**Workflow in a pediatric neuro-oncology center**

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**Abstract**

**Introduction:** Medical workflow is defined as task, process and medical staff working together in a specialized multidisciplinary team to deliver proper healthcare and achieve patient satisfaction with good experience [1]. The Healthcare setting is a complex and dynamic environment as many tasks may be interrupted, paused, performed simultaneously, or may be dependent on other tasks or medical staff. As such, tasks are rarely completed in a linear, stepwise way. In many settings, medical staff manage the care of multiple patients at once [2].

Central nervous system tumors are the most common solid tumor in the pediatric age group, and the second most common tumor after leukemia, it represents 15 to 20% of all childhood neoplasms [3]. Regarding cancer-related death in the pediatric age group, brain tumors are the most common cause [4].

Incidence of pediatric CNS tumors ranges from 1.15 to 5.14 cases per 100,000 children, with the highest rate reported in the United States and this may be on account
The availability of screening and high diagnostic tools
The optimum management of pediatric brain tumors requires a multidisciplinary team consisting of a neuroradiologist, pediatric neurosurgeon, pediatric neurooncologist, and radiation oncologists. The availability of advanced surgical instruments including high magnification microscopes, navigation system, intraoperative ultrasound and endoscopy improves surgical outcomes.

There is a significant discrepancy in healthcare resources between high income and middle to low-income countries. This is reflected in the 5-year survival rates for pediatric brain tumors:
For the US, the 5 years progression free survival to 70–80% [7]; the 5-year relative survival rate is 76.7% (95.4% for non-malignant tumors and 64.7% for the malignant one); in middle- and low-income countries 5 years overall survival ranges from zero to 40% [7].

To address overcome this problem dedicated pediatric oncology centers were established in middle- and low-income countries. An Example is Children’s Cancer Hospital Egypt which aims to provide the most updated diagnostics tools, latest equipment, technology, evidence-based practices, and treatment services including all oncology department; surgery, chemotherapy, radiotherapy, bone marrow transplant, multi-disciplinary clinics, physical rehabilitation, socio-psychological care, palliative care, and in-house schooling.

To improve the health care and reach the hospital vision, four objectives were focused on: encouraging research and development capabilities, improving caliber of healthcare professionals, increasing hospital capacity, and lastly enhancing supportive services for the patients and accompanying families. Today, after 11 years of operation the hospital is recording a 73% average over-all survival. It has become a flagship institution for fighting childhood cancer [8].

The pediatric population diagnosed with cancer in Egypt is approximately 12.8 per 100,000 (2012), with an annual growth rate estimated at 1.3% [9]. A total 1114 cases were diagnosed with CNS tumors in Children Cancer Hospital Egypt in the period between July 2007 and December 2013.

In this review, we will discuss the workflow of a neuro-oncology center regarding the vital component infrastructure and resources to maintain patient quality of care with optimum clinical outcome.

**Mapping pediatric neuro-oncology patient journey**
The first step in activating workflow is to plan and map the pediatric neuro-oncology patient’s journey through the hospital as each step directly affects the patient’s management plan, treatment, and regular follow up [10].

**Screening for admission to the hospital**
**Entry protocol**
On arriving at the pediatric cancer hospital, patients are registered by medical secretaries and booked according to appropriate and available patient screening clinic.

Preliminary clinical review is performed by specialized nurses then followed by another clinical evaluation by an Oncologist who is then assigned as the primary consultant.

Once the oncologist has established a diagnosis of CNS tumor, referral to consultant pediatric neurosurgeon is done to determine the pathway of the case according to its urgency. The neurosurgeon performs his clinical evaluation and reviews the imaging studies. Then makes a determination whether immediate or urgent or deferred admission is required or not for surgical intervention [11]. If no surgery is needed the patient is referred to the primary oncologist consultant as in cases of diffuse brain stem gliomas and chiasmal gliomas which are treated by radiotherapy and chemotherapy, respectively [12, 13].

When the neuro-oncology pediatric center does not have the clinical capability to provide the needed services either due to hospital congestion or unavailability of places, the patient is transferred, referred, or assisted in identifying sources of services to meet the patients’ needs [11, 14].

**Admission to the hospital**
The hospital has an integrated in house process for the workflow of pediatric neuro-oncology cases that includes admitting inpatients (journey from admission point until discharge) [15].

After evaluation each case in the outpatient clinic [16], cases are either directed to emergent hospital admission or elective hospital admission office.

**Emergent hospital admission**
Is indicated for neuro-oncology cases that require urgent surgical intervention, e.g., cerebrospinal fluid diversion in posterior fossa tumors presented with hydrocephalus or cases that require admission for monitoring clinical picture until availability of major operating list like life-threatening tumors or cases with neurological deterioration [17].

