

Review of Quality of Life of UK (United Kingdom) MS (Multiple Sclerosis) Patients

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Background:

The Constitution of the World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being not merely the absence of disease . . .". It follows that the measurement of health and the effects of health care must include not only an indication of changes in the frequency and severity of diseases but also an estimation of well being and this can be assessed by measuring the improvement in the quality of life related to health care. Although there are generally satisfactory ways of measuring the frequency and severity of diseases this is not the case in so far as the measurement of well being and quality of life are concerned. WHO, with the aid of 15 collaborating centres around the world, has therefore developed two instruments for measuring quality of life (the WHOQOL-100 and the WHOQOL-BREF), that can be used in a variety of cultural settings whilst allowing the results from different populations and countries to be compared.

These instruments have many uses, including use in medical practice, research, audit, and in policy making. (1)

WHO defines Quality of Life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.

It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment. (1)

The intention of the project is to review 4 key areas of quality of life in the specific group of MS UK patients, please see below the list of the 4 categories with subcategories of WHOQOL and WHOQOL-BREF form used.

Table 1 – WHOQOL–BREF domains

| Domain | Facets incorporated within domains |
|-------------------------|--|
| 1. Physical health | Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity |
| 2. Psychological | Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration |
| 3. Social relationships | Personal relationships Social support Sexual activity |
| 4. Environment | Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport |

WHOQOL-BREF



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| | Equations for computing domain scores | Raw score | Transformed scores* | |
|-----------------|--|-----------|---------------------|-------|
| | | | 4-20 | 0-100 |
| Domain 1 | $(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ $\square + \square + \square + \square + \square + \square + \square$ | = | | |
| Domain 2 | $Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$ $\square + \square + \square + \square + \square + \square$ | = | | |
| Domain 3 | $Q20 + Q21 + Q22$ $\square + \square + \square$ | = | | |
| Domain 4 | $Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ $\square + \square + \square + \square + \square + \square + \square + \square$ | = | | |

* Please see Table 4 on page 10 of the manual, for converting raw scores to transformed scores.

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ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**? Male Female
What is your **date of birth**? _____ / _____ / _____
Day / Month / Year

What is the highest **education** you received? None at all
Primary school
Secondary school
Tertiary

What is your **marital status**? Single Separated
Married Divorced
Living as married Widowed

Are you currently ill? Yes No
If something is wrong with your health what do you think it is? _____ illness/ problem

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one that appears most appropriate.** This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question might ask:

| | | | | | |
|---|------------|----------|------------|--------------|------------|
| | Not at all | Not much | Moderately | A great deal | Completely |
| Do you get the kind of support from others that you need? | 1 | 2 | 3 | 4 | 5 |

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

| | | | | | |
|---|------------|----------|------------|--------------|------------|
| | Not at all | Not much | Moderately | A great deal | Completely |
| Do you get the kind of support from others that you need? | 1 | 2 | 3 | 4 | 5 |

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.



Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

| | | Very poor | Poor | Neither poor nor good | Good | Very good |
|-------|--|-----------|------|-----------------------|------|-----------|
| 1(G1) | How would you rate your quality of life? | 1 | 2 | 3 | 4 | 5 |

| | | Very dissatisfied | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfied |
|--------|---|-------------------|--------------|------------------------------------|-----------|----------------|
| 2 (G4) | How satisfied are you with your health? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about how much you have experienced certain things in the last two weeks.

| | | Not at all | A little | A moderate amount | Very much | An extreme amount |
|----------|--|------------|----------|-------------------|-----------|-------------------|
| 3 (F1.4) | To what extent do you feel that physical pain prevents you from doing what you need to do? | 1 | 2 | 3 | 4 | 5 |
| 4(F11.3) | How much do you need any medical treatment to function in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 5(F4.1) | How much do you enjoy life? | 1 | 2 | 3 | 4 | 5 |
| 6(F24.2) | To what extent do you feel your life to be meaningful? | 1 | 2 | 3 | 4 | 5 |

| | | Not at all | A little | A moderate amount | Very much | Extremely |
|-----------|---|------------|----------|-------------------|-----------|-----------|
| 7(F5.3) | How well are you able to concentrate? | 1 | 2 | 3 | 4 | 5 |
| 8 (F16.1) | How safe do you feel in your daily life? | 1 | 2 | 3 | 4 | 5 |
| 9 (F22.1) | How healthy is your physical environment? | 1 | 2 | 3 | 4 | 5 |

