Introduction

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"You can make it", "Be a superhero", "You get everything from me – what do I get from you?", "Can we count on you?", "If you believe in organ donation, prove it" – these are just a few of the slogans that have been used in recent public organ donation campaigns in different European countries. Apart from their different tones and framing, what they all highlight is an increasing awareness, that public acceptance of organ donation is a crucial factor for the medical field of organ transplantation.

Transplantation is continuously grappling with the challenge of ensuring the supply of organs can keep pace with the demand for organs. Organ failure does not discriminate – it impacts upon people from a wide range of social, age, gender, educational, cultural, faith and ethnic backgrounds reflecting the diversity of the world's population. Governments, policy makers and transplant professionals continue to strive in their efforts to make transplantation procedures more successful and more common place. The human and economic value of this endeavour is immense as people's lives are saved, quality of life is improved, and the need for long-term organ maintenance treatments is reduced. However, the fact remains that in every country that operates a transplantation programme, there are insufficient numbers of donor organs to meet the demand. Addressing this matter is complex and requires a fresh perspective as to how governments truly engage with their public on issues which touch upon health care, morbidity, and mortality. As a legal-ethical consensus in most liberal, democratic countries, the idea prevails that individuals should decide on their own whether they want to donate – or not. But if we truly wish individuals to freely donate their organs either while living or after death, then we need to consider how we can create the conditions to ensure the public understand the need for and share the value of organ donation. This inevitably requires meaningful public engagement which takes concerns, distrust, and ignorance of the publics seriously. We suggest to speak of 'publics' as a plural to recognise the diversity of the many groups involved and having different attitudes towards the giving and taking of organs. Moreover, 'public engagement' goes even beyond the idea that the public has to be 'informed' by health care professionals or the government solely. Contrastly, it also takes the more balanced stance that each public might have a well-reasoned, meaningful attitude towards organ donation that must be taken into account by governments and health care policy makers. This is particularly pertinent in this case, where the practice of organ donation and transplantation is continuously challenged by new techniques (e.g. transplantation of the face and extremities, gonads, or brain tissue) or new standards of death and dying (e.g. allowing organ donation for non-heart-beating donors or after active euthanasia). Also, the question of who receives or should receive an organ according to which criteria can sometimes be reflective of public/political consensus, and not just medical criteria. Hence, public engagement might include dialogical, participatory, or inclusive means to enable people the opportunity to surface their hopes and fears, their interests and concerns about particular developments within organ donation and transplantation.

Inspiration for this book

The book owes its genesis to ELPAT. ELPAT is a European platform that brings continuity and progress in European research and dialogue on "**E**thical, **L**egal and **P**sychosocial **A**spects of organ **T**ransplantation". Within ELPAT, there are seven working groups. Each working group addresses a specific topic in the field of ethical, legal and psychosocial aspects of organ transplantation. One of the Working Groups, Public Issues (which is co-chaired by the book Editors) had been bringing together a range of experts and professionals from all around the world to share their experiences and insights into why and how public engagement was progressing. It was clear from the evidence presented at various meetings that there was a wealth of innovation, systematic research, and lessons that existed but was not yet bundled together. Given the vast number of publications in the field of ethics, social, legal and psychological aspects of organ donation in the last three decades, it is somewhat surprising to realise that there are rarely editions that collect recent work on public attitudes, opinions, and assessment of organ transplantation. Hence, a book that pulls together these resources can be an important starting point to enlarge the interdisciplinary discussion as well as to inform experts, policy makers, and stakeholders.

Structure of the book

This book is a contribution to assessing how public engagement in relation to organ donation has taken place in various countries around the world. The chapters highlight that such engagement can take different forms to suit the context of the community and country in terms of political, cultural and historical development. In discussing public engagement in organ donation, we have developed a typology of four major issues in which to organize the book chapters:

- Constructing and studying the public
- Donation practice as a public policy issue
- Public and social acceptance
- Cultural and social issues of interventions and concrete decision-making

While the focus of this book is rather on Europe, the number of communities addressed is much beyond the traditional categories of collecting different countries' perspectives. The 18 contributions in this volume provide a timely review of how, in different countries and contexts, engagement and understanding of the public regarding organ donation can and should be investigated. A particular strength of the book is the multi-disciplinary range of contributions and initiatives examining issues from different methodological standpoints such as media studies, socio-empirical studies of opinions and attitudes of different publics, comparative studies along the lay-expert/public-professional division, and cultural or public studies of campaigns and policy making. It was also important to combine macrosocial perspectives of ethnicity and religion with microsocial perspectives of family dynamics, patients' experiences, or doctor-patient communication.

We would like to thank all colleagues from ELPAT in supporting our idea and contributing to this book and in particular we owe ELPAT Chair, Willem Weimar, and Frederike Ambagtsheer thanks for their personal, practical, and financial support that collectively made this book possible.

