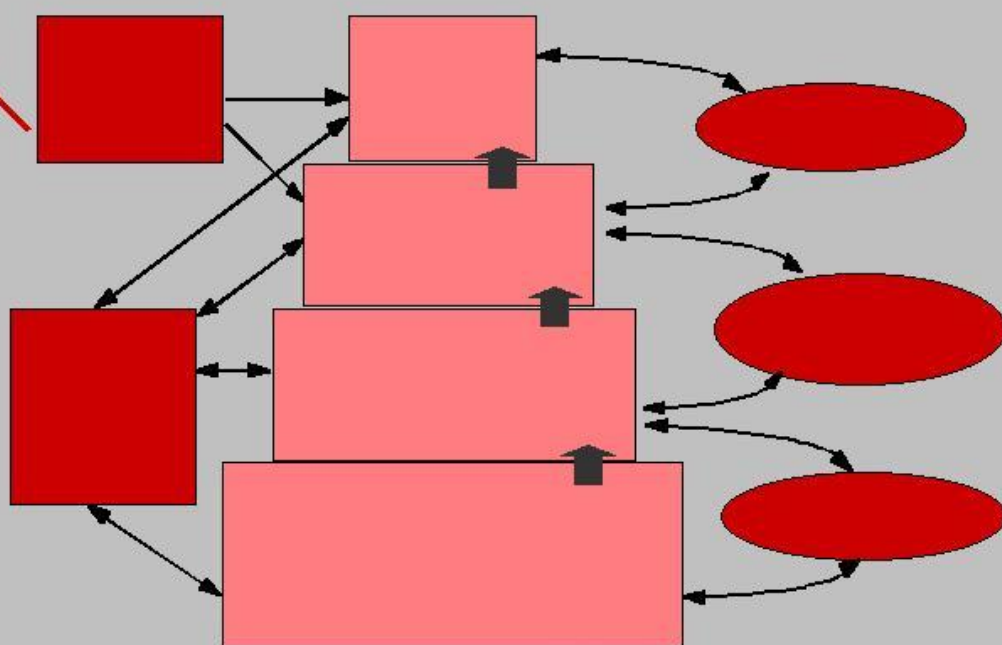


Towards strategic use of nursing information in the Netherlands



William T.F. Goossen

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1. Introduction

William Goossen

1.1. Introduction to the subject

Currently, health care systems in Western countries are influenced by continuous developments in their societies. These developments also apply to the Netherlands, and make it inevitable that the way health care is delivered changes, and that continuous transition is necessary to be able to meet the health care needs of the population (Maas, Gijzen, Lobbezoo and Poos, 1997). Examples of these developments include the ageing of the populations, increasing numbers of patients having chronic diseases, intensifying demands of consumers who want evidence that they receive appropriate and quality care, limitations in available funding of health care, continuous introductions of innovations and technology in health care, leading to growing amounts of patient data to be documented and communicated, a growing interest for 'evidence based' health care, requiring the availability of current research knowledge at the point of care. In addition, the expanding application of information and communication technology in health care, especially in the processes of care delivery, must be mentioned (Franken and Wever, 1995).

As a result of these developments, most countries have set up a system to closer monitor the health status of the population and to determine the effectiveness, efficiency, and other aspects of the quality of care (Maas et al, 1997, Roemer, 1991). These systems to monitor populations and health care delivery require the availability of health care information, and knowledge, methods and skills in information handling of health care providers.

Ageing populations and chronic diseases require more than cure, especially nursing care, and it is expected that the need for professional nurses, and nursing aids is growing (van der Windt, Calsbeek and Hingstman, 1997). However, there is more to do than only addressing the numbers of nurses. The described developments in society and changes in health care are of concern for professional nursing world-wide (Clark and Lang, 1992, Clark 1994) . Clark argues that the value of nursing is no longer self-evident, but must be demonstrated to those who do not have the understanding which is derived from practice, but who do have the power to affect or to determine the nature of nursing through the processes of policy determination and the allocation of resources (Clark, 1994). If nursing is to demonstrate its value, nurses need to have the knowledge and skills to manage information adequately and to apply information and communication technology intelligently in their care activity. The nursing profession is currently not using its information to its full benefits and the use of supporting information and communication technology is limited, which brings new challenges to the profession to deal with the changing health care environment as described above (Zielstorff, Hudgings and Grobe, 1993, Goossen, 1996).

This thesis tries to develop instruments and procedures for the nursing profession in the Netherlands to support its strategic use of its information, and to guide adequate development and use of information and communication technology. Further on in this introductory chapter, different levels of information-needs in the nursing profession, both at clinical and aggregate levels, will be presented. Then, possible procedures to meet these information needs will be described. Finally, the general problem statement for the thesis is given, ending with a description of the different research goals addressed. Although the focus is on nursing data in the Netherlands, examples from the international community are presented where appropriate.

1.2. Nursing's Information Needs

Already in the nineteenth century, Nightingale (1860) stated that it is important to document findings about the patient and about the delivery of care. The essence of nurses' observations of patients and the need for communicating these findings to other nurses and health care workers are in the current information age not different from how it was back in the nineteenth century. However, the many changes in healthcare mentioned above have introduced additional requirements for nurses' information management and documentation. For instance, the need is growing for information that provides insight in the effectiveness and the output of nursing care. Additionally, there is an increasing interest in comparing nursing care across patient categories, time, institutions and nations and to use aggregated data about nursing care to support this comparison. These changing requirements for the documentation and communication of nursing care, and the need for aggregating nursing data must be seen in the context of a changing focus of today's health care, where the patient is in the centre and care delivery becomes increasingly multidisciplinary.

Clark and Lang (1992) identify several needs for information concerning nursing care. These needs include the following items. Clinicians need information and thus adequate documentation for nursing care delivery, support of clinical decision making, continuity of care, and monitoring of quality care. Nursing administrators require measurable, comparable data and summaries on which to estimate the need for care. Nursing researchers need descriptions of care, an international database of care delivery, comparisons of care across settings, and measurements of the effectiveness of care provision and allocation. Nurse educators need information for curriculum planning, to establish some congruence between theory and practice, and research based teaching. Policy makers need comparable nursing data for epidemiological studies, cost-benefit studies, determination of the health status of the population, and for the clarification of the role of the nurse in multidisciplinary teams (Clark and Lang, 1992).

To assist the nursing profession with identifying the detailed information needs, and thus to develop adequate support tools for information management, three models illustrate particular aspects of nursing information management. These models are based on the assumption that health care is a human activity system. According to Checkland (1984), human activity systems are processes in which an ever-changing social world is continuously re-created by its members for some meaningful purposes. Perceived problems in human activity systems are usually 'soft', ill-structured problems of the real world. Checkland (1984) argues that it is possible to identify subsystems in such human activity systems that are systems in their own right. These subsystems may again have sub-subsystems. However, if a subsystem B serves the purpose of another system A, then it is not possible to identify solutions for problems of subsystem B without first doing so for system A. Checkland (1984) suggest that models, such as represented in figures 1 to 3, can assist in expressing problems and finding solutions to improve the situation by comparing the models with reality.

In this thesis, patients and/or their family and health care provider(s), and their mutual relationships, are considered to make up the key system in health care. Human beings have needs with respect to their health, and professionals can help them improve their health status. Thus, this patient to provider relationship serves as system A. The health system at large is a system that serves the purpose of health care delivery to individuals and can be identified as subsystem B. Additionally, the subsystem of nursing care and its information management can be defined as subsystems C (individual level) and subsystem D (for other levels as management, research, education and policy making). Both subsystems for nursing, and the information management in each subsystem will be described hereafter with more detail.

1.3. Nursing care for individual patients

Effective and efficient nursing care is not possible without assessing the patient problems, deciding what should be done, planning and delivering adequate care, documenting what happens, and checking what results are achieved at what cost. This kind of information about the individual is necessary for the provision of care over longer periods and for the co-operation with others. Nursing information is therefore documented regularly, and communicated amongst the many health professionals that care for the individual patient.

Figure 1 illustrates the information and communication process between a patient and a nurse (subsystem C). The figure reads as follows: At the left side is the patient, who is communicating (upper arrows) with a nurse at the right side. This communication has three different aspects. One, the health status of the patient and the delivery of care are observed, documented and communicated continuously. This is illustrated by the rectangles at the left side of the centre, from 'data', to 'outcome'. Two, the thinking about these findings, knowledge based treatment and care decisions, which are represented in the ellipses. Three, informative actions or dialogue about the other two aspects, which are represented by the small arrows that symbolise interaction and conversation. This conversation is required because the patient needs to be able to give informed consent for all diagnostic activities, treatment, care decisions, and the nursing care to be delivered. The two boxes on the right symbolise (a) searching for and using of evidence for adequate care, and (b) the aggregation of data from individual patients for other purposes, such as for the determination of costs, and for research purposes.

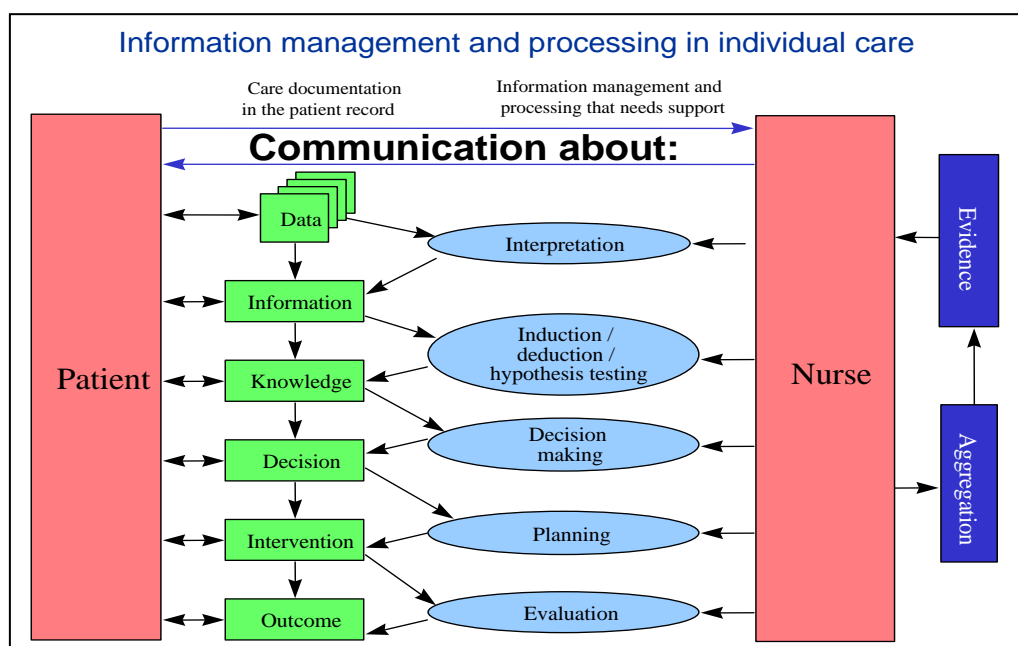


Figure 1. Informing and communicating between individual patients and individual nurses.

