Secrecy-related problems in AIDS management

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Silence is no certain token
That no secret grief is there;
Sorrow which is never spoken
Is the heaviest load to bear.

Frances Ridley Havergal
Misunderstood, Stanza 15.

Patients with AIDS/HIV present with problems that may have to be dealt with by both doctors and counselors. Some of these problems are seemingly of a psychological nature, yet they are inextricably related to the medical aspects of AIDS. Foremost among these are problems relating to information about the disease and the patient's condition, and the dissemination thereof. While aspects of this will inevitably arise in the course of patient counselling sessions, they may have their origins and continue to have to be dealt with in all doctor-patient interaction. This paper sets out to highlight the significance of 'secrets' in the medical context and to describe a theoretical framework in which the management of secrets can be viewed. Some of the clinical situations are identified in which secrecy-related problems present and some guidelines are offered for approaching the problem of secrets.

There is a wide range of associated psychosocial difficulties that confront patients with AIDS and HIV infection [1-3]. Secrecy- and confidentiality-related problems almost inevitably arise at some point in the management of a patient with AIDS. Clearly, these are not new to medicine. Social stigma, individual and public concerns, as well as fear of contagion have, however, drawn attention to the social problems of patients in the context of AIDS and HIV infection [4].

There is a difference between secrets and confidential information. Secrecy implies that no one else is privy to certain information (unless it is a shared secret), while confidential information is a shared secret, perhaps within a sub-system of a health care team. The boundary around a secret, that is, who does and who does not know, is not always easy to discern. A person may declare that he or she had well-founded suspicions about a secret at the time that it is revealed to others. Problems may arise where others suspect that certain information has been kept secret, but they may feel that it is their right to be informed.

Frameworks for problem-solving and decision-making in some of these difficult cases have been described elsewhere [5-8]. Many of these problems concern patient consent for HIV antibody testing and ethical issues associated with the prevention and treatment of HIV infection and AIDS. Their nature and resolution may be specific to the setting in which they occur. Decision-making in relation to an HIV-infected psychiatric patient [9] will necessarily be different in part from the resolution of problems that general practitioners face when requested by an insurance company to provide information about a patient's lifestyle when life insurance is being sought [10]. Furthermore, secrets may also be the solution to some problems, as may be the case where a man chooses to hide his homosexuality from other family members to avoid being shunned by them. It is not the intention in this paper to offer a set of rules for how some of these complex issues should be resolved, but to bring to light an undercurrent that can impede in the management of AIDS/HIV patients, their partners and family.

Conceptual issues

One of the most comprehensive accounts of secrets and their effects is by Karpel [11] who examined this subject in the domain of family life. Secrets 'involve information that is either withheld or differentially shared between or among people'. At least three major kinds of secrets can be described. Individual secrets are those in which one person keeps something private from others, be they members of the family, health care team or any other constellation of relationships. Internal secrets are different from individual secrets insofar as at least one other person in the constellation of relationships (eg two doctors or the par-

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ents in a family) keep a secret from at least one other person. Lastly, shared secrets are between those inside a constellation of relationships (eg the whole family) and information is kept from at least one other person or group outside (eg the general practitioner or the school). Examples of these are described in Table 1.

The 'power' (or burden) attributed to the secret-holder is but one social effect of a secret. This immediately defines those who are excluded from knowing as 'one-down'. Loyalty, the fear of betrayal, protection, altruism, and guilt over disclosure are further dynamics of the interpersonal domain. A view that 'secrecy equals power' is simplistic. It can also work in the reverse where the patient experiences so much stress from the burden of keeping a secret that he may experience anxiety-related symptoms (diarrhoea, sweats, weight loss, exhaustion) which are similar to the signs of AIDS. Invariably, boundaries and alliances between people are created, strengthened or destroyed by secrets. Their effects, therefore, are at all times structural, interactive, emotional and practical. The consequences of secrets are summarised in Table 2.

