Riunione fondativa del Gruppo di Studio
della Società Italiana di Neurologia

Società Italiana di Neurologia e paesi in via di sviluppo

Milano, 20 marzo 2019
Istituto Neurologico Besta, Biblioteca Centrale

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Gianluigi Mancardi

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Serenella Servidei
Mario Zappia

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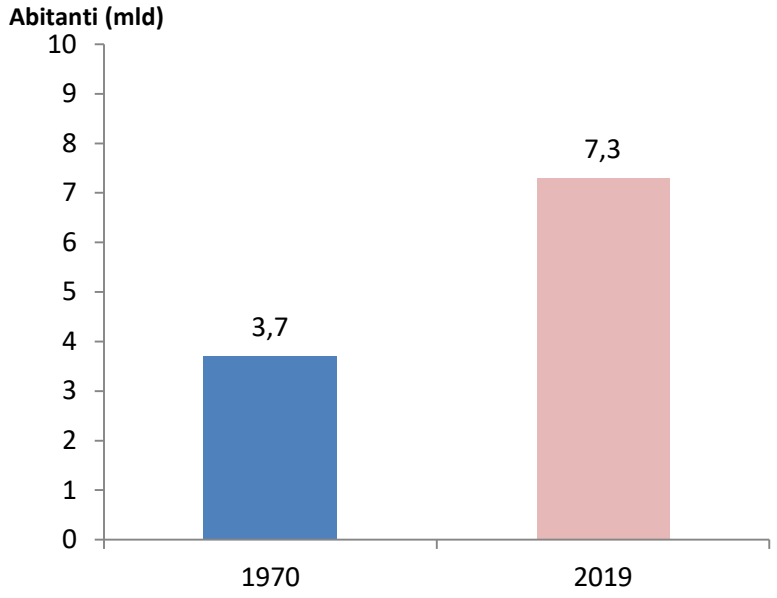
Sin

- Orientamenti del nuovo Gruppo di Studio
- Un primo obiettivo concreto: avviare un centro epilessia in Africa, quali modelli

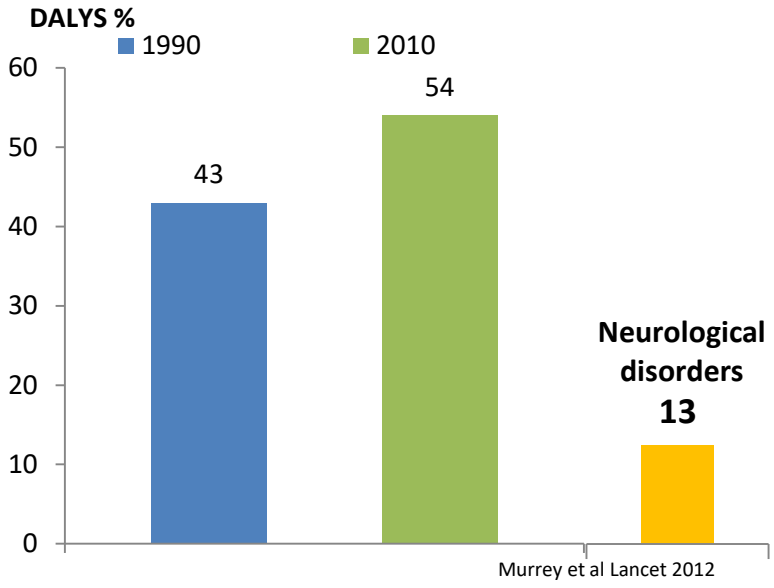
Gruppo di Studio SIN paesi in via di sviluppo - Africa

- Perché
- Gestione delle malattie neurologiche e formazione
- Quali modelli in Africa subsaariana
- Dalla teoria alla pratica: avviare un centro epilessia in Africa subsaariana (e non solo)

Popolazione mondiale

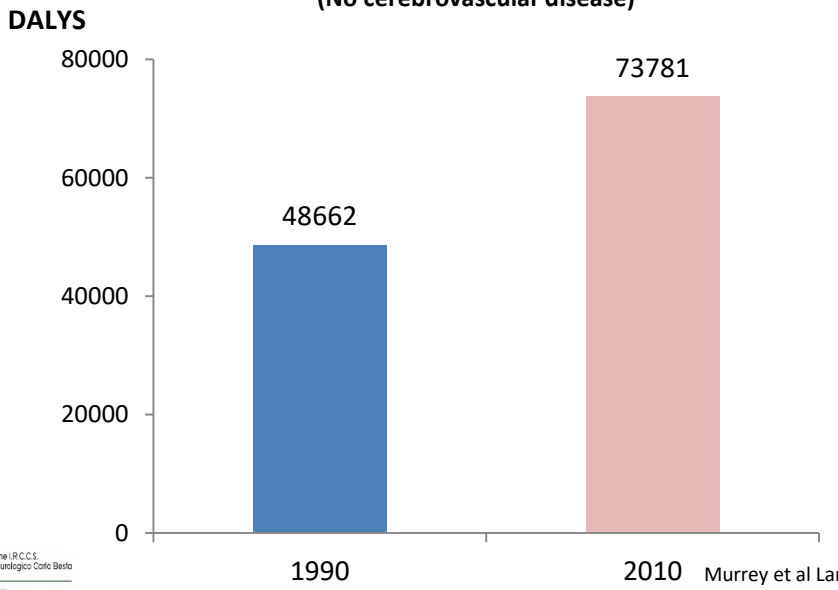


Non Communicable Diseases (NCD)

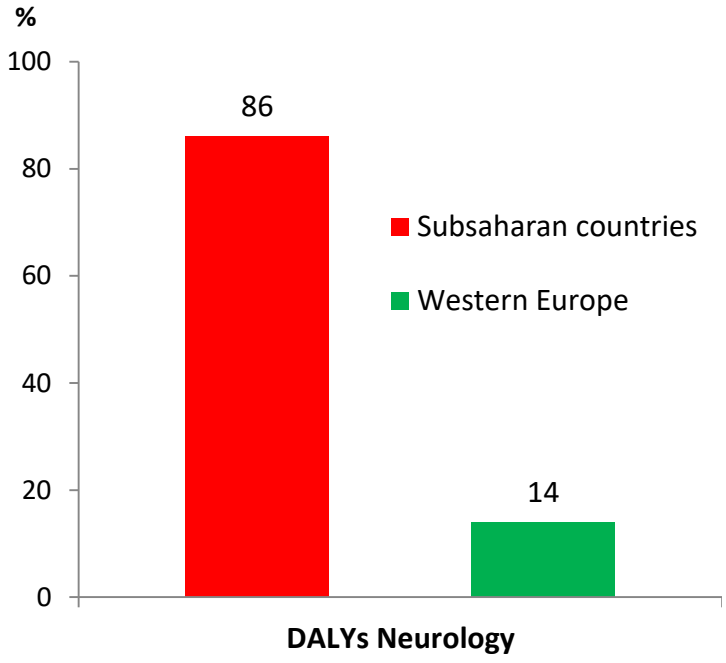


Murrey et al Lancet 2012

Neurological disorders DALYs: + 51,6%
(No cerebrovascular disease)



