EE147

# "I'll Live Less, You'll Live Better, Let's Make It Count": A Qualitative Exploration of Drivers & Barriers for Sacrificing Remaining Life Expectancy to Restore Relatives to Full Health in Time Trade Off Exercises

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## Objectives

- Time trade off (TTO) exercises ask respondents to make trade-offs between length of life and quality of life. TTO exercises are commonly used in utility assessment for use in Health Technology Assessments (HTAs) in drug access decision-making.
- This study was part of a larger study to explore the use of TTO exercise to estimate **non-patient utilities for use in health economic evaluations** (Poster EE448). Previous comparable research showed people may sacrifice large quantities of their remaining life expectancy to restore a family member's health (Krol et al., 2022). However, the reasoning behind these very large trade-off were not understood.
- We sought to better understand respondents' answers to TTO exercises where respondents were asked to sacrifice a part of their own life expectancy to restore a family member's health and factors influencing the trade-offs made.

## Methods

- Semi-structured interviews lasting 45-minutes were conducted remotely with participants from the general population in the United Kingdom (UK).
- TTO exercises were tested with participants (**Figure 1**) describing hypothetical scenarios relating to restoring non-healthy family members (child/partner/parent/grandparent) to full health from moderate and severe health states.
- Questions related to understanding of each exercise, how they would respond (how many years of their remaining life expectancy they would sacrifice) and factors impacting their response.
- Remaining life expectancy was calculated as 87 years minus their current age in line with UK average life expectancy.
- Thematic analysis was used to identify themes in participant responses.

## Results

- Participants (N=10) were male (n=6) or female (n=4). Most did not currently live with a non-healthy family member (n=7). Participants demonstrated good understanding of the TTO exercises, with only minor suggestions for changes/improvements, which were applied to the final exercises as needed (Poster EE448).
- The largest sacrifices (average: 83% of remaining life expectancy) were to restore a child to full health from a severe health state, and the smallest sacrifices (average: 8% of remaining life expectancy) were to restore a grandparent to full health from a moderate health state (**Figure 2**).
- Participants most frequently reported that the degree of pain or discomfort (n=6) experienced in the health state was an important determinant of how they responded.
- Factors impacting the hypothetical number of years to be sacrificed were organized into drivers (n=17; **Figure 3**) and barriers (n=18; **Figure 4**).
  - Key drivers were **altruism** (including improving relatives' quality of life), **benefits for self** (including avoiding providing care for a relative), and the **mutual benefit of having quality remaining time together**.
  - The relative's age, the quality of the relationship with the relative, and one's own goals and ambitions were both **drivers <u>and</u> barriers depending on the context.**
  - When thinking about partners, parents, and grandparents, some participants (n=5) were willing to **balance** their sacrifice with what they expected to be the remaining life expectancy of the relative. For example, if they felt their relative had 5 years remaining life expectancy, they would sacrifice 5 years. They reported that giving any more years than what the relative likely had left anyway would not be a *'fair exchange'* or a *'sensible trade'*.

## Conclusions

- The TTO exercises were well-understood by participants.
- These results are consistent with other research showing that respondents (both general population [Poster EE448], and those living with non-healthy family members [Krol et al., 2022] might be willing to sacrifice large proportions of their remaining life expectancy to restore a non-healthy family member to full health.
- Many factors influence the sacrifices one might hypothetically make to restore a relative to full health.
- Altruism was a strong driver and was the only factor reported by all 10 participants. The strong influence of altruism may need to be corrected for to use this TTO approach to elicit non-patient utilities in order to avoid double counting effects in cost utility analyses.

Participant IDs: Order of recruitment – Age of participant – Sex (M=Male, F=Female) – Parental status (C=Has children, NC= Does not have children) – Currently living with non-healthy family member (Y=Yes, N=No)

References:

Krol, Voronetska, & Batchelder, 2022. Willingness to trade off life years or accept risk of dying in time trade-off and standard gamble exercises to restore the life of a non-healthy family member: Considerations for measurement of non-patient utilities. Value in Health, 25(12), Supp S3.

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### Figure 1. Example TTO exercise

Now imagine that you live with a **non-healthy partner**. Your **partner** would be in the health state described below:

**Health state 1.**
- Your **partner** has severe problems in walking about.
- Your **partner** has moderate problems with washing or dressing oneself.
- Your **partner** has severe problems doing their usual activities (e.g., work, study, housework, family or leisure activities).
- Your **partner** has no pain or discomfort.
- Your **partner** is moderately anxious or depressed.
- Your **partner** will be in this health state for the rest of their life.

