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Towards Enhancement of Cancer Registration at a Clinical Oncology Center in Cairo: How to Start?

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***Abstract*— Identification of problems facing medical records can provide useful insights for strengthening the system in low income resource countries. Objective: This study aimed at assessing the needs of recording and information system at a clinical oncology centre in Cairo. Methods: Operational research followed three steps needs assessment namely; analysis of work flow through direct observation of the system, in depth interviews of the staff, review of records. System flow chart was developed; the requirements and problems of the existing manual recording system were identified and followed by a preliminary intervention to enhance the current system. Results: Nearly all records were incomplete; lack of documentation of information, poor handwriting, and missing of records and absence of important forms within the records were the prominent problems with paper based record system (PBMR). The most completed records contained 65 items (out of 74) and the least contained 17 (mean/SD= 36.3±9.6) . Action plan was provided with provision of a new prototype for data recording provided a standard format for PBMR and serving the purposes of cancer registry. Conclusion: Low grade of completeness, retrieval, usability and incompliance to the standards characterized the PBMR recording system used for cancer registry of an Egyptian oncology center.**

***Keywords*—** Cancer, Data quality, Information system, Medical records.

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I. INTRODUCTION

Improved accuracy and completeness of cancer registration data impacts all areas of public health interventions. Data also provide baseline measures and performance measures for cancer-related interventions designed to reduce cancer incidence or improve early detection.[1] 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 [2] Approximately 20 million people are alive with cancer at present; by 2020 there will probably be more than 30 million. Cancer is one of the leading causes of death in the world; particularly in developing countries [3] Cancer surveillance is a complex system that captures longitudinal data from multiple data sources using a variety of methods. In addition to recording the occurrence of each reportable cancer (or tumor), the reports provide information to public health central cancer registries on the diagnosis, treatment and vital status. Reporting requirements may vary by hospital [1] The goal of a health information system is often narrowly defined as the production of good-quality data. However, the ultimate goal is more than this. Health information system produce relevant information that health system stakeholders can use for making transparent and evidence-based decisions for health system interventions [4] 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. Medical records form an essential component 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. [5] For any health information system to function, various policies, administrative, organizational and financial prerequisites must be in place and thus challenges do face the process. On top of which are the irrelevance of the data collected as it tends to focus on disease reporting and only partially addresses management objectives at the health unit level or at the

patient/client level. Yet, data that are needed are frequently not collected.[6]. Also, poor quality of data is considered a major challenge as data requirements are frequently chosen without taking into account the technical skills of the health workers collecting the data. [7] Furthermore, health workers receive little if any training about data collection methods and definitions of data items, and rarely have standardized instructions and guidelines on how to collect the data, this is coupled with lack of motivation to comply [8]. Since health services supervisors rarely receive feedback on the data reported to higher levels, they have little incentive to ensure the quality of the collected data and to comply with reporting requirements.[9] A major challenge is also the lack of timely reporting and feedback as outdated information, even if of high quality, is of low value to them.[6] To ensure appropriate functioning of information system it is recommended wherever possible starting the modification process should build upon existing initiatives, systems and knowledge. [2] This study aimed at assessment of the needs and requirements of the information and record system of a clinical oncology centre in Cairo as a step for developing a comprehensive information system to help the service providers and decision makers enhancing the quality of cancer care. The study also aimed to provide a prototype on how to the build up on exiting systems.

II. METHODS

Setting and design:

The study was conducted at a clinical oncology centre in Cairo. The center is composed of five units which are served by four outpatient clinics; two inpatient wards, a radiotherapy and a chemotherapy section. The study was an operational research in which system analysis was first done followed by the three main steps of needs assessment including : analysis of the existing record system and work flow; identification of the requirements and problems of the existing manual recording system and finally providing and implementing solutions for the existing situation.

