Cicely Saunders International
Better care at the end of life

WHO Collaborating Centre

KING'S College LONDON

Palliative care for people with HIV: *an essential component of care services*

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Competing or conflicting interests

- None to declare

This presentation draws on forthcoming paper

- Harding R. Lancet HIV (In Press)

“Palliative care:

an essential component of the HIV care continuum”

HIV mortality

- Globally 1m AIDS-related deaths 2016
- UK (PHE 2015):
  - 594 people with HIV infection died
  - 58% aged over 50
  - all-cause mortality aged 15-59 per 1,000

	2005	2015
PLWH	10.2	5.7
General population		1.6

Aging & comorbidity

- **Malignancies**
  - **PLWH in Europe 5 yr estimates from 2011**
  - IRM 28% decrease
  - IURM 44% increase (Shepherd HIV Med 2017)
  - **Increase in death non-AIDS cancer 2009-2011, EU, USA, Australia**
  - 23% of all non-AIDS deaths (Smith Lancet 2014)
- **Comorbidities**
  - UK over 50's 61% 2 comorbidities (Patel IJSTDA 2016)
  - Dutch 28% ≥3 comorbidities by 2030 (largely CVD) (Smit LID 2015)
- **Cardiovascular disease incidence: men in USA by age 60**
  - 20.5% HIV-infected under ART
  - 14.6% HIV-uninfected high-risk persons
  - 12.8% in US general population (Holloway CIHA 2017)
- **Older people's concerns UK**
  - HIV skills, coordination, confidentiality (Pollard IJSA 2017)

Public Health England

NHS England

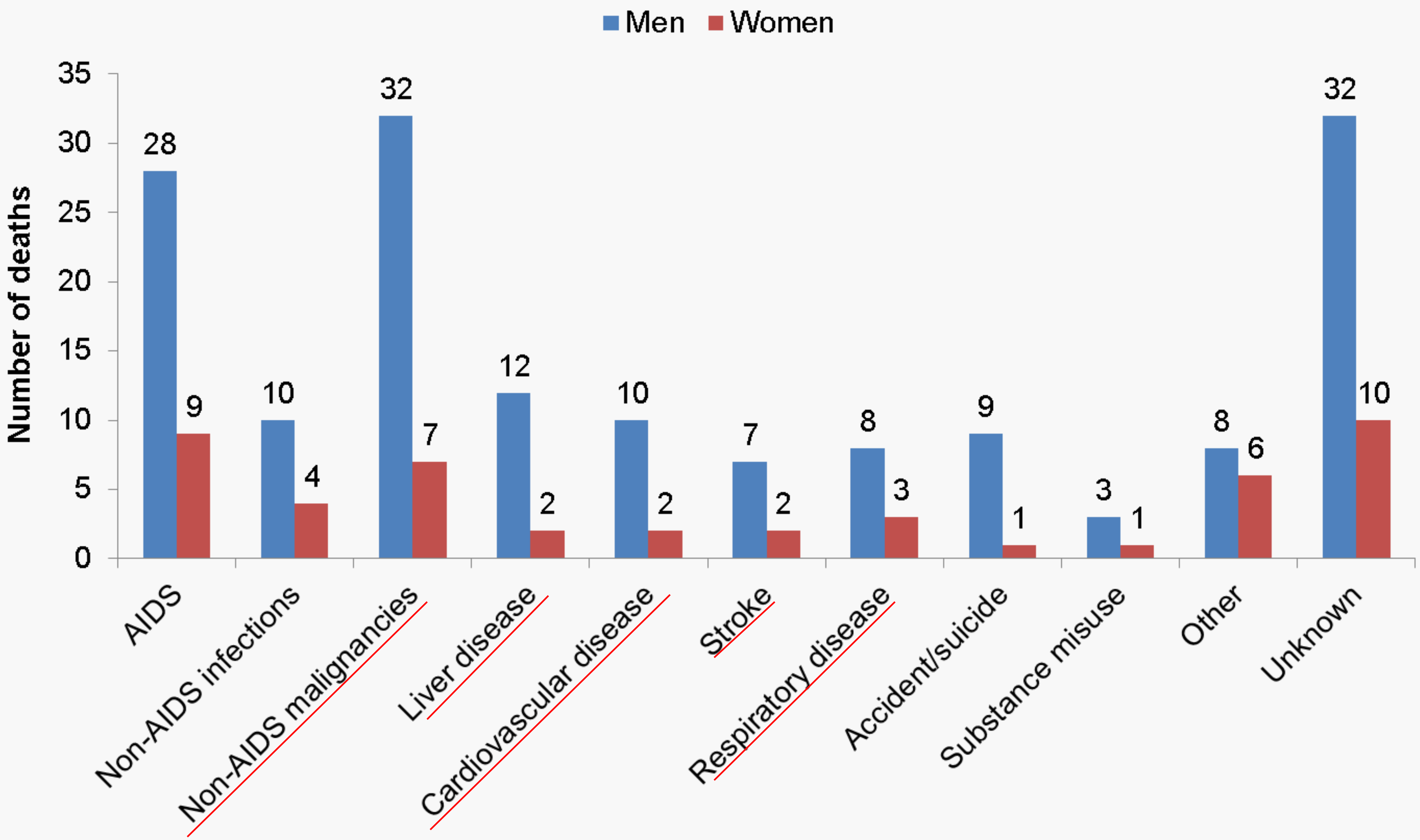
London HIV mortality audit

- Aims:
    - Improve quality of patient care by reviewing the patient pathway of HIV+ patients who die in London, i.e. remediable factors
    - Identify particular scenarios that are worthy of further case investigation, including periodic public case presentation and audit
    - Public health benefit through identifying areas to focus outcomes measures to *prevent people dying early*

- Death data were submitted by 19 centres
- Total deaths reported in 2016: **206**

(Sarah Croxford)

Cause of death by sex: London, 2016



High number of unknown deaths as autopsy reports outstanding

Public Health England

NHS England

End of life care and expected death

- **66%** of expected deaths had an end of life care discussion (70% of men; 56% of women)
- End of life data only available for 57% of patients (N=118/206)
- Place of death among expected deaths:

	Men		Women	
	n	%	n	%
Hospital	48	60%	15	63%
Hospice	15	19%	3	13%
Home	12	15%	4	17%
Community	0	0%	1	4%
Nursing home	4	5%	1	4%
Abroad	1	1%	0	0%

Place of death

- Majority of people (73.9%) would wish to be told of poor prognosis

(Harding Psychooncology 2013)

- The majority of people (67%) wish to die at home

(Gomes Annals Oncol 2012)

- HIV as underlying cause of death 2007
  - more likely to die in hospital in 11/11 high income countries compared to cancer deaths
  - UK 12.0% at home vs 28.1% cancer

