

**Time trends in Health Related Quality of Life after stroke:**

*Analysis from the South London Stroke Register 1995-2011*

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Abstract Word count: 230

Main text Words: 2687

Key Words: Health Related Quality of Life (HRQOL), Stroke, Trends

## **Abstract**

**Background and Purpose:** The global burden of stroke is increasing, potentially impacting on outcomes after stroke, including health related quality of life (HRQOL). This study investigates trends of mental and physical HRQOL after stroke during the period between 1995 and 2011.

**Methods:** First in a lifetime strokes were registered in the South London Stroke Register between 1995 and 2011. Using the Short Form-12 Health Survey (SF-12), trends in self-reported HRQOL at one year after stroke were assessed over a 17 year period using linear regression, adjusting for potential confounders (socio-demographics, risk factors and case-mix variables). Analyses stratifying by age, gender, ethnicity and functional impairment were also performed.

**Results:** No significant overall improvements were found over 17 years in either mental or physical HRQOL scores at one year after stroke after adjusting for confounders. However, mental HRQOL scores significantly improved until 2008 ( $\beta=0.94$ [95% CI; 0.15 to 1.74],  $P=0.02$ ), after which scores worsened ( $\beta=-2.02$  [3.82 to -0.22]  $P=0.03$ ). Physical HRQOL scores remained stable until 2008, after which scores worsened ( $\beta=-1.63$  [3.25 to -0.01]  $P=0.05$ ).

**Conclusions:** These findings suggest that despite declining trends within the general population, stroke survivors have a stable HRQOL, possible due to lower expectations of health among stroke survivors. However, in recent years there has been a significant decline in HRQOL suggesting that despite stroke policy aims to improve HRQOL, more needs to be done to target this decline.

## **Introduction**

In the last twenty years there has been a rise in the global burden of stroke, which has become the third leading cause of Disability Adjusted Life Years (DALYs) worldwide and requires long-term management<sup>1</sup>. There are approximately 15 million stroke occurrences a year worldwide with 5 million people left permanently disabled<sup>2</sup>. A major consequence of stroke is a reduction in health related quality of life (HRQOL)<sup>3-8</sup>. Comparing stroke patients to demographically matched stroke-free controls in the US, Haley et al (2010) found significantly poorer HRQOL in stroke survivors for both mental and physical HRQOL<sup>7</sup>. In the UK, Bugge et al (2001) found significantly poorer HRQOL scores in stroke patients than in the general population<sup>6</sup>. Using data from the South London Stroke Register, physical and mental HRQOL scores were found to be worse among stroke survivors than age-matched general population scores, and were found to fluctuate up to 10 years after stroke<sup>8</sup>.

The World Health Organisation (WHO) describes quality of life as “an individual’s perception of their positions in life in the context of the culture and value systems in which they live and in relation to goals, expectations, standards and concerns”<sup>9</sup>. HRQOL is affected by how physical and mental health relates to an individual’s well-being<sup>10</sup>.

There is evidence that HRQOL in both the acute and long-term stroke time periods is related to age, gender, functional impairment, incontinence and hypertension<sup>10-13</sup>. Previous studies from the 1990s through to the 2000s have also shown that there were worsening HRQOL trends in the general population<sup>14, 15</sup>, however evidence is lacking as to whether such trends exist in a population of stroke patients. There have been significant changes in stroke services and government policy on stroke care both internationally<sup>16, 17</sup> and in the UK over the last 2 decades<sup>18-22</sup>, with aims of giving stroke survivors a ‘good quality of life’<sup>19</sup>, however it is unknown whether the HRQOL of stroke patients has in fact improved.

In this study, HRQOL after stroke were examined within a multi-ethnic population of stroke survivors over a 17 year period since 1995 in a population based study covering an inner city area of South London.

## **Methods**

The study population was derived from The South London Stroke Register (SLSR)<sup>8, 23</sup>, a prospective population-based stroke register set up in January 1995; recording all first-ever strokes (defined using WHO criteria) in patients of all ages in a defined area of South London. At the time of the 2011 census the SLSR source population consisted of 357,308 individuals of which 56% were of white ethnicity, 25% Black (14% Black African, 7% black Caribbean, 4 % Black Other), and 18% other ethnic group.

