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Complementary therapy provision in a London community clinic for people living with HIV/AIDS: A case study

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A B S T R A C T

Aim: To present a case study of complementary therapy (CT) provision within a community HIV multi-agency service in a Northwest London deprived area.
Methods: Anonymised routine service data were provided for all clients (n = 1030) August 2010 to October 2012. Face-to-face meetings provided feedback from volunteers (9 CT-using clients and 9 staff).
Results: CT-users were demographically similar to other clients. Support for coping with HIV was commonly cited as a service benefit. Over 26 months 1416 CT sessions were provided; 875 aromatherapy and 471 shiatsu. CT-users' most common concerns were pain (48%), stress (15%) and insomnia (13%), few had heard of or used CT before. Perceived mental and emotional benefits included relaxation,,stress relief, relieving musculoskeletal aches and pains. Service challenges included time and funding, though staff felt CT may be cost-effective.
Conclusions: CT may provide important support and treatment options for HIV disease, but cost effectiveness requires further evaluation.

HIV is now a manageable chronic disease, but still results in patients requiring a range of medical and psychosocial services which incurs financial costs [1–4]. It has been suggested that current routine HIV services in the UK are unlikely to meet these needs [5]. As the number of people living with HIV disease and their life expectancy is increasing, services need to adapt to address these complex needs. Recent changes to the commissioning of HIV services in the UK emphasise the integration of health and social care for HIV, with local authorities more involved in the commissioning of services for people living with HIV/AIDS (PLWHA) [6].

Collaborative, holistic, patient-centred, individualised services and health promotion are recommended to address the diverse needs of PLWHA [7–9]. An individualised case-management approach, defined as "*a coordinated and integrated approach to service delivery, intended to provide on-going supportive care and to help people access the resources they need for living and functioning in the community*" [10] and mandated in the USA for HIV [3], can help to meet these needs and also improve adherence to HIV medications [11,12].

Multi-agency service approaches to HIV care are common in the USA, but as far as we know much less common in the UK. Evaluations of similar services have found that multi-agency services for PLWHA are appreciated by patients and provide a more integrated service [13,14]. There is a need to evaluate case-management based services to identify appropriate models of care [4]. A recent Cochrane review stated that it was important to prioritise the evaluation of case-management models in HIV disease, as only 3 previous studies had been identified, all of which were carried out in the USA [15].

The service being evaluated includes provision of 3 complementary therapies (CT); shiatsu, aromatherapy and reflexology, in a socio-economically deprived area of North West (NW) London. The authors have recently published a systematic review of the literature on HIV and CT, including studies on the prevalence and determinants of CT use, attitudes to CT, reasons for use and decision-making process, guidance for clinicians, and safety [16]. This review found that most studies were conducted in North America and highlighted the popularity of CT amongst by PLWHA. Between 30 and 90% of PLWHA used CT, particularly women and those with higher education [17–20], with vitamins, herbs and supplements appearing to be particularly popular, followed by prayer, meditation and spiritual approaches [17,18,21–23].

Key reasons for CT use among PLWHA include to: provide a method of self-management of health or give a sense of control [24–27]; cope with uncertainty [25]; manage symptoms [25]; give freedom from and

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additional choice to medical regimens [25–28]; and attempt to normalise health status, maintain health or find wellness [24,25,29]. CT may also be used for personal growth or fulfilment [24]. CT users do not appear to reject conventional medicine [29] and only one study found that a preference for CT predicted non-use of anti retroviral therapy (ART) [30]. In fact, patients were likely to use conventional parameters such as CD4-counts to make their decisions [31]. There is some evidence that CT can benefit PLWHA, namely exercise [32], stress-management [33,34] and massage [35].

This case study provides a description of an NW London community multi-agency service and explores its impact, in particular the CT provision, for both staff and clients.

1. Methods

This case study provides an account of a case-management, multi-agency service which provides a range of health and social care services to PLWHA. Services include clinical nurse specialists (CNS), health promotion, housing support, nutrition and peer support, as well as CT. The service model is a nurse-led 'triangle' of NHS, statutory and voluntary services, working together to create the most appropriate pathway for the client.

