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Mission Impossible? Putting the Patient Back in Patient Care

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Abstract:

The primary focus of this teaching case is the patient journey, as facilitated and influenced by an e-system or electronic health record (EHR) system. The goal of this case is to provide the learner with the knowledge and skills needed to effectively incorporate patient-centered e-health (PCEH) principles into existing and planned e-health systems such as EHRs. This case can be used to help students understand a hospital experience from the perspective of a patient and her family. It is loosely based on an experience one of the authors had with an actual patient. This case is intended for use with upper level undergraduate and graduate health informatics, information systems, and nursing students. Students assigned to this case should have a working knowledge of clinical terms and the general workings of a hospital. This teaching case is best suited to an advanced course in a health informatics curriculum. Possible applications of the case include, but are not limited to, describing the patient journey, modeling the process flow, diagramming the data flow, and applying the principles of patient-centered e-health.

Keywords: patient-centered e-health; patient journey; health informatics; information systems; teaching case

Editor's note: A teaching note for this case can be obtained from hpardue@southalabama.edu

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I. INTRODUCTION

John Davis waited pensively in the emergency department's waiting room for his appointment with the head triage nurse, Sayo Zhu. He surveyed the room full of patients and felt a little ill-at-ease with the hospital staff bustling by and the general commotion around him. He was accustomed to working in environments where people wore suits and there was always a desk to sit behind. John was so focused on preparing for his meeting, which included a tour of the hospital's emergency department, that he almost didn't notice the arrival of two elderly ladies as they came through the entrance and approached the admission desk.

The younger of the two women was helping the older; the latter seemed to be in considerable pain with a significant limp, but was still trying to walk unassisted. The women shared the same features, so John surmised that they were related. As the two women approached the counter, the older woman turned to John and reached out to grasp his shirt sleeve. She leaned away from her companion's support to smile into John's face with an expectant look of recognition. "Ivan! What a long time it has been. Wasn't that such a lovely dance?" John, uncertain as to how to respond, froze momentarily trying to imagine the scene that obviously flitted so vividly behind her tired eyes. A small wave of relief poured over John as the nurse firmly but gently disengaged the older woman's hand from his arm. The nurse escorted both women to the triage room where, exhausted, the younger woman gently eased down her companion and collapsed into a chair next to her and began speaking with the nurse.

John later read the nurse's notes:

> Eva Jamison, 67-year-old white female, arrived to ER in private vehicle assisted by sister Rachel Carlile. Patient was talking incoherently and appeared somewhat lethargic. Facial grimacing rated pain at 7/10, large contusion on forehead to right lateral side with guarding of the right hip and knee. Multiple vertical lacerations noted to her right side ranging from 5–23 cm in length. A large bruise is noted to her right hip and her right knee is swollen significantly with non-pitting edema.

John Davis has fifteen years of experience as a consultant, specializing in optimizing workflow and business process re-engineering. He helped turn around a wide range of failing companies from an insurance claims processor to a consumer airline. Last month, John was assigned to his first medical client, Bradford Regional Hospital (BRH). Two years ago, BRH converted from a paper-based system to a comprehensive turn-key electronic health records (EHR) system. At their first meeting, the IT director confided to John that, subsequent to the conversion, it seemed that the system "took over" and became the primary focus of everything they did. In fact, the IT director had contacted John's company in hopes of obtaining guidance on how BRH could return to their primary focus: *the patient.*

II. THE PATIENT

John has no formal clinical experience but has worked hard to attain fluency in the highly specialized language of the healthcare industry. This was his first formal meeting at the hospital. John snapped out of his reverie as Sayo greeted him and ushered him down the hall for his tour of the emergency room (ER). As the doors swung open, John's attention was drawn to something glimmering on the cuff of his jacket sleeve. It was a small bracelet. Apparently the bracelet had snagged on the fabric and pulled loose from the wearer's arm. John asked Sayo if the two women who had just entered the ER were still here because he thought he had her bracelet and wanted to return it. The nurse checked a wall-mounted LED screen that blinked changes to the current census and confirmed that they were in triage room # 6.

