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Viewpoint Commentary

A Good Death – Can the Concept Be Applied to Anatomy?

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ABSTRACT

The importance of patient-centered decisions is embedded throughout clinical practice. The principle that the patient is at the center of all decisions has helped form the contemporary approach to death and dying. The concept of a 'good death' will naturally mean different things to different individuals, but is based on the foundation of being pain free, comfortable and able to make informed decisions. Potential donors are faced with many personal, ethical and often spiritual considerations when they come to think about their wishes after death. One consideration is that of a 'good death'. This article explores how the concept of a 'good death' may be applied to anatomy. Where first person consent is in place, the motivating factors frequently include the wish for others to learn from the donation, and this notion may form part of the 'good death' for the donor. Such motivations may impact positively on how students feel about dissecting and may provide comfort, assuaging feelings of discomfort and allowing students to focus on anatomical learning. For donors where second person consent is in place, the concept of a 'good death' must depend on whether the individual wanted to donate their body in the first instance. The notion of a 'bad death' may also be considered with body donation where no consent for donation is in place. This article proposes that there is ultimately a place for the concept that a 'good death' may involve an individual donating their body to medical education.

Keywords: gross anatomy education, medical education, body donation, good death, memorial service, dissection, altruism, consent.

INTRODUCTION

There is rich discussion surrounding the concept of a 'good death' amongst philosophers, sociologists, and palliative care specialists; yet no clear definition exists (Meier et al., 2016; Krikorian et al., 2020). For the purpose of this viewpoint, a 'good death' can be thought of as an end to a life which is as pain-free, dignified, and supported as possible whereby the patient's wishes are of paramount concern. Individuals who donate their body for anatomical examination frequently cite that they want their physical body to be of use after death. Most traditional definitions of a 'good death' are concordant with that of Field and Cassel, and states that death should be "free from avoidable distress and suffering for patient, family, and caregivers, in general accord with the patient's and family's wishes, and reasonably consistent with clinical, cultural and ethical standards" (Field and Cassel, 1997). The 'Principles of a good death', provided by the British Medical Journal (Smith, 2000), also outline the importance of knowing that death is coming, and "to understand what can be expected". However, both of these definitions stop at the point of death. Other than spiritual or religious beliefs around burial etc. definitions seem to disregard what happens beyond the point at which the patient's brain function ceases. This article will explore if there is, or can be, a relationship between a 'good death' and the decision to donate one's own body to medical education.

Viewpoint Questions: (1) Can the concept of a 'good death' be applied to body donation? and (2) If some students find the emotional experience of dissection challenging, could it be proposed that the process of first-person donation has contributed towards a 'good death' and hence students can take comfort from this?

WHAT IS A 'GOOD DEATH'?

The World Health Organization states that death is defined as “Death occurs when there is permanent loss of capacity for consciousness and loss of all brainstem functions. This may result from permanent cessation of circulation and/or after catastrophic brain injury” (WHO, 2012), yet does not define what a ‘good death’ may involve.

The term ‘good death’ was originally used as a synonym for euthanasia (Slater, 1987; Kehl, 2006), before later emerging in the 1960s as a key concept in palliative care (Krikorian et al., 2020). However, it is worth noting that the concept has a far more extensive past. Through accounts of death and dying in the Middle Ages, Ariés proposed that the dying no longer had control over their dying and death (Ariés, 1981). This was due to the modern death being characterized by taking place privately, not to evoke strong emotions; a death that can be tolerated by survivors (Hart et al., 1998). The definition of a ‘good death’ has evolved over time. It was initially believed that the standard of one's death was based upon the beliefs and attitudes of those who survived and how they remembered you. This is concordant with Ariés’ description of the ‘natural order’, where the dying person managed their last few days with: blessings, pardons, and farewells as a public event (Ariés, 1981). In the latter part of the 20th Century, the ‘death trajectory’ was proposed by Glaser and Stauss (1996). They described a ‘good death’ as one where all concerned had time for interaction during the dying process. This has helped form the contemporary approach to death and dying, which places the patient at the center of all care and decision-making processes, empowering them to take back ownership

and control of their own death where possible. A patient who dies a good death will have done so pain-free, comfortable and involved in the decision-making process (Miyashita et al., 2008). A systematic review of the notion of a 'good death' was performed by Krikorian et al., (2020) and identified the core elements of a 'good death' including: control of pain and symptoms, clear decision making, feeling of closure, being seen and perceived as a person, preparation for death, and being able to give something to others (Krikorian et al., 2020).

