A Study of the Relationship Between Health and Subjective Well-being in Parkinson's Disease Patients

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ABSTRACT

Objectives

Governments are turning their attention to evidence on subjective measures of well-being to inform policy decisions. In the context of health, there is therefore growing interest in understanding how measures of health-related quality of life relate to subjective well-being, and whether subjective well-being could provide a basis for resource allocation decisions in the future. This study investigates the relationship between health-related quality of life, as measured by EQ-5D, and subjective well-being in Parkinson's disease.

Methods

A paper questionnaire including EQ-5D, four key subjective well-being questions taken from the Integrated Household Survey in England and other demographic details was distributed to people with Parkinson's disease in the UK. Responses were used to estimate multiple regression models explaining subjective well-being using the EQ-5D Index (UK weights), EQ-5D dimensions and EQ-VAS and patient socio-demographic characteristics.

Results

A total of 199 responses were received. Combining EQ-VAS and EQ-5D dimensions, especially anxiety/depression and, to a lesser extent, mobility, yielded the best-fitting models (adjusted R2 range 0.36-0.53). Parkinson's disease patients living in care homes report lower levels of subjective well-being than those living alone. These effects are not captured by the health-related quality of life measures in the analysis.

Conclusions

Usual health-related quality of life measures can partially explain different well-being dimensions, yet they fail to capture part of the broader impact of disease on subjective well-being. Further empirical research into the relationship between subjective well-being and EQ-5D longitudinally, and in different disease areas, is required, and further standardisation of subjective well-being measures is recommended.

INTRODUCTION

Governments across the world, including the UK government [1], and bodies such as the Organisation for Economic Co-Operation and Development (OECD) [2], are increasingly using evidence on subjective measures of happiness as a way of informing decisions about a wide range of public policies.

In the context of the health care sector, this has generated considerable interest in understanding how measures of health-related quality of life (HRQoL), which are widely used to inform decisions about pricing and reimbursement of health care technologies, relate to these measures of happiness or subjective well-being (SWB), and whether the latter might provide a basis for resource allocation decisions about health care in the future. This raises fundamental questions about what the purpose of health care is - to improve health or to improve happiness - and how those outcomes are best measured. For example, does the EQ-5D [3] - a generic measure of HRQoL which is recommended by NICE for use in evidence submitted to its health technology assessment (HTA) process [4] and widely used internationally- capture some aspects of SWB? Which specific dimensions of the EQ-5D relate to which measures of SWB? What aspects of SWB are missed by the EQ-5D?

Some evidence on these questions is available. For example, a number of papers have attempted on the use SWB in *valuing* HRQoL states described in terms of the EQ-5D and SF-6D (as an alternative to current approaches used to value HRQoL states, such as the Time Trade Off) [5-8]. Studies have also explored the extent to which various conditions contribute most to unhappiness. [9] However, to date there has been little detailed examination of the relationship between dimensions and levels of EQ-5D (the EQ-5D profile) and SWB by disease area; how patients' overall assessment of their own health on the visual analogue scale (EQ-VAS) relates to their self-reported SWB, and how these relationships differ across different aspects of SWB that might be measured.

Answering these questions is complicated somewhat by the lack of standardization in the use of the term SWB, the "new science" of SWB, as Layard describes it [10], having emerged relatively recently.

For instance, the terms "happiness" and "subjective well-being" are often used interchangeably [11], although they are not identical according to most definitions. For example, happiness has been described

as equivalent to life satisfaction, quality of people's lives [11] or experienced utility [12]. On the other hand, SWB is frequently used as an umbrella term for how we feel ("affective happiness") and think ("evaluative happiness" or "rewardingness") about life [11]. Recent recommendations from OECD [13] distinguish three different components of SWB: **evaluative** (reflective assessment of life "as a whole" or an aspect of it), **affective** (experience or feelings) and **eudaimonic** (functioning and realisation of the person's potential). Many different instruments have been developed to measure the various nuanced definitions of SWB. A comprehensive collection of the available instruments can be found in Helliwell et al [11], and different guidelines providing advice on the collection and use of such instruments can be found in OECD [13]. In this paper we viewed SWB as a broad concept that encompasses the three components.

In the UK, subsequent to a public consultation and advice from academics, the following SWB questions on an ordinal scale of naught to ten were defined for inclusion in the ongoing Integrated Household Survey beginning in April 2011 [14]:

1. Overall, how satisfied are you with your life nowadays?
2. Overall, to what extent do you feel that the things you do in your life are worthwhile?
3. Overall, how happy did you feel yesterday?
4. On a scale where nought is "not at all anxious" and 10 is "completely anxious", overall, how anxious did you feel yesterday?

Question 1 is intended to capture the evaluative component. Question 2 represents the eudaimonic dimension. Question 3 and 4 may be the basis for the second dimension ("affective") in terms of positive and negative affect [11].

SWB determinants suggested by Helliwell et al [11] embrace a wide variety of factors, for example income, quality of governance, day-to-day joys, trust in one's community, and having someone to count on in times of difficulty. Among all the factors influencing SWB, health obviously plays an important role, and HRQoL is frequently considered as a key dimension of SWB. Since SWB is a broader concept, and captures the individual's own experience of their well-being, advocates of SWB would argue that using

SWB to value health improvements could in theory address many of the limitations of measures of HRQoL. For example, SWB has the potential to be used more broadly as a measure of benefit across different sectors (e.g. across health and social care services), as arguably increasing well-being should be the ultimate goal of most, if not all, government policies whether in health or any other sector. Thus, concerns about whether widely used measures of HRQoL—such as the EQ-5D—are missing dimensions of health that are relevant to patients also is addressed, as individuals would implicitly include these in their own assessment of SWB. However, how SWB relates to HRQoL, and particularly to the EQ-5D, has not been widely studied.

The primary aim of this exploratory study was therefore to investigate the relationship between HRQoL (as measured by both the EQ-5D profile and patients' overall rating of their health on the Visual Analogue Scale or EQ-VAS) and SWB scores (on the four key Office for National Statistics –ONS- questions described above) in a given health condition. The population chosen for this analysis is Parkinson's Disease (PD) patients. PD is a progressive neurodegenerative disorder affecting approximately 120,000, or 1 in 500, people in the UK. The condition is characterized by disabling motor symptoms, including tremor, rigidity and slowness of movement, often accompanied by non-motor symptoms including pain, depression and anxiety, constipation and fatigue.

