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Organ donation as an 'altruistic gift': Incentives and reciprocity in deceased organ donation from a UK Polish migrant perspective

Authors' Contribution:

Study Design A

Data Collection B

Statistical Analysis C Data Interpretation D

Manuscript Preparation E

Literature Search F

Funds Collection G

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Background:

Incentives and reciprocity have been widely debated within the literature as an alternative to altruism to motivate the public to register and consent to organ donation. This pilot study was the first to examine the views of the UK Polish migrant community toward these issues.

Material/Methods:

One-to-one and small group interviews were conducted in English and Polish to collect data. The interviews were recorded and transcribed and interviews in Polish were translated into English. All transcripts were coded, codes were grouped by theme and emergent themes were constantly compared to the new data until

Results:

Participants were motivated to donate altruistically but would accept reciprocity for organs once consent was given. Payment for organs was viewed as unfavourable but participants would accept contribution toward funeral expenses.

Conclusions:

Deceased organ donation was viewed as an 'altruistic gift'. 'Altruism' and 'gift' are problematic in deceased organ donation and could explain the challenges that arise in the incentives and reciprocity debate. Mauss's gift exchange theory could frame incentives as forming the 'obligation to give' and could encourage registration but could lead to coercion. Reciprocity could benefit families and be viewed as 'fair' and a token of gratitude.

Keywords:

attitudes • deceased organ donation • incentives • Polish migrant

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Background

There are ongoing debates worldwide as to how best to procure organs for transplantation. Many countries are grappling with issues of incentives and reciprocity in relation to organ donation. In the UK, demand for transplantable organs far exceeds supply. There are around 7500 patients currently requiring a transplant [1] and of these 1,000 die a year whilst on the waiting list due to lack of organs available [2]. To donate in the UK, it is possible to become a living donor or to donate posthumously by registering on the NHS Organ Donor Register and family supporting the wish through providing consent. Deceased organ donation was the focus for the study, in 2011/12 deceased donors in the UK accounted for half of the total number of organs [1].

Ethnic minorities in the UK currently increase the demand on the transplant waiting list as Black Caribbean, Black African and South Asian communities have higher incidence of Type 2 diabetes and End Stage Renal Failure, however there are low levels of consent [3]. The most recent migrants are from Eastern Europe, particularly Poland since the expansion of the European Union and there are strong signs of settlement in the UK [4]. Little is known about the health needs that this community have in the UK, but it has been reported that alcoholism, substance misuse and hypertension are known health issues [5-7]. In turn, this could lead to an increase on demand for transplantable livers and hearts. Rios et al. [8] conducted a study of East Europeans in South Eastern Spain views toward living donation due to an increase in non-natives requiring a transplant and an increase in non-natives being approached for organ donation requests. Unfortunately, there are no data available in the UK to determine the impact that Polish migrants have had on the transplant waiting list and organ donor requests.

Altruism currently underpins organ donation across UK policy (9-11) and has been argued to motivate donation in the literature [12–15]. Alongside this is the description of the organ as a 'gift' [10]. Mauss's [16] theory of gift exchange has been applied to deceased organ donation to critique donation as a form of 'gift' [17–20]. Mauss found that within gift relationships there is the obligation to give, to receive and to reciprocate but the current use of the term assumes no reciprocation. In the literature this is supported by Ross [21] who argued that based on the four principles of bioethics [22]: autonomy, beneficence; non-maleficence and justice; reciprocity cannot be supported and there is the potential for exploitation [21,23].

In the UK, deceased donation rates are 17.4 per million population [1] demonstrating that relying upon altruism alone

for voluntary registration to opt-in to donation has failed to address the supply problem in transplantation. To address this issue, there have been proposals to introduce reciprocity and incentives to alleviate the harm that altruistically motivated policy is currently doing [21]. Proposals for policy are: financial reward for organs [21,24-30] to legalise the black market that is currently problematic [31]; funeral expenses for families [10,32]; priority for patients on the transplant waiting list who are registered donors [33]; tax breaks [34] and directed donations [32]. To assess how reciprocity and incentives could be applied in reality, it has been suggested that there should be a trial of a regulated system of these theoretically debated ideas [32,35,36]. Omar [37] purported a combination of these proposals to enable the donor family to donate altruistically, accept funeral expenses or donate the money to charity. In practice, some of the debated ideas are policy as paid donation exists in Iran [38], priority on waiting lists is policy in Israel [39], tax incentives are given to living donors in the state of Louisiana, USA [40] and China are currently trialling a system where 'help' is given in the form of social welfare and 'thank you' is a form of gratitude given through the Red Cross Society of China [41].

