TEDAVİNİN ÖTESİNDE HIV ENFEKSİYONU

Dr. Hayat Kumbasar Karaosmanoğlu

SBÜ. Bakırköy Dr. Sadi Konuk EAH

Enfeksiyon Hastalıkları ve Klinik Mikrobiyoloji

Sunum Planı

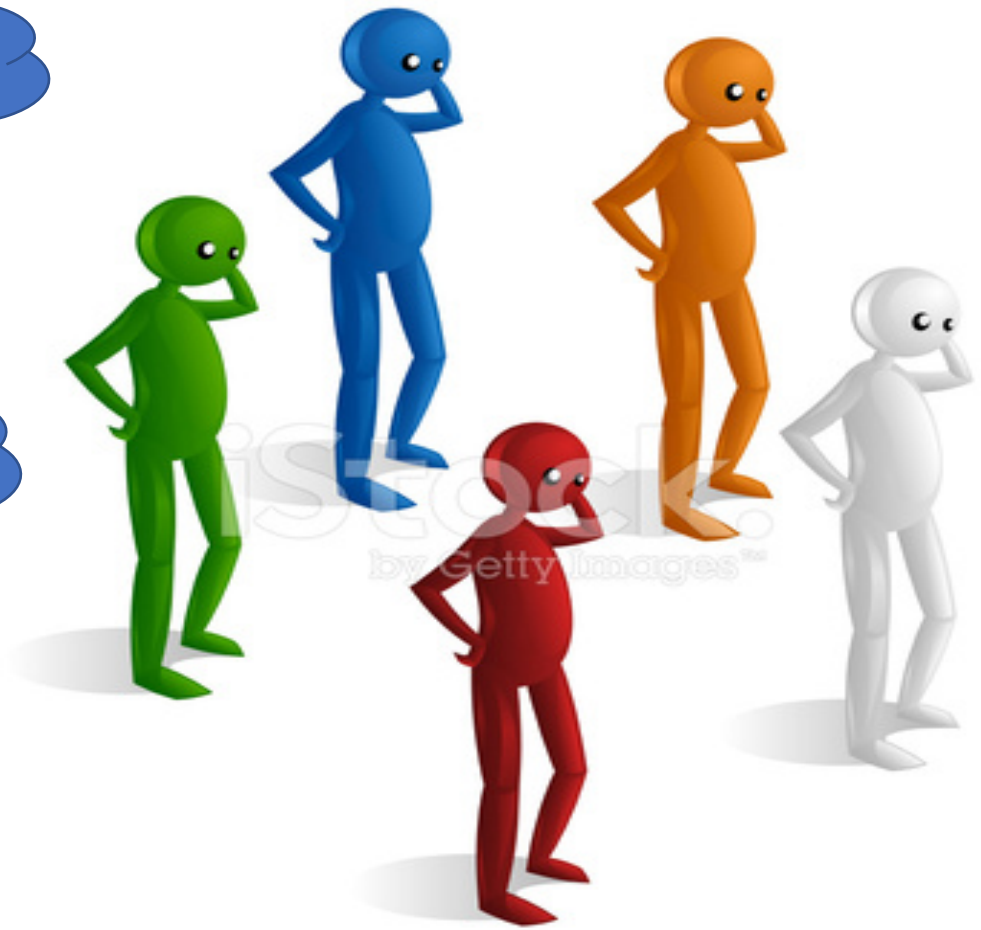
- ✓HIV ile yaşayan bireylerin gereksinimleri neler?
- ✓Dünden bügüne neler değişti?
- ✓Bugün neredeyiz? Gelecek hedefleri neler?
- ✓Viral supresyonun ötesinde ne var?

- ✓**HIV ile yaşayan bireyler için kaliteli/sağlıklı yaşam**

HIV İLE YAŞAYAN BİREY

ORTAK KAYGILAR

ORTAK GEREKSİNİMLER



BİREYSEL KAYGILAR

BİREYSEL GEREKSİNİMLER

DÜN

KAYGI	GEREKSİNİM
• ÖLÜMCÜL HASTALIK	YAŞAMAK
• BİR AVUÇ İLAÇ	İLAÇLARIN AZALMASI KULLANIM KOLAYLIĞI
• YAN ETKİLER	YAN ETKİSİ AZ İLAÇLAR
• CİNSEL YAŞAM/EVLİLİK/ ÇOCUK SAHİBİ OLMA	CİNSEL VE SOSYAL YAŞAM KOLAYLIĞI
• DOKTORLAR TAKİP ETMEK İSTEMİYOR- MERKEZ AZ	DOKTORA/MERKEZE ULAŞMA
• DAMGALANMA/AYRIMCILIK	TOPLUM FARKINDALIĞI

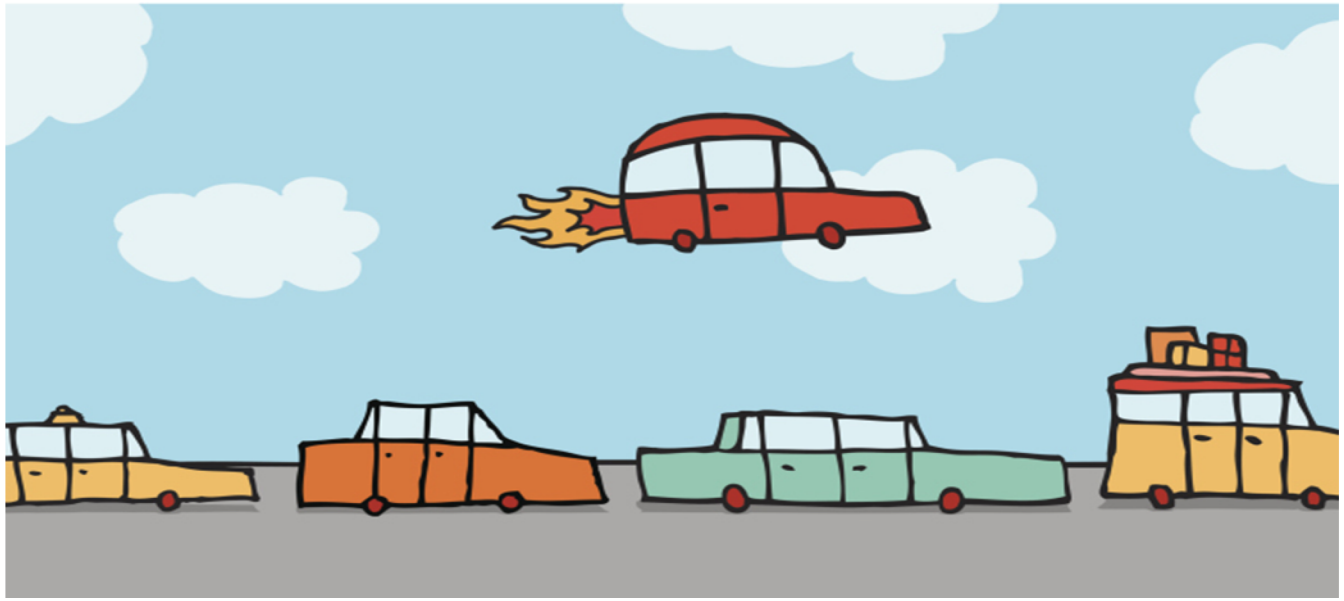
BUGÜN

KAYGI	GEREKSİNİM
• KRONİK HASTALIK	KALİTELİ YAŞAMAK
• TEK TABLET AMA SÜREKLİ	UZUN ETKİLİ İLAÇLAR VE KÜR
• YAN ETKİSİ AZ AJANLAR AMA YA SONRASI?	UZUN DÖNEM YAN ETKİLERDEN KORUNMA
• BELİRLENEMEZ=BULAŞMAZ???	BİLİMSEL NETLİK VE TOPLUM BİLİNCİ
• ÇOK SAYIDA HEKİM VE MERKEZ GÖNÜLLÜ	KALİTELİ SAĞLIK HİZMETİ
• DAMGALANMA/AYRIMCILIK	DAHA FAZLA TOPLUM FARKINDALIĞI

Bilim dünyası sağlık gereksinimlerini karşılamak için var gücüyle çalıştı, çalışıyor…
Peki ya gereksinimlerin ne kadarını karşılayabildi?

Ya diğerleri?
Sağlık otoriteleri? STK'lar? Medya? Toplum? …..