**Elective hospital admission**
This is as per the neurosurgeon request based on an available bed according to the waiting list, e.g., low grade tumor without mass effect or neurological deterioration.
During admission family and patient are provided with extensive information on the treatment plan and outcome from both medical staff and social specialist. This information must be documented in patient records. Orientation to hospital environment and its equipment also ensures the safety of patients and family. Receiving such information allows the families and guardians to make informed decisions on the treatment plan and financial obligations if any [18]. To maintain optimum workflow in the hospital requires proper coordination of patient through put in different hospital sectors: labs, radiology, operating rooms, intensive care units and availability of hospital beds [15, 18].

**Measures to prevent congestion in the hospitals**

**Time of discharge**
The strategy of planning a day ahead for patient discharges and coordinating this with the admissions office helps to decrease patient congestion and optimizes patient throughput [19].

The result of this model was dropping the period of the overall stay and readmission process [20].

**Spreading proven model**
To prevent congestion in the hospital and provide safe, high-quality care for each child with CNS tumor many models have been studied, the number of new discovered cases coming to the hospital per day should be analyzed to provide for them adequate number of stuffs, available beds for admission if required. Each hospital has a peak and valley in patient flow so establishing dynamic stuff pools to fill the gap during hospital peak is so important. Increased patient volume without available stuff increase the incidence of harming the patients, average long stay and rate of infection with readmission [21, 22], scheduling patients admission is the key to smoothing workflow in the hospital by maintaining same peak all the time, by applying this artificial peak through elective admission prevent occurring the valley at any time, this methods requires separating hospital resources for the 2 types of admission elective and emergent in wards and operative rooms, ensuring that a number of elective cases is admitted each day this methods is applied in many hospital, e.g., Johns Hopkins, Cincinnati Children’s, and the Mayo Clinic in Florida [23].

**Centralization of caseload**
One of the most important factors to prevent congestion and improve the outcome in pediatric neuro-oncology center is surgeon experience and hospital volume. In high-volume hospitals with specialized pediatric neurosurgeons performing high volume of brain tumors the outcome regarding the rate of mortality, hospital stay and rate of readmission is significantly improved [24]. In a US study involving 4712 cases of pediatric brain tumor craniotomy, the mortality rate was 2.3% at the lowest-volume-quartile hospitals, compared with 1.4% at the highest-volume-quartile hospitals [25].

Egypt features an example of the model of centralization: the Children’s Cancer Hospital Egypt 57357 (CCHE) widely known as Hospital 57357 with 320 beds. Its mission is providing high quality health carefree of charge to children with cancer. This hospital in the first 5.5 years treated 1114 CNS pediatric tumors [8, 26].

**The flow in operating suites**
Operating room resources must be allocated in order to effect elective surgery while leaving room for emergencies. This is especially important on weekdays when most surgeons prefer to operate. And must be coordinated with availability of admission beds.

When most of the elective surgery is done during the weekdays, it leads to pressure on ancillary services, e.g., radiology during the weekend.

Therefore, proper budgetary and elective surgery planning needs to be done in order to provide adequate ancillary services at the weekend.

**Admission to neurological intensive care unit**
There are criteria for admission to and discharge from intensive care unit. A specialized neuro-intensive care units is costly and limited in space and staffing.

Thus, hospitals may restrict admission only to indicated cases, e.g., post-operative cases to monitor vital signs and proper neurological assessment or cases with reversible medical conditions and not for palliative cases. Once the patient is stabilized and monitoring is no longer indicated, the patient should be transferred out of the ICU If the condition become deteriorates and no longer needs ICU admission the patient should be transferred to palliative care unit [16].

**Continuity of treatment**
After the neurosurgeon completes the surgical procedures and final diagnosis is confirmed from the neuropathologist, the patient is transferred to his primary neurooncologist consultant to continue his treatment plan and receive any needed adjuvant protocols.

There ought to be a coordinated and smooth transfer between different departments of the hospital in order to provide continuity of care.

Proper coordination between different neuro-oncology center department is facilitated by ensuring that the detailed, up to date and comprehensive medical record of the patient is available to every provider [27, 28].
Multidisciplinary team meetings
Regular combined clinical meetings of all specialized multidisciplinary professional teams to discuss the best scientific treatment plan and best protocol for each case is mandatory for proper healthcare outcome. Multidisciplinary teams prevent any delays in patient treatment plan as the meeting allow for faster reaching collaborative decisions and their implementation [29].

