

## **Transcending Taboos in Medical Ethics**

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The following is perhaps what Glaser would call a “theory bit” (1) from a write up of memos inspired by interview data leading up to a grounded theory of De-tabooing Dying Control (2).

This conceptualization of what goes on in medical ethics is the product of the analysis of data from two sources. It is the write-up of memos arising from the secondary analysis of the interview data that initially led to a grounded theory of De-tabooing Dying Control. It is also the product of the analysis of field notes of talks, chats, and discussions which took place at the Swedish Society of Medicine’s medical ethics delegation from 2005 - 2009. Specifically, the data were collected from meetings of physicians engaged in ethical rumination for the purpose of providing statements of opinions on government reports and official documents.

During my years in the Swedish Society of Medicine’s medical ethics delegation, I discovered that transcending taboos conceptualized the medical ethics discourse. Taboo is, by Oxford dictionaries, defined as something “prohibited or restricted by social custom” or “designated as sacred and prohibited”. To manage taboo topics thus explains what is going on when sensitive issues regarding life, death, and sexuality are managed. The task of the ethics delegation is to scrutinize and vet governmental and other official reports on health issues from a medical ethics perspective. Medical ethics deals with what is acceptable and unacceptable behavior in the medical field, especially for health care professionals: What is right or wrong? What is forbidden or unacceptable is often connected with the big taboo subjects—sex, money, death, and dying.

What is politically correct (PC) may set the agenda for what is taboo and what is not. Political correctness changes over time and so do taboo topics and issues. It seems that political correctness aligns itself with what is taboo—to be politically incorrect could therefore be seen as a property of de-tabooing, i.e. acting or talking in such a manner that a taboo is being challenged or transcended. To be PC regarding medical ethics is a necessity for someone who wants to work in health care and be considered respectable. To go against what is PC is a risky endeavor and therefore transcending the taboo is seldom done in the open.

### **Transcending dying taboos**

Legal abortion is time framed, meaning that it is conditioned primarily by time; it has a time window within which it is sanctioned by law to terminate a pregnancy, in other words eliminate the existence of a future human being to some people and a present human being to others. To terminate the existence of a human being is taboo in most cultures with the exception of the death penalty and situations of self-defense and war.

So, with abortion being another exception to the commandment "Thou shalt not kill" it is connected with the taboo of death and dying and thus one could talk about legal abortion being a time framed death taboo transcendence in the first months of human life. Abortion issues were not commonly discussed in the medical ethics delegation in the 2000s with the exception of sex selective abortions that were somewhat taboo at the time. To decide upon the sex of the fetus within the free abortion time window was not considered a good thing to do—it was indeed not PC to hold this position. Yet, a significant number of people used and still use this opportunity of selective family planning.

Sweden has a generous abortion upper time limit—an 18-week gestational age as compared to 12 weeks in most other European countries. Hence, there was a debate of whether it was morally acceptable for non-Swedes to decide the sex of their future child by going to Sweden for an abortion. By ultrasound it was at the time difficult to establish if the fetus was boy or girl before 12 weeks of gestation. The dysphemism "abortion tourism" was then coined in the press.

When using the widespread technique of ultrasound, it is difficult to establish the sex of a fetus before 12 weeks. A practice arose of other Europeans visiting Sweden to establish the sex of their fetus and sometimes obtaining an abortion as a result of that knowledge. The Swedish press reported the phenomenon as "abortion tourism" prompting a debate of whether it was morally acceptable for non-Swedes to decide the sex of their future child by going to Sweden for an abortion.

#### Time framed taboo transcendence at the end of life

Time-framed taboo transcendence is not only happening at the beginning of life but is also apparent when life and death is controlled in ways that disrupt normality during the last months of life. Practices of euthanasia and assisted suicide (EAS), withdrawal of active life support (such as turning off ventilators), and palliative sedation (where the dying suffering person is put to sleep by drugs) are examples of how the death taboo is being transcended within the time frame of the last weeks or months of life. Abortion is a legal time-framed death taboo transcendence at an early stage whereas EAS is a time-framed death taboo transcendence that terminates the life of a human being at a late stage in life. EAS is illegal in most countries and jurisdictions but is de-criminalized or de-penalized in some countries (e.g. the BeNeLux, Canada, and Colombia, whilst physician assisted suicide is legal in five states in the United States of America: Montana, New Mexico, Oregon, Vermont, and Washington (3). In 1942, Switzerland de-criminalized the act of assisting someone to commit suicide if not done for selfish reasons. Swiss physicians are not actively involved in assisted suicide apart from prescribing the necessary drugs.

#### Withdrawing or withholding life support

Withdrawing life support therapy (e.g. ventilator treatment) at the end of life is legal in many countries but illegal in some countries such as Israel, and questionable in many other countries such as Sweden. In Sweden, there have been a few judicial cases of withdrawal of life support where the legality was questioned and physicians accused of malpractice. In consequence, the ethics delegation discussed the option of using delayed response timers to allow a ventilator to be set for a week, or shorter. The ventilator will then stop working when the time is up without human intervention. This practice is tried

in Israel and, if used in Sweden, would bypass laws or legal problems of withdrawing life support since in many cases it is legal to withhold a continuous life support treatment. When the timer need re-setting, a further decision is required of medical staff, often in consultation with relatives, as to whether to withhold or continue the life support ventilator therapy. Not resetting the ventilator will eventually "kill" the patient, but this is then withholding and not withdrawing treatment (4). This circumventing procedure can be seen as an activity to transcend the death and dying taboo.

#### Palliative sedation – reversible or irreversible?

Palliative sedation means to put a suffering dying person to sleep by the use of sedative drugs. If the sleep is reversible, so that the person can be woken, then the practice of palliative sedation is uncomplicated from a legal and ethical perspective in most countries. It is a medical treatment meant to relieve severe pain and anxiety at the end of life. Indeed, the Roman Catholic concept of "double effect" allows a treatment that may unintentionally hasten death if the purpose is to relieve suffering.

Palliative sedation could however also be achieved by increasing the dose of sedative drugs until the patient's consciousness and breathing capacity is depressed until death arrives. This practice of irreversible palliative sedation is actually euthanasia, except that it is given a nicer name. It is an example of a euphemism, the use of which is not uncommon in the de-tabooing and taboo transcendence discourse. Palliative sedation with this irreversible ending has increased in the Netherlands (where euthanasia is legal if certain procedures are followed) since it reduces the large amount of paper work that comes with the procedures required for traditional euthanasia (5).

To conclude, dying taboos are time contingent since transcending taboos in the field of death and dying depends on timing of death. Abortion is always taboo after a certain gestational age. Euthanasia and withholding life support are taboos in persons with an anticipated significant foreseeable future. Time transcendent death taboos can be seen as a "theory bit" from Detabooing dying control (2).

#### **References**

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