This patient cohort is interesting for a number of reasons. First, although EQ-5D appears to work reasonably well as a measure of HRQoL in PD [15], no previous research explored how the UK SWB measures perform in this group of respondents. Second, PD is a good example of a disease area for which the usual measures of HRQoL may fail to capture part of the wider impacts of the disease on SWB. For instance, SWB determinants suggested by Helliwell et al [11] as "having someone to count on in times of difficulty" or "trust in one's community" may not be captured by usual measures of health or utility. We analysed the degree of correlation of proxies for these determinants and SWB for PD patients, with and without controlling for health related factors. If significant differences were found, this would be an indicator that the extent to which a disability affects subsequent well-being depends not just on the severity of the disability, but also on other factors, and the extent to which patients are enabled in

maintaining their social connections. If so, the paper would provide some insights in the appropriateness of using SWB measures as a complement for health resource-allocation in the near term.

METHOD

The Questionnaire and Data Collection

A paper questionnaire was developed for self-completion by individuals with a diagnosis of PD in the UK. The questionnaire included the following items.

1. Demographic questions (age range, sex, years since diagnosis, marital status, employment status, household situation, education). Income data were not collected due to concerns that this might adversely impact the response rate [16]. A tick-box format was used for ease of completion.

2. The EQ-5D-3L instrument [3], including both the patients' EQ-5D health profile and the patient's overall assessment of their health on a visual analogue scale (the EQ-VAS, from 0–100, representing worst- and best-possible health respectively). The EQ-5D health profiles also can be summarised by a single number representing the relative value of that health state on a scale anchored at 1 (full health) and 0 (dead). The value set used for this purpose in this study is the UK value set reported by Dolan [17].

3. The four SWB questions taken from the Integrated Household Survey, as shown in the introduction, and adapted from the verbal interviewer script into a written format to enable self-completion.

Two versions of the questionnaire were developed, in which the order of the EQ-5D and SWB questions were alternated (50:50 split) to control for ordering effects.

Two strategies were used to contact potential participants:

1. Attendance at seven local Parkinson's UK support group meetings and three larger regional Parkinson's UK forum meetings in the southeast of England where objectives of the research

were presented and questions answered. Questionnaires then were distributed to interested members.

2. An email sent to the Parkinson's UK's on-line research network inviting interested members to request a questionnaire by post. Stamped, addressed envelopes were provided for returns. Participants were assured that their responses would be anonymous and participation voluntary. The questionnaire took approximately ten minutes to complete.

Analysis

Participants' responses were analyzed using Stata12. Initially descriptive statistics were performed on each of the independent SWB variables and the dependent variables individually.

- *Regression models*

The SWB data collected are ordinal, i.e. ranked data, rather than cardinal in nature. Since ordinal measures of health are one of the most commonly used indicators, a wide variety of techniques have been developed to make the responses suitable for different regression analyses. The present study uses two different approaches. (A thorough discussion of the measurement scale of health variables can be found in Erreygers and van Ourti [18]).

1. Direct assumption of the existence of a cardinal scale at the response level: the SWB will be interpreted as a continuous value from 0 to 10 with ratio properties (e.g. a difference between the categories 2 and 3 in a SWB measure equals the difference between the categories 4 and 5). This assumption is consistent with the large number of categories in the SWB answers, and it supports the use of common parametric methods as ordinary least squares regression.

2. Projection of continuous, cardinal scales on ordinal measures: we assume the existence of a latent, unobservable well-being variable that is distributed in a particular way across the different categories (e.g. changes in the degree of well-being between two categories are explained in terms of changes in the values of the latent variable). A typical example of this approach is the

ordered probit/logit regression models, as can be found, for instance, in Van Doorslaer and Jones [19].

Health measures of a general population sample usually have a skewed distribution with the great majority of respondents reporting their health towards the high end of the scale. A similar outcome could be expected for well-being measures since (our hypothesis is that) health is a key factor at explaining SWB. This study collects data from PD patients rather than the general population, but skewness in the distribution of most of the SWB variables still is apparent (see Figure 1). This suggests that SWB may better fit the assumption of a skewed distribution. To ensure that the SWB variable (*y*) is skewed in the appropriate direction (for life satisfaction, life worthwhile and happiness dimensions; this change does not apply to anxiety), we need to invert the 0-10 scale and derive a mirror-image "subjective unwell-being" variable (*h*, where *h = 10- y*) that will more closely follow a standard log-normal distribution. A similar method has been applied to health ("ill-health"), e.g. in Cubi-Molla and Herrero [20].

Three types of regressions have been developed to model the distribution of each of the SWB questions. For that purpose, the interpretation of the coefficients will be the most interesting feature from our perspective. Therefore, other issues like retransformation methods for the analysis of the expected values or issues related to truncation or censoring are ignored here.

The first model ("OLS Normal") is the simple ordinary least squares (OLS) regression

$$y = x'\beta + \varepsilon, \quad \varepsilon|x \sim N(0, \sigma^2)$$

where x is the vector of covariates including HRQoL measures, socio-demographic variables and the constant term. This model assumes continuity in the SWB variable and the coefficients have an easy quantitative interpretation. However, the model rules out the existence of skewness.

The second model ("OLS LogNormal") consists of a modification of the first one, still assuming continuity in SWB but now allowing for skewness in the distribution.

$$ln\,(h) = x'\beta + \varepsilon, \quad \varepsilon|x \sim N(0, \sigma^2)$$

The third model ("OPM") is an ordered probit model with well-being as a latent variable, treating SWB as a categorical measure and assuming normal distribution of the error term, conditional on the covariates:

$$y^* = x'\beta + \varepsilon, \quad \varepsilon|x \sim N(0,1)$$

$$y = k \in \{0,1,\ldots,10\} \; if \; \alpha_k < y^* \leq \alpha_{k+1}, with \; \alpha_0 = -\infty, \alpha_{11} = +\infty$$

- ***Explanatory variables***

Four different specifications of HRQoL were used for each model: (1) EQ-5D TTO index [17]; (2) dummy variables for the EQ-5D levels in every dimension; (3) EQ-VAS; and (4) dummy variables as well as EQ-VAS.

