



20 novembre 2021

h. 9:00 - 13:15

7^a EDIZIONE AIDS E DINTORNI

1981-2021: 40 anni di HIV/AIDS. Liberi di, liberi da

Liberi di narrarsi all'infettivologo:
il valore aggiunto dei
Patient Reported Outcomes (PROs)

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HIV is a chronic condition with potentially near-normal life expectancy



Physical and mental health is considered a challenge in HIV management



HIV practitioners may miss patients' needs and symptoms, especially non-physical symptoms



Routine use of PROs, measured using PROMs, helps identify problems/concerns and improves outcomes for patients through healthcare team sharing and planning

UNAIDS 2020: 90-90-90 ...-90

UNAIDS 2030: 95-95-95 ...-95

90%

**of all PLHIV will know their
HIV status**

90%

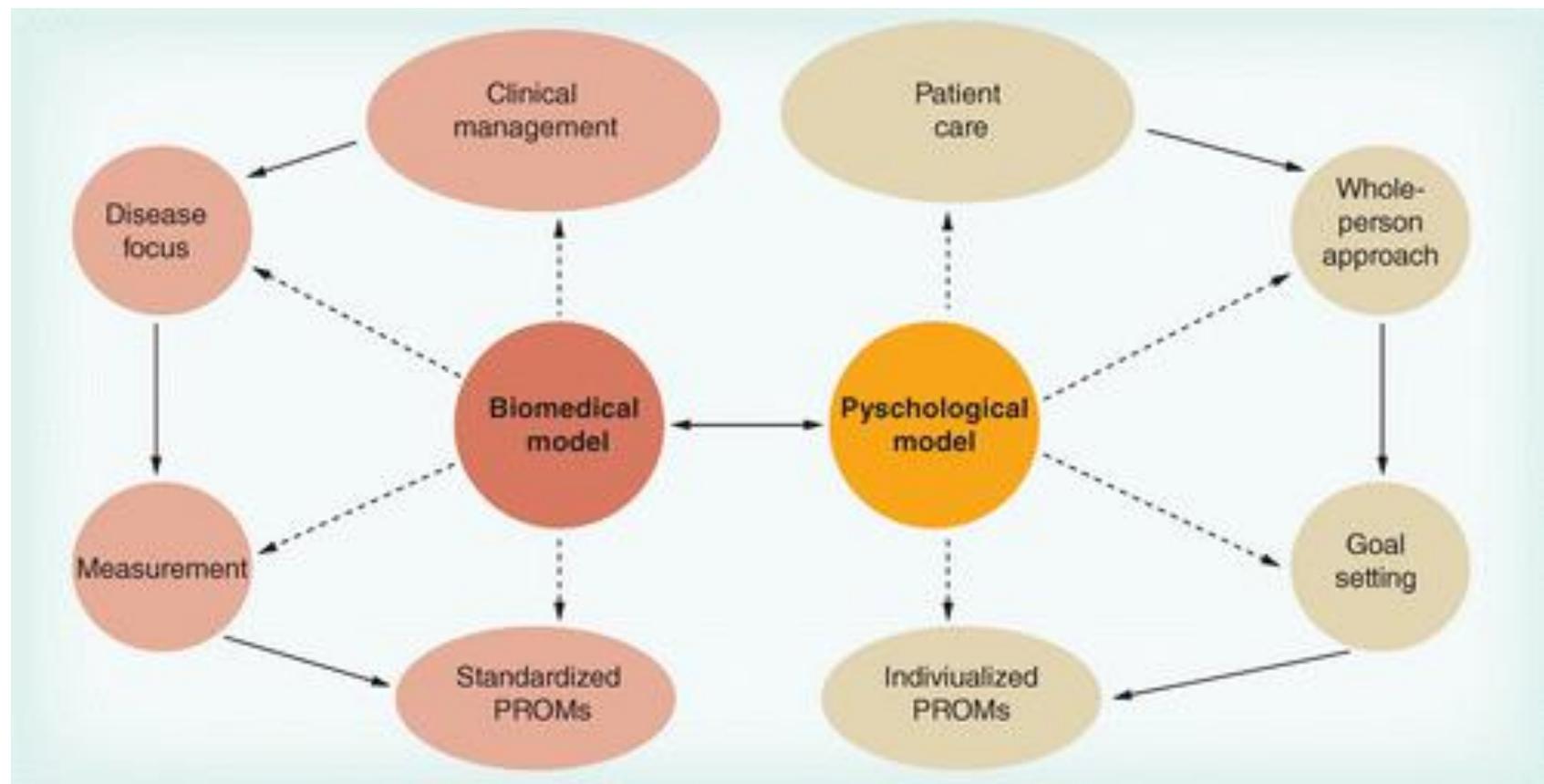
**of all people diagnosed with
HIV infection will receive
sustained ART**