1 Constructing and studying the Public

1.1 Constructing "the public" attitudes toward financial incentives for organ donation: methodological and ethical implications

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Abstract

Waiting lists for organs have stimulated interest in the use of financial incentives for organ donation. In this chapter we reflect on our work with a systematic review of international peer-reviewed research published within 2002-2012 on how members of the general public position themselves toward this idea. Our review of 23 relevant studies found an overall low level of acceptance of financial incentives for living donation; only a slightly higher one for postmortem donation; and a general preference for alternative forms of non-direct payment (Hoeyer, Schicktanz, Deleuran 2013). The review also revealed a high variety in employed methods. We use this review exercise to reflect on the nature of public engagement executed in this area and to suggest directions for future research. Our central message is that comparative reviews of opinion studies can be helpful, but should not be considered as a simple aggregation of data. A review must include reflections on the socio-cultural context and methodological specificities of individual studies and it should stimulate basic reflections on the issues investigated in the study field.

1 Background and overall research question

Most medical issues are decided upon by medical professionals and politicians; only few topics ever come to involve public consultations. One such topic, however, has been how to motivate potential organ donors and, more recently, whether financial incentives might increase donor willingness (Healy 2006; Hippen et al. 2009; Tilney et al. 2010). Public engagement has been suggested as a new mode of governance aimed at a more democratic political ethos and a more socially robust science (Nowotny et al. 2001), but while issues such as genetic testing, stem cell research and health care allocation have stimulated deliberative modes of consultation such as public hearings and consensus conferences (Schicktanz et al. 2011), public engagement in relation to organ donation mainly consists of non-deliberative quantitative surveys and qualitative interview studies. Rather than having the public influence policymaking, concerns have been expressed that public opinion studies constitute attempts of changing the opinions of either policymakers, medical professionals or the public (Ashcroft 2003).

When the American journalist Walter Lippmann introduced the notion of a 'phantom public' in 1927, he reacted to what he saw as increased political instrumentalization of references to public opinion. He pointed out that publics do not simply exist; they are constructed. Who counts as 'public' depends on the nature of the topic investigated, and on the methods used to elicit public

opinion. Depending on the mode of investigating opinions (e.g. by way of language, region, oral or written communication etc.) different publics emerge in different studies.

So how should we approach public opinion studies? On the one hand it would be irresponsible to ignore existing surveys of public opinion or arbitrarily select a few studies from the literature and generalize from them. On the other hand, we must carefully consider what to expect of a review, or a meta-analysis. It is not feasible to sum up opinions with aggregate numbers as if they would say something about a homogenous public. Different studies rarely investigate the same 'public', and therefore we cannot rely on guidelines for meta-analyses such as those for clinical trials. In the case of clinical trials, the assumption is that all studies explore the same biological mechanism whereby aggregate results represent best possible evidence (e.g. the PRISMA guidelines [http://www.prisma-statement.org/], see however critique in Epstein 2007). Simple aggregation of results in opinion studies, in contrast, potentially covers up exactly the type of regional differences a meta-analysis could be interested in identifying. A global public would be a 'phantom' in more than one sense. There are several reasons why surveys come up with different results, for example:

- they study different publics (nations, gender, age, socio-economic, self-selected, patients vs. non affected persons etc.)
- they are performed in different situations (self-selection vs. representative, orally or written, private or public context);
- they formulate questions differently ("Are you in favor of organ donation?" vs. "Are you willing to donate your organs after death?")

Hence, one must seek to understand both similarities and differences between studies, but we should not assume that there is one global public with one set of opinions, and we should read opinion studies with concern for differences among study populations as well as differences between the interests of the scholars conducting the studies.

Unfortunately, it is not uncommon to make selective usage of opinion studies. An often-cited *Lancet* article from 1998, for example, claims that "vendors are themselves anxious to sell" (Radcliffe-Richards et al. 1998: 1950) but the support for this claim is a reference to a book chapter in which it says: "Who are the sellers? No one who is comfortably off will undergo surgery, lose time from his work and suffer pain for someone he does not know. It is always the poor who sell their organs" (Mani, 1992: 165). Also drawing selectively on the literature, a recent consensus statement from the Working Group on Incentives for Living Donation (2012), which is composed of international scholars, suggests to increase the number of living and deceased organs by reducing existing disincentives and also to implement financial incentives under strict legal governance. Here, the authors back their consideration partly on "surveys have shown that the public: (1) support incentives and (2) would be more likely to donate if incentives were offered" (page 307). In contrast to this broad claim, our literature review shows that it is not the case that the public in general, whoever that would be, supports incentives. Indeed, only the most selective usage of public opinion studies can lead to such a conclusion. In the following, we briefly outline our review approach and our results[1] and then suggest three major implications for future studies of public opinions in the context of organ donation.

