

VALUING STILLBIRTHS

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ABSTRACT

Estimates of the burden of disease assess the mortality and morbidity that affect a population by producing summary measures of health such as quality-adjusted life years (QALYs) and disability-adjusted life years (DALYs). These measures typically do not include stillbirths (fetal deaths occurring during the later stages of pregnancy or during labor) among the negative health outcomes they count. Priority-setting decisions that rely on these measures are therefore likely to place little value on preventing the more than three million stillbirths that occur annually worldwide. In contrast, neonatal deaths, which occur in comparable numbers, have a substantial impact on burden of disease estimates and are commonly seen as a pressing health concern. In this article we argue in favor of incorporating unintended fetal deaths that occur late in pregnancy into estimates of the burden of disease. Our argument is based on the similarity between late-term fetuses and newborn infants and the assumption that protecting newborns is important. We respond to four objections to counting stillbirths: (1) that fetuses are not yet part of the population and so their deaths should not be included in measures of population health; (2) that valuing the prevention of stillbirths will undermine women's reproductive rights; (3) that including stillbirths implies that miscarriages (fetal deaths early in pregnancy) should also be included; and (4) that birth itself is in fact ethically significant. We conclude that our proposal is ethically preferable to current practice and, if adopted, is likely to lead to improved decisions about health spending.

VALUING STILLBIRTHS

Estimates of the burden of disease, such as the Global Burden of Disease Study (GBD),¹ attempt to assess the impact of mortality and morbidity as a result of disease by producing summary measures of population health that allow for comparisons between diseases and between regions. For instance, the GBD uses the disability-adjusted life year (DALY), which represents health lost to both death and disability using a common unit. Roughly speaking, one DALY represents the loss of one year of healthy life. While DALYs purport simply to

represent health lost, they are also designed to be used for priority setting in the allocation of funds for research, treatment, and prevention, and have in fact been used for this purpose.² The fact that two diseases differ in the number of DALYs they create may be taken as a basis for prioritizing research into the disease that is associated with more; the fact that one health intervention averts

¹ The Global Burden of Disease Study 2010 [Special Issue]. *Lancet* 2012; 380: 2053–2060.

² C. Murray. Quantifying the Burden of Disease: the Technical Basis for Disability-adjusted Life Years. *Bull World Health Organ* 1994; 72: 429–445: 429; C. Murray, J. Salomon & C. Mathers. A Critical Examination of Summary Measures of Population Health. *Bull World Health Organ* 2000; 78: 981–994; J. Bobadilla, P. Cowley, P. Musgrove & H. Saxenian. Design, Content, and Packaging of an Essential National Package of Health Services. *Bull World Health Organ* 1994; 72: 653–662; C. Lyttkens. Time to Disable DALYs? *Eur J Health Econom* 2003; 4: 195–202.

more DALYs for the same cost than another may be used to justify prioritizing the first over the second within a public health-care system.

As DALYs were originally designed, and as they are currently implemented, they take into account the impact of disease on individuals starting at birth, but not on unborn fetuses. The same is true of other common summary measures of health, such as quality-adjusted life years (QALYs). When a disease kills an infant, that event is associated with a large number of DALYs, since the infant thereby loses many years of life. However, while maternal conditions that result in the unwanted loss of a pregnancy may be taken into account insofar as they affect the health of the mother, the impact of the death on the fetus itself is not, even if it dies during labor. As a result, the loss of the healthy years that the resulting child might have been expected to live does not contribute any DALYs. Policymakers who use summary measures of health, such as DALYs, in decisions about how to spend money on health care and research, are therefore likely to give substantially lower priority to interventions that prevent stillbirths than they would if preventing a stillbirth were considered equivalent to saving an infant's life. Fetal deaths, including stillbirths, are not included in the Global Burden of Disease Study and they are not mentioned in the United Nations Millennium Development Goals.³

The omission of stillbirths is not the result of technical limitations of health measures. They could be modified to include the impact of events prior to birth. For instance, Jamison et al. describe a model on which fetuses begin to 'count' for purposes of DALY calculations from 13 weeks prior to birth.⁴ Nor is the omission (entirely) the result of a lack of data. It is true that collection of data on fetal deaths, particularly outside of high-income countries, is currently limited, and neither the total number of such deaths nor their causes can be determined with certainty.⁵ These limitations would complicate the calculation of DALYs if prenatal deaths were included. However, estimates of disease prevalence and burden already include numerous diseases for which data are imperfect or incomplete; such challenges are not reasons to ignore outcomes that otherwise should be included. Moreover, sufficient information is available regarding the prevalence of prenatal death to at least provide an indication of its bearing on the burden of disease. WHO

estimates suggest that, of the approximately 56.6 million total deaths in 2001, 7.7 million occurred between birth and one year of age.⁶ By comparison, in 2000 an estimated 3.2 million stillbirths went uncounted.⁷

Including stillbirths in summary measures of health is possible, and likely to have a significant impact on priority setting. But should it be done? Summary measures of health by their nature simplify information about health, trading richness of detail for simplicity and ease of use. In doing so, however, they must avoid presenting information in a manner that is likely to lead policymakers to make worse decisions. In this article we aim to defend a proposal that will meet the needs of policymakers, while representing an improvement over current practice from an ethical perspective. We argue that fetal deaths occurring after 28 weeks gestational age that are not the result of voluntary abortions should be taken into account in summary measures of health, and we present a proposal for doing so that we think should command widespread support. We refer to such fetal deaths as 'stillbirths,' consistent with the definition used by the World Health Organization (WHO).⁸

We begin by describing several interventions whose relative effectiveness would be very different if the prevention of stillbirths was counted as a health gain. This shows that the question of whether stillbirths should be included matters for priority-setting decisions. We then present a simple argument in favor of the inclusion of stillbirths. Having thereby provided a *prima facie* justification for including stillbirths, we consider several arguments against including stillbirths for reasons of policy or principle, and show that none is compelling. However, these arguments do suggest that prenatal deaths should not be counted in exactly the same way as other deaths.

