Helen Kohlen

Conflicts of Care

Hospital Ethics Committees in the USA and Germany

campus

Award Recipient of the IMEW trainee's award for an outstanding scientific work

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Introduction

Problem Statement and Research Question

What is the use of Hospital Ethics Committees? Who do they serve? Who gets a voice and who does not get the time and authority to tell what the "real conflicts" are, for example, of a patient, the family or the medical and nursing team. What are the conditions that create problems of and around dying in a hospital? How does a committee actually work behind closed doors? Who demands to have the power of defining what an "ethical" problem is?

These are questions that do not only arise when analyzing empirical data of this work, like the dialogue presented above, but they have also been evolving by exploring the phenomenon of Hospital Ethics Committees within the context of bioethics. Nevertheless, by thinking about these questions and observing Hospital Ethics Committees' discursive practices in Germany, my focus at some point shifted from what is talked about to the unsaid and invisible. Hereby, questions of and around care practices evolved. Like any professional practice, care practices are generally understood as a coherent and complex set of activities with standards of excellence that help to make practice what it is and cannot be fully understood apart from it. Each practice is lived out in a specific way, and influenced in conditions of structural change like health care reforms.

The tradition of medicine has until now been characterized by an aspiration to provide as complete as possible a service of care for the populations for which it had responsibility. The same accounts for nursing and caring practices, but the tradition is loosening. Despite the collective assumption that medical and nursing practice rests on solid grounds of knowledge and a caring ethos, changes of practices have not only come about in a complex and diffuse fashion, but also come along with sacrifices, losses and deficits.

Managed care, invented and developed in the USA, recently implemented in Germany, provides one example that is promising efficiencies by

eliminating assumed "wasteful" and "unnecessary" care. Managed care is an example, reminding that the doctor-patient-relationship as well as the nurse-patient-relationship does not take place as an isolated dyad, but is strongly influenced by its institutional and economic context. What US-American medical sociologists like Charles Bosk and Joel Frader (1998: 94) once commented on for the situation in the USA can now be said for changing processes in German Health Care.

The growth of ethics committees is another new phenomenon in Germany. Ethics committees were created in the USA not only in order to discuss ethical research questions, but also problems in clinical care. In the USA as well as in Germany, the need for ethics consultation and the building up of committees is generally explained by referring to technical progress that had changed Health Care. I will argue, whether and how these changes in medical research and clinical work, cannot simply be explained by technical progress, but possibly by reactions to external economic and socio-political forces as well as to ethical manoeuvres themselves. For the historical analysis my questions are: What were the forces and conditions that drove the increasing numbers of Hospital Ethics Committees? And, what were the manoeuvres for the discursive practices of these committees?

Situating the Field of Analysis and Approaching the Subject Matter

In the past, the community and neighbourhood, also the church, gave comfort and help to someone in need. Problems such as solitude, despair, or fear to go on living were dealt with on a direct communal basis. These rather *informal arrangements* are almost or not completely substituted by an expanding network of health care institutions and formal settings to offer consultations. Health care services are increasing in number and also the role of health care professionals is becoming more important. These specialized and institutionalized organizational forms are called the professional care sector or *care market*. Nursing, understood as a differentiated system of specialized nurses, practices, nursing institutions and nursing science is a part to secure health care.

Not saying this is a good or a bad thing, despite a long exile in the private domain, caring is becoming a subject of public discourse. It is remarkable, that currently in various fields of political debate, like education, family, or

labor politics, an international care-debate has found its attention.[1] One example that care is becoming a political concern in Germany is shown by the current debate on a change of care-arrangements for children, and whether it can be justified that East European women do nursing care at home for the old, ill, and disabled people, earning two Euros for an hour of care work. The minister, who has gone about new governmental regulations in child care has also announced to put policy questions around elderly care on the agenda.[2] The political debate about care shows the prevailing ambivalence that a matter of concern that once belonged to the private domain is now turning into an affair of the state. The work of care falls outside of the field of productive activity and carries the problem of how its worth could ever be expressed in economic terms.

In Germany, along the process of health care *reforming,* modern bioethics as a discipline as well as a practice has become established within the last fifteen years. With regard to burning issues, one impulse for the evolution of applied ethics in German Health Care arose from a widely spread discourse on reproductive technology, gene-therapy, and embryo research.[3] Moreover, care at the end of life and Euthanasia have been incessantly crucial issues of the bioethical discourse in Germany. Since 2004 questions about end-of-life care at the bedside have for the first time been becoming a dominant point of issue by *governmental committees:* Questions in the framework of patients' autonomy, the use of Living Wills and Withholding and Withdrawal of Treatment have become a policy issue for the *Enquete Commission on Ethics and Law in Modern Medicine of the German Bundestag,* for the *National Ethics Council* as well as for a working group established by the *Federal Ministry of Justice*[4] in Germany. Their published drafts for legislation show different positions, revisions were made, but it has not come to an agreement yet.

