

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

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See end of article for authors' affiliations

Correspondence to:
Dr Richard Harding,
Department of Palliative
Care and Policy, Guy's
King's and St Thomas's
School of Medicine,
London SE5 9RS, UK;
Richard.harding@kcl.ac.uk

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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.

The World Health Organization defines palliative care as¹ "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 effects¹⁰ 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

Table 1 Grading criteria for studies

<p>Grade I (strong evidence) RCTs or review of RCTs</p> <ul style="list-style-type: none"> ● IA Calculation of sample size and accurate and standard definition of appropriate outcome variables ● IB Accurate and standard definition of appropriate outcome variables ● IC Neither of the above <p>Grade II (fairly strong evidence) Prospective study with a comparison group (non-randomised controlled trial, good observational study or retrospective study that controls effectively for confounding variables).</p> <ul style="list-style-type: none"> ● IIA Calculation of sample size and accurate, standard definition of appropriate outcome variables and adjustment for the effects of important confounding variables. ● IIB One or more of the above <p>Grade III (weaker evidence) Retrospective or observational studies</p> <ul style="list-style-type: none"> ● IIIA Comparison group, calculation of sample size, accurate and standard definition of appropriate outcome variables. ● IIIB Two or more of the above ● IIIC One or none of the above* <p>Grade IV (weak evidence) Cross sectional study, Delphi exercise, consensus of experts</p>
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*Modified from Clinical Guidance Outcomes Group.²⁰

Citation Index (1981–2003). The search terms were (palliative/hospice*/terminal care/supportive care/terminally ill/palliat*/dying/end of life/home care/advanced/comfort care) and (HIV/AIDS). In order to obtain as comprehensive a search as possible,¹⁹ terms were selected to identify the range of models commonly used as proxies for palliative care, or care mixes that include palliation as a component.

The criteria for inclusion of studies were original research paper in English language reporting on human subjects; a minimum of 50% of study population infected with HIV (or HIV infected subsample analysed and reported separately); the provision of a basic service description and/or evaluation of patient outcomes or patient satisfaction with care. Studies that incorporated elements of palliative care (that is, pain and symptom control, psychosocial support, terminal care) were included regardless of whether they explicitly used the term.

Analysis

Data items were extracted using a standard proforma: year of publication, setting/country, HIV disease stage and referral criteria to service, service description and palliative approach, sample size, study design, outcomes, and findings.

The studies were independently graded by two researchers (RH and DK) using a well described hierarchy of evidence²⁰ (table 1). Studies were further grouped according to intervention model used. A formal meta-analysis with statistical pooling of results across studies was not possible because of the absence of both appropriate study designs and standardised outcome measures.

RESULTS

Characteristics of eligible studies

The 32 eligible studies originated from the following countries: United Kingdom (n = 10); United States (n = 9); sub-Saharan Africa (n = 5); Canada (n = 2); Australia (n = 1); France (n = 1); Italy (n = 2); Netherlands (n = 1); and Norway (n = 1) (table 2). Of those countries that adopted widespread use of HAART from 1996–7 (that is, excluding the five studies based in sub-Saharan Africa), 18 studies were published pre-HAART and nine post-HAART.

Thirty four different palliative care services were described in 32 different studies, although only about half of these services (18/34) stated explicitly that their patient

management was palliative. Of the 34 services, 22 had been evaluated in 17 studies. The different service models were 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) (table 2).

In general, these services offered various combinations of usual disciplines found in palliative care, including consultants in palliative medicine, palliative nurse specialists, pain and symptom control, on-call home care, education and advice, counselling, psychosocial care, pastoral/spiritual care, occupational therapy, social work, dietetics, a focus on family and patient support, and bereavement counselling.

Patient eligibility for the services was described for 30/34 services and ranged from any stage of HIV disease (n = 12) to only those with an AIDS diagnosis (n = 11), or advanced/terminal AIDS (n = 7). As would be expected, the services that offered care to all HIV infected patients were less likely to name palliation as part of the care package (2/12) than were services specifically for people with an AIDS diagnosis (7/11); or those for advanced disease services (6/7). The proportion of services that incorporated an evaluation of their service varied with the type of service model: home based care (n = 13/15); home palliative care and hospice at home (n = 5/7); hospital palliative care (n = 2/4); hospital inpatient and outpatient care (n = 1/2); hospice inpatient (n = 1/4); specialist AIDS inpatient unit = (0/2).

The clinical outcomes used in the evaluation of palliative care services varied. Four studies used the Support Team Assessment Schedule (STAS)²¹ which was designed to assess domains including pain and symptom control, patient and family anxiety, patient and family insight, and communication. Other studies assessed satisfaction with care, medical procedures and investigations, perceived quality of care, patient involvement, support, and quality of life (generally with non-standardised measures).

Of the 22 services that had been evaluated in 17 studies, the strength of the evidence in each study was graded as grade 1 (n = 1); grade 2 (n = 2); grade 3 (n = 7); grade 4 (n = 1). Six studies used only qualitative data.

Findings by evidence grade

Grade 1 (n = 1): strong evidence

In a randomised controlled trial (RCT), integrated multi-professional case managed home care (n = 29) showed a possible advantage over standard home care (n = 28) in terms of both quality of wellbeing and survival (magnitude unreported, figurative representation of data only). However, this did not reach statistical significance.²²

Grade 2 (n = 2): fairly strong evidence

In an observational study 10 patients accessing home palliative care in addition to hospital care were compared to 32 who were attending hospital care only. Small sample size, death and attrition disallowed statistical analysis, and no difference in quality of wellbeing was reported although number of hospital admissions and mean number of days for each admission and overall costs were lower for those receiving home care. In a further observational study, relative to 77 patients receiving standard hospital inpatient care, 10 patients attending a hospital inpatient palliative care unit (PCU) were less likely to have been prescribed antiretrovirals (34% v 10%) and antimicrobial agents (60% v 0%), more likely to have ceased treatment for curable infections (23% v 80%), and more likely to have been prescribed step 3 analgesics (18% v 80%).²³ Depression was also far less common in the PCU (55% v 10%), although a similar frequency of pain was assessed (46% v 50%). However,

