

ORIGINAL ARTICLE

## Incentivizing deceased organ donation: A Swedish priority-setting perspective

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### Abstract

**Aims:** The established deceased organ donation models in many countries, relying chiefly on altruism, have failed to motivate a sufficient number of donors. As a consequence organs that could save lives are routinely missed leading to a growing gap between demand and supply. The aim of this paper is twofold; firstly to develop a proposal for compensated deceased organ donation that could potentially address the organ shortage; secondly to examine the compatibility of the proposal with the ethical values of the Swedish healthcare system. **Methods:** The proposal for compensating deceased donation is grounded in behavioural agency theory and combines extrinsic, intrinsic and signalling incentives in order to increase prosocial behaviour. Furthermore the compatibility of our proposal with the values of the Swedish healthcare system is evaluated in reference to the principles of human dignity, needs and solidarity, and cost effectiveness. **Results:** Extrinsic incentives in the form of a €5,000 compensation towards funeral expenses paid to the estate of the deceased or family is proposed. Intrinsic and signalling incentives are incorporated by allowing all or part of the compensation to be diverted as a donation to a reputable charity. The decision for organ donation must not be against the explicit will of the donor. **Conclusions: We find that our proposal for compensated deceased donation is compatible with the values of the Swedish healthcare system, and therefore merits serious consideration. It is however important to acknowledge issues relating to coercion, commodification and loss of public trust and the ethical challenges that they might pose.**

**Key Words:** *Cost effectiveness, deceased organ donation, ethics, incentives, priority setting*

The impetus for this paper partly arose from an interview with a Swedish organ procurement coordinator during a project exploring priority setting in kidney transplantation (11 May 2009). During the dialogue the coordinator recalled an incident that occurred in her procurement catchment some years back. A sudden spike in the number of calls to her office from individuals volunteering to donate their bodies as cadavers for scientific purposes roused her suspicions and prompted her to investigate their motivation. It became clear rather quickly that there had indeed been motives other than altruism. Callers had been partly motivated by an advert that appeared in a local seniors' newsletter pledging an urn to store the

ashes of all those who donate their bodies for scientific purposes. We began to reflect on the kind of compensation that would be both appropriate and effective, and what challenges this presents to the values of Swedish health care.

### Introduction

Discourse on healthcare priority setting is rooted in the recognition that limits must be set in the face of resource scarcities [1,2]. While financial constraints are the most prominent reasons for priority setting, non-financial factors also lead to limitations in healthcare provisioning as clearly demonstrated by organ scarcities in the field of transplantation.

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(Accepted 26 October 2010)

Organ transplantation has over the past few decades developed into the treatment of choice for end stage organ diseases; unfortunately demand for new organs outstrips supply in nearly all parts of the world [3,4]. Health care must prioritize among potential recipients as a means of rationing the limited supply of organs. The result can be devastating for those who do not receive a transplant as they face the prospect of death. A very unfortunate consequence of the unmet demand has been the proliferation of organ black markets, which callously jeopardize the health of poor organ vendors in the developing world [5,6]. The 2008 Declaration of Istanbul on Organ Trafficking and Transplant Tourism recognized the responsibility of individual countries to reach organ self-sufficiency to address the needs of its citizens, which is also hoped to reduce the demand driving the unregulated commerce in organs [7]. As a consequence of transplantation's efficacy and aging populations there is an emerging trend of accepting older patients as transplant candidates meaning the number of patients waiting for new organs is likely to increase further in the coming years. Thus, finding new ways of addressing the shortage in organs is an important issue for global public health. This paper explores the potential role of a diverse set of incentives to increase the rate of deceased organ donation within the context of Swedish health care. Such a diverse set of incentives would try to capture both self-promoting motives as well as more altruistically based motives in order to increase the supply of organs.

Deceased donation is the cornerstone of organ transplantation, because donors simultaneously provide multiple organ meeting needs within diverse disease categories [3,8]. For many organs, living donation is either not possible (e.g. heart) or decidedly risky for the donor, making deceased donation preferable for bridging the gap in needs. The typical deceased donor is someone who is "brain dead" – breathing on a mechanical ventilator but with irreversible end of all brain activity, after massive trauma to the brain or stroke. Consequently, the situation is decidedly different between deceased donation and living donation as there is no risk to the deceased donor as a result of the donation because the organs are no longer of benefit to him or her. Given these advantages, increasing the availability of deceased donor organs is a goal for public health that merits serious consideration.