### *Case Ascertainment*

Details of notification methods have been described previously<sup>24, 25</sup>. Briefly, patients admitted to hospitals serving the study area were identified by regular reviews of acute wards admitting stroke patients, weekly checks of brain imaging referrals and monthly reviews of bereavement officers and of bed manager records. Additionally, national data on patients admitted to any hospital in England and Wales with a diagnosis of stroke were also screened for additional patients. To identify patients not admitted to hospital, all general practitioners (GPs), community therapists and neurovascular clinics within and on the borders of the study area were contacted regularly and asked to notify the Register of stroke patients.

Completeness of case ascertainment has been estimated at 88% by a multinomial-logit capture-recapture model<sup>26</sup>.

### *Data Collection*

Patients were assessed at 3 months after stroke and annually thereafter. HRQOL was assessed using the UK version of the Medical Outcomes Study 12 or 36 item short-form surveys (SF-12) and (SF-36)<sup>27, 28</sup>. Follow-up data were collected by postal or face-to-face interviews with patients and/or their carers. All interviewers were vigorously trained to administer questions in a standardised way.

The SF-36 was used to measure HRQOL in follow-up interviews conducted before 01/03/1999 after which the shortened version, the SF-12, was introduced. The 12 items of the SF-12 have been adopted from the SF-36 verbatim and summary scores are replicable and reproducible in stroke patients<sup>28-30</sup>. Therefore, the specific items from the SF-36 questionnaires in earlier follow ups were used to derive SF-12 summary scores across all time points, excluding a short period in 1999 where HRQOL data were not collected. The SF-12 was selected to measure HRQOL because of its strong psychometric properties, wide use, reliability, validity and responsiveness<sup>27, 28</sup>. It assesses eight domains of health status, which are then computed to produce two summary scores representing physical and mental HRQOL. The summary scores range from 0-100 with higher scores indicating a better HRQOL. These scores are based on norms with a mean of 50 and a standard deviation of 10. In this study mean scores were analysed in line with other studies<sup>8, 10, 12</sup>.

Stroke was classified by the World Health Organisation Criteria<sup>26</sup> into 3 subtypes- Ischemic, Primary intra-cerebral haemorrhage (PICH) and Subarachnoid haemorrhage (SAH). To assess stroke severity, clinical details at the time of maximal impairment were obtained from information on urinary incontinence and level of consciousness, assessed using the Glasgow Coma Scale dichotomised into a score of < 13 (impaired consciousness) or 13 or more<sup>26</sup>.

Past medical history of vascular risk factors for stroke were collected from data on smoking, hypertension, diabetes, atrial fibrillation, myocardial infarction, transient ischemic attack (TIA) and pre stroke antithrombotic medication (anticoagulants and/or antiplatelets).

Processes of care after stroke were assessed by whether swallowing was assessed (using the 3oz (85ml) water swallow test), admission to hospital and stroke unit (SU), and whether brain imaging (CT or MRI scan) was performed.

General population HRQOL scores were obtained through searching electronic databases (PubMed, Web of Science, Google Scholar) in January 2013 using the search terms 'HRQOL/trends/SF-12/UK (and related terms).

### *Statistical analysis*

Mean mental and physical HRQOL scores at one year after stroke were estimated by socio-demographics, risk factors, severity of stroke and processes of stroke care using one way ANOVA. The 17 years of data were divided into five groups by date of index stroke: 1995-1997, 1998-2001, 2002-2004, 2005-2007, and 2008-2011 to increase each sample size. One way ANOVA was used to examine differences in HRQOL post-stroke among the five year groups. Simple and multiple linear regressions were used to analyse mean mental and physical HRQOL scores, weighted to adjust for variance in each group and to examine trends over the five periods. Within the multiple linear regression models adjustments were made for age, gender, ethnicity (White, Black, Other), Carstairs deprivation scores<sup>31</sup> (obtained from postcode), pre-stroke smoking, number of pre-stroke risk factors (taken from combining hypertension(67%), diabetes(19%), atrial fibrillation(17%), myocardial infarction(11%), transient ischaemic attack(12%)), pre-stroke antithrombotic medication, stroke subtype, Glasgow coma scale score, incontinence and processes of stroke care. Only variables that were measured across all 17 years of data collection were used within these models. To examine trends further, data were stratified