CLINICAL CARE

In 2010, the General Medical Council (GMC) in the United Kingdom (UK) published guidelines entitled 'Treatment and Care towards the end of life: good practice in decision making' (GMC, 2010). This key document guides doctors in the UK on the provision of high-quality care to support patients to live as well as possible until they die. The guidance emphasizes the importance of maximizing support to patients to enable them to make important decisions about where they want to be cared for (Preferred Place of Care), where they want to die (Preferred Place of Death), and to express individualized care and treatment wishes and preferences that are important to them. The desire to decline clinically assisted hydration and nutrition as part of a 'good death' has been described in different countries including Uganda, Japan, Mexico and the United States (Kikule, 2003; Bullock et al., 2005; Hattori and Ishida, 2012; Ko et al., 2013). There may be religious and spiritual preferences that affect what an individual considers a 'good death', it has been reported that for African-Americans and Mexican-Americans, spiritual support is as important as symptom management (Bullock et al.,

2005; Ko et al., 2013). For some, the decision to be an organ donor may also be part of a good death.

Given the importance attributed to patient centered decisions made during life, the same level of importance should be respectfully bestowed after death. Patients' and families' perceptions of a good death include the care that is given after death (Pattison, 2008), and respecting a patient's wishes is fundamental to the provision of holistic care after a patient has died (Sandman, 2005).

BODY DONATION

Patients who request to donate their bodies to medical science after death often do so for reasons of altruism (Richardson and Hurwitz, 1995; Mc Clea and Stringer, 2010; Cornwall et al., 2012; Cornwall, 2014; Champney, 2018; Gürses et al., 2018; Champney et al., 2019; Smith and Farsides, 2020), to provide a valuable contribution after death, and to further learning in the interest of progressing knowledge about their underlying disease (Carmack and DeGroot, 2018). In some cases, the religious and spiritual beliefs held by patients and their families forbid the donation of organs and bodies (Riederer, 2016). It is important to remember that donors have not only consented to donate their bodies, but may have also agreed to have their names and medical history shared with students in many cases (Champney, 2018). This enables students to learn about the person to whom the body belonged, and allow their memory to live on after death.

Studies consistently show that those who bequest their bodies to science cite a wide range of reasons for their choice (Fennell and Jones, 1992; Richardson and Hurwitz, 1995; Bolt et al., 2010; McClea and Stringer, 2010; Cornwall et al., 2012; Delaney and White, 2015; Olejaz and Hoeyer, 2016). Donors' motivation for donating their body for use in anatomical examination can be categorized in several ways, including factors related to benevolence, personal benefits and expression of gratitude. In studies, donors were asked to pick their primary motivator (Richardson and Hurwitz, 1995; Bolt et al., 2010). However, it must be acknowledged that a donors' choice to donate their body rarely stems from a single, definitive reason. In fact, the decision is thought to be part of the larger narrative of the donor's life, arising from their personal experiences, personality and beliefs (Olejaz and Hoeyer, 2016).

ALTRUISM

Altruistic behavior stems from selfless concern for others' wellbeing. Many prominent studies consider this to be the primary motivator of body donors (Richardson and Hurwitz, 1995; Bolt et al., 2010). This notion can be extremely comforting for students who work on the donor's body. Globally, first-person consent is not always in place (Habicht et al., 2018). For a medical student it is currently unknown if the type of consent/or lack of makes a difference to how students approach dissection. Going into dissection with the knowledge that the donor on the table undoubtedly wanted students to benefit and to learn from their final gift can dispel feelings of guilt or discomfort that some may experience. However, it must be noted that attributing donation to altruism suggests that only the recipients (in this case, those using the body for educational purposes) benefit from the act. Patients with long term illness who have