Procedures: Study phases, tools, and sample:

The first phase: Included assessment of the current system available and the present situation with all its strengths and weakness. This was carried out through the following stages:

a- Direct observation of the system in action: Site visits to the oncology center were conducted to observe and record the client flow cycle and data flow cycle from admission till discharge (system flow chart).

b- In depth Interviews of the center of clinical oncology members:: Semi-structured questionnaires were used while interviewing the center of clinical oncology chairman, physicians, and nurses. The questions addressed their opinions about the current medical record used in reporting the patient's data, the presence of policy and procedures that document the current recording system, the problems and needs of the current recording system, information exchange between the staff throughout the process of patient's management and their expectations regarding the future recording system. The interviews were applied on a convenient sample composed of the chairman of the clinical oncology center, 2 consultants, 10 residents (out of 15 residents) in addition to 8 nurses (out of 16 nurse).

c- Review of the present medical records: Medical records were reviewed for the completeness of the records and the compliance to the standards of Egyptian Health Care Accreditation Organization standards for information management in hospitals; the World Health Organization recommendations for medical records development and the SEER program (The Surveillance, Epidemiology and End Results program) recommendation for cancer registration and to explore the strengths and weaknesses of the current system and to identify the needs of the current medical record. A checklist was used to review the completeness of records of 200 patients that had been admitted throughout the period of three months. The checklist was designed based on the standard medical record used at the center of clinical oncology, in this checklist; there was a place for every requested item in the medical record. If the requested information was registered in the sheet correctly, a check mark was consequently placed in the checklist for that specific item and take score 1 and if the item is not recorded, it take score 0.

The second phase: Included identification of the requirements and problems of the existing recording system based on the qualitative and quantitative data collected from the observation of the system in action, the interview with the staff of the center and review of the records, the needs of the current recording system were identified and listed.

The third phase: Setting the priority required action plan based on the information derived from direct observations of the present information system, interviews with the members of the clinical oncology center, reviewing the patients' records as well as comparing the current forms with the Egyptian Health Care Accreditation Organization standards.

Data management and analysis:

The collected quantitative data were analyzed using SPSS version 12.0. Simple frequencies and the percent completeness of every item in the 200 reviewed detailed clinical records were reported. To facilitate the interpretation of the results; we categorized the data of the sheet into the following ten main items with several sub items under each as follows: administrative data: (n=5), the identification data (n=9), the history data (n=5), the menstrual history data (n=9, of the total 200 reviewed record there was 122 records for female patient for which the menstrual history data were reviewed), the general examination data (n=16), the local examination data (n=10), the investigation data (n=4), the diagnosis data (n=5): and lastly the case summary data: which contain (n=14). Each category was given score from 0 (if no item was recorded) to 2 (completed record) while 1 assigned to partially completed recorded item. To produce an overall assessment of the completeness of the records a scoring system was developed based on the calculation of the number of completed items in every record (after exclusion of menstrual history data), the standard record should contain 74 sub-items, if the sub-item is

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recorded it was assigned a score of 1 and nil if not recorded, then the mean, standard deviation were estimated for this sample of records. For qualitative data namely those collected through the in depth interviews, the results were displayed in a narrative form and percentage were used to highlight the reached out come codes and themes.

III. RESULTS

Identification of the requirements and problems of the existing recording system: Based on the qualitative and quantitative data collected from the observation of the system in action, the staff interview and review of the records, the needs of the current recording system were identified and listed. It was clear that nearly all records at this center were incomplete as shown in table (1). Overall assessment of the completeness of the detailed clinical record revealed that the standard clinical record should contain 74 sub-items, in our sample the most completed records contained 65 recorded sub- items and the least completed records contained 17 recorded sub-items. The estimated mean score for completeness was 36.3, while the standard deviation was ± 9.6 and the mode was 43. The qualitative analysis of the present system requirements and problems were identified and could be summarized in the following points:

a- Completeness of the records was one of the most prevalent problems; many items in the detailed clinical records were missed as shown in table (1), and 70% of the interviewed physician mentioned that they never complete all items of the record but they usually complete some items only. b- The illegibility of entries in the medical records**:** Poor hand writing was one of the most encountered attribute of the current paper based medical record system as most of the retrieved items in the medical record were illegible except some papers of the diagnostic tests were computerized and legible. Most of the interviewed physicians and nurses considered poor hand writing is an important problem facing them and interfere with the ease of use and retrieve of the records. c-The availability of the records: The current records keeping system does not protect them from loss or unauthorized access or use. Patients' records were kept in the residents room after discharging of the patient for a period of time before it is delivered to the archive where were piled till patients' next admission. In the resident room there is no special closed place for the keeping of these records with liability to become available for unauthorized access and use. Seven of two hundred reviewed records were lost and new records were re-issued. All physicians and nurses interviewed reported the problem of storing and retrieving patients' medical records with spatial and temporal hinders accompanied these processes especially with frequent patients' admissions. d- Absence of certain forms: Some documents within patient's medical records had no specific forms and the resident had to write it on any white paper as a referral, and progress notes, the consultation request, and the discharge summary sheet. e- Absence of policy and procedures document the current information system: There was no written policy and/or procedures to document the current system, defined the confidentiality and security of information, protecting them from loss or damage, or retention over time.