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

| | | Not at all | A little | Moderately | Mostly | Completely |
|------------|--|------------|----------|------------|--------|------------|
| 10 (F2.1) | Do you have enough energy for everyday life? | 1 | 2 | 3 | 4 | 5 |
| 11 (F7.1) | Are you able to accept your bodily appearance? | 1 | 2 | 3 | 4 | 5 |
| 12 (F18.1) | Have you enough money to meet your needs? | 1 | 2 | 3 | 4 | 5 |
| 13 (F20.1) | How available to you is the information that you need in your day-to-day life? | 1 | 2 | 3 | 4 | 5 |
| 14 (F21.1) | To what extent do you have the opportunity for leisure activities? | 1 | 2 | 3 | 4 | 5 |

| | | Very poor | Poor | Neither | Good | Very good |
|--|--|-----------|------|---------|------|-----------|
|--|--|-----------|------|---------|------|-----------|

| | | | | | | |
|-----------|--------------------------------------|---|---|------------------|---|---|
| | | | | poor nor good | | |
| 15 (F9.1) | How well are you able to get around? | 1 | 2 | 3 | 4 | 5 |

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

| | | Very dissatisfie d | Dissatisfied | Neither satisfied nor dissatisfied | Satisfied | Very satisfie d |
|------------|--|--------------------------|--------------|--|-----------|-----------------------|
| 16 (F3.3) | How satisfied are you with your sleep? | 1 | 2 | 3 | 4 | 5 |
| 17 (F10.3) | How satisfied are you with your ability to perform your daily living activities? | 1 | 2 | 3 | 4 | 5 |
| 18(F12.4) | How satisfied are you with your capacity for work? | 1 | 2 | 3 | 4 | 5 |
| 19 (F6.3) | How satisfied are you with yourself? | 1 | 2 | 3 | 4 | 5 |
| 20(F13.3) | How satisfied are you with your personal relationships? | 1 | 2 | 3 | 4 | 5 |
| 21(F15.3) | How satisfied are you with your sex life? | 1 | 2 | 3 | 4 | 5 |
| 22(F14.4) | How satisfied are you with the support you get from your friends? | 1 | 2 | 3 | 4 | 5 |
| 23(F17.3) | How satisfied are you with the conditions of your living place? | 1 | 2 | 3 | 4 | 5 |
| 24(F19.3) | How satisfied are you with your access to health services? | 1 | 2 | 3 | 4 | 5 |
| 25(F23.3) | How satisfied are you with your transport? | 1 | 2 | 3 | 4 | 5 |

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

| | | Never | Seldom | Quite often | Very often | Always |
|-----------|--|-------|--------|-------------|------------|--------|
| 26 (F8.1) | How often do you have negative feelings such as blue mood, despair, anxiety, depression? | 1 | 2 | 3 | 4 | 5 |

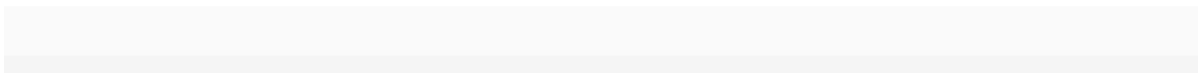
Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

Do you have any comments about the assessment?

.....
.....

THANK YOU FOR YOUR HELP



Objectives:

To review 4 areas of WHOQOL affecting quality of life and initiate further discussion about possible ways of improvement in underscored areas in the UK population of MS patients.

Standards:

The ideal standard is 100 points across all tested categories of the questionnaire, which is unfortunately unrealistic even in healthy population.

The questionnaire scores in the 4 main domains from 0 to 100 points and thus with a lower score might indicate those areas that might need our increased attention.

Methodology:

I requested WHO for permission and received English version of WHOQOL-BREF form with guidelines.

I created anonymous online equivalent of WHOQOL-BREF form, using Survey Monkey (2) online service, accesible anonymously via a link.