Sheehy et al. (2008) indicate that "the greatest opportunity for increasing the rate of donation from the pool of brain-dead potential donors lies in increasing the consent rate" [8]. While seeking ways to increase the rate of deceased organ donation

it is important that such initiatives acknowledge local particularities and ethical considerations. This was underlined in a resolution passed at the Munich Congress on the Ethics of Organ Transplantation in 2002: "Individual countries will need to study alternative, locally relevant models, considered ethical in their societies, which would increase the number of transplants, protect and respect the donor" [9,10]. This is because naturally, "Each country's health care system reflects its own history, culture, political system, and society" [11,12] making it necessary to take a contextual approach to organ donation policies by tailoring them to particular healthcare systems.

In the Swedish context any policy level proposal to increase deceased donation must be in accordance with what is known as the Swedish ethical platform for healthcare priority setting. This platform is comprised of the principles of human dignity, needs and solidarity, and cost-effectiveness. They are legislated as the guiding principles for priority-setting decisions and also represent the core values of Swedish health care [13]. The principles are lexically ordered. The human dignity principle, the highest ranked, is concerned with the equal distribution of value and rights while needs and solidarity stipulates that healthcare resources should be distributed to the areas representing greatest need. Finally, cost-effectiveness calls for a reasonable relationship between cost and effect measured as improvement in health and quality of life.

The aim of this paper is twofold; firstly to develop a proposal for compensated deceased organ donation based on a nuanced incentive scheme that could potentially bridge the gap in transplantation needs. Secondly to examine the compatibility of this proposal with the Swedish priority-setting ethical platform which represents the core values of the Swedish healthcare system and is intended to guide decision making at various levels of the healthcare system. Structurally the paper is divided into four sections; in the first part above we have introduced our contextual approach with the Swedish priority-setting ethical platform. The second section presents a compensation based organ donation model for increasing the number of deceased donor organs, grounded in incentive theory and empirical evidence regarding prosocial behaviour. In the third section we draw together the preceding sections to explore the compatibility of our proposed model with the principles of the Swedish ethical platform. Finally we devote some space to discussing the potential ethical challenges the proposal might present.

### **Incentivizing deceased organ donation**

Using incentives to increase the supply of organs is often associated with a mental imagery of the rich buying organs from the desperately poor. In reality, however, incentives are any factor (financial or non-financial) that motivates individuals to take a particular course of action. In other words, incentives are the expectations that encourage people to behave in a certain way and could hence be tailored in order to achieve organizational success. Financial incentives such as salaries and bonuses are the most obvious types of incentives, but there are also non-financial incentives which in certain settings may be far more powerful tools when trying to influence individual behaviour. When people act against economic self-interest in order to promote wider societal interest, various types of non-financial incentives can usually explain why people choose to behave prosocially.

#### *Incentives and prosocial behaviour*

When trying to explain why individuals engage in activity that cannot be explained by economic self-interest alone (for example, doing volunteer work or becoming an organ donor) two major approaches from behavioural agency theory can be identified. The social preference approach, which focuses on how motives such as altruism, competitiveness, reciprocity and fairness influence prosocial behaviour; the other major approach is the social esteem approach with a focus on self-regarding motives such as pride and shame and their influence on prosocial behaviour. While these two approaches are overlapping to some extent the key distinction which is critical to our discussion is that the social preference approach focuses on the individual's concern for others, while the social esteem approach extends this approach to also include concerns for what others think, as important factors [14].

The incentives for individuals to behave prosocially can, by combining these two major approaches be divided into three sub-categories: extrinsic, intrinsic and signalling motivation [15]. Extrinsic motivation refers to motivation from factors external to the individual. For example, individuals may be motivated by material rewards such as money. These rewards provide satisfaction and pleasure that the behaviour or task itself may not provide. Intrinsic motivation refers to motivation from factors internal to an individual such as the pleasure one derives from the task itself or from the sense of satisfaction in completing or even working on a task. Pure-altruism, meaning a selfless concern for the welfare of others

without regard for reward or the benefits of recognition, could be one such intrinsic motivational factor for behaving prosocially. Finally, signalling motivation refers to motivation from an individual's concern with how he or she is perceived by others i.e. we are more inclined to feel good about ourselves when others hold us in high esteem. These categories of motivations are mutually interdependent, and may interact and possibly crowd-out one another, resulting in less prosocial activity in some instances [16]. Consequently, it is important for policy makers to have a sufficient understanding of how different types of incentives interact in order to increase an individual's willingness to engage in prosocial activities.

