides all other considerations for the donor. Refusing a second donation is

therefore not considered to be an option, despite the possible adverse consequences the donor experiences.⁷ The argument of saving someone's life was probably also the overriding motivation to donate the first time. If the donor refuses to donate, an identity crisis can be the consequence. As already shown in the considerations and studies, being a blood stem cell donor becomes often part of the identity. Den Hartogh (2008) holds therefore that having contact with the recipient does not necessarily threaten the voluntariness of the choice to donate a second time. Donation is a part of the donor's norms, values and identity. Saving someone's life is a consideration that overrides any other.

External pressure

There may also be an external pressure which jeopardizes the voluntariness of the second donation. The donor might feel that the recipient (and his family) expect the donor to donate for the second time. By donating the first time, the donor created the expectation that he is willing to donate his blood stem cells in a life-threatening-situation. These expectations can function as an external pressure. Den Hartogh (2008) argues that the diminished voluntariness is not in the recipient's expectations, but on whether the donor thinks these expectations are legitimate. When the donor does not think these expectations are legitimate, there is indeed a threat of limited voluntariness. Donating a second time is then motivated by fear of the consequences. In that case, the voluntariness of the decision may not be sufficient and the external pressure is higher.

But I think, in case of blood stem cell donors, we can assume that most donors are willing to save the life of the recipient for the second time. (If the donor and physician consider the physical consequences of the donation to be still acceptable). Donors already proved once that they are willing to donate, and consider saving a life to be important.

A hard decision

It seems as if it is assumed that the fact that the donor has to make a decision and both choices are unattractive (i.e. donate again or let the recipient die) does imply that this decision is thus beforehand involuntary. Voluntary decision making does not always – if ever – mean that one should be able to weigh all the information rationally. Sometimes, one argument is sufficient to make the decision, especially if you had to make the same choice before.

This analysis shows that the voluntariness of a donation is not per se threatened by the fact that the donor knows the recipient and has to make a decision. However, external factors are realistic threats to the voluntariness of the decision. A timeframe is therefore still desirable from a moral point of view, mainly to prevent external pressure on the donor. External pressure can jeopardize the voluntariness of

⁷ This argument is limited. If the physical burden on the donor is too big, and physicians dissuade a second donation for the donor's health, this is relevant as well. The overriding argument to save a life then loses its value in comparison to other arguments.

the donation. In case a subsequent donation is required and donor and recipient have already met, it is important to be aware of this specific threat to the voluntariness.

The respondents of the survey referred to the informed consent that the donor signs before anonymity is revealed. Does this imply that the voluntariness of the decision for a second donation is secured? I think in this case one attaches too much value to the notion of informed consent. The possible threat to voluntariness, especially the external pressure, is not taken away with this informed consent. If registries do not want donors to make involuntary choice, referring to the informed consent is senseless, since the voluntariness of the decision to donate a second time mainly depends on the external pressure, as is argued for above. Informed consent does not influence this external pressure. I encourage informing donors about the chance on a subsequent donation before identity is disclosed, because I think that it is an important element for donors on their decision to reveal anonymity or not. This is especially relevant when donors already know that they do not want to donate a second time.

5.6 Meetings as marketing

Till now, only considerations on the level of individual donors and recipients are discussed. From now on, we will discuss the considerations on the level of the registry and/or society. In the survey and interviews professionals mentioned that the meeting between donor and recipient can be used as marketing to recruit new donors. In the United States and in Germany, the meetings are indeed used for this purpose.

Let's assume that using these meetings as marketing attracts new donors. More people subscribe as a donor and more patients waiting on blood stem cell transplantation can be treated. Use the meetings as marketing to attract new donors is a utilitarian argument: it leads to the greatest good. It acknowledges that donors/recipients might have adverse experiences with the disclosure of identity, but this does not weigh against the lives of patients that will be saved. It helps to expand the donor database and the means are justified by the end.

This argument is probably stronger when there is a severe shortage on donors. One can argue that this argument is softened when for a certain percentage of patients (e.g. 90%) a suitable donor is found. The justification has become a weighing advantages and disadvantages. During the rest of the moral analysis, this question was treated with a focus on the individual donor and recipient and their autonomy. This is a purely consequential argument. Since there is no emergent need of donors at the moment, I think we should focus on the consequences for the individual donor and recipient, and not on the possible influence on the size of the database.

