

# Chinese American Service League

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# What it means to live well

# Evaluating quality of life in a community-based sample

**CASL Center for Social impact** 

Chicago, Illinois

Winter 2020/2021

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#### **Suggested Citation:**

Li D, Zou P, Craig D. What it means to live well: Evaluating quality of life in a community-based sample. Chinese American Service League, January 2021.

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# **Executive Summary**

In 2020, the <u>Chinese American Service League</u>, otherwise known as CASL, introduced a new tool to assess quality of life, the World Health Organization Quality of Life-Brief (WHOQOL-BREF). Quality of life is defined by the WHO as "individuals' perceptions 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." The intent for measuring quality of life at CASL is to understand both the extent and frequency clients are affected by their cultural, social, and environmental contexts.

This report contains selection criteria, distribution methods and data collection, analysis, and considerations for use. The WHOQOL-BREF (1995) is a 26-question assessment offered in 19 different languages and takes approximately 10 minutes to complete. The WHOQOL-BREF asks about physical and psychological health, social relationships, and environmental structures. CASL provided English and Chinese versions of the instrument to 371 clients over the span of a month. Taking the assessment had no impact on the services clients received and all responses were kept confidential and secure. The data we collected offers instructive insights to our clinical programming consistent with best practices of accountability, and ongoing evaluation.

Our findings suggest that there may be more to the data than previously imagined. For instance, the participants in this baseline group were predominantly female and older in age. Participants with higher levels of education had higher quality of life scores than others, suggesting the positive impact of additional schooling. Participants who reported feeling ill at the time of taking the questionnaire had lower quality of life scores than their otherwise healthy counterparts. Although a standard cutoff score for *good* quality of life does not exist, the data serves as a valuable reference to perceived quality of life. All conclusions in this report are based on assumptions which are difficult to assess with any sort of absolute certainty, but one can hardly deny the impact of the COVID-19 pandemic on physical, psychological, relational, and environmental quality of life.

The primary intent of this exercise was never to isolate variables as solely responsible for the scores participants had. As with many instruments that measure perception of status or ability, environmental variables are constantly in flux, making it nearly impossible to assess in a controlled environment. From the results we collected, we can begin plotting responses on a timeline, where changes for each individual participant can be monitored.

#### Key takeaways:

- 1. Quality of life depends on a variety of factors, including, but not limited to environmental conditions and social context.
- 2. Age, marital status, gender, and education are among several demographic aspects correlated with quality of life.
- 3. Lower scores were indicative of lower quality of life. Since quality of life is subjective, results should be interpreted with caution as to what led to those responses.

Quality of life is important to everyone<sup>1</sup>. This multidimensional construct has been instrumental in bridging social, mental, and medical services<sup>2</sup> at the local, state, national, and global level. At CASL, we strive to remain at the forefront of high quality social service delivery and this endeavor would not be possible without the availability of the World Health Organization Quality of Life Working Group.

# **Acknowledgements**

This project is made possible through permission granted by the World Health Organization Quality of Life Working Group. CASL obtained <u>permission</u> from the Working Group to use the WHOQOL-BREF on September 16, 2020.

The <u>Center for Social Impact (CSI)</u> at CASL was launched at the beginning of 2020, thanks to CASL's Leadership and Board. Paul Luu, CEO, and Jered Pruitt, COO, were vital towards the founding of the Center in addition to projects like this one. Consistent with CASL's strategic plan, this project represents one of many projects aimed at measuring our impact. For example, in October 2020, CSI released a report <u>A Fresh Perspective on Place and Health in a Community Context: Assessing social determinants of health in a social services setting</u>. That report analyzed responses from a novel assessment targeted at understanding social determinants of health through the lens of CASL clients.

We are also grateful for the insights and support provided by Dr. Lee Washington, a CASL Program Committee Member and expert in fields related to health evaluation and impact.

Finally, CASL's dedicated staff was directly responsible for this project's success. They overcame immense challenges brought on by the COVID-19 pandemic, and nevertheless, explored creative ways to connect with our clients and administer the WHOQOL-BREF. To all CASL staff, this report represents the sum of your efforts. Thank you.

## **Background**

CASL provides communities holistic wraparound services such as—high-quality childcare, afterschool programs, elder care, housing support, financial counseling, public benefits acquisition, career/vocational services, and legal assistance. The impact of these services requires a closer look at the quality of life our community experiences. Capturing quality of life extends past physical health, but also social, psychological, and environmental health. Subsequently, finding an acceptable tool to measure these attributes presents a challenge.

Quality of life (QoL)<sup>3</sup> is defined as "individuals' perceptions 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." CASL's Center for Social Impact selected the WHOQOL-BREF in response to its cross-cultural sensitivity, adequate psychometric properties, its open license to use<sup>4</sup>, and the availability of validated translations. Having this assessment allowed us to shed light on how our clients perceive their quality of life. The questions we sought to answer were:

- 1. How do our clients perceive their quality of life?
- 2. Based on their responses over time, what <u>are</u> the main contributing factors for how they responded?
- 3. Where can we improve our client's quality of life based on the information they provide us?

The reason for introducing this questionnaire now lies in the fact that quality of life data is not well understood in terms of present-day context(s) specific to CASL's primary constituency, Asian American Pacific Islander (AAPI) communities<sup>5</sup>, specifically Chinese immigrants and native-born Chinese Americans. As the fastest growing minority group in the U.S.<sup>6</sup>, not to mention a large percentage that are foreign-born, community integration and quality of life go hand in hand.

#### **WHOQOL-BREF Overview & Administration**

When CASL started investigating quality of life in our clients, there were several environmental conditions to consider: how might they receive it?...do we have access to the tool?...do the questions apply to a majority of clients? That is where the WHOQOL-BREF comes in. The WHOQOL was originally created in 1995 by the World Health Organization in an effort to capture the impact of disease and impairment. Dr. Leslie Fallowfield deemed quality of life as "the missing measurement in health" (1990).

"Quality of life as the missing measurement in health."

Proposed uses for the WHOQOL are plentiful, such as "clinical trials, establishing baseline scores in a range of areas, and looking at changes in quality of life over the course of interventions." The assessment has proven useful in health policy research and will make up an important aspect of the routine auditing of health and social services at organizations like CASL.

#### WHOQOL-BREF advantages:

- It has been cross-culturally validated,
- Contains adequate psychometric properties,
- There are **no licenses to use**,
- Translated (and validated) versions are readily available, and
- It is often cited and referenced in other QoL studies.

#### **WHOQOL-BREF disadvantages:**

- It does not apply to children or youth, 0-18 years old,
- WHO is no longer offers technical support.

#### **CASL's Administration Procedures:**

For CASL, we chose to administer the questionnaire on a rolling, quarterly basis.

- Advantage: comparisons can be made on a single quarter-quarter basis, 6 month, or annual basis with clients with service schedules that allow.
- **Disadvantage**: the frequency of services rendered to clients may unintentionally exclude certain individuals, so it is very much reliant on staff to broaden distribution measures.

The questionnaire was launched from October 21, 2020 to November 20, 2020. All staff members were trained on distribution methods, recording responses, and dropping off paper forms securely in a drop box in our lobby. Our distribution protocol adhered to strict guidelines set by the WHOQOL working group. CASL staff obtained over 400 responses, subsequently recorded confidentially in Salesforce, CASL's client management system.

#### **Overview of Participants**

The average age of participants was 68 and the gender split was approximately 70% female, 30% male. The average age of our sample, limited to adults 18 years and over, was slightly older than the average age of adult CASL clients, 62. When responses were categorized by age, age ranges were determined using recommendations from the American Community Survey (ACS), a product of the U.S. Census Bureau. 55% of all participants reported being married, 10% were single, 25% were widowed, and 7% were either separated or divorced. Based on the demographic profile of our sample, we analyzed responses using 2 regressions, one factoring age and the other, without. This process can be found in Appendix D.