(Harding BMC Infect Dis 2018)

Defining palliative care: WHO

- “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Principles of palliative care (WHO)

1. Relief from **pain** and other distressing **symptoms**
2. **Affirms life** and regards **dying** as a **normal process**
3. Intends **neither** to **hasten** or **postpone death**
4. Integrates **psychological** and **spiritual aspects** of care
5. Help patients **live** as **actively** as possible until death
6. Help **family cope during** the illness and in **bereavement**
7. Team approach including **bereavement counselling**
8. Enhance **quality of life**, **positively influence** the course of **illness**
9. **Applicable early** in the course of illness, in **conjunction** with other **therapies** that are intended to **prolong life**, such as chemotherapy or radiation therapy

Policy & effectiveness

- World Health Assembly resolution 67.19 (2014)
  - *"fundamental to improving the quality of life, well-being, comfort and human dignity of individuals being an effective person-centred health service"*
  - *"Integrate palliative care as an integral component of ongoing education and training"*

- *Universal health Coverage Goals (WHO)*
  - *"the full spectrum of essential, quality health services, from health promotion to prevention, treatment, rehabilitation, and palliative care"*

- *ACP:* voluntary process of discussion and review concerning preferences for future care
  - *Improves costs, preferred place of death, satisfaction, anxiety*

(Dixon JPSM 2017)

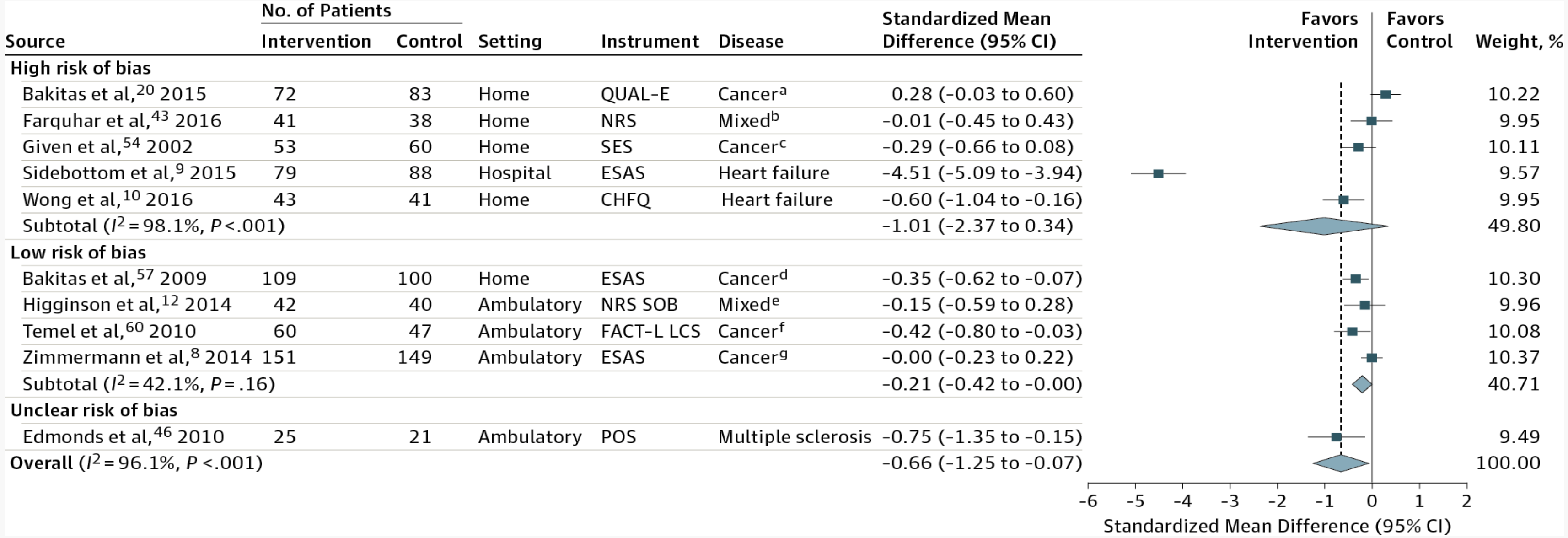
Effectiveness

- Hospital based end of life care
  - Improves end-of-life discussions and documentation, psychosocial distress, satisfaction and concordance in care

(Waller BMC palliative care 2017)

(JAMA 2016 Kavaleteros)

