This editorial refers to Who are the patients with early arthritis with worse than death scores on the EQ-5D? Results from the ESPOIR cohort, by Cécile Gaujoux-Viala et al., doi:10.1093/rheumatology/kes270, on pages 832–8.

In this issue of Rheumatology, Gaujoux-Viala et al. [1] studied a cohort (ESPOIR) with early rheumatoid arthritis (ERA) where 813 patients were followed up for more than 2 years and rated their quality of life (QoL). This valuable study demonstrates that initially 11% and later 3.3% have a utility that is worse than death, which translates as death being a better quality of life than their current RA status.

The EuroQol (EQ) is a QoL instrument that has been studied in RA [2–4]. The EQ-5D is completed by the patient and requires one answer (with three choices) in five domains (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). There is also a scale from 0 to 100 with anchors of worst imaginable health state at 0 (death) and best at 100 [2]. The answers are no problem, somewhat of a problem, a moderate problem or unable to do. Patients do not actually rate worse than death. Results are interpreted from an algorithm linked to average values obtained from the general population using a time trade-off method [5], allowing for negative utility (values worse than death; <0 to 1). In the ESPOIR cohort, the EQ was used. The majority of those rating worse than death were close to 0, so if the cut point was lower for worse-than-death utility; then they would not have a negative utility [1]. As a comparison, the EQ was previously tested in another study on approximately 500 RA, 500 fibromyalgia and 300 OA patients [4]. QoL was similar in OA and RA but worse in fibromyalgia. However, the instrument had validity problems. Patients did not have a continuous Bell curve distribution, with gaps in the distribution where a small proportion of patients had worse-than-death values, another cluster had values of 0.5–0.8 and another cluster had values of 1.0 or perfect health. The EQ health utilities showed scores worse than the EQ visual analogue scale (VAS) and the global severity scale [4].

The ESPOIR study did not document if patients with poor QoL had fibromyalgia. Patients with fibromyalgia in the Wolfe study had a lower QoL than RA [4]. In the ESPOIR study, those with a negative QoL had higher HAQ scores and worse mental health scores [1]. The incidence of fibromyalgia in ERA is increased in the Canadian (CATCH) cohort and is higher in the first year than the second year after ERA diagnosis [6]. The development of fibromyalgia was related to pain and poor mental health, both of which would have a negative effect on QoL. Perhaps pain and fibromyalgia contribute strongly to worse-than-death QoL and not inflammatory arthritis in the ESPOIR cohort. Interestingly, in the regression model from the ESPOIR cohort, pain, fatigue, disease activity and low education (<12 years of education) were not statistically significantly associated with QoL, but were in the univariate analyses. This result could be used as an argument against concomitant fibromyalgia being the reason for worse-than-death QoL.

A strength of the Gaujoux-Viala study is that utilities were derived from population controls in France [7]. This article can be interpreted within the context of the patients included and the methods. For bivariate analysis, \( P < 0.2 \) was used to include items in the regression model. It is unlikely that the results would vary widely if a lower \( P \)-value for item inclusion was chosen, as most items would be included in any model.

Due to the small numbers in this article, it is difficult to compare patients who had a negative utility consistently over time (only three patients over 2 years and five over 1 year) with those who improved utility from negative to \( \geq 0 \) with respect to clinical parameters, socioeconomic status and perhaps treatment. There is variability in utility ratings or adaptation over time to a new disease state or treatment, which helps decrease the worse-than-death utility, as the numbers in a worse-than-death state decrease over time.

Patients probably adapt to their health state, especially rating worse QoL in early disease onset than later (when they get treatment or get used to their state, or both). Patients with RA who have more pain need more improvement in pain to consider themselves improved compared with those with a lower baseline pain rating [8]. Most patients with initial negative QoL ratings (11%) do not maintain that state over time, whereas at any time after the initial rating, some patients (3% approximately) are in this negative state. This article did not collect data on treatment for problems such as pain, anxiety and depression that could have affected changes in QoL over time [1].

A study was done on the stability of fates worse than death in the elderly, asking them about hypothetical states of impaired health. Only moderate stability was found over
a mean of 11 months between performing the question-naire for severe impairment, where many who judged the state as worse than death changed their response to better than death at follow-up, especially if there was a longer interval between the first and second administra-
tion of the questionnaire [9]. This demonstrates that people do change (mostly improve) their determination of worse than death to better than death over time.

The problems with unstable QoL for worse-than-death proportions [1], the abnormal distribution of the EQ-5D [4] and the transformation of data to population norms for cost-effectiveness data make the values in RA suspect, as the skewing to negative utilities has implications on cost when in fact there was not a choice of worse than death in the questionnaires and VAS that the patients completed. Using a utility from the first visit will result in the highest costs, as that is when most patients rate worse than death; and interestingly, the first year of ERA has a higher incidence of fibromyalgia than subsequent years [6].

Perhaps research could involve obtaining actual utilities from RA and ERA patients asking them about their QoL with a scale that allows for values that are worse than death (i.e. changing the 0 to 1 scale to perhaps −0.25 to 1). This, however, would be different from the current method of using values calculated from the general popu-
lation and would probably give far fewer worse than death results, as the general population often rate a condition worse than those living with a chronic disease, as the latter adapt over time or perhaps change their judgement of QoL with experience of a disease.

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