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Community Case Study Of Long-Term Survival With Oesophageal Candidiasis: a primary healthcare nursing study of support for a patient receiving home self-administered intravenous amphotericin.

Poster Presentation No. POI143 to the First International Conference on Home Health Care For AIDS Patients, Palais des Congres Internationaux de Lyon, Lyon, France, October 5th to 8th 1993.

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Introduction

HIV infection predisposes a person to fungal infections because of failure in the host's cell-mediated immunity, which may result in a variety of fungal infections (1,2). Candidiasis is commonly caused by *Candida albicans* which can become a multi-system problem affecting the patient's nails, mouth, oesophagus, lower gastrointestinal tract, genitalia and rectum. Candida oesophagitis is a condition diagnostic of AIDS and characterised by erythematous lesions, pseudomembranous areas and/or ulcerations of the oesophagus. The condition may cause difficulty in swallowing, retrosternal pain, nausea and vomiting. Significant weight loss may also develop secondary to the characteristic symptoms of oesophageal candidiasis (3).

Reports to date suggest therapy failure, incomplete response and decreasing susceptibility to azole medications such as ketoconazole, fluconazole and itraconazole (4). Whilst amphotericin remains the standard treatment for systemic or resistant mycoses (1), hospital experience with amphotericin toxicity may be a limiting factor against

initiating homebased therapy (1).

We report the outcomes for a clinically responding patient with a falling CD4 count diagnosed with oesophageal candidiasis receiving intravenous amphotericin at home for a continuous seventeen month period. This case fulfils current definitions of long-term survival (5,6).

The patient initially presented over three years previously with HIV-related thrombocytopenia, a diagnosis made after counselling and HIV antibody testing showed HIV infection.

Over successive years the patient received out-patient follow up including quarterly CD4 monitoring, treatment with Zidovudine, prophylaxis with Cotrimoxazole against *Pneumocystis carinii* pneumonia, psychological counselling, oral and dental, care and social welfare interventions. The out-patient service included written information for the patient's General Medical Practitioner after each out-patient

visit, on patient request.

On presentation with oesophageal candidiasis due to *Candida albicans* three years later, the patient requested homebased care in association with the General Medical Practitioner (GP) and the rest of the primary healthcare team. The patient wished to keep hospital stays and out-patient visits to a minimum.

The blood results for the patient's serum creatinine, urea and potassium are shown in Figures 1-3, respectively, for a total period of seventeen months during which amphotericin was administered. The data covers both the two week period of hospital based induction therapy and the following seventeen months of homebased maintenance therapy.

Treatment Protocol

Amphotericin induction therapy was administered in hospital over the fourteen day period, following incomplete clinical response to oral azole therapy with ketoconazole, fluconazole, and itraconazole,

respectively. No significant side-effects after induction therapy were observed and indwelling central venous access was achieved before discharge with the *Port-a-Cath* system available from Kabi Pharmacia Ltd.

On discharge home, the patient was prescribed an alternating regime of twice and thrice weekly maintenance doses of intravenous amphotericin 50mg. The drug was reconstituted in 5% dextrose (7) and was continuously self-administered over a period of seventeen months.

Each dose of GP prescribed amphotericin was aseptically prepared, loaded into the *Intermate* system, a portable, non-gravity dependent self-infusion device (Figure 4) and delivered to the patient's home, by Caremark Ltd. The patient was able to self-administer the doses with *Intermate*, which is currently prescribed for homebased therapy in cystic fibrosis and haemoglobinopathies to give antibiotic and iron chelation therapy (8,9), respectively.

The treatment protocol comprises twice weekly venepuncture by the practice nurse working to serum parameters which were set through dialogue between the General Medical Practitioner, the Consultant Haematologist and supported through the liaison practice of the Clinical Nurse Specialist.

Model Of Care

The need for "shared care" for HIV patients has already been addressed in United Kingdom especially for patients with Cytomegalovirus retinitis requiring homebased Foscarnet and/or Ganciclovir (10,11). Shared care is novel and variable within the United Kingdom (12), even though some regions have already developed extensive homebased schemes. However, the community focus of such developments maybe more commonly associated with other country's healthcare systems (13).

Generally, the communication systems which exist spanning acute and primary healthcare to service such "shared care" schemes in the United Kingdom, are poorly developed. General Medical Practitioners may have limited access to the available hospital based expertise (12,14).

To sustain such a model of care, close liaison and sharing of information between hospital and community services is essential to facilitate and improve the choices for homebased therapy. This requires both the liaison work of specialist nurses/Clinical Nurse Specialists (CNS's) to link both the hospital and community services (15,16), as well as regular written and verbal communication between hospital and community physicians.