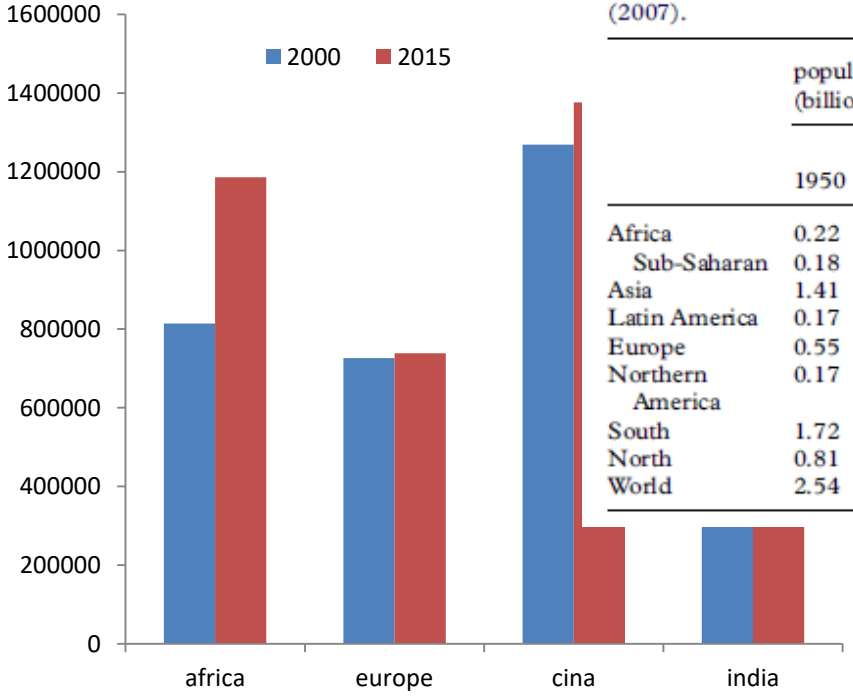
Murrey et al Lancet 2012



Chin JH &Vora N. Neurology 2014

Epidemiologic and health transition in sub-Saharan Africa

Population 2000-2015

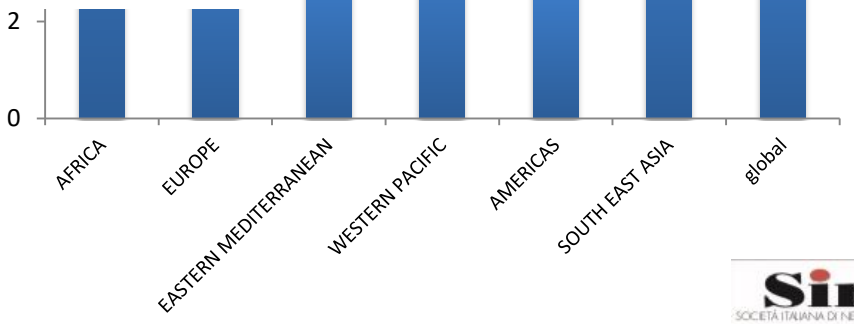


2986 J. Bongaarts *Population growth*

Table 1. Population estimates (1950–2005) and projections (2005–2050), by region. Adapted from United Nations (2007).

	population (billions)			% increase	
	1950	2005	2050	1950–2005	2005–2050
Africa	0.22	0.92	2.00	311	117
Sub-Saharan	0.18	0.77	1.76	327	129
Asia	1.41	3.94	5.27	179	[illegible]
Latin America	0.17	0.56	0.77	233	38
Europe	0.55	0.73	0.66	33	−9
Northern America	0.17	0.33	0.45	94	34
South	1.72	5.30	7.95	208	50
North	0.81	1.22	1.25	49	2
World	2.54	6.51	9.19	157	41

Life expectancy 2000-2016



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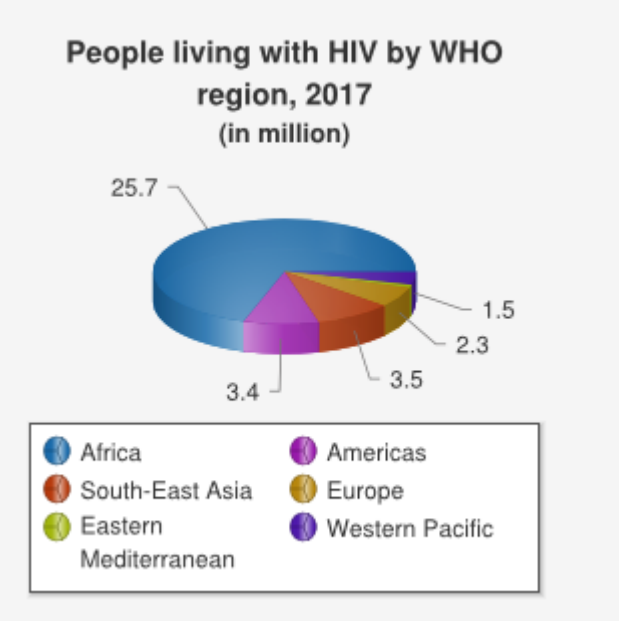
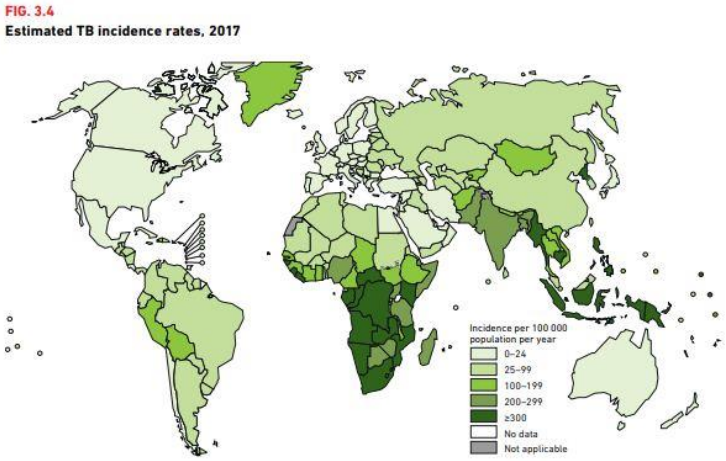
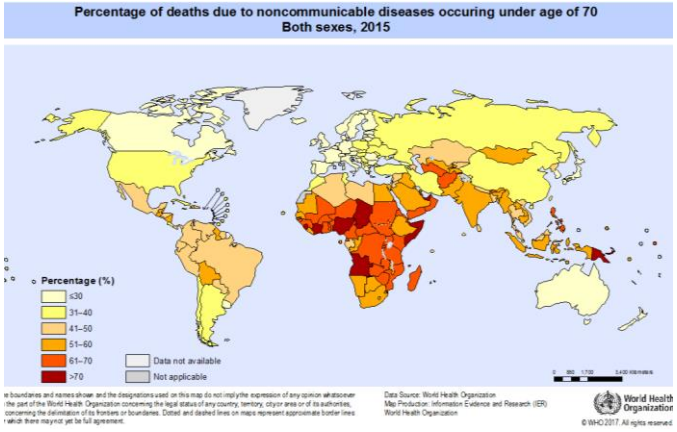
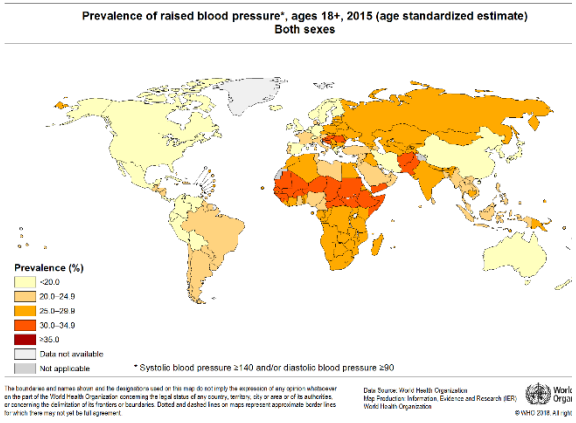
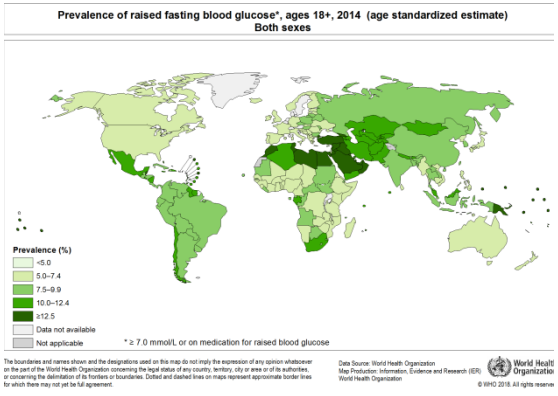
Sub-Saharan Africa: the double burden of CDs and NCDs