In the Netherlands, there is a growing interest in integrated care documentation systems at the clinical level. An integrated care documentation system allows a team of health professionals to document their care for the individual patient. In general, this kind of documentation includes three main information categories. The first category concerns the identification of the patient problems, for which several examinations and assessments of the patients are an important source of data. The problem descriptions include a medical diagnosis of the disease and related health problems such as nursing phenomena, or nursing diagnoses. The second category concerns the documentation of treatment and care performed at different locations and periods and by different professionals including nursing. Finally, the third category includes the actual outcomes for the individual, such as improved health status, no changes, or a deteriorated health status.

Care is usually documented in paper records. With paper systems, it is very difficult to get a good overview of all information of the patient and thus many different record systems have been developed, each with its own advantages and limitations. It is difficult to adapt paper documentation to new circumstances and it is often difficult and time consuming to retrieve information after some time. The content of paper records is not always easy to read and important data may be missing. Further, because of the growing multidisciplinary focus of health care, the information might be needed at different places at the same time, for instance when a patient receives ambulatory care at different locations. With paper systems, this is very difficult to achieve. One important issue with respect to communication and documentation in health care is the need for a unified language, vocabulary or terminology (Clark and Lang, 1992, McCormick, Lang, Zielstorff, Milholland, Saba, and Jacox, 1994, NRV, 1991, Cimino, 1995, Zielstorff et al, 1993) This unified terminology is supposed to support the communication within and between professionals, to assist their documentation, and to allow for comparison of clinical data over time and location.

1.4. Selection and aggregation of health and nursing data

The data about the many individuals that receive care is stored and processed into new information that flows throughout health systems at large. This kind of data processing requires selection, grouping and summarisation of the data from clinical records, which is usually called aggregation. Such aggregated information - encompassing health status, treatment, costs, and outcomes - is necessary to improve health planning, resource allocation and future health outcomes. It is further used in health research, quality assurance, management and administration.

Use of unified terminology in the clinical records can be considered one basic requirement for such selection and aggregation of data for other than clinical purposes (Clark and Lang, 1992, McCormick at al, 1994, Cimino, 1995, Zielstorff et al, 1993). However, Hoy (1997) argues that this unified terminology might need to have different characteristics for different purposes.

The process of aggregation is illustrated in Figure 2 (Goossen, 1997). On the left, the aggregation processes from the clinical to the health policy level are depicted. The rectangles on the bottom left side in Figure 2 symbolise the documentation of care data for the individual, including diagnosis, treatment, costs and outcomes. Then, the arrows going up represent the flow of patient data / health information from lower to higher levels. The rounded boxes represent the processes of selection and aggregation of data into information, which is useful for the upper level(s). The smaller rectangles on the higher levels indicate the smaller amounts of data, for instance via removing details from data at the clinical level.

The large arrow on the right side illustrates the different characteristics of aggregation that Hoy (1997) suggests. Hoy (1997) illustrates with this arrow the flow from natural language to statistical codes. Clinical information is usually expressed in a natural language. For the aggregate levels there are stricter rules necessary to express the information adequately, therefore requiring classifications and codes. The arrow represents the two-way data flow, because the aggregated information also comes back to the clinical level as new knowledge. The natural language, lists, classifications, and statistical codes refer to the kind of manipulation that has to take place before the data is useful at higher levels (Hoy, 1997).

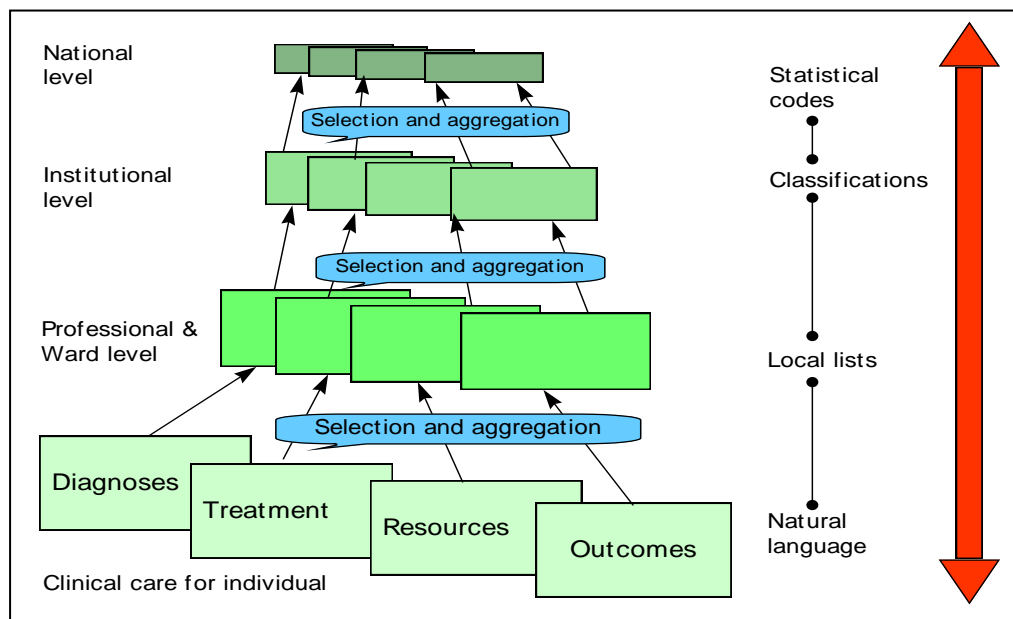


Figure 2. Selecting and aggregating health data, and the required terminology for each level (Goossen, 1997).

Worldwide, there is lack of systematically collected nursing data at the aggregate level, resulting in several problems (McCormick et al, 1994, Zielstroff et al, 1993, ICN, 1996, Mortensen, 1997, Anderson and Hannah, 1993) Because of lacking information, several problems exist with funding of nursing care, and the planning of adequate nursing resources. Further, the contribution of nursing to health care cannot be determined.

This section will illustrate this with Dutch examples of such problems. One problem concerns the health care policy. Given the demographic developments, insight is necessary in the needs of the populations in the future, to plan and develop adequate delivery systems (Maas et al, 1997). There is a continuous wish to express health problems not only in terms of diseases and clinical parameters, but also in terms of consequences for daily functions and quality of life (Ruwaard and Kramers, 1993, Maas et al, 1997, Picavet and Hoeymans, 1997).

Fout! Bladwijzer niet gedefinieerd.For the Volksgezondheid Toekomst Verkenningen (Exploration of Future Healthcare, or VTV) 1997, data are used from the CBS (Central Bureau of Statistics) Health Survey. These data are further analysed for the VTV purpose of presenting information for health care policy (Maas et al, 1997). An identified problem of this survey is that it is representative for the *not* institutionalised population in the age group over 55 years. Data about persons in hospital, nursing homes, etc. are not included in this survey (Picavet and Hoeymans, 1997). The survey does include data about health problems that are usually treated by nurses, such as limitations in activities of daily living (ADL), impairments, and limitations in daily pursuits (Picavet and Hoeymans, 1997). In some studies, these limitations show enormous variations with respect to severity, nature, duration, development, progress, and cause (Picavet and Hoeymans, 1997). Further information is needed

however about the limitations, care dependency, use of aids, informal carers that assist, unfitness for work, and the moment it happens in people's life's (Picavet and Hoeymans, 1997). However, with the currently available data, it is not possible to show the variation of disabilities and impairments in the larger Dutch population (Picavet and Hoeymans, 1997).

Delaney and Moorhead (1995) discuss the advantages that the inclusion of nursing data into health care statistics has for the health care community and for patients. They argue that inclusion of nursing data in health statistics provides information about patient's health problems related to life processes (i.e., how they are becoming dependent of care when ageing) and details about functional status (i.e., how their capabilities in Activities of Daily Living change when having a chronic disease). Thus, nursing data extend beyond the traditional disease, morbidity and mortality outcomes measurement. Further, nursing data give additional information about the costs of providing medical and surgical treatment. With nursing data, the costs of nursing care directed toward health problems can be considered as well.

A second problem concerns paying nursing care in the Netherlands. In 1983, the Dutch government changed the way health care is funded and a system of external and internal budgeting was introduced to control the excessive growth of health care costs. This change in funding has had several disadvantages for the nursing profession in the Netherlands (Commissie Positiebepaling Beroep Verpleegkundig en Verzorgende, 1991, van Dijk, 1994). These disadvantages include a higher intensity of care with a higher workload as the result, and budget cuts that caused problems for adequate staffing.

The balance between the care needs of patients and the necessary nursing workforce is difficult to determine. This is mainly because of the lack of nursing data, and the problems this has given for the profession, the need for a nursing 'budget parameter' was identified to assist in determining the adequate nursing resources to meet patients' demands (Commissie Positiebepaling Beroep Verpleegkundig en Verzorgende, 1991). Unfortunately, in this report it was not described how such a budget parameter for nursing should be defined. Also, the current way the budgets for nursing are determined in the hospitals, varies in the different health care sectors and between institutions (van Dijk, 1994). **Fout! Bladwijzer niet gedefinieerd.** Further, the way Dutch health care is funded is in transition, requiring other approaches for the funding of nursing. Examples of new methods to underpin the funding of health care include managed care and care products such as Diagnoses Related Groups (DRGs), or the Dutch equivalent Diagnose Behandeling Combinaties (DBC's), among others.

A third issue concerns the need to investigate the quality of nursing care, i.e., whether particular nursing care is effective and efficient (Zielstorff et al, 1993). Without information about nursing care it is not possible to compare care between wards, institutions and countries, and thus it is difficult to make informed decisions with respect to quality improvements.

To solve such problems, several initiatives started to develop nursing data sets and to collect and store nursing data in databases (Anderson and Hannah, 1993, Werley, Devine, Zorn, Ryan and Westra, 1991, Sermeus and Delesie, 1994, Australian Council of Nursing Services Inc, 1994, Nielsen and Mortensen, 1994). In the US the Nursing Minimum Data Set was established by Werley et al. This data set is now widely used for studies in nursing, but not yet on a state or national level (Werley et al, 1991). Belgium has established a nursing minimum data set for managerial purposes in the general hospitals and for policy making at the national level (Sermeus and Delesie, 1994). Data is collected nationally on a regular basis since 1988, and a database with several million records is available at this stage (Sermeus and Delesie, 1994). Further, interest is growing in Australia, Canada

and other European countries to develop nursing minimum data sets (Anderson and Hannah, 1993, Australian Council of Nursing Services Inc, 1994, Mortensen, 1997).