by age, sex, ethnicity and functional impairment measured by Barthel Index at one year after stroke (<15 severe functional impairments), removing the relevant stratified variable from the model. Statistical analysis was performed using STATA 12.0 (StataCorp, Texas, USA).

## **Results**

4,253 patients were registered in the SLSR with first-ever stroke between 1 January 1995 and 31 December 2011. 2977(70.0%) survived to one year after stroke, of whom 647(15.2%) were lost to follow-up, and 695(16.3%) did not complete the SF-12. Therefore, 1475 surviving patients were assessed for mental and physical HRQOL at one year post-stroke.

The characteristics of the patients are presented in table 1. The mean (standard deviation) mental HRQOL score of SLSR patients at one year after stroke was 45.9(12.3), while physical HRQOL scores were 36.8(11.6). Low mental HRQOL scores were significantly associated with younger age, females, incontinence and admittance to hospital but not stroke unit. Low physical HRQOL scores were significantly related to older age, females, other ethnicity, a large number risk pre-stroke risk factors, no antithrombotic (anticoagulant and/or antiplatelet) medication, incontinence, ischaemic strokes and admission to both hospital and stroke unit.

Figure 1, shows unadjusted mean HRQOL scores at one year after stroke over time. There were no significant trends in overall mean mental HRQOL scores, but significant differences between the 5 year groups, with score remaining stable until 2008, when there was a small but insignificant decline. There was a declining trend in overall physical HRQOL scores from 1995 to 2011 ( $\beta = -0.56$ , CI=-0.95 to -0.17, P=0.005), with scores remaining relatively unchanged until 2008, after which they fell significantly ( $\beta = -3.00$  P<0.001).

After adjusting for socio-demographics, pre-stroke risk factors, antithrombotic medication, case mix and processes of care; no significant trends were found over 17 years in either mental or

physical HRQOL scores (figure 2). However, mental HRQOL scores showed a significant improvement from 1995-2007 ( $\beta=0.94$ , CI=0.15 to 1.74, P=0.02), and then fell significantly in 2008-2011 ( $\beta=-2.02$ , CI=3.82 to -0.22, P=0.03). Physical HRQOL scores remained relatively stable from 1995-2007, but showed a borderline significant decline from 2008 onwards when comparing the last year group to the earlier years ( $\beta=-1.63$ , CI=-3.25 to -0.01, P=0.05).

HRQOL scores remained unchanged when stratifying by age, gender and functional impairment (figure 3). When stratifying by ethnicity, mental HRQOL scores showed a significant increasing trend among 'other' ethnicity ( $\beta=2.79$ , 0.22 5.37, P=0.03).

## **Discussion**

In this UK population based stroke register from 1995-2011, mental and physical HRQOL scores were lower than comparable UK general population HRQOL scores of 50<sup>32</sup>. Both mental and physical HRQOL remained stable over time at one year post-stroke, even when adjusting for potential confounders. However, HRQOL improved until 2008 in the mental domain and fell after 2008 in both mental and physical domains. HRQOL remained constant over time when stratifying by age, gender and functional impairment. Mental HRQOL improved over time for the 'other' ethnic group consisting of non-white and non-black ethnicities.

The strength of this study is that the SLSR is a longitudinal register with 17 years of follow-up data that can be used to investigate trends over a long period of time, which few other studies have the resources to achieve. To the best of our knowledge, this study is unique in its investigation of trends in HRQOL in stroke patients over a continuous long-term period of time. Data are available on a large number of variables such as ethnicity, which mean a high number of potentially confounding variables could be adjusted for and data could also be stratified by demographics and

functional impairment level. However, some variables such as how much therapy was received could not be included in our models as they were not collected continuously over the 17 years.