been hospitalized in the year prior to death cited “being able to help others” as part of a ‘good death’ (Steinhauser et al., 2000). In a study examining the role of altruism in blood donation, Steele and colleagues found that donors commonly cited prosocial reasons as their key motivators for donation (Steele et al., 2008). However, the study concluded that levels of prosocial characteristics (as self-identified by blood donors) were not the most significant factor in determining donation frequency. This suggests that factors other than altruism are major contributors to the decision to donate. Moreover, Steele and colleagues concluded that altruistic and prosocial motivators are considered more ‘ethically sound’, potentially making donors more likely to put these forwards as the primary instigator for their choice (Steele et al., 2008).

Considering these factors, a benevolence hypothesis could instead be proposed. Based on the idea that both the donor and recipient benefit from the donation- an idea that is more concordant with key anthropological and sociological theories. ‘Egoistic’ and ‘egocentric’ perspectives in particular suggest that gifts are motivated, to a certain extent, by self-interest (Khalil, 2001). An example of this view in the context of whole- body donation relates to personal reputation and emotional reward. It enables individuals to engage in ‘identity work’ (Olejaz and Hoeyer, 2016), whereby they can control the narrative of their life and others’ perception of them. There may be an interlinking nature of key motivators, where even seemingly altruistic acts may have more self-serving components. Several more specific reasons are also included in the category of benevolence. The study conducted by Bolt and colleagues is particularly useful in highlighting this; 69.2% of the study’s 946 participants cited benevolent

reasons as their main motivators (Bolt et al., 2010). These reasons included the desire to advance medical education (22.8%), to contribute to medical science (16.9%) and to be useful (14.5%). Expression of gratitude towards the medical profession was also found by Cornwall et al., (2012). The expression of gratitude is an altruistic motive, in that it has been shaped by a donor's personal experiences in life. Body donors typically register their interest late in life, usually between the ages of 60 and 70 (McClea and Stringer, 2010; Smith, 2018). As a result, they are likely to have come across multiple health professionals and benefitted from the medical care they have received. This has been frequently noted in qualitative studies, where some donors explained that their decision stemmed from wanting to show appreciation for the help they received as patients (Cornwall et al., 2012; Olejaz and Hoeyer, 2016).

PERSONAL BENEFIT

Altruism may be at the heart of most donors' decisions; however, a significant minority of study participants were motivated by factors related to personal benefit. The notion of personal benefit also may fit with components of a 'good death' by knowing certain wishes were in place. Preparation for death was identified as a sub theme seen in 94% of 36 articles reviewed on what makes a 'good death' (Meier et al., 2016). For donors, body donation is part of this preparation. This might be based on a dislike of traditional methods of body disposal or to avoid the expenses associated with burial or cremation (Bolt et al., 2010; Gürses et al., 2018). Donors can circumvent these costs through body donation, as the recipient medical schools covers the costs associated with the transport and cremation of cadavers. Interestingly, just 2% of donors reported that being paid for their bodies would have increased their likelihood of

registering to donate (Richardson and Hurwitz, 1995). Perhaps this is related to identity-building, whereby donors use body donation as a final act to influence others' perceptions of them (Olejaz and Hoeyer, 2016). If a financial incentive is provided, the altruistic component of their behavior is removed and the act no longer enables them to construe a better sense of self, both in the eyes of themselves and others. Financial issues have been reported to play a role in a 'good death', with concern of the patient and family focusing on paying for medical treatment. This has been reported in India, where great importance is placed upon financial arrangements at the end of life (Chacko et al., 2014). Interestingly, at present India predominantly uses unclaimed bodies for anatomical teaching (Habicht et al., 2018) and it is not understood how body donation may interact with the need to have financial arrangements prepared for death. The morality of providing payment for body donation must also be considered by schools. It is illegal in the United Kingdom, and it is unclear how students who work on such donors would feel.

