Measuring quality of life and identifying what is important to Jordanian living with Multiple Sclerosis using the Arabic version of the Patient Generated Index (PGI)

CURRENT STATUS: POSTED

Research Square

Ala' S. Aburub
Isra University

ala.aburub@mail.mcgill.ca*Corresponding Author*
ORCiD: https://orcid.org/0000-0003-3573-7304

Hanan Khalil
Jordan University of Science and Technology

Alham Al-Sharman
Jordan University of Science and Technology

Khalid El-Salem
Jordan University of Science and Technology

DOI:
10.21203/rs.2.21188/v1

SUBJECT AREAS
Health Economics & Outcomes Research

KEYWORDS
Individualized measures; Patient Generated Index (PGI); Quality of life; Psychometric properties; Multiple sclerosis.

Abstract

Background Patients Generated index (PGI) is one of the individualized measures used to measure the quality of life (QOL) in people with different chronic conditions including multiple sclerosis (MS). However, the psychometric properties of the Arabic version of the PGI have not been fully established in Jordanian living with MS. Therefore, the objective of this study is to identify what matters to Jordanian living with MS and to contribute evidence toward the psychometric properties of the Arabic version of the PGI. Method A total of 75 participants with MS completed three QOL measures; PGI, the Patient Determined Disease Steps (PDDS), and EQ-5D. Generalized Estimating Equations (GEE) were used to compare the total score of three QOL measures. Bland-Altman plot and Spearman's correlation coefficient were used to study the relationships and differences between the PGI and the other study measures (PDDS and EQ-5D). Results Only 66 (88%) of the participants were able to complete the PGI. Overall, 36 areas of QOL concern were nominated by the participants using the PGI with the top 3 areas were an emotional function (47%), involuntary movement reaction functions (45.5%) and walking (44%). The average global score of the PGI was lower (34±22) than the global score of the EQ-5D (69±23) and the PDDS (68±24).PGI had a moderate correlation with EQ-5D and PPDS. Conclusion The Arabic version of the PGI is a feasible and acceptable measure among Jordanian with MS and it captures a wide spectrum of important areas that contribute to QOL than EQ-5D and PDDS. PGI could improve the decision making and guide health-care professionals to provide appropriate intervention programs to reduce the burdens from MS disease and improve QOL.

Introduction

MS is a neurodegenerative disease affecting approximately 2.5 million people globally. It is the most common non-traumatic neurological disorder of younger adults with a prevalence of 31-110 per 100,000 adults [1]. The prevalence of MS in Jordan is estimated to be around 39 per 100,000 people [2] indicating similarity to the prevalence reported worldwide. Although symptoms vary considerably among people with MS, the disease has often a major impact on sensory, motor and cognitive systems leading to loss of independence in all functional activities over time which negatively impacts the quality of life (QOL) [3, 4]

Investigating QOL in chronic and progressive diseases is very important for clinical research, clinical practice and may help guide policies, interventions, and services to improve their health [5]. Despite its difficulty to measure [6], QOL is a latent construct and could be only measured from the person's own perspective and not from the perspective of the family, spouse or health-care professional. Many definitions of QOL have been proposed as there is a wide variety of individual experiences contributing to QOL [7-9]. The World Health Organization defined the quality of life as "the individuals' perceptions of their position in life, in the context of the cultural and value systems in which they live and in relation to their goals, expectations, standards and concerns" [10]. This definition provides an insight that when the patient's expectations and goals don not match the reality, QOL is affected. In the presence of chronic diseases such as MS, patient's expectations and goals could be altered due to the disease itself or its treatment and due to the adaptation mechanism overtime which subsequently affects QOL. People with MS are all different and have different sequelae with varying impact on their Lives; standardized measures may not necessarily identify areas that need to be addressed by the health care team. One of the ways to overcome this issue is using individualized measures to assess QOL.

Patient generated index (PGI) is one of the individualized measures that have been used to assess QOL [11]. PGI is completed in 3 stages. In the first stage, patients are asked to nominate the top five areas of their lives affected by their condition. In the second stage, patients are asked to rate the severity of each nominated area on a scale of 0-10, where 0 is the worst imaginable and 10 exactly as they would like it to be. In the third stage, patients are asked to distribute an imaginary 12 spending tokens to improve the nominated areas according to their own priority. To calculate the total score of the PGI, the rating severity of each area in stage 2 is multiplied by the proportion of tokens given to that area in stage 3, then each score is summed to produce an index score from 01-100 with a higher score indicating higher QOL. PGI is validated in different populations including MS, cancer, rheumatoid, ankylosing spondylitis, traumatic brain injury and people with low back pain [7, 12-20]. PGI was also translated into different languages [21] including the Arabic language and forward-backward translation was done among Saudi women with MS [22]. It should be noted, however, that

the psychometric properties of the Arabic version have not been investigated yet.