90%

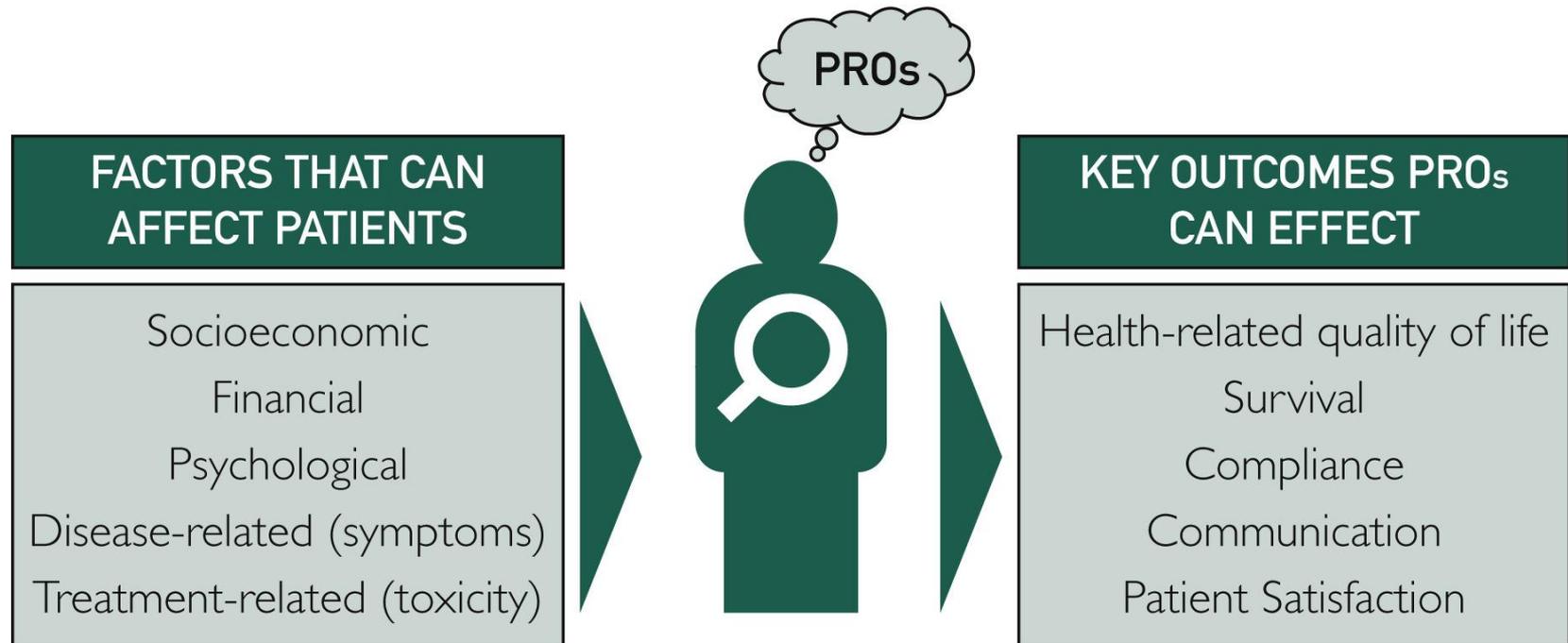
**of all people receiving ART
will have viral suppression**