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Regione Lombardia

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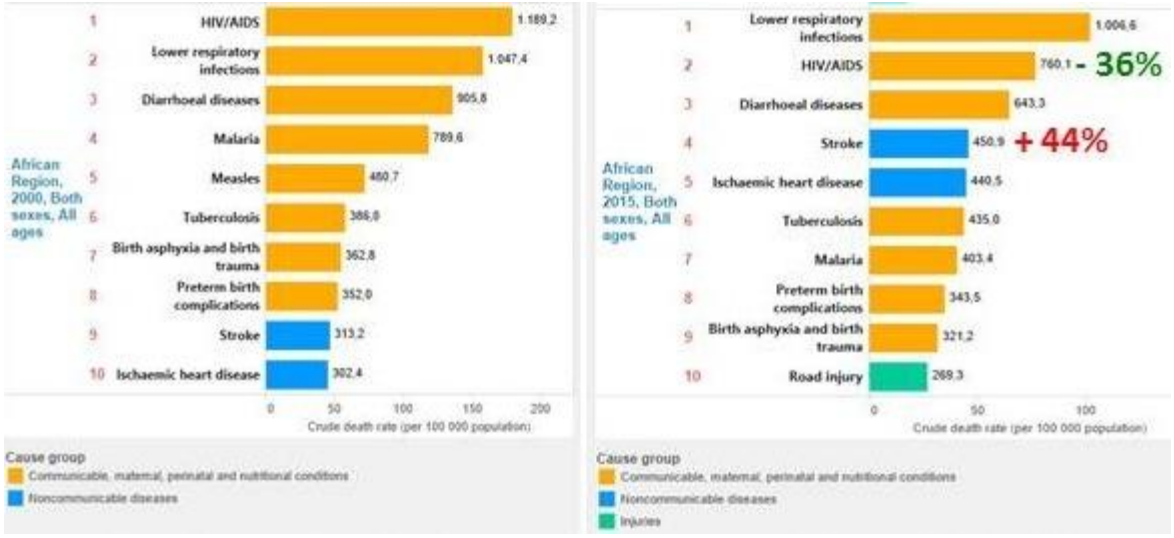
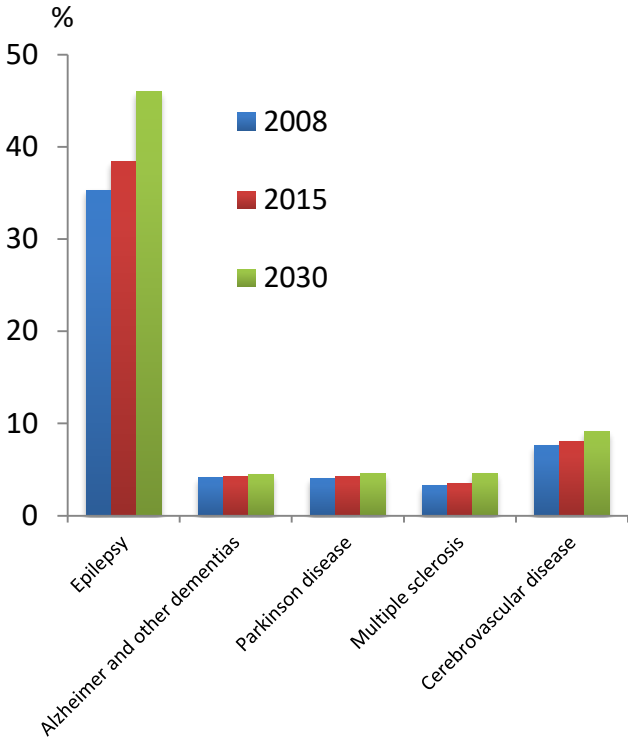
«Boom» delle malattie neurologiche in Africa

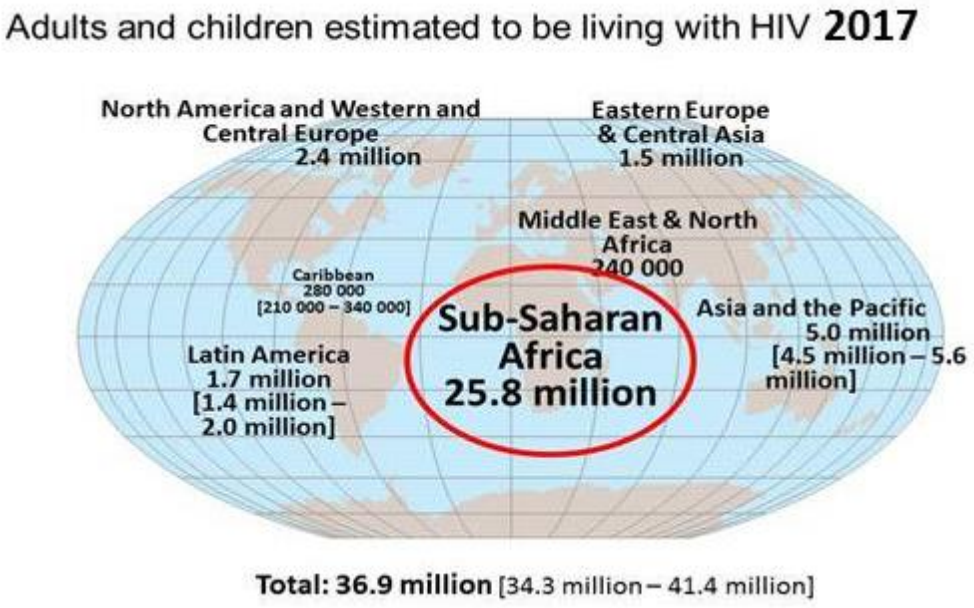


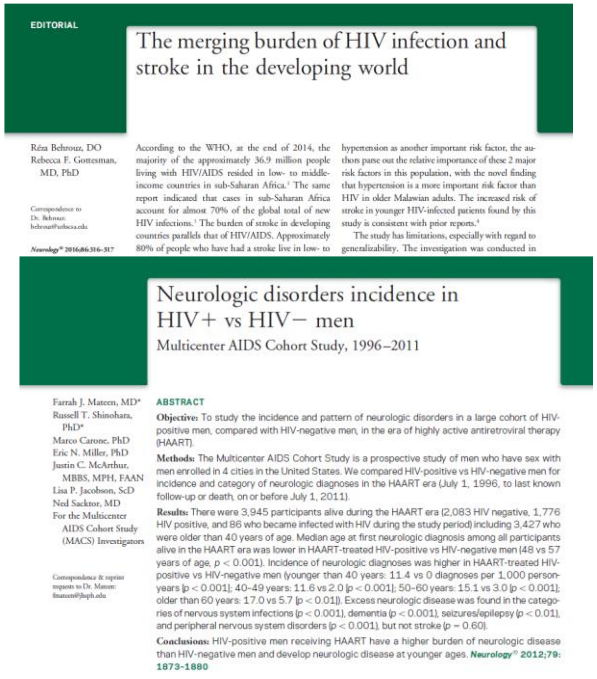


- **In Africa le malattie neurologiche sono divenute la quarta causa di morte**
- **Uccidono più della malaria e della TBC**
- **Fra 10 anni faranno più vittime dell'AIDS (dati WHO)**
- **Quasi un decesso su due per epilessia avviene in Africa**

http://www.who.int/gho/mortality_burden_disease/causes_death/top_10/en/

HIV
A risk factor for main neurologic disorders




EDITORIAL

The merging burden of HIV infection and stroke in the developing world

Rémi Behrouz, DO
Rebecca F. Gottesman, MD, PhD

Correspondence to Dr. Behrouz: behrouz@uthscsa.edu

Neurology® 2016;86:316–317

According to the WHO, at the end of 2014, the majority of the approximately 36.9 million people living with HIV/AIDS resided in low- to middle-income countries in sub-Saharan Africa.[1] The same report indicated that cases in sub-Saharan Africa account for almost 70% of the global total of new HIV infections.[1] The burden of stroke in developing countries parallels that of HIV/AIDS. Approximately 80% of people who have had a stroke live in low- to

hypertension as another important risk factor, the authors panc out the relative importance of these 2 major risk factors in this population, with the novel finding that hypertension is a more important risk factor than HIV in older Malawian adults. The increased risk of stroke in younger HIV-infected patients found by this study is consistent with prior reports.[3]

The study has limitations, especially with regard to generalizability. The investigation was conducted in

Neurologic disorders incidence in HIV+ vs HIV− men

Multicenter AIDS Cohort Study, 1996–2011

Farrah J. Mateen, MD*
Russell T. Shinohara, PhD*
Marco Carone, PhD
Eric N. Miller, PhD
Justin C. McArthur, MBBS, MPH, FAAN
Lisa P. Jacobson, ScD
Ned Sacktor, MD
For the Multicenter AIDS Cohort Study (MACS) Investigators

Correspondence & reprint requests to Dr. Mateen: fmateen@hsph.edu

ABSTRACT

Objective: To study the incidence and pattern of neurologic disorders in a large cohort of HIV-positive men, compared with HIV-negative men, in the era of highly active antiretroviral therapy (HAART).