One suggestion is that the 'good death' rests within the social life of the individual and involves five features: awareness of dying, adjustments to and preparation for death, relinquishing of roles, responsibilities and duties, and the making of farewells (Kellehear, 1990). When applied to body donation, the decision to donate falls into the preparations for death phase. Actively making a decision and putting that decision into place may leave a feeling of completeness. It may be the wish of an individual to donate, but this can often be challenging for family members. In the United Kingdom, donated bodies are held for up to three years unless consent for indefinite retention has been provided (HTA, 2004); this has obvious implications for the

funerals of these individuals (Smith, 2018). Hence even with the best intentions, the family may not feel completely comfortable with the decision. The 'making of farewells' is something that possible donors may also have considered, especially if they know commemorative services take place for donor's relatives.

However, not all body donations around the globe are from first person or self-consenting donors (Habicht et al., 2018). In countries where second person donation exists, the concept of donation being part of a good death may still apply. This may be the case when a family donates the body of an individual who they know would have wanted to be used in this way. However, when bodies are the property of the state and are 'unclaimed' or are donated for other reasons e.g. financial, then the concept of a good death and body donation cannot be linked.

STUDENT PERSPECTIVE

Dissection plays a critical role in a students' personal and professional development (Coulehan et al., 1995) and is often one of only two times when students are faced with a dead body- the other time being at autopsy (Marks et al., 1997). It has also been suggested that working with cadaveric donors is a way to learn professional detachment (Marks et al., 1997), at the same time as upholding their own values and morality. The General Medical Council (GMC), the regulatory body of doctors in the United Kingdom, lists compassion and empathy as key outcomes for graduates, but the importance of a professional distance cannot be overstated (GMC, 2016).

Studies have examined students' perceptions and experiences of dissection, reporting that the majority of students find the prospect of their first dissection session exciting, with a small number experiencing physical symptoms and stress (Horne et al., 1990; Evans and Fitzgibbon, 1992; Tschernig et al., 2000; McGarvey et al., 2001; Quince et al., 2001). The degree of stress experienced by some students has been suggested to be high (Marks and Bertman, 1980; Penney, 1985; Wear, 1989; Druce and Johnson, 1992) and even has been described as post-traumatic stress (Finkelstein and Mathers, 1990). From a student's perspective, the possible undertone of self-interest in a donor's decision can be equally comforting for those who work with the donors' bodies and learn from them. The reality is that these donors will never meet the students who learn so much from them, and will never get to find out the true impact their donation had upon them. Although some schools do introduce students to donors families (Talarico, 2013). Ultimately, this means that their decision is made with the promise of benefiting anonymous strangers. The addition of an element of benevolence allows for both donors and students to feel valued, and to mutually benefit from the experience of donation. This furthers the notion that many donors have lived their lives with altruistic mindsets; making the idea of body donation following death rather fitting. A 'good death' for such individuals is likely to be one that echoes their wishes in life. A final gift that will undoubtedly change the lives of many others. For many students, their donor is their first patient and may be their first experience of death. Students are taught from the very beginning to treat their donor with respect; emphasis is placed upon maintaining the donors' dignity and seeing them first as a human being and then secondly as a means of learning and development. These are the kinds

of lessons that simply cannot be taught in a fifty-minute lecture, or inferred from a textbook. It's not about a 'royal road' or 'rite of passage' as described by Newell (1995), but rather a form of learning that imparts so much more than factual knowledge.

For some, dissection is a distressing concept at first (Marks and Bertman, 1980; Penney, 1985; Wear, 1989; Finkelstein and Mathers, 1990, Druce and Johnson, 1992). There is often a lot of uncertainty and nervous energy on the first day of dissection class; it is a unique experience, and must be handled with sensitivity. Initially, some students battle with feelings of guilt or uncertainty, and coming to terms with the physical process of dissecting a human body is an initial obstacle for many students. Emotionally, it can be helpful to remember that donors (in the United Kingdom) made a conscious, informed decision to donate and that regardless of their motivations- they wanted this to happen. For them, this formed part of their 'good death'. This can help alleviate some of the difficult feelings students may experience and allow them to focus on the learning outcomes and ultimately to honor their donors' 'final gift' by learning as much as possible from every session.