To best of our knowledge, no study has validated the Arabic version of the PGI among Jordanian living with MS. Therefore, the objective of this study was to identify what matters to Jordanian living with MS and to test the psychometric properties of the Arabic version of the PGI.

Method

Participants and study design

This data was collected as part of a cross-sectional observational study investigated participation and its associated factors in people with MS. Sequential MS patients attending routine neurology clinics between October 2018 and June 2019 at King Abdulla University Hospital (KAUH) in Irbid – Jordan were screened for eligibility by a neurology consultant. Eligible participants were invited to participate in this study. Additionally, eligible participants who already participated in other Jordan University of Science and Technology funded research and provided consent to be contacted for future studies were invited to participate. Inclusion criteria were**:**1) diagnosed with MS by a neurologist according to the revised McDonald criteria [23]; 2) patients determined disease steps (PDDS) score less than 7.0 [24]; 2) no exacerbation of symptoms 30 days prior to completing testing; 3) age ≥ 18 years; 4) capacity to give informed consent. Exclusion criteria were: 1) the presence of additional neurological disorders such as stroke; 2) a patient who had diagnosed with aphasia; and 3) the presence of severe visual impairments. All participants gave written informed consent approved by the Institutional Research Committees of the Jordan University of Science and Technology (AS-58/2019).

Outcome measures

In this study, three outcome measures were used. These measures were the patient-generated index (PGI), the Patient Determined Disease Steps (PDDS), and EQ-5D. The PGI was the primary outcome measure of this study.

PDDS

The Patient Determined Disease Steps (PDDS) was developed as a self-report version of the physician reported disease steps by Hoel et al [25]. The PDDS is a valid assessment tool of disease severity as it previously showed strong associations with the EDSS [26]. Originally, the PDDS was developed in the

English language and was provided for use by the North American Research Consortium on Multiple Sclerosis (NARCOMS) registry. The rating system ranges between 0 (normal) and 8 (Bedridden).

EQ5D

The EQ-5D was developed by the European Quality of Life (EuroQoL) group. It is a generic commonly used outcome to evaluate health-related quality of life. The scale has been validated in numerous neurological populations including the MS [27, 28]. EQ-5D assesses 5 domains including mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has 3 levels: no problems, some problems or severe problems; this provides a health profile of the respondents.

Statistical Analysis

Descriptive statistics were used to describe the characteristics of the study sample. Means and the standard deviation were reported for continuous variables while frequency and percentage for the categorical variables. The total score of the study outcomes (PGI, EQ-5D, and PDDS) was calculated and transformed to a scale from 0-100 with a higher score indicating better QOL.

To identify what matters to people with MS, the first stage of the PGI was used. In this stage, participants nominated the top five areas that affected their lives due to MS. These areas were then mapped into an international framework called the international classification of functioning, disability, and health (ICF) [29, 30]. The ICF is a classification system used to describe health and health status from personal, biological and social perspectives at the level of body functions and structure, activities, and participation [29, 30].

Several steps were carried out to test the psychometric properties (content and construct (convergent)) of the PGI. The content validity was tested by mapping the nominated areas onto the ICF and then the top areas were also identified. These top areas were then compared to the study measures to identify how many areas could be found in EQ-5D and PDDS.

The construct validity was tested by measuring the strength of the association between the PGI and the study measures (PDDS and EQ-5D) using Spearman’s correlation (rs) coefficient. A weak correlation was considered when Spearman’s correlation value is less than 0.3, moderate 0.31 to 0.7

and greater than 0.7 was considered strong [31, 32].

The generalized estimating equations (GEE) were also used to compare the total score of the PGI and the study measures (PDDS and EQ-5D). The mean difference between the study outcomes and the 95% confidence interval (CI) accounting for correlations among the study measures were also calculated using the regression coefficients from the GEE. The Effect size (ES) was calculated as the mean difference estimates divided by the standard error.

Bland-Altman plot was used to study the relationships and differences between the PGI and the other study measures (PDDS and EQ-5D). The latent construct of the QOL is shown in the x-axis of the Bland-Altman plot as the average between the two measures while the contribution to the latent construct is shown in the y-axis as the difference between the two measures. When both measures are equal no difference will present along with the latent construct.