Methods: The Multicenter AIDS Cohort Study is a prospective study of men who have sex with men enrolled in 4 cities in the United States. We compared HIV-positive vs HIV-negative men for incidence and category of neurologic diagnoses in the HAART era (July 1, 1996, to last known follow-up or death, on or before July 1, 2011).

Results: There were 3,945 participants alive during the HAART era (2,083 HIV negative, 1,776 HIV positive, and 86 who became infected with HIV during the study period) including 3,427 who were older than 40 years of age. Median age at first neurologic diagnosis among all participants alive in the HAART era was lower in HAART-treated HIV-positive vs HIV-negative men (48 vs 57 years of age, $p < 0.001$). Incidence of neurologic diagnoses was higher in HAART-treated HIV-positive vs HIV-negative men (younger than 40 years: 11.4 vs 0 diagnoses per 1,000 person-years [$p < 0.001$]; 40–49 years: 11.6 vs 2.0 [$p < 0.001$]; 50–60 years: 15.1 vs 3.0 [$p < 0.001$]; older than 60 years: 17.0 vs 5.7 [$p < 0.01$]). Excess neurologic disease was found in the categories of nervous system infections ($p < 0.001$), dementia ($p < 0.001$), seizures/epilepsy ($p < 0.01$), and peripheral nervous system disorders ($p < 0.001$), but not stroke ($p = 0.60$).

Conclusions: HIV-positive men receiving HAART have a higher burden of neurologic disease than HIV-negative men and develop neurologic disease at younger ages. **Neurology® 2012;79: 1873–1880**

- Epilepsy
- Stroke
- Alzheimer
- Polyneuropathies

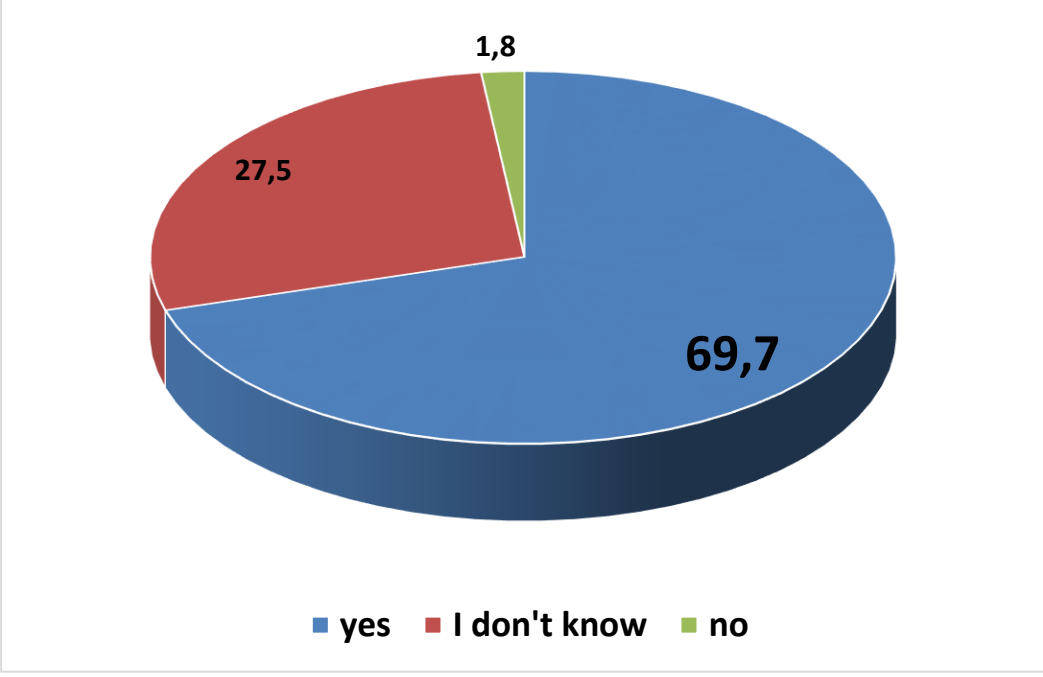
- Mateen et al Neurology 2012;79: 1873–1880
- Benjamin et al. Neurology 2016 ; 86(4):324-33.

Gruppo di studio SIN paesi in via di sviluppo - Africa

- I disordini neurologici in Africa subsaariana sono di interesse per la neurologia italiana?

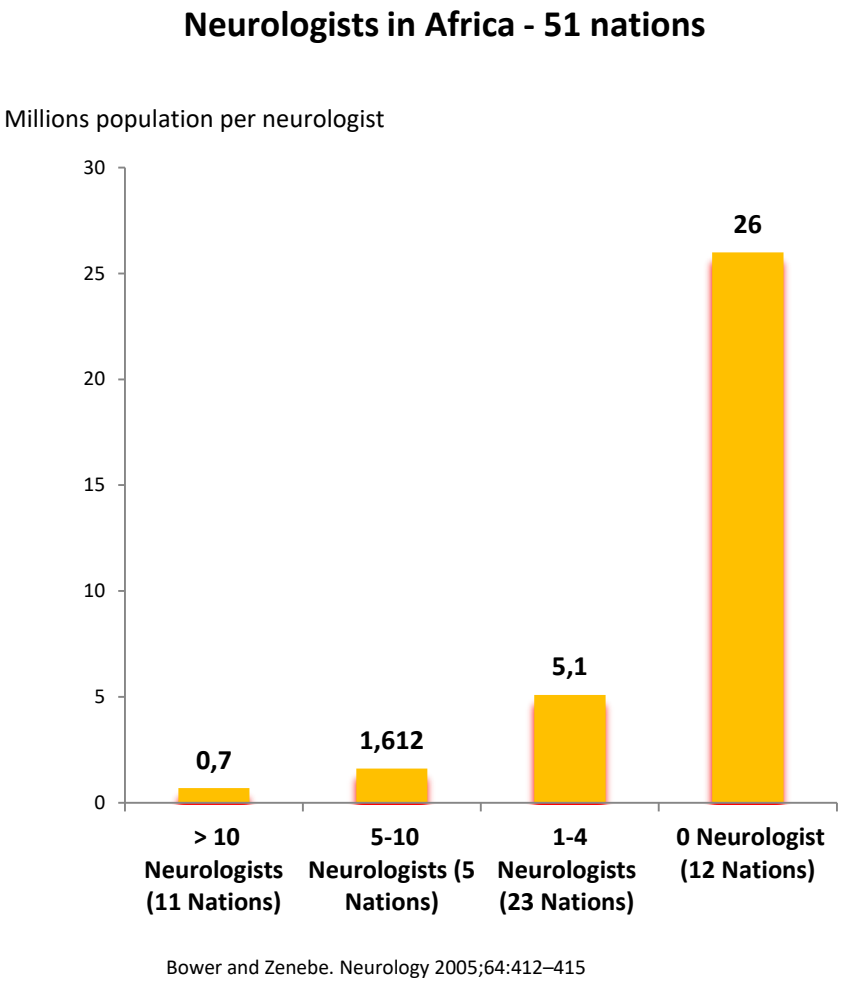
Gruppo di studio SIN paesi in via di sviluppo - Africa

109 giovani neurologi
«Ritieni che la crescente diffusione delle malattie non comunicabili e neurologiche in Africa subsaariana abbia un impatto anche sull'Italia e l'Europa?»