Each model also controlled for different factors that may affect the self-valuation of the well-being. We were interested in particular in analysing one of the SWB determinants suggested by Helliwell et al. [11], "having someone to count on in times of difficulty". To capture this, we used household composition as a proxy. Our hypothesis was that patients living alone would report lower SWB levels than those living with partners or relatives, or in care homes, and that this effect would not be captured by the HRQoL measures. The models also controlled for the number of years since diagnosed, the age, gender and education of the respondent.

The results of the approaches were summarized and compared. The coefficients were be used to investigate the relationship between HRQoL and SWB in PD patients.

RESULTS

Participants

A total of 276 questionnaires were distributed and 199 participants responded (response rate 72%). Of the respondents, 118 (60%) participants were male and 78 (40%) female, although incidence of PD is similar in men and women. About 80% of participants were over the age of 61, consistent with the mean

age of onset of around 65. Approximately 81% of participants lived with a spouse or partner, representing relatively high levels of social support from informal carers. About 47% of participants had a recent diagnosis in the past five years, and a further 27% in the last six to ten years. A summary description of the relevant variables is provided in Table 1.

(Table 1 about here)

Descriptive Statistics of Health and Well-being

As anticipated, a large proportion of patients (58%) reported that they suffered from at least moderate anxiety and depression. The majority of participants also reported moderate problems with mobility, usual activities and pain/discomfort (see Table 2).

(Table 2 about here)

Table 3 and Figure 1 show summary descriptive statistics and histograms of the distribution of the main variables of the study. Table 3 also includes the descriptive statistics in the first release of the SWB data collected by the ONS opinions survey, which was made available in December 2011 [21]. PD patients reported on average poorer SWB scores than the general population (though we do not control for e.g. age or gender). We can also observe that for PD patients, "life satisfaction", "life worthwhile" and "happiness" scores performed similarly in skewed distributions, with mean values around 6.5 and standard deviations around 2 points. At face value, they also appeared to behave similarly in the EQ-VAS. The EQ-5D index had a different shape, displaying a bimodal distribution that is characteristic in patient populations and had a higher standard deviation [22].

(Table 3 about here)

(Figure 1 about here)

"Anxious yesterday" scores behaved differently from all other measures, and had a quite different distribution. On closer inspection of the raw data, it was found that many of those reporting high levels of SWB in terms of life satisfaction, life worthwhile and happiness were also reporting high levels of anxiety. To find people scoring differently in each measure may be highlighting the importance of incorporating the fourth question (anxiety) into the valuation of SWB. However, we should take this interpretation with caution. That is because an alternative explanation may be that the scale used for anxiety is the inverse of that of other SWB questions (i.e. 0 =not at all anxious, the best possible state, whereas for the other SWB questions, 0= not at all satisfied, worthwhile or happy respectively, the worst possible state), which was counter-intuitive and suggested misinterpretation of the scale. This second interpretation is in some way supported by an analysis of SWB anxious scores by EQ-5D anxiety/depression dimension level, whereby it was observed that some non-anxious/depressed individuals had high SWB anxious scores, and some moderately anxious/depressed individuals reported low SWB anxious scores. Therefore the analysis of the SWB-anxiety dimension was included in the paper, but the potential interpretations of the results should be taken with caution.

Multiple Regression Analysis

Results for each of the models estimated for the four SWB variables are reported in Appendix Tables A1–A4.

Comparing results for every SWB question, we can observe that all the models displayed some similarities in terms of the significance of coefficients and direction of the effect (note that OLS LogNormal regression for "life satisfaction", "happiness" and "life worthwhile" results are expressed in terms of effect on ill-health). This result is consistent with other papers as Ferrer-i-Carbonell and Frijters [23], who found evidence that the assumptions on cardinality/ordinality of the variable "happiness" make little difference on the statistical significance and qualitative interpretation of the coefficients.

For "life satisfaction", "happiness" and "life worthwhile", the adjusted R^2s and pseudo R^2s suggest that EQ-VAS performed better than EQ-5D in explaining SWB both in terms of the index values and its

individual dimensions. The models with the best explanatory power, however, were achieved by combining the EQ-VAS and significant dimensions of the EQ-5D (see columns “EQ-5D and EQ-VAS” in the Appendix Tables A1–A3). This outcome is not observable in the “anxiety” dimension, as it will be explained later.

Overall, the model results for “life satisfaction” (Appendix Table A1) are as follows. Regardless of which model we used (OLS or OPM), the EQ-5D TTO Index appeared to be the least useful of the HRQoL variables in explaining the variance in “life satisfaction”. Only the dimensions of pain/discomfort (level 3) and anxiety/depression (levels 2 and 3) were statistically significant across models, in addition to the dimension of usual activities (level 3) in the OPM.

All the OLS Normal models for “life satisfaction” rejected the assumption of normality, and only two of the OLS LogNormal models did not reject it. This suggests that the distribution of “life satisfaction” was certainly skewed. Therefore, the OLS Normal models may not be capturing the distribution properly, despite having a better goodness of fit.

Several socioeconomic factors that usually correlate with HRQoL indicators—such as education, gender or employment status—were not statistically significant in the regressions. However, the household composition seemed to be an important explanatory factor for life satisfaction. In particular, PD patients living with a partner or with other family members report greater life satisfaction than those living alone. This could support the hypothesis suggested by Helliwell et al. [11] that “having someone to count on in times of difficulty” is a key determinant of SWB. It is also notable that patients living in health care homes reported lower life satisfaction levels than those living alone. This result was not expected to be affected by the severity of the illness or by the number of years with PD, since these variables were not statistically significant in the models.

The model results for the SWB variable “life worthwhile”, shown in Table A2, were as follows.

