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OPINION

ETHICS OF RESEARCH AND CARE

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OPINION ON A PROTOCOL FOR RESEARCH ON THE CONDITIONS UNDER WHICH PALLIATIVE CARE IS PROVIDED IN THE HOSPITAL CONTEXT

A research team responsible for an interdisciplinary project : "Practical arrangements for, and implications of the provision of palliative care in hospitals for patients in the advanced phases of HIV infection" has asked for the views of the National AIDS Council. This project is based around a comparison of practices and outcomes in two facilities where such care is provided, one a specialist palliative care unit and the other a department for infectious diseases in which palliative care can be provided.

This research protocol, developed by a social psychology laboratory and two hospital medical teams, proposes a detailed examination of the cognitive aspects of suffering, in response to the requests of patients and carers who feel unable to cope with situations with which they are faced. This protocol focuses on an examination of the cognitive dimensions of pain, the terms on which the decision to place a patient in palliative care is taken, and the interactions between carers and patients.

The issue raised relates to the possibility of extending this survey, hitherto based on purely documentary sources, to a prospective survey of patients, their family and friends and care providers. The proposed questionnaire is in three sections : first, an explanatory letter and a protocol to obtain the patient's free consent; second, a patient interview guide ; and, finally, two notation tables, one relating to interactions between carers and patients, and the other to the decision-making process leading to placement in palliative care.

It would appear that this survey is a response to the wishes of doctors, patients and families, as interactive witnesses to the same situation. Three aspects in particular were debated by the National AIDS Council :

1. The ethical acceptability of conducting a survey of terminal patients : If the question posed relates to the point at which what has been ethical ceases to be so, the answer is to be found in the patient's capacity to formulate clearly and explicitly his or her consent to what is proposed (acceptance of the staged withdrawal of certain curative treatments ; agreement to participate in the survey).

2. Methodology : In the light of current knowledge, the National AIDS Council feels that the methodology proposed is acceptable, i.e. the drawing of lots to select patients whose state of health has been defined by objective criteria.

3. Benefits to patients : The aim of the research is purely cognitive and will yield no direct benefit for the patients questioned. Those living with AIDS are young people, with every right to continue to place their faith in medicine until the very end, having neither lived out their normal lifespan nor ceased to try to give their lives meaning. They may hesitate to allow themselves to be placed in a ward specializing in palliative care, which means abandoning all hope of effective treatment. It is possible that such individuals would prefer a continuum between curative and palliative approaches without leaving the facility where they have been monitored and treated for many years, and where a climate of trust and confidence has been built up between them and the staff. It might be hoped that the proposed survey can help to define not only what is actually provided in terms of care and what is actually achieved in terms of the duration and quality of life, but also what is subjectively desirable for the patients involved. The survey may contribute to this if it sees this question in terms of such goals. This presupposes that it is clearly understood in the ward concerned that such a survey is being conducted and that patients are part of it.

The National AIDS Council emphasizes the advantages in developing procedures for research on the interpretation of emotion and the semiology of pain, and on functional arrangements in palliative care units. The Council underlines the necessity of training carers in such novel attitudes, and of providing satisfactory support for the family and friends of patients.

In the final analysis, the Opinion of the National AIDS Council on this research protocol is a favourable one.