Within the economic literature on prosocial behaviour it has been widely established that social esteem plays a key role in explaining this type of behaviour. For example, Glazer and Konrad [17] illustrate that although anonymous donations are widely considered to be most admirable they typically only constitute 1% of the total number of donations given to charity. Another very telling experiment by Lacetera and Macis (2008) showed that people were more prone to donate blood when awarded bronze, silver and gold "medals" according to the frequency of their donation [18]. However, this positive effect remained only when the rankings were published in newspapers. Mellström and Johannesson (2008) tested if a small monetary compensation (50 SEK – €5) for donating blood crowds-out the supply of blood donors [19]. They found a significant decrease in blood donors when people are offered a small monetary compensation. However they also found that there was no crowding-out effect in cases where people were allowed to donate the payment to charity. This violation of basic price theory results from what economists call, a signal-extraction problem. When there is no financial reward, a prosocial act is often interpreted as genuinely altruistic behaviour. As financial rewards become more substantial, the "meaning" of the act changes: it becomes more difficult to know to what extent it is motivated by altruism or by financial motivation (since individuals differ along both dimensions). The signalling value of prosocial behavior thus weakens, offsetting or even reversing the direct effect of higher financial reward. However, when payments are allowed to be explicitly donated to charity this signalling value is restored.

#### *Establishing appropriate incentives: our proposal for compensated deceased organ donation*

The current system for deceased organ donation in Sweden relies heavily on intrinsic motivation in the

form of altruism as a selfless concern for the welfare of others without regard for financial reward, to generate the required donation rates. Given the increasing gap between need and supply it is apparent that intrinsic motivation alone is insufficient as a tool for bridging the gap. It is our belief that extrinsic and signalling incentives could help increase donation rates. We will in this part introduce our proposal for incentive-based deceased organ donation.

A possible option for compensating deceased organ donation is as a onetime payment to all potential donors at the time of registration for organ donation. However such a model is complicated because payments would be made to all registrants without guarantee of the future usability of organs, or assurance that donors will not renege or families of the deceased will not veto the donation. A model that is likely to be more effective is an on-the-spot contribution offered to the estate/family of the deceased. Such a financial contribution could take different forms. One option is to make the usage of such a financial contribution earmarked for a specific purpose; another is to allow the deceased (as detailed in their will) or family to use the money in any manner they wish. However, in order to limit the influence of coercion on the family of the deceased we believe an earmarked contribution is the preferable option. We propose that this earmarked contribution be approximately €5,000 paid by the state, towards funeral expenses.

While financial compensation in such a scenario would be offered in all instances where the donation process is initiated, we believe alternatives should also be presented so as not to alienate groups of donors who due to the decreased signalling value feel less inclined to become donors. In order to offset this potential crowding-out effect, the family should be able to forego the payment if they feel more comfortable doing so. A further option is that the entire or part of the monetary compensation can be directed as a donation to a reputable charitable organization chosen by the family, or the deceased if their will is known in honour of the deceased and the family. This can, for example, be a contribution to a cancer foundation, or an organization that tackles poverty in the developing world. For practical reasons a list of handpicked charities should be provided from which the donor or the family can choose. This will lighten the administrative load. This potential list of charities would have to be vetted by the authorities but should include a variety of charities dealing with popular charitable causes. These charities would have to be evaluated on a number of characteristics such as efficacy, history of charitable work, connections to banned groups (which can be a concern in

conflict areas). Charities which have a broad appeal, inclusive in their mandate, and work across religious, cultural and political lines should be chosen. Certainly a more sophisticated methodology would be developed when implementing such a proposal to ascertain the type of charities which will qualify. We believe this opportunity in which the act of donation takes on a dual charitable role, saving lives of patients, and contributing to a cause dear to the donor or the family will be an attractive proposal, with outstanding social utility. Providing these alternatives will insure that the greatest numbers of preferences are accommodated since as the theoretical approaches suggest, motivation to partake in prosocial behaviours can be driven by a combination of factors. Several field studies have demonstrated that a donation to charity increases if it is associated with a high degree of publicity [20,21]. According to these findings, a publicized donation, acknowledged through a plaque or certificate, to a reputable charity in honour of the deceased and the family could serve to increase the rates of consent to organ donation.

