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PozQoL

Valuing quality of life among people with HIV

**A quality of life measure for the HIV
community, support and healthcare sector**

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



WHY A NEW HEALTH RELATED QUALITY OF LIFE SCALE?

Community, health and policy organisations in Australia have prioritised improving the quality of life of people living with HIV (PLHIV) in their programs as part of the goals of the National HIV Strategy⁽¹⁾. Health services and community programs have for many years recognised the higher levels of reported isolation, depression, and anxiety among many PLHIV resulting in lower quality of life. This has also been shown to be associated with difficulties in maintaining treatment and continuing care^(2,3). There has also been a strong call for quality of life to be incorporated into the global goals for HIV^(4,5). However, monitoring quality of life within day-to-day health and community service practice is challenging. Most current scales are large, restricted in their use, expensive, or developed prior to the current treatment era.

To this end, HIV community, support and healthcare services in Australia expressed a need for an empirically validated, short and practical way to measure quality of life of PLHIV to evaluate the impact of their programs.

The PozQoL study aimed to develop, test and validate such as scale to be easily incorporated into the day-to-day practice of health and community services, as well as for the purposes of social research.

METHOD

The PozQoL scale was developed through the following four stages: review of the existing literature, conceptualisation, item development, and validation. The PozQoL study was conducted using an approach embedded in the greater and meaningful involvement of people with HIV/AIDS (GIPA) principles⁽⁶⁾. Peer-led organisations were involved in the conceptualisation and prioritisation of the domains, development of items, and decisions concerning the refinement of the final scale.

LITERATURE REVIEW, CONCEPTUALISATION AND ITEM DEVELOPMENT

Based on the review of the literature, the World Health Organisation (WHO) definition of Quality of Life (QoL) was identified as the most comprehensive and relevant for the purposes of the study:

[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.⁽⁷⁾

The literature review formed the basis of the consultation with a panel of experts from PLHIV peer organisations to identify and rank domains within QoL according to their conceptual accuracy, as well as relevance and usefulness to health and community programs. The four identified domains were:

- 1 Psychological domain** (incl. mood, coping, hope and fear of the future and self-worth)
- 2 Social domain** (incl. personal and social life, belonging, support, and social stigma)
- 3 Health domain** (incl. perception of one's health, health-related concerns, energy and HIV management)
- 4 Functional domain** (incl. ability to live a 'normal' life, independence, meaningful occupation and satisfactory standard of living).

Over 100 items across the four domains were developed. The items were pre-tested for face and content validity through an online survey with a panel of experts from PLHIV peer organisations (n=13), and other HIV experts and stakeholders (n=5). Following this, the pool of items was reduced to 64.

VALIDATION STUDY

To select items for the final scale and validate them psychometrically, we conducted an online survey with a sample of 465 adult Australians living with HIV.

Recruitment

Invitations to participate in the study were promoted through a range of mechanisms:

- 1 Collaborating community organisations and PLHIV groups provided significant in-kind support and promoted the study through membership emails, mailouts, and other promotional strategies within their client group and communities.
- 2 Paid advertising online (Facebook, Grindr), relevant online apps and websites.

Participants were also offered the opportunity to participate in a follow-up survey approximately one month after the initial survey to assess test-retest reliability of the scale (n = 51). The questionnaire included the draft PozQoL scale, other validated measures of health and wellbeing, and standard demographic questions. Data collection took place between 22 March and 31 May 2017.

Results

The responses to the 64 items were subjected to multivariate factor analysis to identify the underlying domains and the items which best represented them. Guided by an Exploratory Factor Analysis and conceptual considerations, a 13-item scale was developed. The PozQoL scale demonstrated high levels of fit in a Confirmatory Factor Analysis, very good internal consistency, test-retest reliability, and concurrent validity with other measures that approximated different aspects of quality of life. Selected key validity and reliability results are presented in Table 1 and 2.

Table 1. Mean scores and reliabilities of the PozQoL subscales

	# of items	Alpha	Test-retest reliability	Mean	SD
PozQoL total score	13	0.94	0.95	3.43	0.92
PozQoL health concerns	3	0.91	0.91	3.22	1.13
PozQoL psychological	4	0.90	0.85	3.38	0.97
PozQoL social	3	0.82	0.83	3.26	1.14
PozQoL functional	3	0.87	0.89	3.94	1.10

Note. N = 465 adult Australians living with HIV; higher PozQoL scores indicate better quality of life.