This consideration can also be used to other way around. If someone has extreme negative experiences with the disclosure of identity, this can discourage new donors to subscribe as a donor. The WMDA Ethics Working Group (2006) also observed possible consequence.

5.7 Justice

The study already discussed three of the four principles of Beauchamp and Childress (2009). The fourth principle is also brought in the discussion by the respondents of the survey and the different interviewees. These considerations were related to justice.

Unfortunately, some recipients die within one year after the donation. During the interviews, it was brought forward that direct contact between donor and recipient should therefore not be allowed. It is unfair for donors who do not have the chance to meet their recipient. Some registries try to compensate this disappointment by allowing the donor to meet the recipient's family. According to the calculations of the members of WMDA Ethics Working Groups, only 25% of the donor-recipient pairs will be able to have direct contact, due to the policies and the recipient's death. One can doubt – as I do – whether an argument referring to inference of nature is relevant in an account of justice. Also Beauchamp and Childress (2009) discuss the principle of justice in relation to human interference. It is not a human mistake that a certain donor/recipient pair is not able to meet. The argument of justice as not all donors get the chance to meet, is therefore not a valid argument.

However, this argument could count as an argument for a worldwide universal policy, and I think we should. Not being able to meet the recipient who died, is an inference of a natural cause. Different policies refer to an unfair policy for individual donor and recipient in relation to donors and recipients in other countries. For example, a donor in the United States is able to meet his recipient, while a donor in the Netherlands is not, despite the fact that they have undergone the same treatment. Stem cell donation and transplantation is not a national matter anymore, but has become an international one.

6. Conclusion

This study aimed to give insight in the nature of moral importance of anonymity in post-donation contact and thereby helps blood stem cell registries to re-think their policy. The post-donation contact discussion is about the question whether two people – who have a disproportionate, unequal relation – should be allowed to meet each other, while being aware of the possibility of adverse consequences. Should donor and recipient be allowed to have direct contact? The alternatives are to prohibit all contact or to allow them to exchange anonymous letters and/or gifts, which will be checked by the registries on identifying information. Of course, nuances in these policies have to be made.

This study shows that the moral importance of anonymity comes from the apparent strong personal connection that donor and recipient have, but that allowing them to meet includes a chance on negative consequences or even harm. The registries connect two people, who already have an unequal

relationship, with each other. The one offered a part of his body to save the life of the other. Yet, these are not the only relevant considerations in this discussion.

I tried to visualize the other considerations by also showing how these considerations are related (see *Figure 5*). This overview shows how the principles of Beauchamp and Childress are related to each other, to the considerations of the professionals working in the registries and implicitly, also to the facts. Insight in these moral principles and the relation with the considerations of the professionals is essential to deepen the discussion, but does not solve the problem.

This study evaluated the considerations to deepen the discussion. Several considerations ask for more justification. Firstly, I think professionals should go a step further in their justification on why direct contact should be allowed by questioning the entitlement of donors and recipients for this contact. In the moral analysis, I argued that the motivations for donors to request direct contact strongly depends on which account of donation one holds, but that even in the account of two-sided benevolence, donors might not have sufficient reasons to request direct contact. Recipients might have a bigger entitlement, for they are in the 'lower' state of the unequal relationship and wanting to equalize this relationship by express their gratitude personally. Secondly, several professionals referred to the risk of harm. I think it is important be aware of the different degrees of harm. One can doubt whether disappointment as a consequence of idealization of the donor-recipient relation is really harm that is inflicted. Besides these different degrees, it is important to acknowledge that harm can also be inflicted when donor and recipient are not allowed to meet. To be able to validate the harm-argument, data on how often this harm is inflicted and how donors and recipient experience this, is necessary. Thirdly, there seems to be a consensus that the voluntariness of a donation is jeopardized when donor and recipient have already met and the recipient needs a subsequent transplantation. The moral analysis shows that this concern may be unjustified. Making a hard decision does not automatically imply that one also have to make an involuntary decision. This is of course not valid when the donor is coerced to donate or when the donor is medically unsuitable to donate a second time. Fourthly, the professionals in the registries, and especially proponents of direct contact seems to assume that autonomy is an overriding principle. They overvalue to the informed consent that is gained before the disclosure of anonymity. The risk of harm and the presumed diminished voluntary character of the subsequent donation are tried to be justified by that. Informed consent does not provide an immediate justification. Attaching that much value to autonomy needs more justification.