I would like to point to what is new about these handlings. The fact that currently in Germany difficult end-of-life questions are answered by a demand for written forms of Living Wills to secure patients' autonomy is one remarkable change in medical and nursing practice. Furthermore, the fact

1 As exemplified in the work by Birgit Pfau-Effinger und Birgit Geissler (ed.) (2005): *Care and Social Integration in European Societies.*

2 An example for this current political debate is the "Aktionsprogramm für Mehrgenerationenhäuser" (2005–2007) of the "Bundesfamilienministerium" (BMFSJ).

3 See for example the issues presented in the book *Bioethik. Eine Einführung,* edited by Marcus Düwell and Klaus Steigleder in 2003.

4 See: Bundesministerium der Justiz (BMJ) (2004). See also Volker Lipp (2005) who comments on the debate from a juridical perspective.

that the debate on the use of Living Wills has now prompted governmental intervention is another significant turning point since caring practices at the bedside have never been regulated by political authorities before.

On a micro-political level, the new regulations are discussed by local ethics forums, termed Institutional Ethics Committees (IECs), Clinical Ethics Committees (CECs) or Hospital Ethics Committees (HECs) as they have once been invented in the US in the 1970s. Ethics committees were created in the US not only in order to discuss ethical research questions, but also problems in clinical care. Besides taking responsibility for staying informed on major bioethical issues with clinical relevance like regulations of Living Wills, Hospital Ethics Committees serve to develop, review, and apply the ethics policies or guidelines in and of the institution. In US-American hospitals, the most common form of ethics policy is the "Do Not Resuscitate" (DNR) policy, which sets out the institution's guidelines for withholding or withdrawing life-sustaining treatment. Moreover, Hospital Ethics Committees are responsible for case review. The kind of review varies. The committee can be directly involved in prospective case review and becomes a consultant to assist in the ongoing management of care of patients. Committees do usually also offer retrospective case review. Then, the goal is to determine whether and how the case could have been better dealt with. In addition, these committees play an educational role. Education involves mediation techniques and learning theoretical frameworks as well as the training to use a special "model of ethical decision-making" in order to discuss an ethical issue reasonably. With regard to actors, such committees consist of small groups of people, professionals as well as lay persons, who meet on a regular basis to address so called "ethical" issues that emerge within the health care institution. Those people are mainly clinical professionals, like physicians, nurses, chaplains, and social workers. Among them, there is sometimes a lawyer and, at least one person who is in the position of being an "ethics expert", usually a philosopher or a theologian. The group is acting behind closed doors at a certain place and time, and may serve themselves, the patient, relatives of the patients, a special unit, or the entire hospital.

The number of Hospital Ethics Committees has especially been increasing since the German Accreditation Organizations of Health Care have demanded that hospitals should have policies and procedures to cope with ethical issues. The rapid growth of ethics committees is a new phenomenon in Germany and qualitative research what the actors of and in these committees are actually doing, is missing.

The establishment of Hospital Ethics Committees demands that there is a *room for reflection* – in a denotative as well as in a figurative sense – within the hospital setting. This is unusual for daily clinical work since nursing as well as medical practice is action-orientated. The criteria of urgency shapes the communication culture, not the play on elaborate words based on theoretical frameworks. Dealing with critical situations of ill or dying patients is part of the everyday practice of nurses and medical doctors. An interdisciplinary ethical consultation while sitting around a table – away from the patients' bedside – is in some way odd since it implies the transformation of an original non-verbal act, highly shaped by sensitive competencies, into a discursive matter of fact. Therefore, Hospital Ethics Committees represent a *new type* of coping with conflicts in clinical practice as well as a new way of consultation and participation.

Purpose and Significance of the Study

The aim of this work is to understand the phenomenon of bioethics by committee practices in the hospital setting. Hospital Ethics Committees are the locus of this investigation which is not primarily concerned about bioethics as a discipline, but about its effects *in* and *on* medical and nursing practice. Hospital Ethics Committees are seen as a suitable institutional field to analyze a new type of coping with conflicts in clinical practice as well as a new type of consultation and participation practices. I will use these committees as a vehicle to shed light on a part of the process-transformations in clinical practices and the way caring issues are dealt with. Since caring practices are mainly carried out by nurses they are the actors mostly of interest here.