The effect of any secret is never completely positive or negative. It is always a combination of these, although to varying degrees. On the one hand, a secret brings into focus themes associated with exclusion and dishonesty. On the other hand, almost all secrets serve to protect someone from something. It is not uncommon, for example, for a young, newly diagnosed AIDS patient to say to his doctor that he does not feel that it would be wise to tell his ageing parents his diagnosis as they are in poor health. This may be to protect the parents but at the cost of producing extreme anxiety for the patient. Similarly, the example of an HIV-infected bisexual man who refuses to have protected intercourse with his wife, who is apparently unaware of his HIV status, is the genesis of a potentially hazardous clinical situation. Secrets may also be a symptom of other problems. People who choose not to disclose their HIV positivity at the time of donating blood may, among other problems, be denying their illness. Counselling can help patients to find more constructive ways of dealing with dilemmas and facing up to the consequences of more open communication with others.

Confidentiality and secrecy are related but at times confused with one another. This can lead to misunderstandings in a clinical setting. Some members of health care teams resent not being told of a patient's HIV result, believing that the information is confidential to the whole team. Their colleagues might state that the matter is private and in so doing create a system in which there are secrets, justifying this with confidentiality laws. The context in which the secret is held cannot be separated from the nature of the confidential information, or from those participating in a social system created (or implicated) by the secret. For this reason, a variety of judgements about what constitutes confidentiality will almost always be in evidence. While the Hippocratic Oath clearly states the doctor's duty not to disclose information arising in the course of treatment, this privilege is not without exception or limitation, particularly where harm to the community outweighs the advantages of confidentiality [12]. Discussion about these dilemmas, both within the clinical team and with the patient, is one step towards their management and solution.

### Management of secrets

Health care professionals are not excluded from the effects of secrets. They can create considerable stress and lead to a feeling of being immobilised by the patient. Some may consider it their task to take sides, to advise patients or colleagues, or to expose the secret; others may themselves generate secrets. After a patient has been informed of a positive HIV antibody test result, some doctors prescribe secrecy by suggesting to the patient that he or she does not tell anyone the

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**Table 1. Examples of secrets**

**Individual secret:**
A married man chooses not to tell his wife that he has shared intravenous needles with other drug users in the past. He has recently lost weight, developed dermatological problems, feels tired and is increasingly breathless. He is worried about going to his GP in case she suggests that he be tested for HIV.

**Internal secret:**
At the start of their professional contact, an AIDS counsellor says to his client: 'Everything you tell me is confidential. I won't discuss it with anyone. Feel free to say whatever you want.' After 6 months, the client says he is going to commit suicide and reminds the counsellor that he promised not to tell anyone.

**Shared secret:**
After their son's death from AIDS, a couple was faced with the problem of what to say to relatives. No one in the extended family knew the diagnosis. Suspicion grew and the couple soon found that social support for them was waning and that they were grieving alone. They sought advice and counselling from the medical team which had cared for their son.

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**Table 2. Consequences of secrets**

| Type        | Effects                                                                 |
|-------------|-------------------------------------------------------------------------|
| **Informational** | Deception, distortion, mystification, clarification                      |
| **Emotional**   | Generate anxiety, discomfort, raise tension, reduce tension             |
| **Relational**  | Estrangements, pseudobonds, violation of trust, protection, enable people to get closer, create new possibilities in relationships |
| **Practical**   | Danger of unanticipated or destructive disclosure, accidental discovery, conserve or protect relationships, satisfactory handling of confidential information |
result for fear of the stigmatising reactions of others. The authors take the view that secrecy-related problems are inevitable and that health care workers may have both a personal and a professional view as to how they should be managed. At times, these may be at variance with one another. A number of steps can be taken in order to minimise their sometimes harmful effects. These are at both conceptual and executive levels and are derived from family therapy practice [13,14].