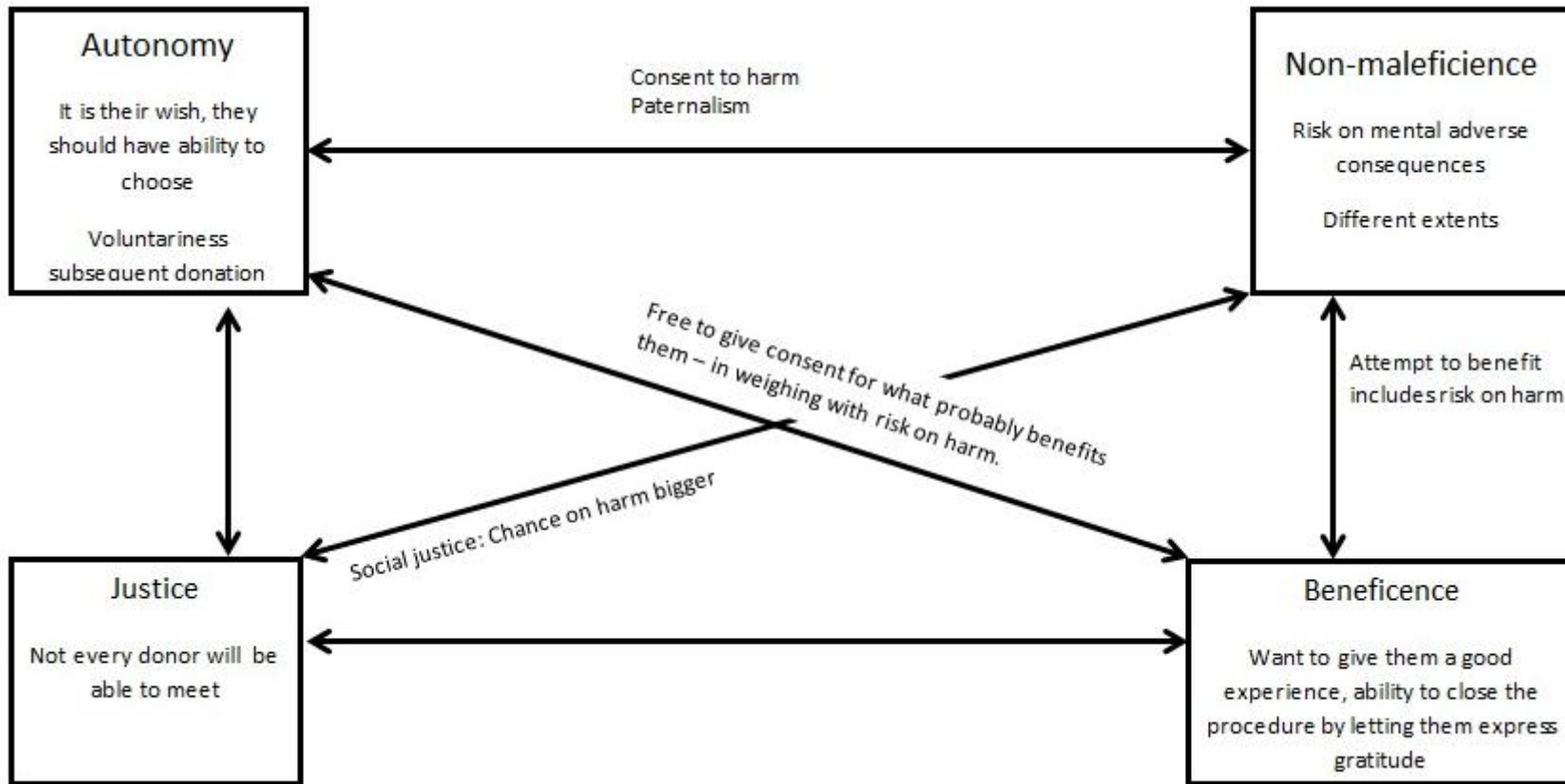


Figure 5: Overview considerations

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Summary and conclusions

The WMDA aims for openness of the post-donation policies of blood stem cell registries. Insight in the morally relevant aspects of revealing anonymity after donation is necessary to enable professionals to develop a well-considered policy. This study aims to give insight in these morally relevant aspects. The research question is: *“What is the moral importance of anonymity in post-donation blood stem cell donation?”*

