

## BEYOND THE ANGLOPHONE WORLD

This new section will summarise important developments and publications reported in languages other than English and not readily available in translation.

Contributions, which should be informative rather than critical, summarising rather than reviewing, should be submitted in duplicate to one or other of the responsible editors. Contributions in Dutch, French, German, Polish, Spanish or Scandinavian languages will be welcome, although English material can be more quickly processed.

## CENSORSHIP AND MEDICAL SOCIOLOGY IN THE NETHERLANDS

I have just finished reading a book which does not exist. Or, to be more precise, I have read a report which was later published as the book *Omgaan met angst in een kankerziekenhuis* ('Coping with fear in a cancer hospital') [1]. That book no longer 'exists' because it was banned and destroyed.

The authors, A. van Dantzig and A. de Swaan, described 'the system of hope' in a cancer hospital in Amsterdam. By 'system of hope' they meant that hope was imposed more or less systematically on people for whom little real hope seemed to exist. Many patients in the hospital had been 'given up' in the medical sense of the word, but hope remained obligatory for them as it were. The fear of cancer (read: fear of death) was suppressed by a regime of 'emotional hygiene'. A strict order of control of personal feelings prevailed in the hospital. Both patients and personnel were subject to it; everyone, the personnel in particular, had reasons to obey that unwritten law. Many patients would have found it too distressing if they had had to face the stark reality of their situation. For nurses and doctors, life would have become unbearable if they had had to immerse themselves in their patients' personal problems. So both parties embraced the safety of the hospital regime.

Using accounts of direct observation in the hospital and quotations from patients, nurses and doctors, van Dantzig and de Swaan provided a lively picture of the hospital's daily routine. Their report showed how the system of hope works in shaping conversation and avoiding it, in controlling information, in allocating tasks and in a certain type of humour. The authors did not criticize the system; they tried to describe it as they saw it. They emphasized that, to a considerable extent, social realities took shape independently of the actors' intentions.

Reading this report it is hard to understand how, in a relatively free society such as The Netherlands, publication could have been prevented. The affair started in 1973, when van Dantzig, a psychiatrist, and de Swaan, a sociologist, together with some colleagues initiated research in the cancer hospital. The team agreed that they would discuss their findings

with the hospital staff and, initially, to distribute the report only to them. Nothing was said about what would happen thereafter.

The authors received full co-operation from both patients and personnel during their research. A first draft of the report was distributed to 400 people working in the hospital and discussed with them (but some copies of the report apparently circulated more widely). The researchers received a mixed response of appreciation and irritation. Discussion of the report with patients never occurred. The hospital's objections can be summarized thus:

1. the report presented a biased and therefore incorrect picture of the hospital;
2. it had a negative, sometimes hostile tone;
3. it paid insufficient attention to the pastoral help given to patients.

Soon quotations from the still confidential report appeared in a Dutch weekly. This marked the beginning of a series of conflicts. The hospital ceased its co-operation with the research team. It was not clear whether the hospital would also oppose publication of a final report; however, when the book appeared in 1978, the hospital successfully sued the authors and publisher and prevented the book's distribution. All printed copies were sent to the shredding machine before they reached the shops.

The legal grounds for this measure were based on the original contract between the hospital and research team. It was ruled that the hospital had 'ordered' the study and therefore owned it. The authors could not publish anything related to it without the hospital's approval [2]. The reason behind the hospital's drastic action was more interesting. One would have expected that the hospital considered the study harmful to its patients. This was not the case; hospital officials and personnel felt hurt by some of the observations and conclusions. The judiciary was enlisted to prevent their grievance from increasing as a result of the book's publication.

Such a drastic step seems surprising to say the least. One might have expected that the hospital would have added its own viewpoint to the report so that

their comments were published as part of it. Indeed, this would not only have been an elegant but also an interesting solution. According to one of the authors, the hospital was invited to do so, but did not act upon the suggestion. The preface of another, also forbidden, book (see below) and later publications [3] made it clear that the case now formed the basis of a fierce and uncompromising conflict.

The outcome was staggering. Censorship and book burning are generally considered outrageous in free societies. Only publications which are outright false or harmful to (a part of) the population are banned. Nothing of the sort had happened in this case. The judiciary was employed in order to have a book destroyed in which a particular viewpoint on hospital care was put forward. In Dutch society there are ample opportunities to criticize viewpoints and to oppose them with others, but that solution was not chosen. It is almost unbelievable that this book, a product of serious academic research, was wilfully destroyed by an institution which is in the vanguard of those seeking to improve the quality of human life.

The authors stressed that 'the system of hope' was supported by the hospital's control over information given to patients. By 'filtering' information concerning the course of the disease or progress made in scientific research, hope was kept alive. The censorship affair suggests that the hospital was also attempting to extend control of information beyond its own boundaries.