Prescribing and clinical responsibility lies with the GP who works in close liaison and collaboration with hospital-based specialists and community-based specialist and generic nurses. Costs of the Intermate infusion device and medication available through FP10 prescribing were refunded to the GP's budget after anonymous clinical case notification of diagnosis to the GP's own Family Health Services Authority's pharmaceutical advisor.

Community Nursing Care

In the case reported, instruction in the use of the *Port-a-Cath* and *Intermate* systems whilst in hospital was lead through the interventions of the CNS, in association with the hospital nursing staff. The patient was instructed in non-touch technique whilst infusing through the *Port-a-Cath*, "gripper" needle insertion, flushing the system, and during safe connection of the *Intermate* system.

The CNS provided the clinical resource for the community nursing staff in terms of education about the disease and addressing training needs. An important role for the specialist nurse was one of professional support for the community nursing staff involved in the patient's care.

Availability of a clinical nurse specialist as a resource was facilitated by close links into the primary network and the quick response times for community nurse enquiries, much enhanced through utilisation of an aircall message paging system.

The practice nurse, as well as assisting with blood monitoring given the agreed acceptable parameters for serum creatinine, urea and potassium, also provided nurse counselling and practical support to this ambulant patient during the twice weekly attendances at the practice.

The role of the practice nurse with this symptomatic patient was integrated into the pre-existing role of the nurse where the caseload already included care for other patients with terminal diagnoses. Focusing this patient's care back into the community helped to "normalise" the patient's treatment, given the patient was fully ambulant and was well enough to return to a manual occupation for the first nine months of homebased treatment, following successful hospital induction therapy with amphotericin.

The client's self-care at home was enhanced initially on hospital discharge and prior to resumption of work, through the interventions of district nursing. District nurses within the United Kingdom work

collaboratively and holistically with patients and the frequency of home visiting will vary according to individual patient's needs.

Care Outcomes

The patient's request for an independent life outside of hospital was supported through the medical and nursing agencies of primary healthcare in association with the Clinical Nurse Specialist acting as a link between the hospital and community staff.

Significant clinical response to therapy at home has been achieved without chills, fever and significant nausea. One documented episode of asymptomatic elevated serum creatinine (> 260 mmol/l) has occurred. The therapy was discontinued for seven days and recommenced on return of the serum creatinine to within less potentially toxic limits.

One episode of line sepsis during the seventeen month infusion period with amphotericin was due to *Staphylococcus epidermis* and one episode of *Candida albicans* septicaemia required hospitalisation and treatment with amphotericin for fifteen days. On discharge home and after

counselling from medical and nursing staff, the patient decided to take retirement from work on grounds of ill-health.

On two occasions a trial of oral fluconazole therapy has been attempted. On the first occasion, intravenous amphotericin was instituted within ten days due to regrowth in the upper oesophagus of *Candida albicans*, with concurrent weight loss. On the second occasion, after seventeen months of intravenous amphotericin therapy, no regrowth appears to have occurred on visual observation of the upper oesophagus, with further endoscopy planned to substantiate these clinical findings.

The specific factors facilitating homecare in this particular instance include the prescribing and blood monitoring role of the General Medical Practitioner, the involvement of a locally available Clinical Nurse Specialist working alongside practice and district nurses, as well as the clinical experience of the hospital Consultant Haematologist with the treatment of systemic mycoses.

The patient's quality of life was maintained at a level which the patient felt gave substantial advantages for independent living. Institutional equipment such as "drip" stands and volumetric infusions, were thereby kept to a minimum as they may limit ambulation at home, are often user unfriendly which may foster dependency. Unsatisfactory alternatives to homecare were in-patient hospital stays or attendance at out-patient clinics for intravenous therapy, neither of which were acceptable to the patient.

Also, the *Intermate* system allowed the patient the freedom of choice to self-medicate at work or home, during convenient times with unrestricted ambulation. The appearance of the *Intermate* device is self-effacing and handling of the complete system is a relatively simple procedure. Therefore, *Intermate* has been useful in this case, for integrating a potentially difficult therapy into the patient's home context and lifestyle.

Therefore, therapies previously considered suitable for administration

in the hospital environment, may be self-administered with appropriate medical and nursing support, by patients in their own home surroundings. Studies have suggested that factors such as satisfaction with, and access to requisite services may be conducive to facilitating survival for people who are living with HIV disease (4).

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