Results

A total of 75 participants with MS were interviewed on the study measures, and only 66 of them were able to complete the PGI. The demographic and clinical characteristics of participants are shown in Table 1. The mean age of the study sample was 35.6±10.2; two-third of the sample (68%) consisted of women with MS. Approximately 90% of the sample had Relapsing-Remitting MS with an average time since diagnosis of 7.6±5.8 years.

Table 2 presents the top 11 areas nominated by the participants using the PGI and compared to the study measures (PDDS and EQ-5D). Overall, 36 areas of QOL concern were nominated by the participants using the PGI. The top 11 areas were emotional function (47%), involuntary movement reaction functions (45.5%), walking (44 %), seeing function (vision) (30%), socializing (29%), sleep functions (23%), doing housework (21%), Work (17%), muscle power functions (14%), fatigue (12%) and moving around (12%). Only five areas out of the top 11 areas were presented in the EQ-5D (Emotional function, walking, doing housework, work and moving around) and two areas (walking, and moving around) were found in the PDDS.

Figure 1 shows the results of comparing the total score of the PGI and the study measures (PDDS and EQ-5D) using the generalized estimating equations. The average global score of the PGI was lower

(34±22) than the global score of the EQ-5D (69±23) and the PDDS (68±24). There was a moderate correlation between the PGI and the study measures (0.48 with EQ-5D and 0.49 with PDDS). The correlation between the EQ-5D and PDDS (rs=0.57) was slightly higher than the correlation between the PGI and both study measures. The mean difference between the PGI and EQ-5D was -35.3 with an effect size of -8.6 and 95% CI ranged from -43.4 to -27.2. The mean difference between the PGI and PDDS was -34.4 with an effect size of -8.6 and 95% CI ranged from -43.4 to -27.2. The mean difference between the EQ-5D and PDDS was 5.3 with an effect size of 0.24 and 95% CI ranged from -43.4 to -27.2, (figure1).

Figure 2a shows the results of the Bland-Altman to evaluate the relationship between PGI and EQ-5D. The latent construct of the QOL is shown in the x-axis as the average between the PGI and EQ-5D. The contribution to the latent construct is shown in the y-axis as the difference between the PGI and EQ-5D. The 95% CI is shown by the upper and lower red lines. The blue dot line represents no difference between both measures (PGI and EQ-5D). The mean difference between the PGI and EQ-5D are shown in the middle red line. The black dots show the score of each participant on both measures (PGI and EQ-5D). There was no specific pattern for the mean difference between PGI and EQ-5D when QOL was poor (at the left end of the x-axis) or good (at the right end of the x-axis). However, all participants scored lower in the PGI than the EQ-5D except for two participants (figure 2a). Similar results were found when PGI was compared to PDDS using a Bland-Altman plot (figure 2b).

Discussion

To our knowledge, this is the first study to identify what matters to Jordanian living with MS and to assess the psychometric properties of the Arabic version of the PGI. In this study, individuals with MS in Jordan were interviewed using an individualized measure (PGI) to identify areas that affected their QOL due to MS disease. Approximately, 88% of our study sample were able to complete the PGI, thus PGI is a feasible and acceptable tool among Jordanian living with MS. These results are consistent with previous studies [13, 14, 20, 33, 34].

In the current study, a total of 36 areas of QOL concerns were identified using the PGI with the top 11 are emotional function, involuntary movement reaction functions, walking, seeing function (vision),

socializing, sleep functions, doing housework, work, muscle power functions, fatigue and moving around. When mapping those top areas to the study measures (EQ-5D, and PDDS), we found that only five areas (Emotional function, walking, doing housework, work and moving around) out of the top 11 were found in the EQ-5D and only two areas (walking and moving around) were included in the PDDS. Our results are supported by previous studies that found PGI captures more important areas to people with chronic conditions including MS than standard measures [13, 20, 34].

Several well-known and common symptoms among people with MS were not captured by the current study measures (EQ-5D and PDDS). For example, sleep function, which affects 50%- 70% of individuals with MS [35-37] was not included in the EQ-5 D or the PDDS. Fatigue, which is one of the most common symptoms of multiple sclerosis (MS) [38-40], reported to affect between 50% and 80% of MS patients at some point in the disease course, has been identified in the PGI but not the other tools (EQ-5D and PDDS). Other areas such as involuntary movement reaction functions, vision, socializing, functions, and muscle power functions were not included in the EQ-5D and PDDS.

