

**28. Robert W.Hankins and Peter J.Fos,
Objectives for a System of Health Care Delivery for HIV Infected People,
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Uncertainty and debate regarding the appropriate general levels of resources that should be provided to fight AIDS, the trade-offs between expenditures on research and care aspects of the AIDS problem will probably be with us for some time.

The general problems of appropriate resource levels, trade-offs of resources among facets of a general remedy, and the efficiency of treatment regimens are certainly not novel to the AIDS problem. There are, however, aspects of the clinical treatment of HIV infected people that are quite different from most other sets of patients.

In early conversations with physicians and psychologists, two closely related aspects of treatment for AIDS patients appeared to be significant. First, AIDS is short lived, fatal, and has no cure. These facts make AIDS different from most other diseases or conditions for which patients seek medical help. These facts also raise the question, "What do we mean by treatment of AIDS patients?" Since we cannot now mean "cure", by default we must mean "care". The relatively short duration of the disease AIDS (as opposed to simple HIV infection) and the limitation of clinical treatment to "caring" significantly affect the level of utility gained from clinical intervention. Unless we see the patient simply as an experimental subject, the patient's choice of objectives affects utility as much, or more than, the physician's. The rationale is that, if treatment cannot cure, the objectives of life within a short period and without cure are appropriately set by the patient from the array of alternatives that could exist. If resources are consumed in treatment processes that do not fit the objectives of the patient, we can certainly question the appropriateness of their use.

Second, a variety of factors combine to directly involve three types of actors in the treatment of AIDS patients. Two have already been mentioned, the AIDS patient and the professional clinical care manager, usually a physician. The third is the person who delivers day-in-day-out (perhaps hourly) personal care to the patient. This person may be a relative, a lover, a close friend, or a concerned volunteer. Whatever the relationship, this person is significant to the delivery of the treatment that is being managed by the physician or other clinical professional. We have not yet found a generally acceptable term for these people. We currently refer to them as continual care givers (CCGs), to differentiate them from the clinical professionals whom we refer to as principal care managers (PCMs).

We hypothesize that if these three actors do not agree on the purpose of care prescribed for the patient, the care will, to a significant extent, be ineffective or ineffectively delivered, and many of the resources used will thus be wasted.

Group Method

When considering issues of care for HIV infected people, the heterogeneity among the three groups of actors is quite evident. Each group has a very different involvement, with different personal stakes. In an effort to identify each group's objectives, a series of group meetings was held.

Because of the issue of confidentiality, the social implications of HIV infection, and the people with AIDS (PWA) community's unfamiliarity with the researchers, assembling a group meeting with PWAs was not an easy task. One solution was to convene a single combined meeting of PWAs and CCGs without individual identification of group members.

Each group meeting followed the expert-centered approach which is a rigorously managed group activity using formally constituted groups of experts. The meetings involved two sessions held on consecutive days. Two tasks were accomplished during the first session. Initially, potential recipients of care were categorized by their stage of progression from no risk (or low risk) of infection to near death from AIDS. Then a consensus list of objectives for a care delivery system was identified for one category. Based on individual perceptions of their relative importance, each expert individually ranked and then rated each objective during the second session.

Developing an Objective Hierarchy for Care Delivery Systems

The elicitation of objectives involved two processes, a telephone interview and a group discussion. To start, one week before each group meeting participants were interviewed individually by telephone. This was done for two reasons : (1) to promote thinking about the subject by each participant; and (2) to initiate the subsequent group discussion with those objectives the experts had already considered.

The Composite Objective Hierarchy

When both the PCMs' and the PWA/CCGs' structured objective sets had been identified, the next step in the analysis was to join these two sets into a composite hierarchy. The hierarchy is simply a presentation of the primary means specified by each group of actors, with redundancies eliminated and categorizations made under the most general means leading to the system's goal. A composite hierarchy was constructed by the authors in consultation with representatives of each expert group. It created one parsimonious set of primary objectives that reflected both groups' interests.