#### Results

Results from the WHOQOL-BREF were analyzed into two dashboards, one displaying responses overall and the other, by separate domains. The WHOQOL-BREF offers a quality of life profile consisting of four domain scores in addition to overall perception of quality of life and health, respectively. Higher scores denote higher quality of life and mean scores are used to calculate domain scores. In-depth scoring procedures for the WHOQOL-BREF, including transformation of raw scores, can be found in Appendix E.

#### **Dashboards Overview**

The assembly of the first dashboard took into account the average overall quality of life score, demographic representation, participant count and average scores by program, in addition to educational attainment and health satisfaction. From our analysis, there were 371 assessments meeting the threshold outlined by the designers of the assessment. The average quality of life score was 59 out of 100. A score of 59 is not indicative of "good" or "bad," but higher scores are considered better than lower scores. Given there are no comparison groups that mirror our clients, what is considered "good" or "bad" quality of life cannot be generalized to other populations and/or subgroups.

What an average score of "59" means to CASL is the opportunity to see if quality of life changes over time. Based on the differences between scores, we can chart positive or negative trends at both the individual and group level. At the time of the changes, the real value comes from what events may have resulted in that change. For example, if the scores we collected during 2020 are lower than 2021, it might be worth investigating what caused the difference. The point of the assessment is to promote positive change by targeting factors most consistent with the change in scores in the first place. If participants indicate lower social relationship scores at year 1, what kind of services we offer have the potential to meet that need and are there opportunities for exploration in year 2?

"The point...is to promote positive change by targeting factors most consistent with the change in [quality of life] in the first place."

Significant differences can be attributed to a number of factors including, but not limited to: age, gender, illness, marital status, and perception of overall quality of life and health status. Despite the necessity for ongoing investigation into what the scores actually mean, we were able to capture which variables and/or domain facets might have a stronger correlation, thereby indicating "some" sort of relationship.

### **Quality of Life in Context**

While a standard for labeling "good" or "poor" quality of life is hardly generalizable, recommendations from other quality of life studies have offered useful insights into determining a median value based on non-representative samples (i.e. context and setting). Because of this, establishing a formal score for "good" or "poor" quality of life rejects the notion that any two datasets can have anything in common. For example, where the WHOQOL-BREF has been piloted in places where "quality of life" is not well defined, what is considered good or poor is subjective. Put mildly, "good" or "bad" quality of life does not exist in a vacuum, but the multi-layered complexities present in any environment.

According to preliminary analysis using regression models, we discovered that several attributes were more strongly correlated to overall quality of life scores. On the whole, age at completion of the assessment, gender, reportedly feeling ill, level of education and marital status had a more substantial impact on quality of life scores, relative to each domain. Prior to the portion of the questionnaire relevant to a particular domain, there were several questions pertaining to perceptions of overall quality of life and health satisfaction. The responses did not contribute to the domain scores, but did offer notable insights relevant to the hypotheses surrounding why participants responded the way they did in subsequent questions.

Participants who were older at the time of taking the assessment consistently scored lower than their younger counterparts. Male participants scored higher on average than female participants. Indication of being ill when asked "Are you currently ill?" contributed to lower scores than presumably "healthy" participants who responded "no" to that question. Not controlling for age, scores for participants who reported their marital status as "living as married" were more likely to report lower quality of life overall.

When not controlling for age, scores for widowed and separated participants were found to be consistently lower than their married or single counterparts. Finally, regardless of age, having a tertiary education and/or schooling beyond secondary education was shown to have a positive correlation with quality of life. See <a href="Appendix I">Appendix I</a> for more on quality of life average scores, scores filtered by demographic properties, and quality of life domain scores and subsequent attributes.

## **Variables Impacting Quality of Life**

Stressing the importance of factors contributing to the responses, the results we collected are indicative of the larger landscape that, unbeknownst to everyday interactions we might have with clients, is constantly changing. At the time of distribution, many conventionally in-person CASL programs had to reorient their activities and/or interventions to function remotely, partially or completely. The results from this pilot were intended to establish a baseline for future modeling, but even so, the conclusions we formed retain value for today.

Social opportunities for seniors were negatively affected by the discontinuation of in-person activities resulting from the COVID-19 pandemic. Although it remains to be seen that this is the only definitive contributing factor, our results suggest that the impact [COVID-19] pandemic could not be ignored. For instance, CASL's Pinetree Senior Council (PTSC)—a program offering social activities for seniors such as calligraphy classes, cultural dance, exercise, and music—went remote in response to the [COVID-19] pandemic. PTSC offered an environment where otherwise isolated seniors could experience a sense of community. Among other programs aimed at serving seniors in our community, seniors from PTSC had lower social relationship scores than seniors in other programs, shown in Appendix I: Seniors (64+) Social Relationship Scores by Program. While the evidence is preliminary at best, it remains indisputable that CASL social programs for seniors have been negatively impacted by the [COVID-19] pandemic.

# Key Takeaways per Domain Significant findings highlighted

Rounded to the nearest whole number

# **Physical**

Activities of daily living; Dependence on medicinal substances and medical aids; Energy and fatigue; Mobility; Pain and discomfort; Sleep and rest; Work Capacity

Domain score average out of 100 (higher score is better)	Domain score by age	Domain score by education (no school, primary school, secondary school, tertiary school)	Domain score by marital status	Domain score by current illness (reported "feeling ill" at time of assessment)	Summary
58	18-29: 79 30-44: 74 45-64: 62 65-84: 54 85+: 49	Not significant	Not significant	Feeling ill: 46 Not feeling ill: 61	Younger participants rated their quality of life higher than their older counterparts.  Participants who felt ill at the time of taking the questionnaire tended to report lower QoL scores

# **Psychological**

Bodily image and appearance; Negative feelings; Positive feelings; Self-esteem; Spirituality / Religion / Personal beliefs; Thinking, learning, memory and concentration

Domain score average out of 100 (higher score is better)	Domain score by age	Domain score by education (no school, primary school, secondary school, tertiary school)	Domain score by marital status	Domain score by current illness (reported "feeling ill" at time of assessment)	Summary
61	18-29: 71 30-44: 71 45-64: 62 65-84: 59 85+: 57	Secondary: 60	Single: 64 Married: 64 Living as married: 54 Separated: 49 Divorced: 61 Widowed: 56	Feeling ill: 52 Not feeling ill: 63	Younger participants rated their quality of life higher than their older counterparts.  Tertiary education was positively correlated with higher QoL scores (the only educational attainment level considered "significant"  Single and married participants reported higher QoL scores than other relationship groups Participants who felt ill at the time of taking the questionnaire tended to report lower QoL scores

			cial Relations	•	
Domain score average out of 100 (higher score is better)	Domain score by age	Domain score by education (no school, primary school, secondary school, tertiary school)	nships; Social suppor  Domain score by  marital status	Domain score by current illness (reported "feeling ill" at time of assessment)	Summary
56	18-29: 78 30-44: 69 45-64: 60 65-84: 53 85+: 48	Secondary: 58	Single: 61 Married: 60 Living as married: 57 Separated: 45 Divorced: 48 Widowed: 48	Feeling ill: 45  Not feeling ill: 58	Younger participants rated their quality of life higher than their older counterparts.  Educational attainment was positively correlated with higher QoL scores  Single participants reported higher QoL scores than other relationship groups Participants who felt ill at the time of taking the questionnaire tended to report lower QoL scores

# **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

Domain score average out of 100 (higher score is better)	Domain score by age	Domain score by education (no school, primary school, secondary school, tertiary school)	Domain score by marital status	Domain score by current illness (reported "feeling ill" at time of assessment)	Summary
61	18-29: 77 30-44: 66 45-64: 59 65-84: 59 85+: 58	Primary: 58 Secondary: 60	•	Feeling ill: 55 Not feeling ill: 62	Younger participants rated their quality of life higher than their older counterparts.  Educational attainment was positively correlated with higher QoL scores  Single participants reported higher QoL scores than other relationship groups Participants who felt ill at the time of taking the questionnaire tended to report lower QoL scores

**Table 1: Key Takeaways by Domain** 

#### **Discussion**

The WHOQOL-BREF is aimed at determining a portrait of perceived quality of life at one point in time. This data provides us with the ability to monitor changes in real-time. Because of this, we have a unique opportunity to improve clients' quality of life through data-informed interventions. This pilot allows us to identify which domains require the most attention, ultimately guiding us in improving services to meet those demands. However, such a process is not without challenges, the biggest being how external variables come into play. Perceptions of how one's quality of life is one day may come in contrast to the next, due to sudden and unexpected life events, such as a global pandemic.