Psikolojik gereksinimler..
Sosyal gereksinimler…



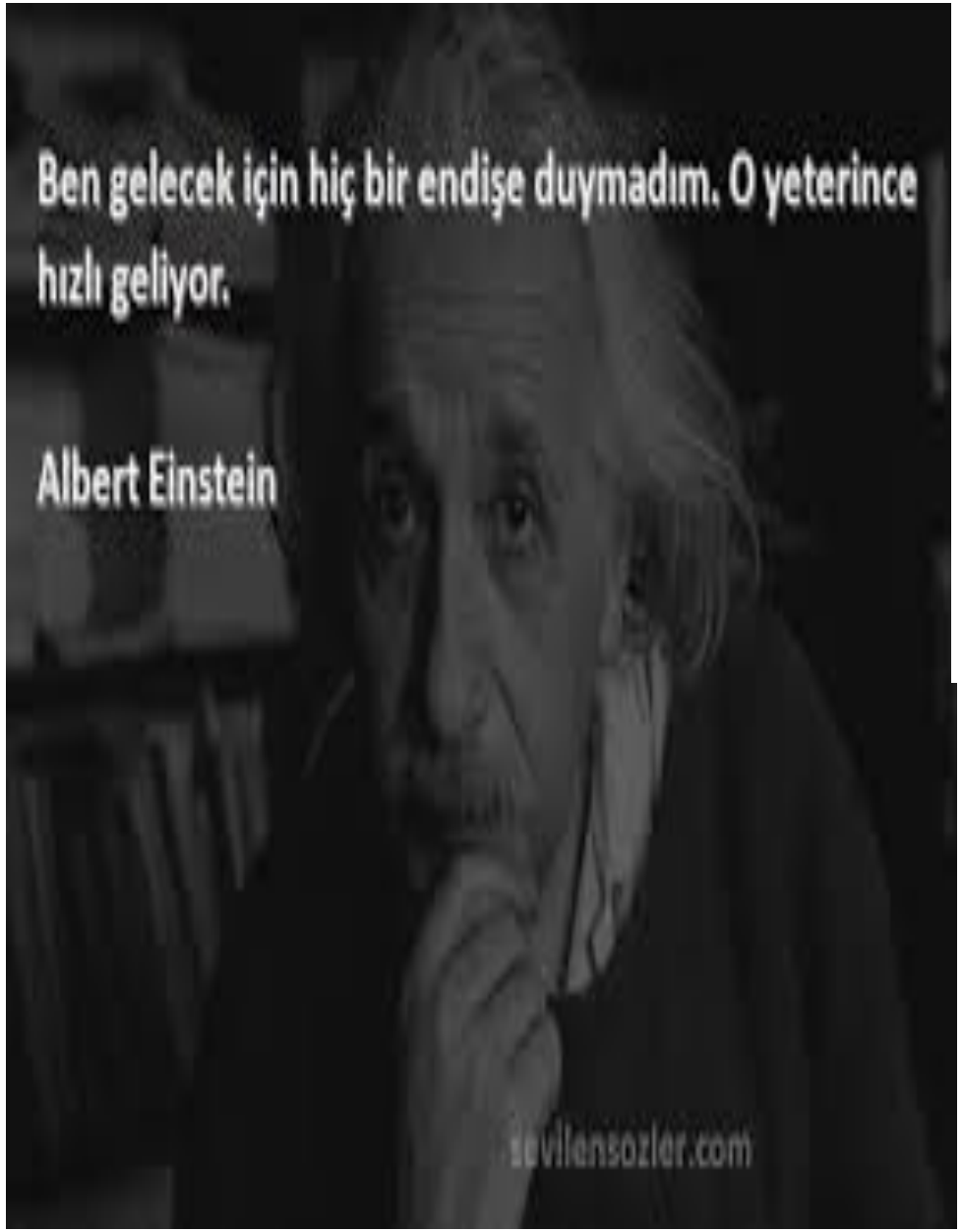
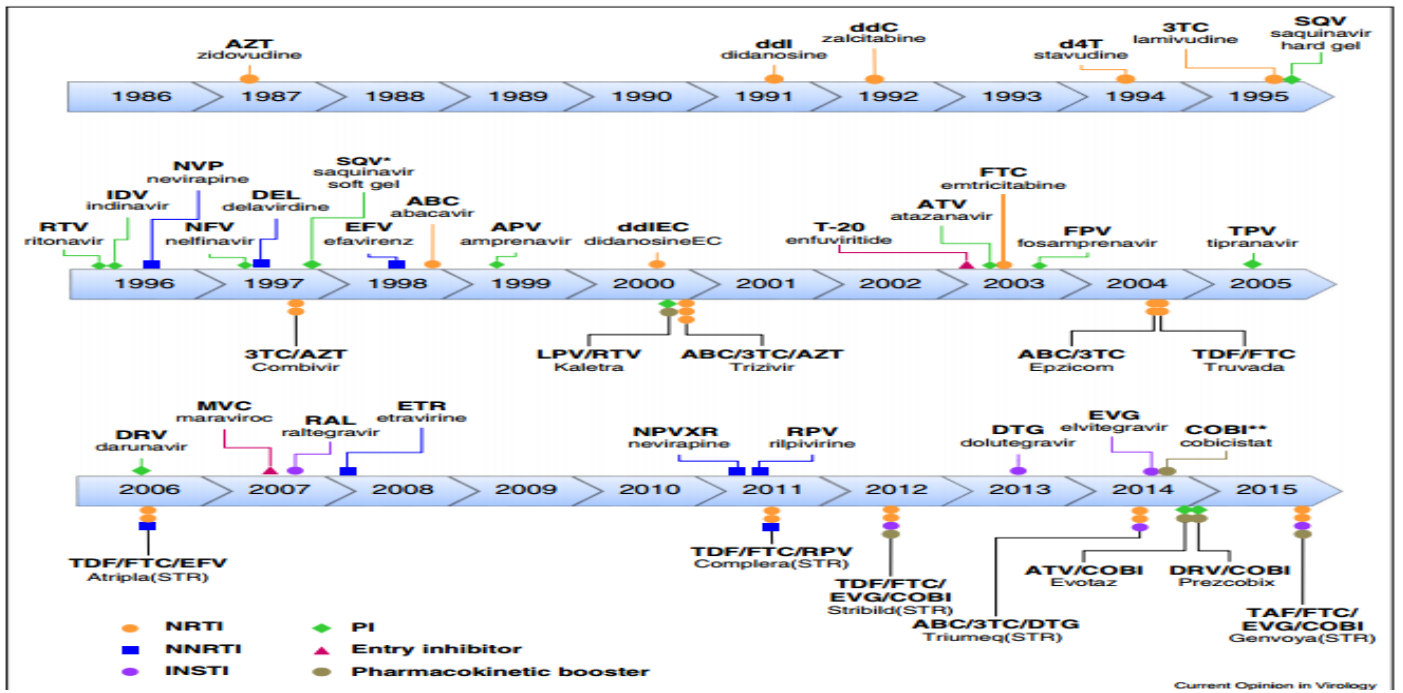
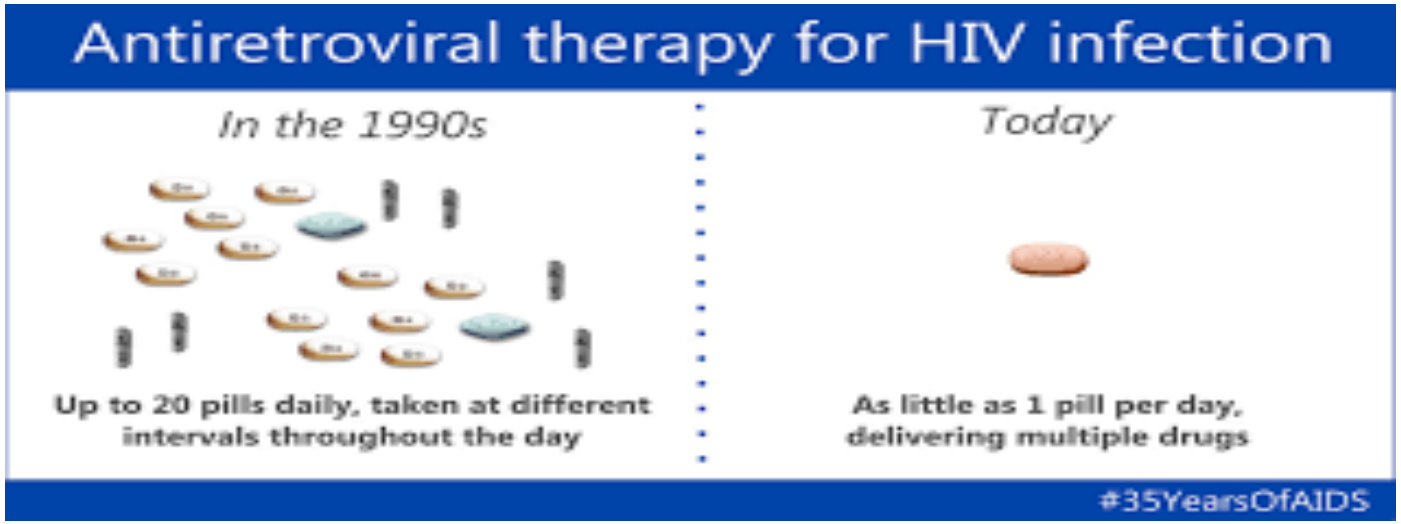
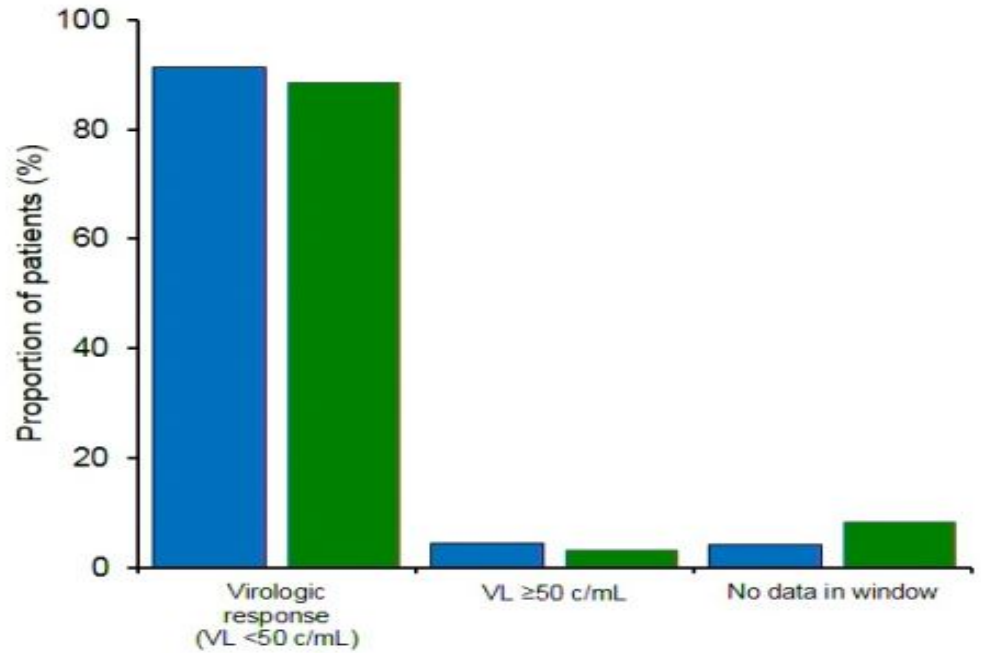

Ben gelecek için hiç bir endişe duymadım. O yeterince hızlı geliyor.
Albert Einstein
sevilensozler.com

Figure 1


AZT zidovudine
ddI didanosine
ddC zalcitabine
d4T stavudine
3TC lamivudine
SQV saquinavir hard gel
1986 1987 1988 1989 1990 1991 1992 1993 1994 1995
NVP nevirapine
IDV indinavir
DEL delavirdine
SQV* saquinavir soft gel
ABC abacavir
RTV ritonavir
NFV nelfinavir
EFV efavirenz
APV amprenavir
ddIEC didanosineEC
T-20 enfuviritide
FTC emtricitabine
ATV atazanavir
FPV fosamprenavir
TPV tipranavir
1996 1997 1998 1999 2000 2001 2002 2003 2004 2005
3TC/AZT Combivir
LPV/RTV Kaletra
ABC/3TC/AZT Trizivir
ABC/3TC Epzicom
TDF/FTC Truvada
MVC maraviroc
RAL raltegravir
ETR etravirine
DRV darunavir
NPVXR nevirapine
RPV rilpivirine
DTG dolutegravir
EVG elvitegravir
COBI** cobicistat
2006 2007 2008 2009 2010 2011 2012 2013 2014 2015
TDF/FTC/EFV Atripla(STR)
TDF/FTC/RPV Complera(STR)
TDF/FTC/ EVG/COBI Stribild(STR)
ABC/3TC/DTG Triumeq(STR)
ATV/COBI Evotaz
DRV/COBI Prezcobix
TAF/FTC/ EVG/COBI Genvoya(STR)
NRTI
NNRTI
INSTI
PI
Entry inhibitor
Pharmacokinetic booster
Current Opinion in Virology


Antiretroviral therapy for HIV infection
In the 1990s
Up to 20 pills daily, taken at different intervals throughout the day
Today
As little as 1 pill per day, delivering multiple drugs
#35YearsOfAIDS

Determinants of efficacy by FDA snapshot



FDA, The Food and Drug Administration; VL, viral load.

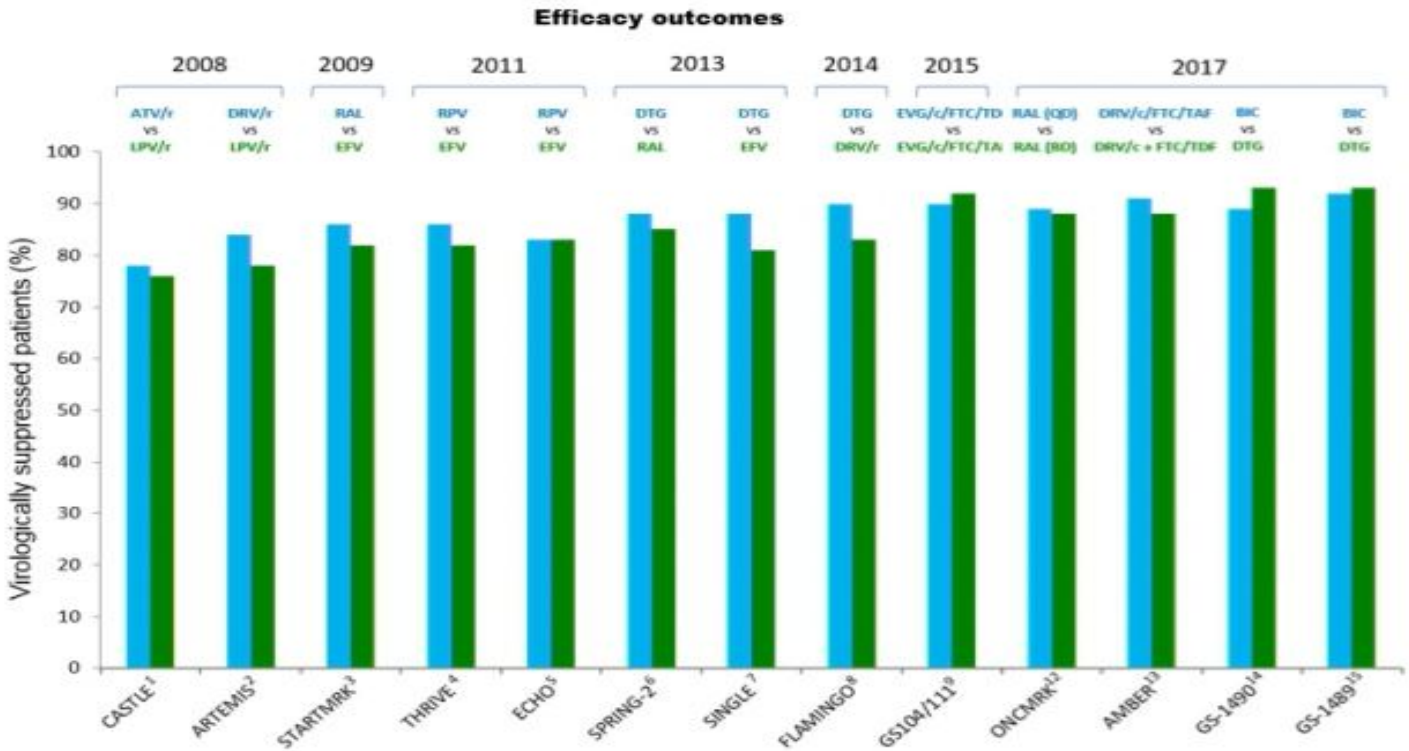
VL <50 c/mL driven by:

- Baseline VL
- Barrier to resistance

No data in window:

- Disengagement from care
- Tolerability (discontinuations)
- Safety (withdrawals)

Overall efficacy outcomes at Week 48



ATV, atazanavir; BD, twice daily; BIC, bictegravir; c, cobicistat; DRV, darunavir; DTG, dolutegravir; EFV, efavirenz; EVG, elvitegravir; FTC, emtricitabine; LPV, lopinavir; QD, once daily; r, ritonavir; RAL, raltegravir; RPV, rilpivirine; TAF, tenofovir alafenamide fumarate; TDF, tenofovir disoproxil fumarate.

