

The care cycle: an overview

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► **Healthcare informatics solutions should be designed to optimize care across the entire continuum.**

In many countries the healthcare system is at risk due to increasing demand and costs, poor quality of care, limited access, and inefficient, poorly coordinated care [1, 2]. Healthcare informatics solutions hold the promise of helping to solve these problems. In its 2001 report “Crossing the Quality Chasm”, the Institute of Medicine (IOM) concludes that such solutions should be designed to optimize care for patients’ needs across the entire continuum of care for a given medical condition [2].

Disease-based care cycles are a useful tool for properly understanding the current status of the care process for a given medical condition. They help understand how to improve cost-effectiveness, access, and quality of care. In conjunction with quality improvement studies, they show the strengths and weaknesses within the healthcare continuum.

The US Department of Health and Human Services and the American Medical Association (AMA) provide a useful generic definition for a care cycle that fits most diseases:

“The array of health services and care settings that address health promotion, disease prevention, and the diagnosis, treatment, management, and rehabilitation of a disease, injury, and disability.”

Included are primary care and specialized clinical services provided in community and primary care settings, hospitals, trauma centers, and rehabilitation and long-term care facilities” [4-6].

Care cycle approaches have been used by many organizations. These range from hospitals, health insurance companies and the healthcare industry, to governments [4, 5, 7-10]. Examples of disease-specific care cycle approaches are those introduced by the National Cancer Policy Board (1999) and American Stroke Association (2005) [3]. The common objective of these organizations is to improve clinical outcomes, cost-effectiveness, healthcare quality, and access to care.

The care cycle as determinant for health outcomes

Figure 2 illustrates the relation between the care cycle (1) and health outcomes (2). Care quality, cost and access (“the iron triangle” in health policy) are important attributes of the care cycle that determine the degree to which actual health outcomes match optimally achievable outcomes [11].

Access to care is defined by the IOM as the extent to which care is available for a patient in case of need (e.g. expertise, capacity, resources, and health insurance) [2].

Quality of care is defined as the degree to which health services increase the likelihood of optimal achievable health outcomes and are consistent with current professional knowledge [2, 12]. To ensure that healthcare professionals follow best clinical practices, professional medical associations (e.g. American Heart Association) develop a series of recommendations known as practice guidelines (3). Guidelines are systematically developed statements to assist a practitioner’s patient decisions for specific clinical circumstances. They are developed through a formal process that combines scientific evidence with clinical expertise and patient values for appropriate decisions that will improve patient care, i.e. evidence-based practice [2, 11, 13, 14].

► Figure 1. Generic care cycle [4-6]. At the center of the care cycle is a patient with a medical condition (disease, injury and/or disability).



