GTDS - A Tool for Tumor Registries to Support Shared Patient Care

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German hospital tumor registries play an active role in the treatment of cancer patients. Besides the documentation of the course of a disease, they directly support medical treatment and follow-up care over a long period. As the treatment of oncologic patients is a shared multidisciplinary task, the availability of information is one of the most valuable outputs. Therefore, the documentation has to be integrated into the medical treatment, which only can be achieved when useful services are based on it. Since 1983 the basis of the documentation has been a uniform basic data set which was revised in 1990 and, according to the requirements mentioned above, allows detailed documentation, especially of therapy. During the last four years a new documentation system for tumor diseases has been developed and was implemented in 30 hospital tumor registries by the "Arbeitsgruppe zur Koordination Klinischer Krebsregister". The so-called "Gießener Tumordokumentationssystem" (GTDS) is the basis of the work in those registries. In this paper the functions and services which were implemented in order to support the individual treatment of oncologic patients and the methods of collecting and delivering that information to the physician are presented.

INTRODUCTION

The treatment of malignant tumors is a task of increasing complexity which requires the cooperation of a variety of medical disciplines. Computers can support this process by providing patient data, comprehensive information and medical knowledge to the physician's desk. Several systems like OCIS[1] and ONCOCIN[2] have been successfully developed to support the management of patient care. OCIS and ONCOCIN both support patient care which is specifically related to the hospital. The requirements for the development of a broader integration of even regional cooperative services were discussed in the report "An Integrated Oncology Workstation".[3]

German hospital tumor registries play an active role in the treatment of cancer patients. Besides the documentation of the course of a disease, they support medical treatment and follow-up care over a long period. Their data are the basis for quality management and statistical evaluation. As the treatment of oncologic patients is a shared multidisciplinary task, the availability of information is one of their most valuable outputs. Therefore the documentation has to be integrated into the medical treatment which only can be achieved when useful services are provided. Since 1983 the basis of the documentation has been a uniform basic data set [4] which was revised in 1990 [5, 6]. In particular, the documentation of therapy was extended in order to meet the physician's interest in more detailed information and analysis, e.g., for quality assurance.

Since many of the documentation systems existing in the registries could not be adapted to this new data set, a new documentation system, the so-called "Gießener Tumordokumentationssystem" GTDS, has been developed [7, 8]. Design and development were influenced by a wide range of experiences made with various existing documentation systems. Thus, GTDS is not especially designed for a specific type of registry (e.g. registry for organizing follow-up care, registry limited to hospital needs) and therefore has a comprehensive functionality for many aspects of cancer patient care.

The "Arbeitsgruppe zur Koordination Klinischer Krebsregister" (AKKK), a central service group for evaluating data, training documentation staff and organizing congresses and scientific working groups in this area, developed the system and implemented it in 30 registries. A CASE tool (IEF from Texas Instruments) was used for the design of the data model.[9] The system is completely realized in an ORACLE environment using the tools SQL*Forms 3.0, SQL*Menu 5.0 and SQL*ReportWriter as frontends. From our point of view, this procedure gave us a maximum of portability and productivity at that time.

GTDS is mainly in use in the "new states", the territory of the former German Democratic Republic, where there was a well-organized comprehensive cancer care, e.g., in outpatients' clinics. This structure could not be preserved after the reunification of Germany, and the newly established registries try to compensate the lack of

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Table 1 - functionality of GTDS (including functions in experimental use * or in development **)

Integration of Data	Management of Follow-up Care	Management of Therapy	Management of Clinical Trials	Information Management	Electronic Data Exchange
diagnostic data and description and classification of the tumors site, morphology and stage therapy • surgery • radiation • chemotherapy follow-up data outcome possibility of registry specific and / or site specific extension	definition of treatment, trial and follow-up schemes (not restricted to follow-up care) automatic and manual scheduling reminders for patients and physicians individually adapted documentation forms supervision of returning documentation automatic inquiries about a patient's state reimbursement of documentation expense	definition of chemotherapy protocols calculation of individual chemotherapy courses overviews of cumulated dosages reminders in critical treatment situations (Arden Syntax) *	management data • addresses • branches • strata • eligibility criteria • patients automatic check of eligibility criteria (Arden Syntax) * support of the course (using features of follow-up and therapy management)	overviews • on-line • on paper • World Wide Web (WWW) * • using third party structures (REGKOM project) ** discharge letters	epidemiological cancer registries HL7 for communication in clinic network * / ** Behandlungs-Daten-Träger (BDT) for communication with physician's office systems / other registries * / **

communication. Whereas the first phase of GTDS was influenced by the need of the registries for documentation and communication, there is an increasing demand for integration into hospital information systems and use of the system during in-patient care now.