Moreover, nurses are by far the biggest group of professional health care, especially in the hospital. The World Health Organization assigns nurses and midwives to have a decisive role in Europe with regard to the development of strategies in health care reforms. Reforms in health care that demand high standards on quality, efficiency and a humanistic ethics at the same time, need to consider the participation of nurses. Nurses – even though not many – do participate within the academic discourse. Nevertheless, care work and those who mostly fulfill caring practices are usually unseen and undervalued. Nursing matters have mostly been invisible on the political agenda of German Health Care. Although nursing has become an academic discipline within the last 20 years in Germany, its lobby is weak in comparison to the medical profession. They are still struggling for more political power, institutionally as well as academically.

Nurses have hardly expressed their own position on bioethical issues within their academic discipline and do rarely show up within the public debate. Even though decisions will have a strong impact on their practice, nurses hardly raise their voice, and are even less listened to. In keeping its development as an academic discipline, nurses want to transform their knowledge from a record of experiences to a logical organization of relevant knowledge.

Within the last 15 years, US-American and Canadian nursing scholars, especially Joan Liaschenko (1993a, b) and Patricia Rodney (1997) have investigated the ethical concerns of practicing nurses and noted in their separate empirical research the invisibility of their conflicts when doing care work. Do these conflicts and concerns find a place in Hospital Ethics Committees?

From a political science perspective, studying professions can open a crucial dimension of the intermediary realm between individual and state. Professions are political entities, not just when they form interest groups, but because in the intermediary realm of civil society, professions possess the power to distract, encourage, limit, and inform public recognition of as well as deliberation over social conflicts. For reasons pointed out above, nurses are a suitable group to investigate into unknown spaces of Hospital Ethics Committees' practices, to question the definition of what counts as an "ethical" problem and who dominates the committee discussions. Moreover, the focus on nursing helps to shed light on different voices and can bring questions of care to a head.

Development of the Research Process and Structuring

The work is structured into four parts. While the first part situates the work in social science research, theoretically and methodologically, the following three parts build the corpus of analysis.

The structure of three analytical parts gradually developed during the research process. The original thesis of this project was that the hierarchical and increasingly economically orientated principles of hospitals, influence the demanded democratic procedures of ethics consultation and Hospital Ethics Committees. Hereby, the participation of the nursing profession might be impeded in a particular way and the conflicts they experience could be excluded. If a group who delivers the biggest amount of direct care is not participating in defining, discussing and resolving what the "ethical" conflicts of daily patient care are, then the search for an argumentation would be in need.

By an international literature review and expert interviews in the US, the phenomenon of Hospital Ethics Committees was approached by a broader social science perspective that included an inquiry of the historical background of these committees. I identified surprising silences in the discourse of Hospital Ethics Committees and had to refine my research questions. Finally, the research process combines three areas: Hospital Ethics Committees, the development of bioethics and care. How was this triangulation brought out?

The decision of exploring the historical background of contemporary Hospital Ethics Committees lead me to the origins and development of bioethics as an influential force that has shaped the work of these committees. The identification of the forces and the analysis of the way questions and issues were constructed in the development of US-American Hospital Ethics Committees revealed what has been becoming at stake, what and who is sidelined, transformed or ignored for whose and what interest (Historical Analysis).

One of the silences I identified in the bioethics discourse concerned questions of care and more specifically caring issues and conflicts. Why care matters, why and how it needs to be seen as something being of relevance, and more specifically, what international empirical literature tells about the work of Hospital Ethics Committees, issues of care and nurses' participation became the following theoretical part of the analysis (Relational Analysis).

Consequently, the study of what has been present and implicated in the history of Hospital Ethics Committees as well as what has *not* been present and implicated (conflicts of care), sharpened my ears and eyes for the participant observations and interviews in the practical arena. The field research was carried out as a parallel process of the theoretical analysis over two years in three Hospital Ethics Committees in Germany (Practical Arena Analysis).

How did the chapters of each part evolve?

The *Historical Analysis of Bioethics and Hospital Ethics Committees* is shaped by the following findings that emerged in the literature review and interviews: The more I read about ethics committees and the more I talked to people who declared themselves to be part of the history of bioethics as the interviews in the US show, the more colorful the picture became. Most authors start with the bright side of ethics committees seeing it as a helpful instrument to meet "moral insecurity" due to technological progress

and a plurality of values. And this, they state, does not only account for professionals at the bedside, but also among people in public. Especially proponents of Hospital Ethics Committees do usually not write about the precursors to modern ethics committees. But as I found out, the history is surprisingly rich to show that consultation by committees can be reconstructed as a sequence of different sorts of problems and events.