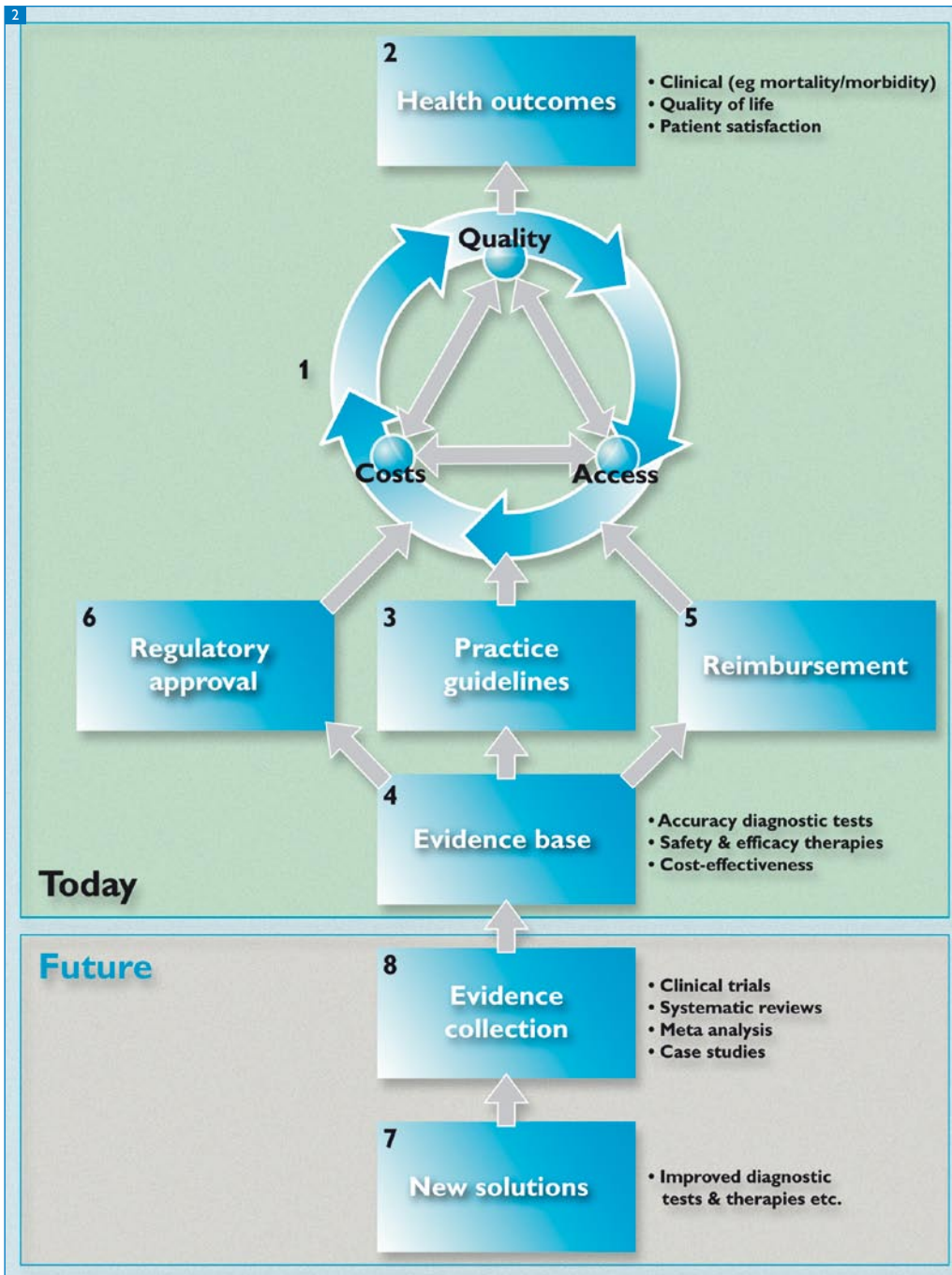


Figure 2. Relation of the care cycle to health outcomes (see text for explanation).

Scientific evidence (4) is obtained from clinical research and (to a lesser degree) from basic medical research. Examples of evidence include:

- the sensitivity and specificity of diagnostic tests
- the power of prognostic markers
- the efficacy and safety of therapeutic, rehabilitative and preventive regimens
- the efficacy of the organization of care processes.

Apart from current best practices, there are other factors that affect health outcomes. These factors include – but are not limited to – reimbursement (5) and regulatory approval (6), such as approval from the US Food and Drug Administration.

Reimbursement decisions and regulatory approval also rely, inter alia, on evidence-based medicine.

It is important to note that care cycles are dynamic. Changes occur as new solutions (e.g. diagnostic tests and treatments) emerge that address weaknesses in the current care cycle (7). Typically, new solutions become part of the evidence base through testing in clinical trials (8). New evidence from clinical research may invalidate previously accepted solutions and replace them with new ones that are more accurate, more efficacious, and safer. Accordingly, these new solutions and ongoing clinical trials determine how the care cycle is