⁶ World Health Organization. 2001. Global Burden of Disease (GBD) 2001 Estimates. Available at http://www.who.int/healthinfo/global_burden_disease/estimates_regional_2001/en/. [Accessed 5 June 2013]

⁷ C. Stanton et al. Stillbirth Rates: Delivering Estimates in 190 countries. *Lancet* 2006; 367: 1487–1494: 1492. Other recent estimates of global stillbirths by the WHO include 3.3 million (2005) and 5.3 million (1995). See World Health Organization. *Perinatal Mortality: A Listing of Available Information*. Geneva: World Health Organization; 2006; World Health Organization. *Make Every Mother and Child Count*. Geneva: World Health Organization; 2005. Available at <http://www.who.int/whr/2005/en/> [Accessed 5 June 2013].

⁸ WHO defines a stillbirth as a death occurring after 28 weeks gestational age or once the fetus has reached a weight of 1000 grams. J. Lawn et al. Global Report on Preterm Birth and Stillbirth (1 of 7): Definitions, Description of the Burden and Opportunities to Improve Data. *BMC Pregnancy Childbirth*. 2010; 10(Suppl 1): 1–22: 9. Different organizations give alternative definitions. For example, the American College of Obstetricians and Gynecologists defines stillbirths as fetal deaths after 20 weeks gestational age (American College of Obstetricians and Gynecologists. Management of Stillbirth. *ACOG Guidelines* 2009; 102: 1–14). We use 'stillbirths' in this article as a term of convenience to refer to those deaths that we propose including in summary measures of health, and our reasons for adopting the 28 week cutoff are independent of its coincidence with the WHO definition.

³ United Nations General Assembly. 2000. United Nations Millennium Declaration. New York, NY: United Nations. Available at: <http://www.un.org/millennium/declaration/ares552e.pdf> [Accessed 5 June 2013].

⁴ D. Jamison et al. Incorporating Deaths Near the Time of Birth into Estimates of the Global Burden of Disease. In: A.D. Lopez, C.D. Mathers, M. Ezzati et al., editors. *Global Burden of Disease and Risk Factors*. Washington, DC: World Bank; 2006; 427–463.

⁵ Ibid: 427.

We close with a conservative proposal for how the burden of disease due to stillbirths could be included in measures of population health. According to our proposal some loss of valuable life is associated with stillbirths after 28 weeks of fetal age and the magnitude of the loss increases gradually from this point as the fetus develops. Our discussion throughout the article and our proposal are couched in the language of DALYs. However, our conclusions apply equally to any summary measure of health used for setting priorities for spending on health.

1. STILLBIRTHS AND THE BURDEN OF DISEASE

The inclusion of stillbirths in summary measures of health has the potential to substantially impact two types of decisions about allocating resources for health. First, if averting a stillbirth is considered a health gain then this provides a reason for funding research and the provision of interventions that only, or primarily, avert stillbirths. Second, many of the interventions known to reduce the occurrence of stillbirths also improve maternal health, for instance by curing infection or improving nutrition. Including stillbirths will increase the measured impact of interventions that improve the health of both the mother and the fetus, and can thereby justify increased priority for funding such interventions over alternatives.

Major risk factors associated with stillbirth include childbirth complications, maternal infections in pregnancy, maternal disorders (especially hypertension and diabetes), fetal growth restriction, and congenital abnormalities.⁹ Approximately 99% of stillbirths occur in low- and middle-income countries; the existence of such disparities between regions suggests that many stillbirths are preventable.¹⁰

The following two examples illustrate the potential that including stillbirth prevention as a health benefit to the fetus has for changing health priorities.

Undernutrition is a major factor contributing to the burden of disease in low- and middle-income countries; for example, childhood underweight is the leading risk factor for DALYs in most of Africa.¹¹ Maternal malnutrition, both during pregnancy and earlier in life, is also a risk factor for stillbirths and for low birth weight, which

in turn can lead to death or disability for the infant. A recent review suggests that balanced protein-energy supplementation for pregnant women across a number of populations at risk for maternal malnutrition reduces the risk of low birth weight by approximately 32%, and of stillbirth by 38%, with even greater effects among malnourished women.¹² Thus, even without counting stillbirths, this intervention has the potential to avert DALYs associated both with maternal health, and with the effects of low birth weight on live-born infants. This finding suggests that, if such supplementation is sufficiently cost-effective, there is some reason to fund it even if stillbirths are not considered. However, if a stillbirth were associated with a number of DALYs similar to that currently associated with an infant death, the inclusion of stillbirths in DALY calculations could plausibly double the number of DALYs preventable through this intervention, and consequently reduce the cost per DALY prevented by half.¹³

An even more dramatic example is given by a study of the cost-effectiveness of an antenatal syphilis screening program in Mwanza city, Tanzania between 1997 and 1999.¹⁴ The program incorporated rapid syphilis screening and treatment with benzathene penicillin into routine antenatal care for pregnant women in Mwanza. Women with untreated high titre active syphilis were estimated to be nineteen times more likely to have a stillbirth and three times more likely to give birth to a low birth weight infant than uninfected women.¹⁵ According to the authors' calculations, the cost per stillbirth averted was \$318.37 and the cost per low birth weight infant averted was \$451.18.¹⁶ This translated into \$92.56 per DALY saved if only the prevention of low birth weight was included in the calculations and \$8.88 per DALY if the prevention of stillbirths was included.¹⁷ The inclusion of stillbirths therefore made a tenfold difference in the apparent

⁹ World Health Organization. Maternal, Newborn, Child, and Adolescent Health. Available at: http://www.who.int/maternal_child_adolescent/epidemiology/stillbirth/en/index.html. [Accessed 5 June 5, 2013]

¹⁰ Stanton, *op. cit.* note 7, p. 1492.

¹¹ S. Lim et al. A Comparative Risk Assessment of Burden of Disease and Injury Attributable to 67 Risk Factors and Risk Factor Clusters in 21 Regions, 1990–2010: A Systematic Analysis for the Global Burden of Disease Study 2010. *Lancet*. 2012; 380: 2224–2260.