These results suggest that PGI captures what matters to people with MS and provides an accurate description of their current health status and QOL. On the other hand, standard measures could not capture all the important areas to people with MS and that might affect the extent to which patients can accurately describe their individual experiences with MS disease. The suggested explanation could be that standard measures (EQ-5D and PDDS) having fixed questions that may not be of importance to people with MS. Therefore, limited item content could restrict addressing and evaluating what matters to people with MS which subsequently impact negatively their QOL. As a result, it is clear that the standard measures were either having not relevant items or missing one’s that might affect the QOL in people with MS. Giving patients the opportunity to choose what matters to them would minimize threats to the content validity [41-44] and this was supported by using PGI, not standard measures.

This study also found that the average global score of the PGI was lower than the global score of the EQ-5D and the PDDS. This finding is consistent with the previous studies using a similar methodology in people with MS [34] and cancer [13]. This result could be explained by the nature of the PGI, where

PGI allows people with MS to nominate areas that affected by their disease, rate, and weights them according to their importance which subsequently could affect the global score of the PGI. Therefore, the global score of the PGI may reflect the reality about the current health status of people with MS while the global score from the standard measures overestimate the current health status of people with MS. Furthermore, lower PGI score as compared to the standard measures would highlight the areas that need to be considered in the health-care professional treatment programs and gives a room for improvement when treatment is applied. All of the aforementioned reasons make PGI an interesting measure to be used in both the clinical setting and the research field to evaluate QOL and guide health-care decisions in people with MS.

This study also found a moderate correlation between the PGI and the study measures (EQ-5D and PPDS), indicating good construct validity. This result supports the idea that PGI measures different aspects of QOL than standard measures as the patients' voices are heard by allowing them to nominate, rate, and weights important areas to them.

This study has some limitations that need to be considered in future research. First, the sample size is relatively small. Second, only one generic measure and one disease-specific measure was administered and compared to the PGI. However, the reason was to decrease the burden on people with MS as many of the common standard measures used in the MS population take a long time to complete.

Conclusions

The Arabic version of the PGI is a feasible and acceptable measure among people with MS. PGI captures a wide spectrum of important areas that contribute to QOL among people with MS than standard measures. PGI is a useful tool to be used in both the clinical setting and the research field. PGI could improve the decision making and guide health-care professionals to provide appropriate intervention programs to reduce the burdens from MS disease and improve QOL.

Abbreviations

MS: Multiple Sclerosis, QOL: Quality of life; PGI: Patient Generated Index; PDDS: Patient Determined Disease Steps; EQ-5D: EuroQol-5D; ICF: International Classification of Functioning, Disability and

Health; GEE: Generalized Estimating Equations (GEE); rs: Spearman’s correlation; ES: Effect Size.

Declarations

Competing Interest

The authors declare that they have no conflict of interest.

Authors’ contribution

ASA The main investigator of the study and carried out the data analysis. All authors (ASA. HK, AA, KE) contributed to writing the manuscript, interpreting the results, reading and approving the final manuscript.

Acknowledgments

This study was not funded by any organization.

Author’s information

ASA is assistant professor and head of physical therapy department at Isra University. HK is associate professor and vice dean at the department of rehabilitation sciences at the Jordan University of Science and Technology. AA is assistant professor at the department of rehabilitation sciences at the Jordan University of Science and Technology. KE is Professor of neurology at the department of Neurosciences at the Jordan University of Science and Technology.

References

1. Alla, S., et al., *The increasing prevalence of multiple sclerosis in New Zealand.* Neuroepidemiology, 2014. **42**(3): p. 154-160.
2. El-Salem, K., et al., *Multiple sclerosis in Jordan: a clinical and epidemiological study.* Journal of neurology, 2006. **253**(9): p. 1210-1216.
3. DeLuca, J. and U. Nocentini, *Neuropsychological, medical and rehabilitative management of persons with multiple sclerosis.* NeuroRehabilitation, 2011. **29**(3): p. 197-219.
4. Al-Sharman, A., et al., *Living with multiple sclerosis: A Jordanian perspective.* Physiotherapy Research International, 2018. **23**(2): p. e1709.
5. Kargiotis, O., et al., *Quality of life in multiple sclerosis: effects of current treatment*

options. Int Rev Psychiatry, 2010. **22**(1): p. 67-82.