The feeling was that “life is worthwhile” is apparently more difficult to model and explain than feelings of life satisfaction, with (pseudo) R^2s that are somewhat lower. The hypothesis of normal distribution of the residuals was not rejected, so that the OLS Normal distribution appeared to fit the data better. Again,

combining EQ-VAS and dimensions of EQ-5D yield the best-fitting models. Only anxiety/depression (levels 2 and 3) and mobility (level 3) were significant in explaining the sense of life being worthwhile. Household situation was again a consistently significant socioeconomic variable, with the same direction of the effects as that for “life satisfaction”. The model assuming an OLS LogNormal distribution showed that age above 50 seems to be directly correlated with life satisfaction, which may suggest that the relationship between life satisfaction and age could be U-shaped –with the minimum occurring around the age of 50-, as others have also suggested [24]. The same association was shown by the OLS Normal regression, but not by the OPM one.

With respect to the models for “happiness” (Table A3), again the OLS Normal model combining EQ-VAS and EQ-5D dimensions explained happiness the best. Similarly to the life-worthwhile models, mobility (level 3) and anxiety/depression (levels 2 and 3) seemed to be the only EQ-5D dimensions that could explain part of the happiness. Interestingly, and in contrast to the “life satisfaction” and “life worthwhile” models, living with a spouse or family was no longer significant, perhaps illustrating the multi-dimensional nature of SWB, and suggesting that having family may be worthwhile, but may not necessarily contribute to happiness. Living in a care home was, however, associated with significantly lower levels of happiness in some of the models, as was true in the other SWB dimensions. Age of the patient was also significant here in some of the models, suggesting again that older patients are more likely to report a higher category of happiness than younger ones, regardless of the number of years since diagnosis.

In the regressions for “anxiety” (Table A4), the EQ-5D dimension for anxiety/depression was found to be significant, as expected. For instance, under the OLS Normal assumptions, a patient reporting “I am extremely anxious or depressed” will be expected to choose a level of SWB “anxiety” four points higher than a patient reporting “I am not anxious or depress”. In the same way, having problems with performing the usual activities are associated with higher levels of SWB “anxiety”. Mobility and pain/discomfort were not significant anymore, contrary to what was observed in the previous SWB dimensions. EQ VAS, when used as the only health-related control variable, was found to be significant (same as EQ-5D TTO tariff). However, it was not when used in combination with the EQ-5D dummies. Contrary to “life satisfaction”, “life worthwhile” and “happiness”, EQ-5D dimensions performed better than EQ-VAS in explaining SWB

“anxiety”. Living in a care home was associated with significantly lower levels of anxiety in most of the models, as in the other SWB dimensions. To a lesser extent, patients more than 20 years diagnosed were associated with lower categories of anxiety.

The dimension of SWB for “anxiety“ produced some startling results, as well. Being unable to wash or dress themselves was associated with lower level of anxiety, compared to those with “no problems in self-care today”. This result was observable across the different models. Since such anomaly can be read as a potential misinterpretation of the SWB anxious scale by the respondents, these results should be taken with caution.

DISCUSSION

The purpose of the study was to examine the strength of the relationship between EQ-5D and SWB as defined and measured by the ONS HIS [14]. The analysis has focused on people with PD, a disease for which the usual measures of HRQoL may fail to capture some of the broader impact of a chronic condition on SWB.

Regression analysis determined that EQ-5D, both its index and dimensions, have a moderate explanatory power for SWB in PD in terms of life satisfaction, life being worthwhile, happiness and anxiety; adjusted R^2s in the OLS models ranged from 0.13-0.40 (OLS Normal) and 0.12-0.36 (OLS LogNormal). It appeared that some dimensions, in particular self-care and ability to perform usual activities, were fairly redundant in explaining SWB (with exception of the “anxiety” dimension) . In contrast, symptoms such as anxiety/depression and, to a lesser extent, pain/discomfort and mobility, were more important. The statistically significant coefficient was typically associated to level 3 and, in some cases, also to level 2. Thus more severe health states seemed to have a higher impact in the SWB measures, compared to lesser deviations from “full health”. Interestingly, the EQ-VAS performed generally better than the EQ-5D index, with adjusted R^2s in the range 0.36-0.45 (OLS Normal) and 0.32-0.49 (OLS LogNormal) for “life satisfaction”, “life worthwhile” and “happiness”. Combining the EQ-VAS and EQ-5D dimensions into one model yielded the best results with R^2s in the range 0.40-0.49 (OLS Normal) and 0.36-0.53 (OLS LogNormal).

It is interesting to reflect on why the EQ-VAS should have performed better than the EQ-5D in predicting SWB. First, if there are any aspects of HRQoL important to people but not reflected in the EQ-5D dimensions, then this will act to influence the EQ-VAS, and probably SWB also. Second, as the EQ-VAS is the overall assessment of their own (experienced) health state rather than the valuation of that individual's EQ-5D profile by members of the general public, intuitively it will be closer to SWB, which is also self-rated, and may take account of phenomena such as adaptation, which EQ-5D does not reflect.

Another important finding of the research is that OPM and OLS regressions of SWB look similar in terms of the significance of coefficients and direction of the effect, suggesting that the SWB data, although strictly speaking ordinal, behaves similar to cardinal data on an interval scale, i.e. in a linear fashion. This result is consistent with other authors' as Ferrer-i-Carbonell and Frijters [23]. As such, it would be tempting to treat SWB as interval data in future research. Dolan [6] supports this view, suggesting the area under a happiness curve over time could be summed, in the same way that QALYs are derived, although it would not represent the same value as a QALY. However SWB questions are not anchored in the same way as, e.g. EQ-5D, that is by "dead" and "perfect health", leading to potential problems of interpersonal comparability. While it is difficult to conceive of anchoring SWB to death, other means of calibrating the scale, e.g. the use of SWB vignettes, might be considered in future to address this concern.

The results also suggest that usual measures of HRQoL fail to capture part of the broader impact of disease on SWB. We observe that household composition is an important explanatory factor for all the SWB dimensions. In particular, PD patients living with partners or relatives are more likely to report higher levels of SWB than those living alone. This result is systematically observed across the models. Thus, the SWB determinant suggested by the OECD as "having someone to count on in times of difficulty" does not seem to be captured by the EQ-5D-related measures. It is notable that patients living in care homes systematically report lower levels of SWB than those patients living alone, after controlling for age and years since diagnosis. This finding suggests concerns that should be explored in more detail.