Eva and Rachel were seated in chairs in a sparsely furnished exam room waiting to be admitted to the ER. The hospitalist who entered Eva's patient demographic information into the EHR was just rising from her chair when John entered. "Ivan, you've come to accompany me? Splendid!" Eva extended her hand to John, which he took without thinking. Her hand was cold but steady. With his left hand, John extended his open palm with the ends of the bracelet dangling off either side. Before he could ask, Eva exclaimed "Oh Ivan… a gift? So thoughtful!" Eva took the proffered bracelet and handed it to Rachel who deftly fastened the clasp around her sister's wrist. In a mirrored and equally deft motion, the attending nurse fastened a bar-coded plastic band around Eva's opposite wrist, and seated her in a wheelchair. Offering the back of the wheelchair for John to steer, the nurse asked, "Sir, will you be accompanying Ms. Jamison to her room?" Rachel exchanged a look and a brief nod with John that confirmed his

unspoken question. Eva smiled up at him from her chair. Though it made little sense to him, he felt he needed to be Ivan if for just the moment. John leaned over to Eva and said that he would, of course, accompany her.

The purpose of John's visit to BRH that evening was to trace the physical flow of a patient through the hospital system from patient encounter to discharge. He had chosen the ER for his first visit because he had heard that all sorts of things happened in the ER. However, he never imagined he'd play an active role in them! John marveled that the staff didn't seem to notice them while simultaneously dodging the group, as if patients in the hall were part of the environment to be navigated. The nurse ushered them into a room, assisted Eva to a sterile bed, flipped a colored flag on the exterior door facing, and merged back into the flow of moving white coats, scrubs, and patients. Once settled, John ventured to ask "So, what happened?" Eva didn't seem to hear so Rachel interjected: "I found her on the kitchen floor. It seems she had tried to get to her phone, but it was out of reach. She dragged herself halfway across the kitchen when she must have collapsed. I think she had been laying there for two days. I normally call a few times every day to check on her but I was out of town and it slipped my mind. Looks like Eva's mind 'slipped' too. The poor dear…."

"That's right. I slipped. I was dancing with Kolasnakov. He handles a lady and his standard issue PSM with equal care. You can imagine my shock when he simply left me there. I don't understand it all." Eva's abrupt entry into the conversation broke the spell of hushed tones instinctively adopted by Rachel and John. Eva followed this with a stream of what John took to be Russian. "Eva is fluent in five languages. I think that was Russian," explained Rachel. Switching back to English, Eva added, "I worked for the CIA for thirty-two years." In response to John's quizzical look, Rachel confirmed, "True. She retired 10 years ago for health related reasons. I believe she was in intelligence, but I'm not entirely sure. She didn't talk about it much. She did spend some time in the field but mostly she worked in the home office. She actually completed a bachelor degree in engineering because the CIA recruiter told her that girls couldn't solve problems or think analytically." John speculated that Eva must have visited quite a lot of countries. When asked where all she had traveled, Eva looked away and said she was "up-to date on all her vaccinations" and refused to say anything more.

After a sharp knock on the door, a nurse entered the room and went immediately to the in-room computer, with her back to Eva and Rachel. Until that point, John had not noticed the computer. Rachel offered up a USB thumb drive that contained a copy of Eva's personal health record (PHR), but the nurse only gave a confused look and then proceeded with her interview. The nurse typed and clicked as Rachel supplied answers to an endless series of questions covering everything about Eva's past medical history from having her tonsils removed when she was 8 years old to her current battle with breast cancer. Occasionally, Rachel would try and lean around to look at what the nurse was typing, hoping that the nurse might turn the computer a bit so that she could follow along, but the nurse did not seem to take the hint and continued to type as before. Eva sat motionless except for grimaces of pain while apparently trying to concentrate on something in the empty right corner of the room. Eventually the nurse asked about current medications. Rachel concentrated for a minute and then started to recite as many of Eva's medications as she could remember. The following was entered into the EHR system:

> Methadone 60mg Q6hrs, Haldol 1mg Q6hr, Multivitamin Daily, Senna S 1tab BID PRN constipation, Miralax 1 capful daily in AM, Phenergan 25mg Q6hrs PRN nausea. Tylenol 500mg PRN headache, Morphine IR 15mg Q4hrs PRN, Vitamin C 1000mg tab daily, Lasix 15mg tab PRN daily for swelling.