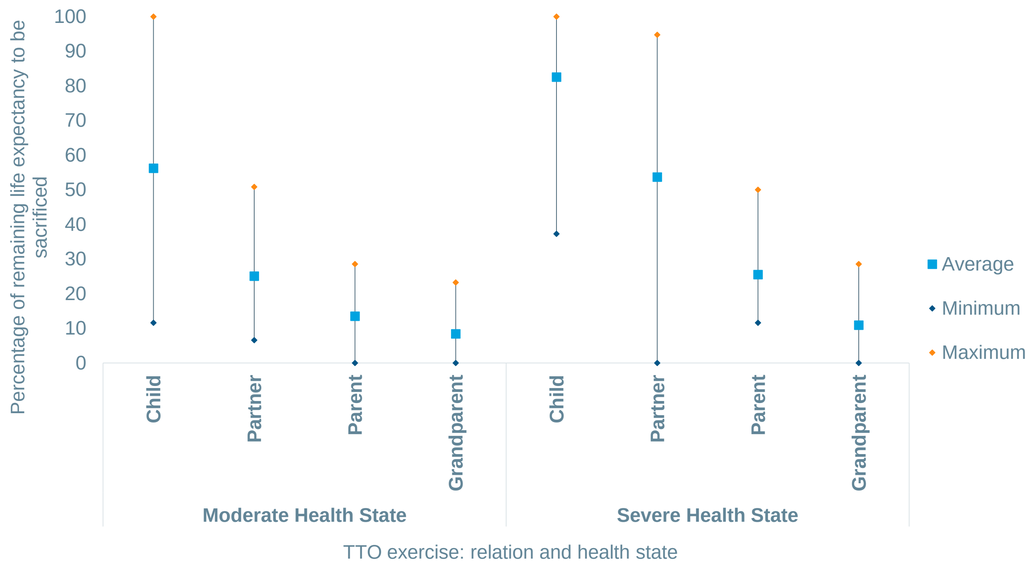
Imagine that a new treatment is available to restore your partner's health. The new treatment will consist of you donating an organ to restore your **partner's** health.

The organ donation will not affect your overall health, but it will potentially shorten your life expectancy. There are no other risks involved with donating this organ.

Please assume that you would live another X years. (X = Average UK life expectancy – age of respondent)

**How much time of your remaining life span would you be willing to sacrifice for your partner to be fully healthy again by donating an organ? Please assume your remaining life span is X.**


### Figure 2. Percentage of remaining life expectancy participants were willing to sacrifice to restore relatives to full health from moderate and severe health states




### Figure 3. Factors increasing years sacrificed (drivers)

*"If there was anything wrong with her, straight away yeah, I'd give her the rest of whatever I had left so she could have a long life… I'd want her to have a good long life."* (07-39-F-C-N)

*"If I don't do everything I can to make it better, then I have regret. Yeah, I'd blame myself I suppose… Because I know that living with the guilt afterwards of, "Oh, you could have done more" would actually be worse."* (03-47-NC-N)

**Benefits for others (altruism)**
- Improving relative's QoL (n=10)
- To improve lives of those caring for relative (n=2)
- Want to help others (n=2)
- To improve quality of life of extended family (n=1)
- To give back to relative (parent) for what they've done for them (n=1)

**Benefits for self**
- To avoid providing care for relative (n=7)
- To avoid feelings of guilt or regret (n=3)
- Companionship received from relative (partner) (n=3)
- To avoid seeing relative suffer (n=3)
- To improve own quality of life (n=2)

**Other factors**

**Own desires and ambitions**
- Participant satisfied with the life they have lived (n=5)
- Participant does not want to live to very old age (n=2)

**Relationship with relative**
- Feel responsibility for relative (n=7)
- Quality of Relationship (more willing to give if have had a good relationship) (n=2)

**Age of relative**
- Relative has long life ahead of them (n=3)
- More difficult to adapt to health issues later in life (n=1)

**Mutual benefits**
- To have quality remaining time together (n=9)

*"…if you give a little bit, then you might have a good few years, then you could enjoy life together."* (02-67-F-C-Y)

*"…ultimately, you'd give your life for your child and that's exactly what this is, really."* (01-44-M-C-N)

### Figure 4. Factors decreasing years sacrificed (barriers)

*"I think it would have to balance what I was sacrificing with the likelihood of, well, the realism of their life expectancy."* (05-44-M-C-N)

*"I would think that my parents would probably not want me to sacrifice any time."* (01-44-M-C-N)

**Age of relative**
- Relative does not have long remaining life expectancy (n=9)
- Relative has already lived long life (n=7)
- Health state described reflects natural aging (n=4)
- Relative may experience other health issues due to age (n=4)
- Partner has already reproduced (n=1)

**Relationship with relative**
- Relative would not want them to sacrifice (n=3)
- Quality of Relationship (less willing to give if have had a bad relationship) (n=2)

**Adaptability of health state**
- Health state is liveable (n=4)
- Relative can be supported in other ways (n=3)
- Relative can adapt to health issues (n=2)

**Own desires, ambitions and responsibilities**
- To spend more time with own immediate family (n=4)
- Not respondent's responsibility (n=3)
- To spend more time with relative (n=2)
- To see relative restored to full health (n=2)
- To be around to support partner (n=2)
- Consider things they would like to experience in own life (n=1)

*"It's because of the condition that's being described. What's more liveable. It's not so life changing."* (06-61-M-C-Y)

*"If I can give an organ to support someone else. I'd like to enjoy a bit of that life with them, especially when it's maybe it's sort of a close relative, partner, and granddad, and parents."* (09-23-M-NC-Y)