90%

**of people with viral load
suppression have
good HRQoL**



Framework for **PROs** utility in clinical care



PROs

- ✓ Health-related quality of life (HRQOL)
- ✓ Symptoms
- ✓ Function
- ✓ Satisfaction with care or symptoms
- ✓ Adherence to prescribed medications or other therapy
- ✓ Perceived value of treatment

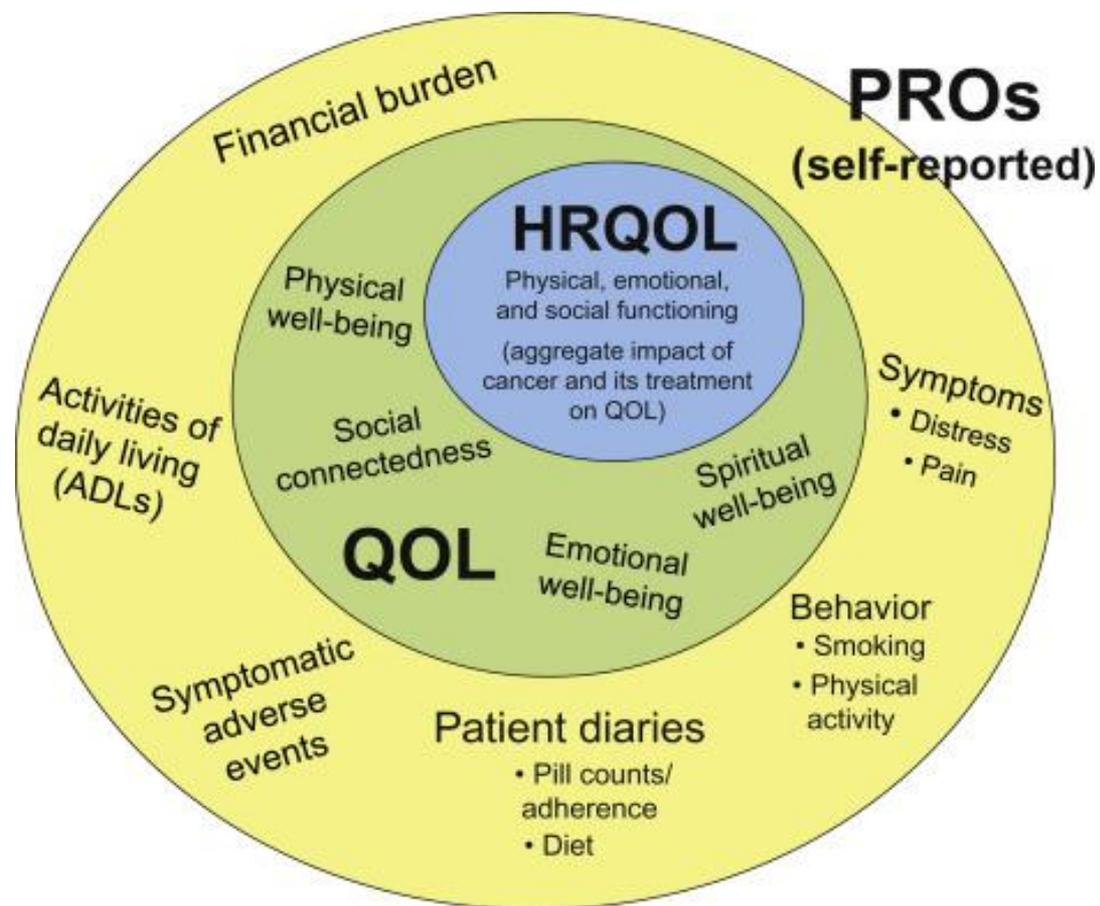
PROs

Any information directly reported by the patient without interpretation by a clinician or anyone else that pertains to patient's health, QoL or functional status associated with healthcare or treatment

PROs put the treatment outcomes within the entire health outcomes context

PROMs

Identifiable, valid and reliable tools or instruments used to measure PROs



I PROs alle Giornate di Nadir 2020 e su Delta n.89



La prima bozza del PRO HIV, VALUTAZIONE DEL MIO STATO DI SALUTE SOCIALE, FISICO, MENTALE, costruita da oltre 40 persone appartenenti a 20 associazioni italiane.