In terms of the SWB "anxious" measure, respondents appeared to have some difficulty interpreting the question, probably given the change in direction of the scale compared to the preceding three SWB

questions. Interestingly, in the first release of the SWB data collected by the ONS opinion survey that was made available in December 2011, the SWB anxious scores had a similarly large standard deviation (SD) compared to our results, which was also larger than for the other SWB questions (see Table 3). This suggested that respondents to the verbally-administered BHPS survey had interpretation difficulties similar to the participants in our study; the format of the question therefore merits some reassessment.

These research findings have several implications. Although the relationship between EQ-VAS, EQ-5D and SWB in PD was not especially strong, a mapping exercise of EQ-VAS and appropriate EQ-5D dimensions onto SWB is not inconceivable if we take the step discussed above and treat SWB as interval-scale data. Brazier et al. [25] noted in a recent literature review of models mapping HRQoL instruments, both disease-specific and generic, that the explanatory power of models, mostly OLS, ranged from a poor 0.17 to 0.71. The OLS models generated in this research fit easily within this range. Such an exercise could potentially yield a wealth of information about the SWB benefits of health care interventions in the past, where EQ-5D and EQ-VAS data were originally collected, to inform future SWB based research and policy.

We should be mindful that the study had several limitations, including the focus on only one disease area, potential selection bias, cross-sectional design due to time constraints, lack of income data collected, the potential focusing effect of the way the happiness topic was presented to participants, and possible problems with participants misinterpreting the SWB anxious scale. Future research should aim to address these limitations, and potentially examine the relationship between EQ-5D and SWB in a more controlled setting and through time—for example, in clinical trials—and in a wider variety of disease areas. Consideration also should be given to mapping EQ-VAS and the EQ-5D index to SWB, as noted earlier. In the longer term, if SWB is to gain further support, then attempts should be made to further standardise its definition, similar to the generic HRQoL measures such as EQ-5D, and its collection should become more routine and widespread. Thought also should be given to anchoring SWB states, as previously mentioned.

CONCLUSION

The results of this pilot study indicate that the EQ-VAS, in combination with certain dimensions of the EQ-5D, particularly anxiety/depression and pain/discomfort, taken together with some demographic variables, can partially explain different SWB dimensions (life satisfaction, life worthwhile and happiness) both in PD and potentially in other diseases. Nevertheless, and as expected, given the different conceptual basis for the approaches, EQ-5D-related measures do not capture all the relevant factors affecting SWB. Evidence is strong that SWB determinants such as “having someone to count on in times of difficulty” or “trust in one’s community” may not be captured by the measures of health or utility typically used in health care decision making. These findings suggest there may be a role for using SWB, as a complement to conventional generic measures of HRQoL, as a basis for evaluations, where (1) interventions may affect both health and social care outcomes, beyond those captured by measures such as EQ-5D, and (2) where it is important to be able to compare outcomes and resource allocation across different areas of the public sector.

As the interest in SWB as a policy tool gathers momentum, proxies for it may be developed using existing data from generic HRQoL measures such as the EQ-5D profile and EQ-VAS. However, these conclusions require further substantiation through a larger body of empirical research into SWB and EQ-5D/EQ-VAS, in other diseases and through time. SWB definitions and measures may require further standardisation and refinement in order to ensure they provide a valid and appropriate basis for social policies.

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Table 1. Summary descriptive statistics for control variables

Years since diagnosed	**Ref**	N	%
less than 5 years	*	198	47.5%
6–10 years		198	27.3%
11–15 years		198	15.7%
16–20 years		198	6.1%
more than 20 years		198	3.5%
Age			
41-50	*	198	4.0%
51-60		198	15.2%
61-70		198	34.3%
71 or older		198	46.5%
Gender			
male		196	60.2%
Education			
beyond leaving school		195	67.7%
Household (with whom do you live?)			
alone	*	197	17.8%
with partner/spouse		197	76.2%
with other family members		197	3.6%
in care home		197	1.5%