The components and details of the compensation proposal can be summarized as follows:

- €5,000 contribution to the estate or family of the deceased towards funeral expenses.
- Deceased (advanced directive) or family could decline the contribution in full.
- All or part of the €5,000 contribution could be directed as a publicized donation to a reputable charity of the deceased (if the will is known) or family's choice.
- In all circumstances the right to self determination of the deceased must be respected; and the decision of the family cannot be in contradiction to the will of the deceased if it is explicitly stated.

### **Compensation and the Swedish priority-setting ethical platform**

Now that we have presented our proposal for compensation, we return to the aforementioned priority-setting ethical platform to explore the compatibility between our proposal and the values of the Swedish healthcare system.

#### *Human dignity*

The human dignity principle holds the foremost position, outweighing other principles, in the priority-setting ethical platform; it denotes that in health care all individuals should have equal value and equal rights regardless of personal characteristics or role in society [13].

Human dignity is a broad concept, lending itself to diverse applications both in health care and beyond. Nordenfelt (2007) distinguishes between four varieties of human dignity. These are the dignities of merit, moral stature, identity, and finally a universal type of human dignity (*Menschenwürde*) [22]. The dignity of merit is attached to an individual's social rank or position, for example that which is derived from one's occupation. The dignity of moral stature is tied to an individual's moral actions or thoughts. The dignity of identity is tied to our image of ourselves as autonomous persons with a history, future, and relationships with other persons [22]. These first three varieties exist in different degrees and are not evenly distributed among individuals in society, and they are subject to change over time depending on shifts in one's social position or actions; consequently they do not fully reflect the intention of the Swedish ethical platform. It is the final variety of human dignity as presented by Nordenfelt, *Menschenwürde* referring to a common and equal dignity based on human value and rights, which is most closely aligned with the intention of the Swedish priority-setting platform. This is a basic dignity independent of personal characteristics and is the basis for equitable health care. Under this conception of dignity all individuals should have equal opportunity in getting their health needs met, that is, patients should not be discriminated based on non-medical factors such as income, gender, race and so on.

#### *Recipient and donor perspectives*

Universal health care in welfare states such as Sweden aims to meet population health care needs irrespective of a patient's non-medically relevant personal characteristics. For instance a patient in need of bypass surgery should be prioritized independent of occupational status, religious observance, or social and biological relationships, attributes which are tied to the dignities of merit, moral stature, and identity. This does not mean that all patients in the same medical situation will receive identical treatment. Living donor transplantation presents a challenge to the aim of the human dignity principle since health needs can be met insofar as the patient is able to bring forth a donor to overcome the systemic shortage in organs. Many people might intuitively find it permissible that the healthcare system encourages patients to rely on their social capital to locate willing donors. However, this can unfortunately create great strain on the patient who must rely on others or face grave health consequences. Understandably, factors determining access to

living donor transplantation fall outside of matters that health can influence. For example, social capital in the form of family and external social relationships enhance the likelihood of accessing living donors [23]. On a financial level those with superior financial capital may circumvent the entire system by travelling to the developing world for transplantation [6]. The current transplantation system can only strictly meet the human dignity principle in the distribution of cadaveric organs, which it can exercise discretion over, through equal access and prioritization on waiting lists irrespective of one's non-medically relevant characteristics. A successful incentive-based organ donation model which results in an increase of deceased donor organs is more able to effectively meet the goal of the human dignity principle, since it will level out differences in access to organs between patients with low social capital and patients with high social capital.

A concern which surfaces in compensated donation is that donors may disproportionately come from lower socioeconomic strata, coerced by the financial incentives, which would mean that personal characteristics – in this case material wealth or the lack thereof – plays a role in the likelihood that one becomes a donor, which would be contrary to the human dignity principle. With regard to our incentive-based proposal it needs to be acknowledged that the concern about coercion does not hold the same implications for deceased donation as it does for living donation owing to the presence of risk associated with the medical procedure for living donors [24]. Furthermore, there are no obvious reasons to believe that the influence of coercion should be any weaker in systems relying on altruism to motivate deceased donation. In such a system social recognition and social esteem (as opposed to money) is more likely to be the potential coercive factors. The amount we propose is not large enough in our opinion that it risks becoming a strongly coercive factor to donors or families to donate against their best judgment.