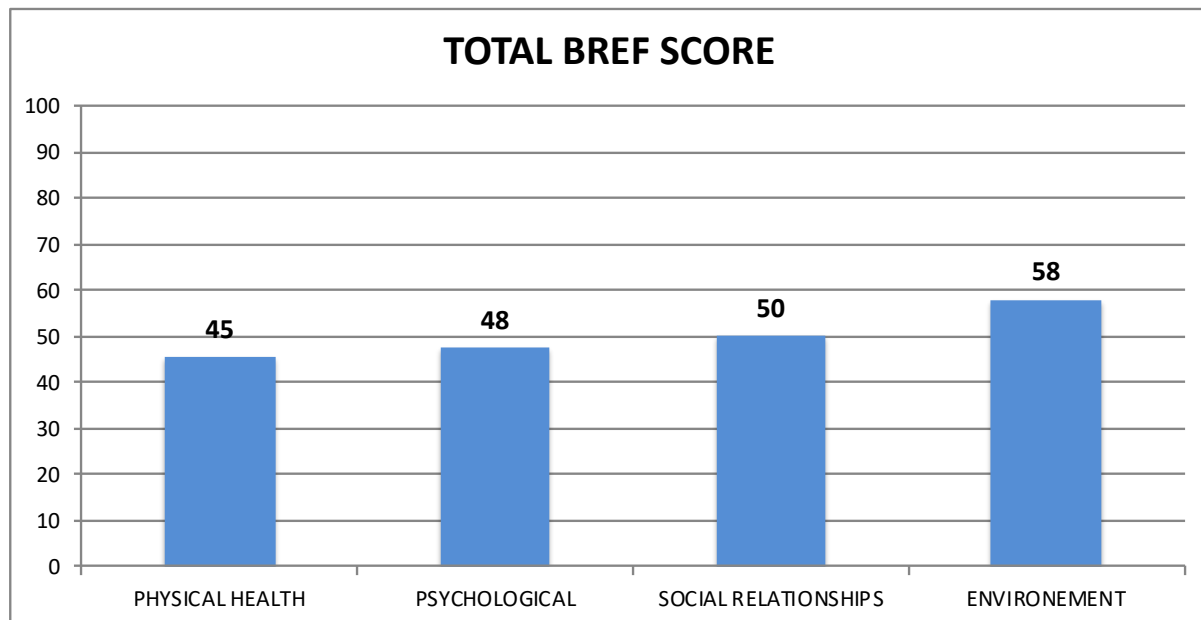
I contacted MS Trust UK (3) and ask them to advertise kindly the project via their Facebook group for UK MS patients. The link was advertised twice in 2 weeks. The respondents were asked to cover in the answers the last 2 weeks of their life, as recommended by WHOQOL-BREF guidelines. The online suvey was completed by 88 respondents, further 10 respondents did not answer all the questions asked.

The information collected was further prossesed and analyzed, using statistical guidelines provided by WHO.



Results:

In **“Total BREF score”**, “Physical health” domain scored the lowest (45/100), closely followed by “Psychological” domain (48/100) and “Social relationships” domain (50/100). “Environment” domain scored the highest (58/100).



In the physical health domain, the worst scores were identified in the questions: “How satisfied are you with your capacity for work?” (36/100), “Do you have enough energy for everyday life?” (36/100), “How satisfied are you with your ability to perform your daily living activities?” (44/100) and “How satisfied are you with your sleep?” (47/100).

In the psychological domain, the lowest score was in the questions: “How satisfied are you with yourself?” (43/100) and “How often do you have negative feelings such as blue mood, despair, anxiety, depression?” (46/100).

In the social relationship domain, the score was the lowest in the question “How satisfied are you with your sexual life?” (38/100).

In the environmental domain, the lowest scoring question was “To what extent do you have the opportunity for leisure activities?” (43/100). The rest of the questions in this domain scored relatively high (54-68/100).