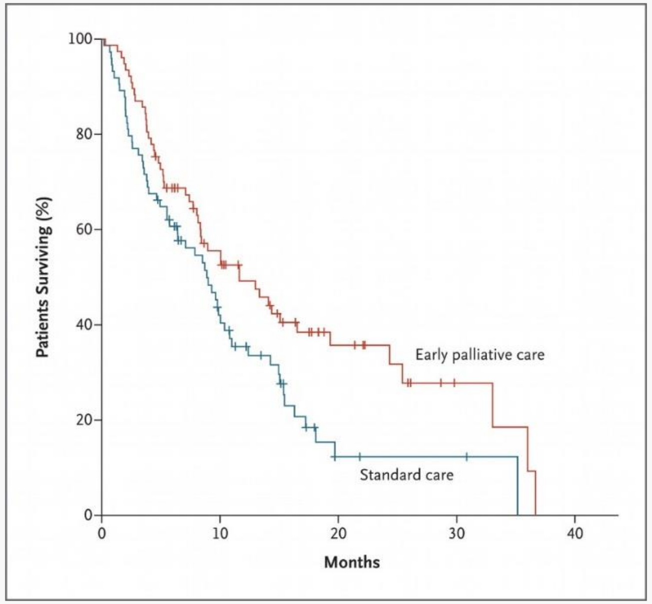
- Specialist teams

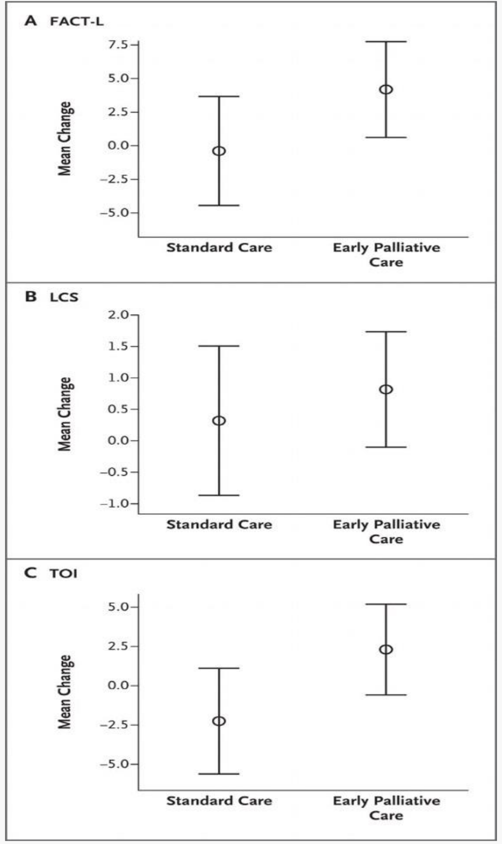


Source	No. of Patients Intervention	No. of Patients Control	Setting	Instrument	Disease	Standardized Mean Difference (95% CI)	Weight, %
High risk of bias							
Bakitas et al,[20] 2015	72	83	Home	QUAL-E	Cancer[a]	0.28 (−0.03 to 0.60)	10.22
Farquhar et al,[43] 2016	41	38	Home	NRS	Mixed[b]	−0.01 (−0.45 to 0.43)	9.95
Given et al,[54] 2002	53	60	Home	SES	Cancer[c]	−0.29 (−0.66 to 0.08)	10.11
Sidebottom et al,[9] 2015	79	88	Hospital	ESAS	Heart failure	−4.51 (−5.09 to −3.94)	9.57
Wong et al,[10] 2016	43	41	Home	CHFQ	Heart failure	−0.60 (−1.04 to −0.16)	9.95
Subtotal ($I^2 = 98.1\%$, $P < .001$)						−1.01 (−2.37 to 0.34)	49.80
Low risk of bias							
Bakitas et al,[57] 2009	109	100	Home	ESAS	Cancer[d]	−0.35 (−0.62 to −0.07)	10.30
Higginson et al,[12] 2014	42	40	Ambulatory	NRS SOB	Mixed[e]	−0.15 (−0.59 to 0.28)	9.96
Temel et al,[60] 2010	60	47	Ambulatory	FACT-L LCS	Cancer[f]	−0.42 (−0.80 to −0.03)	10.08
Zimmermann et al,[8] 2014	151	149	Ambulatory	ESAS	Cancer[g]	−0.00 (−0.23 to 0.22)	10.37
Subtotal ($I^2 = 42.1\%$, $P = .16$)						−0.21 (−0.42 to −0.00)	40.71
Unclear risk of bias							
Edmonds et al,[46] 2010	25	21	Ambulatory	POS	Multiple sclerosis	−0.75 (−1.35 to −0.15)	9.49
Overall ($I^2 = 96.1\%$, $P < .001$)						−0.66 (−1.25 to −0.07)	100.00

Novel approaches in palliative care

- Temel NEJM 2010 metastatic non-small lung cancer

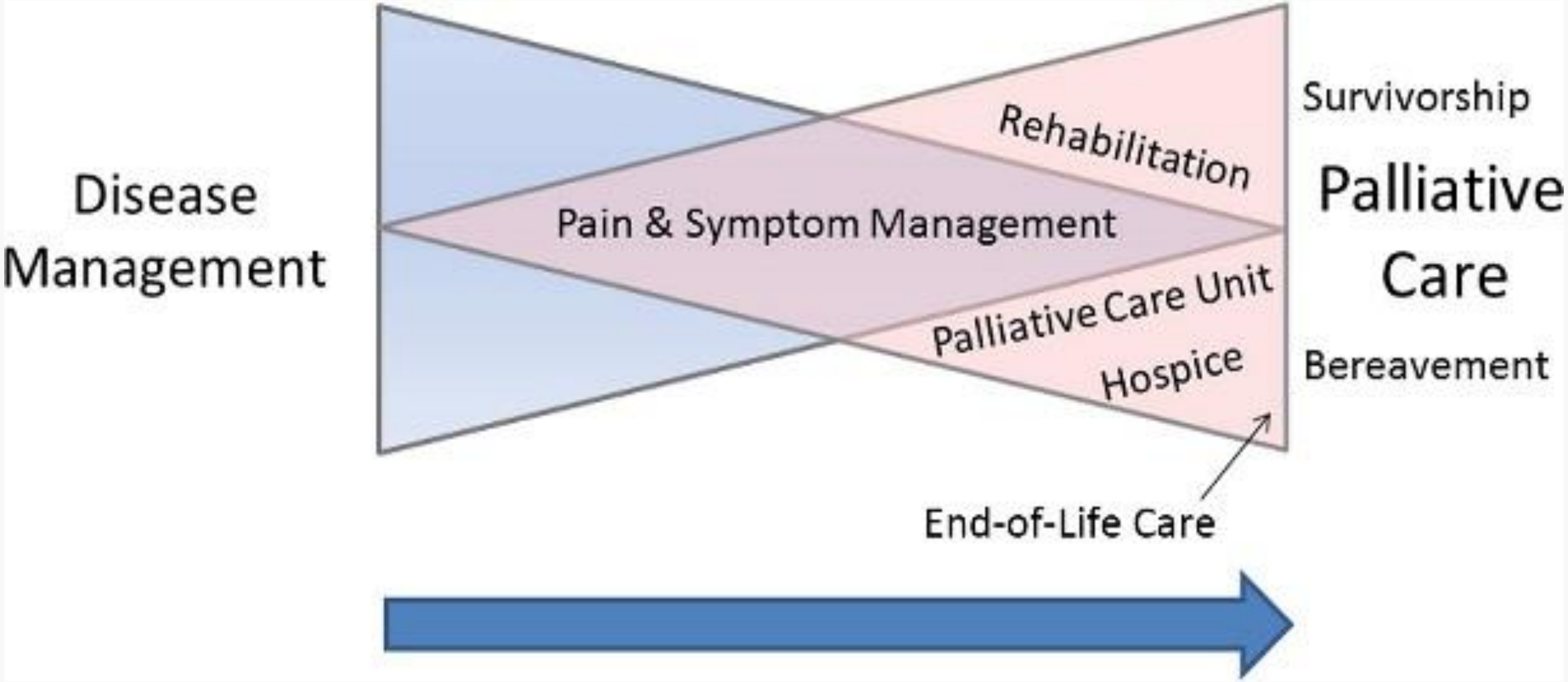




- Bakitas JAMA 2009 (cancer pts)
  - QoL, symptoms, mood
- Higginson Lancet Resp Med 2014 (breathlessness)
  - Mastery, QoL, survival

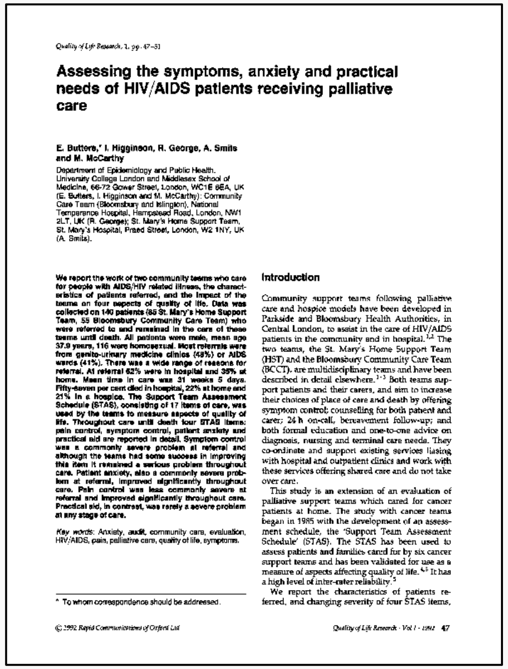
Bowtie model (Hawley 2014)