In the following, the functionality provided for supporting shared multidisciplinary patient care will be presented. First it will be shown, how GTDS supports the collection of the great amount of data which has to be integrated to become the information which is needed for effective patient care in oncology. Then the services to support treatment and follow-up care will be presented. Lastly the importance of the availability of information will be illustrated and the methods of delivering it to the physician's desk will be described.

THE ROLE OF INTEGRATING DATA

As mentioned above, the primary goal of German hospital cancer registries is to collect information about the whole course of the disease, including follow-up care. At present most of the documentation is carried out with paper forms upon which entries are made by registrars. Alternatively, registrars collect information from medical records. Each involved provider of medical care contributes his specific part of the documentation. In Germany in- and outpatient care are, for the most parts, completely separate. Generally, information about therapy is provided by physicians who are permanent staff in the hospital, whereas information about follow-up is collected by family doctors or practicing oncology specialists.

Thus, the documentation of a disease resembles a puzzle to which many people contribute their pieces of information and which forms a rather complete picture of the course of the disease in the end. A strategy is required for collecting and tracking a patient's data. Physicians are reminded of missing documentation forms concerning necessary follow-up observations. Family doctors are inquired about the patient's status when information is lacking for a given period and public registration offices are contacted when any medical information is missing.

When documentation is executed using paper forms there is often a delay until the information is available in the system and can be used for its intended purpose. Therefore, a communication interface was developed which allows the takeover of information already stored in other systems of the hospital. At present, admission, discharge, and transfer (ADT) data, diagnoses and medical procedures (surgery) can be transferred automatically via a Health Level Seven (HL7) interface. Thus, the expenses for entering data are reduced and the data are more readily available. The area of transferred

data is then expanded to laboratory, radiology and pathology.

The plan is that data from the physician's office outside the hospital can also be sent via a communication interface. As interchange format, the Behandlungs-Daten-Träger (BDT) is used, which is a national communication standard in physician's office computer systems in Germany. BDT will be used for the transmission of discharge letters, reports, follow-up data, etc. from the tumor centers to the physician's office system and viceversa. The first tests will begin in summer 1996.

The availability of integrated data enables a large number of functions to support the treatment of cancer patients during therapy as well as during follow-up care. On the other hand, the use of the data for treatment oriented tasks is a means to improve quality and correctness of the data, because incorrect data will not be accepted, e.g., in discharge letters.

SUPPORT OF THERAPY AND OTHER CLINICAL PROCEDURES

One important functionality in GTDS is the support of patient care within the tumor center. As indicated in table 1, there are a lot of functions which support planning and organizing chemotherapy.

Many tumor patients, especially when treated in university hospitals, participate in one or more clinical studies. A module is available which enables the user to keep track of the existing studies and the participant patients. It is planned that clinical trial data will also be stored and automatically exported to the clinical trial center.

The more complex the modern treatments of tumor diseases have become, the more important it is to be able to support a physician's work by reminders generated by computer systems [10]. Although it is not possible to check every critical situation in clinical treatment, it is often useful to be reminded of conditions which one could have failed to notice in the daily routine. Therefore a compiler for the Arden syntax [11] was developed and is being integrated into GTDS [12]. The first application of knowledge-based functions is focused on checking a patient's eligibility for special therapies or clinical trials.

Since all important oncologic information is stored in the GTDS database, medical reports, e.g., discharge letters can be generated, displaying an extract of all relevant information from the past and detailed information from the present, e.g., treatment. Due to the extensive availability of free text in the GTDS database, these letters can be automatically generated and printed or be imported into a standard text processing system.

SUPPORT OF FOLLOW-UP CARE

A standardized sequence of diagnostic measures in the post-therapeutic phase allows recognition of a relapse of the tumor at an early stage and makes a successful therapy possible. As indicated in table 1, GTDS offers various functions to plan and track a calendar of patient appointments for examinations or therapeutic interventions. The date, the place and the diagnostic measures of the next appointment can be calculated automatically, but can be individually adapted to the patient's situation by the physician. Overviews of the most important facts of the medical records are generated regularly.

THE ROLE OF INFORMATION

Because of the multidisciplinary character of oncology, communication and information are important for a high quality of patient care.

Due to the specific organizational structure in Germany there is a risk of losing information when the patient moves from the hospital to outpatient care[13]. On the one hand important details of the patient's treatment sometimes are not reported or are reported too late when the patient is transferred to his family doctor's care. This can result in delayed or inappropriate continuation of therapy or follow-up care. On the other hand, results of follow-up care carried out by the family doctor are often not reported to the providers of primary therapy. In particular, the lack of reporting negative results of therapy (complications, relapse) can result in an inadequate assessment of therapy strategies.

