

Paper-based and electronic assessment of health-related quality of life specific to HIV disease: A reliability study with the PROQOL-HIV questionnaire

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Aims

Electronic Patient Reported Outcomes (PRO) measurement provides a quick and reliable assessment of patients' health-related quality of life (HRQL). It is, however, important to demonstrate the equivalence of measures derived from electronic and paper-based versions of a given questionnaire [1,2]. An electronic version of the PROQOL-HIV questionnaire [3,4], a 43-item questionnaire measuring health-related quality of life in HIV patients, was developed and its face validity and reliability was assessed using standard psychometric methods.

Methods

A total of 80 French outpatients (63% males, mean age 47 years) was recruited for this validation study (Table 1). Hard copy and electronic questionnaires were completed in a randomized cross-over design with a 2-7 day interval between completing the hard copy and the electronic versions. Biomedical and demographic data were collected on a separate questionnaire. Questionnaire version and order effects were tested on full scale scores in a two-way ANOVA with patients as random effects. Test-retest reliability was evaluated using Pearson correlation and intra-class correlation coefficients (with 95% confidence interval) for each dimension. Usability testing was carried out from patients' survey reports, specifically: general satisfaction, ease of completion, quality and clarity of user interface (UI) and self motivation for electronic measuring to monitor HRQL in clinical follow-up.

Results

Questionnaire version (paper/electronic) and administration order effects (N=58 complete cases) were not significant at the 5% level, nor interacting together (p=0.940). Reliability indices were acceptable, with Pearson correlation above 0.7 and intra-class correlations ranging from 0.696 [0.400;0.999] for treatment impact to 0.926 [0.886;0.973] for physical state and symptoms (Table 2 and Figure 1). Mean scores for each dimension were not significantly different (Wilcoxon-Mann-Whitney tests, corrected for multiple testing), confirming scores stability across the two administrations. No adverse events were reported during the study. On 77% of complete surveys, 57% of patients reported being satisfied and interested in electronic assessment of their HRQL in clinical follow up. Individual ratings of PROQOL-HIV user interface (85 to 100% of positive responses) confirmed UI clarity and usability (Table 3).

Table 1: Demographics

Demographic and biomedical informations on study participants. For numerical variables, mean (SD) and inter-quartile range are provided, while for categorical variables reported numbers correspond to frequencies (counts). The number of complete cases for each variable is reported as N.

	N	Centre 1	Centre 2	Combined	
Age (years)	79	46.9 (11.2) [39.5-53.0]	44.4 (8.9) [37.0-51.0]	46.7 (10.9) [39.0-53.0]	P=0.580
Gender	79	63% (44)	89% (8)	66% (52)	P=0.120
No professional activity	78	21% (15)	75% (6)	27% (21)	P=0.005
Level of education (university)	78	41% (29)	50% (4)	42% (33)	P=0.931
Single	77	48% (33)	62% (5)	49% (38)	P=0.680
Living alone	78	44% (31)	100% (8)	50% (39)	P=0.009
Depression	78	13% (9)	38% (3)	15% (12)	P=0.067
Psychiatric disorder	78	1% (1)	0% (0)	1% (1)	P=0.730
Cardiovascular disease	78	13% (9)	38% (3)	15% (12)	P=0.067
Diabete	78	9% (6)	12% (1)	9% (7)	P=0.710
Other comorbidities	78	7% (5)	0% (0)	6% (5)	P=0.430
Lipodystrophy	79	21% (15)	22% (2)	22% (17)	P=0.960
Current treatment	78				
Tuberculosis		0% (0)	0% (0)	0% (0)	---
Prophylaxis		4% (3)	38% (3)	8% (6)	P<0.001
Antidepressant		11% (8)	38% (3)	14% (11)	P=0.045
Lipid-lowering		10% (7)	0% (0)	9% (7)	P=0.350
Year of diagnostic	79	1998 (8) [1990-2005]	2002 (7) [2000-2008]	1999 (8) [1991-2006]	P=0.190
CDC Stage	79				
A		59% (41)	22% (2)	54% (43)	P=0.074
B		19% (13)	22% (2)	19% (15)	
C		23% (16)	56% (5)	27% (21)	
Year of first HAART	66	2002 (6) [1996-2007]	2008 (3) [2007-2009]	2003 (6) [1997-2007]	P=0.024
Hepatitis C	79	20% (14)	0% (0)	18% (14)	P=0.310
Hepatitis B	79	6% (4)	10% (1)	6% (5)	P=1
CD4 counts (cell/mm ³)	79	623 (438) [441-700]	407 (191) [213-527]	598 (422) [424-694]	P=0.044
CD4 %	74	30.3 (10.2) [24-37]	20.2 (9.8) [19-24]	29.6 (10.4) [23-37]	---

Table 2: Reliability Analysis.

Scale scores are summarized as mean (SD) and [inter-quartile range]. Correlation measures stand for Bravais-Pearson linear correlation (r) and Spearman rank correlation (ρ). Results from Wilcoxon signed rank test for paired samples are given in the last column. * Full-scale score was calculated following exclusion of 4 extra items and the GH item.