Anecdotally, the feeling of immense gratitude towards those who donate their body to medical education is common amongst medical students. Students echo the sentiment that the opportunity to dissect cadaveric donors is fundamental to future practice. However, the experience alters their own attitude towards donation, with a reduction in the number of students who would donate their own body (Cahill and Ettarh, 2008). Interestingly, opposition to a family member donating also increased significantly following exposure, whereas the

attitudes towards a stranger donating did not change. A cynic could regard this as hypocrisy- medical students are clearly happy to accept donations, but some are unwilling to consider the possibility of themselves donating. It could be argued that this reluctance is directly related to the role students must take on as dissectors. In order to be able to carry out the task, it is imperative that a degree of professional separation is established. Very few would be able to dissect if plagued with thoughts of their own loved ones in the same position as the donor.

GIVING THANKS

One of the main things that medical students struggle with is not knowing how to or when to say thank you. Those who donate their bodies cannot possibly have expected to receive personal gratitude from students, but that doesn't lessen the desire that many students have to show their appreciation. A large amount of the undergraduate medical curriculum is focused on the fine details, the core syllabus (Smith et al., 2016), the molecular patterns, the mechanisms of action, the intricacies. Cadaveric dissection gives students the opportunity to link these concepts, and to appreciate the relevance of all these small lessons. Donors remind students to be human and teach them how to be doctors. Surely it is only right that they are given an opportunity to say thank you? One way that students can give thanks is through memorial services. The 'making of farewells' or 'saying goodbye' has been reported to be part of Life Completion (Meier et al., 2016) although in the case of body donation the 'farewell' is perhaps more an opportunity for family and friends than it is for the donor themselves.

An example of such a service is held by the London Anatomy Office (LAO) on an annual basis. The LAO coordinates donation across seven medical schools in London and the South East of England (HTA, 2017). The service each year recognizes the ~500 donors who have been bequeathed to its medical schools (Smith, 2018). The service provides a chance for the families and friends of donors to remember their loved one. It provides a platform for medical students to reflect upon their experiences, and to express gratitude for their donor's gift. During the 2018 LAO service, speakers and ushers for the service were provided by Brighton and Sussex Medical School (BSMS). Readings were given by members of the academic faculty before a student addressed the audience with a piece of spoken word poetry entitled '*Confessions of a Second Year*' (see Appendix A). Other services of thanksgiving occur at many universities and it is part of a suggested good practice guide (Riederer and Bueno-Lopez, 2014), there is a wide range of activities that represent giving thanks including: writing letters, singing, ceremony, memorial places and monuments. For families, the chance to reflect on their loved one's decision to donate and hearing the impact that donation made may also provide some solace and reassurance.

BAD DEATH

If there is a concept of a 'good death' then there must also be a concept of 'not so good a death' or a 'bad death'. A 'bad death' can be characterized by a lack of acceptance of death, or a failure to pursue fulfilment of living (Hart et al., 1998) If a body is taken for body donation when no intent to donate was made, does this make it a 'bad death'? In countries where the bodies of the unclaimed or of prisoners can be used, this raises ethical questions about the

practice (Habicht et al., 2018). It is not known how students feel about working on individuals who had a 'bad death' - i.e. bodies donated by the state.

EUTHANASIA

The moral status of euthanasia or physician-assisted death (PAD) remains unclear and strong responses can be identified on both sides of the debate (Kuře, 2011). The concept of a 'good death' is enshrined within the term euthanasia, which literally translates as 'dying well' (Walters, 2004), and has been at the forefront of the right-to-die movement. The term euthanasia evokes strong responses, on the one hand there is argument for respecting a person's autonomy, and their right to decide what happens to their own bodies, whilst on the other side of the argument is the protection of the right to live (Kuře, 2011). The very idea of euthanasia involves returning control of one's life and death back to the individual, allowing them to decide what is unbearable suffering (Walters, 2004). Whether or not such an end could contribute toward a 'good death' seems to be a monumental question far beyond the reach of this article.

However, it is interesting to consider the implications of euthanasia upon body donation. At present euthanasia remains illegal in the United Kingdom (UK), and as a result it is difficult to answer questions about the use of euthanized bodies in the teaching of clinical anatomy.