Table 2 Service descriptions and evaluation evidence

Ref/grade	Setting and country/ disease stage eligibility criteria	Service description	Design and sample size	Outcomes	Findings
Hospice at home/home palliative care					
Tramarin 1992 ⁷¹ /IIB	Home palliative care assistance, Vicenza Italy/terminal AIDS or heavy motor or vision deficit	Multidisciplinary home care assistance (HCA) consisting of nurses, family doctor, psychologist, volunteers, social workers and infectious disease specialists. Aimed to improve quality of life through principles of palliative care and limiting inpatient service use	6 month prospective comparison of n = 10 patients accessing HCA and hospital care to n = 32 with similar disease staging accessing only hospital care	Quality of wellbeing scale calculated weekly	Quality of wellbeing data not presented in numeric form but graph suggests no significant difference. Fewer hospital inpatient days reported for those accessing home care (n = 7, 127 days) than comparison group (n = 35, 866 days) and costs lower for those with advanced disease accessing home care (\$17 237 v \$27 764)
Koffman 1996 ²⁵ /IIIC	Home based hospice, London UK/advanced HIV/AIDS	24 hour palliative nursing, night sitting, consultants in palliative medicine	Single group longitudinal; from entry to last week of life/discharge. N = 36	STAS quality of life (QoL): pain and symptom control, patient and family anxiety, patient and family insight, patient/family/professional communication	All items showed trend to improvement, with two reaching statistical significance: symptom control (from 6% to 33% reporting it as no problem, p = 0.0009) and family insight (from 33% to 67% reporting as no problem p = 0.0006)
Butters 1995 ²⁸ /IIIC	2 hospital and home care, London UK/HIV/AIDS (85% diagnosed AIDS)	Multidisciplinary advice and support in hospital and at home. (A) Home support team (HST) – nursing staff, general practitioner, welfare rights adviser and occupational therapist. Early intervention inc. asymptomatic HIV. (B) Community care team (CCT) – consultant, nurse specialists, social worker, dietician, occupational therapist, registrar. Late/end stage care	Prospective, multicentre longitudinal from referral to death/discharge. N = 234	STAS: severity and nature of patient problems (pain and symptom control, anxiety)	<i>Significant changes from referral to 6 weeks before death.</i> (A) Worsening symptom control (from 22% to 46% rated severe, p = 0.04). (B) Improving predictability (p = 0.00002), spiritual (p = 0.005), patient/family communication (p = 0.02), patient insight (p = 0.04)
Butters 1992 ²⁶ /IIIC	2 community teams, London UK/HIV/AIDS (84% diagnosed AIDS)	Multidisciplinary palliative family and patient support: symptom control, counselling, bereavement follow up, education and advice, 24 hour on call nursing and terminal care, clinical liaison. Coordination and support rather than care management	2 centre longitudinal, entry to last week of life/discharge. N = 140	STAS QoL: pain and symptom control, anxiety, practical aid	<i>Significant improvements after 2 weeks from referral:</i> pain (from 51% at referral to 66% after 2 weeks rated no problem, p = 0.01), symptom control (4% to 16% p = 0.05) and patient anxiety (7% to 16% p = 0.05)
Kimball 1996 ²⁹ /IIIC	Home hospice care USA/AIDS	<i>No service description</i>	Retrospective cohort chart review, last 2 weeks of life. N = 185	Pharmacological management of pain and discomfort	<i>Significant changes from referral to last week before death:</i> Pain no problem 51% to 66% p = 0.0001, symptom control 4% to 24% p = 0.01, anxiety 7% to 47% p = 0.00005. However, 33% reported symptoms as severe in last week of care
Butters 1993 ²⁴ /IIIC	Community support team, London UK/late stage HIV/AIDS illness/uncontrolled pain/symptoms, or need psychological, spiritual or home support	Multidisciplinary team (2 doctors, 3 clinical nurse specialists, dietician, occupational therapist) to increase choice of place for care/death. Symptom control, patient, and carer counselling, 24 hour on call, education, and advice on diagnosis, nursing, and terminal care. Coordination and support of hospital and home care, rather than assume responsibility for care	Single group longitudinal, 3–4 weeks from referral (N = 19/125 eligible) and 4–6 weeks later (N = 6)	9 STAS items and satisfaction in final weeks of life. Score range from 0 = no problem to 4 = severe problems	Those reporting pain and discomfort rose from 54% early in 2 weeks before death to 68% in final 48 hours. Over 2 weeks 88% received opioid analgesic, with 62% of these experiencing relief thereafter Care rated as good/excellent by all. Communication with clinical staff outside the team rated as poor. 2–4 weeks from entering care mean scores above 2 with symptom control, pain control and patient anxiety. 18/19 reported problems with symptom control. Few patients reported severe ratings in final weeks: none for pain, 3 for symptom control, one for patient anxiety. Favourable comments on the role of “talking” care (n = 18/19) and with patients’ control over care (n = 15/19).

Table 2 Continued

Ref/grade	Setting and country/ disease stage eligibility criteria	Service description	Design and sample size	Outcomes	Findings
Crowe 2001 ⁷² /-	Home based hospice, South Africa/ <i>none specified</i>	Nurses and trained rural community carers, home visiting, physical and medical care, counselling, and emotional/spiritual support, social workers. In-patient care for those with greatest need. Orphan support	<i>No evaluation</i>		
Martin 1988 ⁷³ /-	Home Care and Hospice program, San Francisco USA/ <i>none specified</i>	<i>Team supports both home care and 15 bed residential care, mainly HIV/AIDS. Physician consultant advises patients' primary physician</i>	<i>No evaluation</i>		
Martin 1986 ⁷⁴ /-	Home care and hospice program, San Francisco USA/AIDS	Multidisciplinary: physical and occupational therapists, attendants personal care, daily living activities), nurses (symptom control) social workers (psychosocial care), volunteers (practical support), rehabilitation therapists (reducing discomfort, improving environment), consultants (care planning, advocacy, and education)	<i>No evaluation</i>		
Inpatient hospice Gibbs 1997 ²⁷ /IIIC	Generic hospice, London UK/ advanced HIV disease	Terminal care. <i>No service description</i>	Retrospective longitudinal. N=26	Symptom control	Weakness (77%), immobility (73%), and weight loss (62%) most severe symptoms at admission, did not improve. Severe pain for 31% at admission, reduced to mild/none for all but 1 patient. Significant improvement of other symptoms (nausea, vomiting, diarrhoea, constipation, dyspnoea, confusion: not quantified). No symptoms initially rated absent or mild worsened during stay
Murie 1992 ⁷⁵ /-	AIDS hospice, Edinburgh UK/ AIDS: priority given to terminal patients	Respite, convalescence, Nurses and trained rural community carand terminal care. Medical nursing and paramedical staff. 12 single plus 4 double rooms. Emphasis on liaison with community drug health and psychology services. Emotional support, art, and expressive classes, complementary therapy. Family care and inclusion	<i>No evaluation</i>		
Ley 1988 ⁷⁶ /-	AIDS hospice, Toronto Canada/ terminal AIDS	Terminal care 13 beds (including 1 respite bed). Complementary therapies, clinical staff, social worker, psychosocial, and spiritual care. Palliative approach seen as more active than for traditional cancer care. Counselling for family/ carers/friends/patients. Outreach support for those waiting for admission	<i>No evaluation</i>		