	No. items	Paper	Electronic	r (ρ)	ICC (95% CI)	Wilcoxon V
All items*	38	68.3 (16.5) [54.1-82.1]	69.5 (16.2) [56.7-84.4]	0.868 (0.851)	0.868 (0.815;0.931)	P=0.208
BC	4	78.0 (26.1) [54.7-100.0]	76.9 (26.0) [56.2-100.0]	0.827 (0.777)	0.827 (0.708;0.955)	P=0.304
ED	4	68.8 (26.9) [50.0-93.8]	69.4 (26.0) [50.0-93.8]	0.842 (0.874)	0.842 (0.772;0.929)	P=0.966
GH	1	23.5 (20.7) [0.0-25.0]	21.4 (21.7) [0.0-25.0]	0.715 (0.790)	0.714 (0.550;0.881)	P=0.457
HC	4	51.6 (28.3) [25.0-81.2]	55.6 (29.4) [31.2-81.2]	0.785 (0.767)	0.785 (0.680;0.884)	P=0.457
IR	3	57.4 (33.8) [33.3-85.4]	63.4 (31.1) [39.6-91.7]	0.782 (0.782)	0.779 (0.625;0.909)	P=0.054
PHS	9	76.3 (20.8) [63.9-94.4]	75.6 (20.3) [63.9-91.7]	0.940 (0.923)	0.939 (0.905;0.979)	P=0.629
SR	2	80.8 (27.1) [75.0-100.0]	80.4 (28.9) [62.5-100.0]	0.824 (0.803)	0.822 (0.725;0.941)	P=0.987
ST	2	33.3 (33.8) [0.0-50.0]	36.4 (34.5) [0.0-50.0]	0.712 (0.741)	0.712 (0.543;0.893)	P=0.249
TI	10	71.7 (21.2) [57.5-90.0]	72.2 (20.9) [61.2-90.0]	0.708 (0.783)	0.708 (0.444;0.982)	P=0.939

BC: Body concerns, ED: Emotional distress, GH: General health, HC: Health concerns, IR: intimate relationships, PHS: Physical health and symptoms, SR: Social relationships, ST: Stigma, TI: Treatment impact

Table 3: Participants survey responses.

Question	N	% (n)	Mean (SD) [IQR]
Display on screen is comprehensible and easy to follow	63	100 (63)	
Font size looks appropriate	62	98 (61)	
Single page design is satisfactory	62	100 (62)	
Visualization of results is an interesting option	61	95 (58)	
Display of results is comprehensible	60	80 (48)	
Ease of input responses	63		4.6 (0.7) [4-5]
Questions readability	63		4.6 (0.8) [4-5]
Scores readability	61		4 (1) [4-5]
Interested in longitudinal followup of personal scores	60		4.4 (0.9) [4-5]
Difficulty with computing material	60	13 (8)	
Ease of filling (electronic vs. paper)	55		4 (1) [3-5]
Preference			
indifferent		36 (20)	
paper		9 (5)	
electronic		55 (30)	