Few reliable data about nursing and nursing care in the Netherlands are available at the aggregated level, and a nursing minimum data set was not existing in 1996 (Epping, Goossen, Dassen and Hasman, 1996). However, work is underway to develop such a data set (Epping et al, 1996, Goossen, Epping and Dassen, 1997, Epping, Goossen and Feuth, (1988). To guide the determination of the nursing information that is necessary for decisions at different levels in health care, a nursing information reference model (NIRM) is under development (Epping et al, 1996, Goossen et al, 1997). The NIRM is conceptual in nature, and it tries to achieve consistency between data processing and management in the primary process of nursing care and data derived from that process for quality, management, research, and policy purposes. The model is based on the principle of 'collect-once/use-often', which emphasises single collection and registration at the point of care through the electronic patient record, and subsequent multiple use for different purposes of these data. Thus, both the development of nursing information systems for clinical documentation, and the collection of aggregated and digitised nursing information can be based on the NIRM, which is depicted in Figure 3.

At the clinical level the documentation of care delivery, decision-making, and the role of formalised nursing knowledge are discussed. The professional via clinical decisions (lower balloon at the right) transforms atomic level data from the primary process (layer 1) into conclusions, i.e., results of reasoning about nursing diagnoses / patient problems, nursing interventions and results or outcomes of nursing care (layer 2). At the managerial and policy making level, the aggregation of data in clinical records, the use of a nursing minimum data set, and the support of decision making at the institutional and national level are described. The data of layer 2 can be used for obtaining information for management decisions in a certain organisation (layer 3), and / or for policy decisions about the nursing profession on a national or international level (layer 4). However, to be able to do that, the requirement of using a standard terminology applies, illustrated in the box at the lower left side in Figure 3. For the latter two types of decision making there is usually no need for detailed information that can be traced back to an individual person, this allows adequate privacy protection. In fact, layer 3 and 4 represent the nursing minimum data set. One additional element of the NIRM is the identification of external factors in decision making that have no relevance for patient care, but that are relevant to keep in mind in decision making. Examples of these external factors include e.g., the architecture of the hospital or the educational level of the nurses.

The NIRM adds comprehensiveness to the model of Zielstorff et al (1993), by including of the use of terminologies and classifications, that are necessary for transparency and comparison of data at higher levels. Further, the influence of structure elements is indicated and types of decisions are added to the Zielstorff et al pyramid model. The components of the NIRM are intended as a guideline for the design of elementary parts of clinical information systems: the Electronic Patient Record becomes the core part, but terminology servers, decision support systems, large databases of aggregate data, and data-communication systems can be identified as relevant other parts.

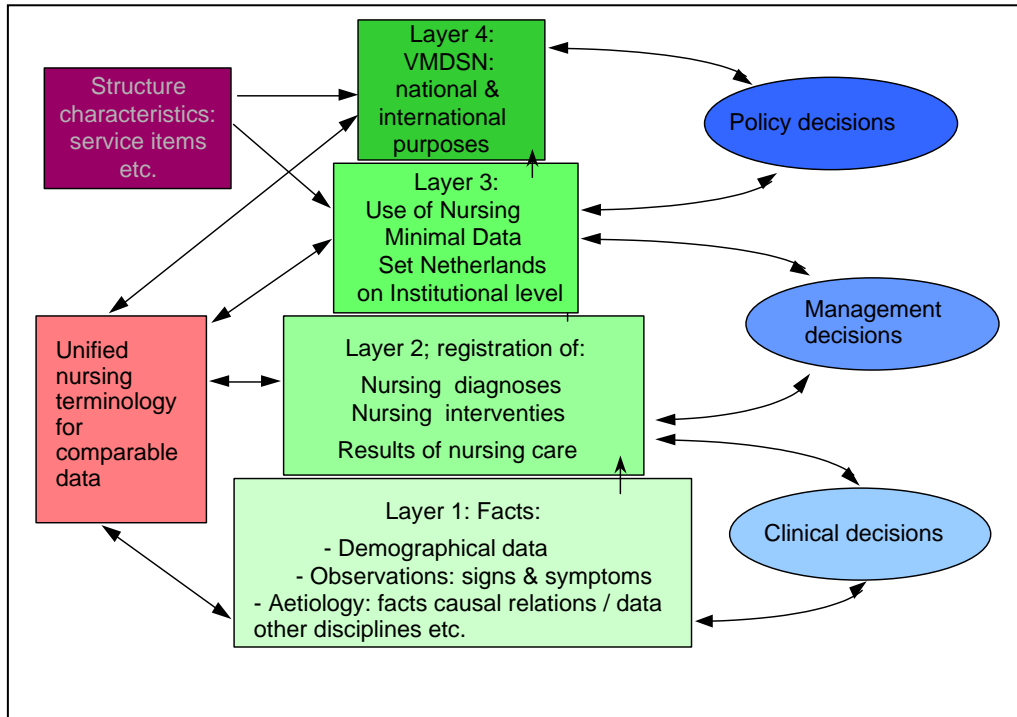


Figure 3. The key elements of the Nursing Information Reference Model (Epping et al, 1996, Goossen et al, 1997).

When clinical records are designed appropriately, they can be used for collecting nursing data that can be used for many purposes. Many initiatives exist, but these initiatives also illustrate the many difficulties associated with it. Nursing itself would benefit from systematic collections of nursing data. Unfortunately, because of the high workload associated with its collection and processing, this information need cannot be fulfilled with paper documentation systems. On the other hand, nurses using technology to support in data management are quite small in numbers, which will be further explained in the next section.

1.5. Information and communication technology

To tackle the problems mentioned in the previous paragraph, and to have the required data readily available for other purposes, the Electronic Patient Record is promoted widely (Dick and Steen, 1991, van Bommel and Musen, 1997, ZON, 1996). The Electronic Patient Record is a computer system to capture, communicate, store, and present patient data, and to assist in transforming these data into meaningful information for authorised users in health care. The users of the system need this information to perform their care activities. Additionally, the Electronic Patient Record allows for easy selection and retrieval of data to be aggregated (Zielstroof et al, 1993, Dick and Steen, 1991, van Bommel and Musen, 1997, ZON, 1996).

Since the Electronic Patient Record is suggested as a tool for nurses to support clinical documentation and to facilitate the aggregation of data for other purposes, it is useful to discuss the actual use of information and communication technology in Dutch health care and nursing. Information systems are abundant in health care in the Netherlands: hospital information systems, home care information systems, and electronic records in private practices are in use (Franken and Wever, 1995, Hasman, 1995, VWS, 1996). The majority of these systems

however are administrative and financial systems, or systems for particular medical diagnostics and to support ancillary departments. The general practitioners in the Netherlands have largely automated their practices since the mid-eighties, and now most of them have computerised information systems for both administrative and clinical purposes (van der Lei, Duisterhout and Westerhof, 1993). The general practitioners are the only clinicians that use the electronic patient record on a regular basis. This situation remains despite the funding of several projects to develop integrated and patient oriented systems (VWS, 1994, Franken and de Koster, 1994). For this reason, the Dutch government is currently funding new projects to develop electronic patient records (ZON, 1996).

Nurses have become acquainted with information and communication systems since these were first used in health care. The discipline that is concerned with the development, use, and evaluation of nursing information systems has become known under the term nursing informatics. The first reports about nursing informatics in the Netherlands date back to the early eighties. Nieman and Pluyter-Wenting (1983) were among the first to investigate the possibilities of computer technology for nursing. They discussed possibilities of health and nursing information systems for practice, education, management and research. Despite this early attention for nursing informatics, specific nursing applications are still scarcely used in health care (Franken and Wever, 1995, Goossen, 1996). There is limited attention for the systematic development and evaluation of nursing information systems. Nursing documentation is, or should be, an integral part of the local documentation of patient care. Nurses have developed many systems that became 'islands of information' because it could not communicate with other departments and professionals. Nevertheless, there are few Dutch development and implementation projects systematically evaluated. Several publications show benefits for the nursing profession when using automated systems for clinical documentation, but also identify problems (Boelhouwer and van Beilen, 1992, van Gennip, Klaassen-Leil, Stokman and Valkenburg, 1994, van der Cingel and Dassen, 1996 (Eurlings, van Asten, Cozijn, Klaassen, Stokman, Valkenburg and van Gennip, 1997).

A nursing information system for home health care was evaluated with a satisfaction survey among patients and nurses (Boelhouwer and van Beilen, 1992). This evaluation study showed that the system contributed to higher quality care plans, and that professionals were better able to document according to the nursing process by using unified terminology. Management and quality of care information was readily available via this system. It further allowed the patient to contribute to care planning and to the care documentation, and patient preferences could be taken into account.

Van Gennip et al (1994) found in another study with a quasi-experimental design, that although no timesaving in nursing activities were actually achieved by using a particular nursing information system, the quality and completeness of the documentation improved. A third study compared paper documentation with computerised documentation (van der Cingel and Dassen, 1996). In this study, van der Cingel and Dassen describe an intervention study that showed improvements in nursing documentation according to the nursing process when a nursing information system with standard care plans is used. Finally, Eurlings et al (1997) report about the effects of components of a nursing information system that is integrated into a large hospital information system. They describe two quasi-experimental studies that show significant positive effects with respect to quality of coordination, nurses job satisfaction and patient satisfaction. Workload measurements revealed a shift in the nurses' activities, but no change in time spent on patient care.

It is evident that, despite the reported results, the promises and the possibilities, nursing does not benefit fully yet from the application of information and communication technology. The few studies that have been performed show that there are potential benefits for patients, nurses, and managers. However, a systematic approach with

respect to the development, implementation and evaluation of patient related information and communication systems is still lacking. The actual use of nursing information systems is limited. Some argue this is mainly because of problems that are of non-technical nature (Berg, Goorman, Harterink, and Plass, 1998) .

1.6. Problem definition and research objectives

The preceding paragraphs illustrate that nursing in the Netherlands could benefit from the use of information and communication technology to support its communication, patient care documentation and data collection tasks. Further, the nursing data, once entered in an electronic patient record, could be used for other purposes like research, management and policy making. However, the use of information and communication by the nursing profession in the Netherlands is still very limited. This situation calls for a further analysis of the problems. Such an analysis is justified by the growing need for information about nursing care, since nurses constitute of the largest workforces in Dutch health care and the potential benefits applying Electronic Patient Records for patients, nurses, and health care at large are tremendous.