1.2 Overview of conducted literature review

Our literature review of studies on public attitudes toward the use of FIs for living and postmortem organ and tissue donation is based on selected elements of guidelines for review of clinical trials in combination with guidelines for reviews of studies of public health policy issues (PRISMA;

[1] We here summarize results of Hoeyer, Schicktanz, Deleuren 2013

Noblit & Hare 1998; Poplit et al. 2006). We included both quantitative and qualitative studies published within the past decade to focus on the current situation (2002-2012), and for quality reasons only included peer-reviewed articles. We developed a search model of keywords with which we started our search in the *PubMed* database based upon database indexation and Medical Subject Headings (MeSH) and limited it to languages understood by the authors (Danish, English, German, Norwegian and Swedish). The search model generated 2,685 titles, which were independently reviewed by the authors. 211 titles were selected for further review of the abstracts. To encompass a wide range of so-called lay persons, i.e. people with no medical training, we included studies with potential future donors, living donors, actual vendors and relatives of deceased donors, but excluded studies on medical students or recipients. The searches were supplemented with material from our own databases; related citations, references, and a focused search in the database *Sociological Abstracts* and *PsychINFO*©. Duplicated publications on the same data were excluded, but studies presenting different elements of the same study were included. As MeSH indexation is lagging behind in publications we also performed a keyword and title word based search in *PubMed* for additional publications published until August 2012. Based on a full text review 23 relevant studies were selected (see Ref # 1-23 in the annex; numbers listed with # in the following indicate specific studies). The majority (N = 14) were surveys (internet based, face-to-face, postal, or telephone interviews) (# 1-3, 5-8, 10-14, 17, 18, 23). All studies differed greatly in length, framing, and content of questions: some used yes/no/not sure-answer options for "Would you donate under this/that condition", others used agree/disagree/neither categories for closed statements. A few used scenarios and whether it would be likely/very likely/less likely/unlikely that they would donate under such a scenario. Some surveys offered a range of answer options (e.g., who should regulate/control incentives?). Overall, we identified categories of financial incentives (direct or indirect payments, e.g., including distinct cash sums, offered by the state, health insurance, or recipients), removing disincentives (e.g., that medical expenses are covered) or of reciprocity (e.g. donations for charity, coverage of funeral expenses).

Six studies were only qualitative (# 11, 16, 19-22) and three (# 4, 9, 15) used quantitative as well as qualitative methods. The 23 studies were conducted in 17 different countries (Argentina, Austria, Brazil, Cyprus, Egypt, France, Germany, Great Britain, India, Iran, the Netherlands, Pakistan, the Philippines, Qatar, Switzerland, Sweden and the USA). We compiled the quantitative data by developing umbrella categories to allow comparison of results of questions used in the different studies. In the following we briefly outline first the results from quantitative studies, then the main points from the qualitative studies.

Comparing the results of the quantitative studies

The studies show great variance in opinions about whether the government should provide financial incentives for organ donation (between 25% and 60%), and similar discrepancy in relation to whether recipients should pay (from below 10% to over 55%). There was generally low support for the idea that the donor receives cash (# 1, 6, 7, 9) (5% to 30%) but higher support for coverage of medical expenses (60% resp. 91%) (# 2, 7), while a general discount in health care gained only moderate support (around 25%). Except for the study conducted in Qatar (# 8), studies consistently show highest agreement with suggestions for non-monetary (altruistic) living donation to a relative (51-89%). When compared with support for altruistic donation, all versions of cash payment (general, or different sums) gained less support. Surveys that asked for particular cash sums (# 9, 10, 12, 17, 23) always indicated an agreement below 30%, except for a US study (# 10) indicating 44% agreement but still double for altruistic donations (89%). There were no considerable differences between the studies in whether the sum is below 1,000 Euro or above 12,000 Euro. One study conducted in the Philippines found high support (96-98%) for some form of remuneration, called a

'token of gratitude' (# 6), but it was unspecific with respect to the kind of remuneration this should be, and only 31% supported cash payments.

For those 11 studies that in one way or another asked for FIs to promote postmortem donation, the picture is even more heterogeneous than in living donation. Only few studies asked about attitudes toward altruistic donation (support varied between 38%-75%), but if they asked explicitly for both altruistic and monetary motivation, they found higher support for the altruistic option (# 1-4, 7-9, 14). Support for the coverage of funeral expenses ranged between 9% and 81%. However, the study with lowest support 9% (# 2) generally showed very low support of any kind of incentive, while the study with highest support (815) (# 3) showed highest support for other alternative models (including donation to a charity (73%) and cash to a family (53%). Agreement with cash to the family ranged between 3-53% (# 1-4, 8, 13, 14). Tax reduction (11-15%) and priority on the waiting list for an organ donor card holder (16-39%) get rather low support. The overall picture we get is that people are slightly less opposed to remuneration in PD than in LD.

Comparing qualitative studies

All 9 qualitative studies (# 4, 9, 11, 15, 16, 19-22) emphasized an opposition toward the idea of regular trade in body parts. Two studies involving very different informants (Scottish donors' families # 9, Indian organ vendors # 11) described that the informants perceived FI as 'immoral'. However, a focus group study compiling data from 4 different European countries indicated some level of support for selected forms of remuneration, mainly for postmortem donation (# 19, 21). Importantly, however, the coverage of funeral costs was here described as a sign of fairness, respect or gratitude, rather than as an incentive. Some informants employ an idiom of ownership in relation to their own body (#19), but it served as a metaphor to stipulate the right of self-determination, not as a stated interest in the sale of one's own body. Informants also expressed concern that money would distort the voluntary decision and destroy their autonomy.