Table 2 Continued

Ref/grade	Setting and country/ disease stage eligibility criteria	Service description	Design and sample size	Outcomes	Findings
Moss 1988 ⁷⁷ /-	AIDS inpatient hospice, London UK/AIDS	Rehabilitation, convalescence, terminal care. Patient centred multidisciplinary holistic care. All care in consultation with patient, aims to improve QoL through symptom control and active treatment where appropriate. Spiritual care and counselling. 9 beds, plus home support. Physiotherapy and occupational therapy; no diagnostic facilities or resuscitation. CNS, nurses, doctors, counsellor, social worker, chaplain, housekeeper. Family facilities	<i>No evaluation</i>		
Hospital palliative care					
Vincent 2000 ²³ /IIB	Two models: (A) Advanced AIDS care in hospital Infectious and tropical disease unit. (B) Hospital palliative care unit, Paris and Villejuif France/(A) Biomedical admissions. (B) "Qualitative" admission criteria in PCU (eg, suffering of patient/family or carer exhaustion)	Care not described, although (A) "Not devoted to palliative care" and (B) "Primary objective of palliation"	Prospective multidisciplinary comparing methods of care between ITDU (N=77) and PCU (N=10). Symptom self assessment for only 52/68 patients because of patient inability/unwillingness	Drugs administered, procedures, and investigations symptoms assessed weekly. Comparison of different therapeutic objectives	Sample sizes too different for statistical analysis. ITDU v PCU per hospitalisation: antiretrovirals prescribed in 34% v 10%; treatment of curable infections ceased in 23% v 80%; antimicrobial agents in 60% v 0%; Step 2 and step 3 analgesics in 57% and 18% v 20% and 80%; Similar frequency of pain (46% and 48%) depression assessed in 55% of ITDU and 7% in PCU
Lucas 1997 ³⁰ /IIIC	Inpatient palliative care unit, New South Wales Australia/AIDS	8 AIDS designated beds in 35 bed palliative care unit in public hospital. Twice weekly visits by pharmacist specialising in AIDS palliative care: assesses appropriateness of prescribing, advises on adverse reactions, interactions, contraindications and therapeutic alternatives, provides information to staff and patients, applies for restricted drugs, updates, case notes.	Retrospective rating of weekly consultations with specialist palliative AIDS pharmacist advice over 6 months. Impact independently evaluated on 6 point scale by three clinicians. N=11	Clinical significance of advice given by palliative AIDS pharmacist	<i>Not quantified.</i> High compliance with recommendations. Most common interventions: rationalisation of inappropriate regimens; warnings about drug interactions. General conclusion: among AIDS patients, palliative care is enhanced with availability of pharmacist with specialist knowledge of AIDS therapeutics.
Cumming 1993 ⁷⁸ /-	Non-HIV hospital palliative care unit, Vancouver Canada/prognosis <1 year, 2/3 AIDS	Respite beds in generic hospital palliative care unit. Goals of pain and symptom reassessment, investigation, care for caregiver	<i>No evaluation</i>		
Singh 1991 ⁷⁹ /-	Dedicated hospital ward, London UK/symptomatic HIV/AIDS	Dedicated 17 bed hospital ward for HIV/AIDS. Provides both continuing active treatment (34%) and no active treatment (66%)	<i>No evaluation</i>		
Home based care					
Nickel 1996 ²² /IB	Home care case management, Ohio, USA/AIDS	Care monitoring and direction by comprehensive assessment and care planning and review by multidisciplinary team: nursing staff, doctors, social worker, psychiatrist, nutritionist, clergy, pharmacist, and dentist. Services available on call	Randomised controlled trial (RCT). N=57	Quality of Well Being Scale, Physical Self Maintenance Scale, Functional Activities Questionnaire	Case managed group showed observable advantage in quality of wellbeing and survival (<i>not quantified</i>), but did not reach statistical significance