At CASL, we are committed to measuring progress, even if that means observing how responses to this instrument changes over the course of several years. As part of CASL's strategic plan to understand our clients' needs, this assessment delivers a fresh perspective on what factors contribute to having a high quality of life. Since quality of life is subjective, we can only speculate based on the conclusions available to us through regular observation.

Considering 2020 was a challenging year in many regards, it comes as no surprise that several scores, overall and by domain, were noticeably lower than others. For instance, where the majority of older participants scored lower than their younger counterparts in the social relationships domain, we can infer that this observation may have something to do with the safety measures CASL implemented in response to the COVID-19 pandemic. More specifically, programs encouraging community activities among seniors presented higher risk for contracting disease given their age and/or underlying health conditions.

Throughout this pilot exercise, our primary intent was never to single out *a* variable contributing to the scores participants had. As with many instruments measuring perception of status or ability, environmental variables are constantly in motion, making a formal experimental design impossible. From the baseline results gathered during this round of data collection, we can begin plotting responses on a timeline, where changes for each individual participant can be monitored.

#### Limitations

The pilot was administered to clients selected by program staff. By using a convenience sampling approach, we were limited to a less accurate representation of the CASL client population. However, all clients who participated in this pilot demonstration were active, meaning they had utilized CASL services in the past year. Consistent with the original design of the field trial version of the WHOQOL-BREF, a minimum of 300 participants was met.

Other limitations we encountered throughout this process included the lack of a standard "cutoff" point, the lack of publicly available micro-use data, the relatively short data collection timeframe, and the onset of a global pandemic.

#### **Lessons Learned**

Throughout this process, our team has learned several valuable lessons. From reviewing assessment literature, coordinating with the World Health Organization working group, and assembling dashboards to tell our clients' stories. We also learned to prioritize organization and map our projects more effectively.

This pilot provided us the necessary means to establish a baseline of quality of life for all our clients. Although limitations are currently present in the distribution pipeline, we can start identifying gaps in the data which will lead to more focused metrics down the line.

## **Using the Data**

What are we doing to improve our clients' quality of life?

Having data is good, but it is only one piece to determining what sort of impact we hope to have on our clients—where do we go from here? Based on how clients respond to a particular question, what steps do we take to understand underlying conditions leading to that choice? Many of the questions in the WHOQOL-BREF seek to engage the services CASL provides in relation to our clients' quality of life--albeit indirectly. The data we collect from the WHOQOL-BREF is just the beginning of what it means to produce "change." Our conclusions on this pool of participants' quality of life are preliminary at best, but as time goes on, we will have the opportunity to map changes, define trends, and navigate appropriate solutions.

While there are many variables that might facilitate improved quality of life, the results from the WHOQOL-BREF capture an incomplete picture. However, where our programs meet the needs of our clients, the data we collect will ultimately help inform the way we communicate and address areas for improvement. For instance, when we collect information on health satisfaction over time as depicted by the overall quality of life score and associated domain scores, we can highlight programs that target those specific needs. The end goal of measuring client quality of life is not simply general improvement, but looking at where we can accompany our clients in attaining their desired outcomes.

#### Conclusion

Quality of life (QoL)<sup>9</sup> is "an individuals' perceptions 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." Understanding what it means to have a "good" quality of life requires knowing what is "satisfactory" and how that plays a role in everyday life. CASL's Center for Social Impact is proud to present a valid and reliable quality of life assessment that promises the ability to identify knowledge gaps, raise new questions—to live better, together.

# **Appendix A: Quality of Life Instrument Selection**

## Selecting a "Quality" assessment10:

When considering an assessment measuring quality of life in a cross-cultural setting, we set the following criteria to guide our selection process:

- Unidimensional concepts and domains: generally accepted, widely used, clear definitions
- Non-disease-specific reference populations (general): applicable to patients and/or clients in the absence of disease or diagnosis
- Test-theoretical construction principles: the measure is consistent both in format and content (i.e. the assessment measures what it is supposed to)
- Behavior or function-oriented dimensions included: subjective measures looking at behaviors are included

Each assessment tool was then presented to select staff and program managers to gather informal feedback. Due to the subjective nature being perceived quality of life, we were intent on using existing tools opposed to reinventing the wheel. Other considerations for selecting an appropriate quality of life questionnaire included length of time needed to complete it, ease of response and scoring, in addition to the setting in which it (questionnaire) would be administered.

## **Quality of Life indicators and tools observed:**

- Beach Center Family Quality of Life Scale (Hoffman et al. 2006)
- Family Quality of life Scale-2006 (Brown et al. 2006)
- GENCAT (Verdugo & Schalock 2011)
- Immigration Policy Lab Integration Index-12 and -24 Item (Harder et al. 2018)
- International Well-Being Index (Renn et al. 2009)
- Multidimensional Quality of Life (Kreitler, S. & Kreitler, M. 2006)
- Personal Well-Being Index-Adult (PWI-A)
- Quality of Life Inventory (QOLI) (Frisch, 1995)
- Quality of Life Profile (QOLP) (Brown et al. 1996)
- Quality of Life Questionnaire (QOLQ) (Keith & Schalock 1993)
- Quality of life Scale (QOLS) (Flanagan 1979)
- The Quality of Life Scale (QOLS) (Burckhardt 2003)
- The World Health Organization Quality of Life-100 and brief versions (WHOQOL-100 & WHOQOL-BREF)

The WHOQOL-BREF was selected based on its robust validity and reliability, its diverse applications, and reputation, having been cited in 1,158 articles<sup>11</sup>. Originally developed by the World Health Organization's Quality of Life Working Group which consisted of fifteen international field centers, the WHOQOL was aimed at assessing quality of life in cross-cultural contexts.

The WHOQOL-BREF has four domains: physical health, psychological, social relationships, and environment, significantly shorter than the longer instrument it was based off of, the WHOQOL-100. The WHOQOL-BREF incorporates one item from each of the 24 facets per domain in addition to two items from Overall quality of Life and General Health facets, making for a total of 26 questions altogether. Individual facets include activities of daily living, mobility, self-esteem, social support, financial resources, and accessibility and quality of healthcare.

## **WHOQOL-BREF Administration**

The assessment is designed to be self-administered, thereby mitigating the level of bias present between administrators and target populations. The recommendation prescribed by WHOQOL working group relies on the context in which the measure is administered. Furthermore, per field testing guidelines, the instrument is intended to be piloted on at least 300 people. Caution was warranted when distributing the measure in shorter time frames since it could lead to a smaller sample size, thereby limiting the generalizability of results.

#### **Administration Frequency**

A time frame of two weeks is indicated in the assessment. However, It is recognized that different time frames may be necessary for particular uses of the instrument in subsequent stages of work.

- Time scales vary, however, patient-reported outcomes are generally dependent on type of diagnosis or targeted (if applicable) populations.
- Recommendations prescribed by WHOQOL working group:
- Quarterly
- Annually
- Weekly for populations with more intense treatment schedules
- For CASL, we chose to administer the questionnaire quarterly as a way to identify seasonal differences and map out trends over time.

