

Defining the concept of a life not worth living in paediatric treatment limitation.

Claudia Brick¹, Dr Guy Kahane², Prof Roger Crisp², Dr Michael Selgelid¹

¹Monash University, ²University of Oxford

Introduction

Although the vast majority of decisions about withdrawal of life support for seriously unwell infants are made through consensus between physicians and parents, disagreement can result in divisive legal battles.

Medico-legal precedent is for treatment withdrawal only if this is in the best interests of the child, and the burdens of life outweigh the benefits: a judgement that, due to a prognosis of severe future disability, this life would not be worth living. However, it is unclear how to evaluate when life is no longer worth living for an infant, and public attitudes towards treatment withdrawal and the role of parents in decisions have not previously been assessed.

Aims

The empirical component aimed to assess public views on when life is no longer worth living for an infant, and whether this justifies treatment withdrawal. The ethical analysis aims to evaluate these public views in comparison to key principles of medical ethics.

Though such empirical data cannot provide definitive answers, it aims to shed light on the ethical views held by the public and inform policy-makers.

Materials & Methods

An online survey was conducted with a sample of the UK public (n=130). Participants were asked to judge the benefit of life for seriously ill infants in a series of case scenarios, as well as their views on treatment withdrawal and parental autonomy. Four of the scenarios were based on significant recent legal cases in the United Kingdom to allow comparison to the legal outcome.

