Working with HIV illness

At a clinic where a fifth of the clients are known to be HIV positive, they've had to come to terms with HIV illness

HOW SHOULD a drug service respond to its clients who are HIV positive, and perhaps showing signs of HIV illness? Responding to this group takes services into what may be uncharted territory, both in terms of the service delivered at the agency itself and in terms of liaison with other services. It can be a daunting challenge.

We focus on some of the good practice concerns of professionals offering a health care service to this group, based on our experience at a drug dependency clinic in an area of relatively high HIV seroprevalence. In recent years our client base of those known to be seropositive has grown to 20 per cent (30-40 people). Each year a number of other clients stay with us for short periods. What follows is an outline of the needs they have presented and how our service has responded.

Unpackaged treatment

Drug services in our area range from specialist information and advice, through short- and long-term detoxification to maintenance prescribing. This is accompanied by different counselling interventions; social work; medical care; health promotion and education; referral to rehabilitation; and psychiatric care.

This whole range of options remains available to clients who are HIV seropositive. There is no special 'package' for these clients, nor for those with HIV illness. We feel that it is imperative to work with the wishes of clients as much as possible, and to ensure that they are aware of all the options. HIV positive clients are treated on an individual basis, just as we would a homeless mother or someone with psychiatric diagnosis. Some have opted for stabilisation, detoxification and drug free rehabilitation, while others have chosen maintenance, and just about all the possibilities between.

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Sex and loneliness

With all our clients we address the issue of HIV and intimate relationships, on the principle that they should have access to accurate information and to the means for change. Also needed is help with managing lapsing and relapsing.

Loneliness is an issue that recurs. Clients are often worried about meeting people, about performing sexually while under the strain of HIV, and about the dilemma of having a sexual relationship and possibly falling 'in love'. There is the ongoing concern about not infecting or harming others emotionally, or yourself being harmed, and the guilt of unprotected sexual intercourse, whether planned or otherwise.

Desperation for human warmth is clouded by fear of becoming ill

by

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A London drug dependency unit where a fifth of the clients are known to be HIV positive emphasises that these clients should have access to the full range of treatment opportunities available to other clients. Experience is that among clients whose drug use is not stabilised, signs of HIV illness can be masked by the effects of drug use. Loneliness and emotional concerns over sexual and intimate relationships are major work areas. Non-drug services need training, advice, and support in working with an unfamiliar client group.

Most clients are clear about how to prevent their infection being spread and are keen to protect others. But still there are times – due to fear, misunderstanding, ignorance about contraception, lack of social skills, desperation, etc – when clients do become involved in unprotected sexual intercourse.

For those who are ill, the desperation for human warmth and physical contact leading to sexual intercourse is clouded by the fear that becoming ill will affect any relationship they may form. There is often a great fear of being left alone, of leaving their partners alone, becoming a burden, becoming disfigured, being in pain and being unsupported. A number of clients wish to become mothers or fathers, and require assistance to work this out.

Finally, ill clients with children need help to work through their fantasies about what might happen and how their children might respond, and to identify support systems for themselves as well as for their children. We help some of these children explore what is happening to them and to their families. Partners are encouraged to participate in the client's counselling along with having their own counsellor.

Our major objective is to enable the client to develop a comprehensive and supportive carer network involving both statutory and non-statutory agencies.

Safer drug use

Drug use for those concerned about HIV illness may be typified by polydrug use and increased confusion. For those who are ill, relapse or lapse is also an issue, often taking the form of self-medication using stimulants to combat depression and lethargy. Episodic use of other drugs can cloud the picture.

Essentially our aim – as with all clients – is to engage HIV positive clients in safer practices. We aim to reduce possible harm due to intoxication with combinations of drugs, accidents, overdoses or reduced immune function. We also aim to reduce harm arising from the social consequences of drug use or HIV infection, such as police

involvement, loss of accommodation, mounting debts or loss of friends and carers. Other issues occur, including the guilt of sharing of injecting equipment.

Those who are ill and need medical care are often unable to comply with the HIV treatment regime due to their illness or due to chaotic drug use. We help in bringing about some stabilisation in their lifestyles and drug use, and encourage contact with outpatient departments, GPs, hospital wards and hospices. The medical director and nurses advise other nursing and medical staff about prescriptions, pain management, and management of care.

Dealing with dying

Death is not a new concern to many of our clients. Already they face the risks of overdose, accident, or infection. Many clients who use drugs and are facing the onset of AIDS decide that they want to stabilise their use or detoxify. Others go through stable phases, with lapses of depression and distress.