#### **Reception of the Assessment**

When the assessment was administered to clients, the reception was neutral, as anticipated (i.e. no particularly strong opinions were voiced by administrators or respondents). Some questions asking for sensitive information produced a heightened level of discomfort for some (e.g. 1 question asks participants to rate their satisfaction with their sex life). Over 85% of respondents answered all or almost all questions with little difficulty. Staff administering the assessments recalled that respondents were generally ambivalent to the instrument and held no particularly strong opinions during the procedure.

## **Appendix B: Permission Authorization to use WHOQOL-BREF**



#### ID: 360894 Permission authorization for WHO copyrighted material

permissions@who.int <permissions@who.int>

Wed, Sep 16, 2020 at 10:42 AM

Cc: permissions@who.int

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Figure 1: Permission Authorization Exerpt to Use WHOQOL-BREF

# **Appendix C: Overview of the WHOQOL-BREF**

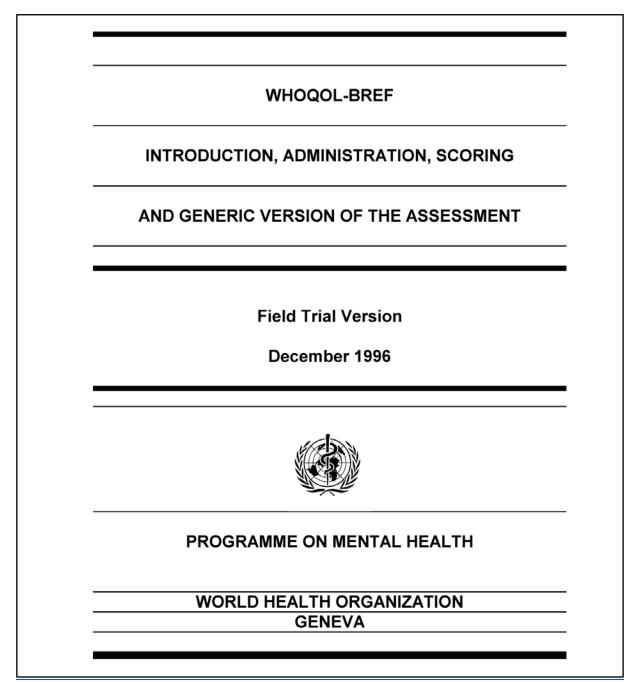


Figure 2: Cover page of WHOQOL-BREF report

# **Appendix D: Scoring the WHOQOL-BREF**

- Participants respond on a 5-point Likert scales (higher number is better)
  - Calculate raw scores:
    - Domain 1 Physical Health: (6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18
    - Domain 2 Psychological: Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)
    - Domain 3 Social Relationships: Q20 + Q21 + Q22
    - Domain 4 Environment: Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25
  - O Then, convert raw scores per domain using 2 methods:
    - Scores can be calculated for each of the 4 domains by transforming raw scores per domain to read between 0-100 (see Table)
    - Scores can be calculated for each of the 4 domains by transforming raw scores per domain to read between 4-20 (see Table)
  - Cutoff values (out of 100):
    - 1 standard deviation below the mean score of total sample<sup>12</sup>
    - General rule of thumb, ≥ 60<sup>13</sup> for overall quality of life<sup>14</sup>
    - No normative data has been definitely determined from the WHOQOL Working Group
  - o In some studies<sup>15</sup>, the following values were extracted within disease-specific populations (e.g. diabetes, spinal cord injury):
    - ≤ 45, poor or bad Health Related Quality Of Life (HRQOL)
    - < 45–65, moderate HRQOL</p>
    - 65, relatively high HRQOL

# **Appendix E: WHOQOL-BREF Raw Scores Transformation**

Table 4 - Method for converting raw scores to transformed scores

		-
DOMA	AIN 1	
Raw Score		formed ires
Score	360	103
	4-20	0-100
7	4	0
8	5	6
9	5	6
10	6	13
11	6	13
12	7	19
13	7	19
14	8	25
15	9	31
16	9	31
17	10	38
18	10	38
19	11	44
20	11	44
21	12	50
22	13	56
23	13	56
24	14	63
25	14	63
26	15	69
27	15	69
28	16	75
29	17	81
30	17	81
31	18	88
32	18	88
33	19	94
34	19	94
35	20	100

DOMAIN 2				
Raw score	Trasni	formed ares		
	4-20	0-100		
6	4	0		
7	5	6		
8	5	6		
9	6	13		
10	7	19		
11	7	19		
12	8	25		
13	9	31		
14	9	31		
15	10	38		
16	11	44		
17	11	44		
18	12	50		
19	13	56		
20	1.3	56		
21	14	63		
22	15	69		
23	15	69		
24	16	75		
25	17	81		
26	17	81		
27	18	88		
28	19	94		
29	19	94		
30	20	100		

DOMAIN 3			
Raw score	Transformed scores		
	4-20	0-100	
3	4	0	
4	5	6	
5	7	19	
6	8	25	
7	9	31	
8	11	44	
9	12	50	
10	13	56	
11	15	69	
12	16	75	
13	17	81	
14	19	94	
15	20	100	

DOMA	DOMAIN 4		
Raw score		formed res	
	4-20	0-100	
8	4	0	
9	5	6	
10	5	6	
11	6	13	
12	6	13	
13	7	19	
14	7	19	
15	8	25	
16	8	25	
17	9	31	
18	9	31	
19	10	38	
20	10	38	
21	11	44	
22	11	44	
23	12	50	
24	12	50	
25	13	56	
26	13	56	
27	14	63	
28	14	63	
29	15	69	
30	15	69	
31	16	75	
32	16	75	
33	17	81	
34	17	81	
35	18	88	
36	18	88	
37	19	94	
38	19	94	
39	20	100	
40	20	100	

### References

Bergner, M., Bobbitt, R.A., Carter, W.B. et al. (1981). The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care*, 19, 787-805.