The present study sits within the context of attitudinal studies in Europe (i.e. [42–44]) but is the first to identify the attitudes of the Polish migrant community in the UK toward the use of incentives and reciprocity in deceased organ donation. This pilot study included an overall examination of gift exchange theory [16], altruism [45], social capital theory [46] and religion in relation to deceased organ donation.

Material and Methods

Participants and recruitment

The study had received ethical approval from the University of Bedfordshire Institute for Health Research Ethics Committee. The study took place in Luton and Dunstable in the UK; Luton is a large town and Dunstable is a smaller neighbouring town to Luton situated close to London. Areas around London have higher densities of Polish migrants according to Worker Registration Scheme data [47] and more recently shown by the Census data 2011 [48]. There was an established Polish migrant community in Dunstable as post-Second World War Poles had set-up a Polish Church, Mother and Toddler group, Saturday Morning School and Polish Stowarzyszeni Polskich Kombatantow (SPK) Club for ex-servicemen, but the club has recently closed. Participants were purposefully sampled and snowballing technique was used to recruit further participants. Interviews lasted approximately one and a half hours to two hours and the interviews with students were conducted at the University of Bedfordshire and non-student participants were interviewed at the participants' homes.

There were 31 participants in total and 10 of these took part in small group interviews and 21 had a one-to-one interview. These interviews were conducted in English and Polish between June and November 2011; 1 group interview and 7 one-to-one interviews were in Polish. The sample could be argued to be small, however according to grounded theory methodology, saturation was reached and data collection ceased.

Polish participants from post-2004 and post-Second World War migration waves took part in the study. The majority of participants that were from the post-2004 sample had been in the UK for up to 8 years and participants that were post-war migrants had been in the UK since 1945. This provided a contrast between different lengths of stay in the UK. In addition, post-war participants mass migrated to the area but overall numbers of migrants from this wave were significantly lower than the post-2004 migration wave [49]. Within the post-2004 group were participants who were students from the University of Bedfordshire, workers in lowskilled occupations such as warehouse workers, workers in semi-skilled occupations such as teachers and administrators, mothers with families with children born in the UK and those who had retired. Participants were generally well-educated having an undergraduate degree or above and young and aged 18-34, this is typical of the post-2004 migrant wave [50]. Participants were recruited through the University of Bedfordshire via a poster campaign, community networks and the Polish Church in Dunstable and its adjoining Mother and Toddler Group.

Data collection tools and data analysis

The interview guide used for the study was semi-structured and had been piloted to test the questions with a focus group. Interviews were recorded and transcribed; interviews that were in Polish were translated into English as closely to verbatim as possible and were triangulated with notes taken in the interview through a 'whispered translator' who repeated the participant's response in English to the lead researcher in each interview. All data was coded using grounded theory techniques, each transcript was coded by incident within the text and codes were grouped by theme to arrive at categories and sub-categories. Throughout the data collection process, categories and sub-categories were being constantly compared to new data to assess the emergence of themes and point of saturation.

Results

There were three key themes that arose when discussing altruism and reciprocity in deceased organ donation with participants: the value of altruism in deceased organ donation; reciprocity in deceased organ donation and reciprocity from a recipient's perspective. The results are presented in the Table 1.

Discussion

It is recognised that the sample size is small but this is the first study to include Polish migrants and will inform future larger studies.

Participants perceived the organ in two forms: a resource to help save a life through an altruistic act and an item in an exchange as repayment and reciprocation were referred to in deceased organ donation. To marry these opposing views of reciprocated and non-reciprocated organ donation, the term 'altruistic gift' is argued to incorporate altruistic intentions but with the Maussian connotations to reciprocate. This is similar to Landry's 'Reciprocity despite anonymity' [51] where the altruistic act of donating is 'reinforced' to 'reward altruists'.

Across the incentives and reciprocity vs. altruism debate, Ravitsky [52] argued that altruism has been favoured as the alternatives could lead to exploitation, motivate families to prematurely withdraw care, encourage families to not disclose information about the patient if it could affect the chances to donate and the body may be treated as a commodity. However Delmonico et al. [32] have argued that exploitation is not possible if there is a regulated screening process as recipients are 'picky' as to whom they are willing to receive organs from. In addition, in the UK, the discussion to become an organ donor occurs after the decision by healthcare professionals that treatment is futile in Donation after Circulatory Death [53] and Donation after Brain Death [54], which means that families could not prematurely withdraw treatment.

Altruism has been problematic in engaging the public and has been argued to be a confusing term as it has been inconsistently used across policy [55] and the medical profession [56]. This may not be surprising due to the numerous ways in which altruism is defined such as being socially constructed in organ donation [13,57] and medical bioethicists arguing altruism as a moral or ethical value in donation [18,58]. Moorlock et al. argued that altruism is shaped by value of the outcome where in this case the potential outcome is the saving of a life but could be unsuccessful [55]

Table 1. Key themes of altruism and reciprocity in deceased organ donation.