Table 2. Concurrent and convergent validity of PozQoL

	PozQoL total score	PozQoL health concerns	PozQoL psychological	PozQoL social	PozQoL functional
r (95% CI)					
Quality of Life					
SF-36 PCS	.68 (.62-.74)	.54 (.46-.62)	.65 (.59-.71)	.45 (.36-.54)	.66 (.59-.72)
SF-36 MCS	.77 (.72-.81)	.57 (.48-.64)	.78 (.72-.82)	.57 (.48-.64)	.69 (.63-.74)
FAHI	.87 (.84-.90)	.69 (.63-.74)	.79 (.74-.83)	.72 (.67-.77)	.77 (.73-.82)
Mental health and wellbeing					
Psychological distress	.75 (.69-.80)	.55 (.47-.63)	.72 (.65-.78)	.60 (.52-.66)	.66 (.59-.72)
Wellbeing	.76 (.71-.81)	.56 (.48-.64)	.77 (.71-.82)	.61 (.53-.67)	.63 (.57-.69)
Satisfaction with Life	.73 (.68-.78)	.53 (.45-.60)	.74 (.67-.79)	.57 (.50-.64)	.63 (.57-.69)
Resilience	.68 (.61-.74)	.47 (.37-.56)	.71 (.66-.76)	.52 (.44-.60)	.57 (.49-.65)
AIDS-related stigma	-.65 (-.70-.59)	-.49 (-.57-.41)	-.47 (-.55-.39)	-.71 (-.75-.66)	-.54 (-.61-.46)
Social support	.59 (.51-.66)	.40 (.32-.49)	.54 (.45-.62)	.56 (.48-.63)	.49 (.41-.57)

Note. All correlations are significant at the $p < .001$ level; N varied between 373 and 407 due to missing data; PCS = Physical Component Score; MCS = Mental Component Score.

- **SF-36:** RAND Short Form 36 1.0⁽⁸⁾
- **FAHI:** Functional Assessment of Human Immunodeficiency Virus Infection⁽⁹⁾
- **Psychological Distress:** K6 Scale⁽¹⁰⁾
- **Wellbeing:** The Short Warwick-Edinburgh Mental Well-being Scale⁽¹¹⁾
- **Satisfaction with life:** The Satisfaction with Life Scale⁽¹²⁾
- **Resilience:** The Brief Resilience Scale⁽¹³⁾
- **Stigma:** Internalised AIDS-Related Stigma Scale⁽¹⁴⁾
- **Social Support:** Interpersonal Support Evaluation List⁽¹⁵⁾ ISEL-12 version⁽¹⁶⁾

insights from PLHIV and other stakeholders supported the balancing of statistical rigour and conceptual accuracy. A full methods and results paper is forthcoming.⁽¹⁷⁾

PozQoL 13 ITEMS

The PozQoL 13 items are listed below. The items are grouped into the four domains. In practice, the order would not be based on domains but a mix 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.”

Conclusion

The PozQoL scale has been tested in a diverse sample of adult PLHIV living in Australia, demonstrating very good reliability and validity. The

	Not at all	Slightly	Moderately	Very	Extremely
Health Concerns					
I worry about my health	<input type="radio"/>				
I worry about the impact of HIV on my health	<input type="radio"/>				
I fear the health effects of HIV as I get older	<input type="radio"/>				
Psychological					
I am enjoying life	<input type="radio"/>				
I feel in control of my life	<input type="radio"/>				
I am optimistic about my future	<input type="radio"/>				
I feel good about myself as a person	<input type="radio"/>				
Social					
I feel that HIV limits my personal relationships	<input type="radio"/>				
I lack a sense of belonging with people around me	<input type="radio"/>				
I am afraid that people may reject me when they learn I have HIV	<input type="radio"/>				
Functional					
I feel that HIV prevents me from doing as much as I would like	<input type="radio"/>				
Having HIV limits my opportunities in life	<input type="radio"/>				
Managing HIV wears me out	<input type="radio"/>				

An implementation trial of the PozQoL scale is being conducted across clinical, community and peer-led programs during 2018. This will include the development of an implementation kit.

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