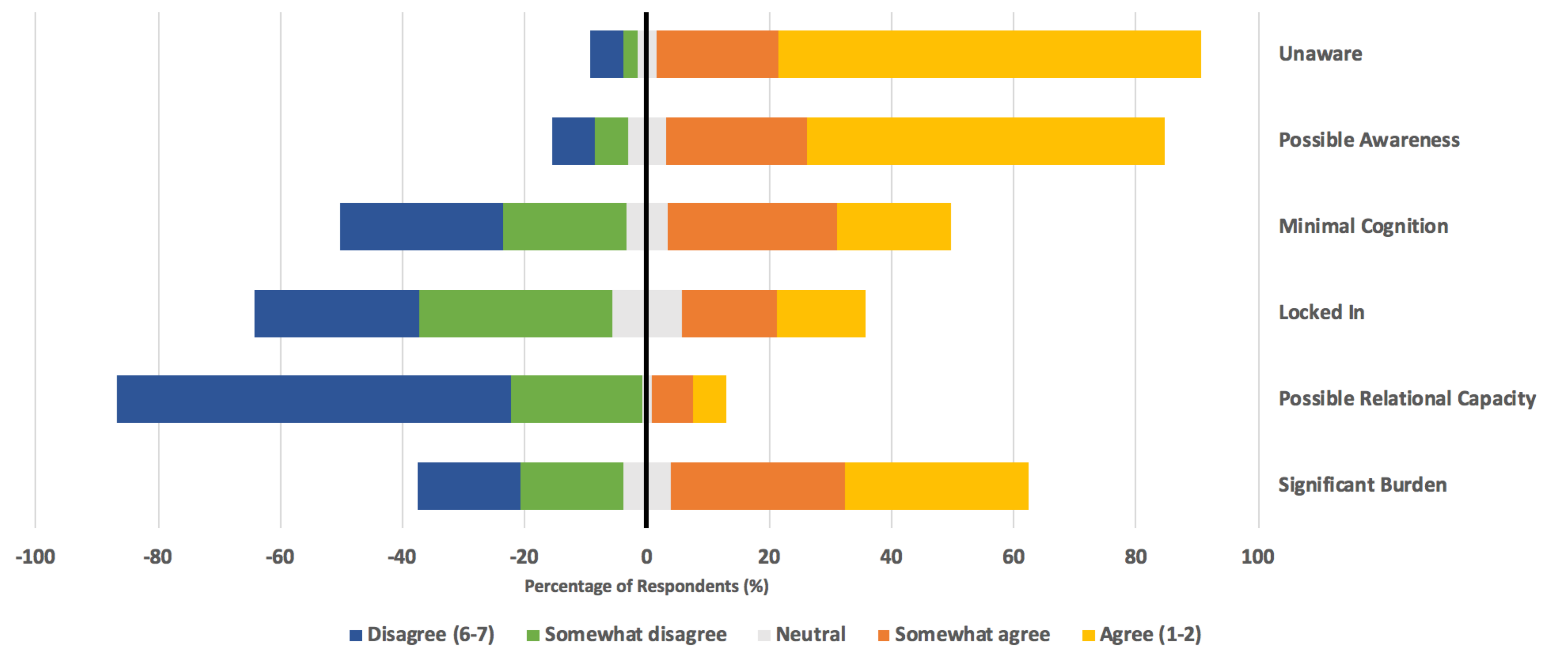