Theme	Finding	% of participants (n=31)	Key comment
Value of altruism in deceased organ donation	People want to donate to help someone in need after he or she died to save a person's life.	35% of participants	'[P]eoplewant to help others[they] no longer need them [the organs], and they give it to people who need [them], and it is because the body feels nothing, and there is no pain, and that basically, thanks to this, to their organs, they can help others live.' (Post-2004, Warehouse Worker, Male, 20)
	A reward was not expected for donating an organ.	58% of participants	'[I]f someone helps, but out of the bottom of their heart, then they don't expect anything in return [for donating an organ]' (Post-2004, Housewife, Female, 32)
	A concern with the organ being rejected as the individual was not helped and affected the value of the 'gift' or 'altruistic act'.	6% of participants	'[I]t can be the case that you do a transplant, but the organ doesn't acceptand then that person dies, and that organ dies too, and it could have been helpful for someone else, and now it wasn't of any use to them.' (Post-war migrant, Retired, Male, 86)
Reciprocity in deceased organ donation	Defining what a 'gift' is in the context of deceased organ donation was problematic when comparing it to the term 'gift' in everyday life.	52% of participants	'You could only compare it [a gift in deceased organ donation] to giving an organ when you're alive, like a father gives a kidney to his daughter or something like this, there's not really anything else that I can think.' (Post-2004, Student, Female, 22)
	An organ is an item in an exchange.	3% of participants	'[W]hen someone says that I am ready to, I don't know sell my house, and you give me your kidney (in return)well then, if both parties are to benefit from it and are happy with it, then it's just the matter of an agreement between both parties will be happy and that is why can it not happen on the basis of a certain agreement' (Post-2004, Factory Worker, Female, 28)
	Donor family would not accept payment for organs.	32% of participants	'[I]f I give him kidney, you give me £20,000 it's just, it's just using people, so I think if it was the case, people would give many organs against their will of their relatives because of the money, I think it's possible.' (Post-2004, Student and Waiter, Male, 20)

Table 1 continued. Key themes of altruism and reciprocity in deceased organ donation.

Theme	Finding	% of participants (n=31)	Key comment
	Donor family would accept payment for organs.	6% of participants	'[I]t's not you that's going to get the benefits, it's your family that's going to get some benefits even [receiving money could] kind of push you to make a decision, like, normally I would not worry about giving organs but because my family is going to get £10,000, I may as well' (Post-2004, Student and Administrator, Female, 24)
	Donor family would accept funeral expenses for a relative's organs.	35% of participants	'That [receiving funeral expenses] would actually be a good idea, and it could also be successful, and like people could sign up to the list because they could think that my family could have better options, for example.' (Post-2004, Warehouse Team Leader, Male, 24)
	The recipient would carry the costs of the funeral expenses offered to the donor family.	6% of participants	'I would feel like, oh my God, probably they would spend a lot of money on the treatment and for that person and now I am expecting them to pay me for my husband's heart or something, no, I would be like, no, that would be more like a transaction, like money transaction, I wouldn't feel good, for me, for myself, but if somebody, like a government, paying for my funeral costs and it doesn't cost the family which are going to get my husband's part of the body for example, yeah? Then, yeah.' (Post-2004, Housewife, Female, 29)
Reciprocity from a recipient's perspective	The recipient would accept if the donor family were paid for the organ of their relative to be donated.	3% of participants	'But I would not care if it was for me or my child, I wouldn't care whether someone was given so I can live whether it was that he got paid £100 or if he was so nice person to donate his organ, it would make no difference to me, the more simple done thing is that I am going to live.' (Post-2004, Student, Male, 24)
	Less pressure on the recipient to repay the donor family if they have received something for donating	3% of participants	'[T]he family of that individual, would receive that organ, they would feel more comfortable with the fact, because they know that they got something in return.' (Post-2004, Housewife, Female, 37)
	No anonymity as relationships would exist between the recipient and donor family if reciprocity was policy.	6% of participants	'[W]hat Kind of gift would it be? Eh, it would be a gift in the sense that I would like to befriend this family and/or that I would give them a very, very expensive gift, and I would like to build a relationship, so that they could be my friends or something of that nature.' (Post-2004, Warehouse Worker, Male, 20)

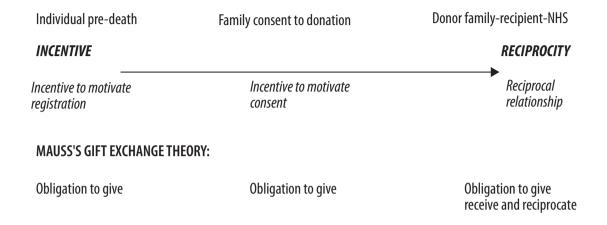


Figure 1. Incentive changing from over time and by party to reciprocity in deceased donation.

and this was highlighted by the participants in the present study as the acceptance of the organ could devalue the 'gift'. It could be argued that if the transplant is not guaranteed to lead to a successful outcome and the likelihood of organ acceptance by the recipient is unknown, perhaps the donor family should be reciprocated due to the emotional difficulty of the decision at a time of grief and loss and a potential feeling of second loss if the organ was rejected, therefore this party may be making the biggest 'sacrifice' [59] in the process.