- Palliative care should be part of maximum or optimal medical management



HIV palliative care provision

MILDMAY



Quality of Life Research, 1, pp. 47–51

Assessing the symptoms, anxiety and practical needs of HIV/AIDS patients receiving palliative care

E. Butters,* I. Higginson, R. George, A. Smits and M. McCarthy

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We report the work of two community teams who care for people with AIDS/HIV related illness, the characteristics of patients referred, and the impact of the teams on four aspects of quality of life. Data was collected on 140 patients (85 St. Mary's Home Support Team, 55 Bloomsbury Community Care Team) who were referred to and remained in the care of these teams until death. All patients were male, mean age 37.9 years, 116 were homosexual. Most referrals were from genito-urinary medicine clinics (48%) or AIDS wards (41%). There was a wide range of reasons for referral. At referral 62% were in hospital and 35% at home. Mean time in care was 31 weeks 5 days. Fifty-seven per cent died in hospital, 22% at home and 21% in a hospice. The Support Team Assessment Schedule (STAS), consisting of 17 items of care, was used by the teams to measure aspects of quality of life. Throughout care until death four STAS items: pain control, symptom control, patient anxiety and practical aid are reported in detail. Symptom control was a commonly severe problem at referral and although the teams had some success in improving this item it remained a serious problem throughout care. Patient anxiety, also a commonly severe problem at referral, improved significantly throughout care. Pain control was less commonly severe at referral and improved significantly throughout care. Practical aid, in contrast, was rarely a severe problem at any stage of care.

Key words: Anxiety, audit, community care, evaluation, HIV/AIDS, pain, palliative care, quality of life, symptoms.

Introduction

Community support teams following palliative care and hospice models have been developed in Parkside and Bloomsbury Health Authorities, in Central London, to assist in the care of HIV/AIDS patients in the community and in hospital.[1,2] The two teams, the St. Mary's Home Support Team (HST) and the Bloomsbury Community Care Team (BCCT), are multidisciplinary teams and have been described in detail elsewhere.[1-3] Both teams support patients and their carers, and aim to increase their choices of place of care and death by offering symptom control; counselling for both patient and carer; 24 h on-call, bereavement follow-up; and both formal education and one-to-one advice on diagnosis, nursing and terminal care needs. They co-ordinate and support existing services liasing with hospital and outpatient clinics and work with these services offering shared care and do not take over care.

This study is an extension of an evaluation of palliative support teams which cared for cancer patients at home. The study with cancer teams began in 1985 with the development of an assessment schedule, the 'Support Team Assessment Schedule' (STAS). The STAS has been used to assess patients and families cared for by six cancer support teams and has been validated for use as a measure of aspects affecting quality of life.[4,5] It has a high level of inter-rater reliability.[5]

We report the characteristics of patients referred, and changing severity of four STAS items,

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- No great heterogeneity in symptom burden across advanced conditions including AIDS (Moens 2014)

Effectiveness of HIV palliative care

- "Home palliative care and inpatient hospice care significantly improve patient outcomes in the domains of pain and symptom control, anxiety, insight, and spiritual wellbeing"

Harding BMJ STI 2005

5

REVIEW

Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence

R Harding, D Karus, P Easterbrook, V H Raveis, I J Higginson, K Marconi

Sex Transm Infect 2005;81:5–14. doi: 10.1136/sti.2004.010132

Background: The need for palliative care in HIV management is underlined by the high prevalence of pain and symptoms, the toxicity, side effects, and virological failure associated with antiretroviral therapy, emergence of co-morbidities, continued high incidence of malignancies, late presentation of people with HIV disease, and the comparatively higher death rates among the infected individuals.
Methods: A systematic review was undertaken to appraise the effect of models of palliative care on patient outcomes. A detailed search strategy was devised and biomedical databases searched using specific terms relevant to models of palliative care. Data from papers that met the inclusion criteria were extracted into common tables, and evidence independently graded using well described hierarchy of evidence.
Results: 34 services met the inclusion criteria. Of these, 22 had been evaluated, and the evidence was graded as follows: grade 1 (n = 1); grade 2 (n = 2); grade 3 (n = 7); grade 4 (n = 1); qualitative (n = 6). Services were grouped as: home based care (n = 15); home palliative care/hospice at home (n = 7); hospice inpatient (n = 4); hospital inpatient palliative care (n = 4); specialist AIDS inpatient unit (n = 2); and hospital inpatient and outpatient care (n = 2). The evidence largely demonstrated that home palliative care and inpatient hospice care significantly improved patient outcomes in the domains of pain and symptom control, anxiety, insight, and spiritual wellbeing.
Conclusions: Although the appraisal of evidence found improvements across domains, the current body of evidence suffers from a lack of (quasi) experimental methods and standardised measures. The specialism of palliative care is responding to the clinical evidence that integration into earlier disease stages is necessary. Further studies are needed to both identify feasible methods and evaluate the apparent beneficial effect of palliative care on patient outcomes in the post-HAART era.

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The World Health Organization defines palliative care as[1] "an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

UNAIDS estimates at least 40 million people living with HIV/AIDS in 2003, and during 2003 there were three million HIV/AIDS related deaths, and five million new infections.[2] The high prevalence of HIV related manageable symptoms including fatigue, anorexia, weight loss, depression, agitation and anxiety, nausea and vomiting, diarrhoea, cough, dyspnoea, fever, sweats, and pruritus,[3 4] as well as often inadequate pain control[5 6] at all stages of HIV disease emphasise the need for palliative therapy.

Although widespread adoption of highly active antiretroviral therapy (HAART) in industrialised countries since 1996 has profoundly impacted on morbidity and mortality, the need for palliative care has continued. Firstly, HIV infected patients continue to die at a higher rate than the uninfected,[7] and the virological failure rate with first and second line therapy remains high.[8 9] Secondly, antiretroviral drugs are associated with a significant rate of toxicity and side effects[10] such as peripheral neuropathy and gastrointestinal problems. Thirdly, as a result of survival prolongation, new co-morbidities have become apparent such as end stage liver disease secondary to hepatitis C co-infection, myocardial infarction,[11] cerebrovascular disease,[12] and diagnoses associated with significant neurological and cognitive impairment such as progressive multifocal leucoencephalopathy.[13 14] Fourthly, some HIV related malignancies such as non-Hodgkin's lymphoma, cervical carcinoma and colorectal and lung malignancies have not declined in incidence with HAART.[15–17] Fifthly, a significant proportion of HIV infected individuals are unaware of their diagnosis, and present only with advanced disease.