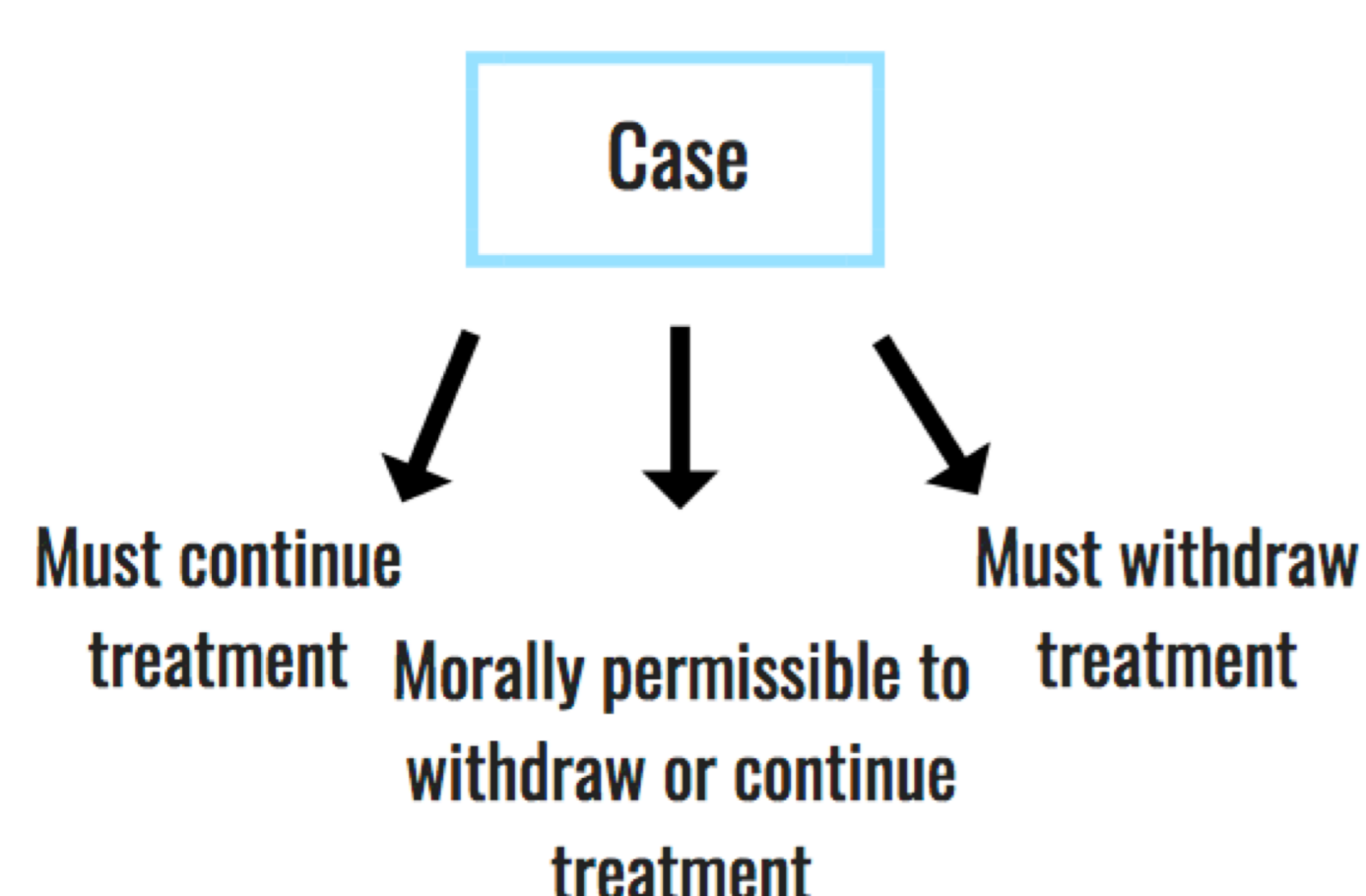