¹² A. Imdad & Z. Bhutta. Maternal Nutrition and Birth Outcomes: Effect of Balanced Protein-energy Supplementation. *Paediatr and Perinat Epidemiol*. 2012; 26(Suppl. 1): 178–190.

¹³ Rough calculations using the same DALY values as those used in the 2003 paper by Terris-Presholt et al. and the absolute numbers from the combined data used in Imdad and Bhutta (2012)'s review suggest that treating 1000 women with balanced protein-energy supplementation during pregnancy would avert approximately 216 DALYs through its effect on low birth weight and 297 DALYs through its effect on stillbirths. For various reasons these calculations should not be relied upon for calculating the actual DALY value of such interventions in a population; however, they do indicate the magnitude of the difference that including stillbirths makes.

¹⁴ F. Terris-Presholt et al. Is Antenatal Syphilis Screening Still Cost Effective in Sub-Saharan Africa. *Sex Transm Infect*. 2003; 79: 375–381.

¹⁵ D. Watson-Jones et al. Syphilis in Pregnancy in Tanzania I. *J Infect Dis*. 2002; 186: 940–947.

¹⁶ Calculated in 2001 US dollars.

¹⁷ Terris-Presholt, *op. cit.* note 14, p. 377. Note that these calculations adjusted the years of life lost using both age-weighting and time-discounting. Averting a stillbirth was therefore calculated as averting 32.40 DALYs (using the life expectancy at birth figures from the World

cost-effectiveness of the program as measured by dollars per DALY saved. In a population with high levels of untreated syphilis, like the one in Mwanza, this is sufficient to change the program from being substantially less cost-effective than current high-priority interventions such as nevirapine for prevention of mother to child transmission of HIV, oral rehydration therapy, or childhood immunizations, to being very competitive with those interventions.

The cost-effectiveness comparisons provided in the above examples assume that all stillbirths are associated with the same number of DALYs as an infant death. Later in this article, we present a proposal for counting stillbirths that weights them less heavily. The examples illustrate the potential impact of choices about how stillbirths are counted, not positive proposals for exactly how to count them.

2. AN ARGUMENT FOR INCLUDING STILLBIRTHS IN ESTIMATES OF DISEASE

We have argued that including stillbirths in calculations of the burden of disease has the potential to make a substantial difference to how priorities are set for certain decisions about healthcare and research. Should stillbirths be included? Here we present a simple argument in favor of including them, based on the counterintuitive consequences of failing to do so at the individual and population level.

Currently, summary measures of health include the effects of disease on very young infants, including those who die nearly immediately after birth, but do not include the effects of disease on fetuses that die before or during labor. This difference has counter-intuitive consequences. Imagine two identical fetuses 36 weeks after fertilization. If one dies during labor, its death is considered irrelevant to the burden of disease. If the other is born alive but then dies five minutes later as a result of injuries incurred during labor, its death is counted as resulting in 86 DALYs – the maximum number that can be associated with any health outcome. In this example, both the two fetuses themselves and the manners of their deaths are very similar. It is difficult to point to any fact about them or how they die that justifies taking one into

account but not the other.¹⁸ Yet such a fact must be identified if the exclusion of stillbirths is to be justified, either from an ethical perspective or from within the internal logic of the summary measure of health being used. One of the four general principles described as underlying DALYs is ‘treating like outcomes as like.’¹⁹ The two deaths described here are apparently like outcomes. Unless birth itself is shown to make infant deaths very different from late stillbirths, it is implausible that they should be treated so differently.

Further counter-intuitive implications follow if measures that do not account for stillbirths are used for priority setting. In a society where a large number of infants die shortly after birth, current practice would describe these deaths as constituting a large burden of disease. However, if this society responded by reducing its prenatal care, in such a way that most pregnancies that once would have resulted in neonatal deaths instead resulted in stillbirths late in pregnancy, the number of DALYs associated with these pregnancies would drop sharply. In fact, the health of the mother aside, a pregnancy resulting in a stillbirth is associated with the same number of DALYs (zero) as a pregnancy resulting in the birth of an infant that goes on to live a full, healthy life. Thus relying on DALYs as currently calculated might make it appear that this society has effectively ‘solved’ its infant death problem. Yet it is highly implausible to think that a population in which many fetuses die late in pregnancy is just as healthy as one in which those same fetuses survive and lead healthy lives until death in old age.²⁰

Failing to count stillbirths as a loss of healthy life, then, has counter-intuitive consequences both in individual cases and for priority setting. The similarities between a fetus shortly before birth and an infant shortly after birth justify a presumption in favor of treating them similarly. Since we assume that counting infant deaths is appropriate, treating these outcomes similarly implies counting at least stillbirths late in pregnancy as well. Unless there is some positive reason to exclude these stillbirths, we ought to include them. We now consider possible arguments for excluding stillbirths and argue that all of them fail.

¹⁸ Cf. M. Kelley. Counting Stillbirths: Women’s Health and Reproductive Rights. *Lancet*. 2011; 377: 1636–1637. Kelley writes: ‘If the 35-week-old stillborn baby and the 35-week-old neonate who dies of respiratory failure 24 h after delivery are developmentally indistinguishable, why the paradox in our mortality statistics?’ (p. 1637).

¹⁹ Murray, *op. cit.* note. 2, p. 431.

²⁰ Of course, it is unlikely that anyone would mistake the conversion of neonatal deaths into stillbirths as a significant health improvement within a single population. A more practical concern is that the burden of disease and the potential for improved health outcomes might be underestimated in a population in which maternal and reproductive health problems commonly manifest as stillbirths rather than neonatal deaths.

Development Report 1993). DALYs calculated using the methodology of the 2010 Global Burden of Disease Study are not age-weighted or discounted for time. Saving the life of a newborn therefore averts 86 DALYs calculated this way. Comparison between the two is complicated; however, the new way of calculating DALYs would give even greater weight to the prevention of early deaths and so the cost per DALY of averting a stillbirth would be even lower.