Another theme was the idea that organ transfer establishes an enduring reciprocal relationship. Possibly, the idea of payment is seen by some recipients to end such relationships and relieve them of their potential sense of debt. In studies of vendors, however, they do not seem to support this perception. According to vendors, an enduring relationship is preferred to a one-time payment (# 16, 22). Kidney vendors from Egypt, Iran and Pakistan (based upon both legal and illegal practice) expressed deep concerns about their health, social stigma and unintended medical harm. Pakistani informants also complained about being paid less than agreed (# 16). Vendors claimed to be worse off than before the organ sale, socially, medically and economically (# 11, 16, 22). They are almost always driven by debts and perceive of the trade as a necessity not a choice. In short, the qualitative studies focus on mostly harmful social, moral and medical consequences of organ transplantation elicited with FIs.

2 Discussion and future perspectives

Our review indicates general support in many locations for the use of various means of expressing reciprocity toward, and of elimination of disincentives for, donors. However, there are quite consistently negative attitudes for direct financial incentives or what would correspond to so-called market models (for an analysis of market models in organ donation, see Hoeyer, 2013). We observe a slight indication in US studies that private health care might be associated with higher acceptance of FIs for organ donation (# 3, 10, 13, and slighter effects in 2, 18). Mid-European studies (Germany, Austria, Switzerland, the Netherlands) report very low approval of direct payments but a moderate acceptance of indirect benefits and higher approval of the coverage of health expenses (# 1, 7, 12,

14, 19-21, 23). Three studies in Great Britain/Scotland share a slightly higher approval of cash payments than Mid-European countries (# 9, 15, 17), though still preferring forms of reciprocity other than cash. Studies from developing countries with vendors overall report more ambivalence and even disappointment with commercialized organ transplantation system (# 4, 11, 16, 22). Given the heterogeneity of the studied population and the surveys, this must be understood as nothing but an initial hypothesis building.

If it is impossible to present more convincing aggregate results, why conduct a literature review? We suggest that reviews help to explore possible factors for discrepancies, unsolved issues and some commonalities despite heterogeneity; they can point to methodological weaknesses of each other and unwanted consequences of particular framings of questions in individual surveys. Furthermore they may provoke important reflections on the categories used in opinion studies, because hard-to-explain discrepancies might in fact reflect the use of categories unfit for the topics at hand. We suggest that this might be the case with the central category of 'financial incentive'.

When people irrespective of context value means of expressing gratitude *after* the donation higher than incentives eliciting sale of organs (i.e., a decision made *prior* to the organ transfer), it might imply that we should begin to realize that economic means are not irrelevant for organ donation, but should be used in a manner other than as incentives: namely to express gratitude and ensure reciprocity. As such they can complement other non-financial means of communicating gratitude. When scholars investigate attitudes toward 'incentives' it is important not to misinterpret the social mechanisms involved when people evaluate the options before them in the various surveys. By reading across both qualitative and quantitative studies, misinterpretation of such categories is easier to identify.

Based on our experience with this review we wish to make three major points relating to single studies and meta-analyses of public opinion studies in the field of organ transplantation:

1. **There is a need for socio-cultural contextualization**
   Investigation of willingness and social acceptance should be culturally contextualized to take into account implicit social factors. For example, we assume that public and private health care systems will influence donor attitudes toward procurement models differently, but we need further studies on how and why. Socio-culturally rooted trust or mistrust in medical systems similarly must inform interpretations of attitudes toward organ transplantation (see Russell et al. 2012). If studies are conducted and related to other studies without consideration of such differences, we lose sight of the specificity of the findings.

2. **There is a need for plurality of perspectives**
   The choice of method has in itself inherent values and biases. Among the identified studies, the quantitative studies tend to view organ donation as a technology with a specific medical effect irrespective of the procurement model. The survey methodology is limited to the measurement of approval or rejection to particular models of FIs, so it cannot explore how participants understand the questions asked. Moreover, it cannot reveal whether a changed procurement method makes respondents think differently about the technology as such. The qualitative studies tend to look upon organ donation as a technology with different (partly unintended) social and medical consequences dependent on the social model of procurement. The qualitative studies in this sample explore how organ donation potentially influences perceptions of bodies and changes social relations and often focus on negative health or social consequences for donors when the procurement models change; while the quantitative studies tend to focus on how many of the approached participants agree or disagree to donation with various models assuming that more people could be helped if more organs could be procured. The strength of surveys relies on their representativeness; the strength of qualitative studies lies in the identification of the unexpected. Both perspectives hold their merits and complement each other, and

therefore we suggest that both should be included in similar future reviews. Furthermore one could begin to analyze and actively enroll so-called 'counter-publics' (Fraser 1986), e.g. through websites, blogs, or even participatory involvement, and thereby enhance our awareness of the multiple perspectives on a given topic.