Please see further details in the table below.

| Question | Domain | BREF SCORE |
|--|--------|------------|
| 1 To what extent do you feel that physical pain prevents you from doing what you need to do? | D1 | 55 |
| 2 How well are you able to get around? | D1 | 51 |
| 3 How much do you need any medical treatment to function in your daily life? | D1 | 49 |
| 4 How satisfied are you with your sleep? | D1 | 47 |
| 5 How satisfied are you with your ability to perform your daily living activities? | D1 | 44 |
| 6 How satisfied are you with your capacity for work? | D1 | 36 |
| 7 Do you have enough energy for everyday life? | D1 | 36 |
| 8 How much do you enjoy life? | D2 | 51 |
| 9 Are you able to accept your bodily appearance? | D2 | 49 |
| 10 How well are you able to concentrate? | D2 | 49 |
| 11 To what extent do you feel your life to be meaningful? | D2 | 47 |
| 12 How often do you have negative feelings such as blue mood, despair, anxiety, depression? | D2 | 46 |
| 13 How satisfied are you with yourself? | D2 | 43 |
| 14 How satisfied are you with your personal relationships? | D3 | 59 |
| 15 How satisfied are you with the support you get from your friends? | D3 | 53 |
| 16 How satisfied are you with your sex life? | D3 | 38 |
| 17 How satisfied are you with your transport? | D4 | 68 |
| 18 How satisfied are you with the conditions of your living place? | D4 | 66 |
| 19 How available to you is the information that you need in your day-to-day life? | D4 | 61 |
| 20 How satisfied are you with your access to health services? | D4 | 61 |
| 21 How healthy is your physical environment? | D4 | 58 |
| 22 Have you enough money to meet your needs? | D4 | 55 |
| 23 How safe do you feel in your daily life? | D4 | 54 |
| 24 To what extent do you have the opportunity for leisure activities? | D4 | 43 |

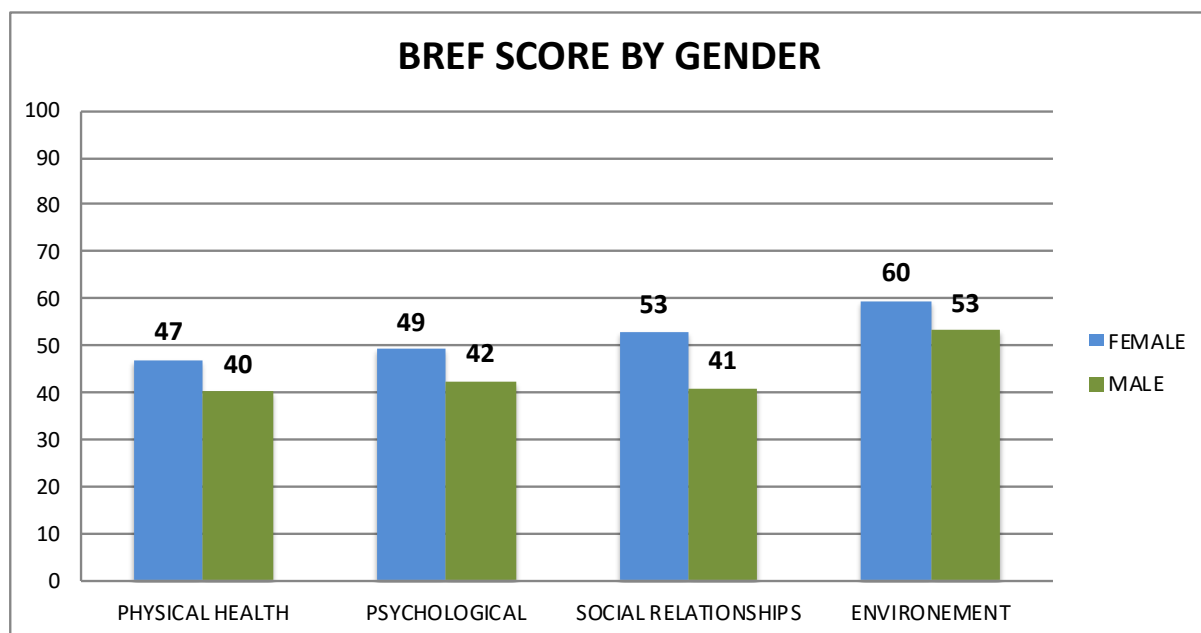
D1: PHYSICAL HEALTH

D2: PSYCHOLOGICAL

D3: SOCIAL RELATIONSHIP

D4: ENVIRONMENT

In “**BREF score by gender**”, women are generally more satisfied with their quality of life within all the domains, compared to men. Please see further details in the domain below.