The complete documentation of the course of the disease and its availability to all participant physicians is a precondition for avoiding redundant or risky diagnostic and therapeutic steps.

BRINGING INFORMATION TO THE PHYSICIAN'S DESK

German hospital tumor registries actively support patient care by providing information. This information consists of patient data as well as general data such access to sources of medical information (Physician Data Query (PDQ),

CANCERLIT, MEDLINE) or to national standards or regional agreements.

Several ways exist to transmit available information to the physician's office. They range from on-line access to the database about providing electronic services to communication by conventional mail. The availability of various access methods is an important precondition for the integration of a registry into a regional communication network.

The most common method to provide information still is to regularly generate summarizing reports and send them to the patient's doctor.

In a hospital network physicians can directly access the GTDS user interface and use the implemented functions for displaying the stored information. Data confidentiality requires that only treating physicians be allowed to access patient data. GTDS is designed to be used in an environment in which many departments and outpatient clinics enter data into a single database. Patient data are stored in relation to the department, the physician or the medical user the patient belongs to and can only be modified by users of the same department. All departments which participate in the treatment of the patient are allowed to see the tumor specific data. Other departments are allowed to see the identifying data of the patient to avoid duplicate record entries, but have no access to the patient's clinical data.

As the present user interface is non-graphic only, few physicians are willing to work with the GTDS directly. A new graphical user interface is being programmed and the first reactions are positive. It has be taken into consideration that physicians are occasional users of systems who need a more sophisticated user interface than regular users like registrars. The first aim of the new design is the comfortable display of available information. This approach is to prepare and motivate physicians for documentation tasks while the documentation itself is still carried out by registrars. The next aim will be to provide possibilities for adding or modifying data, treatment concepts, plans, etc. directly by physicians, which necessitates the use of functions like planning follow-up care and calculating chemotherapy and the reports based on these entries.

External hospitals or departments which are not connected to the clinic network can access data using the public telephone net. Special encryption mechanisms ensure data confidentiality [14].

Shared patient care requires that on-line user access must not be the only possibility to access registry data or use specific functions. On the one hand, physicians may be familiar with existing departmental or ward systems but probably will not be trained or willing to use systems which only cover a limited portion of their patients. On the other hand, for data protection or confidentiality reasons there might be the need to restrict functionality or to forbid direct data entry. Besides the conventional methods mentioned above, there are several projects which deal with alternative methods. In a project with a commercial software manufacturer, a method was developed to call up GTDS services from a ward system and to display the result inside this system. At present the services consist of medical reports. The same method is used in the so-called REGKOM project which allows off-line communication with the cancer registry via EURO-ISDN implementing a high standard of access control and encrypted data transmission. In this project not only hospitals but also physician's offices are able to communicate with the GTDS in the registry. An additional issue of the REGKOM project is on-line access to medical or oncologic information sources.

The access to information sources requires some training and user interaction which often will not be accepted in the busy daily routine. A solution for this problem is to provide access keys to additional information together with patient information [15]. World Wide Web (WWW) browsers and servers are designed for linking information and are even useful when not connected to the Internet, which might be necessary for security reasons. Advantages and problems of using the Internet in respect to WWW browsers and servers as a medium for communication were discussed, e.g. in [15]. In our opinion, the main advantage of using these techniques is to implement a system-independent functionality which is available at low cost for every modern platform.

A scenario already experimentally tested is to provide the earlier discussed GTDS services as hypertext documents instead of simple ASCII files. Using the features of Hypertext Markup Language (HTML) the user will have the possibility of interactively requesting additional data or other services from GTDS such as chemotherapy planning or from general disease specific information sources like PDQ. As a first implementation the summarizing report was prepared in this way. GTDS provides a set of tables in which information sources and even external programs can be linked to specific clinical findings (e.g., topography and morphology

of a tumor). When the summarizing HTML report is generated, the appropriate information links to PDQ are included based on the patient data.

The main impediment to a widespread use of WWW-techniques in patient care is the problem of data protection and confidentiality. The German regulations of data confidentiality are very stringent. The proposals addressing security on the web in [15] are quite reasonable but it is doubtful whether they will pass the German requirements. Regarding the worldwide efforts to also use the Internet for purposes which require a high confidentiality, it can be expected that methods will be developed to guarantee sufficient control of user access and secure data transmission.

CONCLUSION

The "Gießener Tumordokumentationssystem" GTDS is a well-accepted most comprehensive system which is used in about 30 different tumor registries in Germany. It is especially designed for use in the context of multiple cooperating medical disciplines. Many functions and services are available to support the individual treatment of oncologic patients. One of the most important requirements in the multidisciplinary oncologic care is the provision of correct and complete information at the right time and in the right place. GTDS supports this process by taking over relevant data via a communication interface as well as by offering different methods to access data and services.

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