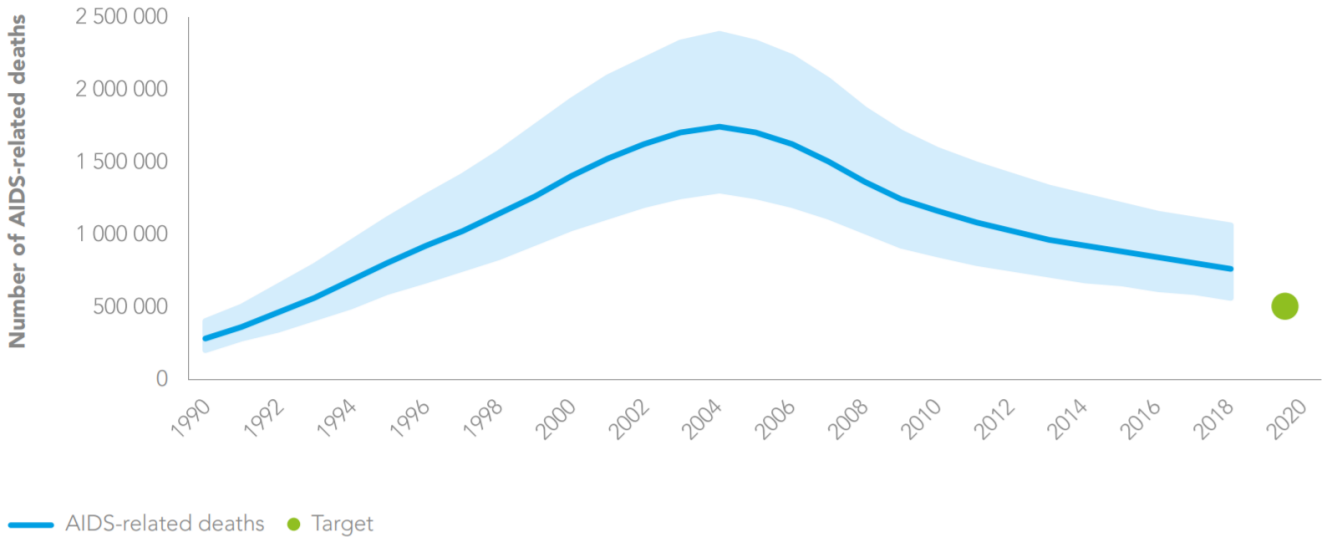
1. Molina JM, *et al. Lancet* 2008;372:646–55; 2. Ortiz R, *et al. AIDS* 2008;22:1389–97; 3. Lennox JL, *et al. Lancet* 2009;374:796–806; 4. Cohen CJ, *et al. Lancet* 2011;378:229–37; 5. Molina JM, *et al. Lancet* 2011;378:238–46; 6. Raffi F, *et al. Lancet* 2013;381:735–43; 7. Walmsley SL, *et al. N Engl J Med* 2013;369:1807–18; 8. Clotet B, *et al. Lancet* 2014;383:2222–31; 9. Sax PE, *et al. Lancet* 2015;385:2606–15; 10. Squires K, *et al. Lancet HIV* 2016;3:e410–20; 11. Orrell C, *et al. Lancet HIV* 2017;4:e536–46; 12. Cahn P, *et al. Lancet HIV* 2017;4:e486–94; 13. TBA; 14. Sax PE, *et al. Lancet* 2017;390:2073–82; 15. Gallant J, *et al. Lancet* 2017;390:2063–72.

Toward zero resistance: 2nd-generation INSTI studies

STUDY	FLAMINGO[1]	ARIA[2]	SINGLE[3]	GS-1489 (ABC)[4]		GS-1490 (TDF)[5]	
Drug	DTG	DTG	DTG	BIC	DTG	BIC	DTG
NRTI	0	0	0	0	0	0	0
INSTI	0	0	0	0	0	0	0

1. BIC, bictegravir.
2. Cilotet B, *et al. Lancet* 2014;383:2222–31; 2. Orrell C *et al. Lancet HIV* 2017;4:e536–46; 3. Walmsley SL, *et al. N Engl J Med* 2013;369:1807–18; 4. Gallant J, *et al. Lancet* 2017;390:2063–72; 5. Sax PE, *et al. Lancet* 2017;390:2073–82.

FIGURE 2.2 **Number of AIDS-related deaths, global, 1990–2018 and 2020 target**



Source: UNAIDS 2019 estimates.

2010-2018 arasında dünya genelinde HIV'e bağlı ölümlerde %33 azalma

HIV ile yaşayan bireylerin yaşam beklentisi

PubMed Central, Table 3: Curr Opin HIV AIDS. 2016 Sep; 11(5): 492–500. doi: 10.1097/COH.0000000000000298 - Google Chrome

ncbi.nlm.nih.gov/pmc/articles/PMC5055447/table/T3/?report=objectonly

Table 3

Estimates of life expectancy at age 20 years by gender.

Study	Country	Period of observation	Men			Women		
			LE in HIV+ men (95% CI)	LE in men from general /HIV− population	Percent of LE in general/HIV− population	LE in HIV+ women (95% CI)	LE in women from general /HIV−	Percent of LE in general / HIV− population
Johnson (2013) [15]	South sAfrica	2001–2010	27.6 (25.2–30.2)	44.8	61.6			
Mills (2011) [16]	Uganda	2000–2009	19.1 (16.6–21.6)	47.0	40.6			
Nsanzimana (2015) [17]	Rwanda	1997–2014	22.2 (20.2–24.2)	46.2	48.1			
May (2011) [14]	UK	1996–2008	39.5 (38.6–40.4)	57.8	68.3			
Lima (2015) [10]	Canada	2003–2013	37.5 (35.1–39.9)	60.8	61.7			
Patterson (2015) [12]	Canada	2000–2012	39.2 (37.8–40.6)	60.0	65.3			

LE, life expectancy

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doi: 10.1097/QAI.0000000000001014

PMCID: PMC5427712

NIHMSID: NIHMS858592

PMID: 27028501

Narrowing the Gap in Life Expectancy Between HIV-Infected and HIV-Uninfected Individuals With Access to Care

Julia L. Marcus, PhD, MPH,[*] Chun R. Chao, PhD,[†] Wendy A. Leyden, MPH,[*] Lanfang Xu, MS,[†] Charles P. Quesenberry, Jr, PhD,[*] Daniel B. Klein, MD,[‡] William J. Towner, MD,[§] Michael A. Horberg, MD, MAS,[||] and Michael J. Silverberg, PhD, MPH[*]

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Erken tanı √

düzenli izlem √

ART ile √

20 yaşında yeni tanılı hastanın yaşam beklentisi

~53 yıl

JL Marcus et al. Jaıds 2016

Akılcı kombine antiretroviral tedavi

(ART)

HIV enfeksiyonu → **yönetilebilir kronik enfeksiyon**

BELİRLENEMEZ=BULAŞMAZ

PARTNER	Prospective observational European study in ~900 serodifferent couples who were not using condoms.	Final results reported zero transmissions after more than 58,000 times couples had sex without condoms when viral load was undetectable <200 copies/mL.	2014 (interim). 2016 (final)	Rodgers A et al. [10, 11]
Opposites Attract	Prospective observational study in 358 serodifferent gay male couples in Australia, Thailand and Brazil.	Zero transmissions when viral load was undetectable <200 copies/mL.	2017	Grulich A et al. [13]
PARTNER2	Extension of PARTNER study to collect additional follow-up in gay male couples.	Zero transmissions after more than 77,000 times gay male couples had sex without condoms when viral load was undetectable <200 copies/mL.	Presented August 2018. Published May 2019	[12, 19, 20]

- **Mesajlar !**

1- UNAIDS B=B kavramını desteklemektedir

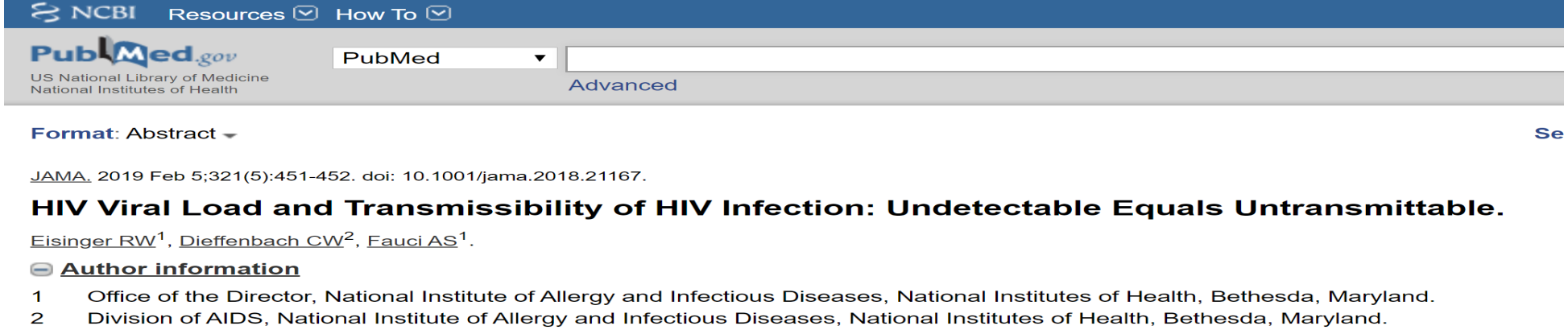
Güçlü bilimsel araştırmalar virolojik suprese bireylerin cinsel yolla HIV'i bulaştırmadığını göstermektedir

2- Bu bilgi stigmayı önleyebilir ve virolojik suprese olmak için bakımda kalmayı motive edebilir

3- Tüm dünyada viral yük tetkiklerine erişimin iyileştirilmesi gerekli (maliyeti düşük ve etkin laboratuvar sistemleri ile kombine)

4- 2016 Birleşmiş Milletler Genel Kurul deklarasyonunda; HIV enfeksiyonunu sonlandırmak için herkesin tedaviye erişebilir olması gerektiği önerilmiştir

5- Kondom vb. önleme stratejileri korunma ve yayılımı önlemede kombine kullanılmalıdır. Cinsel ve üreme sağlığı için güçlü kondom programları gereklidir



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JAMA. 2019 Feb 5;321(5):451-452. doi: 10.1001/jama.2018.21167.

HIV Viral Load and Transmissibility of HIV Infection: Undetectable Equals Untransmittable.

Eisinger RW[1], Dieffenbach CW[2], Fauci AS[1].

Author information

1 Office of the Director, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, Maryland.
2 Division of AIDS, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Bethesda, Maryland.

Bu kampanya (B=B) artık bilimsel bir ses olarak çok önemlidir;

- HIV ile yaşayan bireyleri bakımda kalmaya, tedavi uyumuna ve virolojik suprese olmaya teşvik etme
- Epideminin sonlandırılabilmesi ve yayılımın önlenmesi için tedavinin önemini desteklemesi
- Biyomedikal bilim ve davranışsal ve sosyal bilimler arasında güçlü bir köprü oluşturması
- Stigma, başkalarına bulaştırma endişesi, suçluluk duygularını ortadan kaldırma
- Yasal sorunlara çözüm getirmek

Sağlık otoriteleri, sağlık çalışanları, STK'lar, Devletler..;

- **Daha erken dönemde tanı almalarını sağlamak**
- **Daha erken dönemde tedavi**
- **Tedavi uyumu**
- **Tedavinin sürdürülebilirliği (SGK VS)**

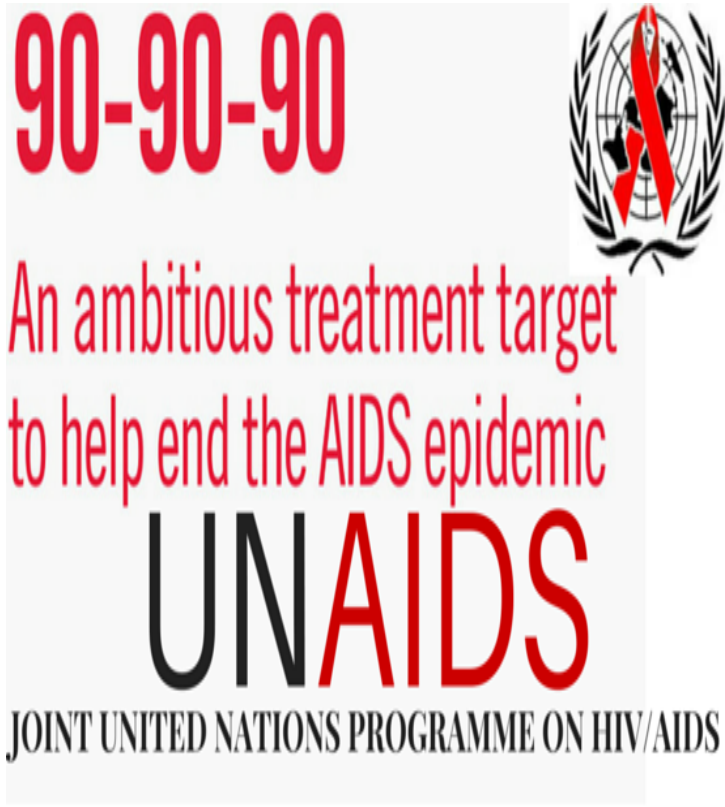
- Komorbiditelerin yönetimi?
- Psikososyal destek?
- **STİGMA ile savaş?**

Gelecek Hedefler

%90-Tanı almış hasta

%90- Tedavi almakta

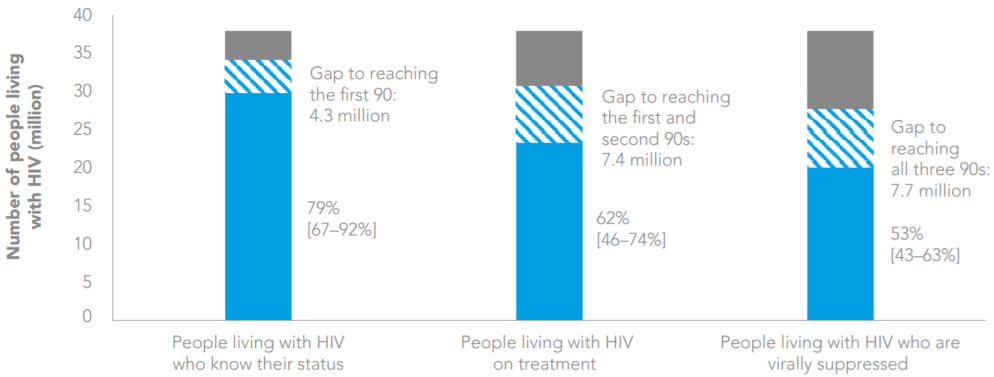
%90-Saptanamaz viral yük



UNAIDS 2014

90-90-90 Hedefinde neredeyiz?

