Metadata for Clinical Narrative

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Abstract: The purpose of the current work is to develop metadata for clinical narrative information. For the metadata development, studies were conducted to identify the resources for patient stories. The resource consulted for the current work is the medical journals and case records. With the patient stories, medical narratives were developed. To identify the elements of narration, narrative theories were studied. These elements were identified in the medical narratives developed. By conducting this study, it was found that the medical narratives lack metadata for describing the clinical narration. Thus, metadata elements were composed for the patient-doctor narration. The work stands out by developing a metadata framework for medical narrative information. This framework addresses the lack of metadata for narrative information in a clinical setting. As a result, this research aids in the recording of patient-doctor dialogue.

Keywords: Narrative Information Metadata, Narrative Ontology, Clinical Narration, Medical Narrative Metadata

1. Introduction

Narrative has acquired its place in the current century. The area has found a place in various domains such as cognitive sciences, political science, digital library, archaeology and so on. Narrative is used from business to software development (Schwabe, Richter, and Wende, 2019). The medical field has also adopted the narrative into their folds. The concept of narrative medicine is a product of this (Charon et al., 2017). Other than this branch of medicine, there are other narratives that occur in the medical domain. These narratives are important as they capture relevant information of the people and roles associated in the healthcare domain.

Clinical narratives are 'story', detailed description of any specific situation or event including the details such as where, when, patient details, special conditions and so on by clinicians. The narratives in medical situations are considered as a mix of fact and creativity (Wood, 2005). They generally are part of pharmacovigilance and patient safety. These narratives back the epistemological basis for medical cognition, analysis of patient illness and research on medical models for efficient healthcare delivery (Goyal, 2013). The narratives describe events, experiences and illnesses in a medical setting. According to Le et al (2017) clinical narratives are of different kinds. They are narrative medical writing, patient narration and health and illness narrative. Narrative medical writing describes the adverse events experienced by the patient. Patient narration and health and illness narrative describes the details of the patient such as age, gender, clinical condition, occurrence and duration of illness. The illness and its effect on the patient are detailed in a personal way in health and illness narratives.

Few components of the medical narratives such as age, gender, condition and occurrence are captured by the electronic health records (EHRs) in a structured manner. EHRs are the electronic counterpart to the paper patient records. Evolving from paper, the records become electronic (Shortliffe, 1999). Generally, EHRs contain daily charting, medication administration, physical evaluation, admission nursing note, nursing care plan, referral, current complaint (such as symptoms), prior medical history, way of life, physical examination, diagnoses, tests, procedures, treatment, medication, discharge, history, diaries, problems, findings, and immunisation. The common fields in an EHR are Patient details/profile, Hospital details, Doctor/Physician details, Measurements details and Drugs details (Alabbasi et al., 2014). The data standards are in plenty in the medical domain. Some majorly referred and cited standards developed to bring about a standardisation in the EHR data entry and exchange are mostly for varying purposes such as (a) transmission of patient data (ASC X12 (EDI)), image or radiology data (DICOM); (b) communication standards for EHR system (CEN's TC/251, EN 13606, and HISA (EN 12967) and for text messages (HL7 (HL7v2, C-CDA)) (c)standardise the continuity of care (CONTSYS (EN 13940), Continuity of Care Record) and (d)technical protocol (ISO – ISO TC 215, ISO 18308). The Government of India and Germany have set up recommendations for the country. The Government of India recommends a minimum dataset (MDS) that the EHR vendors have to

confirm. While the German standard of xDT is developed for data exchange among physicians and healthcare administrators. For clinical narratives, there is a data standard for nursing information developed in the 1990s. The aim of the project was to develop a standard for clinical nursing data and incorporate the standard into the EHRs. The total of 16 elements are in three categories of Nursing care elements, patient or client demographics and service elements (Werley et al., 1991). EHR systems are constantly involving, adding, modifying and deleting components. But the components are from the administrative, technical and medical point of view. Narrative components such as the details of the events, actions and persons, though captured, are recorded as unstructured data information. They are generally recorded in the Notes field of EHRs.