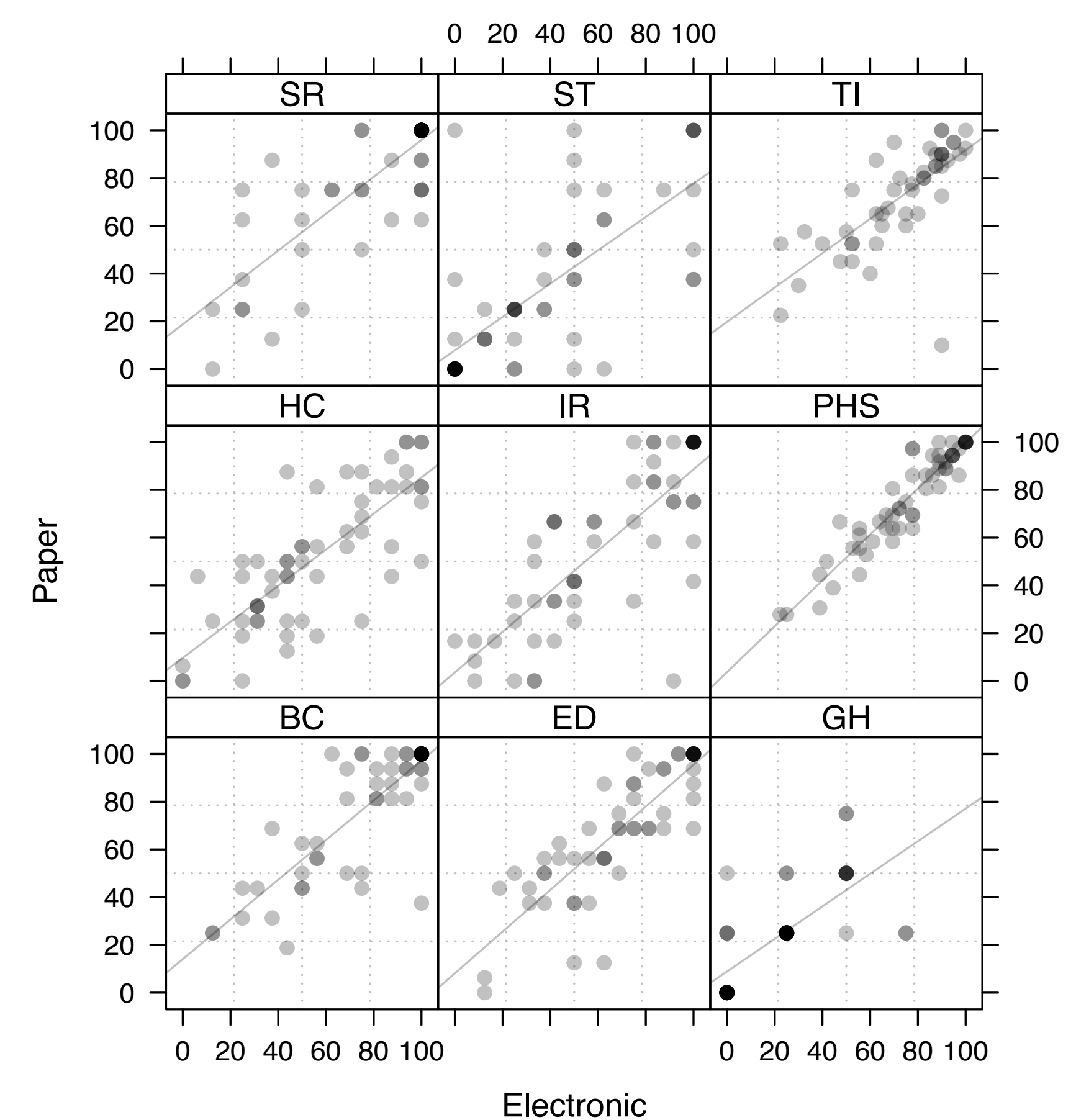
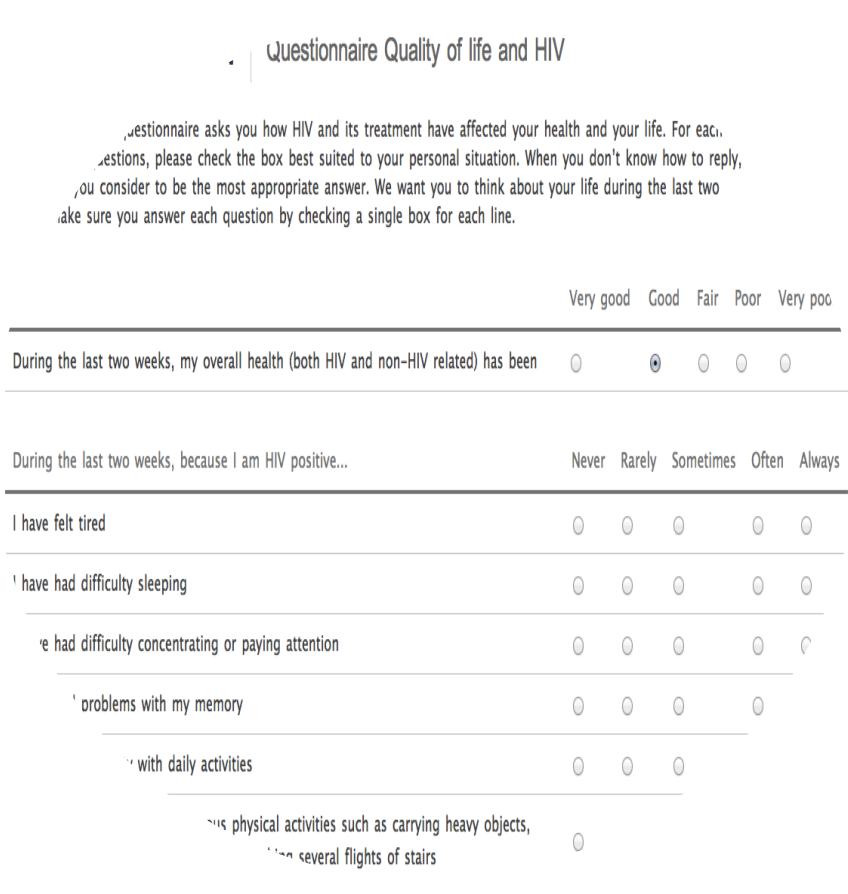


Figure 1: Distribution of participants scores.

Individual scores on electronic and paper versions of the PROQOL-HIV questionnaire. Individual points are displayed with alpha transparency where darker symbols indicate a higher number of identical pairs of scores. A regression line was superimposed for each panel.

Conclusions

The electronic PROQOL-HIV introduces minor modifications compared to the original paper-based version and scores attained from hard copy and electronic version share comparable accuracy and interpretation. The ease in completing an electronic questionnaire and direct visual feedback to patients of their HRQL scores is of interest in a clinical trial setting as well as self-monitoring and clinical practice.

References

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