This paper aims:

1. To describe the provision of CT (including a profile of CT-users, details of service access and client pathways)
2. To compare data on service users who receive CT and those who do not (demographic and clinical variables).
3. To obtain client and staff feedback on the service, in particular the perceived impact of CT provision on clients' coping skills and self-management and access to the service.

Anonymised data were provided by the service from routine medical records for all clients from August 2010 to October 2012. Aromatherapy, shiatsu and reflexology were provided throughout this period. This data provided the demographic profile of service users and CT-users, and an overview of client pathways and service use (including GPs, hospitals and other services). Data included (where available) ethnic group, work status, benefits status, HIV disease status. As individuals were not identifiable across the datasets, bivariate comparison of CT users and non-users was not possible. Data was also provided on client outcomes collected for a previous evaluation using MYCAW ('Measure Yourself Concerns and Wellbeing' questionnaire) between April 2009 and March 2012, carried out by one of the service providers [36].

Verbal feedback from 9 clients and 9 staff was collected through one to one, face to face meetings with clients who had used the CT service and 2 group staff meetings. Clients provided information on the CT service and perceived effects on their health, wellbeing and service use. The staff meetings discussed: client pathways and case management into, within and from the service (including referral for CT); perceived impact of CT provision on service use, client outcomes and costs; perceived cost effectiveness of CT provision and the challenges of providing the service.

2. Results

2.1. Data review

Data on clients receiving CT was available for August 2010 to October 2012 (189 clients) and for the whole sample (all clients seen at the service), attendance data from April 2011 to October 2012, and demographic data from August 2010 to December 2011 (1030 clients).

For the whole sample, data were available for 192 clients (from data for April 2011 to October 2012) on their HIV/AIDS status and showed that most had an AIDS defining illness (139) and/or symptomatic HIV (122) during their time using the service. Twenty six had advanced HIV disease and 30 asymptomatic HIV disease, and 4 were at a palliative care stage. Many clients would have been at more than one of these stages over time. The majority of clients were referred to the service by an HIV/GUM specialist (Table 1).

Between April 2011 and October 2012 a diversity of services were provided at a total of 3576 appointments (Table 2). Referral to other services was a key aspect, as well as dealing with issues of medication, lifestyle impact of HIV, housing, nutrition and rehabilitation.

Although demographic data is limited (Table 3), it suggested no demographic differences for those receiving CT and the whole sample of service-users. CT clients represented a range of ethnic origins, with black people dominating. Almost half were unemployed, although very few disclosed receiving benefits.

CT data documented all CT sessions for 189 clients. A total of 1416 CT sessions were provided over the 26 month period, 875 aromatherapy, 471 shiatsu, 18 reflexology and 52 unidentified CT. Of the 189 clients, 134 were registered with a GP and 106 had disclosed their HIV status to the GP. Table 4 shows that a minority had used other services, with the positive self-management programme (PSMP) being the most popular.

Additional data previously collected using the MYCAW outcome measure for 189 clients found that the most common client concerns recorded were pain (48%), stress (15%) and insomnia (13%). This data identified significant improvements following CT treatment in individual concerns (average improvement of 54%), individual wellbeing scores (56%) and participants' overall profile scores, all $p < 0.005$ [37].

2.2. Client and staff feedback

Nine clients and nine members of staff (manager, CNS, CT therapists, administrators, support staff, dietician) provided verbal feedback. Clients' dates of HIV diagnosis ranged from 1987 to 2012 and most were using a range of services; 2 had received aromatherapy followed by shiatsu, 2 were currently receiving both, 2 received shiatsu only and 3 aromatherapy only (none had received reflexology).

Prior to accessing the service, few (3) clients had heard of or used CT, many citing that they couldn't afford to. Many clients cited

Table 1
How client first heard of the service.

	Number of clients ($n = 189$)
Referral/recommendation by professional at specialist unit	121
Referral/recommendation by professional at local HIV/GUM clinic	32
Referral/recommendation by another NHS professional	4
Friend/family	3
Welfare service – other	3
GP	2
Referral/recommendation by professional	2
Living Well staff/facilitator	2
Charity/voluntary organisation	2
Flyer/leaflet	1
Rain trust	1
Social services	1
Terrence Higgins Trust	1
Housing trust	1