6. McNeil, C., *Quality of life researchers have new tool and new focus on measurement.* J Natl Cancer Inst, 2008. **100**(4): p. 234-6.
7. Gill, T.M. and A.R. Feinstein, *A critical appraisal of the quality of quality-of-life measurements.* Jama, 1994. **272**(8): p. 619-26.
8. Ware, J.E., Jr., *Standards for validating health measures: definition and content.* J Chronic Dis, 1987. **40**(6): p. 473-80.
9. Wood-Dauphinee, S., *Assessing quality of life in clinical research: from where have we come and where are we going?* J Clin Epidemiol, 1999. **52**(4): p. 355-63.
10. Organization, W.H., *PROGRAMME ON MENTAL HEALTH. WHOQOL User Manual . DIVISION OF MENTAL HEALTH AND PREVENTION OF SUBSTANCE ABUSE WORLD HEALTH ORGANIZATION.* 1998.
11. Ruta, D.A., et al., *A new approach to the measurement of quality of life. The Patient-Generated Index.* Med Care, 1994. **32**(11): p. 1109-26.
12. Aburub, A.S., et al., *Agreement between personally generated areas of quality of life concern and standard outcome measures in people with advanced cancer.* Support Care Cancer, 2016. **24**(9): p. 3831-8.
13. Aburub, A.S., et al., *Using a personalized measure (Patient Generated Index (PGI)) to identify what matters to people with cancer.* Support Care Cancer, 2016. **24**(1): p. 437-445.
14. de Achaval, S., et al., *Use of the Patient-generated Index in systemic sclerosis to assess patient-centered outcomes.* J Rheumatol, 2013. **40**(8): p. 1337-43.
15. Garratt, A.M., *Evaluation of the stages of completion and scoring of the Patient Generated Index (PGI) in patients with rheumatic diseases.* Qual Life Res, 2015. **24**(11): p. 2625-35.

16. Haywood, K.L., et al., *Patient centered assessment of ankylosing spondylitis-specific health related quality of life: evaluation of the Patient Generated Index.* J Rheumatol, 2003. **30**(4): p. 764-73.

17. Hogan, M., et al., *Evaluation of the patient generated index as a measure of quality-of-life in people with severe traumatic brain injury.* Brain Inj, 2013. **27**(3): p. 273-80.

18. Lochting, I., et al., *Individualized quality of life in patients with low back pain: reliability and validity of the Patient Generated Index.* J Rehabil Med, 2014. **46**(8): p. 781-7.

19. Martin, F., et al., *Twelve years' experience with the Patient Generated Index (PGI) of quality of life: a graded structured review.* Qual Life Res, 2007. **16**(4): p. 705-15.

20. Mayo, N.E., et al., *In support of an individualized approach to assessing quality of life: comparison between Patient Generated Index and standardized measures across four health conditions.* Qual Life Res, 2017. **26**(3): p. 601-609.

21. Klokkerud, M., et al., *Psychometric properties of the Norwegian version of the patient generated index in patients with rheumatic diseases participating in rehabilitation or self-management programmes.* Rheumatology (Oxford), 2013. **52**(5): p. 924-32.

22. Alaa M. Arafah, M.M.A., Shahnaz Shahrbanian, Asma Alkusayer, Nancy E. Mayo, *What Matters to Women Living with MS in Saudi Arabia. .* Quality of Life Research, 2014. **23**: p. 74-75.

23. Polman, C.H., et al., *Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria.* Ann Neurol, 2011. **69**(2): p. 292-302.

24. Learmonth, Y.C., et al., *Validation of patient determined disease steps (PDDS) scale scores in persons with multiple sclerosis.* 2013. **13**(1): p. 37.

25. Hohol, M., E. Orav, and H. Weiner, *Disease Steps in multiple sclerosis A simple approach to evaluate disease progression.* Neurology, 1995. **45**(2): p. 251-255.

26. Learmonth, Y.C., et al., *Validation of patient determined disease steps (PDDS) scale scores in persons with multiple sclerosis.* BMC neurology, 2013. **13**(1): p. 37.

27. Jones, K.H., et al., *How people with multiple sclerosis rate their quality of life: an EQ-5D survey via the UK MS register.* PLoS One, 2013. **8**(6): p. e65640.

28. Fisk, J., et al., *A comparison of health utility measures for the evaluation of multiple sclerosis treatments.* Journal of Neurology, Neurosurgery & Psychiatry, 2005. **76**(1): p. 58-63.

29. Organization, W.H., *International classification of functioning, disability and health, 2nd revision edn. Geneva: WHO.* 2001.

30. Organization, W.H., *International classification of functioning, disability and health: ICF. World Health Organization.* 2008.

31. Mukaka, M.M., *Statistics corner: A guide to appropriate use of correlation coefficient in medical research.* Malawi Med J, 2012. **24**(3): p. 69-71.