Focus sulla sfera psicologica. La scheda PRO, se compilata prima della visita, servirà per orientare il medico sullo stato di salute del paziente e concordare la soluzione ottimale, sia nella routine, sia di fronte ad una situazione inattesa. Il PRO diventa uno strumento di supporto alla personalizzazione del percorso di salute migliorando la qualità della vita.

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ICAR2021: Measure the HIV Quality of Life through patient-reported outcomes (PROs)

Table 1. Sociodemographic and clinical characteristics of PLWH according with level of disease and treatment burden

Characteristics	L-TBD (N=432;81.3%)	H-TDB (N=99; 18.6%)	p-value	Total
Age, years, median (IQR)	50 (41-57)	44 (34-53)	<.001	49 (39-56)
Gender, Male, n(%)	375 (86.8)	87 (87.9)	0.775	462 (87.0)
Education, n(%)			0.109	
Middle/High School	254 (58.8)	50 (50.5)		304 (57.2)
University/Master	176 (40.7)	47 (47.5)		223 (42.0)
Other/Unknown	2 (0.5)	2 (2.0)		4 (0.7)
Job, n(%)			0.102	
Work (stable)	272 (62.9)	52 (52.5)		324 (60.0)
Work (not stable)	55 (12.7)	15 (15.1)		70 (13.2)
Not Working	44 (10.2)	18 (18.2)		62 (11.7)
Other/Unknown/Retired	61 (14.1)	14 (14.1)		75 (14.1)
Italy Born, n(%)	406 (94.0)	92 (92.9)	0.696	498 (93.8)
Year HIV Diagnosis, n(%)			0.178	
2000-	106 (24.5)	23 (23.2)		129 (24.3)
2001-2010	114 (26.4)	18 (18.2)		132 (24.9)
2011-2015	108 (25)	25 (25.2)		133 (25)
2016+	104 (24.1)	33 (33.3)		137 (25.8)
Year first ARV start, n(%)			0.137	
2000-	89 (20.6)	17 (17.17)		106 (19.9)
2001-2010	109 (25.23)	17 (17.17)		126 (23.7)
2011-2015	116 (26.85)	28 (28.28)		144 (27.1)
2016+	118 (27.31)	37 (37.37)		155 (29.2)
Mode of HIV Transmission, n(%)			0.194	
Homosexual Contacts	274 (63.4)	52 (52.5)		326 (61.4)
Heterosexual Contacts	31 (7.2)	7 (7.1)		38 (7.2)
Other Sexual contacts	88 (20.4)	27 (27.3)		115 (21.7)
Other mode (not sexual)	39 (9)	13 (13.1)		52 (9.8)
Current HIV-RNA, copies/mL, n(%)			0.044	
<50 cps/mL	388 (89.8)	80 (80.8)		468 (88.1)
>=50 cps/mL	19 (4.4)	8 (8.1)		27 (5.1)
unknown/not reported	25 (5.8)	11 (11.1)		36 (6.8)
Current CD4, cells/mm³, n(%)			0.463	
<200 cells/mm ³	39 (9)	12 (12.12)		51 (9.6)
200-500 cells/mm ³	87 (20.14)	18 (18.18)		105 (19.8)
>500 cells/mm ³	251 (58.1)	52 (52.53)		303 (57.1)
unknown/not reported	55 (12.73)	17 (17.17)		72 (13.6)
Current regimen, n(%)			0.011	
2DR STR	85 (19.68)	13 (13.13)		98 (18.46)
3DR STR (w/o booster)	203 (46.99)	46 (46.46)		249 (46.9)
3DR STR (w booster)	32 (7.41)	14 (14.14)		46 (8.66)
2DR MTR	58 (13.43)	8 (8.08)		66 (12.4)