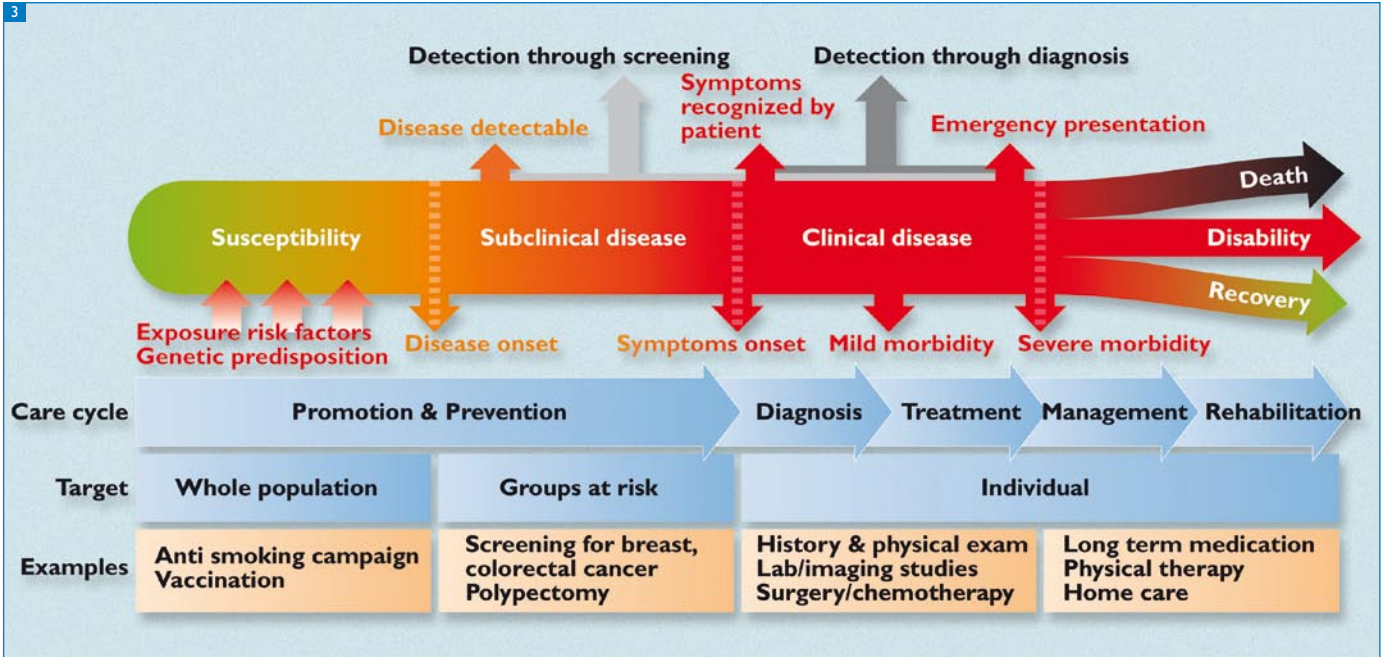


Figure 3. Generic model for the relationship between phases of the care cycle and the course of a disease.

modified. In general, however, changes are slowly adopted into the care cycle. On average it takes 17 years before new knowledge from clinical trials is incorporated into clinical practice, and even then the application is highly uneven [2]. In addition to new solutions, well established practices also shape the care cycle.

Disease-based care cycles

Figure 3 shows a generic representation for the course of a disease, the related phases of the care cycle, and the target groups [5, 15-23].

In general, sufficient exposure to risk factors (e.g. tobacco) triggers the disease process in a healthy but susceptible individual. Usually, a period of subclinical, unapparent pathologic changes follows exposure. This period is called the incubation period for inflammatory diseases, and latency period for chronic diseases. The latency period may be as brief as seconds (e.g. anaphylactic shock) or as long as decades for certain chronic diseases (e.g. atherosclerosis). Even for a single disease, the latency period may vary in duration. The onset of symptoms marks the transition from subclinical to clinical disease. In some people, however, the disease process may never progress to clinically apparent illness. In others, the disease process may result in a broad spectrum of mild to severe presentations. Further disease progression may result in death, disability or recovery. These health outcomes are typically greatly affected by the quality of care that is provided during the course of the disease. Some patients, however, may recover spontaneously (e.g. recovery from infections, due to immune system response).

The phases of the care cycle are closely linked to different disease stages. Health promotion and prevention applies to the first disease stages. Typically, prevention is subcategorized as primary and secondary prevention. Primary prevention aims at reducing the exposure to risk factors and usually targets the entire population or groups that are at risk of developing a disease. Health promotion, health education and health protection are three main aspects of primary prevention.

Secondary prevention is targeted at (asymptomatic) individuals with a subclinical disease in order to prevent or delay the clinical expression of the disease. Secondary prevention strategies include screening activities (e.g. screening for breast cancer or colorectal polyps) and prophylactic treatment. The next phases of the care cycle – diagnosis, treatment, management, and rehabilitation – apply to individuals (patients) with the clinical disease. The purposes of these phases are first, to prevent further impact from the disease by curing, retarding or blocking its progression and, secondly, to prevent disease recurrence (often referred to as tertiary prevention). Depending on the type and severity of the disease, care may include chronic treatment, disease management, surveillance, and palliative care.

