

**Quality of cancer registration:
A needs assessment study
at Kasr Al Aini center of clinical
oncology**

Thesis

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«رَبَّنَا عَلَيْكَ تَوَكَّلْنَا وَإِلَيْكَ أَنَبْنَا وَإِلَيْكَ الْمَصِيرُ»

(الممتحنة: الآية ٤)

Abstract

Introduction: Medical records form an essential part of a patient's present and future health care. As a written collection of information about a patient's health and treatment, they are used essentially for the present and continuing care of the patient. In addition, medical records are used in the management and planning of health care facilities and services, for medical research and the production of health care statistics. In clinical oncology, much of the research is conducted in the milieu of patient care and the traditional medical record is used for collection of data.

Aim of the study: Assessment of the needs of the recording and information system at the center of clinical oncology in Kasr Al Aini university hospital as a step for improvement of quality of cancer registration to serve the needs of a comprehensive medical information system in Kasr Al Aini hospital.

Methodology: We do assessment of the needs of the recording and information system in the center and design a new medical record for data collection according to the standards through the following steps: analysis of the existing system and work flow through direct observation of the system in action, in depth Interviews of the center of clinical oncology members, review of the present medical records, then the requirements and problems of the existing manual recording system are identified and listed followed by designing a new medical record for data recording

Results: it is clear that almost all medical records in this center were incomplete in one way or another. This study revealed that lack of documentation of requested information, poor handwriting, and missing of medical records and absence of certain important forms in the medical records are prominent problems with paper based medical record system (PBMR) in this center.

Conclusion: Due to the low grade of completeness, availability, usability and compliance to the standards of the medical records in this study, it is believed that physicians at this center were not aware of the importance of the medical record as a crucial document for treatment and follow-up of their patients. Although the PBMR system might be more effective at bedside and can not be totally eliminated in the near future, it is necessary to find ways to ensure that the documentation of information will be in a readable and retrievable format.

Key words: Medical records, Information system, Data quality, Cancer registration.

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List of abbreviations

AAAHHC	: The Accreditation Association for Ambulatory Health Care
AHIMA	: American Health Information Management Association
AHR	: Automated Health Record
DFD	: Data Flow Diagram
DIMDI	: German Institute for Medical Documentation and Information
EHR	: Electronic Health Record
EMR	: Electronic Medical Record
EPR	: Electronic Patient Record
HIS	: Health Information System
HMIS	: Health Management Information System
HMN	: Health Matrix Network
ICD	: International Classification of Diseases
ICDO	: International Classification of Diseases of Oncology
IOM	: Institute of Medicine
ISO	: International Standard Organization
ISQua	: international society for quality in health care
JCAHO	: Joint Commission on Accreditation of Healthcare Organization
MECC	: Middle East Cancer Consortium
MOHP	: Ministry of Health and Populations
NCQA	: National Committee on Quality Assurance
PBMR	: Paper Based Medical Records
QA	: Quality assurance
QI	: Quality improvement
QM	: Quality management
SEER	: The Surveillance, Epidemiology and End Results
TNM	: Tumor, Lymph Node, Metastasis
TQM	: Total quality management

US : United State
WHO : World Health Organization.
WWW : World Wide Web

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Introduction

To direct our efforts in cancer control and prevention, we need a broad base of information about cancer patients, such as how the disease is diagnosed and treated, and the outcome. The systematic collection, recording, and analysis of these data provide a fund of information that may be used to identify subjects for clinical and epidemiological research. The value of cancer patient data is enhanced when numbers of cases can be grouped to reveal patterns that may not be obvious from a small number of cases. (SEER, 1999)

In clinical oncology, much of the research is conducted in the milieu of patient care and the traditional medical record is used for collection of data. (Dearth, 2006)

Medical records form an essential part of a patient's present and future health care. As a written collection of information about a patient's health and treatment, they are used essentially for the present and continuing care of the patient. In addition, medical records are used in the management and planning of health care facilities and services, for medical research and the production of health care statistics. (WHO, 2006)

Unsystematic organization and partial or inaccurate completion of medical record can lead to frustration, debate, clinical misadventure, and litigation. Many clinical accidents arise as a result of poor medical notes. (The Audit Commission, 2008)

As pressure to improve the quality of doctors' practice and hospital services grows, with ever-increasing expectations and costs of medical care, well structured and complete clinical records are becoming increasingly important, (Pullen, 2004)

Egypt has had an increase in chronic disease burden, including cancer, so cancer registries are urgently needed in developing countries including Egypt because the cancer burden is poorly known. To fight this burden, the extent of the cancer must be known so that programs for cancer control can planned efficiently, not only to implement standards of care but also to define prevention strategies.