3DR MTR	37 (8.56)	7 (7.07)		44 (8.3)
Unknwon	17 (3.9)	11 (11.1)		28 (5.3)
STR, n(%)	320 (77.1)	73 (82.9)	0.228	393 (78.1)
Treatment Satisfaction, n(%)			0.007	
Yes, completely	243 (56.25)	26 (26.26)		269 (50.66)
Yes, but can be improved	180 (41.67)	61 (61.62)		241 (45.39)
No, I've some issues	9 (2.08)	7 (7.07)		16 (3.01)
Not at all	0 (0)	2 (2.02)		2 (0.38)
Other/Unknown	0 (0)	3 (3)		3 (0.6)
Number of daily assumption of all the drugs>1, n(%)	106 (24.5)	26 (26.3)	0.72	132 (24.9)
Polypharmacy, >=5 drugs/die, n(%)	75 (17.4)	18 (18.2)	0.846	93 (17.5)
Physical Health, per 1 point lower (1-5 scale), median (IQR)	2 (1-3)	3 (2-3)	<.001	2 (1-3)
Mental Health, per 1 point lower (1-5 scale), median (IQR)	2 (1-3)	3 (2-4)	<.001	2 (2-3)
Sexual Health, per 1 point lower (1-5 scale), median (IQR)	3 (2-4)	4 (3-5)	<.001	3 (3-5)
Overall Health, per 1 point lower (1-5 scale), median (IQR)	2 (2-3)	3 (2-3)	<.001	2 (2-3)

Table 2. Factors associated with high HIV treatment and disease burden (H-TDB)

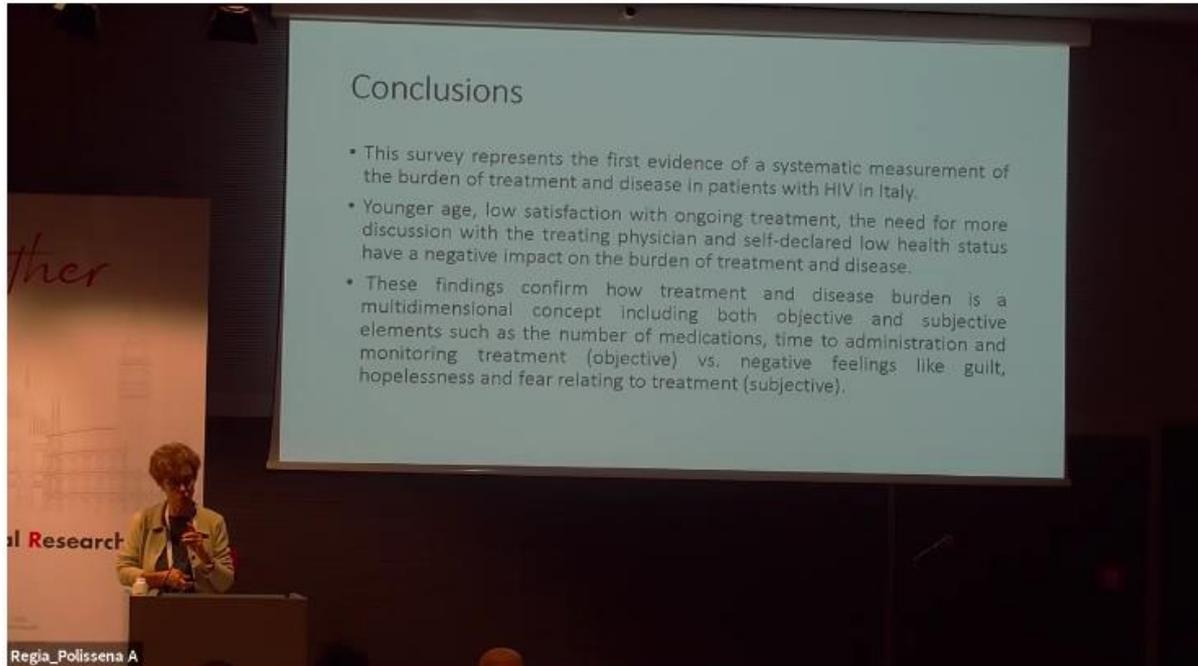
	OR	p	95%CI		aOR*	p	95%CI	
Age (per 10 years older)	0.68	<0.001	0.56	0.84	0.70	0.002	0.55	0.87
Current HIV-RNA								
<50 cps/mL	1.00				1.00			
≥50 cps/mL	2.04	0.104	0.86	4.83	1.96	0.174	0.74	5.20
unknown	2.13	0.047	1.01	4.51	1.29	0.606	0.49	3.37
Current regimen								
2DR STR or MTR	1.00				1.00			
3DR STR (w/o booster)	1.54	0.128	0.88	2.70	1.57	0.227	0.75	3.31
3DR MTR or 3DR STR w booster	2.07	0.033	1.06	4.05	1.44	0.234	0.79	2.62
Unknwon	4.41	0.001	1.82	10.69	3.20	0.031	1.11	9.24
Treatment Satisfaction								
Yes, completely	1.00				1.00			
Yes, but can be improved	3.17	<0.001	1.93	5.21	2.39	0.001	1.40	4.09
No, I've some issues	7.27	<0.001	2.50	21.14	3.51	0.043	1.04	11.80
I would like to have a more sincere dialogue with my ID physician (vs. No)	3.97	<0.001	2.30	6.87	2.75	0.001	1.49	5.05
>1 daily assumption of all the drugs	1.10	0.720	0.67	1.80				
Polypharmacy, ≥5 drugs/die	1.06	0.846	0.60	1.87				
Other comorbidities	1.14	0.585	0.71	1.83				