Malawi: > 80% vive in aree rurali

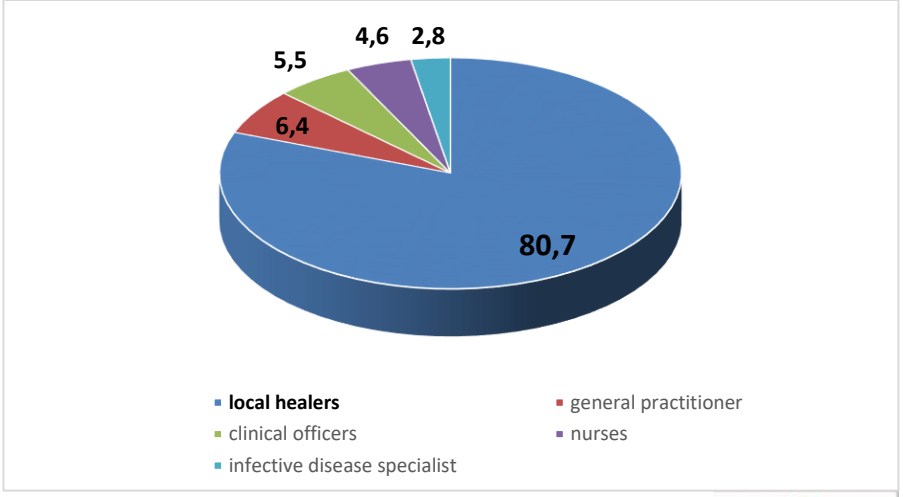
I neurologi in Africa subsaariana sono uno ogni 3-5 milioni di abitanti



Bower and Zenebe. Neurology 2005;64:412–415

Chi intercetta il malato neurologico?

- Il medico di base?
- L'infettivologo?
- I clinical officers?
- Gli infermieri?
- I *local healers* (guaritori locali)?



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Sin Società Italiana di Neurologia

Gestione di malattie neurologiche e formazione in Africa subsaariana

Quali modelli?

- **I neurologi in Africa subsaariana sono uno ogni 3-5 milioni di abitanti:**
- **Con chi ci troveremmo ad interagire?**
- **In quali contesti?**

Nuova demografia, quale neurologia

Formazione in Neurologia ≠

Formare neurologi?

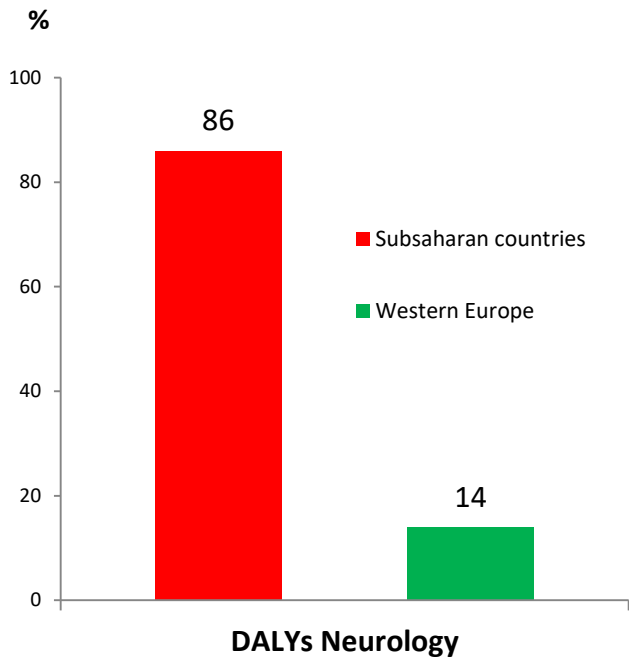
Chi formare?

Dove?

Quali priorità?

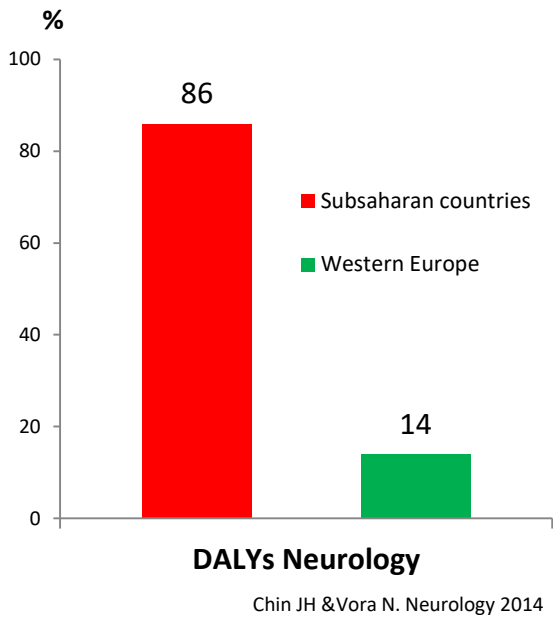
Tempistiche?

Obiettivi?



Chin JH &Vora N. Neurology 2014

Nuova demografia, quale neurologia



Chin JH &Vora N. Neurology 2014

Formazione

- Modello classico *top-top*
- Modello «leggero» *down-top?*
  - *«Unconventional» education in neurology*

Gestione malattie neurologiche (malattie croniche)

Cosa occorre

The Economist | Topics | Current edition | More

→ A crazy system: Nobody spends enough on mental health

First things first

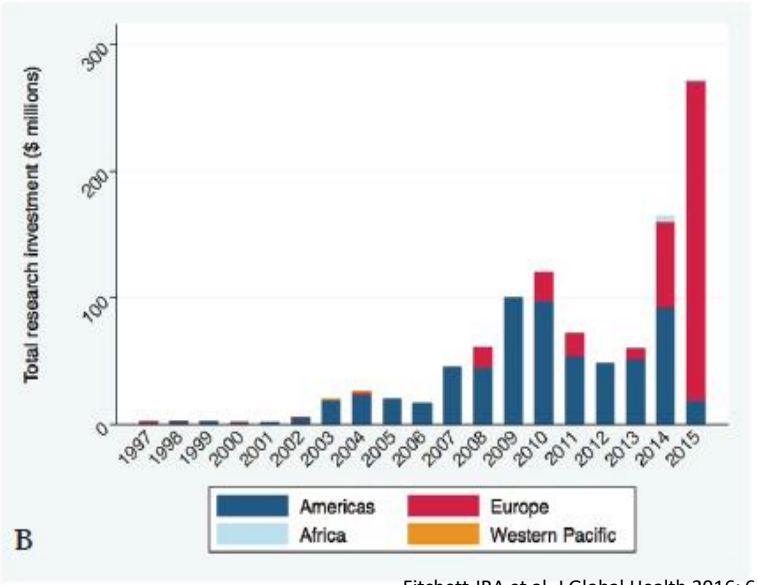
The importance of primary care

Good primary care is an essential precondition for a decent health-care system

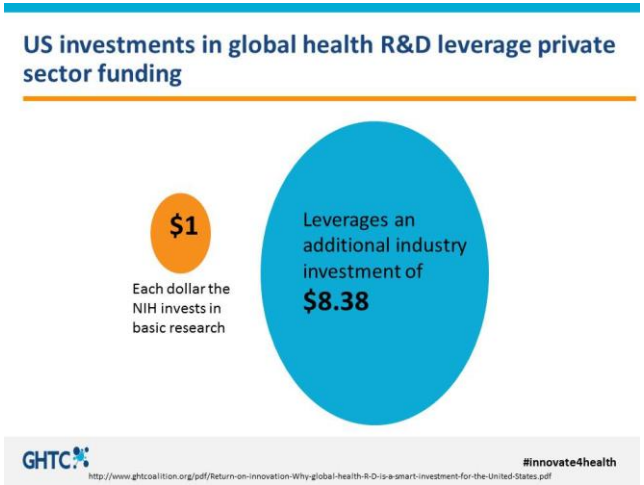
Print edition | Special report ›

Apr 26th 2018

In Africa: su cosa si investe



Fitchett JRA et al. J Global Health 2016; 6 (2): 1-10



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Gestione di malattie croniche

Africa HIV/AIDS, primo «modello» di malattia cronica

Anni 2000

- Personale sanitario
- Strutture
- Cure d'eccellenza
- Retention
- Accessibilità
- Education e training del personale

Gestione di malattie croniche

Africa HIV/AIDS, primo «modello» di malattia cronica

2019

- Personale sanitario
- Strutture
- Cure d'eccellenza
- Retention
- Accessibilità
- Education e training del personale