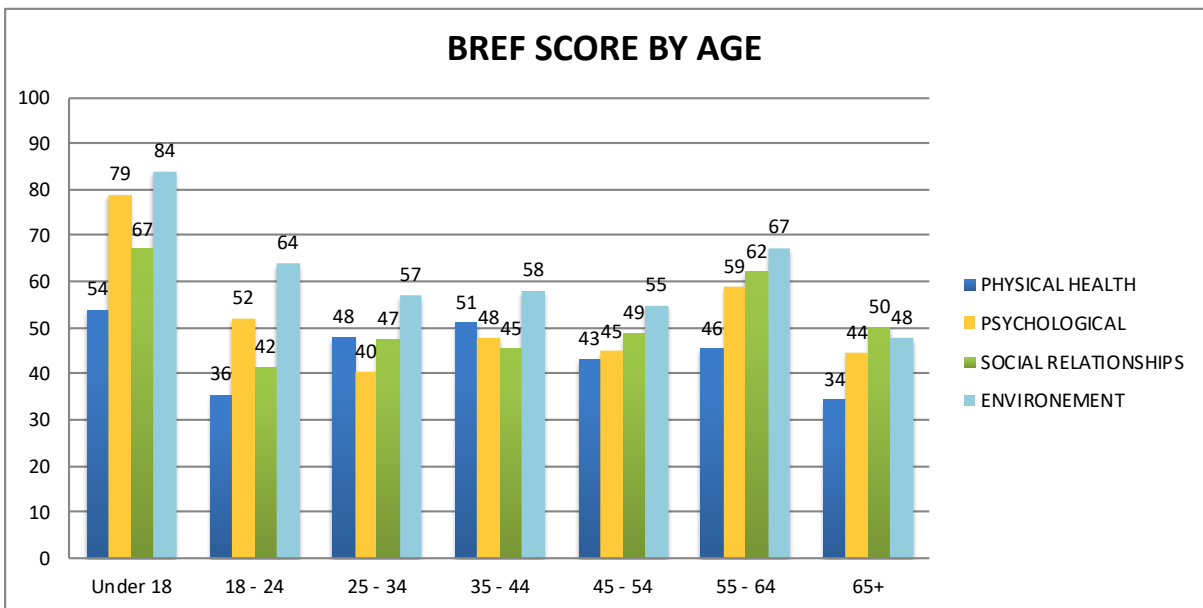


| Answer Choices | Responses | |
|----------------|-----------------|-----------|
| Male | 22.99% | 21 |
| Female | 77.01% | 67 |
| | Answered | 88 |

In **“BREF score by age”**, the most satisfied with the quality of life was the category “Under 18”, which was represented by one respondent, which makes its informational value unfortunately quite limited.

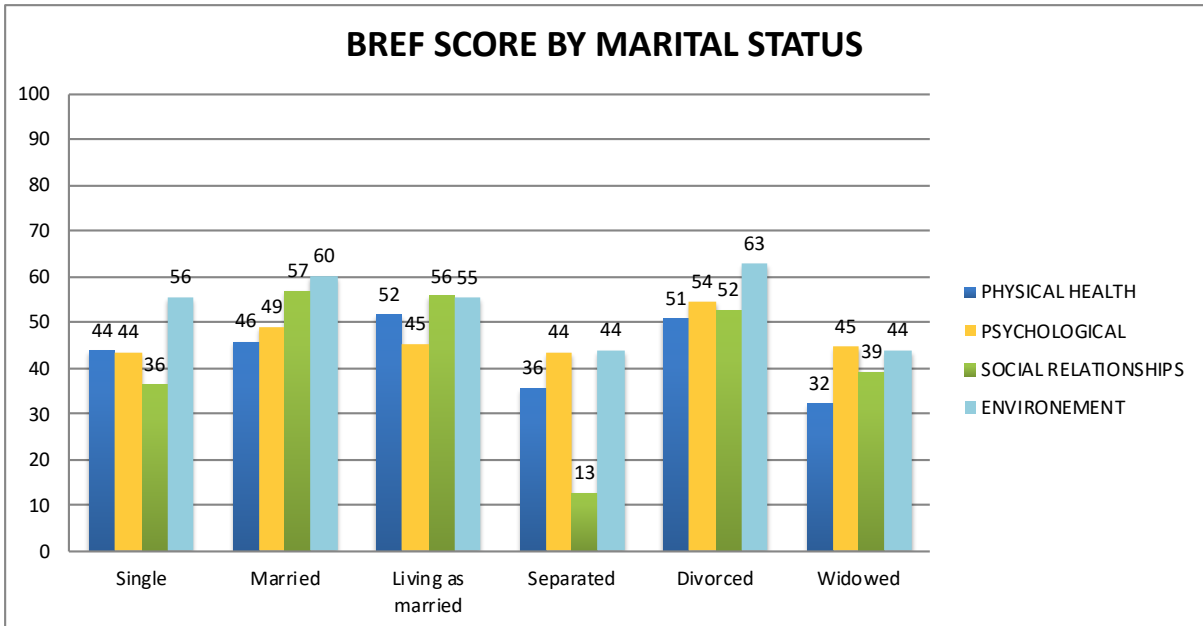
Generally, less satisfied with their quality of life was the category (65+), which might correlate likely with increasing mental and physical neuro-disability and other age-related comorbidities.