Table 2 Continued

Ref/grade	Setting and country/ disease stage eligibility criteria	Service description	Design and sample size	Outcomes	Findings
Foley 1995 ³¹ /IV	Home care, New York USA/ symptomatic HIV/ AIDS	Enhance QoL, providing home nursing and case management, dietetics, rehabilitation, equipment, social work, respite, mental health services, laboratory and pharmacy services	Cross sectional. N= 52	Patient satisfaction (excellent= 1, poor = 5)	Rated quality of nursing care as excellent/very good (mean 1.6), thought had more control over hospital admissions (mean 2.2), vast majority (67%) reported their health status remained unchanged following admission to the service. High value and satisfaction placed on contact and communication (81%)
McCann 1991 ³⁶ / qualitative	Home support team, London, UK/HIV/ AIDS	Hospital based specialist home support team, parallels cancer support, to allow home care and to release hospital beds for acute care. Coordinate and provide continuous care between hospital and community teams through assessment, communication, and care planning	Qualitative structured interview. N=265	Elements of support and satisfaction	Those who had service contact more likely to have AIDS, advice and support main services provided by staff. Nursing care described as very good/excellent by 86%, 60% report receiving much reassurance and support
WHO 1992 ⁸⁰ / qualitative	6 different home care programmes, Uganda and Zambia/HIV/AIDS	(1) Home based patient and family care linked to inpatient and outpatient AIDS unit: medical nursing psychological and pastoral care, terminal care. (2) Home care team working through hospital and community clinics: medication, counselling and information, terminal care. Volunteers also provide care. (3) and (4) Home patient and family care: counselling, information, clinical care. Medical and herbal symptom control. (5) Terminal emphasis, provides continuity of care, reduce inpatient bed pressure. Linked to inpatient and outpatient services. Nursing and pastoral care. (6) Relief of inpatient bed pressure, care for those unable to attend hospital, linked to inpatient, outpatient and pastoral care	Qualitative: staff (n=56), patient/carer focus (n= 16), direct observation (n=64), methods not stated	"Effectiveness"	"Home care improved quality of life; home care is equivalent or better than hospital care" <i>no supporting evidence provided</i>
Bunch 1998 ³⁵ / qualitative	Home hospital, Oslo, Norway/ HIV/AIDS	Home nursing care for hospitalised patients. Nursing care plans devised	Post hoc qualitative, thematic analysis. N= 5/64	Patient satisfaction	Hospital and other agency link valued, independence and feeling physically less unwell. Disadvantages include anxiety, fear, and mastering medical equipment
Uys 2001 ³² and 2002 ³³ / qualitative	Integrated home based community care, under served areas. South Africa/ HIV/AIDS, including asymptomatic	Links community caregivers, patients and families, hospices, clinics and hospitals. Community caregivers provide hygiene care, wound care, symptom control, counselling, psychosocial support, welfare	Retrospective utilisation focused evaluation, focus groups. N= 3/36 participants were patients. Methods not reported	Satisfaction with, and impact of, model on patients	Patients valued information giving, support, welfare assistance, specialist referrals and access to care, better management of OIs.
As above			Qualitative patient data reported but methods and N not stated.	Not stated	Patients reported enhanced human dignity
Moons 1994 ³⁴ / qualitative	Home care, Rotterdam, Netherlands/AIDS, hospital outpatients: CDC classification IV B, C, or D, Karnofsky = 60 or less. Also permanent address, telephone, bathroom an informal caregiver and GP cooperation	Aim to: improve QoL by reducing hospital visits. Home care coordinated following joint hospital and community nurse assessment. Providing technical, medical and nursing care, health education, and psychosocial support to patients and caregivers	Qualitative interviews with patients during receipt of care. Methods not reported. N= 9/13	Patient experience of the service	Patients valued being able to avoid hospital visits and remain at home; less disturbance of their daily routine; emotional support received; high quality of care. However, lack of evening and weekend access to the service was a problem. Poor communication with GP

Table 2 Continued

Ref/grade	Setting and country/ disease stage eligibility criteria	Service description	Design and sample size	Outcomes	Findings
Cherin 1998 ⁸¹ and 2000 ⁸² /-	Medical and surgical home care, Los Angeles USA/ AIDS patients in "final phase of terminal trajectory"	Nurse and social work trans-professional team, employing both curative and palliative care, with training in physiological and psychological aspects of AIDS care. Emphasis on team case management	No evaluation		
Borgia 2002 ³⁹ /-	Home care, Rome Italy/AIDS	Medical and nursing care, assistance with domestic needs and psychological/ social support for patients and family	No evaluation		
Schietinger 1993 ⁸³ /-	Home care, rural Rwanda/AIDS	Family caregivers provide basic nursing: pain control, hygiene, hydration, and nutrition	No evaluation		
Hospital inpatient/outpatient care Gibb 1997 ⁸⁴ /-	Hospital outpatient family clinic, London UK/All HIV disease	Specialist paediatric and adult medical, counselling, and terminal care: paediatricians, nurse counsellor, psychologist, social worker, physiotherapist, genitourinary physician and health adviser, paediatric dietician, and paediatric pharmacist. Shared care and coordination with local hospice and terminal cancer symptom care team	No evaluation		
Specialist dedicated AIDS unit Noe 1993 ⁸⁵ /-	Nursing facility, Seattle USA/end stage AIDS	35 subacute beds. Day care (60 clients). Intervention not described	No evaluation		
Selwyn 2000 ⁸⁶ /-	Long term care facility, New Haven, USA/late stage HIV/AIDS, 88% AIDS (stage C3)	30 bed AIDS designated unit. Nurses, nurse practitioners, interns, psychiatrist, social worker, drug counsellor, recreational therapist, dietician, physiotherapist. Minimally invasive diagnostic tests, and procedures performed on site. Primary reasons for admission: needs 24 hour medical care; completion of acute medical treatment; terminal care	No evaluation		

owing to the small sample size and group size imbalance, statistical analysis was not possible.

Grade 3 (n = 7): weaker evidence

The following studies used single group longitudinal methods. In a home AIDS palliative team, care was rated as good/excellent by 100% of respondents, and qualitative comments reported better communication with palliative care staff than with staff outside the team, and identified helpful elements of care as talking and support.²⁴ Among patients receiving home hospice/palliative specialist AIDS care, statistically significant improvements over time were identified in the following domains: symptom control, from 6% to 33% reporting no problem from entry to last week of care, $p = 0.00009$,²⁵ and from 4% to 16% $p = 0.05$ for the first 2 weeks and from 4% to 24% $p = 0.01$ from referral to the point of death²⁶ and significant (magnitude unreported) improvements for inpatients of a generic hospice²⁷; pain control (from 51% to 66% after 2 weeks reporting no problem, $p = 0.01$, and from 51% to 66% from referral to

death $p = 0.0001$)²⁶; family insight from entry to death from 33% to 67% reporting as no problem $p = 0.0006$)²⁵; patient anxiety (from 7% to 16% from referral to 2 weeks reporting no problem $p = 0.05$, and from 7% to 47% from referral to death $p = 0.00005$)²⁶; patient insight $p = 0.04$ (magnitude of change not reported) and spiritual wellbeing $p = 0.005$ (magnitude of change not reported).²⁸ Conversely, increased pain and discomfort were reported during attendance from 2 weeks to the final 48 hours for patients of another home AIDS hospice team (from 54% to 68%).²⁹ Although reductions in pain (from severe pain for 31% at admission to 3% in last days) and significant improvement for symptom control (unquantified) were found among patients of an inpatient generic hospice providing AIDS care, no improvement was found for most severe symptoms reported at admission,²⁷ and for a community palliative care team, symptom control worsened from referral to death, with the proportion of those reporting severe symptoms rising from 22% to 46% ($p = 0.04$).²⁸ The study reporting significant symptom improvements from referral to end of life also found 33% of

patients having severe symptoms in the last week before death.²⁶ In a further study, specialist AIDS palliative pharmacy input was found to improve complex drug management and patient care (although the effect was not quantified).³⁰

