PozQoL Scale

Implementation Kit

Version 2.0

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Contents

Suggested Citation

Introduction

PozQoL is a partnership project of the Australian Research Centre in Sex, Health and Society (ARCSHS); ViiV Healthcare; National Association of People with HIV Australia (NAPWHA); Living Positive Victoria; Positive Life NSW; and Queensland Positive People.

PozQoL scale is a short, freely available scale assessing the quality of life (QoL) among people living with HIV (PLHIV).

The scale was developed in consultation with a variety of community groups in Australia [1]. It was validated on a sample of 465 adult Australians living with HIV [1].

This guide is designed to assist program and service providers implement PozQoL in everyday client practice. The guide covers:

- The importance of assessing client QoL.
- What is covered by each of the PozQoL domains.
- How to administer PozQoL and calculate the PozQoL scores.
- How to interpret clients' PozQoL scores.

Importance of Quality of Life

Since 2014, UNAIDS and the World Health Organisation have championed the 90-90-90 goals striving for:

- 90% of all PLHIV to know their HIV status
- 90% of those diagnosed to receive sustained ART, and
- 90% of those receiving ART to be virally suppressed by 2020 [2, 3].

There is a growing understanding that achieving these goals will require a concurrent focus on the broader psychological and social wellbeing of PLHIV, both as a means and an end goal. For example, evidence indicates that PLHIV with poor mental health or experiencing stigma are less likely to adhere to ART [4-7]. On the other hand, while improving physical health outcomes, viral suppression in itself does not ensure improved QoL among PLHIV [7].

The PozQoL Scale was developed in response to recommendations to incorporate a stronger focus on QoL into HIV prevention and care policy [8].

PozQoL Scale

The PozQoL Scale was developed in line with the World Health Organisation's definition of quality of life:

> *"[An] individual's **perception** 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**. It is a broad-ranging concept affected in a complex way by the persons' **physical health, psychological state, level of independence, social relationships** and their **relationship to salient features of their environment**." [9]*

Consequently, the PozQoL Scale consists of questions covering the following four domains:

Domain	Description	Scale items
Psychological	mood and outlook about oneself, life and the future	- I am enjoying life - I feel in control of my life - I am optimistic about my future - I feel good about myself as a person
Social	relationships with other people, and sense of belonging and support	- I feel that HIV limits my personal relationships - I lack a sense of belonging with people around me - I am afraid that people may reject me when they learn I have HIV
Health concerns	health management and health-related concerns	- I worry about my health - I worry about the impact of HIV on my health - I fear the health effects of HIV as I get older
Functional	independence and living with HIV	- I feel that HIV prevents me from doing as much as I would like - Having HIV limits my opportunities in life - Managing HIV wears me out

Scale Administration

We recommend interspersing items from different domains when administering PozQoL.

The recommended item order presented below additionally counter-balances the order of positively and negatively worded items.

"This survey is intended for people living with HIV. We would like to ask you about your health, relationships, life satisfaction, and wellbeing. Please indicate how much the following statements apply to you on a scale from 1 (not at all) to 5 (extremely)."

1 – not at all   2 – slightly   3 – moderately   4 – very   5 – extremely

1. I am enjoying life.
2. I worry about my health.
3. I lack a sense of belonging with people around me.
4. I feel that HIV prevents me from doing as much as I would like.
5. I feel good about myself as a person.
6. Having HIV limits my opportunities in life.
7. I worry about the impact of HIV on my health.
8. I feel in control of my life.
9. I am afraid that people may reject me when they learn I have HIV.
10. Managing HIV wears me out.
11. I feel that HIV limits my personal relationships.
12. I fear the health effects of HIV as I get older.
13. I am optimistic about my future.

Scoring

PozQoL scores can be calculated both as a total score and score for each domain (Psychological, Social, Health Concerns, and Functional). Scores can be calculated either as an average or as a sum.

Sum scores are easier to calculate when administering PozQoL as a pen-and-pencil copy in one-on-one consultations (see the scoring template provided in the Appendix). However, sum scores can be only calculated if all responses on a given domain are provided.

Average scores can be calculated even if some responses are left blank. Items for which responses are missing are not taken into account when calculating the average scores. Thus, the scores represent the average for items in the domain that the respondent has answered. We recommend however not computing average scores if a respondent missed more than one item per domain.

In both cases, scoring PozQoL is a two-step process. First, items have to be recoded so that higher scores for all items indicate better quality of life. In step two, items in the same domain are summed or averaged together to create the four domain scores. Response range for each scale is 1-5 for average scores. For summary scores responses can range from 4-20 for the psychological domain; 3-15 for the social, health concerns, and functional domains; and 13-65 for the PozQoL total score.

Step 1

Recoding items 2-4, 6-7, 9-12

(*Note*: Items 1, 5, 8, 13 do not require recoding as they are positively worded)

[original response category → recoded value of]

1 → 5

2 → 4

3 → 3

4 → 2

5 → 1

Step 2

Averaging items to form the final scores

Scale	Number of items	After recoding, average the following items
PozQoL (total score)	13	1-13
Health concerns	3	2, 7, 12
Psychological	4	1, 5, 8, 13
Social	3	3, 9, 11
Functional	3	4, 6, 10

Comparing PozQoL scores to an Australian sample

The following tables three provide an overview of the results of PozQoL from a sample of 465 adult Australians living with HIV (Brown et al., 2018). These can be used to provide a guide or comparison for PozQoL results.