Studying the magnitude and pattern of cancer would be the first step in determining clues to the cause of cancer and having a baseline to plan and assess control measures. Epidemiological studies based on this findings help knowing what is happening and what can be done a bout it. Cancer registries provide the needed information to undertake such investigations. (Gharbia cancer registry, 2002)

The value of these registries strongly depends on the quality of the data contained in the registry (Arts, 2003)

Inadequate registration and utilization of information will affect the quality of care and limits the use of information for supervision; monitoring and evaluation of performance to improve care; our objective in this study is to assess the needs of the recording and information system at the center of clinical oncology in Kasr Al Aini university hospital as a step for improvement of quality of cancer registration to

serve the needs of a comprehensive medical information system in Kasr Al Aini hospital and to help the service providers and decision makers to enhance the quality of cancer care.

Aim of the study

Assessment of the needs of the recording and information system at the center of clinical oncology in Kasr Al Aini university hospital as a step for improvement of quality of cancer registration to serve the needs of a comprehensive medical information system in Kasr Al Aini hospital and to help the service providers and decision makers to enhance the quality of cancer care.

Objectives:

1. Analysis of the existing record system and work flow
2. Identification of the requirements and problems of the existing manual recording system
3. Designing a new medical record for data recording.

HEALTH INFORMATION SYSTEM

Many avoidable shortcomings in the health sector that result in poor quality are due to inaccessible data, information, and knowledge. Health information systems offer the connectivity and knowledge management essential to correct these shortcomings. Better health and a better health system are within our reach. (Detmer, 2003)

Reliable and timely health information is an essential foundation of public health action and health systems strengthening, both nationally and internationally. This is particularly so when resources are limited and funding-allocation decisions can mean the difference between life and death. The need for sound information is especially urgent in the case of emergent diseases and other acute health threats, where rapid awareness, investigation and response can save lives and prevent broader national outbreaks and even global pandemics. (HMN, 2008)

The health information system acts as a backbone to the different levels of national health system and work (Nasar et al, 1993), hospital information systems are one of the most important parts of the national health information system (Blum, 1986).

Definitions:

System A collection of components that work together to achieve a common objective. (Lippeveld, 2000)

Information System A system that provides information support to the decision-making process at each level of an organization. (Hurtubise, 1984)

Health Information System is a set of components and procedures organized with the objective of generating information necessary to improve health services effectiveness and efficiency

through better management at all level of health system (Lippeveld, 2000)

Health Management Information System: An information system specially designed to assist in the management and planning of health programmes, as opposed to delivery of care. (WHO, 2004)

As the health information system is dealing with processing of data, information and knowledge therefore, understanding of the terms: data, information, knowledge, and wisdom are essential to understand health care informatics (Hovenga, 1999)

While some writers make no distinction between data and information (Wang et al., 1998; Huang et al., 1999; English, 1999), some others see the difference as most crucial (Tozer, 1999).

Data, information and knowledge are seen as a hierarchical structure (Devlin, 1999).

Data are those a codified and communicable symbolic representation of entities, properties and their states They have content (representation) and form (record) that allow storage retrieval, transfer, aggregation, and analysis. Data can turn into information if they are put into a context and given meaning. (lillrank 2002).

Information is processing of data to produce meaning. Many techniques are used to process data including classifying, sorting, organizing, summarizing, calculating and graphing. This can be done by using some tools as pencils, papers and computers. Processing prepares data so that they can be interpreted. The actual interpretation of the data is a cognitive process by which data are given meaning and become information. This cognitive process is affected by several factors including education, attitude, emotions, and goals influence, so each individual gives a unique interpretation