The general goal of the reviews and research described in this thesis is to analyse problems associated with information management and the use of Information and Communication Technology (ICT) in nursing and proposing solutions. Based on this analysis, two tools are developed, the application of which eventually will contribute to information management and processing by nurses, and to a competent development of nursing information systems that are part of the electronic patient record. If we find such solutions, it is important that these will be implemented, therefore the implementation possibilities will be explored.

Derived from these considerations, the following research objectives are specified, which are addressed in the subsequent chapters.

1. Analyse problems that are related to professional information management and the use of information and communication technology in nursing.
2. Suggest a well-defined, systematic and scientific approach to the further advancement and development of the field of nursing informatics.
3. Gain consensus about the Nursing Information Reference Model and determine criteria for the systematic development, implementation and use of nursing information systems that are part of the electronic patient record.
4. Identify the implications of formalised nursing knowledge systems for the development of electronic patient record system.
5. Identify relevant patient data and data about nursing phenomena and nursing activities that are useful to get insight in nursing care.
6. Develop a Nursing Minimum Data Set for the Netherlands based on identified categories and items.
7. Evaluate the Nursing Minimum Data Set for the Netherlands for its usability to describe differences in patient populations and nursing activities.
8. Investigate the interrater reliability and discriminative validity of the data collection of the Nursing Minimum Data Set for the Netherlands.

1.7. Specific topics and composition of this dissertation

To achieve these goals, various studies were undertaken, together constituting the dissertation. The chapters 2-9 are written as scientific papers, which have either already been published, are accepted, or are submitted for publication. This means that each chapter can be read separately, but it also implies that a certain overlap was inevitable.

- Chapter two addresses the first research objective, the analysis of problems that exist in nursing information management, and in the development and use of nursing information systems.
- Chapter three proposes a definition, framework, and overview of scientific methods for nursing informatics to meet research objective 2.
- Chapter four addresses research objective 3: getting consensus about the Nursing Information Reference Model and criteria for nursing information systems.
- Chapter five reviews the consequences for the electronic patient record when formalised nursing knowledge, such as unified terminology, and classification systems are used. This to meet research objective 4.
- Chapter six addresses research objective 5 by reviewing existing nursing minimum data sets.
- Chapter seven focuses on the identification and development of the Nursing Minimum Data Set for the Netherlands to achieve research objective 6.
- Chapter eight addresses research objective 7 and describes the evaluation of the NMDSN in 9 Dutch hospitals.
- Chapter nine meets research objective 8, and describes an investigation of the interrater reliability and discriminative validity of the NMDSN.
- Chapter ten presents general conclusions and gives suggestions for using the results of the current studies. It ends with recommendations for future research and development in the area of nursing information systems, electronic patient records, the Nursing Minimum Data Set for the Netherlands and the Nursing Information Reference Model.

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William Goossen

10.1 Introduction

In this chapter a summary of the thesis is presented. For every research objective as formulated in the introduction, it is discussed to what extent it has been achieved, followed with general conclusions. After that, the contribution of the thesis to the field of nursing informatics and to the practice of nursing with respect to the use of electronic information systems is discussed. Finally, methodological remarks and recommendations for future research and development are presented.

10.2. Summary: the extent to which the research objectives are met

The nursing profession in the Netherlands could benefit from the application of information and communication technology to support its communication, patient care documentation, and data collection tasks, and to strategically use this information. The rationale for defining different information-needs in the nursing profession, at both clinical and aggregate levels, is that this allows to further structure and enhance information management in the profession. Nursing data, once entered in an electronic patient record can be used for purposes like research, management and policy making.

The general goal of the reviews and research described in this thesis is to analyse the problems associated with information management and the use of information and communication technology in nursing. Based on this analysis, three tools are developed that allow addressing these problems, criteria for nursing information systems, a nursing information reference model, and a nursing minimum data set.

The following eight research objectives have been specified and are addressed in the thesis.

Objective 1 Analyse problems that are related to professional information management and the use of information and communication technology in nursing.

Chapter two analyses the problems that exist in nursing information management and in the development and use of information and communication technology in nursing. These problems include:

- Negative influences of information systems on nursing practice and on the identity of nurses;
- Lack of adequate nursing terminology and classifications;
- Limited collaboration between nurses and other disciplines in developing electronic patient records;
- Current nursing information systems are inadequate;
- Nursing informatics education is not available at most schools of nursing;

- There is limited evidence for the benefits of nursing information systems;
- Lack of systematic research in nursing informatics;
- Lack of tools to assist in the development of nursing information systems.

To solve the problems, suggestions are presented in the next chapters.

Objective 2 Create a well-defined, systematic and scientific approach to the further advancement and development of the field of nursing informatics.

A systematic and scientific approach is suggested for further developments in nursing informatics. The domain of nursing informatics is defined and scientific methods are suggested:

Nursing informatics is the multi-disciplinary scientific endeavor of analyzing, formalizing and modeling how nurses collect and manage data, process data into information and knowledge, make knowledge-based decisions and inferences for patient care, and use this empirical and experiential knowledge in order to broaden the scope and enhance the quality of their professional practice. The scientific methods central to nursing informatics are focused on: (1) using a discourse about motives for computerized systems, (2) analyzing, formalizing and modeling nursing information processing and nursing knowledge for all components of nursing practice: clinical practice, management, education and research, (3) investigating determinants, conditions, elements, models and processes in order to design, and implement as well as test the effectiveness and efficiency of computerized information, (tele)communication and network systems for nursing practice, and (4) studying the effects of these systems on nursing practice.

A theoretic framework illustrates the key areas of interest in the discipline, which are: the management and processing by nurses of data, information and knowledge to make appropriate decisions, deliver quality care, and evaluate its results. In addition, methods for conducting investigations regarding analysis, modelling and development of nursing information systems are described.

Objective 3 Gain consensus about the Nursing Information Reference Model and determine criteria for the systematic development, implementation and use of nursing information systems that are part of the electronic patient record.

An international panel of 36 experts established criteria for the development and use of electronic patient records in nursing. Use of the Delphi method allowed the construction of a coherent set of criteria in four main areas: communication, organisation, nursing, and technique. Also, the building blocks of the Nursing Information Reference Model were validated. These include several data layers (Epping et al, 1996):

- (1) Atomic level patient data such as observations;
- (2) Clinical conclusions based on decision making such as the nursing diagnoses, interventions and outcomes;
- (3) Aggregated information to support management decisions;
- (4) Further aggregated information to support decisions with respect to nursing by policy makers.

Documenting patient data in the electronic patient record according to the nursing process and based on the 'enter once - use many times' principle, allows data use for other purposes, such as decision support via different presentations of the same data, and for the collection of a Nursing Minimum Data Set. Applying unified nursing terminology is another requirement to achieve this.

These criteria are useful to assist nurses in decision-making concerning the development of electronic patient records. In addition, several criteria allow the establishment of an information policy that reflects nursing care. Particular criteria include the recommendations for adequate human communication during development and use of the electronic patient record. The most important criterion however, is that the nursing information system should be an integral part of the multi-disciplinary electronic patient record, allowing data communication and collaboration between professionals for the benefit of the patients.

Two issues remain after this study. Nurses do not automatically accept control by management when this control is based on data from the electronic patient record. This issue should be addressed very carefully. A possible approach is the use of discourses about system development. The goal could be to achieve agreement about what is allowed and what not with respect to data use.

There was no consensus about the suggested criterion of letting patients entering their own data into the nursing record. All kinds of objections were presented, such as control over the data quality, legal issues, unified terminology, and not being able to take responsibility for the content of the records.

Objective 4 Identify the implications of formalised nursing knowledge systems for the development of electronic patient records.

Because it was considered a requirement for the electronic patient record, the developments in formalisation of nursing knowledge, terminologies and classification systems were reviewed. The initiatives discussed in this review include nursing terminology projects in several countries and the International Classification for Nursing Practice. For many years it has been argued that nursing information systems were difficult to develop because of lacking terminology and classification systems. However, it is obvious that the current nursing language and classification systems can facilitate documenting patient care in electronic patient records.

A master index of nursing terminologies that permits comparing terms from different classification systems could be used for the nursing component in an electronic patient record. If this is realised, health care settings will be able to use their own terminology and classification system and still be able to compare their data with other data sets.

Practical implications of a formalised nursing language include the identification of data that are used during the clinical reasoning of nurses. The results of such studies are important for the layout and structure of data entry and data presentation on computer screens. In addition, the results will also show what nursing data and knowledge should be available in the system. Another example is that the co-operation between disciplines can be supported when their respective data management activities are integrated into one system.

One specific concern is that electronic patient records should allow for updating of the nursing terminology and classifications, without compromising the data-integrity of existing data in the system.

Objective 5 Identify relevant patient data and data about nursing phenomena and nursing activities that are useful to get insight in nursing care.

In chapter four the relevant patient data for nursing are identified, alongside the provider and institutional data of value as contextual information for decision making. A Nursing Minimum Data Set is one component of the Nursing Information Reference Model, and it is situated at the level where it assists in collecting and aggregating the relevant information for decision making by nursing management, and policy makers. The nursing community seems to agree about the value of a Nursing Minimum Data Set. Therefore, existing systems were reviewed regarding their relevance for similar developments.

The advantages and disadvantages of Nursing Minimum Data Sets for nursing practice are discussed, and the differences and commonalities of five international Nursing Minimum Data Set systems that exist or are in a well-advanced stage of development are described. It is concluded that there are differences in purpose, content, sampling, data collection, analysis and feedback methods.

This analysis illustrates the different data categories and items of a number of Nursing Minimum Data Set systems. These categories include: patient demographics, medical care items, nursing care elements, agency and provider items, episode-related items, and elements about resources. The nursing care elements usually include nursing diagnoses, interventions, and outcomes, but in one system only interventions are included.

Objective 6 Develop a Nursing Minimum Data Set for the Netherlands based on identified categories and items

We designed the Nursing Minimum Data Set for the Netherlands. We started the investigation because of the fact that no systematic collection of nursing care data exists in the Netherlands. Via a multi-method, exploratory approach the Nursing Minimum Data Set for the Netherlands was developed. Eight hospitals, with a total of sixteen wards, participated in the study.

The identified categories and items include: five setting and provider items, six patient demographics items, seven items describing the medical condition, ten nursing process items, twenty-four patient problems, thirty-two nursing interventions, four items reflecting outcomes of nursing care, and three complexity of care items.

The content validity of this set is supported by its consistency with the literature, findings from practice and the judgement of potential users. The categories are consistent with the systems developed elsewhere, although the number and nature of several items differ.