Figure 1. Histograms of EQ-5D index, EQ-VAS and SWB scores

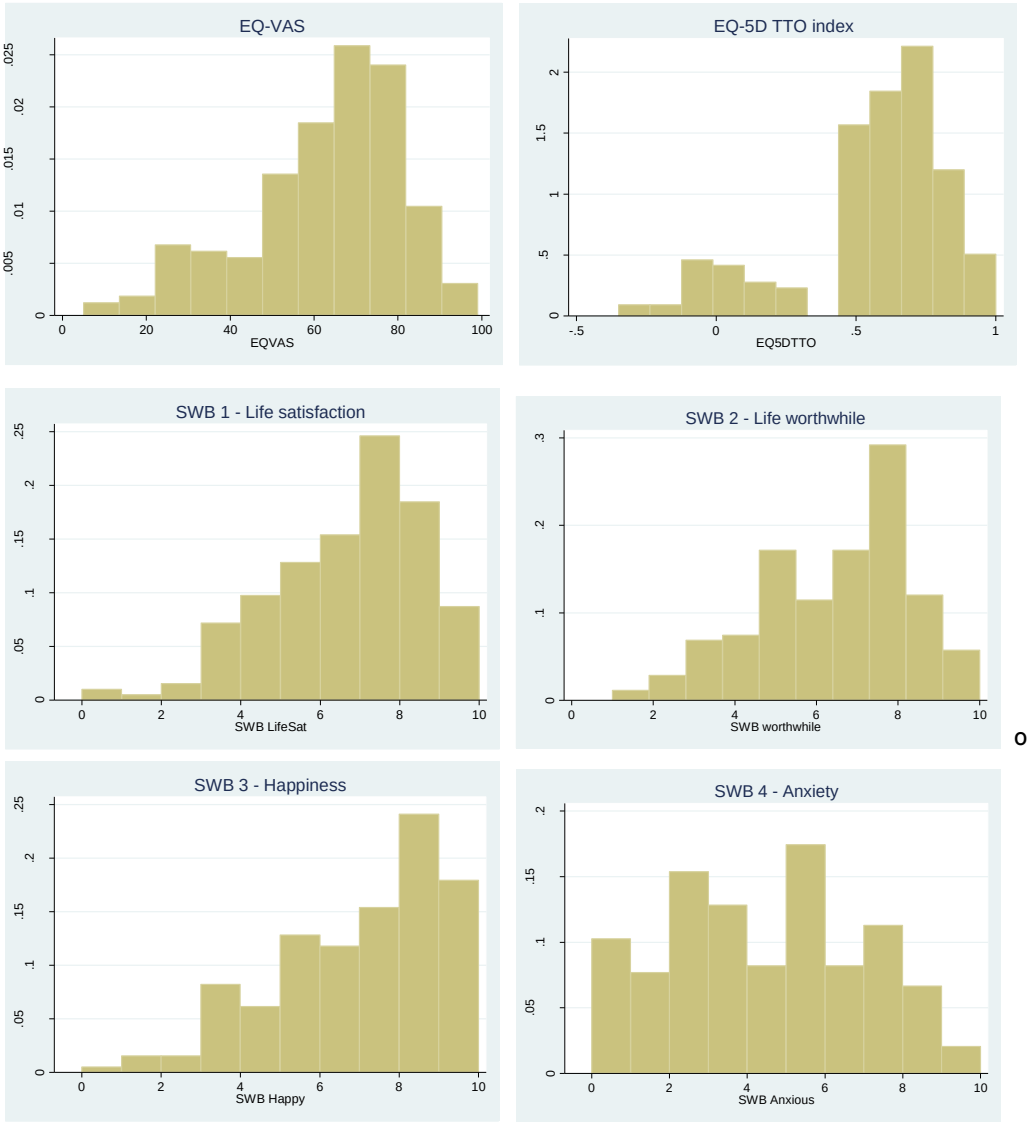

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Table 2. Distribution of EQ-5D responses by dimension and level

EQ-5D profile	No problems (1)	Some problems (2)	Extreme problems (3)	Total
Mobility	45 (23%)	150 (76%)	1 (1%)	**196** (100%)
Self-care	100 (51%)	92 (46%)	5 (3%)	**197** (100%)
Usual activities	35 (18%)	150 (76%)	12 (6%)	**197** (100%)
Pain / Discomfort	53 (27%)	126 (64%)	18 (9%)	**197** (100%)
Anxiety / Depression	82 (42%)	105 (53%)	9 (5%)	**196** (100%)

Table 3. Summary descriptive statistics for SWB, EQ-5D index and EQ-VAS in PD survey respondents and general UK population

	PD Survey Respondents		ONS IHS Respondents	
Variable	Obs	Mean (sd)	Obs	Mean (sd)
Life satisfaction	195	6.22 (1.96)	4,166	7.4 (2.0)
Life worthwhile	194	6.58 (2.08)	4,163	7.6 (1.9)
Happy yesterday	195	6.55 (2.16)	4,168	7.4 (2.3)
Anxious yesterday	195	3.98 (2.51)	4,162	3.4 (3.0)
EQ-VAS	190	62.92 (18.89)		
EQ-5D index	193	0.57 (0.28)		

APPENDICES

Dependent variable: SWB1 (Life satisfaction)	SWB1 continuous								SWB1 categorical			
	OLS Normal				OLS LogNormal				OPM			
	HRQoL measures used as covariates											
	EQ-5D	EQ-5D TTO index	EQ-VAS	EQ-5D and EQ-VAS	EQ-5D	EQ-5D TTO index	EQ VAS	EQ-5D and EQ-VAS	EQ-5D	EQ-5D TTO index	EQ VAS	EQ-5D and EQ-VAS
EQ-5D usual act = 3	-1.082			-0.757	0.182			0.082	**-0.727**			-0.575
	-1.85			-1.55	-1.2			-0.66	(2.04)*			-1.7
EQ-5D pain/disc = 3	-1.154			-0.084	0.378			0.081	-0.7			-0.018
	(2.47)*			-0.17	(3.56)**			-0.65	(2.36)*			-0.05
EQ-5D anx/dep = 2	-0.955			-0.581	0.297			0.193	-0.675			-0.494
	(3.41)**			(2.27)*	(3.67)**			(2.69)**	(3.75)**			(2.72)**
EQ-5D anx/dep = 3	-0.953			-0.147	0.475			0.232	-0.6			-0.059
	-1.16			-0.17	(3.62)**			(2.20)*	-1.15			-0.1
EQ VAS			0.06	0.053			-0.018	-0.016			0.043	0.04
			(8.45)**	(5.63)**			(9.39)**	(6.21)**			(6.14)**	(5.03)**
EQ-5D TTO tariff		2.843				-0.816				1.711		
		(6.23)**				(7.91)**				(5.22)**		
Live with partner/spouse	0.796	0.92	0.709	0.705	-0.154	-0.186	-0.121	-0.117	0.471	0.532	0.452	0.45
	(2.06)*	(2.44)*	-1.88	-1.85	-1.59	(2.01)*	-1.38	-1.32	(2.21)*	(2.60)**	(2.07)*	(2.03)*
Live in care home	-3.035	-1.778	-1.534	-1.699	0.359	0.167	0.072	-0.048	-1.807	-0.953	-0.913	-1.096
	(3.89)**	(3.63)**	(2.69)**	(2.21)*	-1.68	-1.34	-0.38	-0.23	(3.44)**	(2.44)*	-1.65	-1.75
6-10 years diagnosed	-0.297	-0.567	-0.497	-0.337	0.063	0.118	0.097	0.074	-0.187	-0.354	-0.351	-0.238
	-1	-1.87	-1.94	-1.25	-0.78	-1.45	-1.47	-1.05	-1.04	(2.01)*	(2.03)*	-1.28
Constant	6.77	3.301	1.63	2.71	1.01	1.983	2.459	2.196				
	(9.31)**	(4.63)**	(2.33)*	(2.92)**	(4.03)**	(9.30)**	(12.80)**	(7.74)**				
Observations	188	188	183	180	183	183	178	175	188	188	183	180
R-squared	0.36	0.29	0.45	0.49	0.35	0.29	0.49	0.53				
Pseudo-R2									0.11	0.08	0.15	0.17
RESET (*)	ok	ok	ok	ok	ok	ok	Missp	Missp	ok	ok	Missp	ok
Normal dist. residuals (+)	R	R	R	R	R	R	NR	NR				