3. ARGUMENTS FOR EXCLUDING STILLBIRTHS FROM MEASURES OF DISEASE BURDEN

The ethics and health economics literature suggests four distinct possible arguments against the inclusion of stillbirths in summary measures of health: (1) That such estimates are only intended to measure the health of currently living populations; (2) That arguments in favor of including stillbirths implausibly imply that one should count miscarriages early in pregnancy on a par with infant deaths; (3) That including any fetal deaths, such as stillbirths, would undermine the right of women to choose abortion; and (4) That birth is itself ethically significant in a way that justifies excluding stillbirths from measures of the burden of disease. We respond to these objections in turn.

3.1. First objection: Fetuses are not members of the population

DALYs are commonly described as a summary measure of population health; that is, they provide a tool to 'represent the health of a particular population in a single number.'²¹ It might be argued that an unborn fetus has not yet become part of the population that DALYs are intended to describe. The fact that DALYs do not include stillbirths would not then suggest that these deaths do not matter, but only that they fall outside the purview of the measure.

If DALYs were used purely as a descriptive statistic, then such an objection might be reasonable, provided that the restricted scope of the measure was made clear. DALYs including stillbirths and DALYs excluding them would both be valid measures of different things, and versions of DALYs that claimed only to describe the health of people who had already been born could not be faulted for doing exactly that.

However, if DALYs are to be used as a tool for priority setting, then they should take into account those factors that are relevant to priority setting. Murray argues that the important objectives of DALYs include aiding in priority setting for treatment and research, and that 'any health outcome that affects social welfare should in some way be reflected in the indicator of the burden of disease.'²² To the extent that the harm caused by stillbirths is relevant to decisions about how to care for a population, a statistic that fails to account for this harm is not suitable for use in making priority-setting decisions. Thus it is not enough to say that versions of

DALYs that exclude stillbirths would be an accurate measure of *something*. DALYs, *as used for priority setting*, should include them if they are relevant to priority setting. We presume that the death of a fetus whose well-being is similarly important to that of an infant should be taken into account in priority setting; thus, stillbirths should be included in DALYs unless it can be shown that the well-being of even a fully developed fetus is not similarly important to that of an infant.

3.2. Second objection: Including stillbirths requires including miscarriages

If stillbirths are considered in assessing the burden of disease, on the basis that harms to fetuses are ethically significant, then the same reasoning might seem to extend to miscarriages (deaths prior to 28 weeks gestational age). Given that the number of DALYs resulting from a death depends in part on the number of years of life lost, a miscarriage would then result in as many or more DALYs as a stillbirth or infant death. Intuitively, however, preventing the death of infants is significantly more important than preventing a comparable number of miscarriages. One might think that current approaches, which prioritize the prevention of miscarriages only to the extent that they harm pregnant women (but not their fetuses), more accurately capture our judgments of the relative importance of miscarriages and infant deaths. Thus one might object to including any fetal deaths in summary measures of health, in order to avoid giving excess weight to miscarriages in priority setting.

Including stillbirths in measures of the burden of disease, however, does not imply that the deaths of all fetuses and embryos must be considered as equally important. We have argued that fetal deaths late in pregnancy should not be excluded entirely. How to treat miscarriages is a further question: even if late stillbirths were treated similarly to infant deaths, miscarriages could still be associated with fewer or no DALYs. This increase in DALYs over time would make sense if early-stage fetuses and embryos are harmed less by death than infants are, or if for some other reason it were less important to prevent harms to them. If we wish to avoid giving the same priority to preventing miscarriages as preventing infant deaths, refusing to count any fetal deaths to any extent is neither the only nor the most plausible way of doing so. We sketch a specific proposal in Section 5, according to which the harm to the fetus from dying should start to count from the onset of sentience. Fetal deaths before this point should not be counted because the fetus does not have the minimum characteristics needed for harms to them to matter morally. This proposal takes into account the idea that the capacities that matter develop gradually.

²¹ Murray et al., *op. cit.* note. 2, p. 981.

²² Murray, *op. cit.* note. 2, p. 430.

3.3. Third objection: Including stillbirths requires including abortions

Including stillbirths in the burden of disease as negative health outcomes suggests that the death of a fetus is ethically significant, that is, an event that we have ethical reasons to be concerned about, and therefore reasons to try to prevent. One might object that, if it is ethically important to prevent the death of fetuses, then this provides grounds for preventing women from making the choice to terminate their own pregnancies, and thus impinges on an important right.

However, it does not follow that since the unintended death of at least some fetuses is ethically significant, women should be denied the right to have an abortion. First, it might be true both that a fetus is harmed by death, and that causing that death is permissible. The permissibility of causing death is a distinct ethical question that must take into account other considerations such as, at least, a woman's rights to control over her body.²³ Second, even if causing the death of a fetus shortly before birth were ethically impermissible, it might still be the case that abortions earlier in pregnancy, when the vast majority in fact occur, are permissible. The argument presented in Section 2 suggested only that stillbirths late in pregnancy should be included in summary measures of health, not that all fetal deaths should be. It is plausible, for reasons that we elaborate below, that there may be a period following fertilization when a fetal death does not harm the fetus and so is not ethically significant in the way that a stillbirth or infant death is.

Still, if it is true that if a fetus may be harmed by being stillborn, then it may also be harmed by being aborted. If a measure like the DALY attempts to capture all health-related harms to members of a population, then a death late in pregnancy will be associated with a substantial number of DALYs, even if the death was a permissible killing.

However, when measures of health are constructed as a tool to aid in priority setting, they should not include data that will not be of use to priority setters. Different decision-makers may find different information valuable. If it is agreed that voluntary abortions are not an outcome that priority setters should seek to prevent, then they can be excluded from the calculation of DALYs and other similar statistics. The measure would then capture only the deaths of fetuses that the mother intended to bring to term, since those would be the fetal deaths that policy-makers would be concerned to prevent. This is not a denial of the harm done to a fetus by abortion. It is merely a recognition that not all harms are relevant to health priority setting. Including stillbirths in summary

²³ J. Thomson. A Defense of Abortion. *Philos Public Aff.* 1971; 1: 47–66; D. DeGrazia. The Harm of Death, Time-relative Interests, and Abortion. *Philos Forum.* 2007; 38: 57–80; 74.

measures of health does not require adopting any particular stance towards abortion.