Multidisciplinary Team Meetings could improve patients’ quality of life and even survival [30].

Composition of multidisciplinary teams
Multidisciplinary team is essential for proper workflow and avoiding any delay in treatment of pediatric neuro-oncology cases.

It consists of availability of trained skilled pediatric neurosurgeon working together with other highly specialized teams including neuroradiologist, neuro-oncologist, neuro-pathologist and radiotherapist [31].

Neuroradiology services
Neuroimaging is the cornerstone in the diagnosis and follow up of CNS tumors. Neuroradiology services should be available 24 h every day.

Updated imaging modalities is essential for the diagnosis of pediatric brain tumors and follow up.

It includes high tesla magnetic resonance imaging (MRI) and multislice computerized tomography (CT). The system must be digitalized with fully integrated electronic systems for providing best quality service [32].

MRI should be done for all preoperative cases at time of diagnosis and a post-operative study is done within 48 h of surgery to detect any residual tumor and avoid misleading enhancement from the operative bed. Then regular follow up imaging is done either for observation or to detect the effect of adjuvant therapy. MR spectroscopy which can assess metabolites; choline, creatine, N-acetylaspartate (NAA), and lactate in the space occupying lesions with the results displayed in a graphic of metabolite peaks can also provide useful data in CNS tumors [33].

Neuropathology services
Accurate definitive diagnosis of pediatric CNS tumors needs highly experienced neuropathologists with access to the electron microscopes and immunohistochemistry especially since molecular characteristics become important for the diagnosis and the outcome of CNS tumors, e.g., detecting IDH1/IDH2 mutations in CNS gliomas [34, 35].

Neuro-oncologist
Chemotherapy in addition to safe resection and post-operative radiotherapy is an indispensable requirement for the management of pediatric CNS tumors.

The presence of an experienced well-trained dedicated neurooncologist will facilitate the application of updated treatment protocols that will improve the health care outcome [36, 37].

Radiotherapy services
The availability of well-trained radiation oncologists, medical physicists, and radiation technologists play an important role in improving the survival and progression free survival for pediatric neuro-oncology cases. Radiotherapy for medulloblastoma and ependymoma have been reported with excellent survival result [38]. Also, pure germinoma is cured with radiotherapy alone with survival more than 90% in the literature [39].

Furthermore, advances in physics, engineering, atomic sciences, computer science, and telecommunication evolve the radiotherapy. Linear accelerator initiated the new technologies of 3D conformal radiotherapy, radiosurgery and image-guided radiotherapy can all be effectively utilized to optimize treatment. Radiosurgery [40].

Medical records and documentation
Clinical documentation is mandatory and should be comprehensive to document disease progression of the patients and improve insight into the disease itself. It should be fulfilled by medical consultant and specialists. In the past clinical documentation was mainly paper based but now many hospitals have moved to electronic medical records [41]. The efficiency and effectiveness of electronic health records (EHR) and its valuable add is widely recognized.

Clinical workflow is often characterized by the pattern of actions the clinicians utilize to perform routine tasks and generate results so the principle of the workflow not only do the work, EHR enhances managing clinical work by tracking, coordinating and monitoring the progress of the process [42]. Utilizing EHR allow the physician to perform different tasks easily and document patients’ data and clinical progress.

Health IT department play important role in the success of EHR through adapting the program according the tasks required by health staff and workflow of the patients [43].

Systematic documentation has resulted in national cancer registries in many countries with data exchange and nationwide data bases between different registries. This
registry study the epidemiology, surveillance and outcome of cancer disease [31, 44].

**Discharge and follow up**

Once the patient has completed his treatment protocol, a discharge plan is described for him to ensure post-hospital care and avoid the risk of hospital readmission. The discharge plan determines which service the patient needs after discharge to ensure successful transition from one level of care to another. Regular scheduled outpatient contacts with scheduled imaging to determine any tumor relapse or recurrence is mandatory. The instructions include the date and location of the outpatient hospital clinic, time of scheduled radio imaging and when urgent care should be obtained. Patient and family education and instruction are important components of the discharge plan and support the child’s return to previous functional levels [45, 46].

**Conclusion**

A high flow neuro-oncology center requires a well-planned, multidisciplinary based and smoothly maintained workflow system to improve the health care outcome, avoid delay in care giving and ensure a persistent and continuous function in all circumstances. An optimized workflow has a great impact on patient’s compliance and experience.

**Abbreviations**

CCHE: Children’s Cancer Hospital Egypt; CNS: Central nervous system; CT: Computed tomography; EHR: Electronic health records; ICU: Intensive care unit; MRI: Magnetic resonance imaging.

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