Because of the common inability of AIDS patients to sustain their income and the high cost of their care, public resources are needed to reach many of the objectives. Limits on the availability of public resources and other demands for those resources mean that their application to the care of AIDS patients will be constrained. This demand for limited public funds makes the public an additional actor group in the selection of care objectives. Public (PUB) objectives therefore needed to be incorporated into the hierarchy; at least those that would be demanded by the public and, in addition, constrain public expenditures.

Results and Discussion

The categorization process indicated that the physicians and PWA/CCGs have a distinctly different perspective on care needs of people relative to HIV infection and AIDS. Most would probably expect, or demand, that the physicians' perspective be focused on appropriate medical intervention. What was surprising to the researchers is the degree to

which the PWA/CCGs did not incorporate medical treatment needs into their categorization. One possible explanation evolved during later discussion of lower level objectives of clinical care. The PWAs strongly contended that experimental drug protocols should be flexible. Their concept of flexibility was that, as new therapies became available, subjects should be able to switch to the one holding the most promise of cure for them (including life extension at a stabilized quality). For the PWAs, the imminence of death seemed to be a fact. Personal financial constraints (the need to enter a research protocol in order to get hopefully helpful drugs) puts control of much of their life in the hands, not of their physician, but of a research system. Yet, the system cannot now save their lives. They therefore tend to take the processes of formal medical intervention as an element largely outside of their control. Hence, they focus on needs outside the current medically oriented care system.

A side issue related to these attitudes is the validity of current drug research. Apparently, many HIV infected people who enter experimental drug protocols in order to get drugs are not loyal to the protocol. They take other drugs and therapies via "underground" sources. Such introduction of uncontrolled covariants can obviously damage the validity of both experimental and control measurements. The PWA/CCG group indicated that this damage may be extensive.

Objectives of care

The physicians' objective set appears to have two unique categories, "evaluation and testing" and "understanding of the disease". The physicians thought it important to maintain testing through the disease progression. Their purpose was to accurately track the course of the disease and opportunistic infections in order to select appropriate interventions. An additional benefit of such testing is the research data it provides. The physicians were, however, quite emphatic that testing should be at the lowest level of intrusion necessary in order to acquire the data needed.

Physicians also emphasized that patient education should promote understanding of the virus' effects on the body, the progression of the disease, and the care and treatment therapies available. They considered this understanding to be an essential step toward patient compliance. Physicians also considered it important for patients to understand their legal rights and legal issues related to the disease. It is important to note that the physicians were not insensitive to the socioeconomic dimensions of the PWAs' problems. However, physicians generally gave these dimensions a much lower priority in their design for delivering care.

The PWA/CCG group tended to concentrate on social, psychological and daily living needs. Although their meeting's purpose was identical to that of the physicians, their discussion was much different. They emphasized the importance of major objectives other than physical health. As with the PCMs, this group's objective set also has two unique categories: "basic needs and rights" and "self empowerment". An underlying theme in their meeting thus revolved around self-determination, self-authority and self-empowerment. An underlying theme in their meeting thus revolved around self-determination, self-authority and self-empowerment. They believed that the care system should allow them to make

and to support their own decisions about medical intervention, life style and domicile. Further, they felt that the care system should give them psychological assistance in order to maintain their motivation to take responsibility for their lives. However, they believed this was of no value if they did not also maintain the financial ability and authority to choose among real alternatives.

The PWAs were concerned with medical interventions, but only to the extent that it would keep them alive until a cure is found.

Conclusions

Identification and analysis of the unique elements of each actor group's objectives set indicates that there are significant differences between PMCs and PWAs/CCGs in their perceptions of the objectives of a care delivery system for the HIV infected. The most significant of these differences involves appropriateness of physiological testing and medical intervention vs psychosocial support.

The public objectives involve aggregate levels of well-being, or utility, as opposed to the treatment of individuals. Thus, although the public's objectives are generally aligned with those of the other constituencies, they tend to constrain the level of attainability of the PWA, CCG and PCM objectives.

Because spending public resources is necessary in order to reach both PWA/CCG and PMC objectives and because there is some degree of conflict among some goals of different actor groups, design and operation of a system of care is a political (and, at least partially, a governmental) problem.