3. **A critical reflection on political implications of the categories used**
We need public policy to resonate with key moral values identified in the public understood as a democratic practice. Therefore it remains important to investigate public opinion; not to conserve politics in eternity but to develop it in the light of the reasoning that informs the values of affected stakeholders. Though three studies (# 2, 10, 15) conclude that financial incentives hold potential (see also Radcliff-Richards et al. 1998; Working group on Incentives in Organ donation 2012), our review does not support this conclusion as a general insight. Overall, when surveys invite members of the general public to assess procurement models, they rate direct payment and similar FIs lower than so-called altruistic donation models or the removal of disincentives. Importantly, however, rather than giving evidence for support for or against a market model of procurement, the review might indicate a need to rethink the categories used in the studies (along with the reasoning behind them). The studies seem to believe that there are two options only: use of financial incentives or reliance on 'altruistic donation' without economic compensation. But in fact the study results show that remuneration can be seen as an expression of fairness rather than as an incentive. This is the case, for example, when donors are offered to get medical expenses covered. Perhaps it is time to conduct more socio-empirical studies that explore how *means of reciprocity* might work, rather than testing attitudes to *incentives*. This shift could set a new agenda for the study of public attitudes toward procurement models for organs and potentially provide new avenues for development of robust policy solutions in this area.

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1.2 Why the altruism/self-interest dichotomy does not hold and should be avoided also in public perception studies related to 'donation'

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Abstract

This chapter examines the concept of altruistic bodily giving in medicine within public perception studies of live voluntary and unpaid donation of kidneys, blood, eggs or sperm. The analysis discusses problems with the conceptualization of altruistic bodily giving as giving only to *unknown* others, and offers a philosophical argument for the view that also bodily giving to known *others* can qualify as altruistic. Starting with the philosopher Neera Kapur Badhwar's (1993) reasoning that shows how some forms of self-interest can be seen as necessarily compatible with altruism, the chapter examines the conditions under which donations to known others can qualify as altruistic. The chapter ends by discussing implications of this line of reasoning for the design of public perception studies.

Introduction

According to the World Health Organization (2011), the provision of blood should preferably come from blood donations from live voluntary un-paid donors. Richard Titmuss (1970) labeled such donations *altruistic:* the donor donates to unknown others via a collective blood-pool without there being financial gains for the donor or social sanctions that enforce the donation. Titmuss claimed that altruism does not come naturally and that learning to act altruistically – by learning to give blood – would have positive effects on society. It could contribute to a sense of a shared community among its members.

The benefit of altruistic blood donation to unknown others via collective blood pools has seldom been questioned. This can be contrasted with the case of live voluntary un-paid kidney donation to unknown others. While these donations are accepted in many European countries and elsewhere, they have been much debated within medical and medico-ethical communities. Concerns have been addressed as regards why anyone would volunteer as a live organ donor if this person has no relation to the recipient and receives no financial gains (see, for example, Boulware et al. 2005, Hendersen et al. 2003). Are such donors not sacrificing themselves too much, and can they really have understood what this donation implies?

This chapter examines the concept of altruistic bodily giving in medicine. It questions the conceptualization in some public perception studies of live voluntary unpaid donations where altruistic bodily giving is understood as giving to unknown others only (i.e. cases of unspecified donation

according to the new ELPAT classification in the area of live organ donation, see Dor et al. 2011), and offers a philosophical argument for the view that also bodily giving to known others can qualify as altruistic. Starting with the philosopher Neera Kapur Badhwar's (1993) reasoning that shows how some forms of self-interest can be seen as necessarily compatible with altruism, and following her definition of altruistic acts as acts that are motivated primarily by a perception of another's good and by a wish to bring about this person's good as an end in itself, I discuss the conditions under which donations to known others can qualify as altruistic.

First, I examine public perception studies of live voluntary unpaid donation of kidneys, blood, eggs or sperm with the aim to bring out the cultural meaning of the body-part or fluid that is given and show how this informs whether a certain form of donation is likely to qualify as an eligible altruistic act.[1] Second, I suggest that a philosophical basis for the idea that altruistic acts are acts for the benefit of unknown others can be found in a certain reading of Kant. However, turning to Kapur Badhwar's (1993) analysis of how some forms of self-interest are necessarily compatible with altruism, I argue that even if donations to known others are motivated by a mixture of self- and other- regarding motives they can qualify as altruistic. Third, I end by outlining implications of this line of reasoning for the area of public perceptions studies.

1 Altruism in public perception studies

Few public perception studies on live voluntary un-paid donation of kidneys, blood, eggs or sperm examine the meaning attributed to these donations. Instead, these studies typically focus on stated willingness to undergo donation, on reasons and on motivational factors for why someone would donate or refrain from donating.

1.1 Blood donations

Studies on reported motivational factors for voluntary unpaid blood donation within general populations world-wide include a sense of duty, feelings of moral satisfaction, social pressure, desire to know screening results, anticipated regret (i.e. an experience of regret due to inaction or action in an imagined or real situation) and altruism (Godin et al. 2005, Zaller et al. 2005, Lemmens et al. 2005, Glynn et al. 2002). While these studies rarely describe the notion of altruism in detail, some differentiate between motives for donating such as social gains, wanting to help family or friends and altruistic reasons (see, for example, Lownik et al. 2012). When this is the case, altruistic reasons are differentiated from reasons such as wanting to help known others irrespective of whether my reason for donating is that I want to help known others for their own sake rather than out of self-interest or expected future reciprocity.