Figure 3: Table of raw score transformation for WHOQOL-BREF domain scores

# **Appendix F: WHOQOL-BREF English & Chinese (Simplified)**

	wно	QOL-BRE	F				
D. 6							
	ou begin we would like to ask you to an by filling in the space provided	swer a few gene	ral questions a	ibout yourself:	by circling th	e correct	
What is y	our gender?	Male Fe	male		Name:	First	, Last, M.I.
What is y	ou date of birth?	Day	/ Month	/ / Year	Today's date: Phone number		/
What is th	he highest education you received?	None at all					
What is u	in ingless concaron you received:	Primary sel					
		Secondary: Tertiary	school				
What is y	our marital status?	Single Married			arated orced		
		Living as n	narried		lowed		
-	currently ill? Yes No sing is wrong with your health what do	on think it is?			illness/prob	olem	
11 Someth	ing is wrong with your nearth what to	ou unik icis:_			inicss proc	, iciii	
Instru			-141		. m		
	ssment asks how you feel about your questions. If you are unsure about which respon			-			
	te. This can often be your first respons						
Please ke	ep in mind your standards, hopes, pleas	ures and concer	ns. We ask th	at you think ab	out your life in	the last two	
	or example, thinking about the last two			at you amin ao	out your me in	the last two	
		Т	1				1
		Not at all	Not much	Moderately	A great deal	Completely	ı
Dov	you get the kind of support from		2		4		
other	you get the kind of support from rs that you need?	1	2	3	4	5	
You shou		nuch support yo	ou got from oth n others as foll	arers over the la	st two weeks.	So you	1
You shou would cir	rs that you need?	1 nuch support ye	ou got from oth	3 ners over the la		5	
You shou would cir  Do y other	rs that you need?  Ild circle the number that best fits how it to be the number 4 if you got a great deal you get the kind of support from	nuch support ye of support fron  Not at all	ou got from oth n others as foll Not much 2	and the state of t	A great deal	So you  Completely 5	
You shou would cir  Do y other	rs that you need?  Ild circle the number that best fits how recle the number 4 if you got a great deal you get the kind of support from rs that you need?	nuch support ye of support fron  Not at all	ou got from oth n others as foll Not much 2	and the state of t	A great deal	So you  Completely 5	
You shou would cir  Do y other	rs that you need?  Ild circle the number that best fits how recle the number 4 if you got a great deal you get the kind of support from rs that you need?	nuch support ye of support fron  Not at all 1  Usings, and cir	ou got from other as followed by the number of the number	acres over the la ows.  Moderately 3  Deer on the sc:	A great deal 4 ale for each o	So you  Completely 5	
You shou would cir  Do y other  Please r that giv	rs that you need?  Ild circle the number that best fits how a cle the number 4 if you got a great deal you get the kind of support from rs that you need?  The god each question, assess your fee es the best answer for you.	nuch support ye of support fron  Not at all 1  Usings, and cir	Not much 2  Poor 2	acres over the la ows.  Moderately 3  ber on the sc:  Neither poor nor good 3	A great deal 4  ale for each of	So you  Completely 5  Question  Very good 5	
You shou would cir  Do y other  Please r that giv	rs that you need?  Ild circle the number that best fits how a cle the number 4 if you got a great deal you get the kind of support from rs that you need?  The god each question, assess your fee es the best answer for you.	nuch support ye of support fron  Not at all 1  Usings, and cir	ou got from oth others as foll  Not much 2  cele the numl	acres over the la ows.  Moderately 3  Deer on the sc:  Neither poor nor good	A great deal 4  ale for each of	So you  Completely 5  Juestion	
You shou would cir  Do y other  Please r that giv	rs that you need?  Ild circle the number that best fits how a cle the number 4 if you got a great deal you get the kind of support from rs that you need?  The god each question, assess your fee es the best answer for you.	nuch support ye of support fron  Not at all 1  clings, and cir  Very poor 1	Not much 2  Poor 2	and the second state of th	A great deal 4  ale for each of	So you  Completely 5  question  Very good 5	
You shou would cir Do y other Please r that giv	rs that you need?  Ild circle the number that best fits how recle the number 4 if you got a great deal you get the kind of support from rs that you need?  read each question, assess your fee es the best answer for you.  How would you rate your quality of life!  How satisfied are you with your health?	nuch support ye of support fron  Not at all 1  Uery poor  Very poor  Very dissatisfied  1	Dissatisfied	Moderately 3 ber on the sc:  Neither poor nor good 3 Neither satisfied nor dissatisfied 3	A great deal 4  ale for each of Good 4  Satisfied 4	So you  Completely 5  Question  Very good 5  Very satisfied	
You shou would cir Do y other Please r that giv	rs that you need?  Ild circle the number that best fits how a cle the number 4 if you got a great deal you get the kind of support from rs that you need?  Tread each question, assess your fee es the best answer for you.  How would you rate your quality of life.	nuch support ye of support fron  Not at all 1  Uery poor 1  Very dissatisfied 1	Dissatisfied  2  Dissatisfied  2  ertain things in	acres over the latows.  Moderately 3  Deer on the sc:  Neither poor nor good 3  Neither satisfied nor dissatisfied a	A great deal 4  ale for each of Good 4  Satisfied 4	So you  Completely 5  Juestion  Very good 5  Very satisfied 5	
Please r that giv	Id circle the number that best fits how a cle the number 4 if you got a great deal you get the kind of support from rs that you need?  The deach question, assess your fee es the best answer for you.  How would you rate your quality of life.  How satisfied are you with your health?	nuch support ye of support from Not at all lings, and cir Very poor 1  Very dissatisfied 1  Not at all lings, and cir very poor 1	Dissatisfied  Certain things in A little	mers over the la ows.  Moderately 3 ber on the sc:  Neither poor nor good 3  Neither satisfied nor dissatisfied 3 the last two weel A moderate amount	A great deal 4  ale for each of Good 4  Satisfied 4  Very much	So you  Completely 5  Juestion  Very good 5  Very satisfied 5  An extreme amount	
You shou would cir Do y other Please r that giv	rs that you need?  Ild circle the number that best fits how recle the number 4 if you got a great deal you get the kind of support from rs that you need?  read each question, assess your fee es the best answer for you.  How would you rate your quality of life!  How satisfied are you with your health?	nuch support ye of support fron  Not at all 1  Uery poor 1  Very dissatisfied 1	Dissatisfied  2  Dissatisfied  2  ertain things in	Moderately 3 ber on the sci Neither poor nor good 3 Neither satisfied nor dissatisfied a	A great deal 4  ale for each of Good 4  Satisfied 4	So you  Completely 5  question  Very good 5  Very satisfied 5	
Please r that giv	Id circle the number that best fits how is cle the number 4 if you got a great deal you get the kind of support from rs that you need?  The would you rate your quality of life.  How would you rate your quality of life.  How satisfied are you with your health?  To what extent do you feel that physical pain prevents you from doing what you	nuch support ye of support from Not at all lings, and cir Very poor 1  Very dissatisfied 1  Not at all lings, and cir very poor 1	Dissatisfied  Certain things in A little	mers over the la ows.  Moderately 3 ber on the sc:  Neither poor nor good 3  Neither satisfied nor dissatisfied 3 the last two weel A moderate amount	A great deal 4  ale for each of Good 4  Satisfied 4  Very much	So you  Completely 5  Juestion  Very good 5  Very satisfied 5  An extreme amount	
Please r that giv	rs that you need?  Ild circle the number that best fits how recle the number 4 if you got a great deal you get the kind of support from rs that you need?  To what extent do you feel that physical pain prevents you from doing what you need to do?  How meed to you feel that physical pain prevents you from doing what you need to do?  How meed to do?	nuch support ye of support from Not at all 1 Very poor 1 Very dissatisfied 1 Not at all 1	Dissatisfied  Certain things in A little  2	mers over the la ows.  Moderately 3 ber on the sc:  Neither poor nor good 3  Neither satisfied nor dissatisfied as two weele amount 3	A great deal 4  ale for each of Good 4  Satisfied 4  Very much 4	So you  Completely 5  Question  Very good 5  Very satisfied 5  An extreme emount 5	

Figure 4: WHOQOL-BREF (obtained with permissions from WHOQOL working group)

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(ID: 360894 Permission authorization for WHO copyrighted material)
Geneva, World Health Organization (WHO), (2004),
(http://www.who.int/wbstance\_abuse/research\_tools/en/chinese\_whoqol.pdf, accessed 10/15).
WHO does not endorse any specific companies, products or services

44. 27

In	ternal office use only (do not write here)
nternal	code (program abbreviation):
	Staff initials:
	Today's date:

# 世界卫生组织生存质量测定简表(WHOQOL-BREF)

佐始北井口田田。

姓名:			心的出生口朔定://				
日期:	/	_/	日 / 月 / 年				
日	/ 月	/ 年	您的最高学历是?				
电话号码:			无学历				
您的性别是?	男	女	小学 中学				
您的婚姻状况是	什么?		大学				
单身 分居			您目前是否正在生病? 是 否				
已婚 离婚			如果您的健康有问题,您认为是么问题?				
同居			疾病/问题				

以下问题涉及您对生活质量、健康、或生活其他方面的看法。在我读出每一个问题 的同时,请您做出选择。请选择最适当的答案。如果您暂时不能确定,则头脑中 的第一反应往往是最正确的。

所有问题都请您按照自己的标准、愿望或自己的感觉来回答。注意所有问题都是您 最近 4 周内的情况。

		很差	差	一般	好	很好
1.	您如何评价您的生活质量?	1	2	3	4	5
		非常不满意	不满意	一般	满意	很满意
2.	您对自己健康状况满意吗?	1	2	3	4	5