Objective 7 Try out the Nursing Minimum Data Set for the Netherlands for its usability to describe differences in patient populations and nursing activities

In chapter eight it is evaluated whether the Nursing Minimum Data Set for the Netherlands, as we developed it, is suitable for its purpose. Using paper-based forms, patient data were collected from 15 different hospital wards. During one week, nurses manually completed the list for every patient every day. The data analysis methodology from the Belgian Minimale Verpleegkundige Gegevens was used (Sermeus and Delesie, 1994; 1997).

There were 686 individual patients included in the study. For the data analysis, their corresponding 2090 patient days in hospital were used. Frequencies of nursing phenomena, nursing activities and results of care were calculated, transformed into ridit scores, and presented graphically as 'fingerprints'. The applied methodology clearly shows what happens on the nursing wards.

It can be concluded that the Nursing Minimum Data Set for the Netherlands is able to represent, by means of the ridits and the fingerprints, the diversity of patient populations on the basis of nursing phenomena and the variation in nursing practice on the basis of nursing interventions. Therefore, the Nursing Minimum Data Set for the Netherlands has enough potential to be used on a larger scale for visualising nursing care.

Objective 8 Investigate aspects of reliability and validity of the Nursing Minimum Data Set for the Netherlands.

The final study reports about a study towards the discriminative validity and the interrater reliability of the Nursing Minimum Data Set for the Netherlands. Data for the validity study were collected in an intensive care ward, in a nursing home, and in a residential home. These results were compared with those of the fifteen wards in the general hospital. The unit of measurement and analysis was again the 'patient day'. Analysis for validity consisted of ridit calculations and their graphical representations, illustrating differences in most nursing phenomena and nursing interventions.

Interrater reliability was measured in the residential home. The percentages agreement for the residential home vary from 60.4 % to 100%, and the Cohen's kappa statistics from -.09 to .85, indicating a poor to almost perfect interrater reliability.

As expected, intensive care patients and patients in the nursing home have in general more problems and need more nursing interventions compared to general hospital patients, while patients in the residential home have or need less of both. This illustrates the discriminative validity of the Nursing Minimum Data Set for the Netherlands on the level of the individual variables. The kappa values and interrater agreement for various variables are sufficiently high, although for several items it can be doubted if they are relevant for the residential home, and perhaps for every health care setting a core data set of nursing phenomena and nursing interventions needs to be selected.

In the different chapters of the thesis, more detailed conclusions are described. In the next section, the main conclusions about the studies as reported in this dissertation will be discussed.

10.3 Main conclusions of these studies

The analysis of the problems with nursing professional information management as presented in this thesis is, five years later, still valid. This situation means that during these five years the nursing profession in the Netherlands was not able to present adequate information about the care delivered and has not managed to use electronic patient records for its support. Thus, the potential benefits of nursing information for patients, nurses, and health care at large are not achieved yet.

The goal of this thesis was to contribute to the strategic use of nursing information in the Netherlands. This is achieved via giving directions, providing means, and showing proof for the relevancy of the application of information and communication technology in nursing. For adequate nursing information management in the future, a research-based approach has been suggested, and three tools have been developed. These tools are:

- (1) A set of criteria for the inclusion of nursing information in electronic patient records,
- (2) The Nursing Information Reference Model, which allows selecting the relevant data for information system development and for the development of an information policy for the nursing profession,
- (3) The Nursing Minimum Data Set for the Netherlands, which presents useful information about the diversity of patient populations and variations in nursing practice.

Eventually, the application of these tools can contribute to adequate information management and processing by nurses, and to a competent recording and processing of nursing information in electronic patient records. Nevertheless, the tools require ongoing testing and application to achieve this.

10.4 Contribution to the field of nursing informatics

Nursing informatics as a field of scientific inquiry is relative young. Nursing informatics started in the mid-seventies in the USA with pioneer researchers in nursing trying out computers to facilitate their work. An influential paper to put nursing informatics at the scientific level was written by Graves and Corcoran (1989).

This thesis contributes to nursing informatics as science. The identification of the problem areas including the lack of quality and lack of developmental tools, among others, allows further study and research as presented in this thesis. Further, the definition of nursing informatics has been integrated into the materials of the Nightingale project for nursing informatics education in Europe (Mantas, 2000). Additionally, this definition has been adapted by the leaders as a good description of the field (IMIA-NI, 1998).

The overview of research methodologies in nursing informatics can facilitate further advancements. For instance, how information management in nursing progresses from data, information via knowledge to decision, action and results needs to be further investigated.

The established criteria for the nursing component of electronic patient records are relevant for an international audience. National studies in the US (Zielstorff et al, 1993), and the UK (Strachan, 1996) revealed many similar ideas. There is a growing international awareness that nursing information systems must be an integral part of the electronic patient record, and that nursing data can be aggregated for health policy making.

The review of five examples revealed that both at a national and international level, there is no such thing as one single Nursing Minimum Data Set, nor that all underlying data elements are comparable at this moment. The publication concerning the development of the Nursing Minimum Data Set for the Netherlands is the second one in the scientific literature that describes in detail the process of identifying the categories and items. This in contrast to the examples from the US and Belgium, that leave this part of the work implicit.

By combining the strengths of the US approach for selecting data categories (inclusion of nursing diagnoses, interventions and results) and the Belgian way of analysing the data (with ridits and fingerprints) a powerful tool has been constructed to make visible what nursing care is.

10.5 Practical contribution

Although the tools described in this paper have been used on a small scale only, some projects in Dutch healthcare support the criterion of multidisciplinary collaboration and communication. Two examples of development of electronic patient records used a multidisciplinary approach and were quite successful. One example is the Dutch Patient Data Management System project that focused on an information model for patient care on intensive care units (Stoutenbeek, 1993). In this project nurses were involved on an equal basis, and during the past years, several successful implementations of such systems were achieved. A second example is the development of the nursing information system in a psychiatric hospital. This system leads psychiatrists to ask the nurses permission to also use the nursing system for the medical diagnosing and treatment (Klemann, 1994). Again, collaboration and communication made this implementation of an electronic record system a success.

The identification of the core elements of the Nursing Information Reference Model, and the established criteria for nursing information in electronic patient records can be applied in system development and information policies. Rijssenbeek (1997) presented an interesting example of the usefulness of such a model. He developed an electronic patient record system in a psychiatric hospital. Based on a bottom up approach, the professionals started with a flat description of patient findings in a database that allowed free text. Later, the professionals recognised that they were writing similar problem descriptions for different patients every time and therefore added unified terminology in the

system. At the time of presentation, the group had just decided to start to collect statistics based on the unified terminology in the electronic patient record. The process of development was completely based on communication among all professionals involved, and on setting realistic new goals when the preceding ones were achieved. In fact, to some extent Rijssenbeek was illustrating the Nursing Information Reference Model based on experiences in practice.

The work on the Nursing Information Reference Model is currently used in the context of the development of an information reference model for integrated medical care. This project focuses on modelling the information management by the professionals (nurses and doctors) in the general hospital. (Prismant, 1999/2000).

One issue in formalised nursing knowledge concerns the question whether to use a common framework or discipline specific representation for the patient data in the electronic patient record. The conclusion is that a common framework is necessary for the commonalities, while a discipline specific representation suits the differences in tasks of the disciplines. Therefore, using both approaches in system development for nursing and medical professions seems to be the practical result of these considerations.

With respect to the identification of the Nursing Minimum Data Set for the Netherlands, the following aspect is of practical value. Items from existing instruments are included, which will allow comparisons with earlier studies with respect to nursing workload. The present budget parameters (e.g., number of beds, admissions and patient days) are already collected and are necessary data for nurse managers' decision-making. Nurse managers also use other arguments than the current budget parameter and nursing care data to make such decisions.

The Nursing Minimum Data Set for the Netherlands allows to give a detailed description of nursing care and should be considered as an additional information source for the decisions about budgets for nursing, but its potential for budget allocation needs to be further investigated. Important here is that the nurses who participated stated that they recognised that their day to day work was represented in the Nursing Minimum Data Set for the Netherlands. This is an important feature for future acceptance of the material for use in practice.

The ultimate goal of the Nursing Minimum Data Set for the Netherlands is to assist nursing managers and head nurses with adequate personnel allocation, partly based on the nursing activities performed. Further, the Nursing Minimum Data Set for the Netherlands should help policy makers to make informed decisions about necessary resources for particular patient populations. Belgian's example shows that this is feasible, but takes a few years to accomplish (Sermeus and Delesie, 1997).

10.6 Methodological aspects

One goal of the thesis is to bring nursing informatics in the Netherlands on a scientific level. It is therefore important to analyse the methodology used in the different studies. The first chapters review a selection of the literature on the subject of nursing informatics, its problem areas, and feasible approaches for the development of useful tools.

The point of these two papers is to justify the problem situation and to focus on a feasible and desired change in nursing information management. They can be regarded as a kind of position papers representing the view of the researcher on the subject of study, thus giving insight in possible biases, and allowing these positions to be criticised.

The Delphi method proves to be a feasible but time consuming approach to get consensus over the criteria for nursing information in electronic patient records. The method is quite easy to apply, given the available literature on its appropriate application. On the other hand, several features of the Delphi method are criticised. One critique concerns changing the items in succeeding rounds, and setting the limits for consensus after the analysis of the descriptive statistics (e.g., Sackman, 1975). Other critiques concern the focus on achieving consensus, which can cause regression to the average.

To overcome these problems, the criteria for consensus are made explicit beforehand, to prevent biases. Further, in contrast to the normal procedure, which is based on 75% agreement, we set the threshold on 80%, and included the median as additional measure. For some items, this means that there was no consensus reached, which would have been obtained with the 75% threshold.

In the application of the Delphi method we have not striven for consensus unnecessarily, to prevent regression to the average and we also have not used only the numeric criteria. For some items there could have been consensus because a sufficient % agreement and an acceptable median of the answer scores are reached. However, the comments of the panel members - often related to misinterpretation of the item - caused us to decide for a number of items that there in fact is no consensus. Such items are changed, or further explanations have been added. Such strict procedures should be applied in future Delphi studies, in order to overcome these critiques.

Despite the critiques on this changing of items, that is exactly the most important feature of the Delphi method, and should be allowed. Working with two researchers, using the sequence and course of action for the Delphi method, as described by Couper (1984), and feedback on the application of the method from our supervisors has given additional rigour to the study.

The key methodological question with respect to developing Nursing Minimum Data Sets concerns the level of aggregation of the items, and the number and nature of the items. There are differences in the Belgian and the US systems with respect to both issues. For the Dutch development we have used the categories of the US system and the data analysis methods of the Belgian system.

The categories in the US include nursing diagnoses, interventions and outcomes, while in Belgium only the nursing interventions are included. The number of items in Belgium is a limited and fixed set collected every quarter. Using the fixed set allows comparing over time of the same information. It

does not allow however, to include new interventions or other categories such as patient problems or nurse-sensitive patient outcomes, which would be required by changes in the patient population, or in professional practice.