Grade 4 (n = 1): weak evidence

Using a Likert rating scale of 1 = excellent to 5 = poor, a cross sectional evaluation of 52 patients accessing HIV home care found high patient satisfaction with care (mean score 1.6) and personal control over care (mean score 2.2), and with both communication (84.6% reporting a professional available to talk) and regularity of contact with staff (80.6% satisfied), though perceived health status remained unchanged.³¹

Qualitative (n = 6)

Qualitative data from patients receiving home based care reported patients particularly valuing information giving, support, welfare assistance, and specialist clinical intervention and referrals (focus group data, number unspecified)³² as well as enhanced human dignity³³ (patient interviews, number unspecified). Patient interviews in other studies reported less disturbance of daily routine³⁴ (nine interviews)³⁵ (five interviews) fewer hospital visits and high satisfaction and quality of care³⁴ (nine interviews)³⁶ (265 interviews). However, quality and satisfaction with care were tempered by the anxiety and fear induced by being cared for at home for a small unspecified number of patients³⁵ (of n = 5 interviewed patients) and poor weekend/out of hours and primary care communication³⁴ (of nine interviews).

DISCUSSION

In this systematic review of 17 studies, we found that most of the evidence supporting the benefits of palliative care for HIV infected patients is based on seven studies categorised as offering grade 3 evidence. These 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. However, the need for improvements in pain and symptom management was identified even among specialist services.

Only one study employed the most rigorous evaluation methodology of an RCT (that is, grade 1), and although this study suggested that patient outcomes might be improved in terms of quality of wellbeing and survival, this did not reach statistical significance. The lack of grade 1 evaluations is unsurprising given the extensive literature documenting the challenges and logistical problems with palliative care trials.³⁷⁻³⁸ The present review identified a recent RCT of AIDS homecare that failed to adequately recruit and retain patients.³⁹ Similar methodological challenges were present in a recent review of palliative and hospice care teams' effect on cancer patient outcomes which found only studies of mainly grade 2 or 3 quality.⁴⁰ The accompanying meta-analysis documented benefits in the domains of pain, symptom control, and trends towards satisfaction and therapeutic intervention, with evidence generally strongest for home care. The qualitative studies identified in this current review were of generally poor methodology, with sample sizes, data collection, and analysis methods seldom reported.

There are several important limitations and caveats to the interpretation of the findings from this systematic review. The lack of (quasi) experimental evaluations means that firm conclusions cannot be drawn regarding the comparative benefit of palliative care. A number of evaluations also did not adequately identify services as palliative although they aimed to provide services such as home based, specialist, and/or terminal care. Optimal terminal HIV/AIDS care requires a

primary focus on palliation, and palliation requires clear and precise terminology to avoid the inconsistency found in clinical instruction for HIV/AIDS terminal care.⁴¹ The heterogeneous clinical studies included in this review reflect the diverse settings, clinical management strategies, and disease stages relevant to palliative care in HIV disease. A lack of detailed service description for many of the studies meant it was not possible to identify the effective elements of the service that might be replicated, although exceptions were found. For example, the study by Selwyn *et al* clearly defined the range of patient clinical needs at baseline that were related to the goals of palliative care, and subsequently reported on their full or partial resolution.⁴² A further limitation in evaluating palliative care is the set of methodological challenges. These include small sample sizes and attrition,³⁸ selection bias recruitment and gate-keeping particularly among those with advanced disease,⁴³ aggregation of data from heterogeneous populations, the selection of appropriate outcomes in the measurement of broad psychosocial as well as clinical outcomes,⁴⁴ and the resulting lack of successful RCTs.⁴⁵ In the absence of successful RCTs in areas where compassionate but effective care is needed, over-reliance on RCTs may not provide the evidence required.⁴⁶ Other methods such as quasi-experimental and longitudinal cohort designs may be more appropriate for robust but feasible protocols.

There is doubtless greater activity in HIV/AIDS patient management in the field of specialist palliative care than was identified by this review, and the tendency for publication of studies with positive findings may mean an under-representation of studies reporting null findings. We attempted to minimise the bias resulting from terminology by including a broad range of common terms in the search strategy—for example, palliative care approaches being termed comfort care.⁴¹ This review also was guided by the findings from a recent evaluation of systematic reviews of palliative care services.⁴⁷ Similarly, the grading criteria selected were purposefully broad and inclusive, allowing a full body of evidence rather than being narrow (and RCT focused).

In addition, it may be that current activity in less developed regions is not fully represented, and to address this, end of life HIV care in sub-Saharan Africa has been independently surveyed.⁴⁸ The identification of evidence is also hampered by studies combining diagnosis groups. For example, one study⁴⁹ reported palliative care consultations in an acute care hospital where only 8.3% of patients had HIV disease, a second study of the benefits of symptom control by a hospital based palliative care consultant and pharmacist also had only 8% of patients with HIV,³⁰ and a third study of parenteral antibiotics in an inpatient palliative care unit reported 15% of patients having an underlying HIV diagnosis.⁵¹

The potential for a selection bias in HIV palliative care evaluation was demonstrated in a study that found patients reported lower levels of pain, better insight, less anxiety, and fewer spiritual problems than in providers' assessments.²⁴ Patient self reports are also subject to bias because of more unwell patients being unable or unwilling to participate.²³ There is currently a modest amount of clinical research into HIV palliative care, and future efforts should include both qualitative and quantitative approaches to inform feasibility, acceptability, processes, and preferences as well as outcomes. In addition, well standardised quantitative palliative specific outcome measures such as the Support Team Assessment Schedule (STAS)²¹ and the Palliative Outcome Scale (POS)⁵² should be considered, as well as a range of quality of care⁵³ and quality of life measures⁵⁴ in HIV management.

Our findings have several implications for clinical practice. A review of HIV care found that service delivery models are changing: home hospital care is provided for proportionately

Key messages

- The clinical evidence demonstrates that patients with HIV infection require palliative care throughout the disease trajectory in order to control pain and symptoms, to promote adherence through reduction of side effects and toxicity associated with antiretroviral therapy, to manage life limiting co-morbidities such as cancers and end stage liver disease, and to provide quality end of life care for those whom antiretroviral therapy fails or who are unable to access it
- This systematic review of patient outcomes found home palliative care and inpatient hospice care to significantly improve patient outcomes in the domains of pain and symptom control, anxiety, insight, and spiritual wellbeing
- Quality HIV clinical care should offer palliation as a flexible, integrated approach when needed from diagnosis to the end of life across the range of institutional and home care settings alongside new therapeutics

fewer patients, and more frequently for those with less advanced disease.⁵⁵ Palliative care should be part of this shift towards earlier intervention, particularly as our review found palliation to be provided towards advanced and terminal disease stages. Most of the studies were based on patients with end stage disease, and few studies have explored the benefits of palliative care through the disease trajectory. Such longitudinal studies could usefully evaluate the benefits of integrated palliative care, and should be a priority for future research.