FIGURE 1.1 HIV testing and treatment cascade, global, 2018



Source: UNAIDS special analysis, 2019; see annex on methods for more details.

Original research article

INTERNATIONAL JOURNAL OF STD & AIDS

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HIV care in Istanbul, Turkey: How far is the UNAIDS 90–90–90 goals?

Bilgul Mete[1], Alper Gunduz[2], Sibel Bolukcu[3], Hayat K Karaosmanoglu[4], Dilek Yildiz[2], Meliha M Koç[5], Ozlem A Aydın[4], Ilyas Dokmetas[6] and Fehmi Tabak[1]

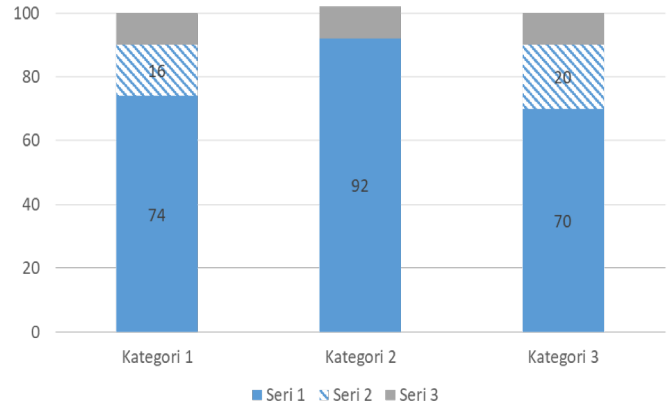
Abstract

The prevalence of human immunodeficiency virus (HIV) infection is low but it is steadily increasing in Turkey. In the current study, we aimed to assess the status of HIV infection management with the proposed 90–90–90 targets in a large HIV cohort in Istanbul, Turkey. The cohort included 2382 patients (2082 male, 300 female, mean age was 36.3 ± 11.3 years). Mean CD4 cell count was 398.5/mm^3 and HIV-RNA level was 576,235 copies/ml. According to the modeling by Modeling tool of European Center for Diseases Control Software, 72 and 74% of all HIV patients have been diagnosed in 2016 and 2017, respectively. Among 2382 patients, 2191 (92%) were under treatment. [AQ2] The third goal of virally suppressing the patients on treatment was achieved among 70.2% of the patients. Current study suggested that the fraction of undiagnosed and those under viral suppression should be targeted to sustain optimal HIV care. Efforts should continue to surpass the goals of 90–90–90.

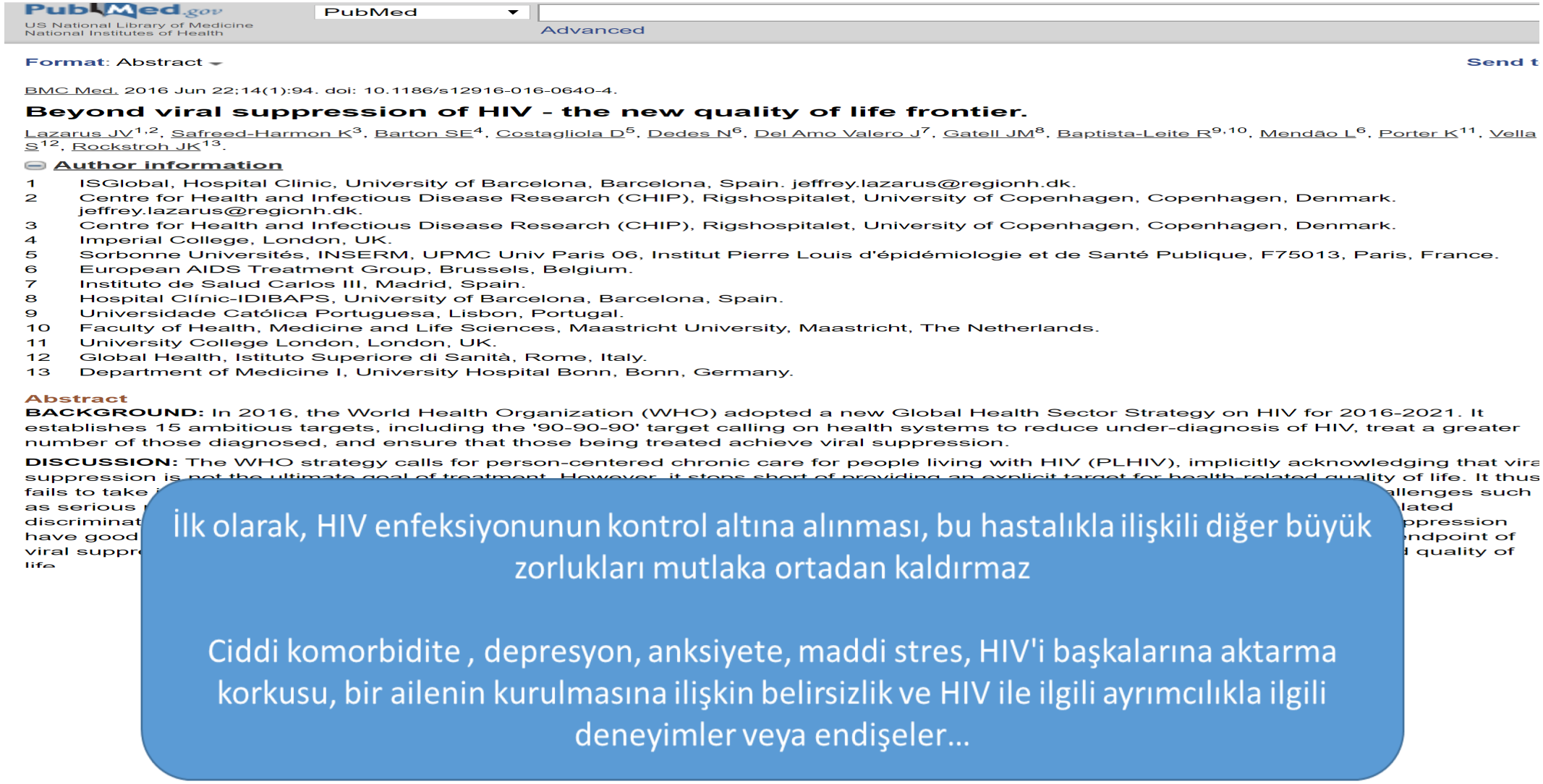
Keywords

Human immunodeficiency virus, diagnosis, antiretroviral treatment, 90–90–90

Date received: 22 February 2019; accepted: 7 July 2019



‘90-90-90 Hedefi’ ihtiyacı karşılıyor mu?



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BMC Med. 2016 Jun 22;14(1):94. doi: 10.1186/s12916-016-0640-4.

Beyond viral suppression of HIV - the new quality of life frontier.

Lazarus JV[1,2], Safreed-Harmon K[3], Barton SE[4], Costagliola D[5], Dedes N[6], Del Amo Valero J[7], Gatell JM[8], Baptista-Leite R[9,10], Mendão L[6], Porter K[11], Vella S[12], Rockstroh JK[13].

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3 Centre for Health and Infectious Disease Research (CHIP), Rigshospitalet, University of Copenhagen, Copenhagen, Denmark.
4 Imperial College, London, UK.
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6 European AIDS Treatment Group, Brussels, Belgium.
7 Instituto de Salud Carlos III, Madrid, Spain.
8 Hospital Clínic-IDIBAPS, University of Barcelona, Barcelona, Spain.
9 Universidade Católica Portuguesa, Lisbon, Portugal.
10 Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, The Netherlands.
11 University College London, London, UK.
12 Global Health, Istituto Superiore di Sanità, Rome, Italy.
13 Department of Medicine I, University Hospital Bonn, Bonn, Germany.

Abstract

BACKGROUND: In 2016, the World Health Organization (WHO) adopted a new Global Health Sector Strategy on HIV for 2016-2021. It establishes 15 ambitious targets, including the '90-90-90' target calling on health systems to reduce under-diagnosis of HIV, treat a greater number of those diagnosed, and ensure that those being treated achieve viral suppression.

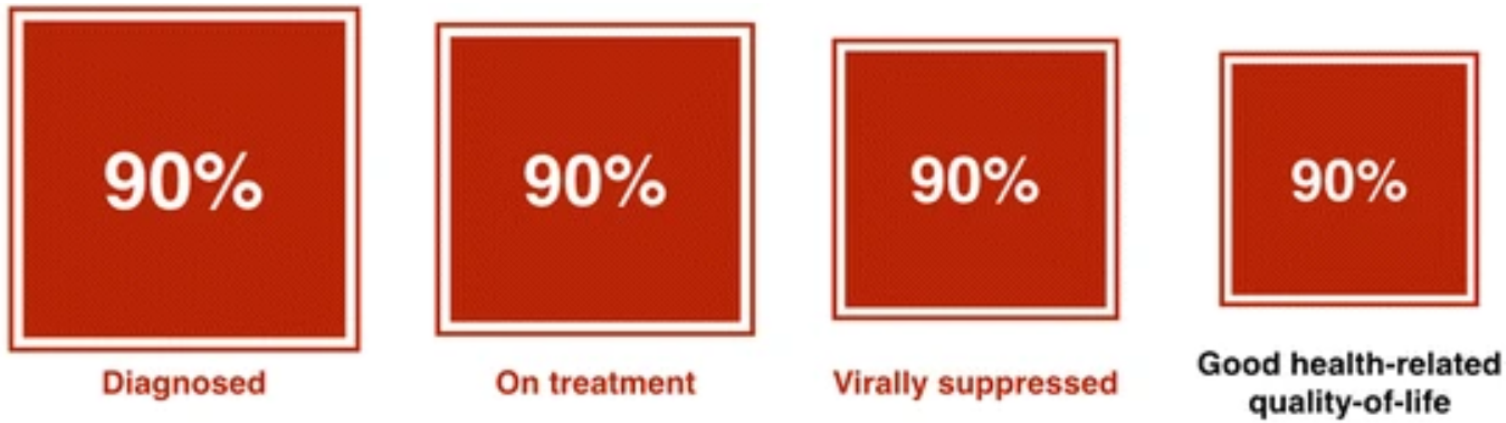
DISCUSSION: The WHO strategy calls for person-centered chronic care for people living with HIV (PLHIV), implicitly acknowledging that vira
suppression is not the ultimate goal of treatment. However, it stops short of providing an explicit target for health-related quality of life. It thus
fails to take i allenges such
as serious lated
discriminat ppression
have good ndpoint of
viral suppr quality of
life.

İlk olarak, HIV enfeksiyonunun kontrol altına alınması, bu hastalıkla ilişkili diğer büyük zorlukları mutlaka ortadan kaldırmaz

Ciddi komorbidite , depresyon, anksiyete, maddi stres, HIV'i başkalarına aktarma korkusu, bir ailenin kurulmasına ilişkin belirsizlik ve HIV ile ilgili ayrımcılıkla ilgili deneyimler veya endişeler…

Dördüncü 90 Hedefi?

Fig. 1



*Adapted from: UNAIDS. 90-90-90: an ambitious treatment target to help end the AIDS epidemic. 2014. Available at http://unaids.org/sites/default/files/media_asset/90-90-90_en_0.pdf. Accessed on 25 April 2016

The 'fourth 90': proposed revision to the UNAIDS 90-90-90 targets*

Sağlıkla ilişkili yaşam kalitesi

‘Fiziksel, zihinsel ve sosyal olarak tam iyilik hali’[1]

WHOQOL-HIV

Physical	Psychological	Social relationships	Environment
Pain and discomfort Energy and fatigue	Positive feelings Thinking, learning, memory and concentration	Personal relationships Practical support	Physical safety and security Home environment
Sleep and rest Mobility	Self-esteem Body image and appearance	Sex	Financial resources Health and social care: availability and quality
Activities of daily living	Negative feelings		Opportunities for acquiring new information and skills
Dependence on medication or treatment	Spirituality, religion and personal beliefs		Participation and opportunities for recreation and leisure
Working capacity			Physical environments Transport

Skevington, S M, (2002). Advancing cross-cultural research on quality of life: observations drawn from the WHOQOL development. *Quality of life Research*; **11**:135-144

1. World Health Organisation. Basic Documents. Forty Eighth Edition. 2014. http://apps.who.int/gb/bd/PDF/bd48/basic-documents-48th-edition-en.pdf - page=7.

Lancet HIV. 2014 Oct;1(1):e32-40. doi: 10.1016/S2352-3018(14)70018-9. Epub 2014 Sep 22.

Health-related quality-of-life of people with HIV in the era of combination antiretroviral treatment: a cross-sectional comparison with the general population.