Finally, it is worth noting that a measure of health that includes stillbirths has the potential to benefit women and support the fulfillment of their rights. Interventions to prevent stillbirth often involve improving the health of the mother. Therefore, independently valuing stillbirths in priority setting is likely to lead to an increased emphasis on interventions that promote the health of women, in general, and of pregnant women, in particular.²⁴ Moreover, even women who might in some instances consider terminating their pregnancies have an interest in having the option of carrying pregnancies to term. A stillbirth is risky for the mother and denies her the opportunity to make her own choice about whether to have a child.²⁵

3.4. Fourth objection: Birth is ethically significant

The argument presented in Section 2 in favor of counting stillbirths suggests that the similarities between a fetus shortly before birth, and an infant shortly after, justify similar treatment of the death of each. There is, of course, at least one difference: one has been born, while the other has not. If the event of birth were itself ethically relevant, then including only deaths after birth in DALY calculations would not be arbitrary. Alternatively, even if birth itself were not ethically relevant, other attributes that are relevant to how bad it is to die might tend to occur very close to the time of birth. In that case, using birth as a cutoff for inclusion in summary measures of health might be a useful heuristic that would present a roughly accurate picture of the impact of disease. However, we will argue that the existing literature on the moral consideration that is due to fetuses and infants does not support treating birth as relevant in this way, and so instead supports counting stillbirths. Much of the literature suggests that those features relevant to the badness of death typically develop either before or after, not simultaneously

²⁴ In Barros et al.'s review of the evidence for the effectiveness of interventions to prevent stillbirths they identify eight interventions that are supported by moderate- to high-quality evidence and which they recommend for use in low- and middle-income countries:

balanced protein energy supplementation, screening and treatment of syphilis, intermittent presumptive treatment for malaria during pregnancy, insecticide-treated mosquito nets, birth preparedness, emergency obstetric care, cesarean section for breech presentation, and elective induction for postterm delivery'

(F. Barros et al. Global Report on Preterm Birth and Stillbirth (3 of 7): *Evidence for Effectiveness of Interventions.* *BMC Pregnancy Childbirth.* 2010; 10(Suppl 1): s3). All of these interventions also provide health benefits to the mother.

²⁵ J. Cacciatore. Psychological Effects of Stillbirth. *Semin Fetal Neonatal Med.* 2012; 18: 76–82.

with, birth. Those arguments that do treat birth itself as ethically significant support at most giving *increased* priority to infants over unborn fetuses; none support discounting fetal deaths entirely, as the current method of calculating DALYs suggests.

Philosophers thinking about abortion and the treatment of non-human animals have developed various accounts of the attributes by virtue of which a creature deserves moral consideration. Most fall into one of two main groups. The first group focuses on capacities that the creature has at present. For example, philosophers in this group have argued that moral consideration depends on sentience (the ability to feel)²⁶ or on awareness of oneself as a subject of experience (such that one can desire one's own continued existence).²⁷ Another group argues that having such capacities currently is not required for moral consideration; instead, one need only have the potential to develop them or be a member of a species that typically develops them.²⁸ That is, a human fetus that is not currently sentient might be viewed as deserving of moral consideration because humans typically develop sentience.

This latter group of 'potentiality' arguments, generally employed to argue for the impermissibility of killing fetuses, need not concern us here. If such a view is correct, when applied to the moral significance of death, then fetuses deserve consideration in virtue of the fact that they have the potential to develop into human persons with whatever attributes make harm to infants a matter of moral concern.²⁹ In that case the argument in favor of including stillbirths in measures of population health would be straightforward.

If the moral consideration that a fetus should be given instead depends on its current capacities, then it is important to ascertain when those capacities first emerge. Current research suggests that capacities often taken to be relevant to moral consideration consistently develop before or after birth rather than concurrently. For instance, the data suggest that sentience begins sometime between 20 and 30 weeks of gestational age,³⁰ while even

the most primitive self-awareness generally does not appear until at least two months after birth.³¹

More generally, it is implausible that a capacity determining whether a human is deserving of moral consideration would consistently appear at the time of birth. Since live births can occur after pregnancies of varying lengths, any capacity whose development was tied to the gestational age at which birth most commonly occurs, rather than to the event of birth itself, would be present in some unborn fetuses and absent in some infants. On the other hand, any capacity that develops as a result of experiences undergone following birth, such as exposure to a wider range of sensory stimulation than is possible during pregnancy, will not be present immediately after birth when many infant deaths occur. For this reason, a number of philosophers have endorsed the claim that birth itself does not alter the extent to which one is deserving of moral consideration. As L. W. Sumner says: birth is 'a shallow and arbitrary criterion of moral standing, and there appears to be no way of connecting it to a deeper account.'³²

Some attempts have been made to argue explicitly, contrary to Sumner's position and ours, that birth itself is morally relevant. Mary Anne Warren argues that although the intrinsic properties of a late-term fetus are the same as those of a newborn infant, we should not treat them identically because the event of birth changes the relations between the infant and other members of the community.³³ However, this argument does not, and is not meant to, show either that fetuses cannot be harmed or that harms to them are not worthy of moral consideration. Instead, Warren's argument is meant to show that it may be acceptable to put in place additional legal prohibitions against killing infants that do not apply to fetuses. As we argued in Section 3.3, the ethics of permissible killing are distinct from questions of harm and moral consideration: there may be reasons why it is worse to kill an infant than a fetus, that do not imply that it is worse for the infant than the fetus to die from disease. Moreover, Warren explicitly acknowledges that 'of course' sentient fetuses are morally relevant and 'need to be protected from a variety of possible harms.'³⁴ Her argument might suggest that infants deserve additional consideration, but since many of the morally important characteristics she identifies are shared by infants and

²⁶ L.W. Sumner. *Abortion and Moral Theory*. Princeton: Princeton University Press; 1981.

