Chapter 7

SUMMARY
During recent decades, attention on clinical ethics has increased in the Netherlands. New kinds of ethics support like moral case deliberation (MCD) have been introduced. The growing attention on and implementation of different kinds of clinical ethics support (CES) gives rise to various questions. What kind of CES is available in health care institutions? What kind of CES is needed for dealing with current ethical issues in health care? In this thesis we will address these questions, focusing on the Dutch context.

The aims of the study were to provide an overview of: 1) the prevalence and characteristics of CES in the Netherlands, and 2) the goals and needs of CES from the perspective of top managers and ethics support staff of health care institutions. The central research question was: what is the state of the art of CES in the Netherlands? The sub questions were:

1. How prevalent is CES and what are its characteristics in the Netherlands?
2. What are the needs and goals of CES in Dutch health care institutions?

This thesis consists of two parts. Part 1 focuses on the prevalence of CES in the Netherlands; part 2 describes the needs and goals of Dutch health care institution in relation to CES.

Chapter 1 provides an introduction to the research questions of the thesis. It describes the increased interest in CES, against the background of new developments in health care. In health care, the patient population has become more fragile, and more active and critical at the same time; health care professionals have got more possibilities of treatment and care as a consequence of the increase of medical knowledge, and increasingly have to cooperate in interdisciplinary teams; organization of health care has become more bureaucratic and formal, but is also increasingly confronted with moral challenges which cannot be solved by using formal approaches only.

The chapter also provides a short explanation of various notions in ethics. It describes how applied ethics implied a move from ethical theory to ethical issues in practice. It also touches upon the notion of bioethics, as an interdisciplinary academic field and public movement which crosses traditional academic boundaries. Furthermore, it introduces the concepts of clinical ethics and clinical ethics support.

This chapter also describes previous survey studies on CES in the USA, Canada and Europe (focusing specifically on the Netherlands). Most surveys describe the use of clinical ethics committees or ethics consultants as the main kind of CES. MCD, which has increasingly been receiving attention in the Netherlands, is not addressed in existing surveys. Furthermore, within the existing surveys, little attention has been paid to what management of health care institutions sees as needs and goals of CES.

Part 1 Prevalence and characteristics of CES in the Netherlands
Chapter 2 describes the prevalence of explicit and implicit kinds of CES in Dutch health care institutions, including hospital care, mental health care, elderly care and care for people
with an intellectual disability. In explicit CES, the ethical dimension of care is structurally and professionally addressed; in implicit CES, ethical issues are handled indirectly and in an organic way. The findings demonstrate that the presence of ethics committees is relatively high in the Netherlands, especially in hospitals. Moral case deliberation is present in about half of all Dutch health care institutions and in two thirds of the mental health care institutions. Ethics consultants are not very prominent. Our findings indicate that explicit CES is often combined with implicit forms of CES, and that MCD might be a bridge between the two.

**Chapter 3** focuses on the prevalence and characteristics of MCD in various settings of Dutch health care. The findings demonstrate that the prevalence of MCD is relatively high in Dutch health care (44% have MCD), especially in mental health care (in which MCD is reported as present in the organization by 62% of the respondents).

Institutions with MCD differ from institutions without MCD concerning size, kind of problems and importance of ideological background. Characteristics of MCD include that it is often carried out for 3 years or more, has a high participation of health professionals and middle managers and is both organized scheduled as unscheduled. In relation to the positioning of MCD, another significant issue is integration in existing policy of key persons as they emerge. We conclude that MCD is a part of an integrated ethics policy and serves as a (bottom up) catalyst for such an integrated ethics policy.

**Part 2 Needs and goals of CES in Dutch health care institutions**

In **chapter 4**, we investigate the need for CES from the perspective of managing directors and ethics support staff to understand which factors are relevant in explaining the presence or absence of such need in health care institutions. This chapter provides an evaluation of the need for CES in Dutch health care and the potential barriers to its development. It shows that the need for CES is not a given and aversion to innovation, negative associations with the notion of ethics support service, and organizational factors, such as resources and setting, limit the considered need for CES. Our findings show that most respondents see a need for ethics support and this is related to the complexity of contemporary health care, the contribution of ethics support to the core business of the organization and to the added value of paying structural attention to ethical issues. The promotion of CES in health care can be fostered by focusing on formats which fit the needs of (practitioners in) health care institutions. The emphasis should be on creating a (culture of) dialogue about complex situations which emerge daily in contemporary health care practice.

**Chapter 5** describes the goals of CES as perceived by managing directors and ethics support staff. Four main clusters of goals were found: 1) encouraging an ethical climate; 2) fostering an accountable and transparent organization; 3) developing professionalism; and, overarching the previous three, 4) good care. Important sub-goals of ethics support were: attention for ethical issues; raising awareness of ethical issues; fostering ethical reflection and supporting employees. The chapter ends with a discussion on the desirability to further operationalize the general goal of good care, the context-boundedness of our findings and
the need to relate goals of ethics support to the features of organizational cultures to further improve the integration of ethics support in health care institutions.

Chapter 6 describes the development of CES in elderly care. Our findings suggest that this setting (and possibly in long term care as a whole) shows specific needs in relation to CES. The data indicate that advice-based forms of CES transcend and do not match up with the nature of moral problems found in elderly care. Advice-based forms of ethics support are far removed from actual practice and not in tune with real issues in the workplace. Many moral issues in elderly care arise daily, and often involve seemingly ‘trivial’ issues. Therefore, CES should (according to our respondents) first and foremost help health professionals recognize and identify these problems as being moral problems.

Our respondents indicate that specific needs for ethics support are also related to the educational level of health professionals, and they draw attention to feelings of powerlessness as a human response to the chasm between their low educational level and the complex questions they encounter. Instead of being acknowledged for the difficult work they do, nurses are overloaded with new assignments and innovations which may, in turn, further increase their feeling of powerlessness. There is a need for empowerment rather than for just ethics support.

Chapter 7 provides a discussion of the outcomes of the thesis. It first summarizes the main findings. Then, Habermas’ notions of system and life world are used to reflect on the findings, and clarify why various kinds of CES are present in the Netherlands and how they are appreciated by managing directors and ethics support staff in health care institutions. Next, the chapter contains a reflection on the methods used, and elaborates on their strengths and weaknesses. Finally, recommendations for research and practice are formulated.