32. Akoglu, H., *User's guide to correlation coefficients.* Turk J Emerg Med, 2018. **18**(3): p. 91-93.

33. Tavernier, S.S., et al., *Validity of the Patient Generated Index as a quality-of-life measure in radiation oncology.* Oncol Nurs Forum, 2011. **38**(3): p. 319-29.

34. Kuspinar, A. and N.E. Mayo, *Do generic utility measures capture what is important to the quality of life of people with multiple sclerosis?* Health Qual Life Outcomes, 2013. **11**: p. 71.

35. Merlino, G., et al., *Prevalence of 'poor sleep' among patients with multiple sclerosis: an independent predictor of mental and physical status.* Sleep Med, 2009. **10**(1): p. 26-34.

36. Veauthier, C., et al., *Sleep Disorders Reduce Health-Related Quality of Life in Multiple Sclerosis (Nottingham Health Profile Data in Patients with Multiple Sclerosis).*

Int J Mol Sci, 2015. **16**(7): p. 16514-28.

37. Boe Lunde, H.M., et al., *Poor sleep in patients with multiple sclerosis.* PLoS One, 2012. **7**(11): p. e49996.

38. Green, R., et al., *Which symptoms contribute the most to patients' perception of health in multiple sclerosis?* Mult Scler J Exp Transl Clin, 2017. **3**(3): p. 2055217317728301.

39. Rottoli, M., et al., *Pathophysiology, assessment and management of multiple sclerosis fatigue: an update.* Expert Rev Neurother, 2017. **17**(4): p. 373-379.

40. Hadjimichael, O., T. Vollmer, and M. Oleen-Burkey, *Fatigue characteristics in multiple sclerosis: the North American Research Committee on Multiple Sclerosis (NARCOMS) survey.* Health Qual Life Outcomes, 2008. **6**: p. 100.

41. Carmines EG, Z.R., *Reliability and Validity Assessment. Series: Quantitative Applications in the Social Sciences. Sage Publication* 1979.

42. Brod, M., L.E. Tesler, and T.L. Christensen, *Qualitative research and content validity: developing best practices based on science and experience.* Qual Life Res, 2009. **18**(9): p. 1263-78.

43. Cronbach, L.J. and P.E. Meehl, *Construct validity in psychological tests.* Psychol Bull, 1955. **52**(4): p. 281-302.

44. Magasi, S., et al., *Content validity of patient-reported outcome measures: perspectives from a PROMIS meeting.* Qual Life Res, 2012. **21**(5): p. 739-46.

Tables

Table 1 Participants characteristics (N=66, Means±SD or Frequency (%))

Age	35.6±10.2
Gender	
Male	21 (31.8)
Female	45 (68.2)
Type of MS	
Relapsing-Remitting MS	59 (89.4)
Secondary-Progressive MS	6 (9.1)
Primary-Progressive MS	1 (1.5)
Time since diagnosis	7.6±5.8
Education	
Primary	4 (6.1)
Secondary	28 (42.4)
College	7 (10.6)
Bachelor	23 (34.9)
Master	4 (6.1)

Table 2 Top 11 nominated areas by people with multiple sclerosis using the patient-generated index (PGI) mapped to the ICF and compared with study outcomes items

Top areas identified	Number of patients reporting the problem and its percentage (N (%)	EQ-5D
Emotional functions	31 (47%)	Y
Involuntary movement reaction functions	30 (45.5)	N
Walking	29 (43.9)	Y
Seeing function (vision)	20 (30.3)	N
Socializing	19 (28.8)	N
Sleep functions	15 (22.7)	N
Doing housework	14 (21.2)	Y
Work	11 (16.7)	Y
Muscle power functions	9 (13.6)	N
Fatigue	8 (12.1)	N
Moving around	8 (12.1)	Y
Total number of areas identified (N=36)		Self-care, School education, Sports, C out a daily routine, Recreation and Dressing, Toileting