In the US, the collections differ, and reveal different nursing diagnoses, nursing interventions and outcomes of care every time. The whole range of possible items is covered, and frequency reports are presented. This approach however does not allow a correct comparison over time of the same items, although frequency profiles of the patient categories can be made.

With respect to the aggregation level, the studies in the US usually deal only with the level of the patient category under study, revealing scientifically interesting details concerning these patients. No attempt has been made yet to bring this to a higher aggregation level. The Belgian system is used up to the highest aggregation level: for the information needs of the ministry of health. Thus, just the sheer number of patient records per year that is collected justifies the limitation to a small number of items: it has to stay manageable, at the risk of losing detailed information.

It therefore depends heavily on the purpose of the data collection and the information that has to be provided how a Nursing Minimum Data Set should be applied. The primary goal for the Dutch system is the managerial level in hospitals. Since this is already a higher level, aggregation, and thus selection of items and reduction of details, is a necessary requirement. The purpose is to develop a *minimum* data set, and thus constraints on the number of concepts to include are necessary. From a clinical point of view, and from a research perspective, this implies that many relevant patient problems and nursing interventions in hospitals are not represented.

If we would have to deliver health policy data that are based on the Nursing Minimum Data Set for the Netherlands, additional reduction of items would be necessary. In contrast, for clinical research of particular patient categories, or specific nursing diagnoses, more details need to be added again. Thus, as suggested in the introduction, the required level of aggregation determines the number and types of data items to be collected.

The use of the 15 hospital wards to develop the Nursing Minimum Data Set for the Netherlands did not allow selection of all possible patient problems or nursing interventions. One area of concern is that no geriatric, paediatric and maternity wards are included in the sample. Such specialities might need additional items. Using the Nursing Minimum Data Set for the Netherlands in practice would therefore require attention to possible additional concepts.

An additional application would be to present prevalence and incidence data according to the Nursing Minimum Data Set for the Netherlands. However, to adhere to epidemiological standards, it is more interesting to present these prevalence data by longitudinal episodes for individual patients in order to see the changes in the existence of nursing phenomena, activities and outcomes over time. Thus, also the design of the data collection depends on the purpose: if epidemiological data are the goal, then the individual person must be the unit of analysis and presentation of the information, and not the patient day as was used in the current study.

Although the current information based on the patient days does not provide explanations about why certain things occur, for the ward it can function as mirror or benchmark information, suggesting additional in-depth analysis.

With respect to outcome research, nursing has a long way to go. At this stage, four of the six ANA nursing quality indicators (Pollard et al., 1996) were used for the test of the Nursing Minimum Data Set for the Netherlands. At the moment using the nursing quality indicators only functions as a feasibility test to investigate whether it is possible to collect this kind of information. This section of the Nursing Minimum Data Set for the Netherlands is not complete, and should be used very carefully.

10.7 Recommendations

This section presents recommendations for applying the criteria for the development or selection of electronic patient records, for the use of formalised nursing knowledge, for the application of the Nursing Minimum Data Set, and for the collection and analysis of patient outcomes in this data set. The criteria obtained via the Delphi study, including the Nursing Information Reference Model, need to be converted into practical tools, and then tested in practice to determine the applicability. These criteria are useful for the support of decisions with respect to the selection and/or development of electronic patient record systems. The criteria are concrete enough to make a scoring list that could guide electronic patient record development, and that allows for evaluation of the process with respect to their adherence to the criteria. A second recommendation is to use the Nursing Information Reference Model to develop information policies for nursing information management in the nursing profession, and in healthcare organisations.

One research question would be whether the integration of nursing information systems into electronic patient records can be facilitated based on the criteria. In the future it is also useful to investigate whether systems that have been developed or implemented according to these criteria, do indeed deliver better - or at least better accepted - information systems for the nursing discipline. The two remaining issues from the Delphi study, control by management, and patients entering their own data need further research.

Additional research is needed in the area of the application of formalised nursing knowledge in an information system for the identification and inclusion of patient data, nursing diagnosis, interventions and patient outcomes. Particular questions to be answered and issues to be resolved in this area include whether nursing information systems and electronic patient records meet the requirements to apply formalised nursing knowledge, and does the quality of nursing practice improve from its use?

Another key question that needs appropriate solutions is that electronic patient records should allow for comparable descriptions of nursing care without inhibiting practitioners in their expressions of the care for the individual patient.

Currently CEN / TC 251 works on a first standard for categorical structures for nursing terminology, and an ISO proposal is accepted to develop a reference terminology for nursing (CEN TC 251, 1998). Both initiatives are important to allow further research and development in this area. Nursing informatics specialists in the Netherlands should be involved in its development and application, and could integrate this knowledge into the nursing information policies and information system developments.

For the analysis of the Nursing Minimum Data Set for the Netherlands the following five issues should be solved. First, the existing data collection obtained via the transversal design should be further analysed with respect to identifying relationships between the Nursing Minimum Data Set for the Netherlands and the time samples of nursing activities that have been collected simultaneously (Goossen, Epping and Feuth, 2000). A feasible approach is a regression analysis with the ridit scores of the Nursing Minimum Data Set items as independent variables and the time spent on particular activities by the nurses as dependent variables. The question here is which items from the Nursing Minimum Data Set for the Netherlands predict nursing workload.

Second, the analysis of the Nursing Minimum Data Set for the Netherlands consisted of ridit analysis and making fingerprints. In addition, in the Belgian MVG a multidimensional scaling technique is applied to develop a 'national map' (Sermeus and Delesie, 1997). It is recommended to develop such a 'national map' for the Netherlands as well. The applicability of such an approach to the Nursing Minimum Data Set for the Netherlands has been explored by Griens (2000). Additional research in this area is strongly recommended.

Third, the data of the Nursing Minimum Data Set for the Netherlands for several of the 686 patients have been collected longitudinally, and can be further analysed on the patient level. For future application a longitudinal design based on episodes from admission to discharge is recommended to achieve the full benefits of the Nursing Minimum Data Set for the Netherlands for research purposes. Then, prevalence data will be more accurate and can be reported on patient level, which is consistent with normal epidemiological research.

Fourth, the validity and reliability studies were based on a convenience sample on the intensive care unit, in the nursing home and in the residential home. This study proved that the Nursing Minimum Data Set for the Netherlands is applicable on intensive care units, and thus meets one of the criteria. Although the two other settings in the validity and reliability study were not the target group for the Nursing Minimum Data Set for the Netherlands, most of its items were relevant as well.

Nevertheless, further validation of the appropriate nursing phenomena and nursing activities in other settings than the general hospitals are recommended. This recommendation is based on the scores in the residential home for interrater agreement for some items, which suggest that these are not relevant in that setting. In addition, although the interrater reliability in the residential home is sufficient, it is recommendable to repeat a reliability study in hospitals with larger samples and with more control in the study design.

Fifth, concerning the necessary resources for the current collection of the data for Nursing Minimum Data Set for the Netherlands, the amount of time for completion should be reduced (Goossen, Epping and Feuth, 2000). Minimising the number of variables could enhance data collection. On the other hand, aggregation of these data using automated data collection tools, such as electronic patient records, could also ease nurses' tasks in data collection. Therefore it is recommended, based on empirical findings in addition to the opinions of the experts in the Delphi study, that the nursing data, information, and knowledge, in particular the Nursing Minimum Data Set for the Netherlands, should be part of electronic patient records.

Another reason to integrate nursing information into electronic patient records is to allow the determination of nurses' contribution to healthcare based on nurse-sensitive patient outcomes. The need for measuring patient outcomes has recently been recognised by the Dutch nursing professional organisations, and will gain more interest in the future.

With the Nursing Minimum Data Set for the Netherlands a first attempt was made to measure nurse-sensitive patient outcomes. The feasibility of doing this has thus been established (Goossen, Epping and Feuth, 1999), although many methodological issues remain. It can be recommended however to further investigate what nursing outcomes need to be included in the Nursing Minimum Data Set for the Netherlands. A logical start would be to include the additional two items of the nursing reporting card (Pollard et al, 1996), which are infection rates and satisfaction with nursing care. Linking the Nursing Minimum Data Set for the Netherlands with the existing registrations of infections and of pressure ulcers is another feasible approach.

Additional testing of outcomes in the Nursing Minimum Data Set for the Netherlands should go hand in hand with the determination of an appropriate research design, which includes additional data for demographics, risk adjustment, problem identification, circumstances, medical treatment, nursing interventions, and possible confounders of results. International co-ordination of Nursing Minimum Data Set projects would be one approach to solve these problems.

To conclude the recommendation section of this thesis, it is obvious that it is becoming increasingly important to obtain nursing information and knowledge from electronic patient records. The focus of nursing system development and use should therefore not only be on the data-entry, and on clinical information management, but also on decision support at different levels, based on nursing information, managed in and aggregated from the records. The examples of data re-use for management information, outcome research, epidemiological research and eventually policy making are now within reach, and should be part of development criteria for electronic patient record and nursing information system, and of future nursing informatics research.

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Samenvatting proefschrift

Promovendus:

Wilhelmus Theodorus Fredericus Goossen

Promotiedatum:

woensdag 18 oktober 2000 om 14.15 uur

Promotores:

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Titel:

Towards strategic use of nursing information in the Netherlands

11. *Samenvatting en conclusie*

William Goossen

11.1 **Introductie**

De verpleegkundige professie in Nederland zou voordeel kunnen ondervinden van de toepassing van informatie en communicatie technologie. Dit om de communicatie, de documentatie van zorg en het verzamelen van gegevens te ondersteunen, waarna de verkregen informatie strategisch gebruikt kan worden.

In dit proefschrift zijn verschillende niveaus van informatie behoeften in de verpleegkundige beroepsuitoefening gedefinieerd; in het primaire proces, de dagelijkse zorg voor patiënten, op het niveau van management, onderzoek en beleid. Verpleegkundige gegevens kunnen, zodra ze eenmaal in het elektronisch patiënten dossier zijn ingevoerd, onder bepaalde voorwaarden, worden gebruikt voor kwaliteitszorg, wetenschappelijk onderzoek, managen van de zorginstelling en ondersteuning van het beleid voor de verpleegkundige zorg.

Deze verdeling in niveaus van informatie maakt het mogelijk om het informatiemanagement in de beroepsuitoefening verder te structureren en te verbeteren. Dit is nodig omdat het huidige informatiemanagement in de verpleging, met name het gebruik van informatie en communicatietechnologie, de nodige problemen kent. Het algemene doel van dit proefschrift is om deze problemen verder te analyseren en het presenteren van drie hulpmiddelen waarmee deze problemen kunnen worden aangepakt. Deze hulpmiddelen zijn criteria voor verpleegkundige informatie systemen, een verpleegkundig informatie referentie model en een verpleegkundige minimale data set. In hoofdstuk 1, de inleiding, wordt het bovenstaande in detail beschreven en verantwoord. Ook worden daar de onderzoeksvragen toegelicht.