Service objectives and the evaluation evidence would benefit from an explicit inclusion of palliative care in service aims and multiprofessional mix.⁵⁶ The historical distinction between early/late stage disease that placed palliative care as solely terminal is inappropriate in the light of the clinical evidence that patients need pain and symptom management (and psychosocial care) throughout the disease trajectory.^{5 6}

Nursing homes,^{57 58} brain impairment units,⁵⁹ hospices,⁶⁰ hospital palliative care teams,^{61 62} prison hospice,⁶³ and hospital paediatric wards⁴¹ face challenges of providing both curative and palliative care for people with HIV/AIDS. Therefore, clinical need throughout the disease trajectory and the range of settings in which patient care is delivered speaks of the need for specialist education and the inclusion of palliative care expertise into the multiprofessional care team. HIV/AIDS palliative care may also be seen as a specialism within palliative care; provider data from a generic hospice highlighted staff concern that the low number of HIV/AIDS referrals prevented them from maintaining skills, fearing poor care as a likely outcome.⁶⁴

Further challenges are presented by resource poor countries and some poorer communities in wealthier nations where the epidemic is most pressing. Psychosocial/“total” care is likely to include additional issues such as orphan care and food security, and care programmes need to consider coverage and not simply strive to provide high quality service to a few patients.⁶⁵ Palliative care remains a novel concept in less developed regions. It is largely absent from the clinical training syllabus for nurses and doctors, and restricted availability of opioids necessitate strategic approaches to ensure the expansion of palliative care.⁶⁶

Patients with HIV/AIDS report needing emotional support, communication, and pain control from their physicians,⁶⁷ and

those patients with advanced AIDS describe a good death as having pain/symptom control, optimum quality of life, choosing where to die, having control of their treatment, and having their spiritual needs addressed.⁶⁸ Palliative care remains an essential component of clinical care, embracing pain and symptom management, advance care planning, and psychosocial support. The changing epidemiology of HIV, and the widely divergent management of patients in the developed world compared to those in developing countries, present clear and necessary roles for the integration of palliative approaches to patient management throughout the disease trajectory. The integration of palliative care throughout all stages of patient care, incorporating flexibility and specialist advice needed, shows the curative versus palliative approach to be false.^{69 70} The need for palliative care continues alongside new therapeutics and should not be associated solely with terminal care.

CONTRIBUTORS

This study was conceived by IJH, VR, and KM; the study protocol was developed by RH and reviewed and agreed by all authors; RH searched the databases, all authors reviewed the search outputs, and data graded by RH and DK; the manuscript was drafted by RH and PE, and reviewed and commented on by all authors.

Authors' affiliations

R Harding, I J Higginson, Department of Palliative Care and Policy, Guy's King's and St Thomas's School of Medicine, King's College, London, UK

D Karus, V H Raveis, Center for the Psychosocial Study of Health and Illness, Mailman School of Public Health, Columbia University

P Easterbrook, Academic Department of HIV and GU Medicine, Guy's King's and St Thomas's School of Medicine, King's College, London, UK

K Marconi, HIV/AIDS Bureau, Health Resources and Services Administration, US Department of Health and Human Services

REFERENCES

- 1 **World Health Organization**. *National cancer control programmes: policies and managerial guidelines*. Geneva: WHO, 2002.
- 2 **WHO/UNAIDS**. WHO/UNAIDS global HIV/AIDS statistics 2002. www.unaids.org, 2003.
- 3 **Selwyn PA**, Rivard M. Palliative care for AIDS: challenges and opportunities in the era of highly active anti-retroviral therapy. *Innovations in End-of-Life Care* 2003;**4**(3).
- 4 **Fantoni M**, Ricci F, Del Borgo C, *et al*. Symptom profile in terminally ill AIDS patients. *AIDS Patient Care and Stds* 1996;**10**:171–3.
- 5 **Breibart W**, McDonald MV, Rosenfeld B, *et al*. Pain in ambulatory AIDS patients. I: Pain characteristics and medical correlates. *Pain* 1996;**68**:315–21.
- 6 **Larue F**, Fontaine A, Colleau SM. Underestimation and undertreatment of pain in HIV disease: multicentre study. *BMJ* 1997;**314**:23–8.
- 7 **Sabin CA**. The changing clinical epidemiology of AIDS in the highly active antiretroviral therapy era. *AIDS* 2002;**16**(Suppl 4):S61–8.
- 8 **Tamalet C**, Fantini J, Tourres C, *et al*. Resistance of HIV-1 to multiple antiretroviral drugs in France: a 6-year survey (1997–2002) based on an analysis of over 7000 genotypes. *AIDS* 2003;**17**:2383–8.
- 9 **Dragsted UB**, Gerstoft J, Pedersen C, *et al*. Randomized trial to evaluate indinavir/ritonavir versus saquinavir/ritonavir in human immunodeficiency virus type 1-infected patients: the MaxCmin1 Trial. *J Infect Dis* 2003;**188**:635–42.
- 10 **Health KV**, Montaner JS, Bondy G, *et al*. Emerging drug toxicities of highly active antiretroviral therapy for human immunodeficiency virus (HIV) infection. *Curr Drug Targets* 2003;**4**:13–22.
- 11 **Mary-Krause M**, Cotte L, Simon A, *et al*. Increased risk of myocardial infarction with duration of protease inhibitor therapy in HIV-infected men. *AIDS* 2003;**17**:2479–2486.
- 12 **Rabinstein AA**. Stroke in HIV-infected patients: a clinical perspective. *Cerebrovascular Diseases* 2003;**15**:37–44.
- 13 **Sperber K**, Shao L. Neurologic consequences of HIV infection in the era of HAART. *AIDS Patient Care and STDs* 2003;**17**:509–18.
- 14 **Hicks C**, Currier J, Sax P, *et al*. Current management challenges in HIV: tolerability of antiretrovirals and metabolic complications. *AIDS Patient Care and STDs* 2003;**17**:221–33.
- 15 **Matheny SC**. Clinical dilemmas in palliative care for HIV infection. *J Roy Soc Med* 2001;**94**:449–51.
- 16 **Yeguez JF**, Martinez SA, Sands DR, *et al*. Colorectal malignancies in HIV-positive patients. *Am Surg* 2003;**69**:981–7.
- 17 **Powles T**, Nelson M, Bower M. HIV-related lung cancer—a growing concern? *Int J STD AIDS* 2003;**14**:647–51.