However, euthanasia has been legal in other countries for some time (Wainmann and Cornwall, 2019) and there are strict criteria which have to be met for a request for euthanasia to be considered. These include (but are not limited to) a voluntary and persistent request for

euthanasia being made by a patient who is experiencing unbearable and enduring suffering (Parry and Munson, 2013). Knowing that such criteria exist, and the extent to which someone has to be suffering for such a request to be considered, it is arguably possible to reconcile the notion that taking control over one's own death represents a 'good death'. At one university in Canada, body donation is received from those who had received medical assistance to end their lives. Students and faculty are informed of the manner in which individual donors died as a matter of routine, including those who received euthanasia. Jones, (2019) explains that openness about the origin of bodies is essential. Formal research evaluating student attitudes towards the procurement of euthanized bodies is yet to be undertaken, but students nor staff at the university in Canada have expressed any concerns about the acceptance of such bodies (Wainmann and Cornwall, 2019). It has been postulated that donors who have undergone PAD may be more 'attractive' to obtain as donors as they may offer 'high quality' anatomy (Jones, 2019).

CONCLUSION

Just as the definition of a 'good death' has evolved, the way that students learn anatomy has also progressed, yet one part remains tried and tested- the use of human cadavers. The first documented medical dissections date back to the Renaissance period where, for the first time, dissection was used as a means to understand the human body (Bouchet, 1996). The process of dissection today has evolved to form a significant part of the learning experience of medical students, junior doctors and other healthcare professionals internationally (Heylings, 2002; McLachlan et al., 2004; Drake et al., 2009). This article asked: "Can the concept of a 'good

death' be applied to body donation?" A 'good death' does not necessarily have to involve medical students or in fact doctors, if the individual doesn't want it to. The present literature on body donation and the components comprising a 'good death' suggest that it can indeed be applied to body donation, but only in the cases where the individual wanted to donate their body and consent was in place to do so. The second question asked: "If some students find the emotional experience of dissection challenging, could it be proposed that the process of first-person donation has contributed towards a 'good death' and hence students can take comfort from this?" It can be concluded that anyone whose 'good death' involved donating their body to medical education did not do so in vain. Their final gift has impacted on the education and training of students and it will undoubtedly continue to do so throughout their careers. The notion of a 'good death' when it involves body donation, is perhaps a helpful focus for donors' families, friends and students. The benevolent component of donation means that the donation benefits all.

In summary, body donation and a 'good death' are interlinked by the following themes

- Preparation for death- body donation may assist in the planning of death.
- Life completion- body donation may assist in the acceptance of death and emotional wellbeing.
- Saying farewell- commemorative services may offer family and friends the chance to say goodbye.
- Financial issues- body donation may alleviate funeral costs, an important consideration for some.

- Religion and Spirituality- body donation may be in line with practices and concepts of life and death.
- Euthanasia- body donation may be part of physician-assisted suicide.

From a thanatological perspective donating one's body for others to use as part of education and/or research may be part of their 'good death'.

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APPENDIX A

Confessions of a Second Year

I did not want to meet you,
I feared the day our paths would cross.

Not because of blood, or nausea- But because I knew what it meant.
Your heart had ceased. Your soul departed.

Departed!?

Where had you gone? What had you seen? How did it feel?
And, more importantly- who had you left behind?

These were all the questions I had, the very first time we met. Although, even if I could have asked you- I wouldn't have Because you were a stranger-
And that would be rude!

So, for the next few weeks I tried to stick to small talk.

Focus on the science.
Cling to the dissection notes.

I marveled at the complexity of your body
Traced the networks of arteries and veins and capillaries and nerves and nodes and fibres
and....

And..

Then it hit me!

I knew more about your insides than I did my own.
And yet- I didn't know what made you tic.
I didn't know what made you happy, or sad, or angry, or mad.

I didn't know the last time you cried,
Or the last movie you watched.
I didn't know the people you loved, Or the lives you'd changed.

But... I knew my life was different.

This was more than science, or anatomy, or academia.
This was about life.

And death. And giving.
And selflessness.

You believed in something greater. And for that - I truly thank you

P.S.

I no longer fear meeting you. In fact... I kind of look forward to it!

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