The care cycle covers an individual's health condition from wellness to illness and back, but not everyone would encounter all phases of the care cycle. Patients who completely recover from the disease return to the first phase (prevention) of the care cycle. However, cured patients are often at high risk for recurrence of the disease,

► The phases of the care cycle are closely linked to the different stages of the disease.

and specific prevention measures may apply. Because of the strong connection between the care cycle and the course of the disease (as indicated in Figure 3) the care cycle differs for each disease.

Care pathways

A useful format to describe a phase of a disease-based care cycle in detail is through a care pathway (also called patient pathway, care map, etc.). A care pathway is an outline of anticipated multidisciplinary care, placed in an appropriate timeframe, which describes how a patient should move progressively through the care cycle [24, 25].

In healthcare, care pathways are used for process mapping from a patient perspective, with the objective of reducing unnecessary variations in patient care and outcomes. Although care pathways are usually disease-specific, a patient may enter into multiple pathways (and accordingly different care cycles).

Care pathways should not be confused with workflows, which map processes from a department perspective. In contrast to care pathways, workflows combine multiple care cycles. Typically, care pathways match evidence-based guidelines, but they are not set in stone. In daily practice, variations from the pathway can occur when clinical freedom is exercised to meet the needs of the individual patient. On the other hand, a patient may not receive ideal care because of care quality and access issues.

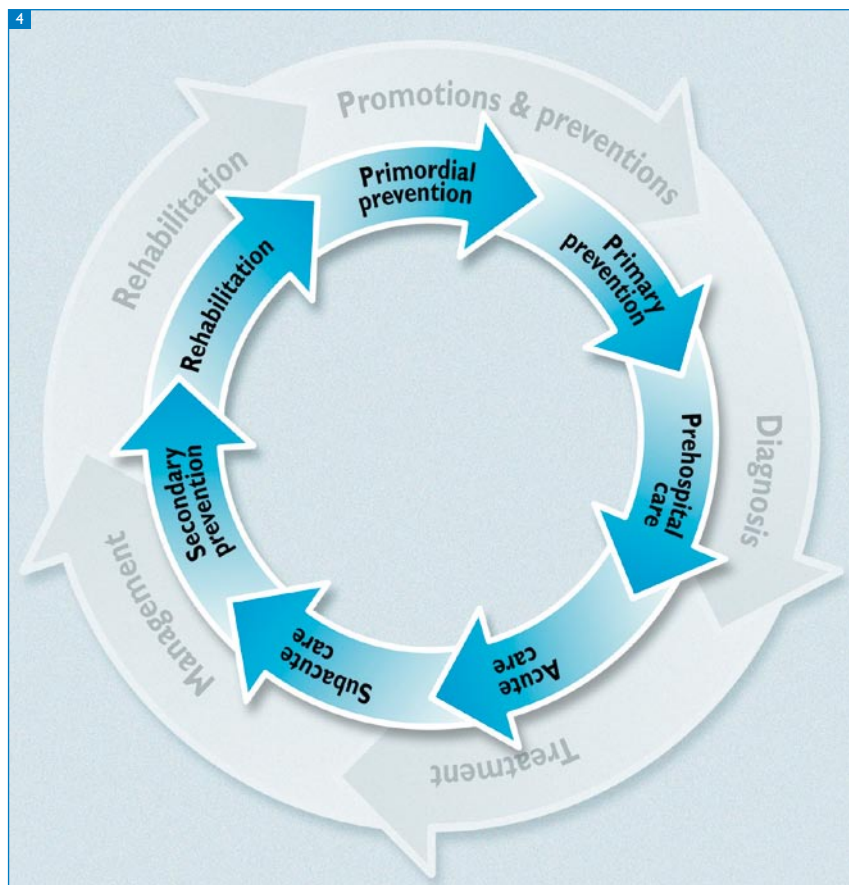
Priority conditions

The IOM has identified 15 priority conditions based on prevalence, burden of illness, costs, variability in practice and the potential to improve outcomes and reduce costs [2]. These conditions are: cancer, diabetes, emphysema, high cholesterol, HIV/AIDS, hypertension, ischemic heart disease, stroke, arthritis, asthma, gall bladder disease, stomach ulcers, back problems, dementias, and anxiety disorders.