²⁷ M. Tooley. *Abortion & Infanticide*. Oxford: Oxford University Press; 1983; 41.

²⁸ D. Marquis. Why Abortion is Immoral. *J Philos.* 1989; 86: 183–202; B. Wilkins. Does the Fetus Have a Right to Life? *J Soc Philos.* 1993; 24: 123–137.

²⁹ Even on potentiality views, moral consideration may not begin at conception. For instance, David DeGrazia argues that early embryos are not future persons due to the possibility of twinning. See D. DeGrazia. Identity, Killing and the Boundaries of Our Existence. *Phil Public Aff.* 2003; 31: 413–442: 426.

³⁰ S. Lee et al. Fetal Pain: A Systematic Multidisciplinary Review of the Evidence. *JAMA.* 2005; 294: 947–954; E.C. Brugger. The Problem of Fetal Pain and Abortion: Towards an Ethical Consensus for Appropriate Behavior. *Kennedy Inst. Ethics J.* 2012; 22: 263–387.

³¹ S. Feigelman. The First Year. In R. Kliegman et al., editors. *Nelson Textbook of Pediatrics*, Nineteenth Edition. Philadelphia: Elsevier Saunders; 2011.

³² Sumner, *op. cit.* note 26, p. 53. See also M. Little. Abortion and the Margins of Personhood. *Rutgers Law J* 2008; 39: 331–338: 332; P. Singer. *Practical Ethics*. Cambridge: Cambridge University Press; 1979; 108.

³³ M.A. Warren. The Moral Significance of Birth. *Hypatia* 1989; 4: 46–65. DeGrazia, *op. cit.* note 23, makes a related argument.

³⁴ *Ibid.*: 58 and 63.

fetuses, this would only imply that infant deaths be given greater weight, not that stillbirths do not matter at all.

José Bermúdez argues that infants, but not late-term fetuses, have a primitive form of self-consciousness; while this primitive self-consciousness would not in itself justify moral consideration, it does so based on its relation to more fully developed self-consciousness.³⁵ Thus he holds that birth is ethically significant. However, Shaun Gallagher has convincingly argued that, granting Bermúdez's interpretation of what counts as a primitive form of self-consciousness, we should ascribe such a capacity to some fetuses as well as to infants.³⁶ Regardless, Bermúdez's argument is subject to objections typically employed against potentiality arguments – it is not clear why the primitive form of a morally relevant capacity should itself be morally relevant. Finally, Bermúdez himself concedes that primitive self-consciousness is only one among several grounds for moral consideration, and that fetuses are worthy of some consideration. Thus his position, like Warren's, at most supports an *increase* in consideration following birth, not a total lack of consideration for fetuses.

Finally, one might argue that, while morally relevant capacities do not generally appear precisely at the moment of birth, they ordinarily develop close enough to that time that it is appropriate to calculate summary measures of health as if birth were significant. David DeGrazia makes a similar argument in a different context, claiming that a number of aspects of an infant's mental life undergo substantial development shortly after birth that justify treating infants differently from fetuses for some purposes.³⁷ Alternatively, it might be thought that uncertainty about exactly when the deaths of fetuses or newborns start to matter justifies taking birth as an approximation.³⁸ However, arguments like these should not be extended to the case of constructing summary measures of health. We have argued that there are good reasons to believe that late stillbirths and early newborn deaths are similarly relevant to priority setting, and these arguments do not give any new reason to discount that belief. However, this similarity would be ignored by an approach that treats important developments after birth as if they occur at the moment of birth. Instead, such an approach will treat preventing infant deaths – even those occurring almost immediately after birth – as much more important than preventing stillbirths. It will therefore

give inappropriate weight to interventions that assist newborns over those that prevent stillbirths. Since the diseases that cause stillbirths are frequently different than those that kill infants, as are the interventions to prevent or treat them, such an approximation fails to capture important information about the harm of deaths occurring near the time of birth and is not appropriate for use in priority setting.

In summary, leading views in the philosophical literature suggest that the qualities that render one deserving of moral consideration typically develop either before or after birth. Even if an argument like Warren's or Bermúdez's succeeds, it will show only that birth *increases* the extent to which one is deserving of such consideration, not that fetuses do not merit consideration. Furthermore, birth is not even a good way of approximating important developments for the purpose of priority setting, so an approach like DeGrazia's is not appropriate here. Assuming that we are committed to considering harms to infants in a summary measure of health, anyone wishing to argue that no fetus should be given any consideration bears the burden of devising a novel argument to show that birth is a necessary condition for moral consideration. Absent such an argument, stillbirths should be included in summary measures of health.

4. COMPLICATIONS IN INCLUDING STILLBIRTHS IN ESTIMATES OF DISEASE BURDEN

Determining the DALY values of fetal deaths at particular stages of pregnancy involves both conceptual and empirical challenges. We have argued that including stillbirths in summary measures of health is consistent with excluding miscarriages, or with weighing them less heavily, and that the characteristics that make fetuses worthy of moral consideration may continue to develop after birth. This leaves open many different ways of weighting deaths at different stages of pregnancy and infancy. Choosing between them will involve identifying characteristics of a person or a fetus that should affect the weight afforded to its death, and then empirically determining the extent to which embryos and fetuses at different stages typically possess these characteristics. Furthermore, the same factors that place a fetus at risk of death may also systematically impede development of the very characteristics that make that death morally significant. For instance, malnutrition, a leading risk factor for stillbirth, can also impede brain development and might therefore delay the onset of sentience or self-awareness.³⁹

³⁹ M. Giorgiuff. Nutrition and the developing brain: nutrient priorities and measurement. *Am J Clin Nutr.* 2007; 85: 614S–620S.

³⁵ J. Bermúdez. The Moral Significance of Birth. *Ethics.* 1996; 106: 378–403.

³⁶ S. Gallagher. The Moral Significance of Primitive Self-consciousness – A Response to Bermúdez. *Ethics.* 1996; 107: 129–140.