Method

Integration of empirical data in a reflective equilibrium (RE) method - the Network Model (NM) - was used to get more insight in the moral importance of anonymity in post-donation contact in blood stem cell donation. In this method moral principles were used to explain, organize and extend the moral intuitions of the professionals working at the registries. It is chosen for its practical orientation, its aim to cohere standpoints and its openness to theory and practice. This method exist of three elements: moral intuitions, moral principles and morally relevant facts. The aim is to harmonize these elements. This study existed of four steps, namely 1) Gaining insight in the morally relevant facts, 2) Gaining insight in the considerations of the professionals working on the registries, 3) Categorize these considerations and 4) Use moral principles to evaluate the considerations. Insight in the moral principles was gained by a literature search.

Morally relevant facts

The morally relevant facts consisted of factual information about blood stem cell transplantation and description of the current policies. This information was gained from a literature search, a survey among WMDA member registries, interviews and the NMDP document (document from the NMDP which describes the post-donation policy of several registries). It shows that most registries allow direct contact, but the policies differ in the procedure to allow this contact, e.g. the required time frame, requirement of anonymous contact first or the way of gaining consent to disclose identity. Information on 47 of the 73 WMDA member registries was used in this part of the research.

Moral intuitions

The moral intuitions refer to the arguments, considerations, intuitions, norms and experiences of professionals working at registries. Insight in these intuitions was provided by a survey, interviews and the recommendation of the WMDA Ethics Working Group from 2006 on donor and recipient confidentiality. Twenty-six respondents on the survey were included in this part of the research and seven interviews were held.

The considerations in favor of contact in general refer to the gratitude and presumed connection between donor and recipient. One respondent argued that contact has a positive influence on the

recipient's mental health. One respondent held that donors are entitled to know what they committed to.

The considerations against direct contact referred to the risk of harm, possible jeopardizing of the voluntariness of a subsequent donation, practical reasons, the nature of donation, possible adverse consequences on the amount of donors and a presumed discrimination between donors.

Considerations in favor of direct contact included some counter-arguments on the above mentioned considerations. It argues that donors and recipient are informed about the possibility for harm and this is sufficient to protect them. To prevent jeopardizing of the voluntariness of a subsequent donations, registries set a required timeframe before identity is disclosed and inform donors about the possibility for a subsequent donation. Additional considerations in favor of direct contact included that meetings can be used as marketing to recruit new donors and that not allowing donor and recipient to meet lowers donor commitment.

Moral analysis

In the moral analysis, the considerations of the professionals will be analyzed and evaluated by; 1) explicating the assumptions, 2) drawing analogies with other kinds of donations and 3) connecting them to the principles of Beauchamp and Childress.

The nature of donation

The nature of donation one holds influences the entitlement of donors to express their gratitude or commitment to the recipient. Three natures of donation are discussed: 1) Altruistic nature; donors only donate for recipient's interest and not for any self-rewarding feelings. This account diminishes the entitlement of donors to have direct contact with their recipient. 2) Act of two-sided benevolence; this account holds that donors do donate to do well for the recipient, but also have an interest in the self-rewarding feelings after donation. When holding this account, the donor's entitlement for direct contact is stronger. 3) Donation as moral duty; this account reasons from the perspective of reciprocity and holds that donation is a moral duty, since all individuals benefit from the database of blood stem cell donation. The wrongness of free-riding implicates that everyone should contribute to the system they benefit from. The entitlement of donors is harder to see in this account. It can be argued that there is no incentive for a follow-up, since it is a moral duty. On the other hand, the moral duty does not imply that donors are not allowed to have positive feelings afterwards and that those do not have to be stimulated.

Expression of gratitude

The donor and recipient feel a need to express gratitude to each other. This need is explained by and linked to the personal connection that donor and recipient apparently have. An analogy with blood donation and organ donation shows that this connection can be explained by the personal character of

blood stem cell donation. A donor is asked to donate for a specific patient. This personal character might give rise to the need to express gratitude. What this means for the justification of a meeting, is explained in the next paragraph.