Some might also raise the objection that the commodification of the human body is incompatible with the idea of human dignity. This would have been a fair objection if we were proposing a free market for organs where individuals are allowed to offer lucrative bids for organs. However we propose that compensation should be equal for all donors regardless of characteristics such as age, race, sex and so on. There will be no bidding for organs, which would clearly violate the human dignity principle and would increase the potential for coercion and commodification. In this proposal all individuals are given equal value, the amount is paid by the state, and all

organs are allocated by the healthcare system according to relevant medically established criteria.

#### *Needs and solidarity*

*Needs.* The needs component of this principle signifies that healthcare resources should be committed to the people or activities representing the greatest need [13].

End stage organ diseases without treatment invariably lead to death, making the need and urgency for care arising from these conditions universally accepted. It is for this reason that end stage organ diseases are found in the highest priority grouping amongst various conditions in Sweden's official priority ranking. It is also well established that transplantation more effectively meets patient needs by providing both better long term survival, and quality of life [25,26]. The degree to which this need can be addressed is, however, constrained by the availability of organs required for transplantation. From a needs perspective, it is self evident that a model which contributes to alleviating the current shortage in organs for transplantation would better meet patient needs.

Although our proposal incorporates the possibility of financial compensation, this does not mean that organs will either be obtained or allocated based on the ability to pay. On the contrary organs will be provided on the basis of relevant medical criteria ensuring adherence to the needs principle in the provision of care.

*Solidarity.* The solidarity component of the need and solidarity principle prescribes equal opportunities for health care, and argues that inequalities in the condition of living a good life should be equalized to the greatest extent possible; it also suggests that those who are more fortunate should demonstrate solidarity by allowing the prioritization of the needs of the less fortunate in the context of health [13].

Healthcare funds, generated through taxation, in welfare states are viewed as shared societal resources. These healthcare funds are utilized to finance other resources such as equipment, infrastructure, and medical personnel which are then also regarded as shared societal resources. According to the solidarity principle these shared resources would be directed at first to the neediest.

To apply this principle to organ donation, deceased donor organs, once available, may also be considered a shared societal resource and distributed to those most urgently in need. Offering payment or incentives for such posthumously donated organs does not defy the principle of solidarity for the following reasons. Firstly, incentives can increase the amount

of shared resources (a necessary element for practising solidarity). Secondly, it increases our ability to distribute these resources according to needs, thus meeting the principle of solidarity. And finally, it provides distinct advantages to relying on living donors. This is because living donors almost always donate an organ to a particular individual (e.g. to whom they have an emotional attachment) rather than donating to a pool of shared resources without a specific recipient in mind, and thus (almost without exception) exercise non-solidarity based preferences in the allocation of their organs.

#### *Cost effectiveness*

Cost effectiveness is the final principle in the priority-setting platform, and denotes that when choosing between different medical interventions there should be a reasonable relationship between costs and effects measured as improvements in health and quality of life. The principle is applied when comparing treatments within the same disease category; for example the comparative cost effectiveness of dialysis vs. transplantation in the treatment of end stage renal disease [13].

Economic analysis plays an increasingly important role in contemporary healthcare decision making [27]. With the growing range of new health technologies, decision makers use this tool to calculate the return on investment for various procedures as measured both by direct financial costs as well as gains in survival, and quality of life for patients. We will rely here on figures presented in the international literature to illustrate the reasonable relationship between costs and effects of our proposed incentives model.