Miners A[1], Phillips A[2], Kreif N[3], Rodger A[2], Speakman A[2], Fisher M[4], Anderson J[5], Collins S[6], Hart G[2], Sherr L[2], Lampe FC[2]; ASTRA (Antiretrovirals, Sexual Transmission and Attitudes) Study.

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1 Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, London, UK. Electronic address: alec.miners@lshtm.ac.uk.
2 Research Department of Infection and Population Health, University College London, London, UK.
3 Faculty of Public Health and Policy, London School of Hygiene & Tropical Medicine, London, UK.
4 Brighton and Sussex University Hospitals NHS Trust, Brighton, UK.
5 Homerton University Hospital NHS Trust, London, UK.
6 HIV i-Base, London, UK.

Abstract

BACKGROUND: Combination antiretroviral therapy has substantially increased life-expectancy in people living with HIV, but the effects of chronic infection on health-related quality of life (HRQoL) are unclear. We aimed to compare HRQoL in people with HIV and the general population.

METHODS: We merged two UK cross-sectional surveys: the ASTRA study, which recruited participants aged 18 years or older with HIV from eight outpatient clinics in the UK between Feb 1, 2011, and Dec 31, 2012; and the Health Survey for England (HSE) 2011, which measures health and health-related behaviours in individuals living in a random sample of private households in England. The ASTRA study has data for 3258 people (response rate 64%) and HSE for 8503 people aged 18 years or older (response rate 66%). HRQoL was assessed with the Euroqol 5D questionnaire 3 level (EQ-5D-3L) instrument that measures health on five domains, each with three levels. The responses are scored on a scale where a value of 1 represents perfect health and a value of 0 represents death, known as the utility score. We used multivariable models to compare utility scores between the HIV and general population samples with adjustment for several sociodemographic factors.

FINDINGS: 3151 (97%) of 3258 of participants in ASTRA and 7424 (87%) of 8503 participants in HSE had complete EQ-5D-3L data. The EQ-5D-3L utility score was lower for people with HIV compared wi
age, and sex/sexuality -0·11; 95% CI -0·13 to -0·10; p < 0·
for anxiety/depression. The difference in utility score was
(ethnic origin, education, having children, and smoking
load strata, but was greatest for those people diagnose
in people with HIV than in the general population (pinte

Discussion

To our knowledge, this is the largest cross-sectional study to compare a standardised measure of HRQoL in people living with HIV in the era of ART directly with the general population, in a setting with universal access to health care, with the ability to simultaneously adjust for multiple potential confounders (panel).[4] Several multivariable models were constructed with different categorisations of HIV status, but they consistently showed that people diagnosed with HIV had reduced HRQoL compared with the general population, across all ART, CD4, and viral load categories. In particular, the difference was apparent even in people who were virally suppressed on ART. Although anxiety/depression levels were the most noticeably affected, all five EQ-5D-3L domains were reduced suggesting that HIV infection continues to have systemic health implications. This effect was greatest in those people diagnosed for the longest time (model 5). Despite the overall impact of HIV, we did not find any evidence that the difference in HRQoL between those people living with HIV and the general population sample was greater with older age.

3151 PLHIV vs 7424 genel popülasyon
Euroqol (EQ-5D-3L)yaşam kalitesi ölçeği ile karşılaştırılmış
Genel popülasyonla karşılaştırıldığı büyük kesitsel çalışma
Virolojik suprese HIV+ olgularda sağlık ilişkili yaşam kalitesi düşük
(Tüm ART ve tüm CD4 düzeylerinde)
İleri yaşla yaşam kalitesi arasında anlamlı ilişki bulunmamış
En düşük düzey anlamlı şekilde **anksiyete/depresyon**
Diğer çalışmalarla benzer

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Published online 2014 Sep 11. doi: 10.1093/heapol/czu082
PMCID: PMC4202918
PMID: 25274634

Explorations on people centredness in health systems

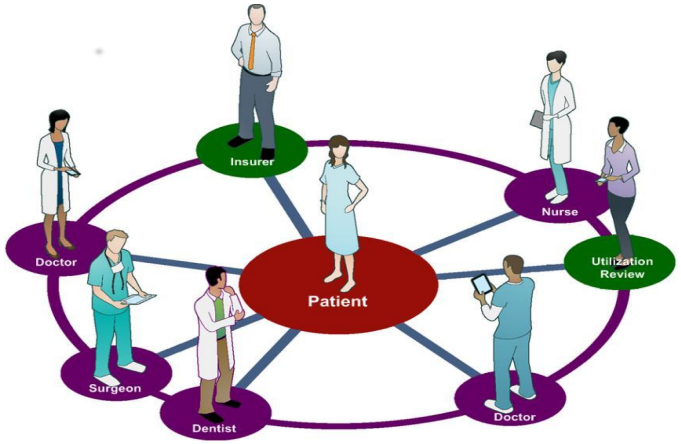
Kabir Sheikh,[1,*] Michael Kent Ranson,[2] and Lucy Gilson[3,4]

Introduction

Go to:

Health systems should ultimately seek to serve people and society. They must aim to bring value in people's lives not only by caring for them when sick or giving support to prevent or limit illness and its effects, but also, more broadly, by offering the promise of economic security to all for times of great vulnerability.

Health systems are also human systems. At their heart is a personal encounter, the interaction between the patient and the health provider—sometimes tenuous, often contested, but always with the potential for humanity and compassion. But many different types of people—individuals, groups and communities—make up health systems, 'live' within them, have roles, stakes and power in them, and are central to their existence and functioning. People make all the most important decisions in health systems—either by accessing services as patients, setting rules and allocating resources as policymakers, or enacting, coping with and subverting those rules, as implementers, managers, providers and service users. Communities and citizens influence these systems by shaping the social norms and contexts in which they operate. Community norms and behaviour drive health market forces and practices, influence how individuals and families access services, and can help hold systems accountable. Citizens may also influence system development through their electoral voting power, exercising the 'long route' to accountability.



İnsan merkezli sağlık sistemi

Yöneticiler, sağlık hizmetleri sağlayıcıları, hizmet kullanıcıları ve araştırmacılar dahil olmak üzere farklı sağlık sistemleri aktörleri arasındaki ilişki zincirleri aracılığıyla faaliyet gösteren sosyal kurumlardır

Box 1. Aspects of people centred health systems (PCHS)

Putting people's voices and needs first

PCHS are ultimately shaped by community voices and needs. Participatory governance mechanisms can channel the power of communities to mould health systems in the public interest, and hold them accountable. People-centred governance can also confront entrenched power imbalances within health systems, and address their broader social determinants.

People centredness in service delivery

PCHS put people's needs first in the design and delivery of health care and services. Important principles of this approach are quality, safety, longitudinality (duration and depth of contact), closeness to communities and responsiveness to changing requirements. Capacity building in PCHS focuses, foremost, on creating capabilities to respond to people's health care needs.

Relationships matter: health systems as social institutions

PCHS are social institutions, which operate through chains of relationships between different health systems actors—including administrators, health care providers, service users and researchers—each acting in their respective contexts. As such, systems thrive on mutual trust, dialogue and reciprocity, and their effectiveness correlates to the quality of these human relationships.

Values drive people centred health systems

In PCHS, decision making is informed by people centred values around justice, rights, respect and equality, and the principles of primary health care. Values drive people's decisions within the health system contributing to change, and conversely, system reforms can have impacts on people's values within the system.

İNSAN MERKEZLİ SAĞLIK SİSTEMLERİ

✓ İnsanların sesi ve gereksinimlerini öne almak
(en önce bireyin gereksinimleri)
✓ İnsan-odaklı bir sağlık bakımı sunmak
(kalite, güvenlik, boylam (temas süresi ve temas derinliği), topluluklara yakınlık ve değişen gereksinimlere karşı duyarlılık)
✓ İlişkilerin önemi: Sosyal kurum olarak sağlık sistemlerinde
(sağlık sisteminde yer alan tüm paydaşlar)
✓ İnsan odaklı sağlık sistemini değerlerin yönlendirmesi
(adalet, haklar, saygı ve eşitlik,sağlık hizmetleri ilkeleri)

Format: Abstract

Send t

BMC Med. 2016 Jun 22;14(1):94. doi: 10.1186/s12916-016-0640-4.

Beyond viral suppression of HIV - the new quality of life frontier.

Lazarus JV[1,2], Safreed-Harmon K[3], Barton SE[4], Costagliola D[5], Dedes N[6], Del Amo Valero J[7], Gatell JM[8], Baptista-Leite R[9,10], Mendão L[6], Porter K[11], Vella S[12], Rockstroh JK[13].

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Abstract

BACKGROUND: In 2016, the World Health Organization (WHO) adopted a new Global Health Sector Strategy on HIV for 2016-2021. It establishes 15 ambitious targets, including the '90-90-90' target calling on health systems to reduce under-diagnosis of HIV, treat a greater number of those diagnosed, and ensure that those being treated achieve viral suppression.

DISCUSSION: The WHO strategy calls for person-centered chronic care for people living with HIV (PLHIV), implicitly acknowledging that vira suppression is not the ultimate goal of treatment. However, it stops short of providing an explicit target for health-related quality of life. It thus fails to take into account the needs of PLHIV who have achieved viral suppression but still must contend with other intense challenges such as serious non-communicable diseases, depression, anxiety, financial stress, and experiences of or apprehension about HIV-related discrimination. We propose adding a 'fourth 90' to the testing and treatment target: ensure that 90 % of people with viral load suppression have good health-related quality of life. The new target would expand the continuum-of-services paradigm beyond the existing endpoint of viral suppression. Good health-related quality of life for PLHIV entails attention to two domains: comorbidities and self-perceived quality of life

Tüm dünyada sağlık sistemleri HIV ile yaşayan bireylerin gereksinimlerini karşılayabilmek için dinamiklerini değiştirmeli, **daha fazla insan odaklı** ve daha entegre olmalıdır

Ancak bu şekilde HIV statüsünden bağımsız olarak daha uzun ancak bir çok komorbidite ile yaşayan tüm bireylerin ihtiyaçları karşılanabilecektir

Lazarus JV, et al. BMC Med. 2016 Jun 22;14(1):94

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www.aidsreviews.com

PERMANYER

AIDS Rev. 2019;21:135-142

"Moving Fourth": A Vision Toward Achieving Healthy Living with HIV Beyond Viral Suppression

Giovanni Guaraldi[1], Joop Arends[2], Thomas Buhk[3], Mario Cascio[4], Adrian Curran[5], Eugenio Teofilo[6], Guido Van Den Berk[7] and Christian Verger[8]*

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Abstract

Since HIV has evolved from being a fatal illness to a chronic condition, this brings new challenges relating to long-term health, as increasing numbers of people living with HIV (PLHIV) navigate their lives beyond viral suppression. This review presents the challenges facing patients and health-care providers managing HIV in Europe today. We highlight the challenges that the evolving landscape in HIV brings, including managing an aging and more diverse population of PLHIV; this requires a shift from managing disease to managing health and may best be achieved by multidisciplinary teams in the long term. We introduce the concept of "health goals for me:" an individualized approach to the management of HIV, and use this as the basis for a proposed framework for assessing health-related quality of life for PLHIV. Our framework comprises a continuous cycle of "ask and measure," "feedback and discussion," and "intervention," based on collaboration between the health-care professional and patient. For improved long-term management of PLHIV, we consider that this framework should become an intrinsic part of HIV care in the future and that the "health goals for me" concept be used as a tool to facilitate healthy living for PLHIV beyond viral suppression. **(AIDS Rev. 2019;21:135-142)**

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PERMANYER

AIDS Rev. 2019;21:135-142

"Moving Fourth": A Vision Toward Achieving Healthy Living with HIV Beyond Viral Suppression

90-90-90 UNAIDS hedefleri;

- PLHIV'in ilişkili zihinsel ve fiziksel komorbiditeler, finansal stresler ve potansiyel HIV ile ilgili damgalama gibi karşılaştığı diğer HIV ile ilgili sağlık zorluklarını kapsamamaktadır.

- Lazarus ve ark, PLHIV için "iyi" sağlıkla ilgili QoL'yi tanımlamamış, ancak iki ana alanı, **başarılı komorbidite yönetimi ve iyileştirilmiş öz algılanan QoL**'nin iyileştirilmesi gerektiğini vurgulamıştır

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AIDS Rev. 2019;21:135-142

"Moving Fourth": A Vision Toward Achieving Healthy Living with HIV Beyond Viral Suppression

- İdeal olarak, bu, sağlık hizmeti sağlayıcısı ile hasta arasında karşılıklı sorumluluk ve ortak hedefler oluşturmak için, sağlık ve terapötik karar vermenin değerlendirmesinde işbirliğine dayalı ve proaktif bir yaklaşım içermeli

Bu yayının amacı;

- Viral baskılamanın ötesinde HIV ile yaşayan bireyler için sağlıklı yaşam tanımlamaktır. Daha sonra, kişiselleştirilmiş bir tedavi yaklaşımı sağlama aracı olarak "**benim için sağlık hedefleri**" kavramı önerilmektir.

"health goals for me"

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AIDS Rev. 2019;21:135-142

"Moving Fourth": A Vision Toward Achieving Healthy Living with HIV Beyond Viral Suppression

Yaşam beklentisi yüksek ama…

- ❑HIV enf kendisi
- ❑Tedavi seçimleri
- ❑Bireysel yaşam tarzı seçimleri ile değişmekte..