Table 3. Association with Health Status and high HIV treatment and disease burden (H-TDB)

	OR	p	95%CI		AOR*	p	95%CI	
Overall Health Status, per 1-pt lower	2.05	<0.001	1.59	2.63	1.76	<0.001	1.32	2.33
Physical Health Status, per 1-pt lower	1.76	<0.001	1.42	2.19	1.52	0.001	1.19	1.95
Mental Health Status, per 1-pt lower	1.74	<0.001	1.43	2.11	1.53	<0.001	1.23	1.89
Sexual Health Status, per 1-pt lower	1.55	<0.001	1.29	1.86	1.44	<0.001	1.18	1.77
<i>4 different models fitted with the following covariates: dialogue with ID, treatment satisfaction, current reported ART, current reported HIV-RNA and age</i>								

	No interest in ILLA			Interest in ILLA			p		
	N	(weighted) mean	95% CI	N	(weighted) mean	95% CI			
Medical information		2.31	2.20	2.42		2.37	2.17	2.57	0.625
Find info on your HIV health status	224	2.21	2.06	2.35	304	2.17	2.06	2.28	0.711
Find info on your HIV treatment	222	2.33	2.19	2.46	294	2.33	2.21	2.45	0.990
Understand eventual changes of your HIV treatment	213	2.32	2.18	2.47	285	2.32	2.20	2.44	0.991
Understand reasons taking a certain HIV treatment	219	2.42	2.27	2.58	294	2.56	2.43	2.69	0.179
Find reliable sources on info on HIV and HIV drugs	222	2.45	2.31	2.59	291	2.70	2.56	2.83	0.015
Understand doctor's suggestions	224	2.14	2.01	2.27	302	2.12	2.01	2.23	0.823
HIV medications		1.84	1.45	2.23		2.07	1.77	2.37	0.311
Daily organization	219	1.74	1.59	1.89	292	1.98	1.83	2.12	0.026
Taking HIV drugs once a day	218	1.44	1.32	1.57	291	1.76	1.63	1.89	0.001
Taking HIV drugs more times a day	117	1.95	1.70	2.19	147	2.18	1.94	2.43	0.188
Supplying of HIV drugs	218	2.22	2.04	2.40	291	2.34	2.17	2.52	0.345
Bother to medications (HIV)		2.43	2.35	2.51		2.83	2.16	3.50	0.227
HIV drug dependence	214	2.41	2.22	2.59	288	3.04	2.86	3.21	<0.001
HIV drug side effects	206	2.46	2.26	2.65	279	2.62	2.43	2.80	0.247
Appointments/practices (HIV care)		1.99	1.86	2.12		2.05	1.94	2.15	0.420
Bureaucracy	198	1.92	1.74	2.10	255	2.08	1.91	2.25	0.213
Booking appointments	209	2.15	1.96	2.33	280	2.16	2.00	2.33	0.922
Circularity of health info among HCPs	200	1.95	1.76	2.13	268	1.96	1.81	2.12	0.884
Waiting time for supplying drugs	206	1.95	1.77	2.12	277	2.00	1.83	2.16	0.685
Interpersonal challenges (HIV)		2.07	1.66	2.49		2.28	1.82	2.74	0.465
Dependence in the HIV management from other people	189	2.02	1.83	2.22	256	2.27	2.09	2.45	0.069
Other people who remind you things concerning HIV health	177	1.62	1.46	1.77	241	1.75	1.59	1.91	0.244
Stress in the relationship with others	188	2.21	2.00	2.42	252	2.42	2.24	2.61	0.129
Misunderstanding with others	187	2.44	2.22	2.67	248	2.67	2.47	2.87	0.134