Figures

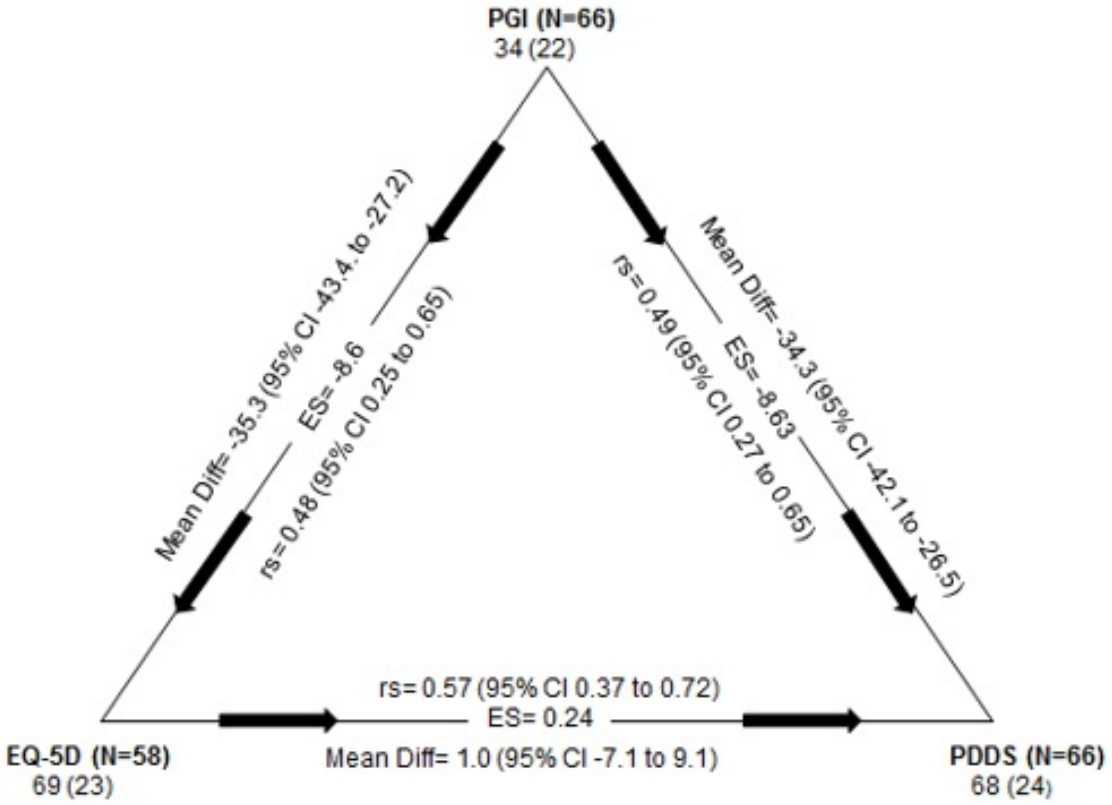
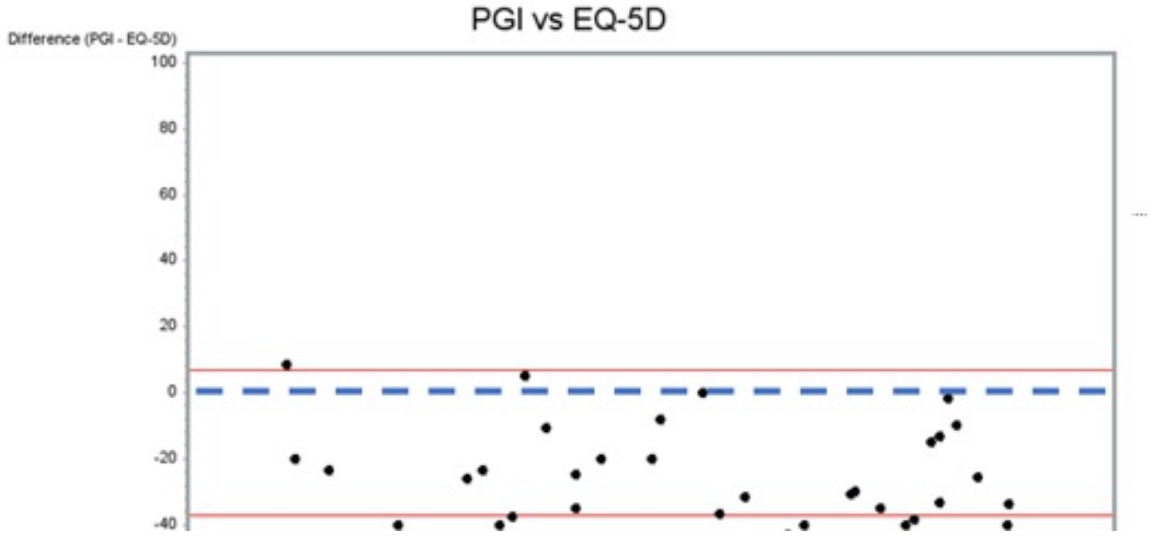
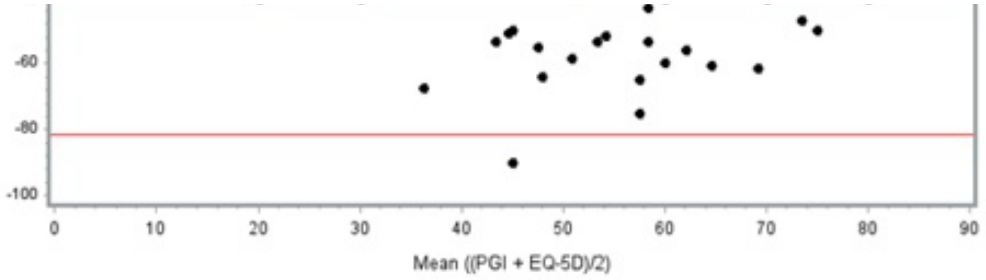