Retention on antiretroviral therapy in sub-Saharan Africa

505,634 patients

Haas AD et al. *Journal of the International AIDS Society* 2018, **21**:e25084
http://onlinelibrary.wiley.com/doi/10.1002/jia2.25084/full | https://doi.org/10.1002/jia2.25084

Table 2. Cumulative incidence of antiretroviral therapy outcomes

	Cumulative incidence of antiretroviral therapy outcomes (95% CI)			
	Recorded in clinic databases[a]	Adjusted with point estimate[b]	Adjusted with lower limits of CI[b]	Adjusted with upper limits of CI[b]
1 year				
Retained on ART	76.8 (76.7 to 77.0)	83.1 (83.0 to 83.2)	79.7 (79.6 to 79.8)	87.5 (87.4 to 87.6)
Lost to follow-up/stopped ART[c]	19.6 (19.5 to 19.7)	8.5 (8.5 to 8.6)	14.2 (14.1 to 14.2)	0.8 (0.8 to 0.8)
Died	3.5 (3.5 to 3.6)	8.4 (8.3 to 8.4)	6.2 (6.1 to 6.2)	11.7 (11.6 to 11.8)
2 years				
Retained on ART	68.8 (68.7 to 69.0)	77.3 (77.6 to 77.8)	72.9 (72.8 to 73.0)	84.1 (83.9 to 84.2)
Lost to follow-up/stopped ART[c]	26.7 (26.6 to 26.9)	11.7 (11.6 to 11.8)	19.3 (19.2 to 19.5)	1.1 (1.1 to 1.1)
Died	4.4 (4.4 to 4.5)	10.6 (10.5 to 10.7)	7.8 (7.7 to 7.8)	14.9 (14.8 to 15.0)
3 years				
Retained on ART	62.8 (62.7 to 63.0)	73.8 (73.7 to 73.9)	67.9 (67.7 to 68.0)	81.6 (81.5 to 81.8)
Lost to follow-up/stopped ART[c]	32.1 (32.0 to 32.3)	14.2 (14.1 to 14.3)	23.3 (23.2 to 23.4)	1.3 (1.3 to 1.4)
Died	5.0 (5.0 to 5.1)	12.1 (12.0 to 12.2)	8.8 (8.7 to 8.9)	17.0 (16.9 to 17.2)
4 years				
Retained on ART	57.5 (57.4 to 57.7)	70.2 (70.1 to 70.3)	63.3 (63.2 to 63.5)	79.5 (79.3 to 79.6)
Lost to follow-up/stopped ART[c]	36.9 (36.8 to 37.1)	16.4 (16.3 to 16.5)	26.9 (26.8 to 27.0)	1.5 (1.5 to 1.6)
Died	5.6 (5.5 to 5.6)	13.4 (13.3 to 13.5)	9.8 (9.7 to 9.9)	19.0 (18.8 to 19.1)
5 years				
Retained on ART	52.1 (51.9 to 52.3)	66.6 (66.4 to 68.8)	58.7 (58.5 to 58.9)	77.4 (77.2 to 77.5)
Lost to follow-up/stopped ART[c]	41.8 (41.6 to 42.0)	18.8 (18.6 to 18.9)	30.6 (30.4 to 30.8)	1.8 (1.7 to 1.8)
Died	6.0 (6.0 to 6.1)	14.7 (14.5 to 14.8)	10.6 (10.5 to 10.7)	20.8 (20.7 to 21.0)

Data are cumulative incidences of antiretroviral therapy outcomes (in %) and 95% confidence intervals for patients starting antiretroviral therapy. Time is measured in years from start of antiretroviral therapy.
[a]Crude estimates show cumulative incidence of death, loss to follow-up and retention on ART as recorded in the clinic database.
[b]Adjusted estimates correct for underreporting of mortality and transfer out based on the point estimates and 95% confidence intervals (CIs) for mortality (20.8%, 95% CI: 11.3 to 35.1%) and self-transfer (35.9%, 95% CI: 16.8 to 60.9%) among patients lost to follow-up. Adjustment parameters are derived from a meta-analysis of tracing studies [11].
[c]In the adjusted analyses patients alive but not retained on ART are assumed to have stopped ART.

Haas AD et al. J Int AIDS Soc 2018, 21:e25084

General Assembly

Distr.: General
24 January 2012

Sixty-sixth session
Agenda item 117

Resolution adopted by the General Assembly

[*without reference to a Main Committee (A/66/L.1)*]

66/2. Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases

The General Assembly

Adopts the Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases annexed to the present resolution.

3rd plenary meeting
19 September 2011

Annex

Political Declaration of the High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable Diseases

27. Note with concern the possible linkages between non-communicable diseases and some communicable diseases, such as HIV/AIDS, call for the integration, as appropriate, of responses to HIV/AIDS and non-communicable diseases, and in this regard call for attention to be given to people living with HIV/AIDS, especially in countries with a high prevalence of HIV/AIDS, in accordance with national priorities;

Disease Relief through Excellent and Advanced Means

dream
Comunità di Sant'Egidio

Gestione di malattie croniche in Africa– Un modello italiano

- Since 2002
- In 11 nations:
  - **Mozambique**, Malawi, Tanzania, Kenya, Republic of Guinea, Swaziland, Cameroon, Congo RDC, Central African Republic, Angola and Nigeria
- 48 health centres plus 25 laboratories including molecular biology
- ≈500,000 HIV+ pts monitored with regular follow up including clinical monitoring, blood samples, education, prevention, communities involvement

HIV in 2000
Western and SSA health systems

Western countries		**Sub-Saharan Africa**	
• Education and training	yes	• Education and training	no
• Triple therapy:	yes	• Triple therapy:	no
• Viral load detection:	yes	• Viral load detection:	no
• ARV during pregnancy :	yes	• ARV during pregnancy :	no
• Test and treat :	yes	• Test and treat :	no
• Specialized centres:	yes	• Specialized centres:	no
• Drugs free:	yes	• Drugs free:	no

HIV in 2000
Western and SSA health systems

Western countries

- Education and training yes
- Triple therapy: yes
- Viral load detection: yes
- ARV during pregnancy : yes
- Test and treat : yes
- Specialized centres: yes
- Drugs free: yes

DREAM in Sub-Saharan Africa

- Education and training yes
- Triple therapy: yes
- Viral load detection: yes
- ARV during pregnancy : yes
- Test and treat : yes
- Specialized centres: yes
- Drugs free: yes