The changing epidemiology of HIV disease in the era of HAART has resulted in new and evolving roles for palliative care, with a shift from the more conventional HIV palliative care of the 1980s and early 1990s to a greater focus on symptom control in patients who may continue to live for an extended period, or the need for active treatment for one HIV related condition and palliation for another simultaneously.[18] However, in the developing world, where the majority of the HIV cases occur, and where antiretroviral drug availability remains limited, the principles of traditional palliative care still apply.

To date, there has been no comprehensive review of the different models of palliative care and their effectiveness for people affected by HIV/AIDS. Our objective was to systematically review the evidence base for the effectiveness of palliative care in improving patient outcomes in HIV/AIDS.

METHODS

Search strategy

In December 2003, we searched the following databases: Medline (1980–2003), CINAHL (1982–2003), PsychINFO (1980–2003), Embase (1980–2003), Applied Social Sciences Index and Abstracts (1987–2003), and Social Sciences

Abbreviations: CCT, community care team; HAART, highly active antiretroviral therapy; HCA, home care assistance; HST, home support team; ITDU, infectious and tropical diseases unit; PCU, palliative care unit; POS, Palliative Outcome Scale; QoL, quality of life; RCT, randomised controlled trial; STAS, Support Team Assessment Schedule

www.stijournal.com

HIV palliative care skill base

- Moss AIDS 1990 *“It could be said that all care in AIDS is necessarily palliative, since no specific cure has yet been found”*
- Selwyn BMJ STI 2005 *“Early in the epidemic HIV care providers were by definition palliative care providers. Now the challenge is to reacquaint.”*
- Simms Lancet Infectious Diseases 2012 *“Modern palliative care offers effective ways to improve outcomes, not as an alternative or last resort”*

ACCESScare

- *“it’s hard work going through twenty, thirty odd years of history… and you can’t get your breath… and you’re trying to explain and try and talk at the same time which makes it worse.’*

White British gay man 52, living with HIV and COPD

- *‘But not knowing what's out there or what's going on out there, I, I can, I find it difficult asking the right questions… And I finish up spending an hour or somebody's time just trying to work out what's good for me.*

White British gay man 64, living with HIV and Prostate Ca

(Bristowe Palliative Medicine 2017)

Challenges to quality of care

- Multimorbidity with HIV
  - attention to communication when crossing specialty areas
  - additional support to decrease stressors from HIV stigma

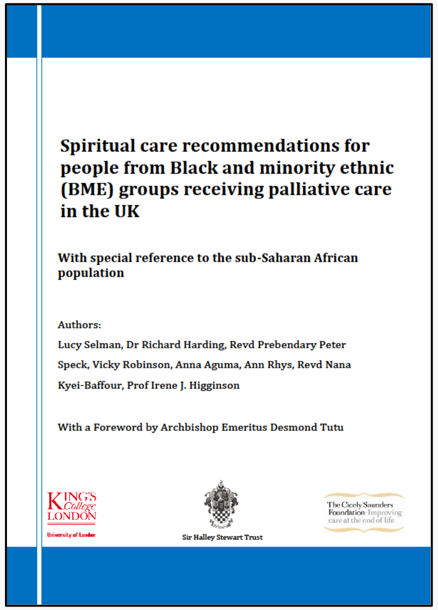
(Slomka JANAC 2017)

- Retrospective study of deaths Ontario
  - 570/264574 deaths were PLWH
  - dying younger 56.1 vs 76.6
  - more time in hospital 20/90 vs 12.1/90
  - costs last year of life $80,885.62 vs. $53,869.77

JAIDS Kendall 2017

Spiritual wellbeing & cultural dimensions

- **Spiritual care reccs**
  - Know your patient’s beliefs
  - Assess spiritual distress
  - Know you local spiritual care providers
  - Invite providers in to your setting
  - Encourage mutual training



Spiritual care recommendations for people from Black and minority ethnic (BME) groups receiving palliative care in the UK

With special reference to the sub-Saharan African population

Authors:

Lucy Selman, Dr Richard Harding, Revd Prebendary Peter Speck, Vicky Robinson, Anna Aguma, Ann Rhys, Revd Nana Kyei-Baffour, Prof Irene J. Higginson

With a Foreword by Archbishop Emeritus Desmond Tutu

King's College London
University of London

Sir Halley Stewart Trust

The Cicely Saunders Foundation · Improving care at the end of life

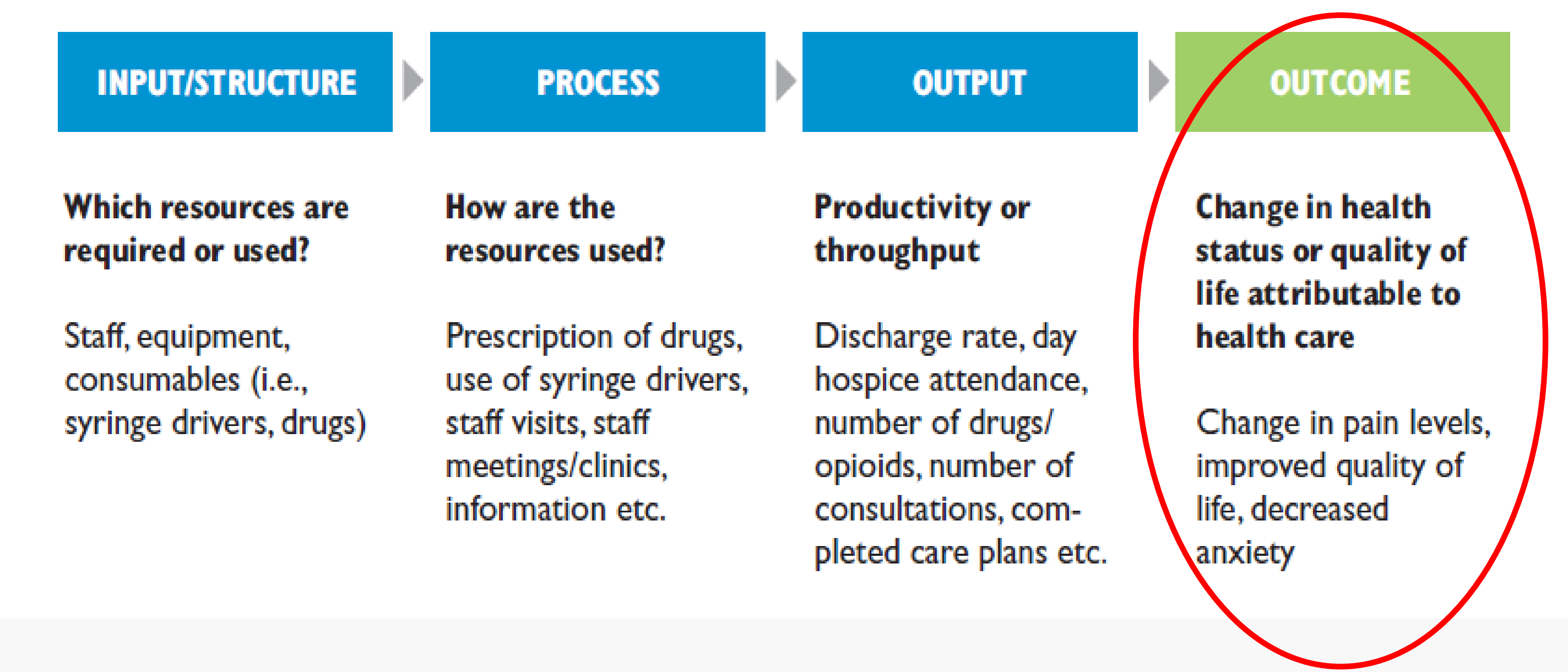
- **Culture and pain**
  - Patients of African & Caribbean origin have under-treatment of pain
    (Hoffman 2016 Nat Acad Sci USA)
  - In UK advanced cancer pts pain as “*punishment*” and “*test of faith*” that doesn’t need analgesia
    (Koffman Pall Med 2008)