This study has some potential limitations. Firstly, within the 17 year of data collection HRQOL measures were not collected for a period in 1999. The effects of this missing data on trends are unknown; however the data were clustered into 5 yearly groups to counteract this issue. Also, the socio-demographic characteristic, functional impairments and cognitive impairments of patients with missing data did not significantly differ from those within our analyses and the clustered data was weighted to limit this effect.

Secondly, the sample size of this cohort was relatively small for a study that spans 17 years. Some parameter estimates have wide confidence intervals. Some patients were registered retrospectively and could not contribute data at one year post-stroke. South London has a mobile population with patients moving with no forwarding address, making some patients harder to contact for follow up. However, numerous sources were used to ensure contact with patients was not lost although the lost to follow up rate remained high.

The findings of overall unchanged HRQOL in stroke survivors and improving trends in the other ethnic group for physical HRQOL over time are contradictory to studies within the general population. Audureau et al (2012) compared two cross-sectional surveys in 1995 and 2003 in France and found a significant decline in HRQOL<sup>14</sup>. Also, from 1993 to 2001, HRQOL in the general US adult population worsened overtime<sup>15</sup>. A UK study found that over a five year period from 1999- 2004 HRQOL declined in the general population<sup>33</sup>. Our study did however, find declines from 2008-2011 which reflect general population trends, although this does not explain why previous years did not show such declines, and even showed improvements in mental HRQOL.

Evidence from studies investigating HRQOL over a continuous period of time within a population of stroke survivors is lacking. Edwards et al (2010) compared HRQOL measured by the Health Utilities Index Mark 3 (HUI3) in stroke survivors in Canada between 1996 and 2005, which found a declining trend in HRQOL after stroke<sup>34</sup>. However, the study compared data from two different cross sectional population health surveys conducted in 1996 and 2005, only including self-reported strokes. In other chronic diseases, HRQOL trends have been analysed somewhat over a continuous period of time. In kidney transplant recipients in the US, physical HRQOL have been found to decline slightly although not significantly, while mental HRQOL significantly increased over a period from 1997 to 2006<sup>35</sup>. Our findings within stroke survivors were consistent with these studies during the same time period. Yet, a decline was observed in HRQOL shortly thereafter.

In England, the National Stroke Strategy was introduced in 2007 stating one of their aims was “for those who have has a stroke...to achieve a good quality of life”<sup>19</sup>. The fact that HRQOL in stroke survivors remained relatively unchanged over 17 years and even show improvements in the other ethnic group, while the general population show declining HRQOL trends, could suggest that stroke policy aims are being met in curbing these declines. However, although the overall trends remain relatively stable since 1995; after 2008 HRQOL worsened suggesting that there is no evidence of improvements reflecting to the recent stroke strategies.

Another possible explanation of this decline could be related to the global recession, occurring in 2008 with unemployment and suicide rates rising within the general population<sup>36</sup> leading to worsening self-reported HRQOL. However, this does not explain the reason for stable trends over time and improvements in mental HRQOL until 2008. Further investigations are needed to understand if these recent declines are related to policy changes between periods of time, or to psychosocial hazard exposures during the economic recession, or simply to an evolution in expectation of health of stroke survivors.

Stable HRQOL in stroke survivors and declining HRQOL in the general population over time could be due to expectations of stroke survivors. Expectations of recovery after stroke can determine the experiences stroke survivors face and their perception of health<sup>37</sup>. In 2009, the Department of Health launched the ‘Stroke-Act F.A.S.T’ Media Campaign, which brought about a 171 per cent increase in the number of patients presenting within three hours of having a stroke to a hyper acute unit from 2008 to 2009<sup>21</sup>, indicating an increased awareness of stroke symptoms. With more information readily available to stroke survivors, they may be more aware of their health limitations than the general population leading to lower expectations of HRQOL. However, a recent study found that 54% of stroke survivors in the UK reported a need for more information about stroke<sup>38</sup>.