Table A1. Model results for "life satisfaction". (*) The Ramsey RESET test has been used as a diagnostic test for the correctness of the functional form ("ok" if the test has not detected misspecification, "Missp" otherwise). (+) "Normal dist residuals" shows the results of a test to check the assumption of normal distribution of the dependent variable, where "R" = rejected and "NR"= not rejected. Robust t statistics in parentheses. * significant at 5%; ** significant at 1%

	SWB2 continuous								SWB2 categorical			
	OLS Normal				OLS LogNormal				OPM			
	HRQoL measures used as covariates											
Dependent variable: **SWB2 (Life worthwhile)**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**
EQ-5D mob = 3	-2.37			-1.051	0.567			0.185	-1.184			-0.524
	(2.53)*			-1.05	(2.17)*			-0.68	(2.22)*			-0.86
EQ-5D anx/dep = 2	-1.016			-0.736	0.215			0.154	-0.581			-0.458
	(3.18)**			(2.32)*	(2.18)*			-1.55	(3.24)**			(2.44)*
EQ-5D anx/dep = 3	-1.474			-0.613	0.431			0.252	-0.856			-0.421
	-1.78			-0.67	(2.25)*			-1.23	-1.69			-0.72
EQ VAS			0.05	0.044			-0.014	-0.012			0.03	0.027
			(6.28)**	(4.02)**			(5.62)**	(3.40)**			(5.39)**	(3.90)**
EQ-5D TTO tariff		2.208				-0.662				1.203		
		(3.87)**				(4.27)**				(3.72)**		
age51_60	1.366	1.456	0.793	0.799	-0.643	-0.675	-0.338	-0.448	0.77	0.78	0.439	0.474
	-1.89	(1.98)*	-1.23	-1.08	(3.63)**	(4.02)**	-1.58	(2.11)*	-1.74	-1.73	-1.05	-0.98
age61_70	0.369	0.451	0.013	-0.065	-0.319	-0.354	-0.069	-0.162	0.133	0.173	-0.086	-0.123
	-0.53	-0.63	-0.02	-0.1	(2.07)*	(2.44)*	-0.38	-0.93	-0.32	-0.4	-0.23	-0.27
age71_	0.352	0.545	-0.058	-0.118	-0.325	-0.373	-0.06	-0.157	0.075	0.189	-0.165	-0.209
	-0.49	-0.77	-0.1	-0.17	(2.12)*	(2.66)**	-0.34	-0.92	-0.17	-0.44	-0.44	-0.46
	0.85	1.009	0.724	0.697	-0.231	-0.249	-0.173	-0.188	0.514	0.577	0.453	0.457
Live with partner/spouse	(2.16)*	(2.53)*	(1.98)*	-1.82	(2.16)*	(2.33)*	-1.8	-1.84	(2.49)*	(2.88)**	(2.31)*	(2.17)*
	1.221	1.05	0.617	0.818	-0.561	-0.519	-0.342	-0.421	0.752	0.624	0.418	0.565
Live with othe family members	-1.86	-1.37	-0.91	-1.21	(2.81)**	(2.31)*	-1.66	(2.14)*	(2.10)*	-1.52	-1.11	-1.48
Live in care home	-4.921	-3.019	-2.699	-3.081	0.755	0.454	0.392	0.41	-3.9	-2.428	-2.517	-2.76
	(4.97)**	(4.77)**	(4.63)**	(3.34)**	(2.94)**	(2.47)*	-1.85	-1.59	(4.40)**	(3.57)**	(4.05)**	(3.45)**
	-0.74	-0.388	-0.609	-0.729	0.293	0.258	0.2	0.234	-0.433	-0.171	-0.37	-0.46
16-20 years diagnosed	-1.48	-0.61	-1.26	-1.52	(2.00)*	-1.69	-1.46	-1.64	-1.62	-0.49	-1.48	-1.73
Constant	7.111	4.253	3.173	4.021	1.225	2.013	2.163	1.98				
	(8.08)**	(5.29)**	(4.01)**	(3.63)**	(5.65)**	(11.27)**	(9.55)**	(6.08)**				
Observations	187	187	182	179	178	178	173	171	187	187	182	179
R-squared	0.32	0.24	0.36	0.41	0.28	0.24	0.32	0.36				
Pseudo-R2									0.1	0.07	0.11	0.13
RESET (*)	ok	ok	ok	ok	ok	ok	ok	ok	ok	Missp	ok	ok
Normal dist residuals (+)	NR	NR	NR	NR	NR	R	NR	NR				

Table A2. Model results for "life worthwhile". (*) The Ramsey RESET test has been used as a diagnostic test for the correctness of the functional form ("ok" if the test has not detected misspecification, "Missp" otherwise). (+) "Normal dist residuals" shows the results of a test to check the assumption of normal distribution of the dependent variable, where "R" = rejected and "NR"= not rejected. Robust t statistics in parentheses. * significant at 5%; ** significant at 1%