PROMs in the UK

- NHS policy drive for use of PROMs
- PROMs are central to:
  - promoting patient-centredness
  - clinical care, audit & research
- Routine use of PROMs data can improve
  - communication with staff (Greenhalgh 2015)
  - outcomes for patients (Boyce 2013)
- In palliative care we are
  - using outcomes for minimum data set DoH & informing tariff
  - routine implementation through NIHR Programme Grant & CLAHRC

What is an outcome?

Outcome = "the change in a patient's current and future health status that can be attributed to preceding healthcare"
(Donabedian, 1980)



INPUT/STRUCTURE	PROCESS	OUTPUT	OUTCOME
Which resources are required or used?	**How are the resources used?**	**Productivity or throughput**	**Change in health status or quality of life attributable to health care**
Staff, equipment, consumables (i.e., syringe drivers, drugs)	Prescription of drugs, use of syringe drivers, staff visits, staff meetings/clinics, information etc.	Discharge rate, day hospice attendance, number of drugs/opioids, number of consultations, completed care plans etc.	Change in pain levels, improved quality of life, decreased anxiety

www.pos-pal.org

You are not logged in. Login or Register

The Palliative care Outcome Scale (POS) is a resource for palliative care practice, teaching and research. This website has been established by a not-for-profit organisation to help advance measurement in palliative care. Free resources and training are available.

The POS measures are a family of tools to measure patients' physical symptoms, psychological, emotional and spiritual, and information and support needs. They are validated instrument that can be used in clinical care, audit, research and training.

The POS measures are specifically developed for use among people severely affected by diseases such as cancer, respiratory, heart, renal or liver failure, and neurological diseases.

The POS measures are widely used globally including in Europe, Australia, Asia, Africa and America.

POS can be downloaded from this website and is available in 11 languages including English.

few minutes).

Get involved

We are always looking for academic and clinical centres interested in translating and validating POS measures in new languages, settings and disease groups. Contact us.

We also want to hear from professionals using POS measures locally and nationally.

News and Events

POS 2016 workshops: Clinical day Thurs 11th and Research day Fri 12th February 2016, programmes now available on the Courses and Workshops page. Click here to book.

Quality of life in multiple myeloma: Recent international research and future developments, Thursday 31st March 2016. For more information and to book click here.

Now available; a Clinical Decision Support Tool for using POS in clinical practice & Guidance for Implementing PROMS in clinical care; including a newly published paper. Free to download.

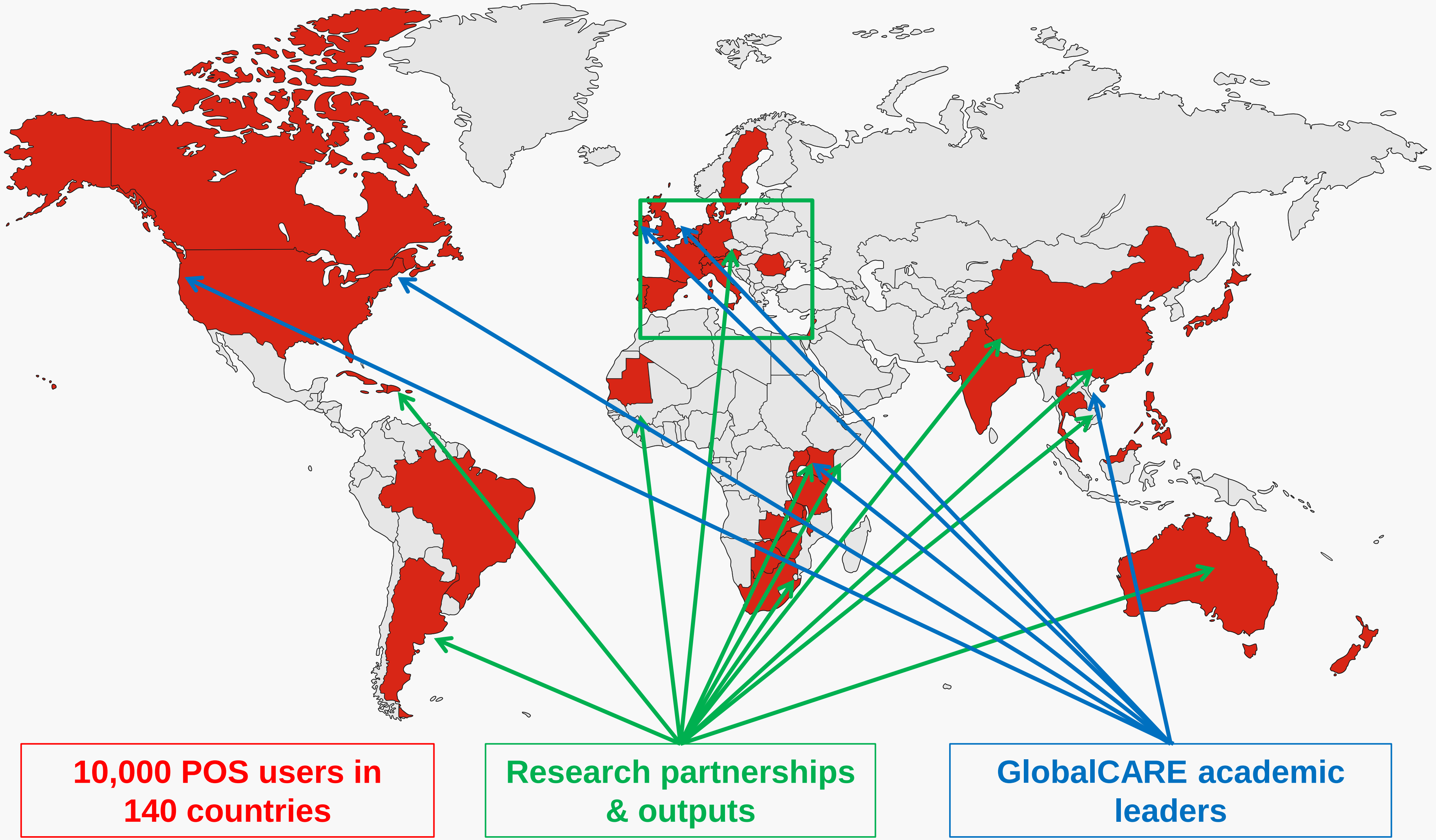
POS mentioned in a Marie Curie recent publication "triggers for palliative care: improving access to care for people with