These narratives consist of information important for better healthcare delivery. These unstructured data need to be structured for discoverability and to avoid manual processing. In order to structure these narratives, we need to define the identifiers. Despite the significance and importance of the clinical narratives, either electronic health records (EHRs) fields or any data standards exist for it. Since the standards are based on the existing EHR components and systems, they also lack descriptors for narrative information in medicine. As is evident, there is a lack in the metadata standard for the clinical narratives. With this work, we hope to define the elements that aid in the description of clinical narration and help in the efficient healthcare delivery.

The paper is divided as follows. The literature review follows the introduction. The methodology is section 3. The Narrative framework is detailed in section 4. The findings and discussion are detailed in section 5. The paper concludes by mentioning future works.

2. Literature study

Studying the relevant literature is important. The previous and similar works act as guidelines towards achieving the current goals. There are projects undertaken to identify the best possible metadata set for describing the resources in libraries. Some of the literature are a guideline for the current work is detailed here. For digital archiving and preserving, through a collaborative approach, the University of Houston Libraries developed a set of 23 metadata elements. This is in addition to the already existing element set for their digital assets (Washington and Weidner, 2017). In another collaborative work, libraries at the University of Nebraska-Lincoln (UNL) worked together to create a metadata application profile (MAP). This was done in order to record and disseminate information about the metadata standards and content procedures used by each of the four digital repositories. Platform-specific restrictions, content limitations, approaches to metadata and description, and contrasting ideologies were the main roadblocks. Through cooperative work, the group discovered similarities and decided on a minimal set of necessary metadata components for all of their repositories. After deciding on the bare minimum of metadata components, the team created and made available a LibGuide for the UNL MAP. (Mering & Wintermute, 2020). Works on metadata mapping or extension are also significant in this study. These works help in understanding the kind of metadata creation, modification and extension that happens in the same domain or among domains. A crosswalk of the standards (either of the same domain or of the same purpose) will also enable interoperability among the standards. Works such as Marketakis et al (2017), Habermann (2019), Martin et al (2019) and Jung et al (2022) discuss metadata unification and information integration with respect to cultural heritage, geographical data, digital humanities or computational engineering. This study has helped in guiding the current work on metadata for medical narrative.

There are metadata standards developed for describing various resources. Metadata can be generic or domain specific. Metadata for resources on the web, for archaeological and cultural artefacts , biodiversity and natural history, for data, for describing ontologies. Some of the standards are Dublin core, a domain independent standard for describing resources, VRA Core for visual culture, images and the document that describes them, CIDOC-CRM for museum and cultural heritage documentation, Darwin Core for biological diversity information exchange, ABCD for data exchange in the domain of biological specimen data, DDI for data in the domain of social and behavioural sciences, DCAT for datasets in data catalogues, MOD for describing the ontologies and so on.

Particular to narrative, there are frameworks that play the role of descriptors or metadata. Certain works were studied to develop ideas on the metadata for narratives. The Archetype Ontology (Damiano and Lieto, 2013) was built to navigate the digital archive using the narrative relations among the resources. The founding idea of the model has been the narrative situation (Klarer, 2013). Narrative situations demand characters and objects which are part of a larger story once connected. The major classes of this framework are Artifact, Archetype, Entity, Dynamics, Story. These entities are connected to each other

via the relations such as evokes (connecting Artifact and Archetype) and displays (connecting Artifact and Entity). Fisseni et al (2013) conducted a preliminary study to compare the stories. In order to perform the study, they studied the aspects of narratives. The findings of the work identifies elements such as characters, entities and the relationship between them. Since the case is to compare stories, the other elements identified were the pattern of the stories, any metaphorical or allegorical interpretation, and the recipient 's perspective. Ciotti (2016) initiates a formal ontology towards developing narratives. The ontology has classes, namely - Action, Object, Event, Actor, Place, Quality and Actant. The classes are major components of any narrative. Bartalesi et al., (2016) is a formal model for narratives.The model is based on the classical theory of narratology. The elements of the models are Fabula- sequence of events in a chronological order, Narration- text that narrates the fabula, Narrative fragments- a portion of the narration, Event- something that happens at a time and place and Action- a subdivision of event, is doing something. The elements of narratives identified by Bartalesi et al (2016) are the Generalised event (where action and objects exist in a particular time and space), Process (events with a beginning, middle and end), Time (temporal factor including the start, end and interval), Physical objects (physical object present in particular time and space), Mental events (events occuring in the mind of the agent) and Mental objects (objects present in the mind of the agent). Lombardo et al (2018) developed an ontology for encoding the drama and its elements. Four major classes of the model are DramaEntity (the dramatic entities), DataStructure (class that organises the elements of the ontology into common structures), DescriptionTemplate (contains the patterns for the representation of drama) and ExternalReference (class that bridges the description of drama to commonsense and linguistic concepts situated in external resources). Meghini et al (2021) developed Nont ontology. The work is an attempt to describe the resources in museums or archives using narratives. The ontology provides provision for extending NOnt with other existing narrative models. This provision achieves the goal of narrative description of the resources in the museums and archives.