下列问题是有关您在过去 4 周中经历某些事情的感觉

		根本没有	有点	中等	很大	极其
3.	您因躯体疼痛而妨碍您去做					
	需要做的事感到有多烦恼?	5	4	3	2	1
4.	您对保持日常生活的医学治					
	疗的需求程度有多大?	5	4	3	2	1
5.	您觉得生活有乐趣吗?	1	2	3	4	5
6.	您觉得自己的生活有意义					
	吗?	1	2	3	4	5
		根本不	有点	中等	很大	极其

Translation of this document was performed on behalf of the World Health Organization by Dr Yuan Wu, National Institute on Drug Dependence (NIDD), Peking University; Dr Li Xiaoling, NIDD, Peking University; and Associate Professor Shi Jie, NIDD, Peking University. Translation was conducted in collaboration and consultation with the following team of experts: Professor ZHAO Chengzheng; Professor LIU Zhimin; Professor XU Guozhu; Professor CAI Zhiji; Professor CAO Jiaqi; and Professor ZHENG Jiwang

Figure 5: Translated and validated Chinese version of the WHOQOL-BREF (obtained with permissions from original authors)

## **Appendix G: Analysis (including regression tables)**

In accordance with scoring procedures outlined by the WHOQOL working group, *if* more than 20% of the data was found missing from a single assessment, that assessment was thrown out. In other words, if any assessment had more than two items missing in a domain, that domain score could not be calculated since it would have a notable effect on the other domain scores. From our results, there were very few instances of missing data, with over 95% of participants having completed most items in the questionnaire (meaning no more than 2 missing responses from any domain, or approximately 88%).

By limiting the sample size to unique responses where no more than 20% of the data was found missing in any assessment, we controlled (as much as we could) for statistical "noise"--the introduction of variables clouding the true impact of one over another. Using a 95% confidence interval<sup>16</sup>, we took the p-value<sup>17</sup> for all demographic variables side-by-side with overall quality of life scores. To do this, we used t-tests<sup>18</sup> to infer the difference between two averages, such as the average scores of one domain with another. Since participants for this pilot were slightly older (~6 years) than the overall average of adult CASL clients (62), two regressions were computed, one factoring on account of age and the other, without age as a consideration.

SUMMARY	OUTPUT							
Regression Statistics								
Multiple R	0.47489							
R Square	0.225521							
Adjusted R	0.199561							
Standard E	12.38522							
Observatio	371							
ANOVA								
	df	SS	MS	F	gnificance F	:		
Regression	12	15990.68	1332.557	8.687174	1.45E-14			
Residual	358	54914.92	153.3936					
Total	370	70905.6						
		andard Erro			Lower 95%	, ,		, ,
Intercept	60.89539	3.167475	19.22522	4.32E-57	54.6662		54.6662	
Male?	-1.18679	1.462833	-0.8113		-4.06362	1.69003	-4.06362	1.69003
III?	-10.4592	1.711515	-6.11106	2.59E-09	-13.8251	-7.09329		
III Blank	-5.73577	5.136967	-1.11657		-15.8382	4.366652		
Married	0.441731		0.199512		-3.91247	4.795928		
Living as M		4.307182		0.549112	-11.0534	5.887712	-11.0534	
Seperated	-9.85725	5.145992	- <b>1</b> .91552	0.056223	-19.9774	0.262924	-19.9774	0.262924
Divorced	-3.46588	3.501658	-0.98978	0.322949	-10.3523	3.420525	-10.3523	3.420525
Widowed	-6.42382	2.445665	-2.62661	0.008994	-11.2335	-1.61414	-11.2335	-1.61414
Blank Educ	-4.86662	6.656251	-0.73114	0.465175	-17.9569	8.223644	-17.9569	8.223644
Primary	-1.04869	2.756373	-0.38046	0.70383	-6.4694	4.37203	-6.4694	4.37203
i illiary	2.051875	2.706018	0.758264	0.448792	-3.26981	7.373564	-3.26981	7.373564
Secondary	2.0516/5							

**Figure 6: Sample Regression Analysis by Selected Characteristics** 

# **Appendix H: Dashboard Assembly (Samples)**

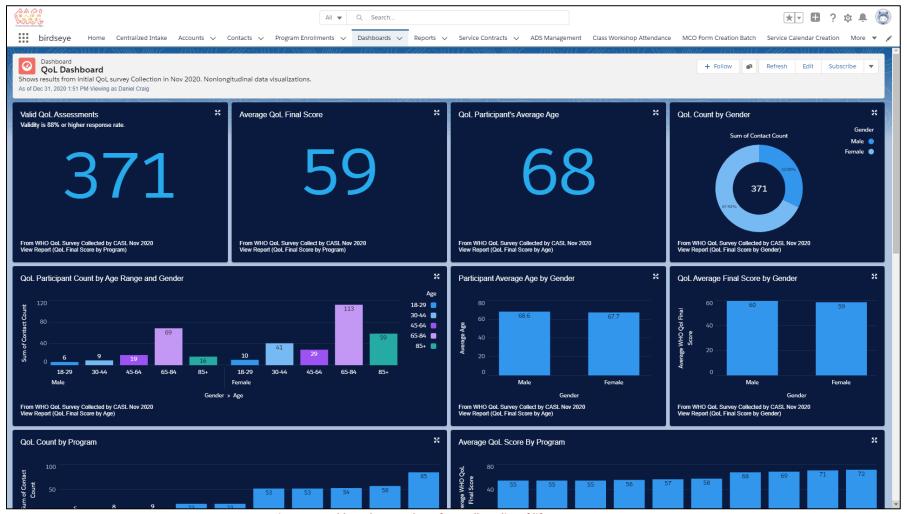


Figure 7: Dashboard screenshot of overall quality of life responses

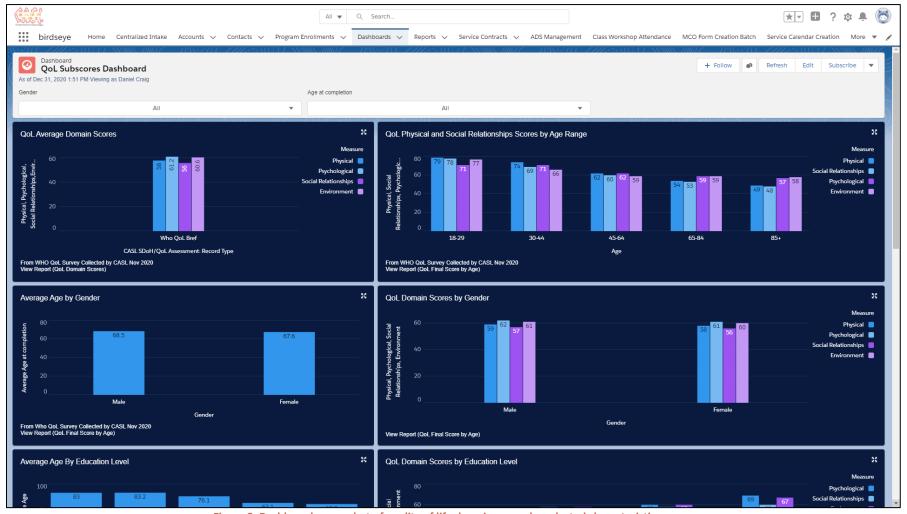


Figure 8: Dashboard screenshot of quality of life domain scores by selected characteristics