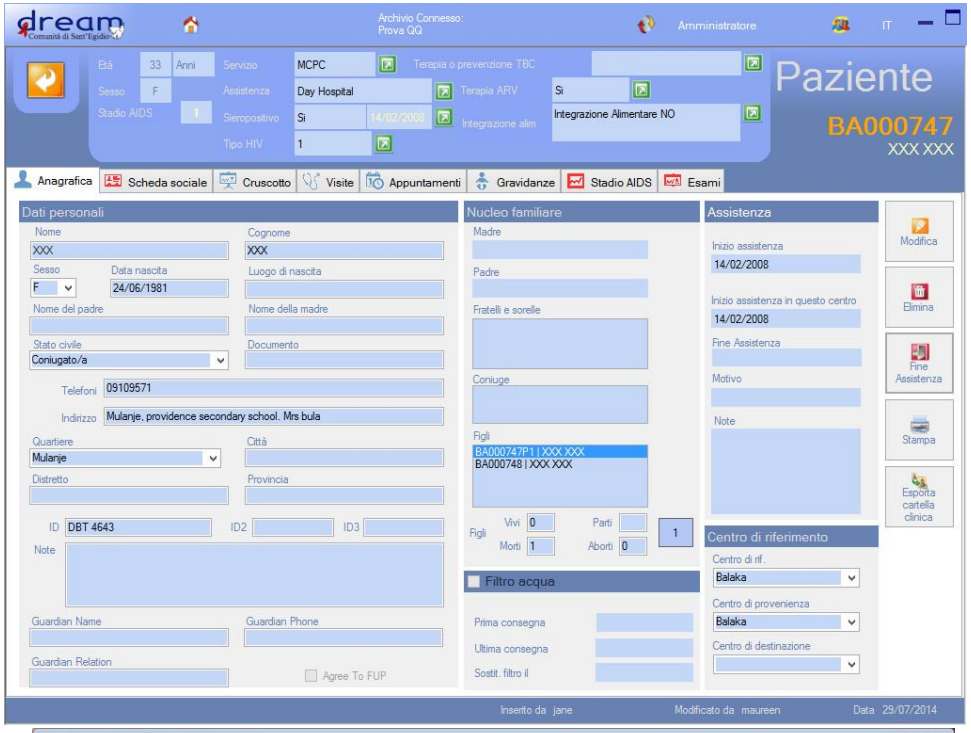
DREAM is education and training

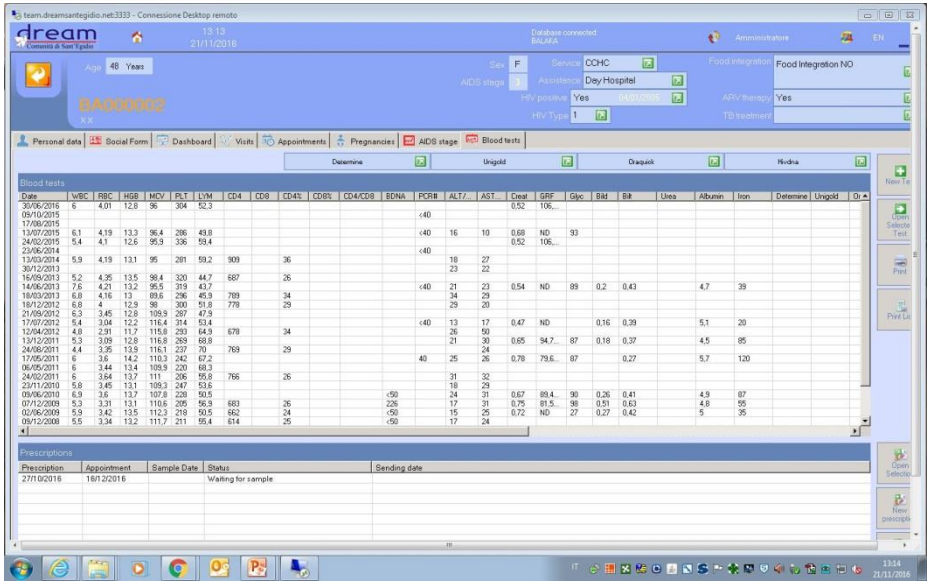
- More than 10,000 african personnel: doctors, clinical officers, nurses, biologists, lab. technicians, coordinators, managers, health personal – home casre, counselling etc-, technicians for pc, networking, renewable energies. 28 Pan-African courses 2002–2016.

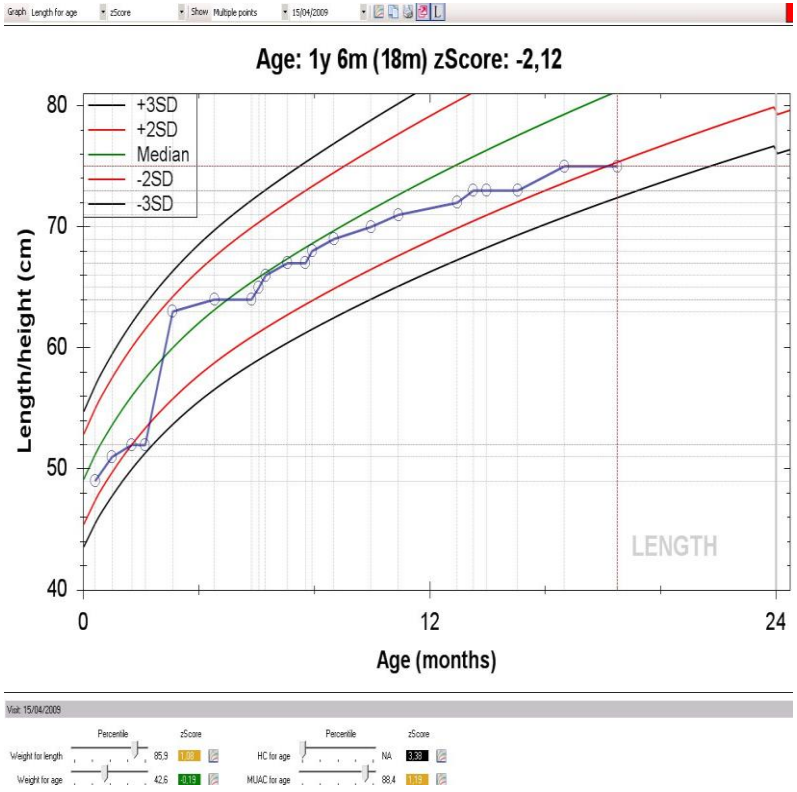
Modifies from Liotta et al. Int J Environ Res Public Health 2015; 12: 1324-39

dream
Comunità di Sant'Egidio

The DREAM software







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DREAM laboratories

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Retention in DREAM

DOI: 10.1111/hiv.12492

HIV Medicine (2017), 18, 573–579

ORIGINAL RESEARCH

Who will be lost? Identifying patients at risk of loss to follow-up in Malawi. The DREAM Program Experience

S Mancinelli,[1] K Nielsen-Saines,[2] P Germano,[3] G Guidotti,[3] E Buonomo,[1] P Scarcella,[1] R Lunghi,[4] H Sangare,[4] S Orlando,[3] G Liotta,[1] MC Marazzi[5] and L Palombi[1]

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Objectives

Retention of subjects in HIV treatment programmes is crucial for the success of treatment. We evaluated retention/loss to follow-up (LTFU) in subjects receiving established care in Malawi.

Methods

Data for HIV-positive patients registered in Drug Resource Enhancement Against AIDS and Malnutrition centres in Malawi prior to 2014 were reviewed. Visits entailing HIV testing/counselling, laboratory evaluations, nutritional evaluation/supplementation, community support, peer education, and antiretroviral (ART) monitoring/pharmacy were noted. LTFU was defined as > 90 days without an encounter. Parameters potentially associated with LTFU were explored, with univariate/multivariate logistic regression analyses being performed.

Results

Fifteen thousand and ninety-nine patients registered before 2014; 202 (1.3%) were lost to follow-up (LTFU) (1.3%). Nine (0.5%) of 1744 paediatric patients were LTFU *vs.* 1.4% (n = 193) of 13 355 adults ($P < 0.001$). Subjects who were LTFU had fewer days in care than retained subjects (1338 *vs.* 1544, respectively; $P < 0.001$) and a longer duration of ART (1530 *vs.* 1300 days, respectively; $P < 0.001$). Subjects who were LTFU had higher baseline HIV viral loads ($P = 0.016$) and higher body mass indexes ($P < 0.001$), were more likely to live in urban settings (88% of patients who were LTFU lived in urban settings) with better housing [relative risk (RR) 2.3; 95% confidence interval (CI) 1.67–3.09; $P < 0.001$], and were more likely to be educated (RR 1.88; 95% CI 1.42–2.50; $P < 0.001$). Distance to the centre and cost of transportation were associated with LTFU (RR 3.4; 95% CI 2.84–5.37; $P < 0.001$), as was absence of a maternal figure (RR 1.57; 95% CI 1.17–2.09; $P < 0.001$). Viral load, distance index, education and a maternal figure were predictive of LTFU.

Conclusions

Educated, urbanized HIV-infected adults living far from programme centres are at high risk of LTFU, particularly if there is no maternal figure in the household. These variables must be taken into consideration when developing retention strategies.