- 18 **Easterbrook P**, Meadway J. The changing epidemiology of HIV infection: new challenges for HIV palliative care. *J Roy Soc Med* 2001;**94**:442–8.
- 19 **Petricrew M**. Why certain systematic reviews reach uncertain conclusions. *BMJ* 2003;**326**:756–8.
- 20 **Clinical Guidance Outcomes Group**. *Guidance on commissioning cancer services—the research evidence*. Leeds: NHS Executive, 1996.
- 21 **Higginson IJ**, McCarthy M. Validity of the support team assessment schedule: do staffs' ratings reflect those made by patients or their families? *Palliative Medicine* 1993;**7**:219–28.
- 22 **Nickel JT**, Salsberry PJ, Caswell RJ, et al. Quality of life in nurse case management of persons with AIDS receiving home care. *Research in Nursing and Health* 1996;**19**:91–9.
- 23 **Vincent I**, D'Herouville D, Moulin P, et al. Modalities of palliative care in hospitalized patients with advanced AIDS. *AIDS Care* 2000;**12**:211–19.
- 24 **Butfers E**, Higginson I, George R, et al. Palliative care for people with HIV/AIDS: views of patients, carers and providers. *AIDS Care* 1993;**5**:105–16.
- 25 **Koffman J**, Higginson I, Naysmith A. Hospice at home—a new service for patients with advanced HIV/AIDS: a pilot evaluation of referrals and outcomes. [see comments.]. *Br J Gen Pract* 1996;**46**:539–40.
- 26 **Butfers E**, Higginson I, George R, et al. Assessing the symptoms, anxiety and practical needs of HIV/AIDS patients receiving palliative care. *Quality of Life Res* 1992;**1**:47–51.
- 27 **Gibbs LME**, Ellershaw JE, Williams MD. Caring for patients with HIV disease: the experience of a generic hospice. *AIDS Care* 1997;**9**:601–7.
- 28 **Butfers E**, Higginson I. Two HIV/AIDS community support teams: patient characteristics, problems at referral and during the last 6 weeks of life. *AIDS Care* 1995;**7**:593–603.
- 29 **Kimball LR**, McCormick WC. The pharmacologic management of pain and discomfort in persons with AIDS near the end of life: use of opioid analgesia in the hospice setting. *J Pain Symptom Management* 1996;**11**:88–94.
- 30 **Lucas C**, Glare PA, Sykes JV. Contribution of a liaison clinical pharmacist to an inpatient palliative care unit. *Palliative Medicine* 1997;**11**:209–16.
- 31 **Foley ME**, Fahs MC, Eisenhandler J, et al. Satisfaction with home healthcare services for clients with HIV: preliminary findings. *J Assoc Nurses in AIDS Care* 1995;**6**:20–5.
- 32 **Uys LR**. Evaluation of the integrated community-based home care model. *Curationis S Afr J Nursing* 2001;**24**:75–82.
- 33 **Uys LR**. The practice of community caregivers in a home-based HIV/AIDS project in South Africa. *J Clin Nursing* 2002;**11**:99–108.
- 34 **Moons M**, Kerkstra A, Biewenga T. Specialized home care for patients with AIDS: an experiment in Rotterdam, The Netherlands. *J Advanced Nursing* 1994;**19**:1132–40.
- 35 **Bunch EH**. AIDS in Norway: a post hoc evaluation of an AIDS home care project. *J Clin Nursing* 1998;**7**:183–7.
- 36 **McCann K**. The work of a specialist AIDS home support team: the views and experiences of patients using the service. *J Advanced Nursing* 1991;**16**:832–6.
- 37 **Rinck GC**, Geertrudis AM, van den Bos JK, et al. Methodologic issues in effectiveness research on palliative cancer care: a systematic review. *J Clin Oncol* 1997;**15**:1697–707.
- 38 **McWhinney IR**, Bass MJ, Donner A. Evaluation of a palliative care service: problems and pitfalls. *BMJ* 1994;**309**:1340–2.
- 39 **Borgia P**, Schifano P, Spadea T, et al. Assessing effectiveness of home care for persons with AIDS: analysis of methodological problems. *AIDS Care* 2002;**14**:645–50.
- 40 **Higginson IJ**, Finlay IG, Goodwin DM, et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Management* 2003;**25**:150–68.
- 41 **Henley LD**. End of life care in HIV-infected children who died in hospital. *Developing World Bioethics* 2002;**2**:39–54.
- 42 **Selwyn PA**, Rivard M, Kappell D, et al. Palliative care for AIDS at a large urban teaching hospital: program description and preliminary outcomes. *Innovations in End-of-Life Care* 2002;**4**(3).
- 43 **Patrick DL**, Curtis JR, Egelberg RA, et al. Measuring and improving the quality of dying and death. *Ann Intern Med* 2003;**139**:410–15.
- 44 **Grande GE**, Todd CJ. Why are trials in palliative care so difficult? *Palliative Medicine* 2000;**14**:69–74.
- 45 **Rinck GC**, van den Bos GAM, Kleijnen J, et al. Methodologic issues in effectiveness research on palliative cancer care: a systematic review. *J Clin Oncol* 1997;**14**:1697–707.
- 46 **Keeley D**. Rigorous assessment of palliative care revisited. *BMJ* 2004;**319**:1447–8.
- 47 **Goodwin DM**, Higginson IJ, Edwards AGK, et al. An evaluation of systematic reviews of palliative care services. *J Palliative Care* 2002;**18**:77–83.
- 48 **Harding R**, Stewart K, Marconi K, et al. Current HIV/AIDS end of life care in sub-Saharan Africa: a survey of models, services, challenges and priorities. *BioMed Central Public Health* 2003;**3**(33).
- 49 **Manfredi PL**, Morrison RS, Morris J, et al. Palliative care consultations: how do they impact the care of hospitalized patients? *J Pain Symptom Management* 2000;**20**:166–73.
- 50 **McQuillan R**, Finlay I, Roberts D, et al. The provision of a palliative care service in a teaching hospital and subsequent evaluation of that service. *Palliative Medicine* 1996;**10**:231–9.