Compliance of the present record system to the standards: Detailed assessment and comparison of the existing recording system with the Egyptian Health Care Accreditation Organization standards to explore the strengths and weaknesses of the current system was conducted and revealed the following findings:

a- Strengths of the current system: The presence of the unique identifier for each patient evaluated and treated. (The unique identifier used in the center is the registry's number not the hospital number). Each medical record should contained sufficient information to ensure the following: Identification of the patient, including name, address, and age; support to the diagnosis; as well as justification to the treatment; documentation of the course and results of treatment. The nurses document directly in the patient medical record. The diagnostic and therapeutic orders are signed by the ordering practitioner. The results of diagnostic tests are documented in the patient medical records within a defined timeframes. All treatment are documented and signed by the person providing the treatment. The medical records for the discharged patient are completed within 30 days. The medical record forms are familiar to the clinical oncology center residents and nurses.

b- Weaknesses of the current system The following points were spotted: not all entries in the medical records are dated; authors of all entries in the medical record cannot be clearly identified by name and title; not all entries of the medical records are legible; the closed medical record does not contain a discharge summary; there is no referral sheet form and no copy is kept in the patient medical record; the organization has no systematic process for review of the medical records including review of the completeness and legibility of entries; and finally was no any written policy and procedure to define and document the current information system .

Table [1]. Percent distribution of degree of completion of the categorized items of the reviewed records, Cairo Oncology Center, Egypt.

Data Categories	Completeness: No. | %						
	All sub-Items Completed		Some sub –items partially completed		All sub-Items Not recorded		Total examined records
Administrative data	0	0	200	100	0	0	200 (100%)
Identification data	1	0.5	199	99.5	0	0	200 (100%)
History data	139	69.5	61	30.5	0	0	200 (100%)
Menstrual history data	0	0	77	63.1	45	36.9	122* (100%)
General examination data	1	0.5	169	84.5	30	15	200 (100%)
General examination data	1	0.5	169	84.5	30	15	200 (100%)
Local examination	51	25.5	114	57	35	17.5	200 (100%)

data							
Investigation data	103	51.5	78	39	19	9.5	200 (100%)
Diagnosis data	26	13	171	85.5	3	1.5	200 (100%)
Treatment data	1	0.5	199	99.5	0	0	200 (100%)
Case summary data	0	0	0	0	200	100	200 (100%)

Designing of a new medical record for data collection:
Based on the information gathered from direct observations of the present information system, interviews with the members of the clinical oncology center, reviewing the patients' records as well as comparing the current forms with the Egyptian Health Care Accreditation Organization standards, a new medical record was developed to meet the needs of the system. The new medical record was developed based on: 1- Modification of the present medical record by excluding some irrelevant variables, and adding some variables according to: the clinical oncology center staff recommendations; to meet the requirements of Egyptian Health Care Accreditation Organization standards for information management in hospitals[10]; the World Health Organization recommendations for medical records development[11] and the SEER program (The Surveillance, Epidemiology and End Results program)[12] recommendation for cancer registration. *2*- The new medical record is composed of different sub-forms as follow: *the hospital admission request*; *the detailed clinical record* which included (front sheet for identification and summary sheet; admission notes sheet contains sections for history, general and local examination, investigation, protocol of treatment; chemotherapy sheet and /or radiotherapy sheet; a summary of chemotherapy and /or radiotherapy; the consents for radio and chemotherapy; and follow up sheet); progress note sheet; case summary sheet; referral sheet; discharge summary sheet; consultation request; medication record sheet; medication doctor instructions sheet; nursing notes and finally nursing assessment sheet..