Furthermore, public perception studies on blood donation world-wide highlight that voluntary unpaid blood donation to unknown others is not always seen as desirable nor acceptable for potential donors. Indeed, there may be cultural, structural and risk-related reasons for people to prefer blood donation to known others. As one such example, a study on perceptions of blood donation within African communities in Australia indicate that blood is conceived as symbolic fluid that define families and is imbued with tribal and kinship properties (Polonsky et al. 2011). Such conceptions of blood in combination with distrust towards blood collection agencies, inadequate structural support that enable donation, and concerns about blood safety can make donation to unknown others via a blood pool appear less acceptable than donation to known others in need (Polonsky

[1] Due to the lack of public perception studies within this field, the article does not offer a systematic review of such studies.

et al. 2011, Lownik et al. 2012). As another example, studies of conceptions of blood donation in China have examined the extent to which blood is seen as a vital life force that carries life energy and donation implying a loss of vitality *and* a potentially disloyal act towards one's ancestors (Zaller et al. 2005, Shan et al. 2002).

Instead of dismissing these conceptions of blood as false and in need of being corrected, I will focus on the *conception of altruism that makes live unpaid voluntary blood donation to known others disqualify as altruistic*. Many reasons can be given for why live voluntary unpaid blood donation to a blood pool is a good route in order to secure blood for general populations (see Archer 2002, Singer 1973, Titmuss 1970). Why, however, adhere to the view that it cannot be altruistic (also) to give to known others?

If we hold on to this view, individuals who understand the meaning of blood in ways that make them *likely* to donate only to known others will be *unlikely* to qualify as altruistic blood donors – such as individuals in the African community just mentioned. Some may see this as a justifiable consequence of how the term altruism has been used. However, if altruistic acts are seen as morally approvable and praise-worthy as is sometimes the case,[2] and noting how the common conception of blood in Western countries (as exchangeable and not having any kinship properties) enables individuals who share this conception to qualify as candidates for altruistic acts, we may question the usage of the term altruism only for giving to unknown others – on the grounds of fairness. Is it really fair that those who give blood to known others rather than unknown others should disqualify as altruistic, even if they donate to others for these others' own sake, when the reason for this is that they hold on to another conception of what it is that one gives in blood donation?

Now, Titmuss was well-aware of how values and cultural orientations could inform and permeate systems of recruiting and rewarding donors and individuals' perception of what the donation meant. He also argued against a market of blood among other reasons because this would be imperialistic in the sense that commercial blood programs would, eventually, be "driving out the voluntary system" (Titmuss 1970:223). For these reasons, it is somewhat ironic that a sole focus on altruistic blood donation to unknown others also has an imperialistic ring to it – though in the sense that the global call for this donation will be easier to respond affirmatively to if one shares the conception of blood that is common in many western contexts rather than the one in for example some African communities.[3]

1.2 Live kidney donation

The global call for blood donation to unknown others via a collective blood pool has no similarity within the context of live kidney donation. Most live kidney donations, world-wide, are donations to known others with exceptions to countries such as Saudi Arabia and Iran (Horvat et al. 2009). Public perception studies report stated willingness to donate as live kidney donors to known others in need among around half or more of the participants (see Meng et al. 2012, Conesa et al. 2004). At the same time, public perception studies in Spain, the USA and Canada also report that one third to one fourth of the surveyed populations declare themselves willing to donate as live voluntary unpaid kidney donors to *unknown* others (Conesa et al. 2004, Spital 2001, Landolt et al. 2001, Landolt et al. 2003). In the light of these donations, concerns have been evoked from within medical and medico-ethical communities as regards to the limits of altruistic acts.

This highlights a twist to the discussion of altruism and bodily giving. Whereas altruistic bodily giving to unknown others sometimes is seen as morally praise-worthy (as in cases of blood do-

[2] See Schefscyk and Peacock, 2010, for an overview of altruism conceptions.

[3] Having said this, it is worth remembering recent research that indicates different conceptions of the meaning of blood is also within a Western context (see Waldby et al. 2004).

nation), it can also be seen as too self-sacrificial (as in cases of live kidney donation) depending on what is given, the value attributed to that which is given, and the risks involved in this giving.

1.3 Gamete donation

Another twist in discussions about live voluntary unpaid giving to unknown others comes from within discussions about egg and sperm donation. British studies indicate that there is public support for egg donation to unknown others (though more so in some ethnic groups than others, see Purewal et al.2006), and a recent review of public perceptions studies on gamete donation indicates support for sperm donation to unknown others (Hudson et al. 2009). At the same time, research is inconclusive as regards willingness to give gametes to family-members or friends, and there is a concern that known donors may be "interfering" with the child's upbringing (Hudson 2009: 67). Furthermore, Simpson (2004) found that while Buddhists in Sri Lanka had a strong inclination for others forms of bodily giving within kinship systems, such as organ and blood, the disclosure of male infertility to relatives was regarded as highly stigmatizing, which resulted in sperm donation to known others being seen as problematic. Again, this brings out the cultural meaning of that which is given and shows how this informs what donations become perceived as acceptable, at all, in a specific cultural context.