Hospital Ethics Committees are identified as a part of the development of bioethics. By foregrounding the evolution and the style of bioethics, its move into the practical arena of hospitals is described in the first chapter. Then, traces and beginnings of consultation by committees will be presented. The rise of research ethics committees and the forms of governmental intervention will be included in the second chapter. In chapter three, the history of contemporary Hospital Ethics Committees will be traced back by starting with the story of Karen Quinlan. Since it is the United States where Hospital Ethics Committees were first invented, German literature mostly refers to US-American committee models, and even looks back historically by re-telling the "Quinlan case". As said in the introduction, social science research on these committees is missing. For these reasons of analysis, a description of the German development of Hospital Ethics Committees comes short at the end of the historical part. The historical analysis is summed up in the end (chapter four).

The following considerations and questions are relevant for the turn to *Care and Hospital Ethics Commitees in the Relational Analysis:* What are the reasons why caring issues have never been at the forefront of bioethical debates, especially on a political level? First, an overriding as well as convincing argument for this marginalization is seen in the protection of keeping care as a private activity. Second, it is common sense, that caring is something practical that simply needs to be done and that there should be a kind of obligation to integrate caring within one's daily activities. Thus: Why theorizing about a daily private activity? However, there are also plausible reasons to defend a public debate on care since care work has been more and more institutionalized over the last century, at least in Western societies. Especially for a growing number of the elderly the need for care is increasing. While media reports on (health) care tend to focus on the high costs of the health care system, other dimensions and aspects of social service can get easily played down. The quality of care practices are of rare interest except when care has gone wrong, is done badly, or has even led to abuse. Then, public attention is aroused.

The aim of this part is to approach a refined understanding of care that lays out a language to describe the meaning of care and caring practices. These theoretical approaches are all written in a remarkable non-technical language, but unfortunately, some, especially the nursing ones, lack some clarity. Nevertheless, what I am not going to do is what Doris Lessing has once warned against in her *Golden Notebook* (1972), is: to criticize the criticism of ideas. I will neither atomise and belittle the weak parts of the concepts of care, although, of course, I will sum up the main critique that was put forward against them.

In the first chapter, I present the transitions of the care ethics debate since the 1980s when professional nursing care expanded. The chapter gives an overview to understand concepts of care within their specific contexts of ethical debates. Chapter two presents those ideas that have contributed to develop an understanding of care as a practice from a feminist as well as a political perspective. By referring mainly to the theoretical approaches by Joan Tronto, Elisabeth Conradi and Margaret Urban Walker, I want to contribute to the development of a language that realizes concerns regarding issues of care in medical and especially nursing practice. In chapter three, concerns of care in hospital nursing practice will be analysed and nurses' chances of making them a subject of discussion in Hospital Ethics Committees will then be outlined. While chapter one and chapter two are based on a literature review of mostly foundational texts from the US and Germany, chapter three will also make use of interviews (see Appendix)[5]. In the end, I will give a summary (chapter four) by focusing on those findings that are mostly relevant for the practical arena analysis, the empirical part.

The *Practical Arena Analysis* of three Hospital Ethics Committees in Germany took place from 2004 to 2006. In the field study, I examined the process of establishing a Hospital Ethics Committee by participant observations and interviews. In chapter one, the field research is introduced. A description will be given of how the methodological design, presented in the beginning, is specifically applied for the analysis of the practical arena. Then, each committee case story and their organizational structure will be outlined.

In the second chapter, the analysis of the field data that I collected out of twenty-three participant observations in the Hospital Ethics Committees and interviews, is presented. The look inside the committees has revealed

5 For all detailed interviews and participant observations, please refer to: www.campus.de/isbn/9783593388144

diverse practices with regard to the committee functions of education and policy making that I will show first. Then, I will turn to an analysis of the case discussions and evolving issues of concern. Finally, the analysis of the practical arena will be summarized. The *Appendix* contains the complete transcripts of the participant observations that I will refer to in the analysis by indicating the fictive names of the field subjects who talk and give reference signs. In the end (chapter three), I will discuss the findings of the practical arena analysis in connection with the findings of part one and two and then the conclusion will be drawn.

State of the Art, Theoretical Framework and Methodological Considerations

1 State of the Art in Social Science Research

Hospital Ethics Committees in Germany have neither been examined by foregrounding bioethics, nor in relation to caring and nursing. In 1998 the US-American sociologists Charles Bosk and Joel Frader published an article they called *Institutional Ethics Committees: Sociological Oxymeron, Empirical Black Box.* Bosk and Frader reflect the emergence and purpose of such forums by asking for more qualitative research that needs to be done (Bosk, Frader 1998). This accounts for the current situation in Germany.