	SWB3 continuous								SWB3 categorical			
	OLS Normal				OLS LogNormal				OPM			
	HRQoL measures used as covariates											
Dependent variable: **SWB3 (Happiness)**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**
EQ-5D mob = 3	-2.442			-1.453	0.649			0.348	-1.278			-0.792
	(2.51)*			-1.42	(2.31)*			-1.2	(2.46)*			-1.35
EQ-5D anx/dep = 2	-1.547			-1.126	0.459			0.353	-0.892			-0.74
	(5.02)**			(3.94)**	(4.56)**			(3.69)**	(5.11)**			(4.00)**
EQ-5D anx/dep = 3	-2.119			-1.266	0.528			0.286	-1.189			-0.757
	(2.59)*			-1.57	(2.19)*			-1.19	(2.85)**			-1.69
EQ VAS			0.06	0.056			-0.017	-0.016			0.035	0.035
			(7.94)**	(5.86)**			(7.67)**	(6.23)**			(7.11)**	(5.97)**
EQ-5D TTO tariff		2.459				-0.669				1.249		
		(4.08)**				(3.73)**				(3.90)**		
age51_60	1.308	1.635	0.909	0.918	-0.328	-0.415	-0.252	-0.163	0.712	0.823	0.378	0.527
	-1.82	(2.10)*	-1.22	-1.21	-1.41	-1.64	-0.94	-0.66	-1.89	(2.11)*	-0.78	-1.2
Live in care home	-3.223	-1.993	-1.657	-1.345	0.442	0.357	0.228	0.09	-1.815	-0.921	-0.799	-0.677
	(2.91)**	(2.36)*	(2.79)**	-1.32	-1.69	-1.96	-1.25	-0.34	(2.84)**	(2.16)*	(2.18)*	-1.1
Between 16 and 20 years diagnosed	-1.209	-0.821	-1.079	-1.214	0.369	0.322	0.261	0.317	-0.604	-0.355	-0.597	-0.714
	(2.07)*	-1.05	-1.87	(2.09)*	(2.93)**	(2.06)*	-1.89	(2.55)*	(2.13)*	-0.9	(2.08)*	(2.42)*
Constant	7.201	3.848	2.207	2.803	0.842	1.706	2.252	2.033				
	(8.48)**	(4.19)**	(2.35)*	(2.48)*	(3.27)**	(6.45)**	(7.71)**	(6.17)**				
Observations	188	188	183	180	181	181	176	174	188	188	183	180
R-squared	0.3	0.19	0.36	0.42	0.29	0.18	0.34	0.42				
Pseudo-R2									0.09	0.05	0.1	0.13
RESET (*)	ok	ok	ok	ok	ok	ok	Missp	ok	ok	ok	ok	ok
Normal dist residuals	R	R	NR	NR	NR	NR	NR	NR				

Table A3. Model results for 'happiness'. (*) The Ramsey RESET test has been used as a diagnostic test for the correctness of the functional form ("ok" if the test has not detected misspecification, "Missp" otherwise). (+) "Normal dist residuals" shows the results of a test to check the assumption of normal distribution of the dependent variable, where "R" = rejected and "NR"= not rejected. Robust t statistics in parentheses. * significant at 5%; ** significant at 1%

	SWB4 continuous								SWB4 categorical			
	OLS Normal				OLS LogNormal				OPM			
	HRQoL measures used as covariates											
Dependent variable: **SWB4 (Anxiety)**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**	**EQ-5D**	**EQ-5D TTO index**	**EQ VAS**	**EQ-5D and EQ-VAS**
EQ-5D self care = 3	-3.001			-2.795	-0.931			-1.043	-2.603			-2.469
	(4.54)**			(4.12)**	(2.54)*			(2.80)**	(4.97)**			(4.89)**
EQ-5D usual act = 2	1.043			1.097	0.352			0.376	0.565			0.593
	(2.35)*			(2.40)*	(2.36)*			(2.46)*	(2.54)*			(2.60)**
EQ-5D usual act = 3	2.144			2.22	0.7			0.74	1.199			1.232
	(3.04)**			(2.81)**	(3.15)**			(3.08)**	(3.11)**			(2.94)**
EQ-5D anx/dep = 2	2.238			2.149	0.492			0.471	1.098			1.049
	(5.95)**			(5.36)**	(4.93)**			(4.34)**	(5.33)**			(4.84)**
EQ-5D anx/dep = 3	3.961			4.309	0.788			0.863	2.091			2.261
	(4.70)**			(5.13)**	(4.35)**			(4.76)**	(4.62)**			(4.84)**
EQ VAS			-0.042	-0.011			-0.008	-0.002			-0.019	-0.006
			(3.87)**	-0.89			(2.94)**	-0.65			(4.00)**	-1.06
EQ-5D TTO tariff		-2.99				-0.784				-1.313		
		(3.76)**				(4.54)**				(3.54)**		
Live with partner/spouse	-0.161	-0.54	-0.198	-0.119	-0.245	-0.317	-0.233	-0.23	-0.076	-0.24	-0.089	-0.057
	-0.32	-0.89	-0.33	-0.23	(2.28)*	(2.58)*	-1.83	(2.07)*	-0.3	-0.89	-0.34	-0.22
Live in care home	2.964	0.904	1.613	2.668	0.575	-0.096	0.175	0.634	2.149	0.339	0.593	1.96
	(2.75)**	-0.98	(1.98)*	(2.20)*	-1.91	-0.52	-0.95	-1.96	(3.37)**	-0.81	-1.59	(3.12)**
More than 20 years diagnosed	-1.857	-1.538	-0.011	-1.774	-0.087	0.115	0.405	-0.07	-1.097	-0.779	-0.06	-1.049
	(2.14)*	-1.28	-0.01	-1.98	-0.63	-0.54	-1.68	-0.46	(2.03)*	-1.32	-0.1	-1.91
Constant	0.934	5.85	6.538	2.231	0.897	2.046	2.132	1.134				
	-1.11	(5.68)**	(6.04)**	-1.77	(4.11)**	(8.47)**	(8.10)**	(3.14)**				
Observations	188	188	183	180	169	169	164	162	188	188	183	180
R-squared	0.38	0.14	0.13	0.4	0.34	0.16	0.12	0.36				
Pseudo-R2									0.11	0.03	0.03	0.11
RESET (*)	ok	ok	ok	ok	ok	Missp	ok	ok	ok	ok	ok	ok
Normal dist residuals	NR	R	R	NR	R	R	R	R				

Table A4. Model results for 'anxiety'. (*) The Ramsey RESET test has been used as a diagnostic test for the correctness of the functional form ("ok" if the test has not detected misspecification, "Missp" otherwise). (+) "Normal dist residuals" shows the results of a test to check the assumption of normal distribution of the dependent variable, where "R" = rejected and "NR"= not rejected. Robust t statistics in parentheses. * significant at 5%; ** significant at 1%