Finally, concern about both sperm and blood donation can be seen in the light of another debated feature of altruism: should an act qualify as altruistic if it involves only minor or no costs for the agent (see Schefszyk and Peacock 2010)? Such concerns can be traced back to ideas that recur in Western moral philosophy, i.e. that self-interest motivated acts are acts for one's own good and that altruistic acts are incompatible with self-interest. If combined with the ideas that all human behaviour can be reduced to self-interest and that self-interest motivated acts are pleasurable, some may reach the conclusion that to act altruistically should be unpleasant and/or at least imply costs or risks for the agent. This is not the place to enter a discussion of the possible place of a sacrificial element in altruism. In the following, however, I will assume that what matters most is whether my act is motivated by a concern for the other's well-being and not whether I give all I have, including my whole bodily self, to another individual.

2 Bodily giving beyond the altruism/self-interest dichotomy

Consider now the following (in)famous quotes from Immanuel Kant. Even if some individuals act without any "motive of vanity or self-interest" but instead "find pleasure is spreading joy around them," these persons' action "however amiable it may be, has nevertheless no true moral worth" (Kant 2008:16). It is when an action is performed "without any inclination to it, but simply from duty, then first has [this] action its genuine moral worth" (Kant 2008: 17). These quotes have been topic of much dispute. For example, it has been suggested that Kant may have had two views on moral worth and that only one of them required the absence of motives such as wanting the other person's good because one cares about this individual (see Herman 1981, Henson 1979).

Irrespective of what stance we may take in this debate, my point is that the idea that donation to known others cannot qualify as altruistic may be derived from a certain reading (or misreading) of Kant that starts in the quotes above. *If* the views i) self-interest motivated actions have no moral worth and ii) only acts that are performed without any self-interest have such worth, are combined with the idea iii) donations to known others are always performed for both self- and other-regarding motives, then we have a reason for seeing these donations as devoid of moral worth. If altruistic

acts are seen as having moral worth, then donation to known others simply cannot qualify as altruistic. But, are really all forms of self-interest incompatible with altruism?

I will briefly present Neera Kapur Badhwar's (1993) philosophical defense of the view that some forms of self-interest are *necessarily compatible* with altruism. While Kapur Badhwar discusses the behavior of individuals who rescued Jews in Nazi Europe during the world wars (hereafter referred to as rescuers), I will show how her reasoning becomes relevant for the discussion of altruistic acts towards unknown and known others.

2.1 The case of rescuers

Empirical studies of rescuers' actions, statements and stories suggest that these individuals typically did not act as a result of a conscious deliberation of costs and benefits. Instead, they described their actions in retrospect as natural, the only option and as something they "just" did. While being aware that others acted differently, the rescuers nevertheless stated that no other choice was possible for them (see Monroe et al. 1990; Oliner and Oliner 1988; Hallie 1979). Many rescuers also expressed a sense of oneness-with-others-who-all-belong-to-humankind which included an *inclusive* (every other is experienced as a part of oneself; as "basically you") and *universalistic* orientation (every other is seen as part of humankind) towards others. These features were combined with a perception for others' needs. As an example, one of the rescuers stated that "you help people because you are human and you see that there is a need …" (Monroe et al. quoted in Kapur Badhwar 1993:97).

Kapur Badhwar underlines that this sense of oneness-with-others-who-all-belong-to-humankind must have been combined with a capability to see oneself as a distinct individual who can act contrary to most others, based on her or his one's own judgment about the value and importance of this act. Otherwise, rescuers would not have been able to act the way they did: after all, others did act differently. Furthermore, she suggests that this combination could have made rescuers see omission or refusal to help refugees as a betrayal of their own *sense of identity,* of who they are, namely individuals with a sense of belonging together with others, who act for the sake of others be they known or unknown.

This is a core point as regards to the relation between self- and other-regarding motives for acts of rescuing. On the one hand, Kapur Badhwar states, rescuers' acts seemed to be motivated by the desire that others be helped – for their sake. On the other hand, she notes that this motive can be combined with the actor's wish to affirm her or his sense of oneness-with-others-who-all-belong-to-humankind *even if* the rescuer did not reflect upon this. Indeed, she explains, the act of rescuing could be an expression of self-affirmation (and not a means to it): to act for the benefit of others, for rescuers, could be an expression of who one is and wants to be.

However, Kapur Badhwar's (1993: 114) point is stronger. In her view, an altruistic act must be motivated primarily by a perception of the other's good and a desire to bring about that good for the other's own sake. This makes rescuing activities for the sake of social reward disqualify as altruistic. Still there are some self-affirming acts that are compatible with altruism: in the case where altruistic value – the value of helping others for their own sake – is central to the individual's identity. In such cases, Kapur Badhwar explains, the wish to help others is *"necessarily* compatible with, their altruistic motivations, for acting out of the self-interested desire to affirm their own altruistic identity required that they also act out of their altruistic motivations" for individuals with a strong sense of oneness-with-others-who-all-belong-to-humankind. In other words, some forms of self-interest motives can be necessarily compatible with altruism.