³⁷ DeGrazia, *op. cit.* note 23, p. 77.

³⁸ We might, for example, be confident that the death of a recently conceived embryo is not morally significant and that the death of a one-year old infant is morally significant, but be uncertain about exactly what point in development marks the change. Our thanks to an anonymous review for *Bioethics* for suggesting this possibility.

Failing to account for such differences could potentially exaggerate the number of DALYs attributable to stillbirths.

Even once the weightings of individual health outcomes have been determined, assessing the impact of considering stillbirths on the total number of DALYs prevented by an intervention will not be straightforward. Preventing a stillbirth does not guarantee that the resulting child will live a full and healthy life. Instead, it might die in infancy or suffer disability. For example, antenatal screening by ultrasound may, by detecting signs of placental insufficiency, reduce the risk of stillbirth. However, even when a stillbirth is prevented in such a case, the child is likely to suffer lasting negative health effects, potentially resulting in a number of DALYs.⁴⁰ Such infants may also face higher mortality rates in low- and middle-income countries where neonatal intensive care facilities are scarce. Thus some interventions that achieve apparently positive health impacts by preventing stillbirths are very likely to be offset, in part, by negative effects associated with the factors that placed the fetus at risk for stillbirth. If infant deaths, or adult disabilities, are weighted substantially more heavily than stillbirths in calculating DALYs, the intervention could even increase the burden of disease, despite allowing some children, who otherwise would have been stillborn, to survive.

5. A CONSERVATIVE PROPOSAL FOR INCORPORATING STILLBIRTHS INTO SUMMARY MEASURES OF HEALTH

How ought we to proceed, given both a compelling argument in favor of including stillbirths in summary measures of health, and significant unresolved questions about how they should ideally be incorporated? Such questions are not a reason to exclude stillbirths entirely, even for the time being. Health-spending decisions must be made, even when some uncertainty is present. Our goal here is to describe an approach that allows for the inclusion of stillbirths in summary measures of health, avoids placing excessive value on the prevention of deaths early in pregnancy, and represents an improvement over current practice from the perspective of policymakers regardless of their positions on the permissibility of abortion. An approach that meets those criteria should be widely endorsed as an improvement over current practice.

First, we propose that fetal deaths be included in measures of health when they occur after the onset of sentience, which is best judged by when the fetus gains the capacity to experience pain. Prior to sentience, there may be good reasons not to kill a fetus, but it is hard to see

how the fetus itself could be harmed by its death; instead, the death of the fetus would have disvalue insofar as it lead to harms to other family members, particularly the pregnant woman. On the other hand, while capacities other than sentience may also be relevant to moral consideration, if sentience did not justify some degree of moral consideration it would be difficult to explain the importance of avoiding harms to newborn infants.⁴¹ Many – perhaps most – philosophers who have considered this question agree that the possession of some form of sentience is sufficient for an individual to be capable of being harmed in a way that matters morally.⁴²

While the exact time at which sentience begins is a subject of ongoing debate, the expert consensus is that there is a reasonable possibility that fetuses can feel pain by 28 weeks gestational age.⁴³ Until the onset of sentience can be more firmly established, it is reasonable to begin counting stillbirths that occur at any time after 28 weeks, in order to ensure that the deaths of sentient beings do not go uncounted. By not counting fetal deaths prior to 28 weeks, this approach avoids placing a counter-intuitive degree of priority on the prevention of miscarriages.

Second, we propose that the disvalue attached to a fetal death should gradually increase from zero, at 28 weeks gestational age, to a value equaling that of the death of a

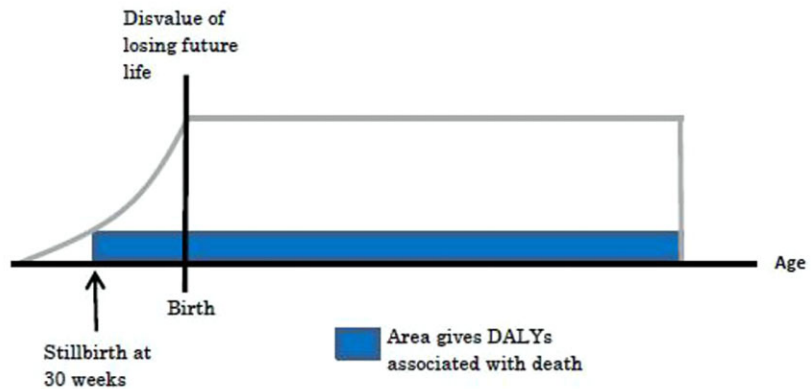
⁴¹ Some people may agree that we should treat stillbirths and newborn deaths equivalently, but think that it is not bad for either late-term fetuses or newborns that they die. On these grounds they might then prefer a policy that only counts newborn deaths to one that counts both, even though they think that the former still counts too many deaths. If someone with this view accepts that it will be impossible to convince policymakers that newborns should not count, she should still argue for a gradualist view like the one that we describe in this section, since that reduces the relative priority given to very young deaths. Moreover, she would still have some reason to endorse our view about stillbirths. It would remove the huge gap that currently exists between calculations of the cost-effectiveness of interventions to save newborns and of the cost-effectiveness of interventions to prevent stillbirths (as we argued in Section 3.4). It would therefore treat parents and prospective parents more fairly. Since we consider it highly plausible that a being can be harmed by death once she is sentient, we do not examine this possibility further here.

⁴² See, e.g. Sumner, *op. cit.* note 26; Warren, *op. cit.* note 33.

⁴³ D. Benatar & M. Benatar. A Pain in the Fetus: Toward Ending Confusion About Fetal Pain. *Bioethics*. 2001; 15(1): 57–76; Lee et al., *op. cit.* note 29. E. Christian Brugger argues that there is sufficient uncertainty about the evidence that we cannot rule out fetal pain as early as 20 weeks gestational age (Brugger *op. cit.* note 29). In the face of this doubt and the minimal burden a precautionary policy would place on others, Brugger contends that pregnant women undergoing abortions should be informed and offered pain relief for their fetuses. A similar strategy should not be adopted here. First, if stillbirths are counted for the purposes of making priority-setting decisions, as we are arguing, then over-counting stillbirths will lead to giving less to other patient groups than they deserve, just as under-counting stillbirths will lead to the neglect of morally important fetal deaths. Second, as previously noted, even for those who think that fetal deaths matter earlier than 28 weeks, our proposal is an improvement over current practice, which does not count fetal deaths at all.