Improvements were found in mental HRQOL within the other ethnic group over the 17 years, although they scored lower mental and physical HRQOL scores than the white and black ethnic groups, which has also been found in previous studies<sup>12</sup>. This trend could be due to improvements in raising awareness of stroke in these communities<sup>21</sup> and adapting campaign materials into different languages as the other ethnic group largely consists of Asian stroke survivors whose first language may not be English. However, the sample size of this group is small so further investigation into ethnicity and HRQOL trends are needed using a larger ‘other’ ethnic population.

### *Conclusions*

With policies aiming for patients to become more involved in their medical care<sup>19</sup>, self-reported HRQOL is an important factor to consider when improving stroke care. This long-term study has provided some evidence of HRQOL remaining stable over 17 years within stroke survivors despite general population declines, possible due to lower expectations of health among stroke survivors. However, in recent years there has been a significant decline in HRQOL within stroke survivors

suggesting that despite stroke policy aims to improve HRQOL, more needs to be done to target this decline.

## **Acknowledgements**

We wish to thank all the patients and their relatives and the health care professionals involved. Particular thanks to all the fieldworkers and the team who have collected data since 1995 for the SLSR.

## **Sources of Funding**

The research was funded/supported by the National Institute for Health Research (NIHR) Biomedical Research Centre based at Guy's and St Thomas' NHS Foundation Trust and King's College London, and a NIHR Program Grant (RP-PG-0407-10184). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

## **Disclosure**

None

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**Table 1: Patients characteristics by mean HRQOL at one year post-stroke**

Variable	N(1475)	Mental HRQOL		Physical HRQOL	
		Mean score(s.d)	P-value	Mean score(s.d)	P-value
<b>General HRQOL score</b> <i>Non-stroke population</i> <sup>32</sup>	1475	45.9(12.3) 50(9.72)		36.8(11.6) 50(9.72)	
<b>Age</b>					
0-64 <i>Non-stroke population</i> <sup>39</sup>	562(38.1)	44(12.8) 51.8(8.8)	<0.001	38.9(12.1) 51.3(8.8)	<0.001
65-74 <i>Non-stroke population</i> <sup>39</sup>	425(28.8)	47(12.0) 53.2(9.1)		37.1(11.4) 45.3(11.2)	
75+ (No non-stroke data)	488(33.1)	47.2(11.6)		34.2(10.6)	
<b>Gender</b>					
male <i>Non-stroke population</i> <sup>32</sup>	790(53.6)	46.6(12.2) 51.4(8.94)	0.0301	38.0(11.6) 51.2(9.2)	<0.001
female <i>Non-stroke population</i> <sup>32</sup>	685(46.4)	45.2(12.2) 49.0(10.2)		35.5(11.5) 19.0(10.0)	
<b>Ethnicity</b>					
White <i>Non-stroke population</i> <sup>40</sup>	1034(70.1)	46.0(12.4) 49.4(10.5)	0.205	37.3(11.7) 49.9(10.5)	0.049
Black <i>Non-stroke population</i> <sup>40</sup>	346(23.5)	46.5(11.8) 47.8(11.0)		35.9(11.3) 49.9(10.3)	
Other <i>Non-stroke population</i> <sup>40</sup>	79(5.4)	43.3(12.2) 46.7(9.8)		34.4(10.3) 48.4(10.7)	
<b>Carstairs Deprivation score</b>					
1 Least-deprived	516(35)	46.2(12.5)	0.5714	37.5(12)	0.2258
2	481(32.6)	46.1(12)		36.5(11.5)	
3 Most-deprived	478(32.4)	45.4(12.3)		36.4(11.1)	
<b>Smoker</b>					
non-smoker	927(62.9)	46.4(12.0)	0.1314	36.7(11.6)	0.63
smoker	517(35.1)	45.2(12.9)		37.2(11.6)	
<b>Pre-stroke co-morbidities</b>					
0	325(22.0)	45.9(12.3)	0.38	39.1(12.1)	<0.001
1	574(38.9)	45.4(13.0)		37.5(11.8)	