This brings new light to the discussion of whether my delight in someone else's well-being really disqualifies altruism: if the reasoning above is accepted then this is not the case. And because the dichotomy between altruism and self-interest is untenable in all cases, it is misleading to focus *either* on the other *or* on the self in order to understand altruistic behaviour.

2.2 How this matters for donation to known and unknown others

There are differences between the case of rescuers and that of donors in medicine. While rescuing activities could come at the cost of the rescuer's own life, and while the risk ratio varies with different kinds of donations and with national contexts, some forms of donations – such as sperm or, depending on the safety of the procurement, blood – imply very low risks. However, Kapur Badhwar's argument does not hinge on the level of risk but on how to understand the combination of self- and other-regarding motives, and the different risk ratios become irrelevant for the point she makes and for the one I want to make.

First, consider the case of live voluntary unspecified kidney donation. A few qualitative studies have examined the reasoning on behalf of the donors in these situations. Interestingly, some donors stated that they did not feel that helping unknown others was different from helping someone they did know. They also explained that they volunteered since they wanted someone else to be able to live a "normal" life, improve the other's quality of life, and that this was an opportunity to give an unconditional gift to a fellow-being (Tong et al. 2012: 3, Henderson et al. 2003).

The statement that there is no difference between donation to unknown and known others, for these donors, is at odds with the view that there is indeed a major ethically-relevant difference between the kind of relation that exist between donor and recipient in the case of known vs. unknown donation. At the same time, this view seems to have some affinity with the views of the rescuers. Such statements and views result in questions: perhaps altruistic donors – just as the rescuers – have a sense of belonging together (also) with unknown others and perhaps this motivates their act? Do subjects in both cases act for the benefit of others in a way that expresses who they are or want to be? As a tangent, we may ask ourselves why we admire rescuers – as many of us do – but perhaps remain sceptical to altruistic live kidney donation also in cases where donors have undergone the necessary psycho-social and medical tests and been accepted for the procedure?

Turning now to the case of live kidney donation to known others, and keeping in mind how rescuers and donors to unknown others down-play the difference between the unknown and known others, it is worth noting that what they downplay is what has become central in much ethics discussions: the specialness of the relation between donor and recipient.

The emphasis on the specialness of the relation between self, family-members and friends is particularly well articulated in Aristotelian work. As one example, Nancy Sherman (1987:595) expresses the view that to have friends and family-members is to "have interwoven in one's life, in an ubiquitous way, persons towards whom and with whom one can most fully and continuously express one's goodness." This is not to say that families are always harmonious; the idea is rather that the special relations that can exist between friends and family-members can make self and other identify and be entangled with each other to such an extent that it becomes pointless to try to discern to what extent an act was motivated by a wish to help the other, for her own sake, and to what extent this also was motivated by a wish for a continued shared existence for the sake of both self and other, at all, or a shared existence where the other suffers less than in the present.

Now, arguably, also individuals who donate body-parts, tissue or blood to known others can do this primarily for the sake of others' well-being, motivated by their perception of these other's needs, even if we acknowledge how self and other can value their shared existence. Indeed, acts for the sake of the other's good may be based on a sense of attachment and belonging-together with these others and express who these donors are and want to be: someone who acts out of care towards others – in this case emotionally close ones. In line with the reasoning earlier, acts for the benefit of others can be necessarily compatible with the kind of self-interest that I have when I act in a way that expresses my sense of identity. Whether these others are known others shouldn't make a difference for this argument.

Consider now parental live kidney donation. Empirical research shows that parents with experience of considering and/or undergoing this donation describe this donation as "natural" for them

and as the "only option" for them. Some put this even stronger and described the decision not to donate as a decision after which you "couldn't live with yourselves" (Zeiler et al. 2010: 231).

Parental live voluntary unpaid kidney donation needs to be understood in the light of parental norms according to which parents should always put their children's interest first may make it difficult for parents to express anything but the naturalness of the act (ibid.). At the same time, parents typically express strong emotional bonds to their child and motivate their acts with love and concern for the child. This is where the parallel to Kapur Badhwar becomes crucial. In cases where donation to known recipients, such as one's child, is motivated primarily by a perception of the other's good and performed for the other's own sake, then donation should qualify as altruistic *even if* this act is experienced as self-evident, natural and even necessary because it expresses and affirms my sense of who I am, someone who cares for close-ones for their sake. From within this reasoning, also some donations to known others can qualify as altruistic.

3 Relevance for public perception studies related to 'Donation'

This reasoning has implications for the design of public perception studies of live voluntary unpaid donations. The concept of altruism needs to be defined in these studies and framed in a way that it does not beforehand position donations to unknown and known others as sharp contrasts in terms of altruism. Questionnaires should preferably be designed so that they distinguish between different motives within the broader framing of "wanting to help family-members and friends." In order better to understand what motivates these bodily exchanges, we need to be able to differentiate between the motive "I donate because I want the other to be there for me, in the future" and "I donate because it promotes the other's well-being and this is how I want to be."

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