11.2. **Samenvatting van de hoofdstukken**

Hoofdstuk 2 beschrijft de problemen in het informatiemanagement en het gebruik van informatie en communicatie technologie in de verpleging. Deze problemen omvatten zaken zoals de negatieve invloed van informatie systemen, gebrek aan verpleegkundige classificaties, beperkte samenwerking, slechte kwaliteit van de huidige verpleegkundige informatie systemen, onvoldoende aanbod van onderwijs in verpleegkundige informatiekunde, beperkte bewijzen voor de voordelen van verpleegkundige informatie systemen, gebrek aan systematisch onderzoek op dit gebied en gebrek aan hulpmiddelen bij de ontwikkeling van verpleegkundige informatie systemen.

Hoofdstuk 3 beschrijft een wetenschappelijke aanpak voor de verpleegkundige informatiekunde. Het onderzoeksdomein van de verpleegkundige informatiekunde is in dit hoofdstuk gedefinieerd. Een theoretisch raamwerk illustreert de centrale gebieden die voor onderzoek in aanmerking komen. Dit zijn het managen en verwerken van data, informatie en kennis door verpleegkundigen opdat ze correcte besluiten kunnen nemen, kwalitatief goede zorg kunnen geven en de resultaten ervan kunnen evalueren. Tot slot worden er methoden beschreven voor informatieanalyse en -modellering en de ontwikkeling en evaluatie van verpleegkundige informatie systemen.

Hoofdstuk 4 beschrijft een Delphi onderzoek waarin criteria werden vastgesteld voor de ontwikkeling en het gebruik van een elektronisch patiënten dossier in de verpleging. De criteria zijn opgenomen in vier hoofd domeinen: communicatie, organisatie, verpleegkundige informatie en techniek. Verder werden de bouwstenen van het verpleegkundig informatie referentie model gevalideerd. Dit omvat de volgende niveaus van gegevens:

gedetailleerd niveau: patiënten gegevens zoals feitelijke observaties;

conclusies die zijn gebaseerd op beslissingen in het primaire proces zoals verpleegkundige diagnoses, interventies en zorgresultaten;

geaggregeerde informatie om managementbeslissingen te ondersteunen, aan de hand van een verpleegkundige minimale data set;

geaggregeerde informatie om beleidsbeslissingen aangaande de verpleging te ondersteunen.

Het documenteren van patiënten gegevens in het elektronisch patiënten dossier dient het verpleegkundig proces te ondersteunen en gebaseerd te zijn op het 'een keer invoeren – vaker gebruiken' principe. Het gebruiken van eenduidige verpleegkundige taal is een vereiste om dit te bereiken.

Specifieke criteria omvatten de aanbeveling voor communicatie tijdens de ontwikkeling en het gebruik van een elektronisch patiënten dossier. Het verpleegkundig informatie systeem dient namelijk een integraal deel te zijn van multidisciplinaire elektronische patiënten dossiers. Daarbij moet data communicatie mogelijk zijn waarbij door uitwisseling van gegevens de samenwerking tussen professionals wordt bevorderd ten behoeve van de patiëntenzorg.

Twee discussiepunten blijven over na deze Delphi studie. Verpleegkundigen accepteren geen controle door het management die gebaseerd is op gegevens uit het elektronisch patiënten dossier. Er bleek ook geen consensus over de suggestie de patiënten hun eigen gegevens te laten invoeren in het verpleegkundig dossier.

Hoofdstuk 5 geeft een overzicht van beschikbare verpleegkundige vakkennis, terminologieën en classificaties uit verschillende landen. Het gebruik daarvan is een criterium is voor het elektronisch patiënten dossier. Sinds lang wordt gediscussieerd over de moeilijkheden om verpleegkundige informatie systemen te ontwikkelen door het gebrek aan classificaties. Op grond van het overzicht blijkt echter dat er meerdere verpleegkundige classificaties zijn die het eenduidig documenteren van patiëntenzorg in elektronisch patiënten dossiers kunnen ondersteunen.

In hoofdstuk 6 zijn bestaande verpleegkundige minimale data sets met elkaar vergeleken voor de ontwikkeling van een dergelijke dataset voor Nederland.

De voor- en nadelen van verpleegkundige minimale data sets voor de verpleegkundige praktijk zijn bediscussieerd en de overeenkomsten en verschillen zijn beschreven. De conclusie is dat er verschillen zijn in het doel, de inhoud, de verzameling van gegevens, de analyse en de methoden van feedback geven.

De overeenkomsten betreffen de gegevenscategorieën: demografische gegevens van patiënten, medische gegevens, verpleegkundige zorg, instelling en hulpverleners gegevens, episodegerelateerde gegevens en gegevens over de beschikbare middelen. De verpleegkundige gegevens omvatten verpleegkundige diagnoses, interventies, en resultaten.

In het 7e hoofdstuk is het ontwerp van de verpleegkundige minimale data set voor Nederland toegelicht. Dit project werd gestart omdat er geen systematische collectie van verpleegkundige gegevens beschikbaar is in Nederland. Via verschillende verkennende methoden is de verpleegkundige minimale data set voor Nederland ontwikkeld. Acht ziekenhuizen namen deel aan dit onderzoek met in totaal 16 verpleegafdelingen. De vastgestelde gegevenscategorieën omvatten: vijf items over de instelling en de hulpverlener, zes demografische gegevens van patiënten, zeven items over de medische conditie, tien items over het verpleegkundig proces, 24 verpleegproblemen/ verpleegkundige diagnoses, 32 verpleegkundige interventies, vier resultaten van verpleegkundige zorg en drie items voor de complexiteit van zorg.

De inhoudsvaliditeit van deze set wordt ondersteund door de literatuur, het gebruik van dergelijke gegevens in de praktijk en de beoordeling door gebruikers. De categorieën zijn consistent met de systemen zoals die elders zijn ontwikkeld, hoewel de aard en het aantal van de items enigermate verschilt.

In hoofdstuk 8 is de evaluatie beschreven van de verpleegkundige minimale data set voor Nederland. Met behulp van papieren invulformulieren werden patiëntengegevens verzameld van 15 ziekenhuisafdelingen. Een week lang vulden de verpleegkundigen deze formulieren dagelijks in voor elke patiënt. Voor de analyse zijn de methoden van de Belgische Minimale Verpleegkundige Gegevens gebruikt. Er namen 686 individuele patiënten deel aan de studie. Voor de analyse werden de totale aantallen dagen dat deze patiënten in het ziekenhuis verbleven gebruikt (N = 2090). De aantallen verpleegproblemen / verpleegkundige diagnoses, verpleegkundige interventies en resultaten van zorg zijn geteld, omgezet naar zogenaamde ridit scores en daarna weergegeven als grafieken in de vorm van 'vingerafdrukken'. Deze methode laat duidelijk zien wat er gebeurt op verpleegafdelingen en bij welke verpleegproblemen en verpleegkundige interventies patiëntengroepen en afdelingen van elkaar verschillen.

Daardoor kan de verpleegkundige minimale data set voor Nederland op grotere schaal worden gebruikt om inzicht te krijgen in de verpleegkundige zorg.

Hoofdstuk 9 beschrijft een onderzoek naar een aspect van validiteit en van de interbeoordelaars betrouwbaarheid van de verpleegkundige minimale data set voor Nederland. Gegevens voor deze studie werden verzameld op een intensive care afdeling, in een verpleeghuis en in een verzorgingshuis. De resultaten werden vergeleken met de gegevens van de vijftien afdelingen in het algemeen ziekenhuis. Ook hierbij is de patiëntendag gebruikt als eenheid voor de analyse. Deze analyse bestond uit het berekenen van de ridits en weergave van de vingerafdrukken, die de verschillen in verpleegproblemen en verpleegkundige interventies laten zien. De vraag is of verwachte verschillen tussen de soorten instellingen en afdelingen goed naar voren komen. Zoals te verwachten blijken patiënten op de intensive care en in het verpleeghuis in het algemeen meer problemen te hebben en meer verpleegkundige interventies te krijgen vergeleken met de verpleegafdelingen van het algemeen ziekenhuis. Bewoners in het verzorgingshuis hebben daarentegen minder van beiden. Dit aspect van validiteit van de verpleegkundige minimale data set voor Nederland betekent dat de gegevens het toestaan om verschillen zichtbaar te maken van verschillende patiëntenpopulaties.

De interbeoordelaars betrouwbaarheid van het registreren van de gegevens werd gemeten in het verzorgingshuis. De percentages overeenstemming in de beoordeling van dezelfde patiënt door twee verschillende verpleegkundigen op hetzelfde tijdstip variëren van 60.4 % tot 100%. De Cohen's kappa varieert van -0,09 tot 0,85. Deze uitslagen geven een slechte tot bijna perfecte interbeoordelaars betrouwbaarheid weer.

De kappa waarden en de percentages overeenstemming voor diverse variabelen zijn voldoende, hoewel voor een aantal items de vraag gesteld kan worden of ze relevant zijn voor het verzorgingshuis. Wellicht dient voor iedere sector in de gezondheidszorg afzonderlijk een set van verpleegproblemen en verpleegkundige interventies te worden vastgesteld.

11.3 Algemene conclusies

Het doel van dit proefschrift is om een bijdrage te leveren aan het strategisch gebruik van verpleegkundige informatie in Nederland. Voor een adequaat verpleegkundig informatiemanagement in de toekomst wordt een op wetenschappelijk onderzoek gebaseerde aanpak voorgesteld en zijn er drie hulpmiddelen ontwikkeld. Deze hulpmiddelen zijn:

- (1) Een set criteria voor onder andere de invoer, verwerking, communicatie, opslag en presentatie van verpleegkundige informatie in een elektronisch patiënten dossier;
- (2) Het verpleegkundig informatie referentie model (VIRM), dat behulpzaam is om relevante gegevenssoorten vast te stellen voor informatiesysteem ontwikkeling en voor de ontwikkeling van een informatiebeleid voor de verpleegkundige professie,
- (3) De verpleegkundige minimale data set voor Nederland (VMDSN), die bruikbare informatie verstrekt over de diversiteit van patiënten populaties en variaties in de verpleegkundige praktijk.

Deze hulpmiddelen kunnen bijdragen aan een competente vastlegging en verwerking van verpleegkundige informatie in elektronisch patiënten dossiers. Desalniettemin dienen de hulpmiddelen verder te worden uitgetest en te worden toegepast om dit in de praktijk ook feitelijk te bereiken.