Figure 1

Comparison between the total score of the PGI and the study measures (PDDS and EQ-5D) using the generalized estimating equations (GEE)

a) PGI vs. EQ-5D





b) PGI vs. PDDS

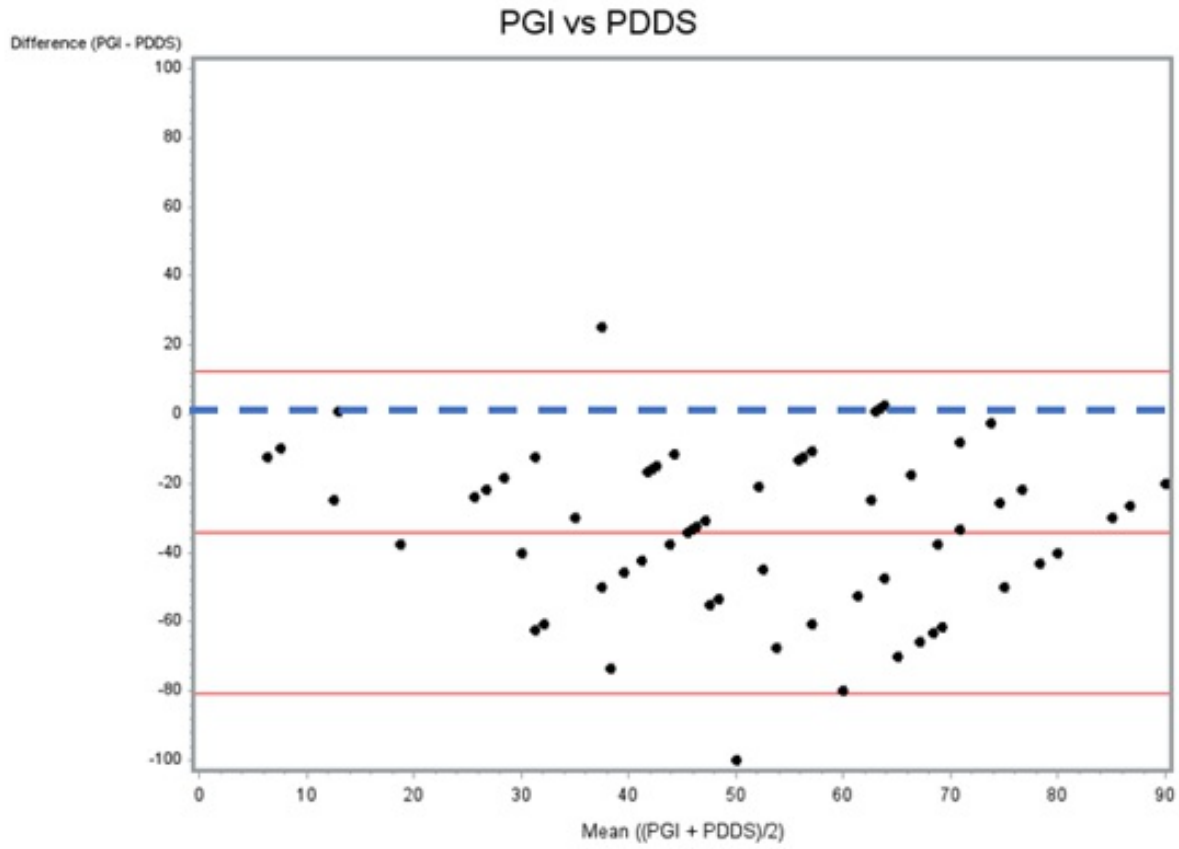


Figure 2

The relationship between the PGI and study measures (EQ-5D and PDDS) using the Bland-Altman plot.