Research plan – May 31, 2007

Internship at MOHAN Foundation, Hyderabad, India.

Mieke van Kollenburg
Master Science Communication, Utrecht University
Supervisors: prof Arend Jan Waarlo, Utrecht University and K. Raghuram, MOHAN Foundation.

Principal
Principal for the project is Mr. K. Raghuram, Chief Executive Officer from MOHAN Foundation in Hyderabad, India.

Motive
Transplantation of human organs is one of the great medical breakthroughs of the twentieth century. However, very few Indian patients can benefit from this till now. In India, it is estimated that over 100,000 people are diagnosed to have kidney failure and would be needing a transplantation. Due, mainly, to non-availability of organs, only about 2,500 kidney transplants are done. Heart and liver failure patients hardly have any hope of a transplantation.

MOHAN Foundation (Multi Organ Harvesting Aid Network) is an organization working to create more awareness on cadaveric organ donation. For this purpose they give presentations to patients, public and doctors. Besides, they develop brochures, posters, stickers, Donor Cards (comparable to the dutch Donor Codicil), video material etc. In this way, they hope more people can be helped by an organ transplantation in the future. Moreover, they believe this is the only way to fight the illegal commercial dealing of organs that takes place in India.

Assignment
The main purpose is to perform a research to the communication policy of the organization.
Besides this research, I will participate in the organization. I will perform several tasks like improving, producing and giving presentations, to improve and produce questionnaires, attend meetings etc.

Research questions:
- What is the policy with regard to organ donation in different countries like The Netherlands and Belgium, and what are the differences with India in this respect?
- What are the causes of these differences, is it of cultural basis?
- What is the position of organ donation in India? Who takes care of informing the population about it? Is it the government of private institutes? How is this organized?
- What are the communication methods used in the organization? Is the main goal to inform or to convince? What arguments are used to inform/convince people of the ‘benefits’ of organ donation? Are these methods effective?
- What ethical dilemmas exist in organ donation among the Indian population? What is the perception of the body and of organs in the Indian population?
- What is the influence of religion and social economic status on the decision to become donor or not?
- How do people (relatives of an organ donor) experience the process of organ donation? How do they feel after donation of their relatives’ organ(s)?
- How essential is organ donation in India? How many lives can be saved?
- What is the procedure that is followed when a transplantation is possible?

Research methods:
- Literature research
- Topic-interview/questionnaires
- Observation & participation in the MOHAN Foundation

The research will be qualitative, partly describing (i.e. Theory is probably not applicable). I will try to gain as much validity and reliability of the research as possible by means of triangulation; besides participation and observation I will also interview different people about the different topics regarding organ donation, and read literature and documentation.

In interviews with transplant coordinators, I will focus on their communication methods and their motives. In interviews with patients and donor relatives, I will focus on their experiences and feelings.

In these interviews, I will try to create rapport with the interviewed person to avoid ‘social desirable’ answers.

Conditions of execution
Research can only be performed if enough literature on involved topics is obtainable, if documentation on the projects is available and if enough people are willing to participate in interviews and/or questionnaires.

Quality control
During the internship, Arend Jan Waarlo will guide me from the master Science Communication, and Mr. K. Raghuram from MOHAN Foundation.

I planned two evaluation moments with Mr. Raghuram: one in the beginning of July (mid-internship) and one at the end of September/beginning of October (end evaluation).

Planning

Phase 1: Project preparation
- Write research plan
- Literature research

Phase 2: Carrying out the research
- Read documentation of MOHAN Foundation
- Participate and observe in MOHAN Foundation
- Approach people for interviews (transplant coordinators, transplanted patients, donor relatives)
- Interview people
- Work out interviews
- Develop evaluation and advice for MOHAN Foundation regarding communication methods

Phase 3: Completion of project
- Write report
- Prepare presentation
- Final evaluation

Learning goals
- Gain experience in performing qualitative research.
- Gain insight into the (communication) policy regarding organ donation in another culture.
- Gain insight into the association of health, disease and the human body in a different culture.