The nurse provided a quick physical assessment of Eva's head, lungs, and lesions; briefly typed something in the computer; and then promptly rose and left the room saying, "The doctor will see you shortly."
Ninety minutes later, the admitting physician entered and pulled a chair over in front of Eva so he could sit and face her. He checked her eyes, pulse, and physical condition, and then asked Eva a few questions to which she made no reply. The physician turned to Rachel and asked, "What happened?" For the fourth time Rachel explained how she found Eva on the kitchen floor. "She has been using a walker for the past three months due to increased weakness and fatigue. Recently she has had problems with forgetfulness and occasional hallucinations; though Eva's smart and will often catch herself when she realizes that something is not real based on your response. She'll then try to dismiss it as a 'dream' she had. She hides it well."

The physician wheeled around to approach the computer keyboard and inadvertently bumped Eva's knee. Eva winced and leaned away. The physician consulted a sequence of computer screens and read aloud in a flat tone over his shoulder. "Left breast mastectomy seven years ago. Looks like despite chemotherapy and radiation, cancer has progressed to a Stage IV. Metastasis to the bone, liver and lung. Last round of chemo was two months ago but problems with decreased appetite and nausea remain." The physician clicked to a different computer screen and typed in Eva's orders: an IV for dehydration with Dextrose 5%, CT scan of the head, X-ray of right hip, morphine 15mg NOW, complete blood workup, and U&A. While the physician was typing, Eva stirred, leaned over to John,

and confided, “My mother came to see me today. But she just stood there when the ambulance came and got me.” John offered, “Well, she knew you had Rachel to take care of you, and she didn’t want to be in the way.” Eva sighed and looked off again at that empty corner. Rachel, assuming the physician had overhead this exchange, said in an undertone to the physician, “Our mother has been dead for forty-eight years.” The physician asked Rachel to repeat what she had just said and then added “psych evaluation” to the list of orders.

John stepped out of Eva’s ER room while the staff cleaned and bandaged her lacerations, changed her into a hospital gown, and shifted her to a bed. Rachel went to admissions to fill out insurance paperwork. She spent thirty minutes in line and twenty minutes with a staff member. Rachel asked the staff member if they would be able to look at Eva's PHR or at least access her medical records at her oncologist's office, to which the nurse replied, “I don’t know. See if you can catch the doctor before he leaves.”

When John was permitted reentry, Eva appeared to be sleeping. He held her hand as they rolled her bed to CT. John watched Eva’s IV bag sway as the bed rounded each hallway corner. The ER floor nurse modified the census, changing Eva’s status from ER to PET/CT. The census screen blinked accordingly in triage room #6.

The CT showed no hemorrhaging in Eva’s head. There was a delay in radiology due to a flu breakout that thinned the clinical staff. Therefore, Eva’s X-ray was delayed until the following day. As a result, Eva was admitted to the hospital for dehydration and with hip precautions until an X-ray could be done. Eva was admitted to the fourth floor in room 4012. John stood in what looked to him like a freight elevator, still holding Eva’s hand as they ascended floor by floor. Rachel stood to one side reading over an insurance paper. Rachel asked no one in particular, “I wonder what the doctor is planning to do and how long she will have to wait." John didn’t venture a reply. It was 02:00. A nurse modified the census changing Eva’s status from ER to MedSurg.

Eva was given a private room. Once settled in, a bubbly nurse named Janice entered pushing a computer on wheels (COW). The nurse read Eva’s wrist band and did an assessment of Eva’s vitals and condition. Janice alternated between doing an assessment on Eva, giving medications, typing and clicking data into the EHR, and talking with Rachel about the blood work done in the ER. “Her albumin was normal, oddly enough, but her BUN and creatine levels were extremely high despite her being dehydrated, but your neighbor down the hall, Mr. Shelton, came in after having a few too many and once we got him rehydrated his levels rebounded nicely so I wouldn't be too worried. I noticed that her white blood count was high. Yes, I saw in her history that she’s been fighting cancer, bless her heart. How often has she had to take Lasix for swelling?” After completing the assessment Janice pulled up a few rails, set the bed alarm, pushed the COW into the hall, and made a few additional entries into the EHR before moving on to the next room on her rounds. Rachel started to ask Janice a question, but she was gone before Rachel could manage it. Moments later John bade Rachel and Eva goodnight and went in search of the family comfort room to sleep until morning.

John woke to the alarm of his smart phone. It was 06:30. He rubbed his eyes, rolled off the couch, and followed the smell of coffee. It didn’t occur to him to question why he had slept the night in the visitors “comfort” room. He did it for Eva, a woman who thought his name was Ivan.