With regard to clinical narratives, the closest works are the modelling of EHR or of clinical case reports. Ogbuji (2011) developed Computer Based Patient Record (CPR). The ontology contains the elements of clinical finding, procedure, bodily feature, organism, pharmacological substance, recorded clinical situation and clinical artifact. In another work, the co-occurrence matrices of the pair of terms that occur in the EHRs were mapped to the medical concepts. This matrix helps establish relationships between the disease, drugs and devices (Finlayson et al., 2014). The unstructured data in the clinical case report make it difficult for it to be machine readable. In order to efficiently do this a Metadata Acquired from Clinical Case Reports (MACCR) was developed containing the terms for the demographics, disease presentation, treatments, and outcomes. The work also curates diseases into 15 groups and maps them to the ICD-10 diagnostics codes (Caufield et al., 2018). Developed as an annotation tool for clinical records, the ACROBAT categories, events, properties and entities in the clinical document. For example, the events are classified as clinical event, diagnostic procedure, medication, therapeutic procedures etc. The entity types contain the demographic information like age, sex, occupation and so on (Caufield et al., 2019). Studying the existing theories for narration and the ontology models, a partial knowledge graph was constructed to capture the patient-doctor narration. This identifies the narrative elements in general that can be reused for the medical narrative domain. The elements identified were Story, Actor, Event, Action, Theme, Time and Space (Varadarajan & Dutta, 2021b).

3. Methodology

Once the literature study was conducted, a methodology was adopted to achieve the objective of the current work. The figure illustrates the workflow of the process.

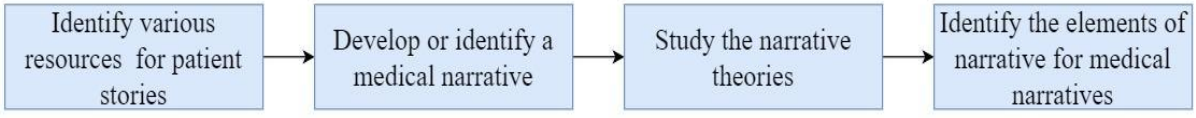

Fig 1 The workflow for developing elements for medical narratives

Step 1 : Identify various resources for patient stories
As a first step, we need to identify the patient stories. There are various sources that will assist in providing the patient stories. Sources include interview the patient for their experience of the disease,

refer the first hand reports in medical journals, newsletters and openly available case records and secondary sources such as newspapers that reports the patient stories

Step 2 : Develop or identify a medical narrative
The source of patient stories will contain many stories and cases. From the multiple sources identify the medical narrative that suits the purpose. If the stories were collected from the patient through interviews, there is a need for developing the transcript into stories.

Step 3 : Study the narrative theories
Once the stories are developed and at hand, we need to identify the elements of narration. For this, we need to have an overview of the theories of narrative. The theories were identified by searching across the academic databases such as SCOPUS, ScienceDirect, JSTOR and so on. The theories identified are described in the following section.

Step 4 : Identify the elements of narrative for medical narratives
The theories studied help in identifying the elements of narration. Once the elements are identified, these elements are mapped to the medical narrative that was identified in step 2. The elements of narration in medical narratives are described in the following section.

4. Descriptors for Medical Narratives

The first step is to identify the various resources available for patient stories. For the purpose of the current work, medical data openly available in medical journals, newsletters, openly available case records and newspapers were referred to. The details of the patient are still protected even in these platforms. Few resources that contain the clinical stories are The New England Journal of Medicine, Journal of American Medical Association and the New York Times Magazine Column 'Diagnosis'. Stories in a free-text manner are available from these resources. The following step details the patient story.