Keywords: HIV, loss to follow-up, Malawi, predictors, retention

Accepted 17 November 2016

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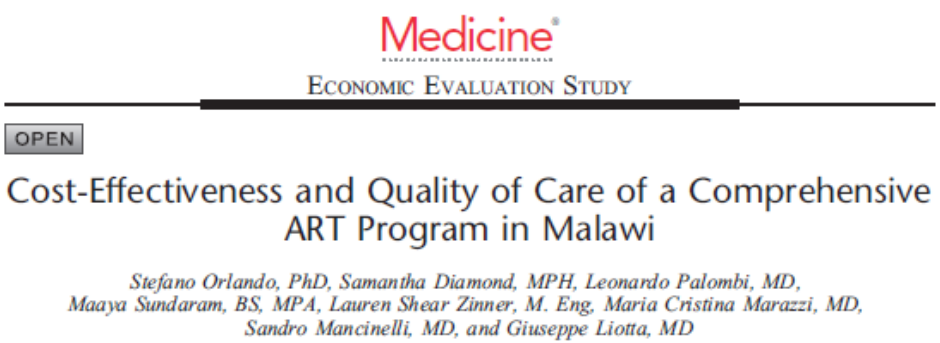
DREAM, a cost-effective model



Medicine®

ECONOMIC EVALUATION STUDY

OPEN

Cost-Effectiveness and Quality of Care of a Comprehensive ART Program in Malawi

Stefano Orlando, PhD, Samantha Diamond, MPH, Leonardo Palombi, MD, Maaya Sundaram, BS, MPA, Lauren Shear Zinner, M. Eng, Maria Cristina Marazzi, MD, Sandro Mancinelli, MD, and Giuseppe Liotta, MD

- DREAM vs Malawi Ministry Health Program
- After 5 years
  - Costs per patient per year: 223,1 vs 136 USD
  - Living patients 79,8% vs 60%
  - DREAM
    - Income per patient/year : 1° year 64,65 – 5°year 606,89USD

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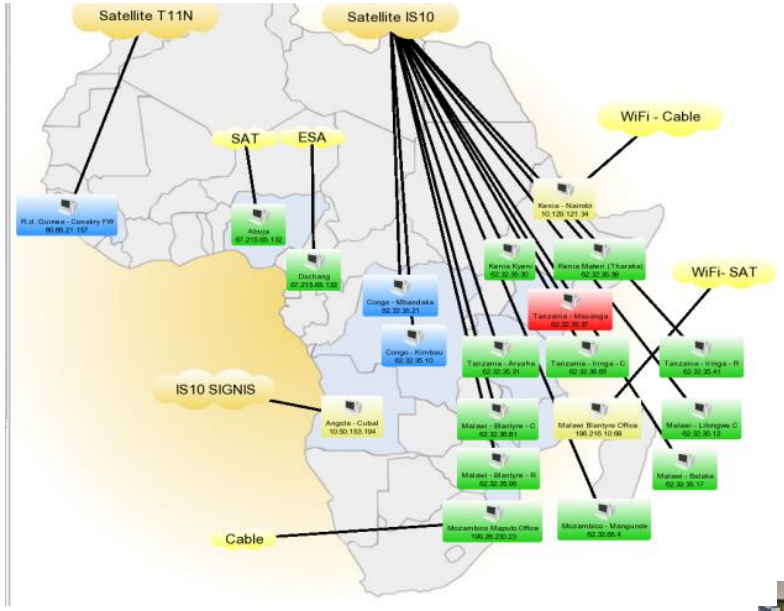
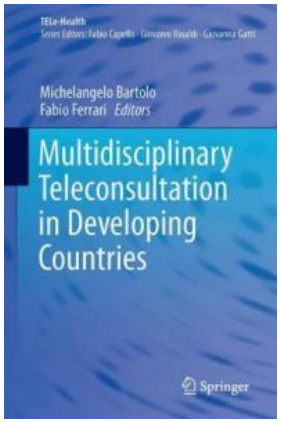
DREAM and telemedicine





a)

b)

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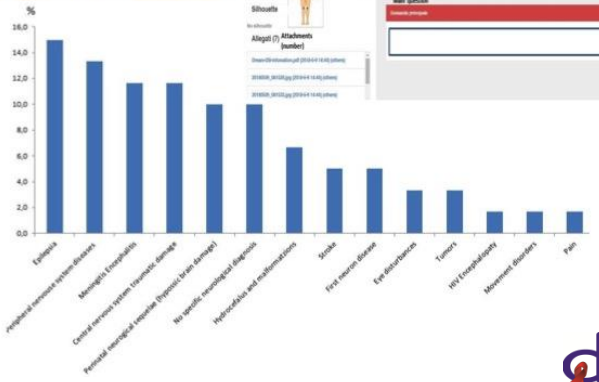
Letter to the Editor

Teleneurology in sub-Saharan Africa: Experience from a long lasting HIV/AIDS health program (DREAM)



c)

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DREAM and sustainability

Plant for Africa and Renewable Energy 14

Energy for Life: Electrical Wiring and Renewable Energy
Plant Design for Small-Scale Health Facilities in Africa

Giorgio Barbaglia

Fig. 14.3 AROS SPS hybrid solar inverters powering DREAM center and laboratory. Balaka, Malawi

Fig. 14.15 Installing a hybrid solar power system at the DREAM center and laboratory. Mthengo wa Ntenga (Lilongwe) Malawi

Fig. 14.2 Solar plant on DREAM center. Balaka, Malawi

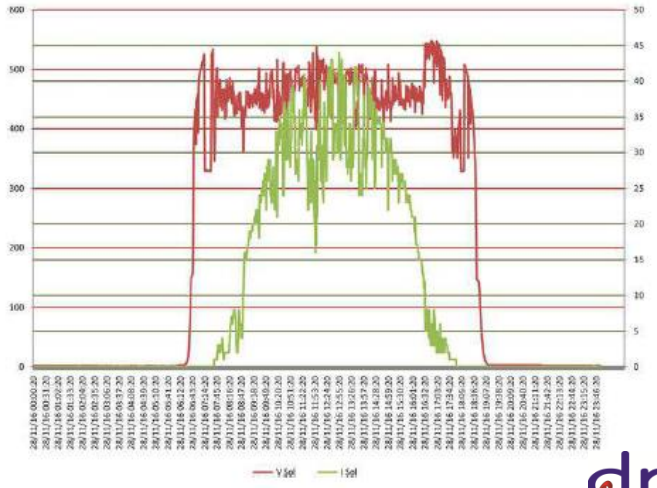

Fig. 14.13 Photovoltaic voltage (V) and current (A) on a 24-h basis

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Disease Relief through Excellent and Advanced Means

- Modello extra-ospedaliero per la gestione delle malattie croniche e non comunicabili

Epilepsy, changes in behavior and mental illness

Improving epilepsy in sub-Saharan countries
The need to improve culture

World Health Organization

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Mental health

- Mental health home
- Mental Health Action Plan 2013-2020
- mhGAP
- Evidence and research
- Policy and services
- Maternal and child mental health
- Neurology and public health
- Mental disorders
- Suicide prevention
- Mental health in emergencies
- Mental health publications

International Epilepsy Day

Leigh Lacobucci

Health nurse, Ghana

9 February 2018 - International Epilepsy Day, on 12 February, is an opportunity to raise awareness of epilepsy, what it is, how it can be treated, and what is needed to bring treatment to all people who need it.

The ability of health workers to diagnose epilepsy, the availability of medicines and research into the health and social care response to epilepsy are just three areas of action for WHO and partners.

For more information on epilepsy
International Epilepsy Day

Highlights | International Epilepsy Day | Treating and defeating epilepsy in Ghana | WHO Information Kit on Epilepsy: What you can do

ww.who.int/news-room

Africa subsaariana
STROKE

- Percorso formativo per la prevenzione
- Ipertensione arteriosa (uccide 4 volte di più in Africa che altrove)
  - Diagnosi
  - Misurazione della pressione arteriosa a tutti (in Africa il 50% della popolazione non ne ha accesso)
  - ECG e valutazione cardiologica. Telemedicina!
  - Bioumorali di base, glicemia, elettroliti, funzione renale, esame urine, profilo lipidico etc
  - Educazione stile di vita: fumo, alcool, **peso**, sedentarietà, carica virale virus HIV, altri fattori di rischio
  - Garantire i farmaci per l'ipertensione arteriosa, il **diabete** etc
  - Ridurre il carico ospedaliero: rete territorio - ospedale
  - Retention dei pazienti

Riunione fondativa del Gruppo di Studio
della Società Italiana di Neurologia

Società Italiana di Neurologia e paesi in via di sviluppo

Milano, 20 marzo 2019
Istituto Neurologico Besta, Biblioteca Centrale

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