Limitations of role and social activity (HIV)		1.68	1.58	1.77		1.81	1.68	1.94	0.116
Work	188	1.62	1.46	1.78	268	1.75	1.60	1.90	0.236
Family responsibilities	193	1.74	1.56	1.91	269	1.94	1.78	2.10	0.099
Daily activities	202	1.63	1.49	1.78	278	1.84	1.70	1.99	0.051
Free time activities	201	1.66	1.51	1.81	279	1.75	1.61	1.88	0.401
Spending time in the family	202	1.55	1.40	1.70	278	1.59	1.46	1.71	0.708
Travelling	196	1.86	1.68	2.05	274	1.99	1.83	2.16	0.305
Physical and mental exhaustion (HIV)		2.42	2.13	2.71		2.58	2.28	2.88	0.417
Angry	201	2.42	2.25	2.60	278	2.63	2.48	2.77	0.075
Worried	202	2.81	2.66	2.96	278	2.97	2.83	3.11	0.128
Depressed	200	2.53	2.36	2.70	277	2.60	2.46	2.74	0.542
Exhausted	199	2.03	1.86	2.19	277	2.14	2.00	2.29	0.279
Frustrated	199	2.33	2.15	2.50	277	2.57	2.42	2.72	0.041
Total HIV therapy burden score		2.09	2.08	2.10		2.24	2.23	2.24	0.109

Table 4. Single items, domains and total results of “HIV treatment and diseases burden” questionnaire adapted from *DT Eton et al., QUA Life Res 2017*, according to interest in injecting long acting (mean weighted mean and weighted linear regression)



531 responders, età media: 49aa, 87% maschi

Ampia variabilità tra alto e basso carico di trattamento. Soddisfazione al trattamento maggiore quando il carico di trattamento è inferiore. Non sono emerse differenze correlate al numero di farmaci assunti complessivamente ogni giorno.

Età giovanile, soddisfazione al trattamento medio-bassa corrispondono a carico di malattia elevato. Significativi il rapporto col medico e lo stato di salute complessivo.

TAKE HOME MESSAGES:

- I Patient Reported Outcomes (**PRO**) sono **qualsiasi indicazione di esito clinico riportata direttamente dal paziente**, senza l'interpretazione del dato da parte del medico o di qualsiasi altra figura professionale. La misurazione dei PRO riguarda qualsiasi aspetto della *salute* del paziente intesa come non soltanto assenza di infermità ma *benessere globale*, cioè *fisico, mentale, sociale*.
- Gli ambiti su cui si possono utilizzare i PRO riguardano principalmente la **qualità della vita**, la qualità della vita correlata alla salute (**HR-QoL**), l'**aderenza** alla terapia, i **sintomi**, la **soddisfazione** circa il trattamento farmacologico.
- I PRO aiutano ed approfondiscono la relazione di fiducia reciproca medico-paziente, l'empowerment e la responsabilizzazione della PLWH, in un'ottica di cura paziente centrica.

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GRAZIE per l'attenzione!



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