

POZQOL: VALUING QUALITY OF LIFE AMONG PLHIV

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PLHIV IN RESEARCH

Thank you to the people living with HIV who have generously shared their time, experience, and body for the purposes of this research.

Much of the fight against HIV and AIDS relies upon people living with HIV continuing to put themselves forward and this research and our fight against HIV and AIDS is indebted to those past and present.”

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- *Indebted to the participation of PLHIV in research*

QUALITY OF LIFE AND HIV CARE

The interrelationship between quality of life, stigma and treatment adherence has been well established. (3-7)

- PLHIV with poor mental health and/or experiencing stigma are less likely to adhere to treatment [3-6].
- Improving health outcomes through viral suppression does not by itself ensure quality of life among people living with HIV [6].

POzQoL Project was
an alignment of
priorities of

- peer organisations,
- research, and
- industry

POZQOL

VALUING QUALITY OF LIFE AMONG PLHIV



WHAT IS THE POZQOL SCALE

13 items across 4 domains

Health 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

Psychological

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

I feel that HIV limits my personal relationships
I lack a sense of belonging with people around me
I am afraid that people might reject me when they learn I have HIV

Functional

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

IMPLEMENTATION TRIAL OF POZQOL

The next step was an implementation trial

- To assess the usability, acceptability, and usefulness of the PozQoL scale in the day to day work of different health and community services
- To assess how sensitive the PozQoL scale is in measuring changes in health-related quality of life as a result of interventions or services

Where: clinical services, peer programs, community/welfare services, (7)

Uses: Evaluation of programs, monitor clients, enhance the client/provider discussion

Summary sensitivity data available if questions

IMPLEMENTATION TRIAL OF POZQOL

Usability Feedback (online survey n=19, interviews n=9, from 7 orgs)

Benefits

- supported understanding of the client group accessing the program/service
- influenced communication or topics discussed with the clients
- supported efforts to increase a focus on quality of life alongside quality of care

This was in addition to most respondents (n=15) reporting that PozQol was easy for staff to use.

IMPLEMENTATION TRIAL OF POZQOL

Challenges

- Time – particularly in clinical services
- Capacity/readiness of organisational record management systems
- English only (at that time)

Suggestions

- Digital solutions for collection and analysis
- Enhancing the implementation kit and online resources

IMPLEMENTATION TRIAL OF POZQOL

Sensitivity

- 95 completed pre/post data sets including PozQoL from across the community organisation services.
- PozQoL showed statistically significant changes across the community programs – demonstrating sensitive enough to measure changes in QoL over a two month period
- Changes within the PozQoL domains (Health concerns, social, functional and psychological) corresponded with the aims of the programs

IMPLEMENTATION TRIAL OF POZQOL

Sensitivity

Scale		Post – Pre (change)	95% CI	p value	N
PozQoL Total Score		0.291	(0.178, 0.404)	0.000*	95
PozQoL Health Concerns		0.286	(0.080, 0.492)	0.006*	95
PozQoL Psychological		0.272	(0.096, 0.448)	0.002*	95
PozQoL Social		0.364	(0.206, 0.522)	0.000*	95
PozQoL Functional		0.168	(-0.014, 0.351)	0.070	95

Intervention	Scale	Average Score at Pre	Post – Pre (change)	95% CI	p value	N
Newly Diagnosed PLHIV workshop	PozQoL Total Score	2.821	0.520	(0.297, 0.744)	0.000*	23
	PozQoL Health Concerns	2.341	0.732	(0.332, 1.132)	0.001*	23
	PozQoL Psychological	3.185	0.293	(-0.043, 0.630)	0.084	23
	PozQoL Social	2.710	0.526	(0.269, 0.782)	0.000*	23
	PozQoL Functional	2.928	0.488	(0.105, 0.872)	0.015*	23
PLHIV Retreat	PozQoL Total Score	3.267	0.236	(-0.035, 0.507)	0.084	17
	PozQoL Health Concerns	3.196	0.196	(-0.082, 0.474)	0.154	17
	PozQoL Psychological	3.515	0.132	(-0.294, 0.559)	0.520	17
	PozQoL Social	2.765	0.590	(0.209, 0.972)	0.005*	17
	PozQoL Functional	3.529	0.052	(-0.394, 0.498)	0.807	17
Welfare/Community Services Combined	PozQoL Total Score	3.163	0.212	(0.057, 0.368)	0.008*	55
	PozQoL Health Concerns	2.964	0.127	(-0.180, 0.434)	0.410	55
	PozQoL Psychological	3.185	0.306	(0.051, 0.561)	0.020*	55
	PozQoL Social	3.085	0.226	(-0.004, 0.457)	0.054	55
	PozQoL Functional	3.321	0.071	(-0.178, 0.319)	0.572	55
All services combined	PozQoL Total Score	3.089	0.291	(0.178, 0.404)	0.000*	95
	PozQoL Health Concerns	2.854	0.286	(0.080, 0.492)	0.006*	95
	PozQoL Psychological	3.244	0.272	(0.096, 0.448)	0.002*	95
	PozQoL Social	2.937	0.364	(0.206, 0.522)	0.000*	95
	PozQoL Functional	3.263	0.168	(-0.014, 0.351)	0.070	95

CURRENT DEVELOPMENTS FOR POZQOL

- Incorporated into some clinical services but logistical and time barriers to be worked through
 - Incorporated within most PLHIV peer programs across Australia and increasing number of community support programs.
 - Implementation kit and resources being refined
 - PozQoL Website in development
- PozQoL incorporated into Australian national PLHIV studies, and some implementation science studies.
 - PozQoL is now the PLHIV QoL indicator for the Australian National HIV Strategy
 - Translated into 13 languages (to date)
 - PozQoL used social research and implementation research in North America and planned studies in Europe

IN CLOSING...