# **Appendix I: Analyzing the Results**

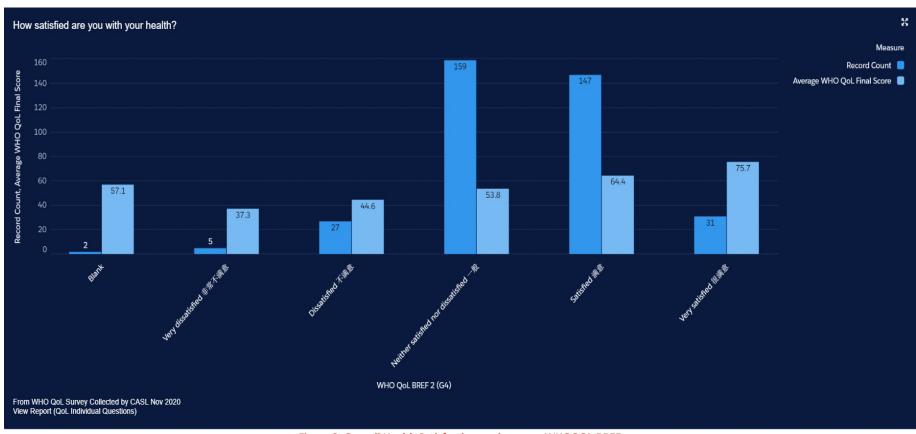


Figure 9: Overall Health Satisfaction as shown on WHOQOL-BREF

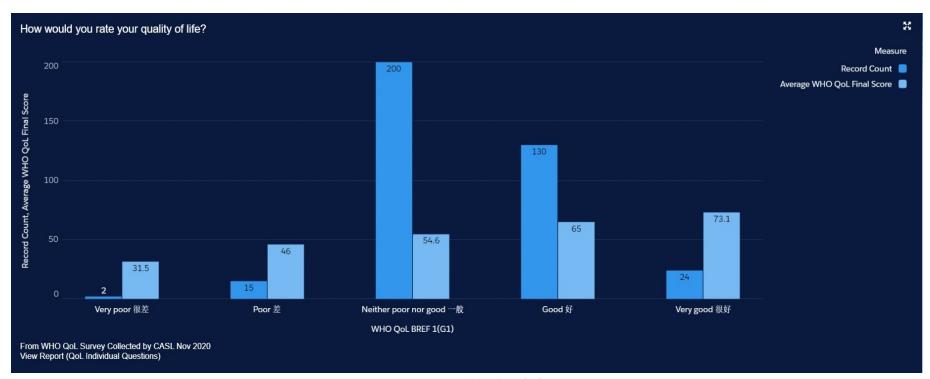


Figure 10: Overall Quality of Life

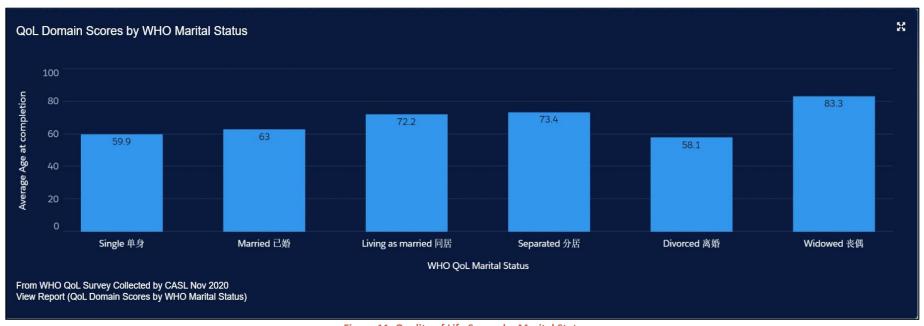


Figure 11: Quality of Life Scores by Marital Status

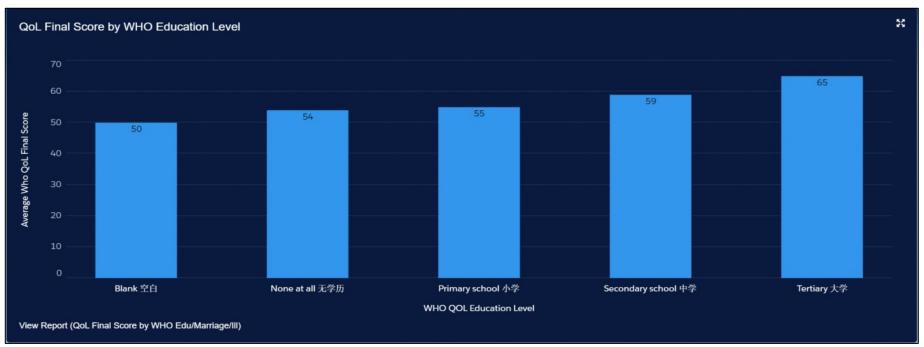


Figure 12: Quality of Life Scores by Education Level

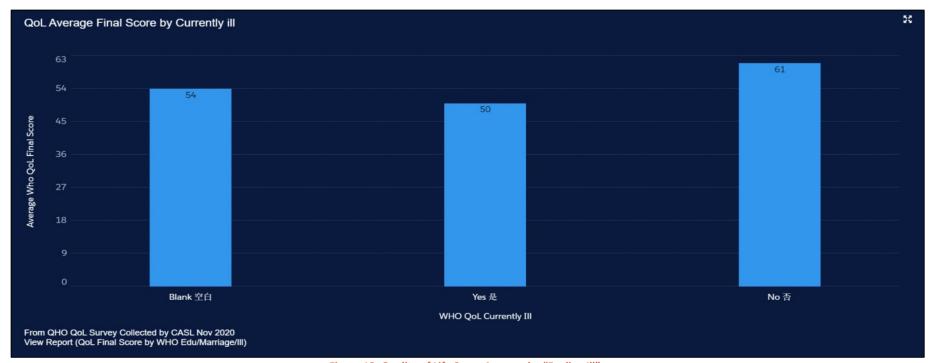


Figure 13: Quality of Life Score Average by "Feeling Ill"

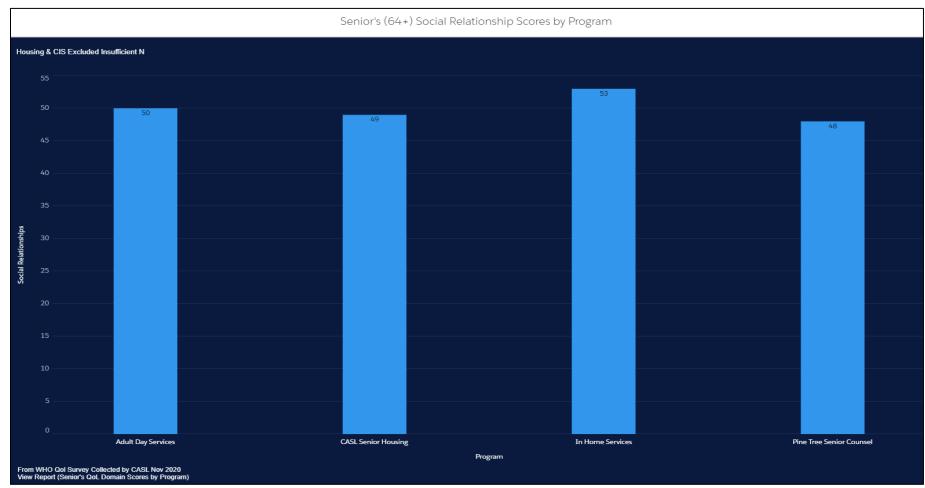
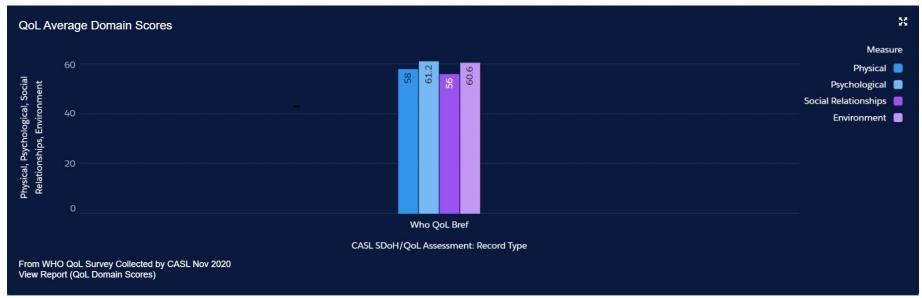