11.4 Bijdragen aan de verpleegkundige informatiekunde

De verpleegkundige informatiekunde is een jong gebied van wetenschappelijk onderzoek. Deze dissertatie draagt in beperkte mate bij aan de verpleegkundige informatiekunde als wetenschap. De identificatie van de problemen en methoden staan verdere studie en onderzoek in de toekomst toe.

De definitie van verpleegkundige informatiekunde is opgenomen in de materialen van het Nightingale project voor onderwijs in verpleegkundige informatiekunde in Europa. Bovendien is deze definitie erkend door internationale deskundigen als een goede beschrijving van het domein.

De criteria voor het verpleegkundig deel van een elektronische patiënten dossier zijn relevant voor een internationaal publiek. Nationale studies in de VS en Groot Brittannië brachten vergelijkbare ideeën naar voren. Er bestaat een groeiend internationaal besef dat verpleegkundige informatie systemen een integraal onderdeel van het elektronisch patiënten dossier zijn en dat verpleegkundige gegevens geaggregeerd kunnen worden voor gezondheidsbeleid.

Het overzicht van de verpleegkundige minimale data sets laat zien dat er niet zoiets bestaat als een unieke verpleegkundige minimale data set. Ook zijn niet alle onderliggende data elementen vergelijkbaar. Dit is belangrijke kennis voor de verdere ontwikkeling van internationale vergelijkingen van verpleegkundige zorg op basis van dergelijke data sets waar in toenemende mate belangstelling voor bestaat.

11.5 Praktische bijdrage

Hoewel de beschreven hulpmiddelen nog niet, of nog op kleine schaal zijn uitgetest, blijken ze nuttig te zijn. Uit sommige projecten in de Nederlandse gezondheidszorg blijkt dat verschillende van de criteria voor verpleegkundige informatie systemen in de praktijk worden ondersteund. Twee projecten gebruikten bijvoorbeeld een multidisciplinaire aanpak waarin samenwerking en communicatie de implementatie van een elektronisch patiënten dossier tot een succes maakten. Uit deze praktijkprojecten komen daardoor vergelijkbare inzichten naar voren als in dit proefschrift zijn beschreven.

Het verpleegkundig informatie referentie model wordt op dit moment gebruikt voor de ontwikkeling van een informatie referentie model voor geïntegreerde medische zorg. Dit gebeurt in het VIZI project (Virtuele Integratie van Zorg Informatie) dat zich richt op het modelleren van informatie management door de verschillende professionals in het ziekenhuis, met name verpleegkundigen en artsen.

In de verpleegkundige minimale data set voor Nederland zijn items opgenomen uit bestaande instrumenten waardoor vergelijkingen mogelijk zijn met bijvoorbeeld studies naar werklast van verpleegkundigen. De verpleegkundige minimale data set voor Nederland biedt een gedetailleerde beschrijving van de verpleegkundige zorg en dient te worden beschouwd als een aanvullende bron van informatie voor beslissingen over budgetten voor de verpleging. Het potentieel voor de budgetverdeling dient verder te worden vastgesteld. Van belang is dat verpleegkundigen die deelnamen aan de studie vertelden dat zij hun werk goed zagen weergegeven in de verpleegkundige minimale data set voor Nederland. Dit is relevant voor de acceptatie in de praktijk.

11.6 Methodologische aspecten

Een van de doelen van dit proefschrift is de verpleegkundige informatiekunde in Nederland op een wetenschappelijk niveau te brengen. Het is daarom belangrijk de gebruikte methodologie te analyseren. De beschrijvingen in de eerste hoofdstukken zijn te zien als het verantwoorden van de aanpak, waardoor deze kritisch beschouwd kan worden: noodzakelijk voor wetenschappelijk werk.

De Delphi methode bleek een geschikt maar tijdsintensieve aanpak om consensus te krijgen over de criteria voor verpleegkundige informatie in elektronische patiënten dossiers. De methode is redelijk makkelijk toe te passen, mede gezien de beschikbare literatuur hierover. Anderzijds zijn verschillende eigenschappen van de Delphi methode aan kritiek onderhevig. Belangrijke kritiek betreft de aanpassing van de items in de verschillende rondes en het achteraf bijstellen van de grenzen voor consensus zodra de eerste statistieken beschikbaar zijn. Andere kritiek betreft de focus op het bereiken van consensus wat soms een verschuiving naar het gemiddelde geeft. Om deze problemen te voorkomen zijn de criteria voor consensus vooraf duidelijk gemaakt. Verder is de limiet op 80% overeenstemming gesteld, in tegenstelling tot de normale procedure die gebaseerd is op 75% overeenstemming. Bovendien is de mediaan als aanvullende eis opgenomen.

Dit betekent dat een aantal van de items geen consensus bereikten, die er wel zou zijn geweest bij de 75% limiet. Verder is ook rekening gehouden met de commentaren van de panelleden. Als bleek dat het item niet goed begrepen werd is in een aantal gevallen, ondanks de op cijfers gebaseerde consensus, toch besloten een item aan te passen of verdere uitleg te geven in volgende rondes.

Er is duidelijk gerapporteerd over de items waarover geen consensus is bereikt. Dergelijke strikte procedures kunnen in toekomstige Delphi studies worden gebruikt om de methode te versterken. De kritiek op het veranderen van de items is genegeerd. Dit aanpassen vormt juist de kracht van de Delphi methode omdat daarmee de discussie vorm en inhoud krijgt.

De centrale vragen voor de ontwikkeling van verpleegkundige minimale data sets betreffen het aantal en de aard van de items en het niveau van aggregatie. Er zijn verschillen tussen het Belgische en het Amerikaanse systeem. Voor de Nederlandse ontwikkeling zijn de categorieën van het Amerikaanse systeem en de analyse methoden uit België gecombineerd. De categorieën in de VS omvatten verpleegkundige diagnoses, interventies en zorgresultaten. In België zijn dit alleen interventies.

Het aantal items in België is zeer beperkt en betreft een vaste set die elk kwartaal wordt verzameld en geanalyseerd. Hierdoor is het mogelijk om dezelfde soort informatie over tijd met elkaar te vergelijken en trends weer te geven.

In de VS verschilt de wijze van gegevens verzamelen in elke studie en worden telkens andere verpleegkundige diagnoses, interventies en zorgresultaten gepresenteerd. Deze aanpak staat echter geen vergelijkingen op grote schaal & in de tijd toe op dezelfde items, of om op grotere schaal vergelijkingen te maken.

Op het niveau van aggregatie zijn er ook verschillen. De VS studies presenteren de informatie op het niveau van de patiëntencategorie die wordt onderzocht, waardoor in wetenschappelijk opzicht interessante details beschikbaar komen. Er is echter nog weinig gedaan om dergelijke gegevens tot een hoger aggregatie niveau te brengen, met uitzondering van enkele resultaten van zorg.

Het Belgische systeem wordt gebruikt tot op het hoogst mogelijke niveau van aggregatie: het ministerie van Volksgezondheid.

Het formuleren van concrete doelen voor de gegevensverzameling en de verstrekking van de informatie is van groot belang voor de ontwikkeling en toepassing van verpleegkundige minimale data sets. Het primaire doel van het Nederlandse systeem richt zich op het management in ziekenhuizen. Omdat dit een hoger niveau is dan de individuele patiëntenzorg is selectie en aggregatie van items, en dus een keuze uit items en reductie van details, een noodzakelijke eis. Vanuit het perspectief van het primaire proces en vanuit onderzoek betekent dit dat een aantal relevante verpleegproblemen en interventies niet zijn vertegenwoordigd of dat wellicht voor dergelijke toepassingen details moeten worden toegevoegd. Het gebruik van 15 afdelingen over acht ziekenhuizen voor de ontwikkeling van de data set betekent bijvoorbeeld dat mogelijk niet alle belangrijke elementen zijn opgenomen die voor andere afdelingen belangrijk kunnen zijn. Kortom, het gewenste niveau van aggregatie bepaalt min of meer het aantal items dat verzameld kan worden en hoe minimaal de data set dus is.

11.7 Aanbevelingen

Dit laatste deel presenteert aanbevelingen voor het gebruik van de beschreven hulpmiddelen voor het informatiemanagement in de verpleging en de ontwikkeling van het verpleegkundige deel van elektronische patiënten dossiers.

- De criteria die via de Delphi studie zijn verkregen, inclusief het verpleegkundig informatie referentie model, dienen verder te worden ontwikkeld tot praktisch hanteerbare instrumenten.
- Het verpleegkundig informatie referentie model kan worden gebruikt om beleid op te stellen voor verpleegkundig informatiemanagement in de verpleegkundige professie en in instellingen voor gezondheidszorg.
- De twee overgebleven onderwerpen uit de Delphi studie, controle door management en de invoer van gegevens in het dossier door de patiënten zelf dienen nader te worden onderzocht.
- De huidige ontwikkelingen van een CEN / TC 251 standaard voor categoriale structuren voor verpleegkundige terminologie en het ISO voorstel om een referentie terminologie voor de verpleging te ontwikkelen zijn belangrijk om lokaal verschillende terminologieën en classificaties te kunnen gebruiken, waarbij toch op landelijk niveau gegevens vergeleken kunnen worden.
- Voor de Verpleegkundige Minimale Data Set voor Nederland moeten de volgende problemen worden opgelost:
 1. Vaststellen van de relaties tussen de verpleegkundige minimale data set voor Nederland en de tijdstudie gegevens.
 2. Ontwikkelen van een 'nationale map' via multi-dimensionele schaaltechnieken.
 3. De longitudinaal verzamelde data van de Verpleegkundige Minimale Data Set voor Nederland analyseren op het niveau van de individuele patiënt.
 4. De validiteit en betrouwbaarheid vaststellen in algemene ziekenhuizen.
 5. De hoeveelheid tijd die nodig is om de verpleegkundige minimale data set te verzamelen verminderen door het aantal items te verlagen of door automatische collectie uit elektronische patiënten dossiers.
 6. Verder onderzoek naar resultaten van verpleegkundige zorg, waarbij zowel de gegevens als de wijze van verzamelen ervan belangrijk zijn.

Het blijkt dat het in toenemende mate belangrijk is de verpleegkundige informatie en kennis te verwerken in elektronisch patiënten dossiers. De focus van verpleegkundige informatie systeem ontwikkeling moet daarbij zowel liggen op informatie management in het primaire proces als op het ondersteunen van beslissingen op verschillende niveaus op basis van geaggregeerde informatie. Daarmee kan een situatie worden bereikt dat de verpleegkundige informatie strategisch wordt gebruikt.