Tweets by CSI Palliative Care

CSI Palliative Care @CSI_KCL 4 Feb

Register now for #Myeloma Conference 31st March with speaker from @MyelomaUK goo.gl/DkFRHB #hpm pic.twitter.com/vAr5wWdZLa

Global research & partnership activity



10,000 POS users in 140 countries

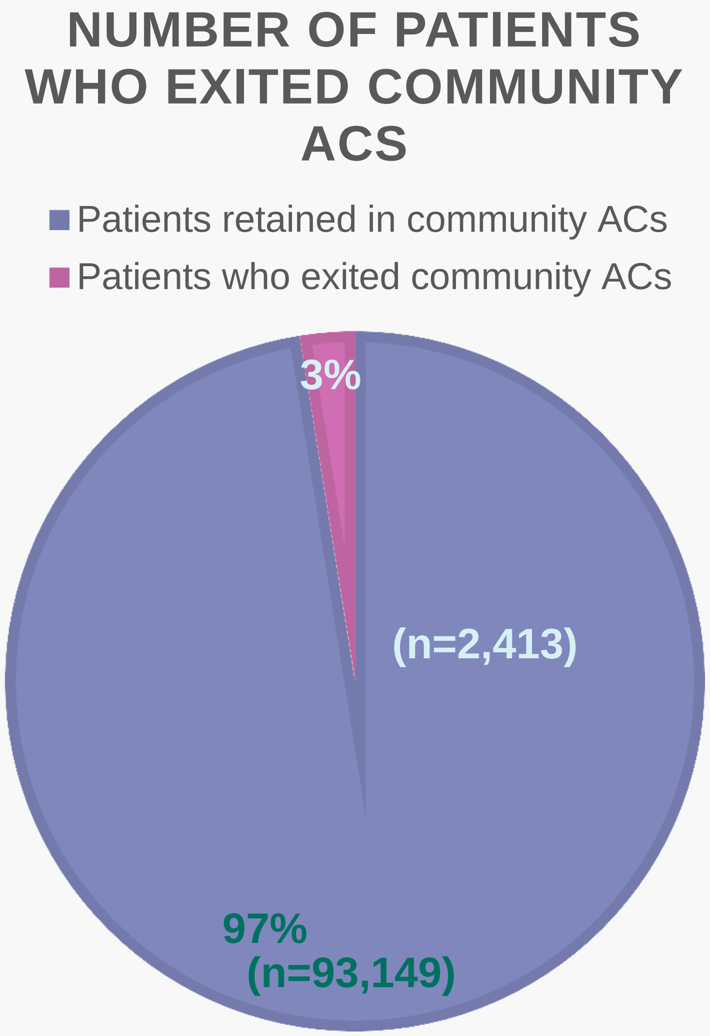
Research partnerships & outputs

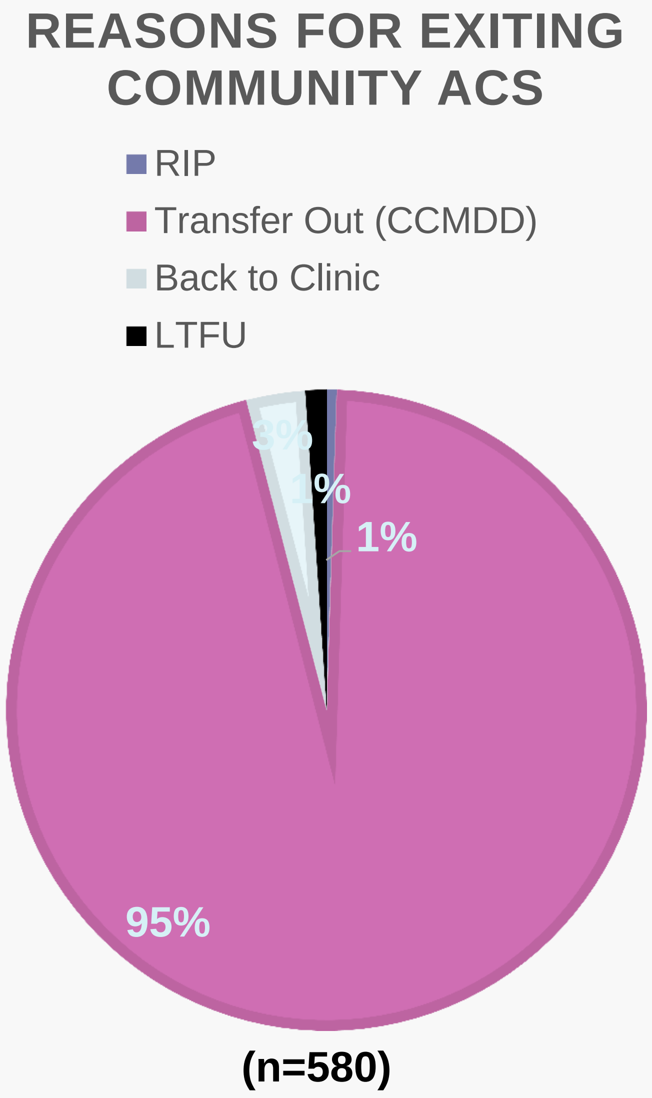
GlobalCARE academic leaders

Principles of palliative care in practice (TOPcare, Lancet HIV 2015)