- **HIV ile yaşayan bireylerin mortalite ve morbiditeyi minimuma indirmek için HIV-negatif bireylerden daha fazla sağlık bilincine sahip olması gerekir**

HIV ile yaşayan bireylerin çeşitliliği ⬆

Bu durumu sadece komorbiditeler yansıtmaz;

- Yaş,
- sosyoekonomik durum,
- tıbbi bakıma erişim,
- cinsellik, cinsel sağlık ve üreme sağlığı,
- ruh sağlığı sorunları
- HIV ile ilgili damgalanmayı da içermektedir

Hekim-Hasta Bakış Açısı

- HIV ile yaşayan bireyler sağlık hizmeti sağlayıcıları tarafından öngörülenlerden farklı kaygı ve önceliklere sahiptir.[1]

- Her bir bireyin kişisel kaygılarını ve önceliklerini tespit etmede Sağlık hizmeti sağlayıcılarını destekleme ihtiyacı vardır, böylece tüm PLHIV gereksinimlerinin uygun şekilde karşılanabilir

Yelverton V. AIDS Patient Care STDS. 2018; 32:340-8.

HIV'i uzun vadede yönetmek için dikkat edilmesi gerekenler

- Rehberler tedavi önerileri,viral supresyon sağlanması, komorbidite yönetimi, ilaç-ilaç etkileşimlerine vurgu yapar

- Bunun ötesinde sağlıkla ilgili yaşam kalitesinin iyileştirilebilmesi için polifarmasinin yönetilmesi, mental ve cinsel sağlık, stigma ve sosyal gereksinimler ile ilgili pek az rehberlik vardır

- HIV ile yaşayan bireyler böyle pek çok konuyu çok erken yaşlarda deneyimlerler

- HIV-pozitif hastaların tedavisi için uluslararası kılavuzların, tedavinin başarısının ölçüsü olarak sağlıkla ilişkili yaşam kalitesini içermesi gerektiğini savunmaktadır

Multidisipliner Yaklaşım

- Tedavi yönetimi ve hastaların duygusal ihtiyaçlarını karşılamak için sağlık hizmeti sunucuları işbirliği içinde olmalı

- Çok yönlü yönetim sağlık hizmeti taşıyıcıları için tecrübe ve odaklanmayı ve ciddi bir multidisipliner yaklaşımı gerektirir

Hasta katılımını iyileştirme

"I THOUGHT IT MIGHT HELP YOU IF I LISTED MY SYMPTOMS."

- Hastaların kendi tedavi planlarına tam olarak katılmaları teşvik edilmelidir.
- Hasta katılımının, uyumun iyileşmesine yol açan tedaviye bağlılık üzerinde olumlu bir etkiye sahip olduğu gösterilmiştir.[1]
- Gereksinimlerinin daha iyi anlaşılması ve davranışlarındaki değişimin desteklenmesi için daha fazla araştırma yapılması gerekir;
- Birçok hasta kendi durumundaki uzmanlar olarak kabul edilebilir ve bilgileri hastane kliniklerinde kullanılmıştır, böylece hasta-sağlık çalışanı arasındaki çalışma ilişkisini güçlendirmiştir.[2]

1. Münene E, et al. AIDS Care. 2015;27:378-86.
2. Tenthani L. BMC Health Serv Res. 2012;12:140.

Hasta Bakımında Bireyselleştirilmiş Yaklaşım

- Sosyoekonomik durumu veya coğrafyaya bakmaksızın, HIV ile yaşayan her bireyin tedavisine kişiselleştirilmiş bir yaklaşıma dayanmaktadır.

- Bu yaklaşım; hastanın koşulları, hedefleri, değerleri ve özellikleri hakkında bilgi gerektirir.

- Sağlık değerlendirmesi ve terapötik karar verme için,sağlık hizmeti sunucusu ile hasta arasındaki karşılıklı sorumluluk ve anlayışla desteklenmiş, işbirliğine dayalı ve proaktif bir yaklaşım benimsenmeli

‘’ Benim için sağlık’’ hedefi

- DSÖ'nün yaşlılığın refahını sağlayan fonksiyonel yeteneği geliştirme ve sürdürme süreci olarak tanımlanan “sağlıklı yaşlanma” algısının bir genişlemesidir

- Birçok sosyal ve psikolojik faktör, cinsiyet, HIV açıklanması,cinsel yönelim, HIV ile ilgili damgalanmayı içeren risk / zarar azaltma gibi konularda daha genç hastalar için daha geçerli

- Sadece hastalıktan ziyade sağlığı yönetmeyi amaçlayan HIV ile yaşayan bireyler için sağlığa bağlı QoL'nin değerlendirilmesi için bir çerçeve

”Benim için sağlık”

AIDS Reviews. 2019;21

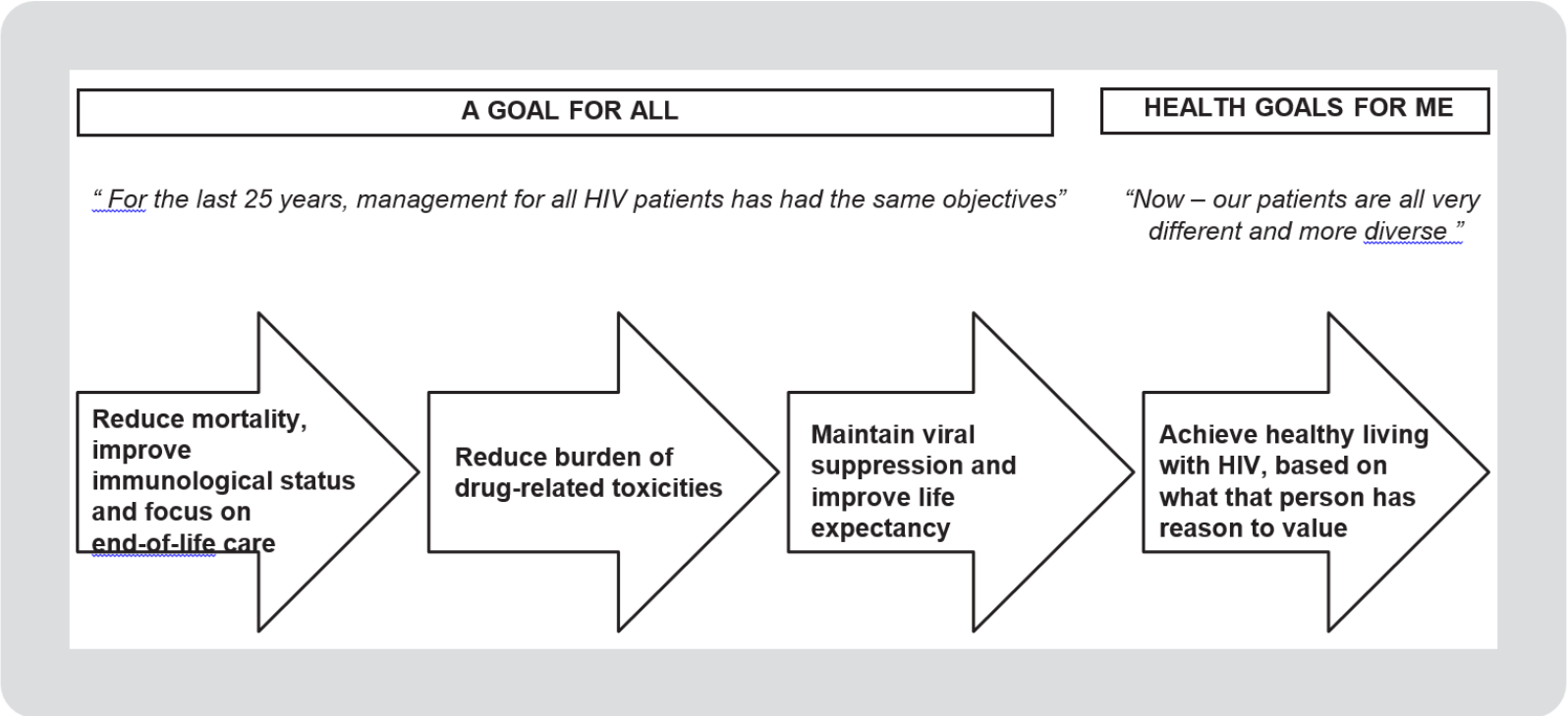

Figure 1. *Healthy living with HIV: “Goal for all, health goals for me” concept.*

Sağlıkla ilgili yaşam kalitesinin değerlendirilmesi için önerilen çerçeve

Figure 1. *Healthy living with HIV: "Goal for all, health goals for me" concept.*

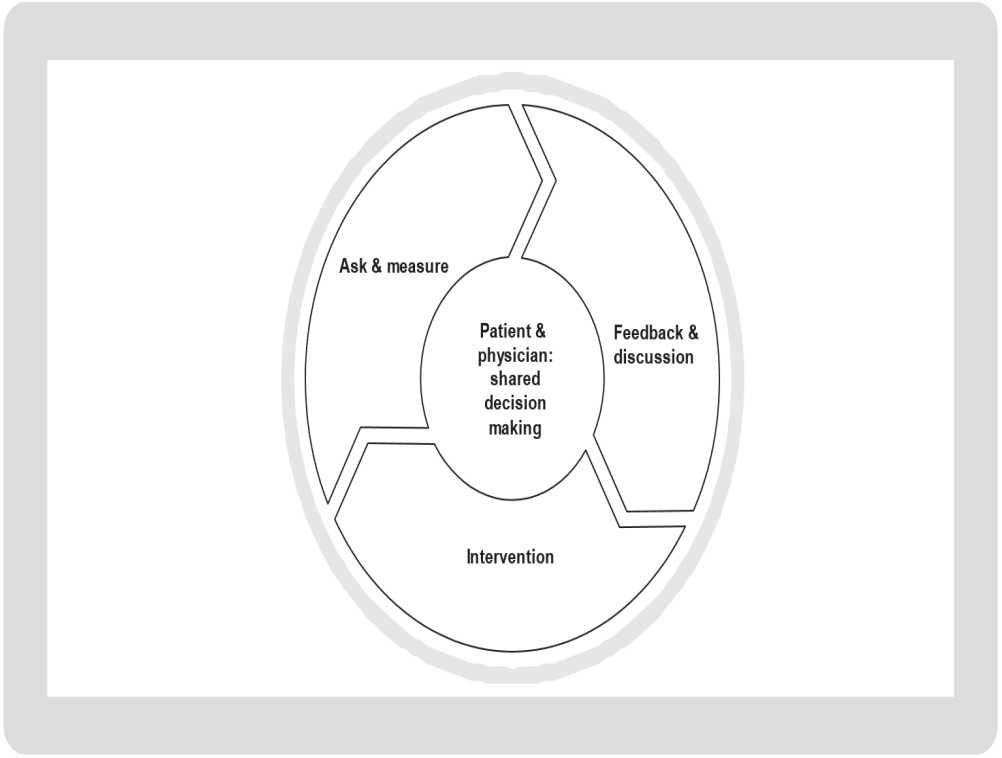

Figure 2. *The proposed "health goals for me" tool is a continuous cycle involving the patient and the physician at all stages of the process.*

1. sor ve ölç
2. geribildirim ve tartışma
3. müdahale

- ✓ Vizit öncesi periyodik olarak hastalar için geniş bir sorgulama (e-anket)
- ✓ Vizit öncesi sağlık hizmeti sunucusunun sorunları tespiti
- ✓ Paylaşım ve birlikte çözüme odaklanma

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HIV Outcomes Beyond Viral Suppression

Published: November 25, 2019

Executive Summary

In the era of modern antiretroviral therapy people living with HIV can expect to live a normal lifespan. However substantial barriers to accessing non-HIV related care exist and impact the wellbeing of this population.

Current targets for the HIV response focus on testing, treatment and viral suppression. This Series explores wider aims, beyond viral suppression, and argues for an additional measure focusing on health-related quality of life. The role patient-reported outcomes could play in measuring progress and how stigma undermines health-related quality of life are also examined.

Editorial

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The Lancet HIV
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Related Content

Global Health HIV

1. Viral supresyonun ötesinde HIV ile yaşayan bireylerin bakımında sağlık sistemlerini yeniden düzenlemek

HIV Outcomes Beyond Viral Suppression 1

Reorienting health systems to care for people with HIV beyond viral suppression

Kelly Safreed-Harmon, Jane Anderson, Natasha Azzopardi-Muscat, Georg M N Behrens, Antonella d'Arminio Monforte, Udi Davidovich, Julia del Amo, Meaghan Kall, Teymur Noori, Kholoud Porter, Jeffrey V Lazarus

The effectiveness of antiretroviral therapy and its increasing availability globally means that millions of people living with HIV now have a much longer life expectancy. However, people living with HIV have disproportionately high incidence of major comorbidities and reduced health-related quality of life. Health systems must respond to this situation by pioneering care and service delivery models that promote wellness rather than mere survival. In this Series paper, we review evidence about the emerging challenges of the care of people with HIV beyond viral suppression and identify four priority areas for action: integrating HIV services and non-HIV services, reducing HIV-related discrimination in health-care settings, identifying indicators to monitor health systems' progress toward new goals, and catalysing new forms of civil society engagement in the more broadly focused HIV response that is now needed worldwide. Furthermore, in the context of an increasing burden of chronic diseases, we must consider the shift that is underway in the HIV field in relation to burgeoning policy and programmatic efforts to promote healthy ageing.