- 51 **Clayton J**, Fardell B, Hutton-Potts J, et al. Parenteral antibiotics in a palliative care unit: prospective analysis of current practice. *Palliative Medicine* 2003;**17**:44–8.
- 52 **Hearn J**, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Quality in Health Care* 1999;**8**:219–27.
- 53 **Wu A**, Gifford AL, Asch SM, et al. Quality-of-care indicators for HIV/AIDS. *Disability Management Health Outcomes* 2000;**7**:315–30.
- 54 **Lin MK**, Wu AW, Revicki DA. Incorporating quality of life measures in HIV clinical trials. [Review] [68 refs]. *HIV Clinical Trials* 2002;**3**:202–18.
- 55 **Orchi N**, Girardi E, Antonucci G, et al. Changing patterns of "hospital-at-home" care use by persons with AIDS in the era of combination antiretroviral therapy. *AIDS Patient Care and STDs* 2001;**15**:625–32.
- 56 **Armes PJ**, Higginson IJ. What constitutes high-quality HIV/AIDS palliative care? *J Palliative Care* 1999;**15**:5–12.
- 57 **Heath JM**. Care of persons with AIDS in the nursing home. *Family Medicine* 1998;**30**:436–40.
- 58 **Buchanan RJ**, Wang S, Huang C. Profiles of nursing home residents with HIV. *J Health Care for the Poor and Underserved* 2002;**13**:379–91.
- 59 **Baker A**. Dedicated palliative care. *Nursing Times* 1997;**93**:36–7.
- 60 **Stephenson J**, Woods S, Scott B, et al. Clinical update. HIV-related brain impairment: from palliative care to rehabilitation. *Int J Palliative Nursing* 2000;**6**:6–11.
- 61 **Frank RR**, Campbell ML. Caring for terminally ill patients: one hospital's team approach. *J Critical Illness* 1999;**14**:51–5.
- 62 **Adelstein W**, Burton S. Palliative care in the acute hospital setting. *J Neurosci Nursing* 1998;**30**:200–4.
- 63 **Maul FW**. Issues in prison hospice: toward a model for the delivery of hospice care in a correctional setting. *Hospice Journal—Physical, Psychosocial, and Pastoral Care of the Dying* 1998;**13**:57–82.
- 64 **Salt S**, Wilson L, Edwards A. The use of specialist palliative care services by patients with human immunodeficiency virus-related illness in the Yorkshire Deanery of the northern and Yorkshire region. *Palliative Medicine* 1998;**12**:152–60.
- 65 **Drew RS**, Mgombane G, Nyaruwa T, et al. Estimating coverage of a community-based home care programme. *Tropical Doctor* 1997;**27**:210–14.
- 66 **Barnard D**, Jagwe JGM. The introduction of palliative care in Uganda. *J Palliative Medicine* 2002;**5**:159–63.
- 67 **Curtis JR**, Wenrich MD, Carline JD, et al. Patients' perspectives on physician skill in end-of-life care: differences between patients with COPD, cancer, and AIDS. *Chest* 2002;**122**:356–62.
- 68 **Pierson CM**, Curtis JR, Patrick DL. A good death: a qualitative study of patients with advanced AIDS. *AIDS Care* 2002;**14**:587–98.
- 69 **Selwyn PA**, Forstein M. Overcoming the false dichotomy of curative vs palliative care for late stage HIV/AIDS. *JAMA* 2003;**290**:806–14.
- 70 **Finlay I**. UK strategies for palliative care. *J Roy Soc Med* 2001;**94**:437–41.
- 71 **Taramin A**, Milocchi F, Tolley K, et al. An economic evaluation of home-care assistance for AIDS patients: a pilot study in a town in northern Italy. *AIDS* 2004;**6**:1377–83.
- 72 **Crowe S**. Home truths. *Nursing Times* 2001;**97**:26–7.
- 73 **Martin JP**. Hospice and home care for persons with AIDS/ARC: meeting the challenges and ensuring quality. *Death Studies* 1988;**12**:463–80.
- 74 **Martin JP**. The AIDS home care and hospice program. A multidisciplinary approach to caring for persons with AIDS. *Am J Hospice Care* 1986;**3**:35–7.
- 75 **Murie R**. A milestone in AIDS care... benefits of a specialist hospice in Edinburgh. *Nursing Times* 1992;**88**:24–7.
- 76 **Ley DC**. Caring for persons with AIDS: initiatives. The Casey House model. *J Palliative Care* 1988;**4**:111–15.
- 77 **Moss V**. Caring for persons with AIDS: initiatives. The Mildmay approach. *J Palliative Care* 1988;**4**:102–6.
- 78 **Cumming M**. Difficulties in developing a respite program. *J Palliative Care* 1993;**9**:18–22.
- 79 **Singh S**, Hawkins D, Connolly M, et al. Model of care for the hospital treatment of individuals with HIV infection. *Health Trends* 1991;**23**:55–9.
- 80 **WHO Global Programme on AIDS**. Battling AIDS through home care in Uganda and Zambia. *Caring* 1992;**11**:56–70.
- 81 **Cherin DA**, Huba GJ, Brief DE, et al. Evaluation of the transprofessional model of home health care for HIV/AIDS. *Home Health Care Services Quarterly* 1998;**17**:55–72.
- 82 **Cherin DA**, Melchior LA, Brief DE. Issues in implementing and evaluating a managed care home health care system for HIV/AIDS: visiting nurse association foundation of Los Angeles. *Drugs and Society* 2000;**16**:203–22.
- 83 **Schietinger H**, Almedal C, Marianne BN, et al. Teaching Rwandan families to care for people with AIDS at home. *Hospice Journal—Physical, Psychosocial, and Pastoral Care of the Dying* 1993;**9**:33–53.
- 84 **Gibb DM**, Masters J, Shingadia D, et al. A family clinic—optimising care for HIV-infected children and their families. *Arch Dis Childh* 1997;**77**:478–82.
- 85 **Noe M**. The Bailey-Boushay House: an AIDS facility. *J Ahima* 1993;**64**:46–7.
- 86 **Selwyn PA**, Goulet JL, Molde S, et al. HIV as a chronic disease: implications for long-term care at an AIDS-dedicated skilled nursing facility. *J Urban Health* 2000;**77**:187–203.