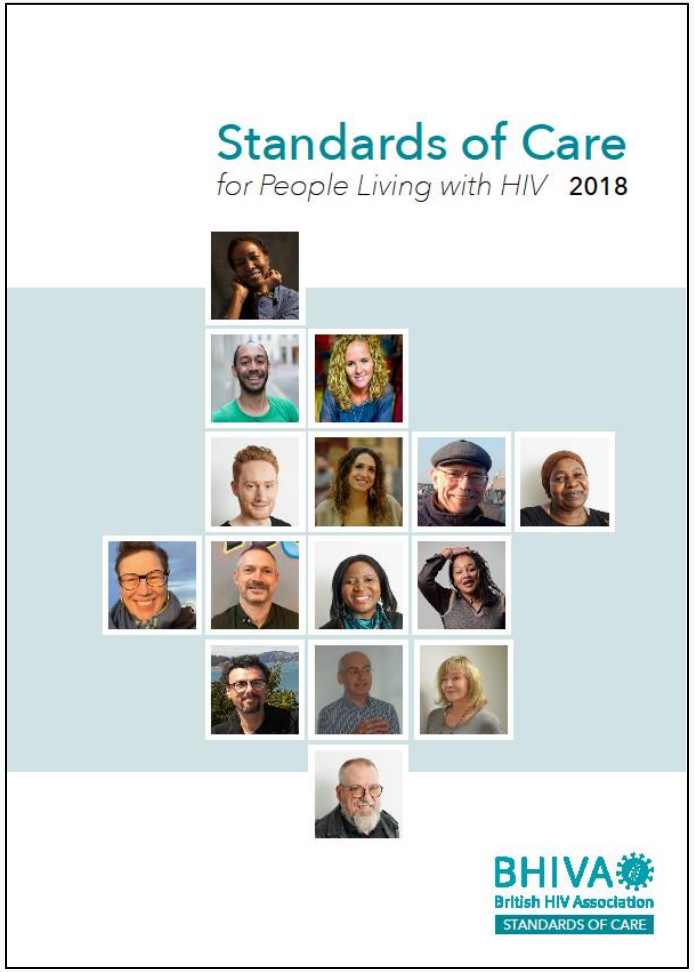
	Variable	Coefficient (95% CI)	P value
MOS-HIV (Health related quality of life)	Physical Health sub-scale (in quartiles)	0·44 (-0·02- 0·91)	p=0·06
	Mental Health sub-scale (in quartiles)	0·61 (0·13-1·10)	p=0·01*
GHQ-12 (Psychiatric morbidity)	GHQ-12 (in quartiles)	-0·50 (-0·97- -0·03)	p=0·04*
APOS (Multidimensional palliative care needs)	Total APOS (in quartiles)	0·69 (0·26-1·12)	p=<0·01*
	Symptoms	-0·05 (-0·39-0·29)	p=0·78
	Worry	-0·37 (-0·09-0·83)	p=0·11
	Ability to share (in quartiles)	0·93 (0·28-1·57)	p=<0·01*
	Feeling life worthwhile (in quartiles)	0·23 (-0·48-0·94)	p=0·52
	Feeling at peace (in quartiles)	0·37 (-0·18-0·93)	p=0·19
	Help and advice for family to plan for the future (in quartiles)	0·78 (0·28-1·28)	p=<0·01*

Hospice Palliative Care Association SA





BHIVA standards 2018



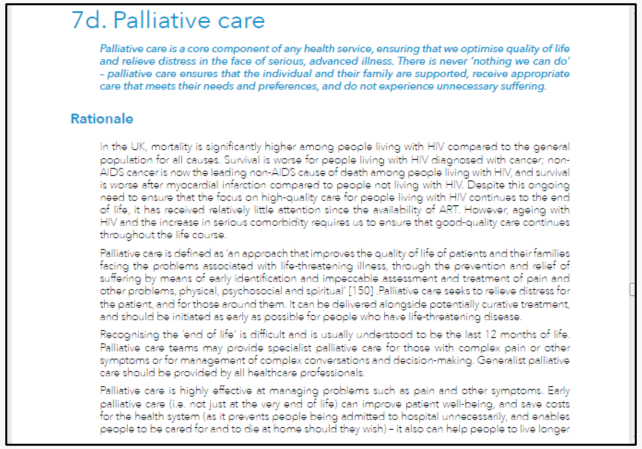
Standards of Care
for People Living with HIV 2018

BHIVA
British HIV Association
STANDARDS OF CARE

7. HIV across the life course

7a. Young adults and adolescents living with HIV

Adolescents, as defined by WHO, include all young people aged 10–19 years, and all young people aged 20–24 years. The Standards refer to young adults and adolescents living with HIV,



7d. Palliative care

Palliative care is a core component of any health service, ensuring that we optimise quality of life and relieve distress in the face of serious, advanced illness. There is never 'nothing we can do' – palliative care ensures that the individual and their family are supported, receive appropriate care that meets their needs and preferences, and do not experience unnecessary suffering.

Rationale

In the UK, mortality is significantly higher among people living with HIV compared to the general population for all causes. Survival is worse for people living with HIV diagnosed with cancer; non-AIDS cancer is now the leading non-AIDS cause of death among people living with HIV, and survival is worse after myocardial infarction compared to people not living with HIV. Despite this ongoing need to ensure that the focus on high-quality care for people living with HIV continues to the end of life, it has received relatively little attention since the availability of ART. However, ageing with HIV and the increase in serious comorbidity requires us to ensure that good-quality care continues throughout the life course.

Palliative care is defined as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' [150] .Palliative care seeks to relieve distress for the patient, and for those around them. It can be delivered alongside potentially curative treatment, and should be initiated as early as possible for people who have life-threatening disease.

Recognising the 'end of life' is difficult and is usually understood to be the last 12 months of life. Palliative care teams may provide specialist palliative care for those with complex pain or other symptoms or for management of complex conversations and decision-making. Generalist palliative care should be provided by all healthcare professionals.

Palliative care is highly effective at managing problems such as pain and other symptoms. Early palliative care (i.e. not just at the very end of life) can improve patient well-being, and save costs for the health system (as it prevents people being admitted to hospital unnecessarily, and enables people to be cared for and to die at home should they wish) – it also can help people to live longer

The need for a set of palliative care standards

- “*HIV treatment has improved so much that the focus has shifted away from end of life care. This standard is crucial to guide professionals and patients when the focus changes*”

Dr Sarah Cox, Chelsea & Westminster NHS Foundation Trust

- *“Now is the time to look forward and plan how to die well. It should not only be with dignity and respect, but with self-knowledge too”*

Roy Trevellion, HIV i-Base

Conclusions

- “There is **never** nothing we can do”
- Increasing needs for
  - education & training
  - “generalist” palliative care (Murtagh BMJ 2015)
  - collaborative working & decision making
  - clear information sharing
  - early palliative care
  - professional comfort with death & dying
- BHIVA standards 2018
  - enable audit
- Anticipate, plan, communicate
  - for optimal clinical management, quality of care & life