In the following sections, stroke is used as an example of a disease-based care cycle, together with an example of a care pathway.

Stroke care cycle

Stroke is a leading cause of death in industrialized countries: it is the first cause of death in Japan, the second in China, and the third in the USA. Worldwide there are 5.5 million



▲ Figure 4. Care cycle for stroke (blue) compared with the generic care-cycle definition (gray).

deaths due to stroke per year. One in three stroke survivors requires some form of assisted living, making stroke a leading cause of long-term disability and therefore expense to society. The World Health Organization estimates the total number of years of life lost to stroke and years lost to disability (DALY – Disability Adjusted Life Year) to be 46 million years per year worldwide. According to the American Stroke Association, the stroke care cycle consists of seven phases [3]. Figure 4 shows these phases in relation to the generic care cycle phases. It is important to note that some of the phases of the stroke care cycle not only occur sequentially but also simultaneously. The phases in detail are:

- Primordial prevention
- Primary prevention
- Pre-hospital care
- Acute care
- Sub-acute care
- Secondary prevention
- Rehabilitation.

Primordial prevention

Primordial prevention is one of three prevention phases of stroke. It focuses on strategies designed to decrease socially influenced risk factors such as obesity, alcohol consumption, smoking, poor nutrition, physical inactivity, and oral

Figure 5. Poster used in a stroke education campaign in the Netherlands. Reproduced by courtesy of the Nederlandse Hartstichting.



► Acute care encompasses the emergency diagnosis and treatment of the stroke patient in a hospital setting.

contraceptives. Education is also a large part of this phase, with many national initiatives in place to inform the general public of the signs and symptoms of stroke, because it is important to recognize stroke as early as possible; failure to recognize stroke is the major factor behind the fact that less than three percent of stroke victims receive optimal care. Figure 5 shows an example of an education campaign from the Netherlands.

Primary prevention

Primary prevention focuses on detecting and treating co-morbidities such as hypertension, elevated lipid levels, diabetes, and atrial fibrillation. Initial detection may come from regular checkups. Patients at high risk of stroke may also be monitored more frequently.

Pre-hospital care

Pre-hospital care is provided by the emergency medical system after a patient has suffered from an acute stroke. It includes the initial recognition of a stroke, first aid, and transportation of the stroke patient to an appropriate medical facility that can treat strokes. In the United States, programs exist to certify hospitals as “primary stroke centers”. In general, ambulances bypass local hospitals in favor of these certified hospitals.

Acute care

Acute care encompasses the emergency diagnosis and treatment of the stroke patient in a hospital setting. This phase includes: notification of the stroke team by the ambulance personnel or the hospital’s triage nurse, initial patient assessment, patient stabilization, neurological assessment, and treatment. Physicians must correctly distinguish stroke mimics, ischemic strokes, and hemorrhagic strokes from one another, so as not to harm the patients with the wrong treatment (for example, the treatment for ischemic stroke could kill a hemorrhagic stroke patient).