Following the identification of the resources for patient story collection, these stories were gathered. The stories were downloaded as text files in .pdf format. One such patient story is that of a 41 year old woman. She visits the emergency department (ED) with cold feet on New Year's eve. On Christmas she received new boots. Since then she has been experiencing pain on her right foot. The foot was cool to touch. She experienced pain upto her ankle. Three days before the visit to the ED, the feet turned into the colour purple. The left foot was normal, with no pain or discoloration. She also had chills 2 days before arrival to the ED. She had received treatment for endocarditis 2 years before this presentation and sought evaluation because she was worried she had another infection. The patient undergoes examination for numbness, tingling or weakness in the legs. Followed by this, the patient was asked about the cramping of the legs. The family history on the clotting disorder was checked. The patient did feel numbness in the legs, but was able to move the toes, but did not experience any cramping of the legs nor has any history of clotting disorder. The physical examination of the patient did not reveal any abnormality with the lung, heart, abdomen, hair loss, ulcerations or any region of atrophy. But the physical sensation was missing in the right foot.

In order to identify the elements of medical narrative to the elements of narration, a study was performed of the existing narrative theories. Aristotle's theory identified the elements as exposition (initial situation in a narrative), crisis (disturbances in the initial situation), and denouement (resolution of the crisis leading to new exposition) (Klarer, 2013). Todorov and Weinstein (1969) discuss the elements of narration in terms of the balance in the story. They structure the narrative as beginning with 'equilibrium'. A 'problem' in the balance causes 'disequilibrium'. When the problem is resolved, they attain a new 'equilibrium'. This is similar to Aristotle's classification. Freytag's Pyramid or Freytag's analysis (Abbott, 2003; Gustav, 1900) is narrative theory that explains the plot structure of the story. The elements of the Pyramid are:

a) Exposition
b) Rising action
c) Climax
d) Falling action
e) Catastrophe

Propp proposed 31 functions and 8 roles for a fairytale. The 31 functions include introduction of the hero, manipulation of the hero, action by the central character, resulting in victory for the hero and defeat for the villain. The eight roles in the fairytales are the villain, the hero (character with grey shades, the central character), the donor and helper (who aids with object with some special property), the princess (a character of the fairytale and object of the villain's schemes), her father, the dispatcher (who sends the hero on the quest) and the false hero (Propp, 2009). Greimas's contribution to the narrative has been to propose six actants (the actantial model). They are paired as binary units. The six actants are- subject/object, sender/receiver, helper/opponent. Some tasks are performed by the actants. They are search, aim, desire (by subject/object), communication (by sender/receiver), and support or hindrance (by helper/opponent) (Hébert, 2020). Similar to this theory is the philosophy of Levi-Strauss (Puckett, 2016). "Stories have shapes which can be drawn on graph paper, and that the shape of a given society's stories is at least as interesting as the shape of its pots or spearheads" (Case Western Reserve University, 2016). This theory comes from Kurt Vonnegut. He plots a line on the mathematical x and y axis. The 'Beginning-End' (BE axis) or the x-axis traces the time of the story. The 'Ill Fortune-Great Fortune' (GI axis), or the y-axis, follows the fortune of the protagonist.
From the theories studied so far, we can list the elements that can be used to describe the medical narratives. This is listed in table 1 and illustrated in figures 2 to 4.

Table 1. Elements for describing narratives

Elements	**Definition**
Storyline	Whole story
Plot	What happens
Agent	Person present in the story
Behaviour	Way an agent behaves towards another agent(s)
Day-to-day	Change in the way an agent behaves towards another agent(s) day-to-day
Healthcare professional	Change in the way an agent behaves towards another agent(s) who is a health professional
Physical behaviour	Change in the way an agent behaves physically
Emotional state	The state of a person's emotions
Event	Something that happens at a given place and time
Event type	The type of the event
Action	Series of events that form a plot
Action type	The type of action
Spatial factor	Space or location where an event occurs
Temporal factor	Time in which event occurs
Object	Object present during the event
Role	Function of the agent in the event
Direct participant	Function of the direct involvement of agent in the event
Indirect participant	Function of the indirect involvement of agent in the event
Cause	Phenomenon that provides the generative force for other event
Effect	Phenomenon that follows and is caused by some previous phenomenon
Theme of a story	Subject matter