Problem solving for secrecy-related concerns

1. Identify whether there may be a secret.
2. Identify whether there is a problem in relation to the secret, and for whom. Sometimes discussion about secrecy in general is sufficient to lead to the resolution of a secrecy-related problem.
3. Spell out dilemmas involved in maintaining the secret. Balance should be attained between the advantages and disadvantages of maintaining the secret.
4. The professional need not prescribe to the patient how the secret should be dealt with; some neutrality can be retained by addressing both the advantages and disadvantages. This often has the effect of increasing tension around the secret.
5. The effect of secrets on relationships, as well as the anticipated effect of them, should be discussed with the patient. A range of possible outcomes, including the patient’s perception of the worst or most damaging, should be identified. Future-oriented and hypothetical questions [15,16] are particularly helpful in this regard. A patient who does not want to tell his partner that he has AIDS may, for example, be asked ‘How would you see things if you became unwell and you were admitted to an AIDS ward and your lover asked you why you were on that ward?’ This technique has also been used successfully in helping HIV-infected asymptomatic patients to cope with the stress associated with an uncertain future [2,17].
6. In addition to the steps described above, at least four options are open to the health care worker when faced with problems relating to secrets:
   a Collusion: agreement to preserve the secret.
   b Challenge: disagreement over keeping the secret.
   c Opt out/refer: dissatisfaction over the need for (against) secrets and the problem is referred on to a colleague.
   d Comment: discuss the problems that arise for the health care worker in keeping a secret with the patient in the first instance.

A clinical example is described in which a potential impasse resulting from secrets is avoided. Clinical details have been altered to preserve the confidential nature of the case.

Clinical case example

Thomas, a twenty-nine-year-old HIV antibody positive married bisexual man insisted that he would not tell his wife that he had come for a test. The hospital doctor was concerned that his wife may be at risk of being infected by him, if she was not already infected. Before discussing the problem with the patient’s general practitioner, the consultant decided to counsel Thomas on the implications of refusing to disclose his diagnosis.

Consultant: Thomas, if you were a doctor in my position, what would you think your patient should do?
Patient: I really don’t care. There’s no way I’m going to tell her. That would be the end.
Consultant: What might be the worst thing that would happen if you did tell her?
Patient: She’d probably leave me. I mean, she doesn’t know I’ve had boyfriends. Anyway, I’ve got the kids to think about.
Consultant: Fine. Presumably you don’t use condoms with your wife. What if she gets infected? Do you think she’d rather know now, while there’s some chance she can prevent herself from being infected, or say at a later point, when you or she or maybe both of you are ill? Whom would you choose to look after your children?
Patient: ....Uh....Those are good questions. I think she’d leave me and tell everyone. Also, she’d never let me see the kids.
Consultant: So which of those is the worst for you?
Patient: Perhaps if she left me. I don’t know what I’d do.
Consultant: Well, how might you cope?
Patient: I’ve got a boyfriend I could stay with. Look, now I’m beginning to worry about my youngest kid too. Is it possible that he’s got it? Can you test him?
Consultant: Yes, we can test him. But what will you say to your wife about that?
Patient: Yeah, look, maybe it’s better to tell her sooner than later. But I don’t think I can face it alone. Will you tell her?
Consultant: I don’t mind. Why don’t you pretend I’m your wife. Practise telling me now. Then we can arrange to meet together—you, your wife, one of our counsellors and me. We can then help all of you in the family with this.

Future-oriented and hypothetical questions are often the key to breaking this all too common impasse in patient management and care. The worst consequence of maintaining or breaking a secret should be discussed. A technique of asking questions on the part of the doctor is sometimes regarded by patients as less direct and threatening. This gives them the opportunity to change their views without having to feel blamed or disconfirmed.

Conclusion

Secrecy-related problems are a recurring feature of the management of AIDS patients. They arise at different
interfaces, including those between doctors and patients, patients and their families, and between health care workers themselves. Often, the limits of confidentiality are tested. We have found it helpful to inform our patients from the outset of the general limits of confidentiality, as recommended by the American Psychiatric Association [18]. This may prevent some secrets from becoming problems in the clinical setting. Where secrets do lead to interpersonal difficulties, their resolution may increase a patient's confidence in the consulting doctor.

Discussion of the dilemmas incurred by secrets and elucidation of their current and anticipated effects can sometimes help to remove this source of stress. This has the effect of returning to patients some of the responsibility for resolving problems. The use of future-oriented and hypothetical questions can help some patients to consider, in a non-confronting way, ideas and views they might fear to address. This can also reduce feelings of stress in doctors.

Secrecy-related problems might be viewed as an opportunity for making overt significant issues which may be difficult to face. Therefore, the effect of the management of secrets can itself lead to more open communication between not only the doctor and patient but also the patient and the social systems of which he is a part. The AIDS pandemic has done much to push this testing and often complex issue to the forefront of more general discussions about good clinical practice, ethics and doctor–patient communication.

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