The terms 'gift' and 'altruism' are unclear in policy and among medical professionals therefore it is no surprise that there is little consensus among the public as to whether organ donation should be reciprocated or not [60,61]. In the present study, defining the 'gift' in the context of deceased organ donation was problematic and was conflated with altruism, also found by Ben-David [59]. Language was used among the participants such as the 'gift of life', which is part of the gift rhetoric of deceased organ donation and may be used without the intention of Maussian connotations of reciprocity but reciprocation was accepted, similar to that of giving gifts in everyday life. Titmuss [13], who studied voluntary and paid blood collection, suggested that there was no pure altruism but did find that nonpaid donation produced better blood but this is contested [63]. Donors who gave blood voluntarily did so for a number of reasons, such as a 'sense of obligation, approval and interest' (p. 306) also evidencing that reliance on altruistic opting-in policy is inefficient and a concept that is too simplistic. However, Titmuss's study has been viewed as problematic in its methodology and its application to a modern day society [63,64].

In a recent review of the literature on public attitudes toward reciprocity and incentives in donation [61] it was found that there is a shift toward reciprocity in donation and that reciprocity and incentives should be demarcated. Here, it is further argued that there is a temporal element that could change the perception of the difference between an incentive and form of reciprocity. Incentives in this context would encourage the public to register pre-death and for families to be motivated to consent to their relative's organs to be donated and reciprocity would be at the point once a family had already consented to donate. Within a Maussian reciprocal relationship, reciprocity would be in 'exchange' for the organ. From this perspective, this raises the question as to what point does the 'reward' turn from an incentive to a form of reciprocity and where the motivations lies to want to accept a reward and whom benefits (Figure 1).

As the findings have illustrated, there was a dichotomy of views toward accepting funeral expenses and payment for a relative's organs. Through the lens of Mauss's gift exchange theory, only those who enter into the 'gift relationship' after consenting to deceased organ donation based on sound and regulated medical processes can benefit from the reciprocal relationship. The current issue of mistrust in

professionals [65–67] and hastening death [68–70] found across a number of attitudinal studies highlights that this is important to overcome if a family were to accept funeral expenses and enter into a reciprocal relationship in organ donation. However, reciprocity has been argued to make up only part of the decision to be a donor and may not motivate organ donation in a recent study that investigated the role of monetary incentives in living kidney donation [71].

One of the participants suggested that the organ is an item in an exchange but those who viewed it as a 'gift' that should be reciprocated could also view the organ as an item in an exchange. The organ has been argued to already be viewed as an item in multiple exchanges between the donor and recipient [72,73]. In addition, the other parties in the exchange are repaid such as the staff and in successful cases the recipient is repaid with an organ. The participants believed that the motivation that was behind the donation would not affect the recipient as their main concern is the transplantable organ for their recovery.

If the state were to reciprocate the family with funeral expense contributions, what impact could this have on the recipient? The participants perceived the recipient to have less pressure to have to repay the family, an issue that Fox and Swazey [20] termed 'the tyranny of the gift' in organ donation. If funeral expense contributions were to be an accepted form of reciprocity in the 'gift relationship' in deceased organ donation further hurdles to overcome would be ascertaining the value of the contribution of the expenses [74] and deciding whether this contribution would

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go immediately to the funeral home. This study was conducted at a time where Nuffield Council on Bioethics had released their findings that funeral expenses could play a role in deceased organ donation. However, among the participants there was a perceived lack of anonymity between donor family and all the recipients in the process as a deceased donor can help up to nine people [2] and the possibility that the recipients may have to contribute personally to the donor family, in turn this could lead to the perception that there is extra burden on the recipient.

Conclusions

This article has demonstrated the Polish migrant perspective toward the use of incentives and reciprocity in deceased organ donation as the organ was viewed as an 'altruistic gift'. This has contributed toward viewing the debate on incentives and reciprocity through a Maussian gift lens. Here, incentives may be used to justify the 'obligation to give' for the individual to register their donation wish. However, providing incentives could lead to coercion and exploitation but reciprocity is where the donor family are reciprocated and can be seen as a token of 'fairness' [61]. The impact of providing incentives or benefits on donation and transplantation would only be known through a trial [35,36].

Conflict of interests statement

The authors have no conflicts of interest.

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