But there is another disconcerting aspect to the affair. If one-sidedness was a sufficient ground for preventing publication of research, my own work on medicine distribution in Cameroon would not have been published. The Cameroonian authorities rightly accused me of having paid attention mainly to the deficiencies of their system. But I am not an exception. Most scientific work is characterized by some kind of one-sidedness. If the Azande people in colonial Africa had had access to the judiciary, they could have prevented the publication of Evans-Pritchard's ethnographic masterpiece about them because of its bias. Malinowski's work on the Tobrianders, Bateson's on the Iatmul, and Kleinman's on medical systems in Taiwan would never have appeared for the same reason. These are examples only from cultural anthropology; what would have happened to the work of authors as different as Nietzsche, Marx, Freud, Keynes, Einstein and Foucault? Indeed, if one-sidedness was a valid reason for destroying books, our libraries would be empty.

Four years later de Swaan published a collection of ten essays under the title *De mens is de mens een zorg* (hard to translate because of its triple meaning: 'Man is of concern to man', 'Man is a worry for man', and 'Man doesn't care about man'; the title is reminiscent of the Latin adage '*Homo homini lupus*'). It included three essays about 'the medical regime', one of which dealt with 'the order of the cancer hospital'. The latter contained verbatim passages from the banned book and summarized its main conclusions. History more or less repeated itself. As soon as the book appeared in the bookshops, the hospital went to court and succeeded in having the essays removed from the shelves. The judge's ruling was that since the 1978

book had been banned, it could not be quoted in a new publication. A year later, in 1983, a revised version of the book [4] was published, with a 'clean' essay on the hospital regime. Significantly, the author was awarded a cultural prize for the book.

De Swaan's essays deal with several forms of 'medicalization'. Departing from Norbert Elias' 'civilization theory' de Swaan describes illness as a gradual process in which social functions are lost. This contrasts with the medical view which defines illness as a loss of bodily functions. Many sick people eventually enter hospital. De Swaan takes the cancer hospital as a—perhaps extreme—example of the new environment in which people find themselves after they have been cut off from ordinary social relations. As indicated above, the new reality is a 'medical regime', which is designed primarily to keep emotions under control. Here de Swaan applies Elias' concept of 'affect economy' to the hospital culture. Using ideas from Goffman, Glaser and Strauss, Freidson, Sontag, Foucault and others, he presents a convincing picture of the way medical workers and patients manage to avoid the only issue that counts: their fear of a deadly disease.

I asked de Swaan whether he had considered avoiding the hospital's obstruction by publishing the report under a double pseudonym, concealing both the hospital's and his own identity. Giving fictitious names to people and places is a normal practice in anthropological and sociological case studies. The use of pseudonyms by social scientists themselves is rare, however, although I do know of cases, the most famous being James West (pseud.) who wrote about a rural American town, Plainville (pseud.). De Swaan replied that such a trick would probably work in a large country such as the U.S.A., but not in The Netherlands, which only has two cancer hospitals.

However, even in a large country concealing identities could prove difficult. Librarians hate pseudonyms and do not rest until they have found the author's true name and added that information to the catalogue entry. In West's case, his identity (Carl Withers) was soon discovered as was the town's real name. Art Gallaher, who did a restudy of 'Plainville' 15 years later, wrote to me that "some unthinking students paid visits to the community and asked questions which irritated many people". A copy of Withers' book was placed in the local public library. In the margins of the book some unknown person had added the real names of all those mentioned by the author under their pseudonyms.

Withers' case shows how difficult it is to publish 'true-to-life' ethnographic accounts about delicate issues, at least in Western communities where informants may become readers. Anthropologists working in 'foreign' cultures are in a more comfortable situation. They can still afford to describe in detail fairly sensitive events or quote embarrassing statements without being criticized (or sued) by their informants, as the latter are unlikely to see, let alone read, their books. But that 'privileged' position is hardly better than censorship; in a sense the ethnographer becomes the unchallenged censor of his informants' words.

There is a rather cynical implication of the censorship affair, the one which impelled the writing of this note. The hospital's successful blockade of the two

books underlines the main conclusion of de Swaan's research: increasingly we are becoming subject to a medical regime which dictates what we should do, think and, yes, read. I wonder whether colleagues elsewhere have had similar experiences. If so, I would appreciate it if they would write about them.

#### REFERENCES

1. Van Dantzig A. and de Swaan A. (with S. Tuinier, M. Groen-van Beverwijk, P. Hirschler and V. Kense) *Omgaan met angst in een kankerziekenhuis*. Aula No. 583, Utrecht, 1978 (banned).
2. Such legal cases are more common than we may realize. Many researchers are employed by companies or institutions and are never allowed to publish their research findings. One other example from the Dutch scene may be mentioned briefly. In 1986 the Sports Federation of The Netherlands (NSF) forbade a medical researcher, Peter Vergouwen, from publishing an article about injuries incurred by members of the national gymnastic team. The Federation gave as its reason the fact that the gymnasts' identities could be easily discovered.
3. De Swaan has written a reflection on the affair, published in the Dutch weekly *Vrij Nederland* 1 October, 1983.
4. De Swaan A. *De Mens is de Mens een Zorg*, 2nd rev. edn. Meulenhoff, Amsterdam, 1983. An English version is in preparation under the title 'The management of normality: critical essays on health and health care'.

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