Hospice at home — a new service for patients with advanced HIV/AIDS: a pilot evaluation of referrals and outcomes

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SUMMARY

Between 50 and 70% of patients with a terminal illness indicate a preference to remain at home for as long as possible until their death. Nevertheless, a much smaller percentage actually die at home in England and Wales. A new hospice-at-home service in North London for patients with HIV/AIDS is described in this report. Terminal care for HIV/AIDS patients can be provided at home by a multidisciplinary team which offers 24-hour care.

Keywords: terminal illness; hospice; home; quality of life.

Introduction

STUDIES have demonstrated that between 50 and 70% of patients with terminal illness indicate a preference to remain at home for as long as possible until their death.[1] However, in 1990 in England and Wales, only 23% died at home.[2] Patients in rural areas are even less likely than those in urban areas to die at home. Even within specialist home support services, only a small proportion (24%) of people with HIV/AIDS die at home.[3] Suggestions for the reasons for this include a lack of a supportive carer in the home, poor availability of 24-hour nursing and home care support services, areas of high social deprivation, uncontrolled symptoms, and changes in patient and family preferences as death approaches.

In central and north-west London, we have developed a new hospice-at-home service for patients with advanced HIV/AIDS who wish to be cared for at home. Care is provided by nursing staff trained in palliative care and HIV/AIDS, and bank nurses who provide a night-sitting service. Specialist medical input is provided by two consultants in palliative medicine from local hospices. The service covers a population of approximately 567 500 people where there are approximately 40–50 HIV/AIDS related deaths per year. This descriptive pilot evaluation reports patients cared for by the service between February 1993 and April 1995.

Method

Data were collected on newly referred patients, including sociodemographic and clinical details, place of referral and death. Clinical and psychosocial outcomes were measured by nurses using a shortened version of the Support Team Assessment Schedule (STAS), a previously validated measure of palliative care.[4] Items covered pain control, other symptom control, patient anxiety, family anxiety, patient insight, family insight and communication between patient and family, communication between professionals, and communication between professionals and patient and family. Each item was rated using a five-point scale: no problems (0) to severe or multiple problems (4). Assessments were made at the point of entry to hospice-at-home, and then at weekly intervals until the last week of life or discharge from the service. We tested for a difference between paired ratings at referral and death using Wilcoxon's matched paired signed-ranks test.

Results

Between February 1993 and April 1995, 40 patients were referred for care to the hospice-at-home until their death or discharge. Most patients were male (88%, n = 35), aged between 25 and 44 years (68%, n = 27), single (65%, n = 26), homosexual or bisexual (80%, n = 32), and most referrals (48%, n = 19) were from the St Mary's Hospital and Home Support Team — the main local hospital caring for most patients. Fifty-five per cent (n = 22) of patients lived alone, and of these patients, 55% (n = 12) had no lay carer at all. At referral, only 43% (n = 17) of patients were at home and 30% (n = 12) were in hospital. Eighty per cent (n = 28) of patients who died did so at home.

Completed STAS scores were available for 36 patients (Table 1). Although all STAS items showed a trend towards improvement between referral and the last week of life or discharge, only two items reached significance: control of other symptoms (Wilcoxon Z = 3.32; $P = 0.0009$) and family insight (Wilcoxon Z = 2.73; $P = 0.006$).

Discussion

The aim behind the development of the hospice-at-home was taken as the sufficient physical and mental comfort of patients and their carers to find remaining life worthwhile, despite the effects of advanced HIV/AIDS. The service does appear to have met this aim, caring for people at home and enabling most patients to remain at home until their death: a very high proportion of patients with HIV/AIDS die in hospital.[5] This achievement is particularly impressive given that the majority of patients lived alone, and just over one-quarter of patients had no carer.

This descriptive pilot evaluation should be viewed within the following limitations. First, the number of patients cared for by the service was relatively small, but these patients represent approximately half of the HIV/AIDS deaths within the area. Secondly, we did not evaluate the care received by a control or comparison group. This would be required in order to determine if care provided by hospice-at-home is superior or inferior to other services. We are currently in the process of incorporating a comparison group within the evaluation.

Nevertheless, the results of this evaluation demonstrate that terminal care for HIV/AIDS patients can be provided at home by

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Submitted: 2 November 1995; accepted: 22 April 1996.

© *British Journal of General Practice,* 1996, **46,** 539-540.

Table 1. Support Team Assessment Schedule (STAS) ratings for Parkside hospice-at-home ($n = 36$).

	Rating at referral		Rating in last week of life	
STAS items	No problem	Severe/ overwhelming problem	No problem	Severe/ overwhelming problem
Pain	18 (50%)	—	19 (53%)	—
Other symptom control	2 (6%)	15 (42%)	12 (33%)	3 (8%)
Patient anxiety	5 (14%)	2 (6%)	9 (25%)	2 (6%)
Family anxiety	—	3 (8%)	3 (8%)	—
Patient insight	12 (33%)	—	16 (44%)	—
Family insight	12 (33%)	—	24 (67%)	—
Communication between patient and family	11 (31%)	2 (6%)	15 (42%)	—
Communication between professionals	21 (58%)	1 (3%)	27 (75%)	1 (3%)
Communication between professionals and the patient and family	25 (69%)	2 (6%)	25 (69%)	—

a multidisciplinary team which offers 24-hour care and improves quality of life for patients and their carers. It also importantly demonstrates a way that measures can be made for patients during advanced illness, which has been a limitation in other studies.[6]

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