Sub-acute care

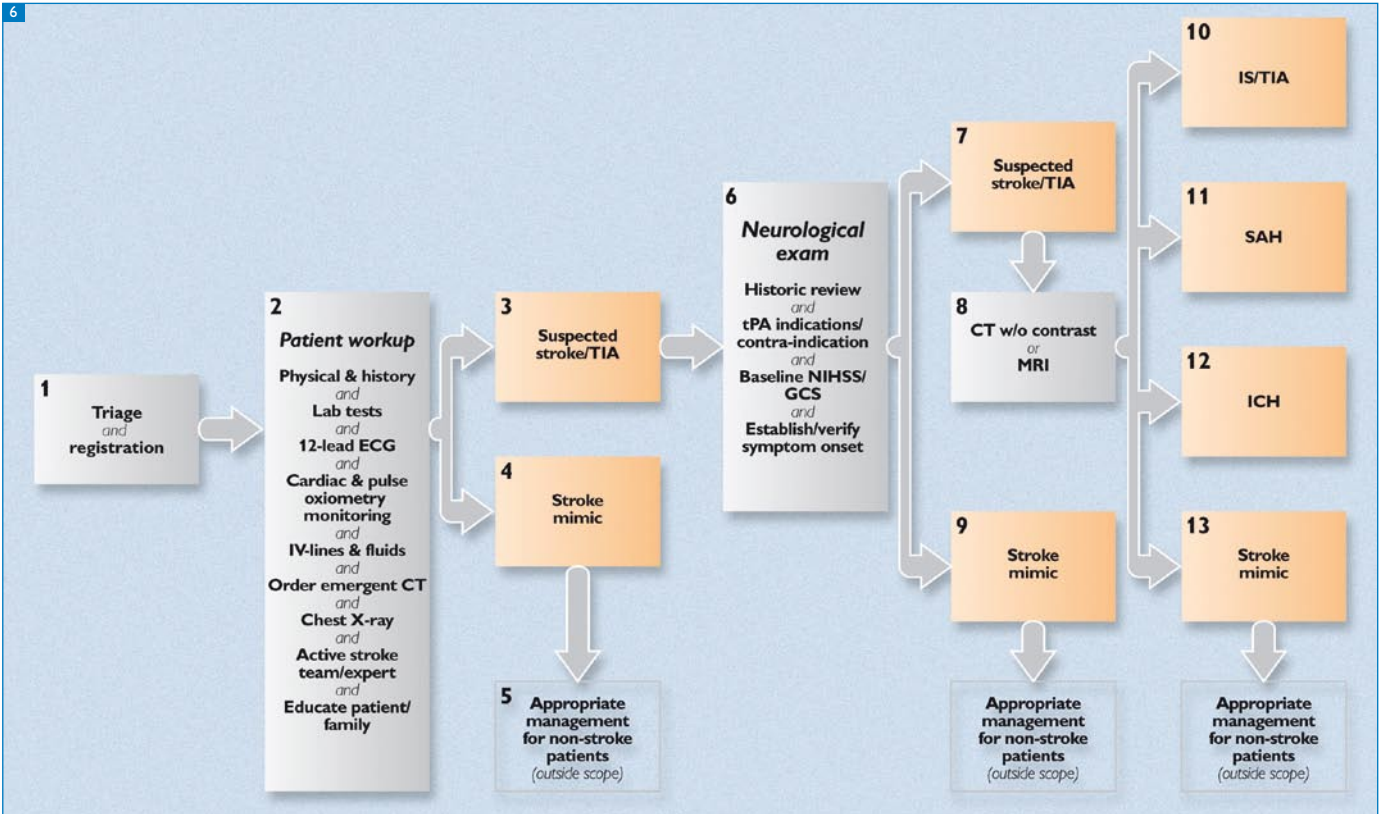
Sub-acute care comprises further stabilization of the patient, continuous monitoring of vital signs, and treatment of complications.

Secondary prevention

Secondary prevention is characterized by determining the underlying cause of the stroke and addressing it. It is similar to the Primary Prevention phase, but it occurs after a stroke incident and it is consequently part of the regular workup.

Rehabilitation

Rehabilitation includes physical and occupational therapies to help restore patients to an optimal



▲ Figure 6. The care pathway for stroke patients.

functional level. Typically, patients start rehabilitation in the hospital and then continue their therapies as outpatients in a rehabilitation center. Discharge may be to home or to a long-term care facility such as a nursing home, but still with rehabilitation on an outpatient basis. When rehabilitation in the professional setting has ended, it should still be continued in the home, as many studies show degradation of capabilities once formal rehabilitation has ended.

Acute care pathway

For each phase of the stroke care cycle described above there is a care pathway, which specifies in detail how stroke patients should be managed. Figure 6 shows a simplified version of the acute care pathway.

The sections below explain the diagram in detail.

1. Triage and registration

This step should be done immediately upon the patient's arrival to determine whether the patient had an acute stroke and thus needs to be seen immediately. A delay in this phase typically results in reduced patient outcomes. This step may be improved by training the triage personnel and by providing them with tools to recognize stroke patients.

2. Patient workup

This step includes an interview with the patient (and possibly the patient's family) to obtain the

medical history, the current medications, and the time of onset of symptoms. A brief physical exam is conducted and laboratory tests are ordered. This step takes about five minutes to complete.

Depending on the patient's situation, healthcare professionals are also concerned with identifying and treating acute situations (e.g. breathing difficulties) and administering first aid (e.g. administering oxygen). Because this step involves many processes that are carried out by different individuals, the healthcare professionals could be provided with computerized tools that ensure the completion of all necessary tasks in a timely fashion.

