COMMENTARY

Standard Pediatric Oncology Data and Information Technology: Necessities for Cancer Care Management

Elham Maserat[1*], Mehrdad Mirza Rahimi[2], Elnaz Maserat[3], Mohamad reza Zali[4]

Abstract

    Cancer is the second leading cause of death in children and survivors require life time follow-up. There is a growing recognition of the need to base cancer control policies on accurate, detailed and timely information on cancer management and outcomes. Coordination and central documentation ensure quality of treatment and permit clinical and scientific investigations. The combined data thus obtained create a comprehensive picture of disease, leading to more effective prevention and cure. Medical information can be gathered, processed and analyzed in different ways and the importance of precise language cannot be overestimated. All medical activity arises from the ability to observe and communicate intelligibly and a lack of standardized documentation leads to insufficient integration of clinical work. The Minimal Standard data set is the result of a global effort to establish a common structure and vocabulary for electronic reports. In addition, information technology combines research aspects of decision support and clinical documentation, allowing formal representation of general protocols, calculating of a particular therapy for a patient, data acquisition in the clinics. Our aim in this papers is to stress the need for standard pediatric oncology data and information technology as an approach to cancer care management.

Keywords: Data set - pediatric oncology - cancer care - information technology

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Introduction

    Cancer occurs relatively rarely in children, but it is the second leading cause of death in children from ages 1 to 14 (Parkin et al, 1998; American Cancer Society, 2010). In the United States in 2007, approximately 10,400 children under age 15 were diagnosed with cancer and about 1,545 children will die from the disease (American Cancer Society, 2003). Although this makes cancer the leading cause of death by disease among U.S. children 1 to 14 years of age, cancer is still relatively rare in this age group. On average, 1 to 2 children develop the disease each year for every 10,000 children in the United States (Ries et al., 2004).

    Worldwide, the need is felt for life time follow up of survivors of childhood cancer and for the establishment of registries of the late effects of pediatric oncology treatments (Jaspers et al., 2000). The information generated by cancer registries has a wide variety of uses, in epidemiological research, in planning and evaluation of cancer control measures, and in monitoring some standards of clinical care (International association of cancer registries, 2010). Coordination and central documentation ensure the quality of treatment and permit clinical and scientific investigations. This kind of cooperation requires a vast amount of documentation, which by itself has become a

critical factor in answering important medical questions. The problems result from non-standardized documentation systems in different studies, from insufficient integration of clinical work and documentation and from a lack of application of modern computer based data management systems (Sauter et al., 1994). Researches show clearly the enormous impact that the use of health information technology can have on the quality of health care for children. However aim of this study is standard pediatric oncology data and information technology as approach for cancer care management.

Necessity of Oncology Data Sets

    There is a growing recognition of the need to base cancer control policies on accurate, detailed and timely information on cancer management and outcomes. With the development of the National Cancer Control program it is obvious that an integrated cancer information system, incorporating a national cancer dataset, is needed to provide detailed timely and consistent information across the country. This would ensure that the care received by cancer patients is consistent and in conformity with national guidelines; that information on trends in incidence, survival and mortality is readily available for planning and evaluation and that inequality in the

*[1]Educational Development Center, Ardebil Medical Sciences University [2]Research Center for Gastroenterology and Liver Disease, Shahid Beheshti University, (MC), Tehran, Iran *For correspondence : elhammaserat@gmail.com*
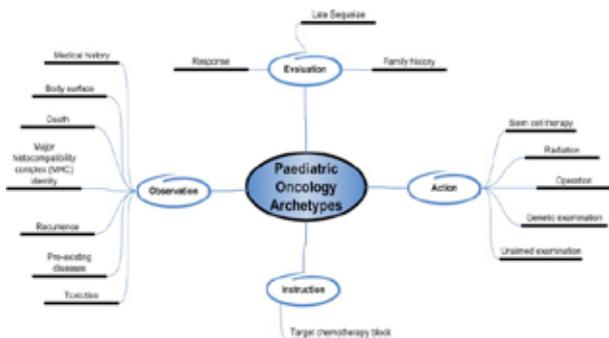
Figure 1. Pediatric Oncology Archetypes

delivery or outcome of services are quickly identified (Joe McDevitt et al., 2010). The minimum datasets for reporting tumors are used in the system of standard setting, data collection, audit and feedback for those involving in caring for these patients (Royal College of pathologists, 2000).