As John rounded the corner, a nurse with a COW was just leaving Eva’s room. He detained her to ask, “How is she?” The nurse replied professionally, “She is awake, has had her medication, and is stable.” “Yeah, but how is she?” John asked irritably. “I’m sorry, I can’t discuss it,” retorted the nurse. John had not registered that this was a different nurse from the previous night and that she was obviously unaware or unwilling to speak about Eva’s condition. He let the nurse leave, and she wheeled the COW to the next patient’s room.

John tapped on the door, heard Rachel’s response, and entered quietly. Eva was awake and looked in the direction of the wedge of light that skirted across the floor of her room. She smiled. “Oh, good morning, Ivan. I got your note. I would love to walk with you at Lefortovo Park, but my leg rather hurts. Rachel says I should stay in bed.” John smiled, “That’s OK, Eva. I’ll just keep you company.” John sat in a chair on the side of the bed and took the hand Eva extended. A monitor next to the bed beeped an irregular rhythm softly into the silence.

The psych physician arrived at 09:23. She asked Rachel and John to step out for a moment while she spoke with Eva. They both stood off to one side of the door. John leaned a shoulder against the wall, facing Rachel. John asked, “What do you think?” Rachel answered, “I don’t know. She is very sick. Since retirement she has spent much of her time tending to her flowers. It has been over a year since she could work in her flower garden. Mostly weeds now.” John asked, “Does she have family besides you?” “She has one son that she had out-of-wedlock in her thirties and raised alone, tall blonde-haired blue-eyed. Nice enough boy but can’t take care of his mother properly due to his work schedule. Both of our parents died in a car accident when she was nineteen. That’s pretty much it,” sighed Rachel. Rachel added almost as an afterthought, “Her hip is not broken. That’s a blessing.”

Earlier in the morning, the transport team had wheeled Eva to radiology for an X-ray where the radiologist reported no breaks or fractures. The door to Eva's room opened and the psych physician swung past Rachel and John without a glance in their direction. John called out, "What's the diagnosis, doc?" The psych physician responded over her shoulder, "The attending physician will have my report within the hour." With that she disappeared into the nurse's station. Rachel never learned of the result. John later read the report himself: "Patient completely aware of surroundings but showing signs of mild end-stage dementia. Manifesting symptoms include occasional hallucinations, irritation and forgetfulness. Start on low dose of haldol 1mg BID immediately. Recommend an acute care hospice facility." John hadn't seen any sign of irritation in his time with Eva and wondered if the irritation the psych doctor noted was due to Eva's lack of sleep.

Rachel and John reentered Eva's room and resumed their previous stations. The next visitor was a social worker. She asked who had medical power of attorney for Eva. Rachel wearily raised her hand. The social worker spoke with Rachel about the local nursing homes and then handed Rachel a pamphlet for a local hospice stating, "Eva shouldn't live alone." Rachel asked why Eva needed to be in a hospice. "Doesn't hospice provide end-of-life care?" Instead of answering Rachel, she said that Rachel really needed to speak with the attending physician when he came to discharge Eva. "So she is leaving today?" The social worker shrugged her shoulders. "I'm sorry I can't discuss that with you. HIPAA regulations you know." She patted Eva's feet as she left the room.

Eva looked up at John and asked, "Ivan, do you still have that red Bugatti? Remember when I asked you why it didn't have a radio and you said the hum of the engine was music enough? Oh that was such fun!" John answered, "No, unfortunately I had to get rid of it. Terrible gas mileage you know." "Yes, I suppose so," agreed Eva, nodding absently.

A brief knock on the door announced the entrance of the attending physician. He carried a blue folder and flipped pages as he walked to Eva's bedside. "Well, the blood work shows her BUN/Creatine levels are elevated. That is to be expected given her dehydration, the metastatic CA to her liver, and reduced kidney function. Nothing's broken. They've patched her up so I think she can go. I'm ordering some physical therapy (PT) to help her with the physical decline."

"If she is going to Hospice, why bother with physical therapy?" Rachel asked, puzzled. The physician paused for a minute and replied, "Well, there's no telling how long she will hold on. You can choose the PT or not, it's your call. I've entered her discharge order and the transportation team will be up sometime this afternoon." With that, he closed the folder with an air of finality, turned, and left the room.