Please see further details in the domain below.



| Answer Choices | Responses | |
|----------------|-----------------|-----------|
| Under 18 | 1.14% | 1 |
| 18-24 | 2.27% | 2 |
| 25-34 | 14.77% | 13 |
| 35-44 | 22.73% | 20 |
| 45-54 | 37.50% | 33 |
| 55-64 | 15.91% | 14 |
| 65+ | 5.68% | 5 |
| | Answered | 88 |

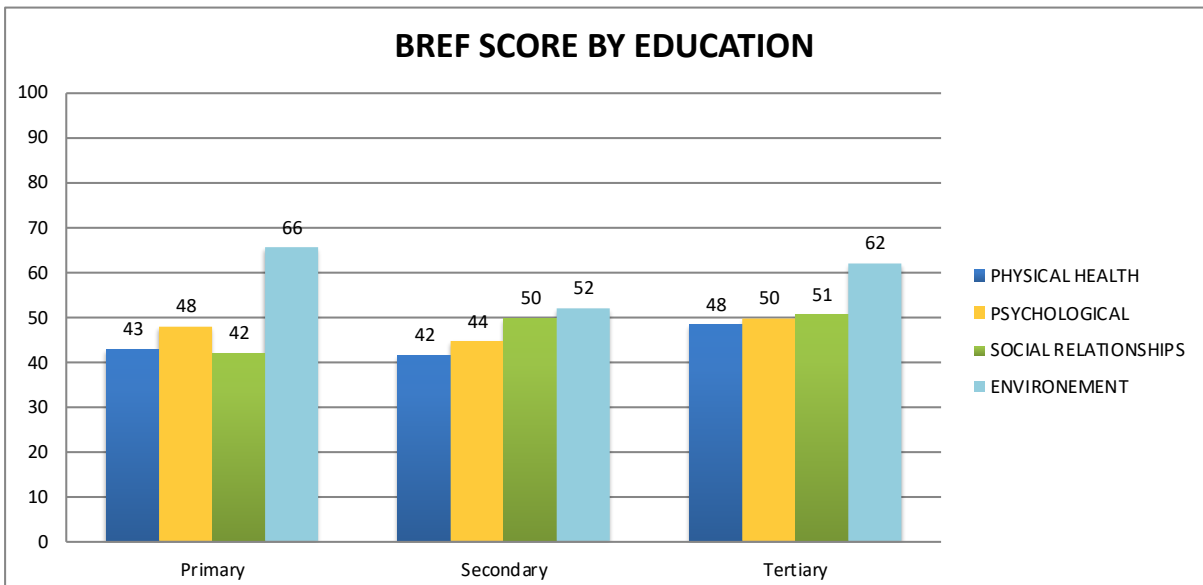
“BREF score by marital status” demonstrated the lowest score in the category “Separated” in “Social Relationship” domain. Please see further details below.



| Answer Choices | Responses | |
|-------------------|-----------------|-----------|
| Single | 22.73% | 20 |
| Married | 56.82% | 50 |
| Living as married | 6.82% | 6 |
| Separated | 2.27% | 2 |
| Divorced | 7.95% | 7 |
| Widowed | 3.41% | 3 |
| | Answered | 88 |

“**BREF score by education**” demonstrated the lowest score in the domain of “Physical health” mainly in patients with primary and secondary education.