IV. Discussion

This study assessed the needs of the recording and information system in one of the Cairo clinical oncology centers to identify the requirements and problems of the system as a step for improvement of data quality in cancer registration to serve the needs of a comprehensive medical information system helping the service providers and decision makers to enhance the quality of cancer care. The assessment of the needs of the current system was done through a comprehensive situation analysis of the recording and information system in the clinical oncology center, and identifying areas of strengths and weaknesses in the system by direct observation of the system in action, interviewing personnel involved, and review of records**.** Health information system strengthening must start with a broad-based assessment of the system's own environment and organization, responsibilities, roles and relationships; and of the technical challenges of specific data requirements.[3] It is believe that the most important aspect is to relate information needs to interventions with focus on how information generated could be used and influence local decisions. [13] While considering the 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, missing of medical records and absence of certain important forms in the medical records are prominent problems with PBMR system in this center. The completeness of the records is one of the most important problems of the records; many items in the detailed clinical records were missed , and most of the interviewed physicians and nurses said that they never complete all items of the record but they usually complete some items only, the incompleteness of medical record is mostly due to high workload and the big time needed to complete these records, in addition to the unawareness of the physicians and nurses about the importance of completeness of medical records. What would happen if the present incomplete PBMR system continues to be used at the center? If physicians are not able to find needed information from the medical records, they will most probably try to repeat examinations and laboratory tests, which in both cases would waste time and money for the center, physicians and patients. The medical records are not only used for treatment purposes, but are also considered as a source of information for research and education. At hospitals, physicians might be also responsible for conducting research, and sometimes the medical records are the only source of information, and incomplete Medical Records could affect the results of the researches [14]. Ornstein, et al in 2004 revealed that consequence of missing information causes repeating of diagnostic test and procedure, and delays in treatment. In addition, paper records cannot provide reminders, nor can they provide real-time decision support for practice guideline and other actions.[15]. The presence of a process for systematic review of the records by the staff and proper training of the physician a bout the importance of completed medical records can solve this problem, this goes in accordance with Mark Porcheret, et al 2004 who said that developing a program for repeated assessments, feedback, and training appears to improve data quality in a range of practices. Health workers receive little if any training about data collection methods and definitions of data items, and rarely have standardized instructions and guidelines on how to collect the data. [8] Also most of interviewed physician and nurses consider the poor hand writing of the items of the records is an important problem facing them and interfere with the ease of use and retrieve of the records, some of them suggest computerization of medical records to insure legibility of entries in records and other suggest if there is some sort of predefined tables or checklists could be designed and be filled in only by check marks. Poor hand writing make retrieving of information is almost impossible. It indicates that if a machinery system was in place (i.e. EMR system) that could probably improve quality of Medical Records in terms of readability. [14] In this study we found the absence of formats for some important forms in the medical record and the resident had to write it on any white paper as the referral sheet, the progress note sheet, the consultation request, and the discharge summary sheet without any standardization for the contents of these sheets. The medical, financial, administrative and operational data are essential; these data are frequently collected and or presented to