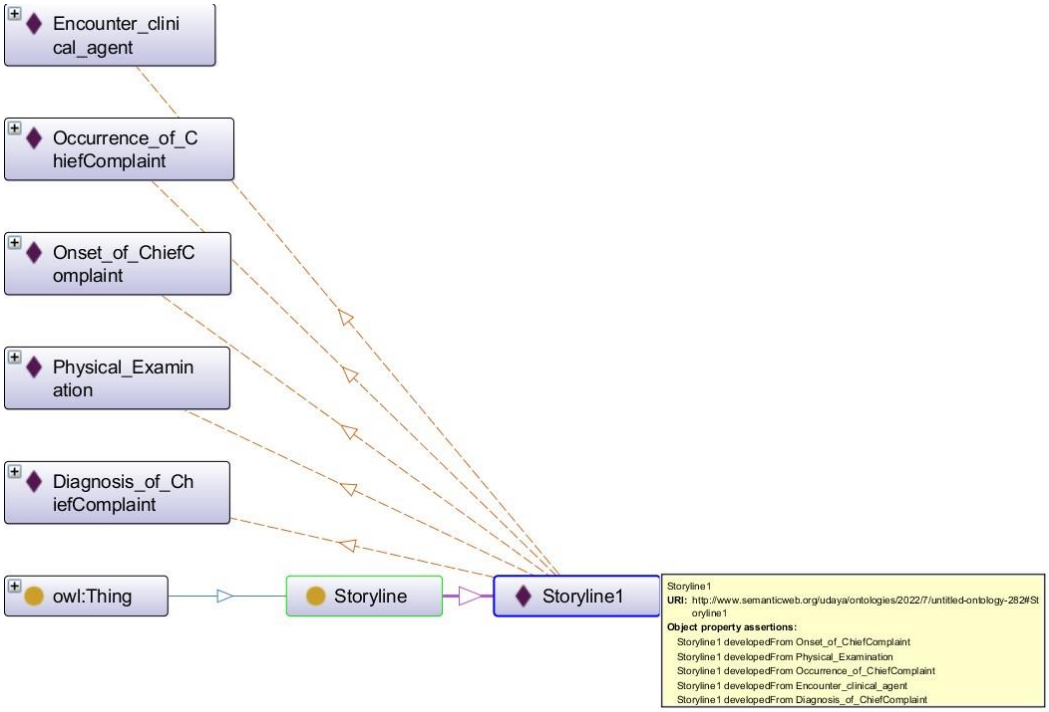

Fig 2. An example storyline. The popup dialogue box details the Plots that form one single storyline.

