Patient Generated Index in HIV Chemosensory & auditory complaints: An observational study

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Appendix A PGI Patient Generated Index of Quality of Life

Your answers to the following steps will tell us how your life is affected by your Smell, Taste and Hearing senses. It will also tell us how you would like to see your life improved

Step 1: Identifying Areas	Step 2: Scoring each area	Step 3: Spending points
We would like you to think of the most important areas of your life that are affected by your Smell, Taste and Hearing senses. Please write up to FIVE areas in the boxes below	In this part we would like you to score the areas you mentioned in step 1. This score should show how badly affected you are. Please score each area out of 10 using this scale: 10= Exactly as you would like to be 9 = Close to how you would like to be 8 = Very Good but not how you would like to be 7 = Good but not how you would like to be 6 = Between good and fair 5 = Fair 4 = Between poor and fair 3 = Poor but not the worst you could imagine 2 = Very poor but not the worst you could imagine 1 = Close to the worst you could imagine 0 = The worst you could imagine	We want you to imagine that any or all the areas you mentioned could be improved. You have 12 points to spend to show which areas you would like most to see improved. Spend more points on areas you would most like to see improvement and less on areas that are not so important. You only have 12 points to spend
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>
Areas affected by other health problems	<input type="text"/>	<input type="text"/>

PGI

HIV is a chronic manageable disease. The disease and/or antiretroviral therapy treatment may lead to patient complaints regarding their hearing and chemosensory perception. Patient Generated Index (PGI) has been a validated patient generated questionnaire, which is flexible to capture areas relevant to patients. It has not been used before to assess the chemosensory (smell and taste) and auditory concerns of HIV positive patients. Methods: PGI questionnaire was distributed to nineteen HIV patients attending the research clinic. Patients had five areas to record their perception in relation to senses (smell, taste and hearing). They then score how do they feel about this particular area, then they spend points to improve the area when needed. Patients were recruited from a HIV clinic after giving their informed consent matching inclusion/exclusion criteria. The questionnaire had five sections where patients identify problems matter to them in relation to smell, taste and hearing. The sixth question is generated by the patient in relation to other health areas of concern to the individual. Results: PGI scores (n=19) mean was 5.39 (range 1.08 – 8, SD 1.93). Smell mean scores 1.1, taste was 1 and hearing was 0.97 Smell was 20.4% of the total PGI score; taste was 18.6% and hearing 18% of the PGI score. Patients scored 2.32 (43% of the total PGI score) in other areas (back pain, arthritis, stomach pains, ...)

Conclusions: This is an observational cohort study to document the PGI results in relation to auditory and chemosensory perception in HIV positive patients. Although auditory and chemosensory problems in five areas scores altogether 57% of the PGI score, others (one area question), patients scored 43% of the total PGI score. other complaints preoccupied patients and were relatively more cumbersome than the three senses.