the user via forms. Inefficiencies in the forms design or maintenance may occur because of the large number of forms utilized by multiple users with different needs. Inadequate data collection, laxity in documentation, duplication of effort and mistakes could result from poorly designed forms. So every health care facility has the responsibility to provide forms to fit its needs. If forms are not well designed, the collection of data could be affected, resulting in poor quality data [16]. Moreover there is absence of complying to the standards with the absence of written policy and procedures to document the current system. The policy in which health information is generated and used are important as they enable mechanisms to be established to ensure data availability, exchange, quality and sharing. Legislation and regulation are particularly significant in relation to the ability of a health information system to draw upon data from the private and public health services, as well as non-health sectors. Particular attention to legal and regulatory issues is needed to ensure that non-state health-care providers are integral to the health information system, including the use of accreditation where appropriate. Existence of a legal and policy framework consistent with international standards enhances confidence in the integrity of results. A legal framework can also define the ethical parameters for data collection, and information dissemination and use. [3]. It seems that there is a gap between what physicians and nurses have learned and what they do in practice in terms of medical records. To solve this problem, they should attend workshops or courses after graduation to get more training and information about the importance of complete Medical Records. [14]. Also healthcare professionals need to be aware of, and comply with, standards. House officers should be given information about standards at departmental induction or during medical training. [17]. Analysis of the existing recording and information system in the center of clinical oncology and identification of the requirements of the users and problems of the system help us in developing a new medical record for data collection. Clinical data items needed for proper management of the patients and the policy maker were identified, listed and unified through reviewing of the records, interviewing the involved personnel and observation of the system. Another study [18] also noted the importance to identify needed data elements, identify how these data are collected, and determining whether additional elements are needed to support the desired functionality. Logical ordering of items in the form was defined to simulate the order by which the physician proceed with the patient examination. To be able to follow the standard guidelines the system should be based on a structured design with maximal simplicity to ensure cooperation from physician and force them to answer multiple choice questions, aiming at collection of only relevant data essential to evaluate the patient and help in decision making. [19]. Data are limited to a selection list whenever possible to overcome forgetfulness and allow for standardization. This is supported the statement quoted "Examination variables are best recorded as structured data, choosing from various entries on a list or table [20] Modification of the present medical record by excluding some irrelevant variables, and adding some variables according to the clinical oncology center staff recommendations to meet their needs was done. The already present medical record of the center was one of the bases to build on the new one, this deal with the recommendations of W.H.O. in developing new recording system which said “Do not destroy existing systems; build on the strengths and learn from the weaknesses of what already exists”. [21] The Egyptian Health Care Accreditation Organization standards for information management in hospitals: these standards are accredited from the international society for quality in health care (ISQua) [22]. In 2007, these standards provide both a significant challenges and a roadmap for everyone to work collaboratively to achieve quality performance in health care. [10] Implementing a national standard for structure and content of the clinical record should provide immediate benefit by improving ease and accuracy in communication of clinical information, and the quality and safety of patient care, as well as enabling more accurate clinical coding. Homogeny across patient records will also be associated with significant benefits in relation to the implementation and audit of adherence to evidence-based practice guidelines. [10] The World Health Organization recommendations for medical records development [11] as well as the SEER program standards for cancer medical records [12] were also, revised as it was important to use the forms present from a common reference information model. A common set of data elements, a common terminology, common data structures, and a common transport standard can help sharing of data between independent sites and support the exchange of such data [24] The most important forms that were not present in the current medical record and were required by the standards were the discharge summery sheet and the referral sheet in addition to the new admission request sheet. Discharge notes is a crucial piece of evidence regarding the inpatient treatment of a patient. It is important to give a proper discharge summary as this is the summary document that will be kept by the patient which reflects the treatment received. A copy of this must be preserved in the case file for future use if required. Discrepancies in the summary given to the patient and what is kept in the hospital records can cause suspicion about tampering with the medical records. These discrepancies should be avoided at all costs as the benefit of this usually goes in favor of the patient [25] Referral notes are an important component of patient records. They should include the date and time of issue, the patient's general condition, cause of reference, and the course of action to be taken. It is wise to keep a duplicate copy of the referral note with the patient's signature. The fact that the patient did not go immediately on reference as advised could be proved by the duplicate copy of the referral note kept by the doctor. This could save a doctor who could be sued for alleged late referral after the patient's condition deteriorated. [25]. 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 [26] Whenever clinical records with standardized structure and content are in routine use, data can be extracted for research purposes. This could potentially open the doors to the establishment of evidence for best practice in clinical areas for which there is currently none [23] Periodic needs assessment and

monitoring of the work plan is mandatory through systematic methods to ensure that the documentation of information will be in a readable and retrievable format. Therefore, a process for systematic review of the medical records at least quarterly that include a review of representative sample of all disciplines and staff should be established. Checking procedures should be a part of the design of an information system; this is one of the most cost effective methods to improve the quality of data. Proper training and follow up of the physician is essential to improve quality of performance, they should attend workshops or courses after graduation to get more training and information about the importance of complete records, training is crucial for improving the quality of data, training should cover the information system itself, data collection tool, data processing, analysis and decision making. The archiving system of the records should be reviewed by the center, the medical record should be readily available to all practitioners who encounter the patient in the proper time, access to the to the medical record should be provided only to those who have been authorized by their department, Records shall not be sequestered in places such as lockers or desks or in any other way made unavailable for immediate access.

V. CONCLUSIONS

A great deal of low grade of completeness, availability, usability and compliance to the standards of the medical records was found while assessing an Oncology care center in Cairo, Egypt. Although the PBMR system might be more effective at bedside and cannot be totally eliminated in the near future, it is necessary to find ways to build up on the existing systems**.**

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