The information obtained in this step is used to decide whether the patient is still suspected of having a stroke (3. Suspected Stroke/TIA) or another condition that resembles an acute stroke episode (4. Stroke mimic).

3. Suspected Stroke/TIA

The physicians conclude from the clinical evidence that the patient has suffered an acute stroke or a Transient Ischemic Attack (TIA). A TIA is an acute condition caused by a temporary oxygen deprivation of the brain. Ideally, stroke patients should be identified within 15 minutes of arrival, because they need to be treated immediately. Since the diagnosis of stroke can be difficult, computerized decision support could help healthcare

► The distinction between ischemic and hemorrhagic strokes is very important.

professionals identify stroke patients (for example, by analyzing lab test results and the history and physical findings).

► **Some medical conditions present with stroke-like symptoms.**

4. Stroke mimic

The possibility of stroke is ruled out. In other words, the patient has a medical condition that presented with stroke-like symptoms. For example, the patient could have had an acute episode of hypoglycemia (low blood sugar). Some of the diseases that present as strokes are just as concerning as strokes. Therefore, it is important to find the cause of the stroke mimic and to start the appropriate clinical pathway.

5. Appropriate management for non-stroke patients

It is important to identify the underlying cause of the stroke mimic. Management is variable, depending on the cause. Some mimics are still time-critical.

6. Neurological exam

In this phase, physicians conduct a neurological exam and determine the severity of stroke symptoms. They use a standardized scoring system known as the NIH Stroke Scale, which provides them with a baseline severity score. The baseline score is a reference against which the success of treatment can be monitored. Based on the neurological exam, physicians may get an indication of the stroke type. There are two basic stroke types: ischemic and hemorrhagic strokes. Ischemic strokes are caused by a blood clot occluding an artery in the brain. They are treated with tissue Plasminogen Activator (tPA), a drug which dissolves clots. Hemorrhagic strokes are caused by an acute bleeding in the brain and must be treated surgically. Given the different treatments, the distinction between the two stroke types is very important. A bleeding in the brain is an absolute contraindication for administering tPA.

7. Suspected Stroke/TIA

This is the final assessment opportunity, based on information collected to date, before imaging is done. As imaging needs to be initiated as soon as possible (within 25 minutes), this step should be completed within 20 minutes. The medical/financial concern is that imaging is a costly procedure and should only be done if a stroke (not stroke mimic) is suspected. After the information has been collected, it could be helpful to have a decision support system to help with the differential diagnosis, and on whether any other tests should precede the CT/MR.

► **Care cycles and care pathways are models of optimum patient care for specific diseases.**

8. CT w/o contrast or MRI

An image of the brain is obtained in order to rule out intracerebral bleeding. This step should ideally occur within 25 minutes of a patient's arrival. In this step, a computer aided diagnosis application could help physicians by highlighting a suspected hemorrhagic lesion in the brain image.

9. Stroke mimic

The possibility of a stroke is ruled out. See 4. Stroke mimic above.

10. Ischemic stroke/TIA

At this point, the physicians have ruled out a hemorrhagic stroke, which is one of the major contraindications for the thrombolytic treatment of an ischemic stroke. In addition, they must rule out other contraindications for tPA (for example, coagulation disorders). If the patient's symptoms are rapidly improving, physicians must also consider the presence of a TIA. Since TIA patients will not have morphological brain damage, they should not be treated with tPA (which would only put them under an unnecessary risk of bleeding). Once all the risks and benefits of a thrombolytic treatment have been considered, physicians will give tPA. A computerized decision support application could help physicians and patients with this difficult decision.

11. Subarachnoid hemorrhage

The physicians have diagnosed a subarachnoid hemorrhage (SAH) and initiate the SAH-specific pathway. Like the diagnosis of an ischemic stroke, this decision should be made within 45 minutes.

12. Intracerebral hemorrhage

An intracerebral hemorrhage (ICH) has been diagnosed and the ICH-specific pathway is started.

13. Stroke mimic

The possibility of a stroke is ruled out. See 4. Stroke mimic above.

Conclusion

Care cycles and care pathways are models of optimal patient care for specific diseases. They help understand the dependencies between the various care steps provided by different healthcare professionals, and can show how the deployment of new technology could affect overall disease management ■

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