⁴⁰ R. Gagnon. Placental Insufficiency and its Consequences. *Eur J Obstet Gynecol Reprod Biol*. 2003; 110(Suppl.): S99–S107.

Incorporating stillbirths on standard view of badness of infant death



Incorporating stillbirths on gradualist view of badness of infant death

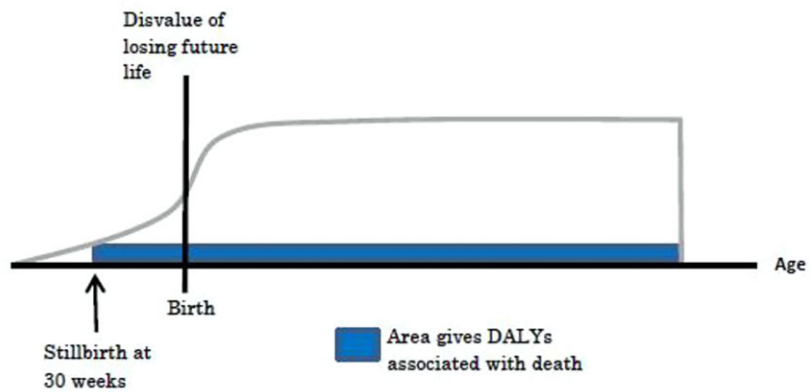


Figure 1. Calculating DALYS associated with stillbirths.

newborn infant, at the time of birth. This factor should increase more rapidly close to the time of birth, such that late stillbirths are weighed much more heavily than early stillbirths, to reflect the greater confidence that we can have in the moral consideration due to fetuses that are highly similar to infants. Our proposal implies that the loss of future life is more important for a fully developed infant than for a barely-sentient fetus. Such an approach avoids discontinuity at birth and reflects the intuition that stillbirths involving highly developed fetuses close to birth are worse health outcomes than earlier stillbirths and miscarriages.⁴⁴

As the literature we discussed in Section 3.4 suggests, how bad it is for a fetus to die may depend on more than just whether she is sentient. It may also depend on the development of other important capacities, such as self-awareness or psychological continuity. This would imply that the development of morally important capacities

continues after birth, too. Thus, a decreased weighting for neonatal deaths, relative to the deaths of older children, would be consistent with the approach employed here.⁴⁵ Figure 1 illustrates this possibility. The first graph displays our proposal for incorporating stillbirths into DALYs using the current method for valuing deaths after birth. The second displays our proposal within a framework in which how bad it is to die gradually increases from the onset of sentience through to a point in early childhood when all the morally relevant capacities have developed. The proposal is consistent with both approaches.

⁴⁵ DeGrazia, *op. cit.* note 23; J. McMahan. *The Ethics of Killing: Problems at the Margins of Life*. New York: Oxford University Press; 2002. p. 165–185. According to McMahan, how bad it is to die is a function of both the future goods of which the decedent is deprived and the degree of psychological unity she has with the future self who would have experienced those goods. The cognitive requirements for psychological unity mean that very young children are not as psychologically unified with their future selves as are older children or adults. This implies that it is not as bad for a very young child to die as it is for an older child or a young adult.

⁴⁴ Thus we would propose the number of DALYs attributed to a stillbirth should be determined by a method similar to that proposed by Jamison et al., *op. cit.* note 4.

Third, on the conservative approach we propose, summary measures of health intended for use in priority setting should not include losses to the fetus as a result of voluntary termination of pregnancy. The harm of death for an aborted fetus is similar to that resulting from a stillbirth at a similar gestational age; therefore, preventing some abortions may result in health gains. It does not follow that the same priority should be given to preventing the termination of an unwanted pregnancy as to preventing the stillbirth of one that a woman intends to bring to term. The ethical status of late voluntary abortions remains a contentious issue; some policymakers may wish to prioritize the prevention of such abortions, while others will not. The proposal presented here, which associates DALYs with stillbirths but not voluntary abortions, should represent an improvement over current practice from the perspectives of both groups. It is also worth noting that, since our proposal counts only those stillbirths occurring after the onset of sentience, the overwhelming majority of voluntary abortions would in any case be irrelevant to the measure.⁴⁶

6. CONCLUSION

The similarities between a stillbirth occurring shortly before birth and the death of an infant shortly after birth justify treating them similarly for purposes of a summary measure of health. The arguments against including stillbirths fail to demonstrate an ethically significant intrinsic difference between the fetus and the infant, or an important societal reason for excluding harms occurring before birth.

⁴⁶ For example, according to the CDC, 98.7% of abortions performed in the United States in 2009 were prior to 21 weeks gestational age. Centers for Disease Control and Prevention. 2012. Abortion Surveillance – United States, 2009. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6108a1.htm?s_cid=ss6108a1_w. [Accessed 5 June 5, 2013].

Outstanding questions, both conceptual and empirical, must be answered to determine exactly how stillbirths should ideally be counted in summary measures of health. Similar difficulties are present with other features of such measures. For instance, DALYs attempt to quantify how much worse it is to be blind than to suffer from lower back pain. Certainly there are bound to be errors and imprecisions in the methodologies used to compare these conditions, but that is not a reason either to treat the two as equally bad or to exclude one entirely from DALY calculations. Similarly, uncertainty about the proper weighting to give to stillbirths as compared with infant deaths should not prevent us from recognizing, and taking into account in priority setting, the fact that a late and unwanted stillbirth is a poor health outcome and one that we have some reason to try to prevent. If stillbirths are ethically significant, and therefore relevant to priority setting, even an imperfect manner of including them is likely to make summary measures of health more accurate.

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