- Indicators of health related QoL may be useful as both an input to, and an outcome of, optimising care.
 - **Input** – such as guide care plans as well as referral to peer and other community/support services
 - **Outcome** – to monitor how the adaptations we are all making across our services are working across different groups.
- The development of PozQol means we are closer to having something for day to day practice of services (rather than only in larger research studies), and so increase the viability of including quality of life in PRO guidelines,

PozQoL Website

Website is currently in development

We have a temporary website which hosts most of the key documentation and translations

www.pozqol.org.au

THANK YOU

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465 PLHIV who completed a survey to create a survey!!!

ADDITIONAL SLIDES IF QUESTIONS

CONVERGENT VALIDITY

	SF-36 PCS	SF-36 MCS	FAHI
PozQoL (total score)	.68	.77	.87
Health concerns	.54	.57	.69
Psychological	.65	.78	.79
Social	.45	.57	.72
Functional	.66	.69	.77

MEAN SCORES AND RELIABILITIES

Scale	# of items	Alpha	Test-retest reliability	Mean	SD
PozQoL (total score)	13	0.94	0.95	3.43	0.92
Health concerns	3	0.91	0.91	3.22	1.13
Psychological	4	0.90	0.85	3.38	0.97
Social	3	0.82	0.83	3.26	1.14
Functional	3	0.87	0.89	3.94	1.10

1. UNAIDS: **90-90-90 An ambitious treatment target to help end the AIDS epidemic**. In. Geneva: Joint United Nations Programme on HIV/AIDS (UNAIDS); 2014.
2. World Health Organization: **Global health sector strategy on HIV 2016-2021. Towards ending AIDS**. 2016.
3. Erdbeer G, Sabranski M, Sonntag I, Stoehr A, Horst H-A, Plettenberg A, Schewe K, Unger S, Stellbrink H-J, Fenske S: **Everything fine so far? Physical and mental health in HIV-infected patients with virological success and long-term exposure to antiretroviral therapy**. *Journal of the International AIDS Society* 2014, **17**(4Suppl 3).
4. Katz IT, Ryu AE, Onuegbu AG, Psaros C, Weiser SD, Bangsberg DR, Tsai AC: **Impact of HIV-related stigma on treatment adherence: systematic review and meta-synthesis**. *Journal of the International AIDS Society* 2013, **16**(3Suppl 2).
5. Maiese EM, Johnson PT, Bancroft T, Goolsby Hunter A, Wu AW: **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):2039-2046.
6. Miners A, Phillips A, Kreif N, Rodger A, Speakman A, Fisher M, Anderson J, Collins S, Hart G, Sherr L: **Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: a cross-sectional comparison with the general population**. *The lancet HIV* 2014, **1**(1):e32-e40.
7. Lazarus JV, Safreed-Harmon K, Barton SE, Costagliola D, Dedes N, del Amo Valero J, Gatell JM, Baptista-Leite R, Mendão L, Porter K: **Beyond viral suppression of HIV—the new quality of life frontier**. *BMC medicine* 2016, **14**(1):94.
8. Power J, Brown G, Lyons A, Dowsett G, Lucke J, Thorpe R: **Health and wellbeing of people living with HIV**. In. Melbourne: The Australian Research Centre in Sex Health and Society; La Trobe University. ; 2016.
9. Power J, Brown G, Lyons A, Thorpe R, Dowsett GW, Lucke J: **HIV Futures 8: protocol for a repeated cross-sectional and longitudinal survey of people living with HIV in Australia**. *Frontiers in Public Health* 2017, **5**(50).
10. Thorpe R, Power J, Brown G, Lyons A, Dowsett G, Lucke J: **HIV Futures 8: Experiences of Antiretroviral Treatment**. In. Melbourne: The Australian Research Centre in Sex Health and Society; La Trobe University. ; 2016.
11. Australian Government: **Seventh National HIV Strategy 2014-2017**. In. Canberra: Commonwealth Government of Australia;; 2014.
12. Moons P, Budts W, De Geest S: **Critique on the conceptualisation of quality of life: a review and evaluation of different conceptual approaches**. *International journal of nursing studies* 2006, **43**(7):891-901.
13. Engler K, Lessard D, Lebouché B: **A review of HIV-specific patient-reported outcome measures**. *The Patient-Patient-Centered Outcomes Research* 2017, **10**(2):187-202.
16. World Health Organization: **WHOQOL: measuring quality of life**. 1997.