2+	469(31.8)	46.3(11.7)		34.3(10.6)	
<b>Antithrombotic Meds</b>					
no	828(56.1)	45.5(12.9)		37.5(12.0)	
yes	472(32.0)	46.4(11.6)	0.2225	34.8(10.7)	<0.001
<b>Severity</b>					
<b>GCS</b>					
Severe/moderate	146(9.9)	44.3(12.0)	0.105	34.8(10.0)	0.073
Mild	1296(97.8)	46.0(12.3)		37.4(10.4)	
<b>Incontinence</b>					
no	1087	46.4(12.1)		37.7(11.9)	
yes	348(23.6)	44.5(12.9)	0.041	33.9(10.1)	<0.001
<b>Stroke Subtypes</b>					
Ischemic	1207(81.8)	46(12.2)	0.422	36.6(11.6)	0.0154
PICH	133(9)	45.6(12.8)		37.2(11.4)	
SAH	57(3.9)	43.4(12.8)		41.5(12.5)	
<b>Admission</b>					
no	223(15.1)	47.3(12.5)	0.024	38.6(12.8)	<0.001
yes, but no stroke unit	448(30.4)	44.9(13.3)		38.0(12.1)	
yes and stroke unit	783(53.1)	46.3(11.6)		35.7(10.8)	
<b>Brain imaging</b>					
no	27	45.2(16.1)		36.9(12.8)	
yes	1401	46.0(12.2)	0.88	36.9(11.6)	0.37
<b>Swallow test done</b>					
no	1347	46.0(12.3)		36.8(11.7)	
yes	128	45.0(11.7)	0.356	37.0(10.5)	0.802