Many such clients are lonely. They may find that they do not fit comfortably into the current support organisations. Often disclosure of their HIV status to their current or past drug using contacts leads to isolation. Consequently our work has been about developing personal confidence and group skills so that clients can participate in their own treatment and support, developing a personal network of supportive groups and services. Our successful group for HIV positive clients is well attended.

Much of our work is about helping people through periods of depression, helping them to identify reasonable goals, and allowing them to feel safe enough to be frightened, confused, sad and angry. Like the physical manifestations of HIV illness, the psychological impacts are periodic rather than continuous.

Finally, we want to offer clients some security about their final illness. It is important for clients to be aware that there is a knowledgeable, skilful and reliable network of support. We aim to develop a supportive network based on service delivery and on personal counselling and on facilitating the client's communication with the services that can help them.

Our long-term (if episodic) work with many clients means we are able to help them complete their 'unfinished business'. We offer pain control, and hopefully enable them to die in the place, with the people, and in the manner of their choice. To our clients' families, friends and partners, we offer guidance and support during our clients' periods of treatment with us, and bereavement counselling after their death.

Presenting needs and diagnosis

Illness related to HIV is complicated by the effects of the client's drug use. Clients on a prescription programme or using illicit drugs in a stable manner show clearer symptoms of HIV illness and are easier to treat. Often illness manifests as difficult-to-treat skin and mouth conditions such as fungal infections and mouth ulcers. Persistent diarrhoea, weight loss and chest ailments are also common. Care is needed in diagnosis because chaotic drug use itself can lead to poor diet, weight loss, anxiety, reduced immune function and short-term memory disturbance, leading to some of the symptoms associated with HIV illness.

What kind of problems do clients present with? Two 'identikit' examples compiled from our experience will help to give a flavour of the challenges they present.

❶ **The partner left behind.** A couple, who have been in and out of treatment, both positive, one with recurrent HIV illness, both in their 20s. One partner dies. The remaining partner needs to do the grief work, needs to be encouraged to be as safe in HIV prevention terms as possible, to come to terms with loneliness associated with the reduced chance of finding an intimate partner. All of this within the context of their own possible drug use.

❷ **Family man in crisis.** A man, who is generally stable, with a partner and a family, loses his job. He has been HIV positive for some time, and becomes unstable, concerned about various issues including provision for his wife and children. Periodic, chaotic drug use leads to peripheral vascular disorder leading to amputation of a foot. Help offered includes pain management – physical and psychological. He needs help to address his concerns over self-image and progression to the terminal phase of HIV illness, and over the difficulties associated with maintaining his current partnership.

Professional networks

Many of the carers who become involved with our clients have little knowledge of drug use, dependence and counselling. We offer advice about setting boundaries, drafting contracts, medication, management, counselling, and about support networks for staff. We also need to emphasise our belief that clients have ultimate control over their care. Many medical and social agencies are used to clients who defer to their authority and comply with the treatment. They need advice on how to work with clients who very clearly make their needs known, and who will be explicit about what they do and do not want.

To these agencies we offer information and advice about negotiating flexibly with drug using clients within clear professional and ethical boundaries. We also offer consultation, education and training, and professional supervision. Many workers become 'over-involved' and 'dump' their expectations upon the client, inducing embarrassment and guilt and making long-term work difficult. We emphasise that liaison and joint planning, with the explicit involvement of the client, are imperative. There is little to be gained from devising helpful plans that the client neither understands nor agrees with.

The challenge for staff

Staff who attempt to offer a good quality and humane service may be sucked into a client's periods of hopelessness, responding by offering a 'happy pill' solution. Whether due to pressure of time, demand from clients or carers, or confusion about how to help the client progress, the temptation to prescribe a problem away needs to be faced.

Clients and staff want answers about HIV, illness and drug use, but information on HIV is still patchy. Staff face the problem of finding the time to read and digest the plethora of research and policy documents and to implement changes.

It can be difficult working in ignorance, relying on varying and often questionable research results and working with the fact that predicted outcomes can only be expressed as probabilities. Learning in this environment – sometimes from mistakes – is arduous. To help plug the information gaps our work includes research on the promotion of healthier behaviours.

Remaining flexible while under pressure and allowing the client choice can sometimes be difficult. Work pressure often leads staff to be rigid, to plan without negotiation. Usually they feel their imposed plans are generally for the 'best', but they may not be in the interests of that *particular* client. The service provides an externally facilitated support group for staff to enable team building, conflict resolution, support and personal development. ■