Two hours later, a nurse returned with some printouts of educational material. She handed them to Rachel. "These papers describe proper care of her wounds, the extent of her disease, and information on life-sustaining treatment should you choose to pursue them. Be sure she drinks plenty of fluids." Rachel asked if she could have digital copies of Eva's treatment records to add to her PHR, but the nurse replied, "As far as I know only paper copies are available, and you have to pay $.10 a page for those."

"Are those my papers, Ivan?" Eva had watched the exchange with interest. "Yes. Looks like you are supposed to keep an eye on Semenko. He's a tough customer." Eva smiled and began to reply but was cut off by the entrance of the transportation team. Eva was rolled to a loading entrance where she was picked up by an ambulance to be taken on to the local hospice facility Rachel had researched in the last couple of hours.

As the bed approached the loading entrance, Eva looked over at John and asked, "You aren't riding on the ambulance with me, are you?" John patted her hand, "No, I'd just be in the way." John gave Rachel his business card, said goodbye, and watched through the large double glass doors as Eva was hoisted into the ambulance and driven out of sight.

A month after his visit to the ER, John received a padded envelope from BRH in his office mailbox. On the face of the envelope was written "To John." John opened the envelope and extracted a single sheet of notepaper. The note was from Rachel. "Eva passed in her sleep yesterday. She asked me to thank you for the lovely dance and wanted you to have this. Sincerely yours, Rachel." John emptied the envelope into his open palm; it was Eva's bracelet.

III. CONCLUSION

John replayed his brief encounter with Eva and his time at BRH. The hospital IT director was expecting John's report soon detailing how BRH could become more patient focused while still obtaining the benefits that health information systems could provide. John thought about the interactions that he had witnessed and wondered if there was

anything that could have been done differently so that Eva's experience might have been better. John slipped the bracelet into his shirt pocket and began to write his report.

IV. SUGGESTED EXERCISES

Patient Journey

- Describe the concept of a patient journey.
- List the steps in Eva's patient journey through BRH.
- Enumerate activities, roles, and responsibilities involved in Eva's patient journey.
- Write a narrative similar to the teaching case of a patient journey. This could be a personal experience or the result of interviewing a healthcare professional.

Process Flow Modeling

- Depict a patient journey as a process flow diagram.
- Depict a patient journey in terms of EHR process flow (this requires the student to have access to an EHR system). In our curriculum, we integrate a fully functional EHR system throughout.
- Identify places in process where the patient can/does interact with system/data.

Data Flow Diagramming

- Draw a context diagram and Level 1 DFD for all or a portion of Eva's patient journey.

Entity Relationship Diagramming

- Draw an ERD for all or a portion of Eva's patient journey.

Patient-Centered E-Health

- Rewrite the teaching case narrative to illustrate how Eva could have been meaningfully engaged and empowered.
- Rewrite the patient flow diagram to illustrate how Eva could have been meaningfully engaged and empowered.
- Rewrite the DFD diagrams to illustrate how Eva could have been meaningfully engaged and empowered.
- Draw screen mock-ups or story boards for EHR screens that provide meaningful engagement and empowerment in the context of Eva's patient journey.
- Discuss human factors as related to the system interface for the patient, healthcare staff, and EHR interaction.

Sample solutions and extended teaching notes are available by emailing the corresponding author, Harold Pardue.

SUGGESTED ADDITIONAL READINGS/REFERENCES

Editor's Note: The following reference list contains hyperlinks to World Wide Web pages. Readers who have the ability to access the Web directly from their word processor or are reading the article on the Web can gain direct access to these linked references. Readers are warned, however, that:

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Pamela Wisniewski is a post doctoral scholar at the Pennsylvania State University. She received her PhD in Computing and Information Systems from the University of North Carolina at Charlotte in 2012. Pamela is a socio-technical researcher who is intrigued with how humans and technology interact, and how humans interact with one another through the use of technology. Pamela has over seven years of experience as a systems developer for the financial services and the medical consulting fields. Her current research areas include human-centered computing, social networking, and Internet privacy. Her work has been published in *Computers in Human Behavior*, the *Conference on Human Factors in Computing Systems*, the *ACM Conference on Computer Supported Cooperative Work*, the *Americas Conference on Information Systems*, and the *Annual Meeting of the Academy of Management*.

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