

## Chapter 16 The AIDS pandemic

### CASE STUDIES

#### Case study: changing concepts of AIDS in Do Kay, Haiti

Farmer<sup>15</sup> described how concepts of acquired immune deficiency syndrome (AIDS) (*syndrome d'immunodéficience acquise*, or *sida*) gradually changed during the period 1983–89, in the rural village of Do Kay, Haiti. In 1983–84, the village had heard only vague rumours of a 'city disease' (*maladi lavil*); very few knew how it was transmitted, or how serious it was. By 1985–86, and drawing on folk models of illness causation, the idea had become common that *sida* was a 'sickness of the blood', something that 'spoils your blood, and makes you have so little blood that you become pale and dry'. Partly owing to public health programmes, these beliefs gradually became linked to vague understandings of *sida* as caused by an irreversible pollution resulting from blood transfusions or same-sex relations, as well as by weakness from overwork in the city, or by travel to the USA. In 1987, a consensus about the symptoms of *sida* had begun to develop, especially its association with diarrhoea and tuberculosis. That same year, the first resident of Do Kay fell ill with the disease; this was widely blamed on a 'sent sickness', or sorcery, due to envy. The victim's

family consulted a voodoo priest, who confirmed this, and identified certain individuals responsible for it. When another villager fell ill with the disease, though, most did not believe that she actually had *sida*, as she was considered 'too innocent' to be the victim of envy. By 1988–89, after both villagers had died and a third had fallen ill, a consensus about the disease had developed in Do Kay. *Sida* was seen as two entities, both caused by a microbe: a 'natural' illness, caused by sexual contact with someone who 'carries the germ', and an 'unnatural' illness sent by sorcery from a malicious person. Condoms were helpful against the former, but useless against the latter. The 'unnatural' *sida* could only be prevented by using charms that could 'protect you against any kind of sickness that a person would send you'.

Thus, as Farmer pointed out, over the 6-year period 'the term *sida* and the syndrome with which it is associated came to be embedded in a series of distinctly Haitian ideas about illness'. These in turn link the sudden appearance of the disease to wider social and political issues, which he described as 'the endless suffering of the Haitian people, divine punishment, the corruption of the ruling class, and the ills of North American imperialism'.

#### Case study: alternative approaches to treating HIV/AIDS in the USA

O'Connor<sup>49</sup> has described the many forms of self-treatment and alternative strategies being used in the USA in the mid-1990s, especially by gay men in the PWA (people with AIDS) community. Since the mid-1980s there had been a well-organized grass-roots response to the epidemic, with the proliferation of self-help organizations and networks of information. They aim not only to help those with the disease, but also to promote further research and different forms of treatment, especially as conventional medicine seems to offer little but palliation. She describes dozens of alternative or complementary forms of self-treatment, including:

- nutritional approaches, such as macrobiotic and yeast-free diets, the 'Immune Power Diet', food supplements, antioxidants, and mega-doses of vitamins or minerals
- herbal treatments, such as echinacea, ginseng, garlic, St John's wort, aloe vera, astragalus or Bach flower essences
- homoeopathic treatments, such as nux vomica for severe nausea, or arnica for muscular pains)
- traditional Chinese medicine, both herbal preparations and acupuncture
- New Age holistic approaches, such as guided imagery, visualization, therapeutic touch, *reiki*, *Qi Dong* or crystal healing
- psychological and metaphysical approaches, such as religious healing services, prayer, and positive thinking to increase 'psycho-immunity'
- conventional pharmaceuticals used in 'unofficial' ways, or before being given official approval (such as 'underground drugs' obtained from 'guerrilla clinics', treatment study groups or from abroad).

O'Connor points out that most of these treatments are intended to *supplement* rather than supplant conventional medical treatment. For the PWAs, they are ways of taking personal responsibility for their health, and asserting their rights and expertise in their own condition and its treatment.