Another explanation for this need can be given by the word: 'stem cell donation'. This makes it feel special for people, while 'bone marrow donation' might less impact. Research to the difference in word-use is necessary to investigate the impact.

Weighing of perspectives

The considerations referred to the presumed entitlement for donors and recipients to reveal anonymity. I am somewhat reluctant to hold that confirmation of identity, curiosity and a need to know whether the transplantation was successful are sufficient reasons to justify the donor's request for revealing the anonymity. A follow-up and anonymous letter should be sufficient to fulfill the donor's entitlement. The recipient's entitlement stems from an emotional perspective for he has been ill and is cured now. His life is saved and he is in the 'lower-side' of the unequal relationship, which he wants to equalize by expressing his gratitude. It can therefore be hold that the recipient's entitlement to reveal anonymity is bigger than the donor's.

Harm

Several respondents referred to the risk of harm when identity of the donor and recipient is disclosed. It is hard to say what is exactly meant by harm in this context. Some examples are: not able to handle the emotional involvement, feeling of guilt in case of unsuccessful transplantation or disappointment when the donor or recipient does not want to disclose identity. Respondents refer to the harm that is inflicted when identity is disclosed, but harm can also be inflicted when identity is not disclosed, which has to be taken into account in the weighing of the considerations.

Different extents of harm are possible. A feeling of disappointment after an idealization of the relationship is harm to a different extent than a request for money that is been made by the donor. It is important to be aware of these different degrees. Further research to this harm is necessary to be able to see the relevant of this argument.

Respondents seem to value autonomy more than the principle of non-maleficence, and this is mainly implicitly. They argue that informed consent is gained from donor and recipient. In this procedure, donor and recipient are informed about the risk of harm and therefore this risk is justified, or that it is paternalistic to forbid this contact. Referring to informed consent or paternalism requires more justification to count as an argument.

Voluntariness of a subsequent donation

Respondents assume that the voluntariness of a subsequent donation is diminished when donor and recipient have already met. It is argued that this is only the case in an external, coercive pressure, since

it is then made a threat instead of a choice. The voluntariness does not have to be diminished by an external pressure due to the expectations of the recipient and his family. This is only the case when a donor does not agree with those expectations, but since the donor already showed that he is willing to donate his blood stem cells, this is not relevant for him. Internal pressure may be bigger when one already met the recipient, but this neither does lead to an involuntary decision, it just means that argument to save someone's life is overruling. Making a hard decision does not imply that it is an involuntary decision.

PR as moral argument?

Using the meetings as PR can be used as recruitment methods for new donors, which is a consequential argument. I argue that this argument becomes stronger when there is a shortage on donors. Negative publicity on these meetings can also have the adverse consequences, which discourages people to donate.

Justice

Justice is used as an argument to forbid direct contact. Just 25% of the donors is able to meet their recipient, due to registry restrictions or the death of the patient. It can be questioned to what extent the recipient's death can be used as an argument of justice, since it is natural interference. Justice can be used as an argument for a uniform policy worldwide.

Conclusion

This study shows that the moral importance of anonymity comes from the apparent strong personal connection that donor and recipient have, but that allowing them to meet includes a chance on negative consequences or even harm. Yet, these are not the only relevant considerations in this discussion.

This study evaluated the different considerations to deepen the discussion. Several considerations ask for more justification. Firstly, I think the professionals should go a step further in their justification on why direct contact should be allowed by questioning the entitlement of donors and recipients for this contact. Secondly, several professionals referred to the risk of harm in the survey and interviews. I think it is important be aware of the different degrees of harm. Besides these different degrees, it is important to acknowledge that harm can also be inflicted when donor and recipient are not allowed to meet. To be able to validate the harm-argument, data on how often this harm is inflicted and how donors and recipient experience this, is necessary. Thirdly, there seems to be a consensus that the voluntariness of a donation is jeopardized when donor and recipient have already met and the recipient needs a subsequent transplantation. The moral analysis shows that this concern may be unjustified. This is of course not valid when the donor is coerced to donate or when the donor is medically unsuitable to donate a second time. Fourthly, several professionals in the registries seem to assume that autonomy is an overriding principle. They overvalue the informed consent that is gained before the disclosure of anonymity. Valuing autonomy to that extent needs more justification.