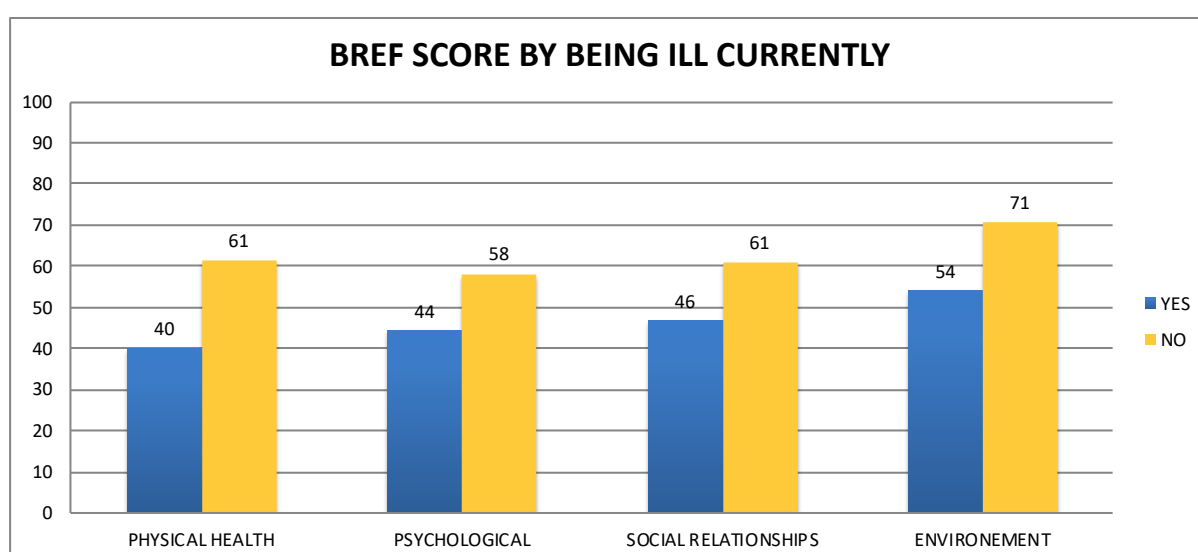
Please see further details below.



| Answer Choices | Responses | |
|------------------|-----------------|-----------|
| None at all | 0.00% | 0 |
| Primary school | 1.15% | 1 |
| Secondary school | 41.38% | 36 |
| Tertiary | 57.47% | 51 |
| | Answered | 88 |

“BREF score by being ill currently” demonstrated the lowest score in all domains in patients being ill currently.

Please see further details below.



| Answer Choices | Responses | |
|----------------|-----------------|-----------|
| Yes | 75.58% | 66 |
| No | 24.42% | 22 |
| | Answered | 88 |

Roughly, the lowest scores have been identified mainly in the “Physical” and “Psychological” domain, which can be positively influenced by early and adequate treatment of MS, its complications and comorbidities to prevent/postpone/slow down mental and physical neuro-disability as much as possible to keep the patients able to be active members of the society, which helps them to feel more satisfied with their lives.

In “Social relationship” domain, the most significant negative influence on the quality of life has separation/divorce from the patient’s partner and in the specific questions of relationship, the patient’s sex life might also significantly influence generally the patient’s quality of life.

In “Environment” domain, the lowest score was in the area of availability of leisure activities for patients with progressive mental and physical neurodisability, which might significantly influence all the other domains above, with complex positive impact on the physical, mental and social status of the patients.

Recommendations/Action Plan:

- Presentation of the results to specialists at MS Masterclass in June Sheffield 2018 to initiate further discussion about possible ways of improvement of the quality of life of UK MS patients
- Feedback to respondents and other MS patients via MS Trust
- Considering the usage of the data further for publication or expansion of the project

Limitations of the audit:

- Anonymous online questionnaire
- Statistically still quite a low number of respondents
- No geographical, ethnical or other further potentially important specifications were not recorded as WHO approved just usage of the original form.

References:

- (1) World Health Organisation, WHOQOL: Measuring Quality of Life, <http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>
- (2) Survey Monkey, <https://www.surveymonkey.co.uk/>
- (3) MS Trust UK, <https://www.mstrust.org.uk/>
- (4) Facebook, <https://www.facebook.com/>