Sands & Tommy's Policy Unit

Working together to save babies' lives

Is reproductive health and childbirth research over-funded? How pregnancy loss is ignored by disability-adjusted life years

In the latest analysis of public and charity funded health-relevant research, the UK Clinical Research Collaboration (UKCRC) concluded that there is relatively poor matching of the UK's burden of disease and research spending (1). The report flagged reproductive health and childbirth[1] as one of the areas of health which received a higher proportion of research funding than the corresponding burden of disease (measured by disability-adjusted life years).

Is reproductive health and childbirth research over-funded? This briefing will explore the disability-adjusted life years metric in more detail, question its relevance for reproductive health and childbirth and suggest what changes are needed to better reflect the impact of pregnancy loss.

The use of DALYs to compare the burden of health conditions

Comparing spending across a range of health areas can be challenging due to the diversity of health conditions and their effects on the population. Disability-adjusted life years (DALYs) were developed to measure the burden of a disease or health condition in a single metric. DALYs combine years of life lost due to premature mortality (YLLs) and years of life lost due to time lived in states of less than full health, or years of healthy life lost due to disability (YLDs). This can be used to compare the burden of disparate health issues, for example comparing those that cause premature death but little disability (e.g. drowning) with those that do not cause death but cause disability (e.g. cataracts causing blindness). DALYs have been used to inform strategic decision-making, including healthcare policy and research prioritisation, and research into the cost-effectiveness of health interventions (2).

Why don't DALYs capture the impact of pregnancy loss?

Although neonatal deaths are included in DALY calculations, stillbirths, miscarriages and other forms of pregnancy loss are not. This contradicts one of the four general principles underlying DALYs: to "treat like outcomes as like" (3). A baby that dies during labour and is stillborn would not be counted in the metric but a baby that shows signs of life but dies within a few minutes of birth would be. While the baby has sadly died in both situations, only one would be measured by DALYs. This exclusion ignores the impact of stillbirths and other forms of pregnancy loss and vastly underestimates the benefits of pregnancy interventions[2]. One study suggests that including stillbirths in DALYs would yield between 2 – 10 times greater impact in evaluations of pregnancy interventions (3).

Here we explore some of the most common reasons for excluding pregnancy loss from DALY calculations and their limitations.

1. **Babies should not be included in population statistics until birth:** DALYs are commonly described as a summary measure of population health. Some view birth as ethically significant and believe that the unborn baby has not yet become part of the population, thereby falling outside of the metric (4). However, DALYs are not purely descriptive statistics, they are used as a tool for

1 This is the health category that includes research related to saving babies' lives alongside a broader range of reproductive health care. Disaggregated analysis that focuses only on maternity and neonatal care is not available.
2 Other cost-effectiveness measures, including Quality-adjusted life years (QALYs), have faced similar critiques leading to questions about the robustness of cost-effectiveness analyses for maternity care compared to other clinical disciplines (8).

priority setting. If we agree that stillbirths are as important as neonatal deaths, then they should be included in the measure (4).

2. **Data availability**: DALYs are an international metric and part of the reluctance to include pregnancy loss is due to the lack of reliable data. Data on stillbirths are still limited in low- and middle-income settings (3) and there is no routine reporting of miscarriages in any setting. However, stillbirth data are available for the UK and could be included in a modified DALY measure. As miscarriage reporting improves, DALYs could be further modified in the future to capture miscarriages.
3. **Including stillbirths requires the inclusion of abortions:** Data are available on abortions and there are concerns that counting stillbirths would require the inclusion of abortions, which could compromise women and birthing people's reproductive rights. However, when measures of health are constructed as a priority setting tool, they should not include data which are not of use to priority setters. Therefore, if it is agreed that legal terminations are not an outcome that priority setters should seek to prevent, then they should be excluded from the calculation of DALYs or other similar measures (4).

Further limitations of DALYs

UKCRC does acknowledge some limitations to DALYs for comparative analysis, including variation in research costs (with some research approaches being much more costly than others) and the impact of UK research on the global burden of disease. In addition to these caveats, and the exclusion of pregnancy loss, analysing current spending against DALYs ignores historical funding patterns – as several areas, including reproductive health and childcare and mental health have been neglected historically (7). Also, DALYs do not capture the wider effects of health conditions, including the impact on carers' and families' quality of life or the social and economic consequences (7). One study estimated that the health utility of bereaved parents is 13% lower than general population values, equating to 1.1 quality-adjusted life years over 10 years due to perinatal bereavement, driven by anxiety and depression (8). Another study estimated that the average cost to the NHS of care related to a stillbirth and a first subsequent pregnancy was £4,191 for each stillbirth, or £13.6 million for the UK each year (9). Beyond the cost of providing care, the study also revealed the impact on families, the NHS and the wider economy: clinical negligence payments to bereaved parents were estimated at £2.5 million per year, parents were estimated to spend £1.8 million per year on funerals, the cost of parents' workplace absence was estimated to cost £8.1 million per year, and the loss of a baby as an individual with the potential to become a valued and productive member of society is estimated at £333 million per year (9).

Proposals for a modified DALY

Some studies have proposed modified DALY measures which include stillbirths in their calculations (3,4), although this would still not overcome the other limitations outlined above. One study suggests that the disvalue attached to a stillbirth should gradually increase from 0.0 at 28 weeks' gestation to 1.0 at full term (equal to that of a live birth) (4). However, this calculation does not reflect medical evidence as at 28 weeks' gestation survival without major morbidity is closer to 1.0 than 0.0 (3). And it still assumes that the impact of stillbirth at 28 weeks is 0.0. The study uses the international definition of stillbirths (post-28 weeks), but this could be reduced to 24 weeks to align with the UK definition of stillbirth and clinical capabilities. 24 weeks' gestation is also the legal limit for abortion in the UK and only 0.1% of abortions occur after this threshold[3] (5).

Another cost-effectiveness study of magnesium sulphate for the prevention of eclampsia looked at the impact of different gestational ages[4] on cost-effectiveness calculations for treatment (6). Using different thresholds had a significant impact on the economic evaluation: the cost-effectiveness ratios ranged from

3 Abortions may still be performed after 24 weeks' gestation in certain circumstances, such as if the mother's life is at risk or the baby would be born severely disabled.
4 The three thresholds used were 0 weeks' gestation, 24 weeks', and birth.

$9,422 to $17,777 per life year gained and between $316 to $8,182 per DALY averted for high-income countries. This variation shows the impact that properly accounting for pregnancy loss could have on economic evaluations.

What next?

DALYs should not be used to compare reproductive health and childbirth with other areas of healthcare. At the very least, UKCRC should explicitly state that stillbirths are not measured as part of this metric and should therefore be cautious about implying that reproductive health and childbirth is over-funded.

Instead, UKCRC or another national body could establish consensus on an appropriate methodology for a modified DALY that recognises the impact of stillbirths.

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