

To the Editor:

Cameron et al investigated treatment preferences using a discrete choice experiment reporting that people with CF were willing to accept 4.4% FEV₁ reduction or 2.3 years of reduced life-expectancy to halve the time spent on inhaled medicines.¹ Preference elicitation studies are vulnerable to variations in health literacy, case composition and the cognitive bias of future discounting, hence uncritical application of their results to inform clinical decision-making may adversely impact health outcomes.

An important methodological issue is the vulnerability of study findings to the coherence of attribute combinations.² Whilst discrete choice experiments have been successfully used to study job preferences where relationships between attributes requires no esoteric knowledge, in clinical scenarios health literacy must be sufficient to interpret complex attribute combinations. Rowe's editorial discussing the potential of CFTR modulators highlights that a small increase in annual FEV₁ decline from 1% to 2% might reduce life-expectancy by 30 years.³ Rowe is highlighting the lock-step relationship between FEV₁ and life-expectancy, which might be considered a necessary "health literacy" competency in interpreting discrete choice scenarios involving both FEV₁ and life-expectancy. However, in the study by Cameron et al,¹ participants were willing to accept 5 years of reduced life-expectancy to gain 10% FEV₁ (Table 4), and participants in Class 1 strongly valued life-expectancy increases but were indifferent to FEV₁ reductions (Table 5). These findings suggest that participants may be unaware of the FEV₁/life-expectancy relationship, resulting in choices inconsistent with the real world.

Secondly, the potential bias from future discounting was not considered. Humans focus on and over-value immediate benefits (reduction of inhaled medicines) over longer-term benefits (normal life-expectancy).⁴ It is therefore possible that the study is detecting and over-valuing the immediate salience of reducing treatment whilst discounting the more distant, cognitively-unavailable, impact of treatment choice on life-expectancy. A crucial skill of clinicians supporting people with long-term conditions to achieve optimum health is the sensitive framing of the sacrifices of daily self-care, by making salient the long-term health benefits that investment today creates in the future.

Finally, perceived burden may not be linearly correlated with the amount of treatment or time spent on treatment. Once a nebulizer is set up, adding mucoactive therapy to inhaled antibiotic in that session may add minimal extra burden. The ACtiF trial,⁵ the largest CF randomized controlled trial in the UK, created a habit formation intervention that increased the amount of inhaled medicines taken whilst reducing perceived burden.

REFERENCES

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