Introduction

After the antiretroviral therapy (ART) breakthroughs of the late 1990s dramatically improved the prognosis for people living with HIV, high-income countries had rapid declines in HIV-related deaths.[1–3] The scale-up of ART has been much slower in low-income and middle-income countries, but sustained efforts have yielded steady progress, and 59% of the world's estimated 36·9 million people living with HIV received ART in 2017.[4] The UNAIDS 90-90-90 target, introduced in 2014, continues to spur countries at all income levels to try to bring the epidemic under control. It calls for 90% of all people living with HIV to be diagnosed, for 90% of those diagnosed to receive ART, and for 90% of those receiving ART to be virally suppressed.[5]

Life expectancy for people living with HIV, although lower than that of the general population, has increased considerably since the late 1990s.[6] Progress toward the 90-90-90 target thus means that health systems are responsible for the care of increasingly large numbers of ageing people with HIV. These individuals face the full array of health and social challenges commonly associated with ageing, such as decreasing physical mobility,[7] cognitive decline, chronic comorbid diseases, social isolation, and suboptimal family support.[8] At the same time, their HIV-positive status might exacerbate these challenges,[9,10] as might their identification with marginalised groups such as men who have sex with men, transgender people, sex workers, migrants, and people who inject drugs. They also can have ongoing financial instability as a result of living with HIV-related health issues for many years. Stigma and discrimination remain implicated in health outcomes for people of all ages living with HIV.[11,12]

Providing this population with the knowledge, skills, and tools to prevent onward transmission of HIV continues to be a challenge in many settings worldwide. There is a recognised need to comprehensively address the syndemic nature of HIV and its most commonly co-occurring psychosocial conditions, including substance abuse, violence, mental health problems, and sexual risk behaviours, particularly in key populations. Multidisciplinary interventions that more effectively address the intersection of HIV with these conditions are necessary to achieve and maintain viral suppression.[13]

In this complex landscape, the traditional focus on viral suppression as the ultimate goal of HIV care is beginning to give way to recognition that additional goals are needed, such as our fourth 90 target proposed to address the

Key messages

- Because life expectancy has increased greatly for people living with HIV, health systems face the challenge of meeting the complex health-care needs of growing numbers of ageing people living with HIV in the coming years
- People living with HIV have higher comorbidity than their HIV-negative peers, and face challenges relating to polypharmacy and health-related quality of life
- Viral suppression has long been regarded as the goal of HIV care, but health systems need to adopt new goals relating to long-term wellbeing
- The broader HIV care agenda that is emerging calls for health systems to focus on health-system integration, HIV-related discrimination, new measures of progress, and new roles for civil society
- As the global response to HIV is redefined, efforts should be aligned with the healthy ageing agenda for the general population

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This is the first in a Series of three papers on HIV outcomes beyond viral suppression

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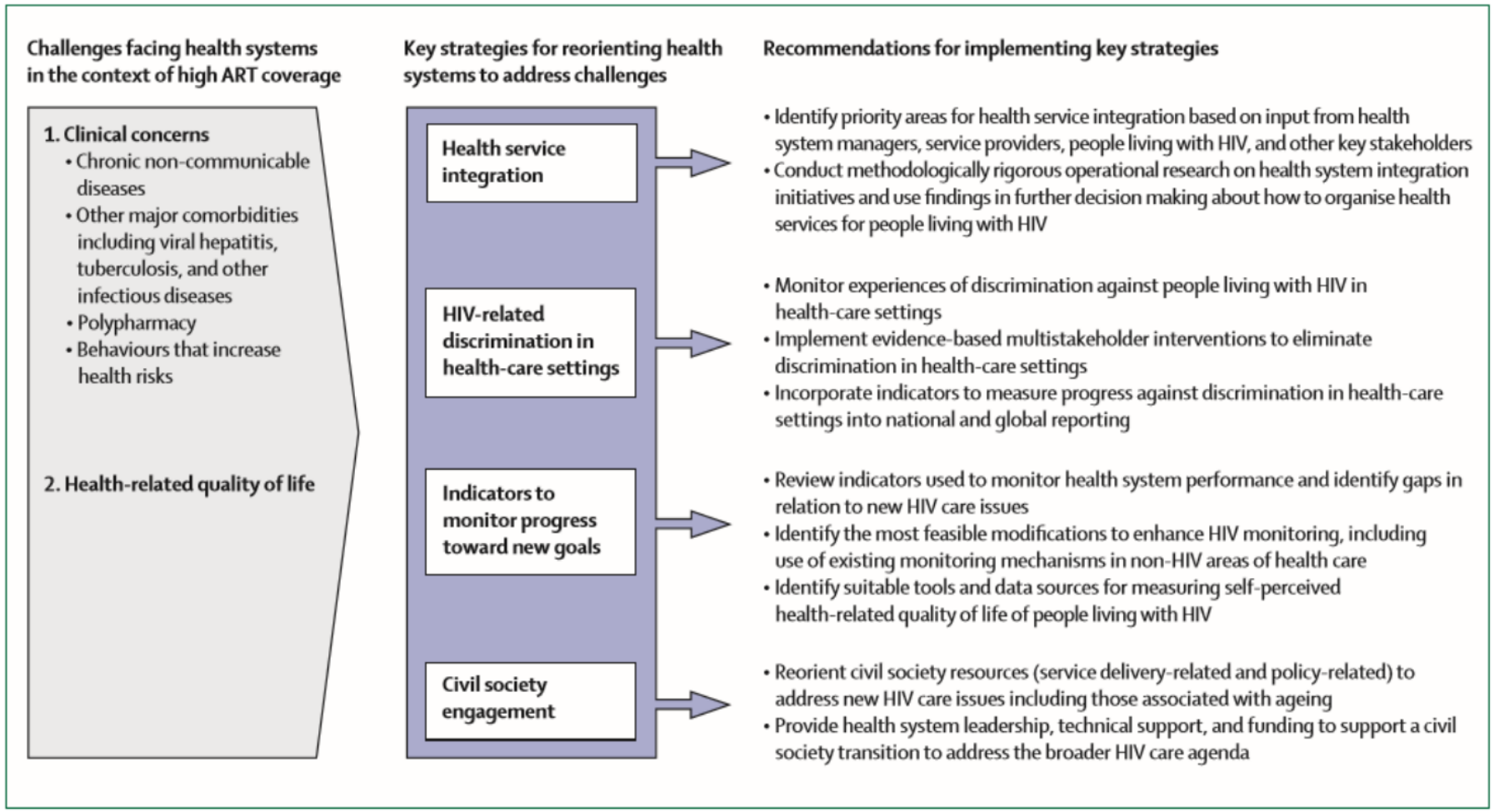

Figure 2: **Meeting key health system challenges of the new HIV era**
ART=antiretroviral therapy.

2. İnsan-odaklı HIV bakımını geliştirmek için hasta tarafından bildirilen sonuçlar- Anketler/Ölçekler

HIV Outcomes Beyond Viral Suppression 2

Patient-reported outcomes to enhance person-centred HIV care

Meaghan Kall, Fabienne Marcellin, Richard Harding, Jeffrey V Lazarus, Patrizia Carrieri

Quality of life has been proposed as the fourth 90 to complement the UNAIDS 90-90-90 targets to monitor the global HIV response, highlighting a need to address the holistic needs of people living with HIV beyond viral suppression. This proposal has instigated a wider discussion about the use of patient-reported outcomes (PROs) to improve the treatment and care of an ageing HIV population with increasing comorbidities and a disproportionate burden of social problems. PROs can provide a first-hand assessment of the impact of HIV treatment and care on patients' quality of life, including symptoms. The field of PRO measures is rapidly expanding but still no gold standard exists, raising concerns about tool selection. Challenges also remain in the collection, interpretation, and use of PRO data to improve the performance of the health system. An emerging concern is how to adapt PROs to different sociocultural and geographical settings.

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Introduction

Global progress is being made towards achieving the UNAIDS 90-90-90 HIV targets: 90% of people with HIV diagnosed, 90% of those diagnosed on treatment, and 90% of those on treatment virally supressed. As the HIV sector reviews the challenges and future priorities for optimal management of HIV, focus is slowly shifting away from a predominantly biomedical approach and the idea that viral suppression is the ultimate goal of HIV care.[1] The concept of a fourth 90 has emerged, in which good health-related quality of life (HRQoL) is held to be of equal importance to the other 90-90-90 targets that health systems should aspire to achieve.[2] This shift requires a holistic approach that addresses overall health, and the social and psychological aspects of HIV that can lead to poor health outcomes.[3]

Person-centred health care is central to achieving this goal: delivering services that patients need, can access, and which address the wider determinants of poor health. To ensure that people living with HIV enjoy healthy ageing with sustained viral suppression, clinicians and health systems must respond to the lifelong needs of people living with HIV, from diagnosis until the end of life.

How can one know what patients need, unless we ask? Involvement of patients in designing health-care services has been shown to improve engagement and retention in care, increase resilience, and empower people to take a more active role in the management of their condition.[4,5] Since the start of the HIV epidemic, the advocacy of the HIV community has been integral to how HIV prevention and treatment services have been designed. The prolonged life expectancy and the consequent rise of ageing HIV groups with unmet needs require a substantial change in how health systems provide care for HIV and age-related conditions.

One of the most efficient ways to ensure that care reflects patients' needs and priorities is by collecting and using patient-reported outcome (PRO) data. Involving people with HIV in PRO development and adaptation can help to better identify HIV or treatment-related symptoms and detect stigmatising attitudes from the health system, which are among the main barriers to engagement in HIV care.

What are PROs?

A PRO can be defined as any report of the status of a patient's health condition that comes directly from the patient, without interpretation by a clinician or anyone else.[6] PROs capture a person's experience as a patient in

Key messages

- Patient-reported outcomes (PROs) provide vital information about a patient's first-hand account of their experiences that cannot be directly measured and provides a more holistic view of their health and wellbeing
- PROs can be used to instigate and support interventions at all levels (ie, clinical, institutional, and population) to ensure optimal HIV care and prevent ill health
- Recent technological advances have made PROs more accessible to patients and investigators, streamlining data collection and analysis (ie, with electronic PROs and linkage to medical records)
- Further research is needed to show the utility of PROs in the field of HIV, making a clear link between improvements in PROs to improvements in health and clinical care
- New PROs need to be developed and existing PROs cross-culturally adapted to populations with special attention to children and adolescents, the elderly, and settings in which key populations are highly stigmatised or criminalised
- Patient involvement in the development of PROs is vital to ensure their usability and acceptability in the population of interest

	Generic or developed in other diseases (number of items)	HIV specific (number of items)
Core patient-reported outcomes		
HRQoL	EuroQol (EQ-5D) and EQ-5D-Y (Y)* (5 + Visual Analogue Scale); HUI2 and HUI3 (15-16); MQOL (16); MOS SF-36 (36);MOS SF-20 (20); MOS SF-12 (12); WHOQOL-BREF (26); PedsQL* (15 core + 30 supplementary)	ACTG-21 (21); MOS-HIV (36); PROQOL-HIV (43); WHOQOL-HIV BREF (31); FAHI (47); PozQoL (13); Positive Outcomes (23); QOL-CHAI* (47)
Self-rated health	SF-36 (first question)	..
Patient empowerment	CD-RISC (25); CD-RISC-10 (10) and CD-RISC2 (2); BRS (6); PAM-13 and PAM-22; HCEI (8)	..
Life satisfaction	PWB (4); FLZM (28)	..
More patient-reported outcomes		
Stigma and discrimination	..	People Living with HIV Stigma Index† (10 areas [can be adapted to local context]); HSS (40) and derived versions; HSSC (10 and 12)*
Antiretroviral therapy adherence, treatment side-effects	SMAQ (6); MASRI (12)	ACTG Adherence Questionnaires and derived versions (5–20); HIV Symptom Index and ACTG; Symptom Distress Module (20)
Fatigue or sleep disorders	FIS (40) and derived versions; ESS (8); GSQS (15); PSQI (19)	HRFS (30)
Mental health (anxiety, depression, stress, etc)	CES-D (20, 10 [short version]); HAD (14); BDI-II (21); DASS-21 (21); GHQ (12, 28, 30 and 60); PHQ (9 and 15); GAD-7	..
HIV status disclosure	..	HIV Disclosure Scale (14); Adolescent HIV Disclosure Cognition and Affect Scale* (18)
Weight management	IWLS (9); BIS (10)	..
Pain and function	Visual Analogue Scale; McGill Pain Questionnaire (20); BPI (9 [short form]); BCPQ (2)	HDQ (69)
Use of alcohol, tobacco, and drugs	AUDIT (10); AUDIT-C (3); Fagerstrom (6); CAST (6); DUDIT (11)	..