Figure 1. Public agreement with the statement "Life has no benefit" for this infant

Empirical Results

At a certain level of wellbeing, life may no longer be worth living.



This belief varied significantly between cases: participants seemed to place most value on the objective goods of awareness and capacity for basic relationships when making this judgement.

Treatment withdrawal

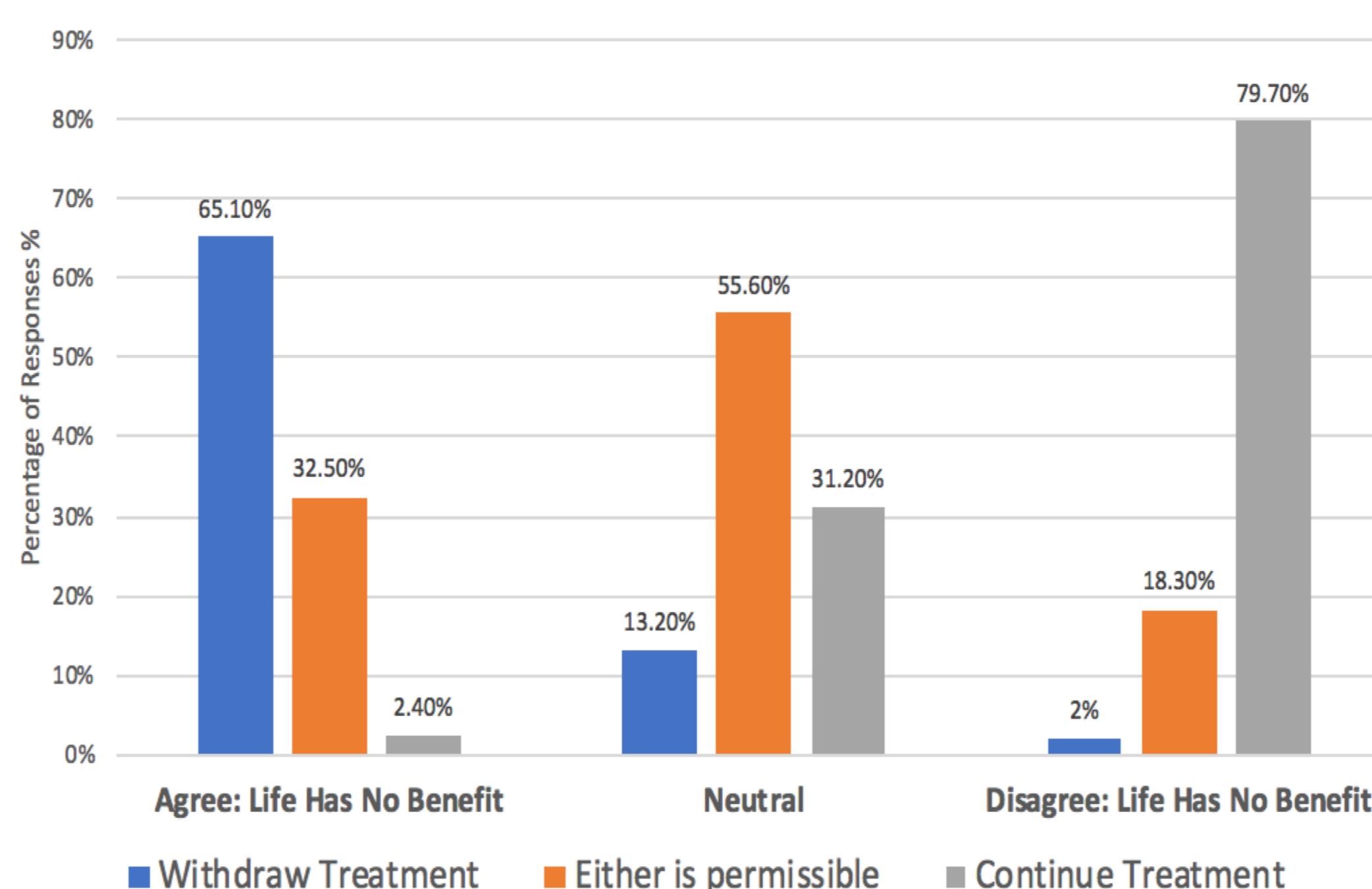


Figure 2. Aggregate data comparing responses to 'Life has no benefit' to belief about morally correct treatment decision

Up to 50% of participants in each case believed it was permissible to either continue or withdraw treatment (i.e. that it was not morally obligatory to do one or the other). Data was aggregated across all cases to demonstrate that where respondents agreed that life had no benefit, 65.1% thought treatment should be withdrawn and 32.5% that either was permissible. This may represent recognition of the moral and prognostic uncertainty when wellbeing is very close to the 'zero-point' of life having no benefit.

Parental autonomy

In 5 of 6 cases, a majority of participants supported parental autonomy to continue indefinite treatment. In more severe cases, greater numbers of participants believed treatment should be withdrawn regardless of parental wishes

Resources

Little importance was placed on limited medical resources, highlighting the significant gap between the conversation of medical ethicists and the views of the public.

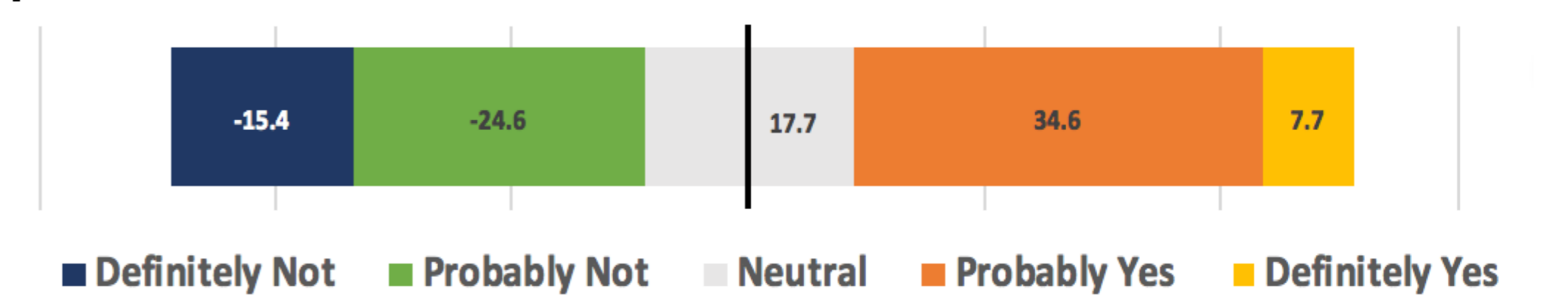


Figure 3. Responses to whether financial constraints should influence decisions.

Conclusions

Despite the controversy associated with high profile legal cases, there is a level of wellbeing at which most people agree that life is not worth living: one where cognition is so limited that the infant has no awareness of themselves or their surroundings, even if suffering is minimal.

Public opinions were not markedly different to the legal outcomes, suggesting that media attention and controversy may be based on the amplification of a vocal minority rather than being representative of population values.

Significant support for the permissibility of withdrawal of treatment (where it is not morally obligatory to either withdraw or continue) in the most divisive cases as well as for parental decisions may be useful when constructing further guidelines for clinical practice.