Figure 1: 1 Year Post Stroke HRQOL Scores Over Time

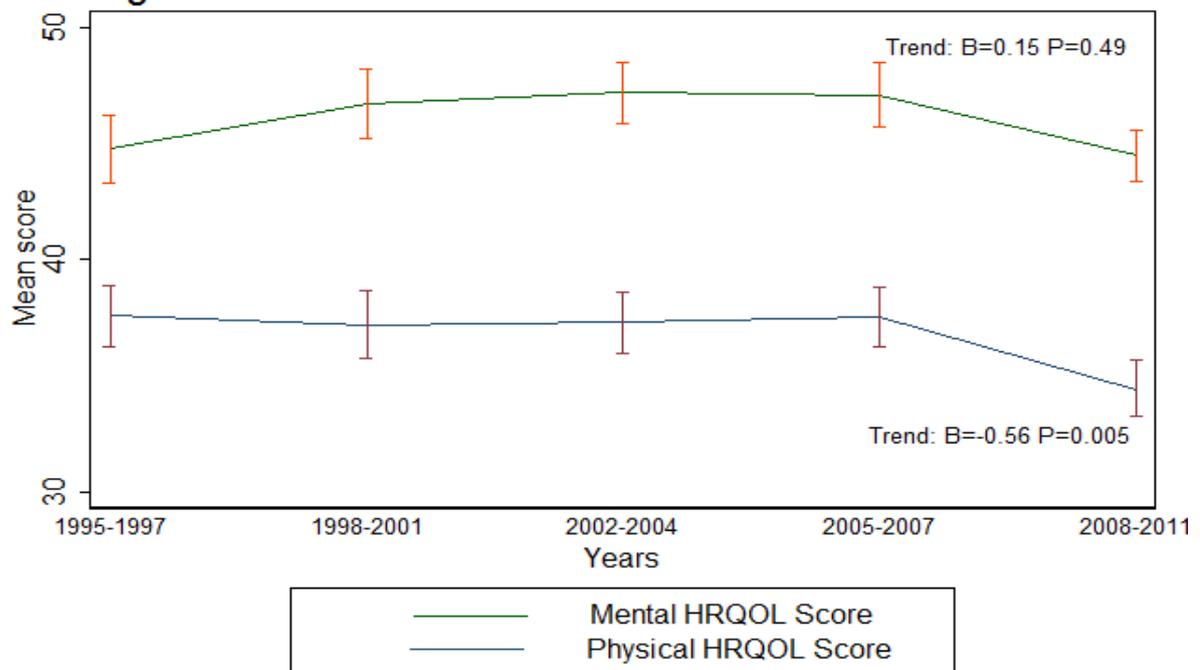


Figure 2: Adjusted HRQOL trends Over Time

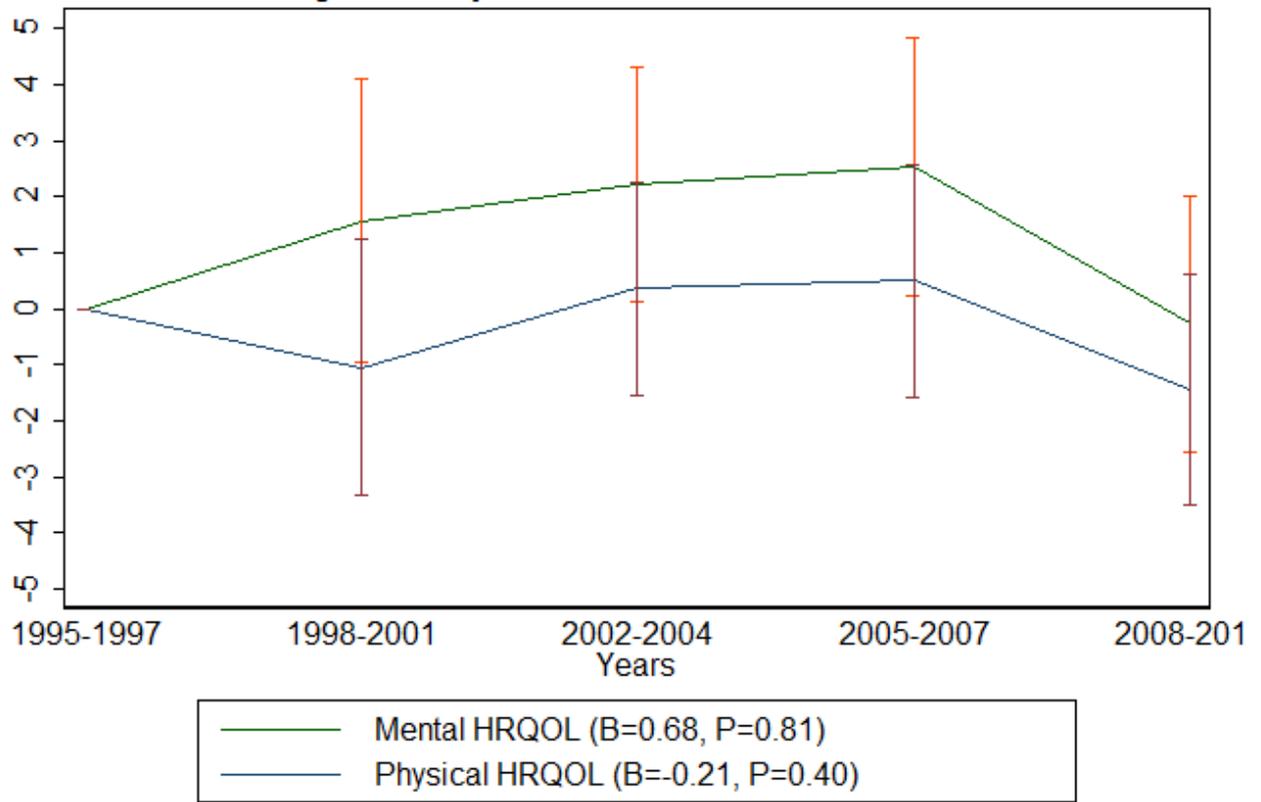


Figure 4: Adjusted HRQOL Trends Over Time