ACTG=AIDS Clinical Trials Group. AUDIT=Alcohol Use Disorders Identification Test. BCPQ=Brief Chronic Pain Questionnaire. BDI=Beck's Depression Inventory. BIS=Body Image Scale. BPI=Brief Pain Inventory. BRS=Brief Resilience Scale. CAST=Children of Alcoholics Screening Test. CD-RISC=Connor-Davidson Resilience Scale. CES-D=Center for Epidemiologic Studies Depression Scale. DASS=Depression Anxiety Stress Scales. DUDIT=Drug Use Disorders Identification Test. ESS=Epworth Sleepiness Scale. EuroQol=European Quality of Life. FAHI=Functional Assessment of HIV Infection. FIS=Fatigue Impact Scale. FLZM=Questions on Life Satisfaction. GAD=General Anxiety Disorder Assessment. GHQ=General Health Questionnaire. GSQS=Groningen Sleep Quality Score. HAD=Hospital Anxiety and Depression Scale. HCEI=Health Care Engagement Index. HDQ=HIV Disability Questionnaire. HRFS=HIV-Related Fatigue Scale. HRQoL=Health-related quality of life. HSS=HIV Stigma Scale. HSSC=HIV Stigma Scale Children. HUI=Health Utilities Index. IWLS=Impact of Weight Loss Scale. MASRI=Medication Adherence Self-Report Inventory. MOS=Medical Outcomes Study. MQOL=McGill Quality of Life questionnaire. PAM=Patient Activation Measure. PedsQL=Paediatric Quality of Life Inventory. PHQ=Patient Health Questionnaire. PROQOL-HIV=patient-reported outcomes quality of life–HIV. PSQI=Pittsburg Sleep Quality Index. PWB=Personal Well-Being. QOL-CHAI=Quality of Life (health-related) of Children Living with HIV/AIDS in India. SF=Short Form health Survey. SMAQ=Simplified Medication Adherence Questionnaire. WHOQOL-BREF=WHO Quality of Life—abbreviated. Y=youth. References for table 1 can be found in the appendix (pp 1–4). *Measure developed or adapted specifically for young people with HIV. †Available via enquiry only.

Table 1: **Patient-reported outcome measures and instruments commonly used in HIV**

For **People Living with HIV Stigma Index** see http://www.stigmaindex.org/

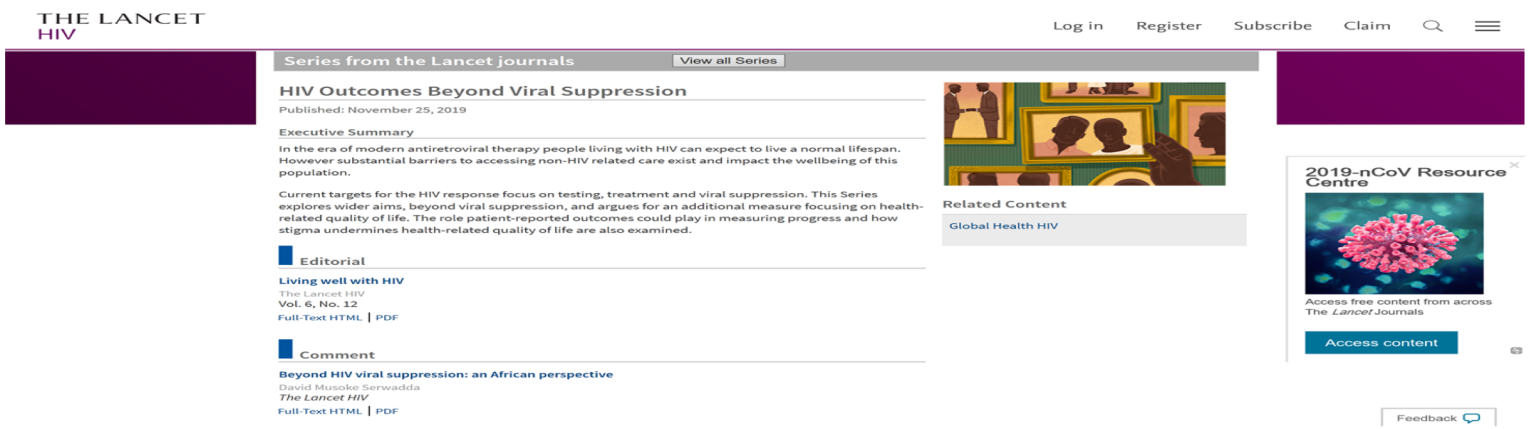
See Online for appendix

Tartışma

- HIV’de klinik bakımı iyileştirmek için PRO’ların yaygın kullanımı sağlanmalı
- Klinik uygulamada PRO'ların kullanımı ile ilgili sağlık hizmeti sağlayıcılarının toplama ve yorumlama eğitimini artırmaya ihtiyaç vardır
- Farklı coğrafyalarda ve risk popülasyonlarında PRO'ları kullanmak ve uyarlamak
- HIV ile yaşayan bireyleri bu çalışmaya tamamen dahil etmek önemli

- Sonuç olarak;

HIV ile yaşayan insanlara yönelik damgalanmayı azaltmak, bakıma katılımlarını artırmak ve HIV popülasyonunun karşılanmamış ihtiyaçlarını daha iyi ele almak, bakım modellerini belirlemek için müdahaleler yapılmasına yardımcı olacaktır.



- HIV ile on yıllardır yaşayan insanların sağlıkla ilgili ihtiyaçları diğer temel ihtiyaçlarla derinden iç içedir.
- Bu nedenle, viral baskılamanın ötesinde iyi HIV sonuçları elde etmek için sağlık sistemi gündemi, HIV ile yaşayan insanların gıda güvenliği, finansal güvenlik, yeterli barınma ve diğer sosyal destek biçimlerine sahip olmalarını sağlama çabalarıyla bütünleştirilmelidir.

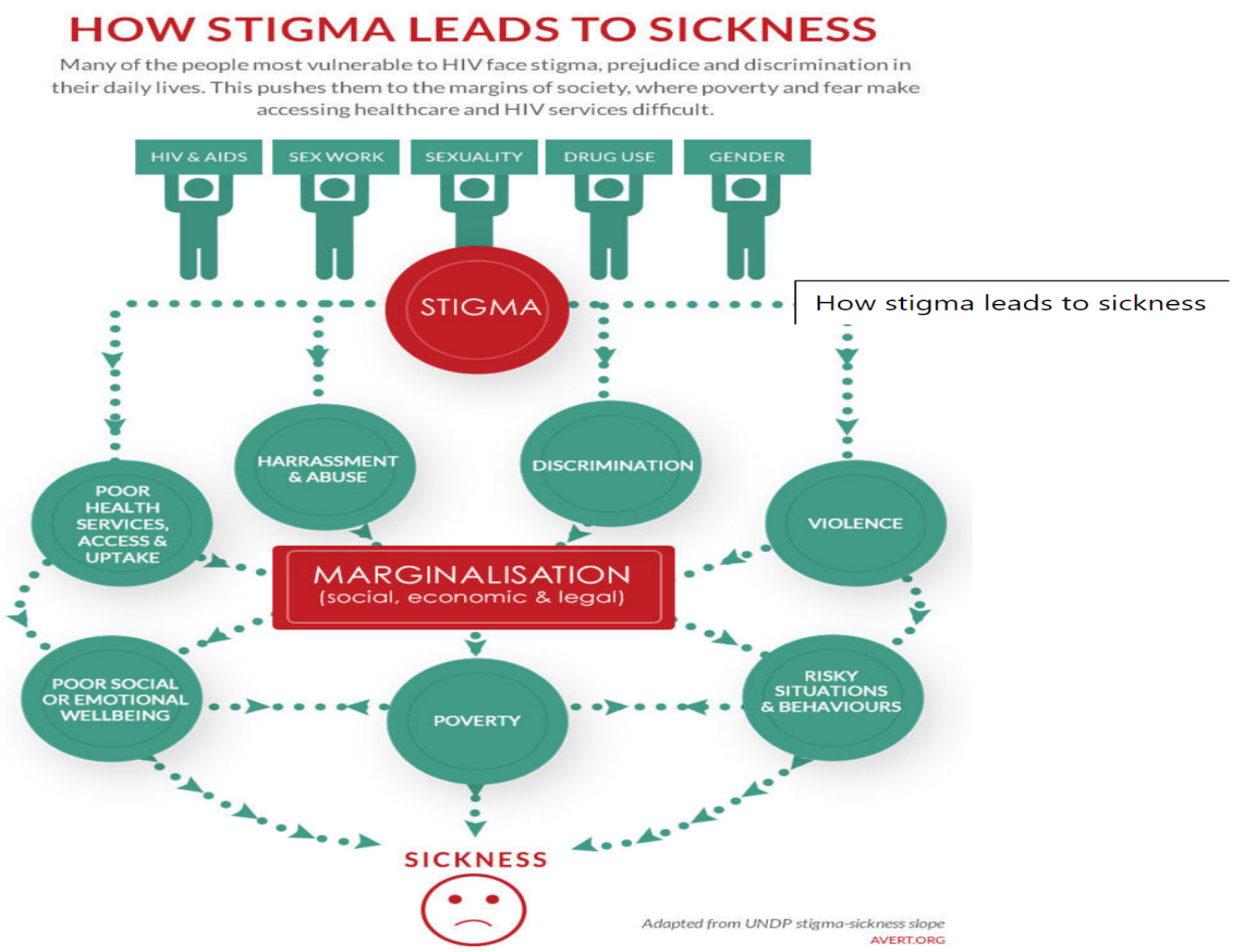
Değişmeyen kaygı

DAMGALANMA VE AYRIMCILIK

Değişmeyen gereksinim

DAMGALANMADAN, AYRIMCILIĞA UĞRAMADAN YAŞAMAK

DAMGALAMA VE AYRIMCILIK



https://www.avert.org/professionals/hiv-social-issues/stigma-discrimination

DAMGALANMA VE AYRIMCILIK

- **Öz-damgalama**

  Kendi kendini yargılama, suçluluk duygusu, olumsuz bir topluluk reaksiyonundan korkma, utanç duvarı

- **Devlet tarafından damgalanma**

  Yasalarla korunmama, ayrımcılığa maruz kalma

- **Giriş, seyahat ve konaklama ile ilgili kısıtlamalar**

  35 ülke girişi kısıtlıyor, 17 ülke + saptanırsa sınır dışı ediyor

- **Sağlık hizmetinde damgalanması**

  Zorunlu HIV testi ,hastalarla teması en aza indirme, tedaviyi geciktirme veya reddetme, hizmetler için ek ödeme talebi, izole etme, cinsel kimliği yargılama, mahremiyet ihlalleri….

- **İşyerinde damgalanma**

  Sosyal izolasyon, alay etme ve iş akdinin feshi veya reddedilmesi…..

https://www.avert.org/professionals/hiv-social-issues/stigma-discrimination

DAMGALAMA VE AYRIMCILIK

- Yaklaşık 40 yıl önceki kimliğinden bu yana ,HIV ile yaşayan insanların karşılaştığı en büyük zorluklardan biri sosyal leke ve ayrımcılıktır

- Stigma ve ayrımcılık epideminin yayılımına neden olmakla kalmaz, aynı zamanda hastaları sosyal izolasyon, stres ve duygusal başa çıkma , sosyal ve ekonomik kaynaklardan mahrum olma zorlukları..

- Literatürde bu konuda yapılmış >2500 çalışma

Tran BX, et al.Int J Environ Res Public Health. 2019 May 29;16

International Journal of
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Article

Understanding Global HIV Stigma and Discrimination: Are Contextual Factors Sufficiently Studied? (GAP$_{RESEARCH}$)

Bach Xuan Tran [1,2,*], Hai Thanh Phan [3], Carl A. Latkin [2], Huong Lan Thi Nguyen [3], Chi Linh Hoang [4], Cyrus S.H. Ho [5] and Roger C.M. Ho [4,6,7]

- HIV ile ilgili damgalama; genellikle utanç , depresyon , kaygı, intihar düşüncesi ve düşük yaşam kalitesi ile ilişkilidir

- Sağlık kurumlarında damgalanma, optimal tedavinin önündeki en büyük engellerden biri

- HIV ile ilgili damgalanmanın deneyimlerinin HIV tedavisine daha az erişim, HIV bakım hizmetlerinin düşük kullanımı, daha zayıf ART uyumu ve dolayısıyla daha kötü tedavi sonuçları ile sonuçlandığını göstermektedir

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- Damgalanma ile uyuşturucu kullanıcıları, erkeklerle seks yapan erkekler ve seks işçileri gibi en fazla risk altındaki topluluklar arasında güçlü bir ilişki olduğunu vurgulamakta

- Damgalanmayı azaltmak için müdahalelerin tasarlanması için, damgalanmanın nedenlerinin tanımlanmasına bağlam ve kültüre özgü önemli faktörler dahil edilmeli

- HIV / AIDS'li hastalara yönelik damgalanma ve ayrımcılık, salgının uzun ömürlü tedavi sürecindeki dinamik yapısı göz önüne alındığında, acil bir sorun olmaya devam etmektedir.

Sonuç olarak;

- **Damgalama ve ayrımcılığın önüne geçecek stratejilerin geliştirilmesi-toplum farkındalığının arttırılması**
- Multidisipliner yaklaşım için daha gelişmiş bir sağlık hizmeti sağlanması
- Sadece uzun değil kaliteli bir yaşam için kendilerinin de sisteme dahil edildiği insan odaklı sağlık sistemi
- Yaşam tarzı değişikliklerine (sigara, madde, beslenme, spor, iş vs) daha fazla odaklanabilmesi için çok yönlü destek
- Sağlık hizmeti sunucularına hastaların bireysel gereksinimlerine odaklanabilmesi için daha fazla zaman ve destek sağlanması

Teşekkür ederim