Figure 14: Social relationship scores among CASL Seniors (by program)



**Figure 15: Average Quality of Life Domain Scores** 

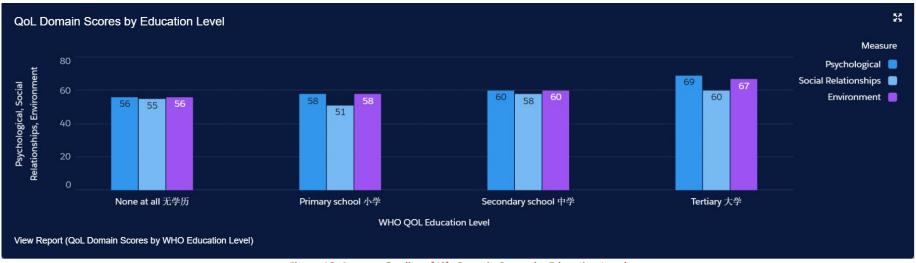


Figure 16: Average Quality of Life Domain Scores by Education Level

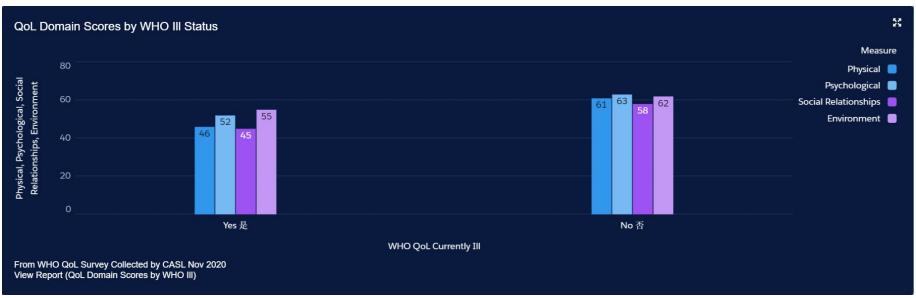


Figure 17: Average Quality of Life Domain Scores by "Feeling Ill"

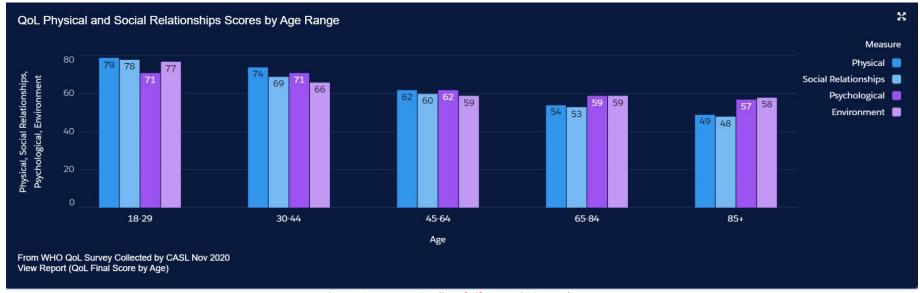


Figure 18: Average Quality of Life Domain Scores by Age

<sup>&</sup>lt;sup>1</sup> Center for Disease Control & Prevention (2020). *Health Related Quality of Life*. National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health. Available at <a href="https://www.cdc.gov/hrqol/concept.htm">https://www.cdc.gov/hrqol/concept.htm</a>

<sup>&</sup>lt;sup>2</sup> Ibid.

<sup>&</sup>lt;sup>3</sup> World Health Organization. Division of Mental Health. (1996). WHOQOL-BREF: introduction, administration, scoring and generic version of the assessment: field trial version, December 1996. World Health Organization. https://apps.who.int/iris/handle/10665/63529

<sup>&</sup>lt;sup>4</sup> With adequate permissions.

<sup>&</sup>lt;sup>5</sup> Choi, S., Lee, S., Kim, J. H., & Na, J. (2019). Effects of community integration on quality of life among Asian Americans. International Social Work, 62(5), 1404–1415. https://doi.org/10.1177/0020872818798009

<sup>&</sup>lt;sup>6</sup> Pew Research Center (2013) 'The Rise of Asian Americans'. Available online at: http://www.pewsocialtrends.org/2012/06/19/the-rise-of-asian-americans/

<sup>&</sup>lt;sup>7</sup> World Health Organization. Division of Mental Health. (1996). WHOQOL-BREF: introduction, administration, scoring and generic version of the assessment: field trial version, December 1996. World Health Organization. <a href="https://apps.who.int/iris/handle/10665/63529">https://apps.who.int/iris/handle/10665/63529</a>

<sup>&</sup>lt;sup>8</sup> It should be noted that "significance" here does not refer to high level of statistical rigor, but correlatory remarks supported by anecdotal evidence (e.g. hypotheses). Since this is the first time participants were exposed to the instrument, logic follows that point-in-time data captures very little in terms of what specific actions can be taken to improve clients' quality of life.

<sup>&</sup>lt;sup>9</sup> World Health Organization. Division of Mental Health. (1996). WHOQOL-BREF: introduction, administration, scoring and generic version of the assessment: field trial version, December 1996. World Health Organization. https://apps.who.int/iris/handle/10665/63529

<sup>&</sup>lt;sup>10</sup> Bullinger, M., & Quitmann, J. (2014). Quality of life as patient-reported outcomes: principles of assessment. Dialogues in clinical neuroscience, 16(2), 137–145. https://doi.org/10.31887/DCNS.2014.16.2/mbullinger

<sup>&</sup>lt;sup>11</sup> Citations should not be considered the sole metric for widespread acceptance of a tool and/or resource. The figure surrounding the 1,158 citations was pulled from <a href="https://pubmed.ncbi.nlm.nih.gov/9626712/">https://pubmed.ncbi.nlm.nih.gov/9626712/</a>, in reference to the article: Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group. Psychol Med. 1998 May;28(3):551-8. <a href="doi:10.1017/s0033291798006667">doi: 10.1017/s0033291798006667</a>. PMID: 9626712.

<sup>&</sup>lt;sup>12</sup> Jetté M, Sidney K, Blümchen G. Metabolic equivalents (METS) in exercise testing, exercise prescription, and evaluation of functional capacity. Clin Cardinol. 1990;13:555–65. <a href="https://doi.org/10.1002/clc.4960130809">https://doi.org/10.1002/clc.4960130809</a>

<sup>&</sup>lt;sup>13</sup> Silva, S., Santana, A., Silva, N., & Novaes, M. R. (2019). VES-13 and WHOQOL-bref cutoff points to detect quality of life in older adults in primary health care. Revista De Saúde Pública, 53, 26. <a href="https://doi.org/10.11606/S1518-8787.2019053000802">https://doi.org/10.11606/S1518-8787.2019053000802</a>

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<sup>8910.2014048004912

15</sup> Not mentioned due to the irrelevance of findings and/or the sample was not comparable (e.g. study took place in a different country, setting, sample size was too small, results limited to a particular subpopulation and/or diagnosis, etc.).

<sup>&</sup>lt;sup>16</sup> meaning we are 95% sure that a relationship between two variables is not random

<sup>&</sup>lt;sup>17</sup> The p-value refers to a statistical value assigned to how responses tend to fall under regular and/or normal conditions.

<sup>&</sup>lt;sup>18</sup> [i] A t-test, as defined by the University of Connecticut, is "one type of inferential statistics. It is used to determine whether there is a significant difference between the mean [or average] of two groups." The probability of a particular outcome, in this case, how CASL participants stack up to Chicago Health Atlas data, is compared with a critical value known as a t-score using a one-tailed t-test. Our t-scores were calculated using a 95% confidence interval, meaning that based on a t-table, we can isolate (within our limitations) the degree to which quality of life scores (overall and by domain) differ among participants.