Reliability, Mean Scores and Variability of PozQoL in the Validation Study

Reliabilities and descriptive statistics for the total scale and each of the four domains are summarized in the table below.

Scale	# of items	Alpha	Test-retest reliability	Average score		Summary score	
				Mean	SD	Mean	SD
PozQoL (total score)	13	0.94	0.95	3.43	0.92	44.62	11.94
Health concerns	3	0.91	0.91	3.22	1.13	9.66	3.40
Psychological	4	0.90	0.85	3.38	0.97	13.52	3.88
Social	3	0.82	0.83	3.26	1.14	9.83	3.42
Functional	3	0.87	0.89	3.94	1.10	11.65	3.31

Note: n = 465 adult Australians living with HIV

Current thresholds for interpreting the PozQoL scores

The score thresholds presented below are can serve as a guideline in initiating discussions about a client's quality of life, and how they compare to other PLHIV in Australia.

The score thresholds draw on the results from the PozQoL validation study. We used the levels of quality of life reported by 25%, 50% and 75% of Australians living with HIV who participated in the validation study, respectively. This provides the thresholds for identifying low quality of life, moderate quality of life, high quality of life, and very high quality of life compared to other people with HIV in Australia. We have provided a table detailing the score categories for average scores as well as the summary (non-averaged) scores.

Average scores

Score range	Low QoL	Moderate QoL	High QoL	Very High QoL
PozQoL (total score)	≤ 2.84	2.85 - 3.53	3.54 - 4.14	≥ 4.15
Psychological	≤ 2.74	2.75 - 3.49	3.50 – 3.99	≥ 4.00
Social	≤ 2.32	2.33 - 3.32	3.33 – 3.99	≥ 4.00
Health concerns	≤ 2.32	2.33 - 3.32	3.33 – 3.99	≥ 4.00
Functional	≤ 3.32	3.33 - 4.32	4.33 - 4.66	≥ 4.67

Note: n = 465 adult Australians living with HIV

Summary (non-averaged) scores

Score range	Low QoL	Moderate QoL	High QoL	Very High QoL
PozQoL (total score)	≤ 36	37 – 45	46 – 53	≥ 54
Psychological	≤ 10	11 – 13	14 – 16	≥ 17
Social	≤ 6	7 – 9	10 – 12	≥ 13
Health concerns	≤ 6	7 – 9	10 – 12	≥ 13
Functional	≤ 9	10 – 11	12 – 14	≥ 15

Note: n = 465 adult Australians living with HIV

How to understand your client's/patient's PozQoL scores

PozQoL Domain		Suggested referrals
Psychological (P)	A person with a low score on this domain might be experiencing some psychological difficulties such as low mood and negative outlook about oneself, life and the future. **PozQoL is not a diagnostic tool.** It may be advisable to discuss further, assess using diagnostic mental health tools, and/or consider referral to counselling services.	Care and support, counselling
Social (S)	A person with a low score on this domain might be experiencing some difficulties in relationships with other people, HIV-related discrimination, lacking a sense of belonging and support. Meeting PLHIV peers can assist in overcoming isolation due to fear of stigma, or in managing disclosure and confidence.	Peer support or peer navigation, care and support
Health concerns (HC)	A person with a low score on this domain might be currently experiencing some difficulties managing their health or be concerned that their health will deteriorate due to HIV, even if they are enjoying good health at the moment. They may benefit from discussing treatment options or revisions, speaking with PLHIV peers about managing HIV, or provide information on good health prospects managing HIV.	Medical services, health promotion and peer education, care and support, counselling
Functional (F)	A person with a low score on this domain might be experiencing some difficulties with incorporating HIV into their everyday life, lacking functional independence, perhaps experiencing some financial distress as a consequence. Raising their awareness of organisations who can provide community and financial support/ advice may be of benefit	Community support, financial and housing assistance, personal development

References

1.   Brown, G., et al., *Development and validation of PozQoL: A scale to assess quality of life of PLHIV.* BMC Public Health, 2018. **18**: p. 527.

2.   UNAIDS, *90-90-90 An ambitious treatment target to help end the AIDS epidemic*. 2014, Joint United Nations Programme on HIV/AIDS (UNAIDS): Geneva.

3.   World Health Organization, *Global health sector strategy on HIV 2016-2021. Towards ending AIDS.* 2016.

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6.   Maiese, E.M., et al., *Quality of life of HIV-infected patients who switch antiretroviral medication due to side effects or other reasons.* Current Medical Research and Opinion, 2016. **32**(12): p. 2039-2046.

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8.   Lazarus, J.V., et al., *Beyond viral suppression of HIV – The new quality of life frontier.* BMC medicine, 2016. **14**(1): p. 94.

9.   World Health Organization, *WHOQOL: Measuring quality of life.* 1997.

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Acknowledgement

If you produce any written works or other media related to your use of PozQoL, you must cite PozQoL using the following:

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