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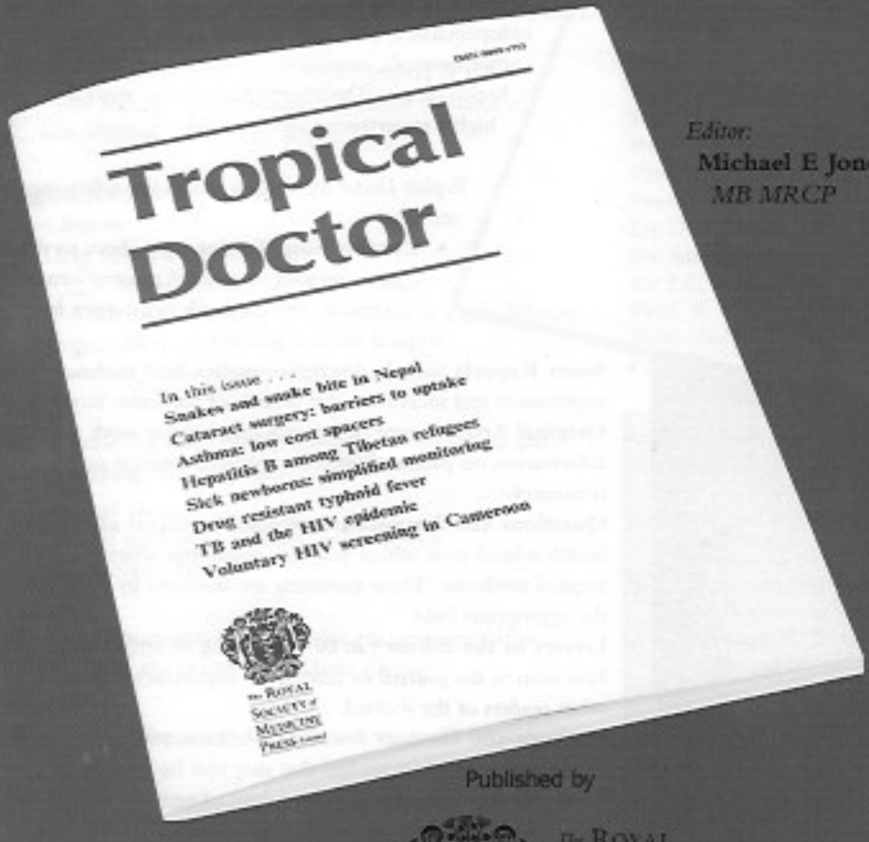

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VIEWPOINT

Community-informed consent for HIV testing and a continuum of confidentiality

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The Western medical concept of confidentiality has at its heart the one-to-one relationship between the doctor and the individual patient. The UK General Medical Council guidance on HIV and AIDS emphasizes that:

> the relationship is founded on mutual trust which can be fostered only when information is freely exchanged between doctor and patient on the basis of honesty, openness and understanding[1].

Documentation of experience-based approaches in the last decade has consolidated understanding that in all cultures the 'continuum of confidentiality' is broader than the personal one-to-one relationship, embracing family relationships and responsible relationship with the community. Confidentiality may still be developed in a wider relationship with and between the family of the patient or his or her community. When this enlarged model of confidentiality is grasped then it becomes possible to think in terms of community-informed consent. This is particularly seen in non-western cultures where often the power of the group is a protection against the hardships of life and children grow up with a group identity that is internally formed and owned, not imposed.

If community-informed consent is to be recognized one must understand the dynamics of relationships which are common to all communities: a desire to care and be cared for; belief that change is possible; and recognition that information leaks out regardless of any barriers of secrecy and privacy[2].

Community members may make decisions together in the common interest and will recognize specific areas of change in community values and beliefs[3].

The determining factor of a good working relationship is the history of that relationship. If the history of the relationship between hospital and community has been one of partnership, the evidence will be that people chose to come to that particular hospital. If, however, there has been a breakdown in the relationship, this will result in distrust and an emergent desire to avoid that hospital at all costs. Where there is a good long-standing relationship there is a sense of shared, informed, corporate trust by the community in the hospital as a whole of which the vital unseen ingredient is unspoken mutual respect. Such a privileged relationship can never be assumed to exist; where it does exist it must be fully understood by the hospital team. The existence of community-informed consent demonstrated by adequate mutual trust leads to an effective response in hospitals to issues like HIV. When community participation becomes the accepted norm and the relationship with the hospital is one of trust, this may obviate the need for a rigid adherence to the standard rules of the pre-test counselling which are the norm where a hospital-community relationship is deficient or in Western settings.

Testing for HIV may be frequently accepted by a community as a part of life or may be refused by the community.

The concept of a wider confidentiality differs from the standard confidential procedures of disclosure, 'breaking the news' and informed consent. It is worth noting that where issues are treated with confidentiality it is far easier for the community to declare, in its own way (not necessarily spoken), a sense of collective informed consent about the suitability of a particular clinic or hospital to explore the issue of HIV. This can mean that testing may be appropriate when a person walks through the door seeking help, even if the presenting issue named is not HIV.

Many developing world communities are now more open about issues connected with HIV. They have moved beyond the stage of denying that HIV is an infection endemic to their community. The evidence that denial has receded is that it is less of a struggle to obtain informed consent. In such circumstances it may be accepted that a state of community-informed consent has been achieved, although this will not always apply to every person who seeks help. If community-informed consent operates, then lack of time for pre-test counselling does not pose a major barrier to proceeding with HIV testing. Patients and families do not become reactive when HIV tests are given, for example, before delivery. The broader continuum of confidentiality may be seen most clearly where great efforts have been made to integrate community counselling and informal consent with systematic home visits to provide care and support.

Care and change processes are not mechanical. They are associated with emotions, with values, home, relationships, community, belonging and change. All these are central to the effectiveness of any programme development. The notion of a wider confidentiality

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and community-informed consent challenges standard patterns of programme development because, once achieved and recognized, they will encourage fully integrated care and prevention and enhance the community's response. In responding to HIV in the mid 1980s in Africa there was much to learn from a decentralized participatory approach to leprosy. What we learned there was then applied to the emergent HIV epidemic. A wider concept of confidentiality which encourages the emergence of community agreement, or informed consent is a vital foundational link between effective care for infected patients and a community led effective prevention response.

This particular concept has important implications for the development of effective programmes apart from HIV, such as leprosy, nutritional deficiency and disability.

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3 Salvation Army. *Community Counselling: A Handbook For Facilitating Care and Change*. London: The Salvation Army International Headquarters, 1998

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The paper should be concerned with health and disease among the sort of people for whom the Barkers worked—the dispossessed, or poor urban or rural communities.

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