Mendeloff et al. (2004) have specifically investigated the amount healthcare systems can cost effectively invest for the addition of each donor to the donor pool [28]. After a review of the costs and effects associated with various forms of organ transplantation the authors conclude that an investment of roughly \$1.3 million for each additional deceased donor would be considered cost effective. The exact value can change depending on the assigned value per quality-adjusted life year (QALY); the authors assign a value of \$100,000 per QALY, which is a widely accepted and used value per QALY. Whiting et al., (2004) have investigated the cost effectiveness of an initiative called Donor Action [29]. The authors conclude that in the Canadian context an investment of up to \$1 million can be considered cost effective so long as it generates as little as three additional donors. Matas and Schnitzler (2004) calculate that each living kidney donor saves the US medical system

approximately \$100,000 [30]. However the cost saving arising from finding new deceased donors is likely to be even bigger. If one takes into account the multiple organs which are retrieved from a single deceased donor the potential savings multiply across a number of recipients. In addition, the costs of donation are also likely to be much lower for diseased organ donations because there will be less cost associated with medical treatment of the donor. Consequently, from a pure cost perspective compensation will prove cost-saving. Furthermore recipients of the transplants will contribute to the cost effectiveness through gains in survival, and gains in the quality of life during those years of additional survival.

The literature uniformly indicates that efforts to increase organ donation are highly desirable even at a high cost per additional donor. The figures above are much higher than the €5,000 we have suggested as a contribution to the funeral expenses or as a donation on behalf of the deceased person and his or her family. The introduction of small incentives to increase deceased organ donation with its large potential for cost effectiveness makes it attractive according to the cost effectiveness principle. Contrary to most health interventions on a purely financial basis introducing compensation for deceased organ donation would be both cost saving and life saving.

### **Final discussion and conclusion**

Although it is greatly admirable to donate organs based on a pure will to help others in need, it cannot be denied that the current system, which relies solely on altruism to motivate donation has failed to bridge the gap between demand and supply for organs. As a consequence organs that could save lives are routinely missed. And despite various efforts to increase rates of organ donation the gap persists; it is obvious that a new approach is required. This paper has discussed compensated deceased organ donation as one such approach. Based on this discussion we conclude that our proposal to introduce compensated deceased organ donation is compatible with the values of the Swedish healthcare system, and that it therefore merits serious consideration. While coming to this conclusion, it is however important to acknowledge the moral challenges that introducing compensation for deceased organ donation might bring. Three of these challenges that we wish to re-emphasize are the risk that families will be coerced by the compensation, concerns related to

commodification of the body, and the potential loss of trust in the healthcare system.

Introducing compensated deceased organ donation may be deemed impermissible if the incentives which it creates are so forceful that it makes individuals or their families donate against their true wishes. It cannot be ruled out that some people may feel coerced by the compensation. However we believe this effect associated with our proposal will be limited. We see no obvious reason why our proposal should be more coercive than the current system, where individuals might feel coerced through factors related to social recognition. Furthermore the proposal is varied to attract individuals motivated by various incentives. The concern about coercion is, however, an issue which requires careful consideration and monitoring.

Secondly, concerns regarding commodification also deserve some attention with regard to our proposal. It is important to stress that our proposal does not support a free market for organs. We believe that it should strictly remain a buyer's market in the sense that the buyer should be the state with a fixed programme for how donors should be compensated. This will avoid price mechanisms making organs from younger individuals more lucrative to donate, for example, which would indeed lead to undesirable commodification of the body.

Thirdly, potential loss of trust in the healthcare system merits recognition. Without the support and maintained trust of the public in the healthcare system such a proposal cannot be successful. As a result it is of utmost importance that any initiative to introduce compensation is accompanied by an open and transparent public discussion. It must be made clear that this proposal is part of the universal healthcare system for all citizens and will not benefit only a subset of society.

The issue of compensated donation is without any doubt a difficult one. However the issue is unlikely to go away given the growing need for organs. As illustrated, there are features related to compensation and deceased organ donation that can be viewed as ethically objectionable, where the risk of coercion is probably the most significant in our view. The fundamental question that we need to ask ourselves is: are these objections so strong that it should hinder society from introducing compensation in order to increase the pool of organs (something which undeniably will save lives)? In the case of our incentive-based proposal we do not view these objections as strong enough for allowing people to die. Consequently we suggest that the potential benefits of introducing a regulated system of compensated deceased organ donation outweigh

potential disadvantages in the context of Swedish health care.

### Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### Acknowledgements

We are grateful to Zeynep Gürtin-Broadbent, Alena Buyx and three anonymous reviewers for helpful comments and suggestions on earlier drafts of this paper. GT would also like to send a special thank you to the Brocher Foundation which supplied him with excellent research facilities and a stimulating environment while working on this paper.

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