Hospital Ethics Committees in Germany appear to be unknown discursive spaces behind closed doors. Published research has been limited to surveys which mostly provide quantitative data, e.g. about the numbers of committees that have been established.

The first clinical ethics committees were established in 1997. The German Lutheran and Catholic Church Association published a brochure that encouraged and called up to establish clinical ethics committees according to the US-American model. In 2000 a survey revealed that among 795 members of the Christian churches' association, 30 hospitals declared to have an ethics committee or a comparable arrangement to offer consultation.

A recent survey (Dörries, Hespe-Jungesblut 2007) shows that most of the German hospitals that have been established, or are in the process of building up, any kind of ethics consultation service, have decided for Hospital Ethics Committees. Most of the hospitals felt that they should have a committee in order to become certified by agencies that audit the quality standards of health care institutions. According to the survey, especially Lutheran and Catholic hospitals were motivated to build up a committee due to impulses given by the Christian Association of Hospitals. Hospitals also thought that an ethics committee could be an answer to a concrete ethical conflict they have currently been coping with. Finally, ethics committees were built up because the staff wanted it.

Like this publication, articles on Hospital Ethics Committees are written by philosophers, physicians, and sometimes theologians and biologists (Simon, 2000; Neitzke 2002, 2003; May 2004; Vollmann, Wernstedt 2005; Dörries 2007).

Unfortunately, at the time of writing, findings of the research projects on Hospital Ethics Committees in social science have not been published yet. The department of sociology of the Ludwig-Maximilian University in Munich in cooperation with the Lutheran-theological department of the University in Göttingen have been working on an interdisciplinary research project on organizational forms of Hospital Ethics Committees, and the department of Cultural Studies in Essen worked on a research project called *Clinical Ethics Committees, its Organizational Forms and Moral demands in Theory and Practice*.[6]

US-American social science publications explicitly on Hospital Ethics Committees are limited. Daniel Chambliss (1996) observed during his ten years of hospital field study that first, Hospital Ethics Committees tended over time to become somewhat dominated by legal, rather than ethical issues, and second, that these committees only enter the discussion after the health professionals at the bedside cannot or don't want to make a decision themselves, or the family disagrees with the professionals.

The research that my study can mostly relate to in its whole composition, is the dissertation by Patricia Flynn of the University of California, San Francisco, advised by Adele Clarke, called *Moral ordering and the social construction of bioethics* (1991a). She examined the emergence of the discipline of bioethics and its move into Hospital Ethics Committees as well as into a larger policy arena: community based bioethics committees. Flynn found that the disciplinary emergence of bioethics was an attempt to deal with developing problems of justice, and that decision-making processes in ethics both, at the policy level and at the local committee level (like Hospital Ethics Committees) are based upon a process of what she identified as "moral ordering". She defines rather generally:

6 Both projects were named at a conference I attended in Essen in 2002. Matthias Kettner and Arnd May wrote about the conference in a short report (2002), which however does not include findings.

"Moral ordering in health care is but one part of a broader moral ordering processes. […] In bioethics today there is no […] fixed moral order but instead a moral ordering and re-ordering about who is a person, what is an acceptable or unacceptable quality of life, how is death defined, and when shall we withhold or withdraw treatment. Many of these decisions are clearly social and ethical and not exclusively medical ones" (1991b: 146).

For the most part, however, Flynn argues that bioethical knowledge has been produced and re-produced in the image of medicine, and the medical profession has protected an incursion by law, ethics and government into their realm by "extending its own boundaries to include these other factions now reframed in medical terms […] While government has attempted to define the boundaries of medicine's practice […] , the medical profession has been successful at reclaiming its authority" (1991b: 155). Her study reveals that medicine absorbed the language of ethics and law, even transformed their principles into a new vocabulary and process used in committees. Thus, Flynn concludes that ultimately *biomedicine* defines the terms of the work of bioethics. "Having a committee to discuss bioethical issues implies that ethical issues will be discussed. […] In fact, this is not true. The advice requested, and decisions made, are framed in terms of medicine and not ethics" (Flynn 1991a: 182). She also observed that in committee discussions there is much that is simply not picked up "[…] much that is cut off, many questions and interruptions […] [since the] […] medical discourse often cuts off contextual issues and redirects the focus to technical concerns. But it is not just physicians who do this. All who are using the medical discourse do so" (Flynn 1991a: 185).