Pediatric Oncology Data Sets and Documentary Language

The documentary people are confronted with a variety of different forms; collect the same information many times in different ways. It is not only a major training effort is in the different documentation languages, including the electronic exchange of information with other application systems, the individual hospital information systems is difficult. Both factors can lead to a loss of quality of the information collected. To avoid these problems, there are numerous efforts, documentation systems and in particular the documentary language used within an organization or even to standardize across organizational boundaries (Silva et al., 1999). This also applies to the Pediatric Oncology. Since 1991, at various levels worked to unify the language of documentation within the therapy optimization studies (TOS) of the Society of Pediatric Oncology and Hematology (GPOH). A first result was published in 1994, the basic data set for the Pediatric Oncology (Sauter et al., 1994).

DOSPO

DOSPO or documentation System for Pediatric Oncology is currently provided by the Department of Medical computer science at the University of Heidelberg in cooperation with the GPOH. The computer-aided documentation system DOSPO to facilitate the documentation in the field of pediatric oncology developed (Knaup et al., 1999). In addition to the documentation of the basic data set of GPOH and the diagnoses and performance documentation in preparation for the DRGs, it offers clinicians support the calculation of chemotherapy and doctor's letter. The basic technical requirements for an electronic data export to the Children's Cancer Registry and the study centers were created in principle. Interfaces to exchange information with other computer-based application systems are in development in order to avoid double counting of data (A Merzweiler et al., 2002). DOSPO combines research aspects of decision support and clinical documentation: formal representation of general protocols, calculating of a particular therapy for a patient, data acquisition, communication interfaces for transferring the data to the trial centers (Wiedemann et al., 1998). Archetype is defined by adding data items of the appropriate type, binding data items to internal codes or terminologies like SNOMED CT (Sebastian Garde et al., 2007). Figure 1 was shown pediatric oncology archetypes.

Chemotherapy and Information Technology

Chemotherapy is the most important treatment available for childhood cancer. The chemotherapy planning process, however, is complex and time-consuming (Teich et al., 1996). Its correctness is crucial: due to the high toxicity of the applied cytostatic drugs, an error within the calculated therapy plan can lead to severe consequences. The process of calculating the chemotherapy is defined by therapy protocols. For these reasons, computer-assisted therapy planning can be of great value to pediatric oncology to provide correct and up-to-date calculation of dosages based on patient characteristics like age, height, weight, etc. Thus, an application system which acquires protocol knowledge, formally represents it, and-on this basis-calculates the individual therapy of a particular child is of particular value for pediatric oncology (Sebastian Garde et al., 2006).

Web-based Pediatric Oncology Information and Registries

Cancer registries have benefited tremendously from the use of databases and electronic data transfer. The use of the Internet is thus a natural evolution. The Internet offers great potential for bridging the knowledge gap. The instant availability of up-to-date information for medical

Table 1. Part of Main Classification of International Classification of Childhood Cancer, Third Edition (ICCC-3) Based on ICD-O-3

Site Group	ICD-O-3 Histology (Type)	ICD-O-2/3 Site	Recode
I Leukemias, myeloproliferative diseases, and myelodysplastic diseases			
(a) Lymphoid leukemias	9820, 9823, 9826, 9827, 9831-9837, 9940, 9948	C000-C809	011
(b) Acute myeloid leukemias	9840, 9861, 9866, 9867, 9870-9874, 9891, 9895-9897, 9910, 9920, 9931	C000-C809	012
(c) Chronic myeloproliferative diseases	9863, 9875, 9876, 9950, 9960-9964	C000-C809	013
(d) Myelodysplastic syndrome and other myeloproliferative diseases	9945, 9946, 9975, 9980, 9982-9987, 9989	C000-C809	014
(e) Unspecified and other specified leukemias	9800, 9801, 9805, 9860, 9930	C000-C809	015

practitioners can increase the speed of diagnosis. The availability of accurate cancer profiles in each country, resulting from work done by the national registries, can guide professionals to the most likely diagnosis, and help governments and private initiatives to direct their resources to treat cancer more effectively (André Nebel de Mello, 2010).

International Classification of Childhood Cancer (ICCC)

The classification of childhood cancer is based on tumor morphology and primary site with an emphasis on morphology rather than the emphasis on primary site for adults. The tables below provide the International Classification for Childhood Cancer (ICCC) definitions based on site and morphology coded according to ICD-O-2 or ICD-O-3. Table 1 was shown part of Main Classification of International Classification of Childhood Cancer.: le

Conclusion

The use of information technology by physicians in a pediatric critical care unit was associated with almost-complete elimination of medication prescribing errors especially in pediatric chemotherapy. Data managers can be trained to effectively collect basic pediatric oncology data. Addressing inadequacies in the medical record system while providing specific training in protocol-based care and determination of cause of death for both physicians and data managers will improve information and care quality.

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