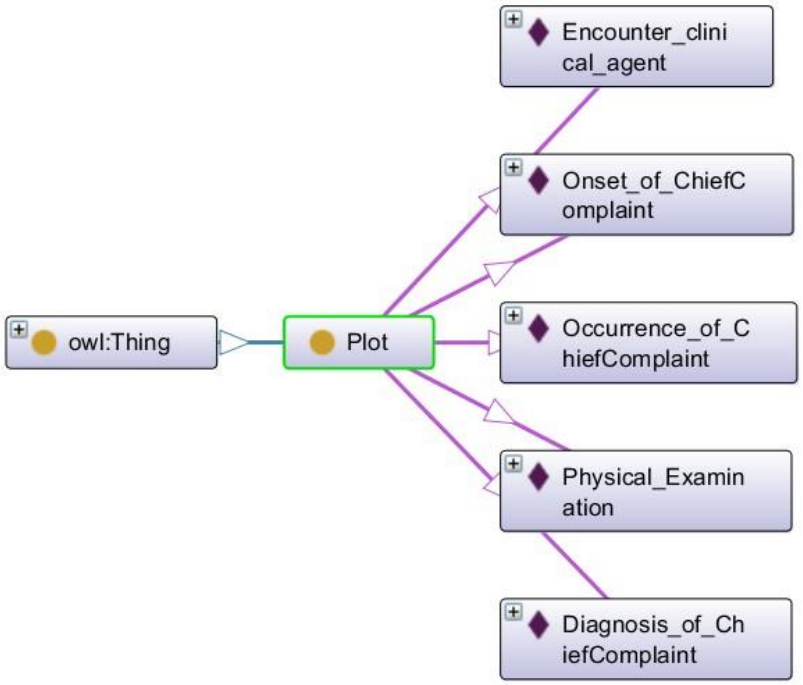

Fig 3. Plots that form the example storyline

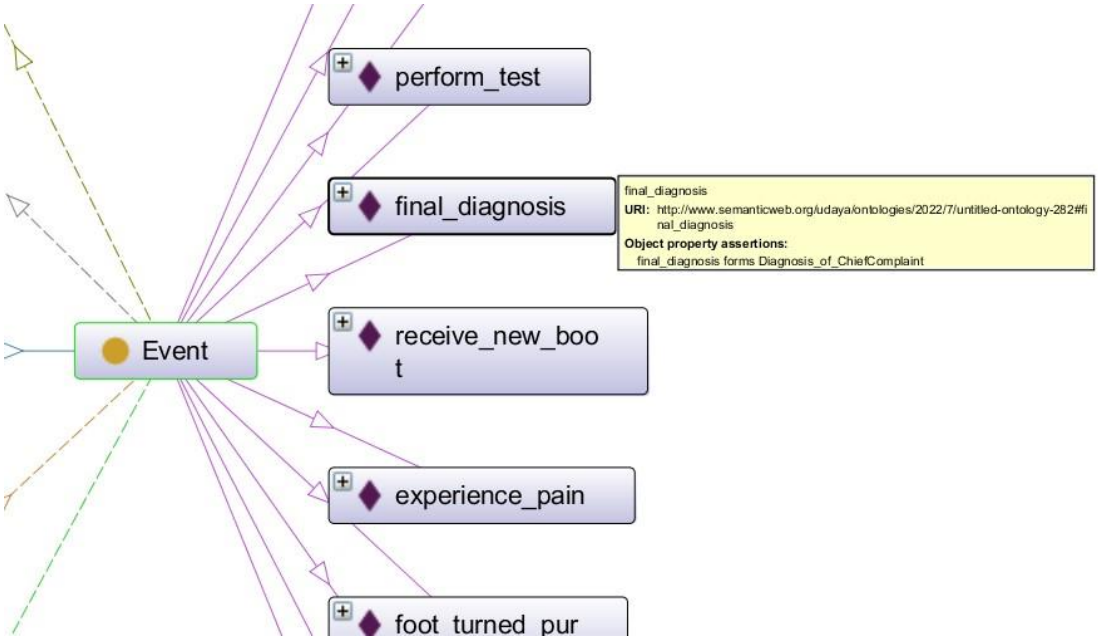

Fig 4. The event 'final_diagnosis' is a single event in the plot 'Diagnosis_of_ChiefComplaint'

5. Findings & Discussions

The work is an attempt towards identifying the descriptors for the medical narratives. The descriptors for narrative were used to model the medical narrative. This work has identified events, plots and actions that make up a story or the storyline of a single person from the patient story identified in step 2 of the methodology. The action 'touch_the_area_affected' and 'pinprick_the_area_affected' are part of the event 'examination_for_tingling' and 'examination_for_weakness'. The two events are part of the plot 'Physical_Examination' which is part of the storyline for this patient. The event and action types were identified to further classify the event and action. This classification helps in organising the medically significant event or action from others. By the definition of event, it is a phenomenon that happens in a particular time and place. The spatial and temporal descriptors for the narration are also described. The objects and agents participate in the plot development, event or action. The role of the agents such as a professional role (physician, nurse etc) or a role in the event (as direct or indirect participant) are also described. Though the use case at hand doesn't have a variety of roles, in the future with more use cases, it will be modelled efficiently. The emotional and behavioural attributes of the agents are also of significance to the narrative. Such factors in most probability drive the plot of the story.

6. Conclusion

The aim of the work was to describe the identifiers for medical narration. This was achieved by identifying a patient story and the narrative elements in the story. A study on the existing models and theories of narrative were conducted to understand the components of a narrative. The existing studies on modelling the clinical narratives are all an attempt made towards improving healthcare delivery. The realisation that the narratives hold the significance in opening up to information never captured before makes these types of works significant. Works such as (Varadarajan and Dutta, 2021a) and (Varadarajan and Dutta, 2021b) have attempted to develop a machine processable artefact for narratives in the medical domain. In the future, work will include expressing the identifiers using the OWL language and to expand it by further studying EHRs and consult experts such as doctors and nurses.

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