Appendix: Survey

This is non-anonymous survey and the answers are linked to the registry.

Dear member of the WMDA,

This survey is part of a thesis for the master Applied Ethics at the University of Utrecht in the Netherlands. The aim of the thesis is find out what is important – or not – about the anonymity of the donor towards the patient and the other way around. Some countries allow donors and patients to have direct and personal contact after the stem cell donation, while some do not.

This is a non-anonymous survey, so the answers will be linked to your organization. You only provide the contact details to the WMDA office in order to give the possibility to contact you in case clarification or more information is needed.

For my research, I consider it important to be aware of the policies of the different countries and the considerations behind that policy. Therefore I made this survey, which will take 5 till 10 minutes of your time. This survey will be open till April 24, 2015.

Thanks in advance!

Your sincerely,

Eline Schiks

E-mail: e.t.m.schiks@students.uu.nl

Survey Contact Between Donor and Patient:

Please provide here the contact details of your organization.

Name of your organization:.....

Country:.....

Name of person filling in the survey:.....

E-mail address of person filling in the survey:....

Does your organization allow donor-patient contact after stem cell donation?

- Yes, we allow direct contact
- Yes, we allow anonymous contact
- Yes, we allow anonymous contact of small gifts
- No, we do not allow any contact

Allow direct contact

- In case your organization allows direct contact between donor and patient, what are the criteria defined by your organization? (*Multiple answers possible*)
 - Timeframe between donation and contact
 - Please define timeframe:
 - Oral permission from donor and patient
 - Written permission from donor and patient
 - Other criteria, please describe:

- Can you estimate a percentage of the requests that either a donor or patient refuses to have contact?

- In the case of refusing, is the donor or the patient that refuses contact?
 - DONOR REFUSES TO MEET THE PATIENT
 - Almost never
 - Regularly
 - Often
 - PATIENT REFUSES TO MEET THE DONOR
 - Almost never
 - Regularly
 - Often

- Why is direct contact between donor and patient considered to be important by your organization?
- Has – to the best of your knowledge – direct contact ever lead to any inconvenience?
- What is your view on the counterargument that contact between parties jeopardizes voluntary choices of the donor in case a second donation is required?
- Are you available for a telephone interview to share your experiences?
- In case you have any comments you would like to share, please write in the following text box

Anonymous contact

- Why is contact considered to be important by your organization?
- Why is the anonymity of this contact considered to be important by your organization?
- Are certain regulations applicable for your country which forbid direct contact between donor and patient?
 - Policy of my organization

- Local Regulation
- National Regulation
- EU Regulation
- International Regulation
- Other, please describe....
- Has – to the best of your knowledge – this policy ever lead to any inconvenience?
- What is your view on the counterargument that this is something you have to allow, since it gives the patient the opportunity to thank the donor and that the patient has the right to know who saved this live? Please describe
- Are you available for a telephone interview to share your experience?
- In case you have any comments you would like to share, please write in the following text box.

Do not allow any contact

- Why is it considered important for your organization to not allow direct contact between donor and patient?
- Has – to the best of your knowledge – this policy ever lead to any inconvenience?
- What is your view on the counterargument that this is something you have to allow, since it gives the patient the opportunity to thank the donor and that the patient has the right to know who saved this live? Please describe
- Are certain regulations applicable for your country which forbid direct contact between donor and patient?
 - Policy of my organization
 - Local Regulation
 - National Regulation
 - EU Regulation
 - International Regulation
 - Other, please describe....
- Are you available for a telephone interview to share your experience?
- In case you have any comment you would like to share, please write in the following text box.

For my inquiry, it is interesting to compare different policies regarding post-donation donor-patient contact. If you have a written policy (in English or Dutch) on this topic, it would be very helpful for me if you can attach it to this survey. This will only be used for this inquiry and handled with due care.

Thank you very much for filling in this survey. If you have any questions or remarks about this survey or in general, feel free to let me know. You can do this by sending an e-mail to:

e.t.m.schiks@students.uu.nl.

Kind regards,

Eline Schiks