Implementing a Kidney Transplant Management System
(Technical Topic)

Health Information Technologies' Influence on Professionals and Patients
(STS Topic)

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By
Natalie Zhang

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Technical Team Members: Josie Lamp

On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

Rider Foley, Department of Engineering and Society

Lu Feng, Department of Computer Science

Introduction

Patients needing organ transplants can wait for more than five years for a donation in the United States (Wu et al., 2018). The deceased-donor waitlists, lists of organ receivers waiting for donations from deceased organ donors, are long due to low supply (Trotta, 2021). Transplant coordinators ensure that patients on deceased-donor waitlists receive organ donations. Communication between the coordinators and the donor's family, recipient, doctors of the patients, hospitals, medical laboratories, and surgeons are vital to a successful transplant (University of Virginia, 2021). Considering the amount of information to track, such as test results, appointments, and waitlist updates, it may come as a surprise that this is currently being done manually. With no standardized technical system in place, the risk of human error increases and the work for communication takes away time from other life-saving tasks a coordinator could be doing. UVAHealth provides kidney transplant services, and a software-based technical management and support system that transplant coordinators can use to monitor patients and assist in tasks is an appealing solution.

My technical project entails implementing a kidney management system that automated visualization and tracking for coordinators and patients to utilize. The system provides visualization on deceased-donor waitlist information while prioritizing those who have been on the waitlist longest. It also utilizes a relational database to store information via tables on patients and coordinators, allowing for efficient information accessibility and retrievals. Both coordinators and patients can log in and access the information needed in a secure manner that requires authentication as dictated by the Health Insurance Portability and Accountability Act (HIPAA). HIPAA sets a standard of protection of patient data to prevent their data from being released without their consent (U.S. Department of Health & Human Services, 2018). The

system will bring a clean and organized user interface and user experience to offer both patients and healthcare professionals refined communication and information accessibility.

It is important to examine how the management system will affect the interactions in transplant services. Like any other office space, there are also political and institutional dynamics that occur within hospitals to consider, such as office politics and physician-nurse relations, that can affect patients (Jerrard, 2018). Implementing the foundation for a kidney transplant management system aims to ease communications between different healthcare professionals as well as patients and to provide organized information. Later, I will be looking into how advanced technology has affected communication/interactions between doctors, healthcare workers, coordinators, and patients.

Developing a Kidney Transplant Management System

Over the decades, hospitals and healthcare systems have adopted various health information technologies (HIT) to improve practices and procedures. In terms of communications and data collection, electronic health records (EHRs) and the Internet have provided greater protection, storage, and more accessible modes of connecting patients, healthcare professionals, and others involved. Nowadays, there are systems in place that allow patients to view their information electronically. Some database applications, such as MyChart, now allow patients to have access to medical information and doctors notes immediately after a doctor appointment concludes (Epic, 2017). However, hospitals and healthcare systems are slow when investing HIT to and frustrations that healthcare professionals face when using HIT have been well-documented (Coye and Kell, 2006). These problems indicate that HIT still needs to consider the requirements of the users operating on the system in their functions.

Attempts at implementing a kidney management system incorporate key features, including a secure database. For example, Bircan et al. (2015) designed a similar system for healthcare professionals to track patients on the deceased-donor waitlist and ensure patients were prepared to receive an organ. Major features of the system included a search tool, an alert or reminder feature, and distributed system management permissions. This database system attempted to lower the high mortality rate of patients on dialysis, a procedure that continuously filters a patient's blood due to the kidneys' inability to do so (Cleveland Clinic, 2021), and to increase the rate of receiving a deceased donor kidney. The system would decrease the number of potential rejections due to patients not meeting the required tests and checkups necessary. Although future clinical trials need to be performed to assess the success of this system, the features created were designed considering the need for organizational information to track tests and to increase the chances of patients receiving transplants from the deceased-donor list. The technical project aims to incorporate these considerations and features.

Previously, researchers on the technical project created a conceptual kidney transplant management system for the University of Virginia (UVA) Kidney Transplant Clinic. Current issues with HITs identified in previous studies examining transplant systems found a lack of support for communication between healthcare professionals as well as their patients. This includes challenges with healthcare professionals tracking patients' lab results and appointments as well as the patients' confusion on the process and tests necessary. The kidney management system will have the necessary features to address these needs. The main feature that is the focus of the project is the visualization of a patient waitlist. Coordinators can view the waitlisted patients they are responsible for and track their attendance in appointments ensuring that patients are following routine tests. Formatting and prioritizing the information coordinators want to view

will be enhanced while allowing them to measly access more detailed information on a specific patient or test. Automated reminders and alerts will be the next step. These features provide patients a greater chance of receiving an organ, hence a database system that focuses on automating reminders and ease of looking up patient information (Demirag et l, 2021). By having automated tracking that can update information about patients immediately and providing a more comprehensive way of seeing patient data, healthcare professionals can make more informed decisions on treatments, administration of testing, and waitlist decisions. Transplant coordinators can view the patients on the deceased-donor waitlists and their laboratory tests. Patients can view notes from tests or previous appointments and reminders for upcoming ones. We plan on having patients access their information via a portal that can be accessed by computers, and later provide access from mobile devices. Currently, the main priority of the project is on the coordinators' side who will be utilizing patient information as part of their jobs. The prioritization of these features was a result of feedback from stakeholders, including clinicians working at the UVA Kidney Transplant Clinic.

This system addresses frustrations users have faced, such as simplifying technical systems and providing other modes of comprehending patient data via visualization. With this, coordinators can communicate about diagnosis and treatment options that can be later discussed as well as provide patients understanding of medical knowledge while also having a smooth user experience for both parties. Visualization techniques, such as explanations, biometric statistics of a patient, and alerts and reminders, can better be used to enforce communication between patients and healthcare professionals. Visualizations facilitate a better understanding between them and can prevent negative perceptions of medicine that patients may have. They also suggest that visualization techniques would result in several beneficial effects, such as providing patients

a greater understanding of their health and the diseases or conditions that affect them (Rajwan and Kim, 2010).

Healthcare Information Technologies' Influence on Communication

While the focus of the technical project is designing a management system for kidney transplant coordinators and clinicians, I will also explore the current way technology is used for communication between healthcare professionals and patients and the issues related to them. The solutions that the technical project addresses issues of incorporating HIT into existing systems. When it comes to designing technical systems, engineers consider the design criteria to support their purposes. In practice, knowing the requirements, covering all use cases, designing features, and gathering feedback from stakeholders is challenging. For example, several technical challenges were identified when performing usability tests for EHRs. They can be costly or require significant effort to conduct and still have issues with consistency and accuracy. The EHR system not only needs to integrate with the current HIT a hospital has, but it must also communicate with other EHR systems to exchange data (Swanson and Lind, 2011). Although these challenges are specific to them, most of the issues can be expanded to HITs. Creating an environment that routinely tests medical systems can be difficult, especially the risk healthcare systems face by using technology going through testing as well as additional effort and costs. Procedurally establishing and generating rational quality requirements, such as the MOQARE method which creates countermeasures and minimizes unintended consequences from potential defects, is an approach that developers use to create and secure technical systems to mitigate issues from lack of usability testing (Paech and Wetter, 2008).

Users of HITs, which includes healthcare professionals and patients, have experienced the benefits and unintended consequences from them. Expanding upon EHRs, nurses depend on

EHRs to plan for patient care since it requires specific assessments to match the needs of the patient and maximize the time spent with them. With this, however, they may ignore concerns a patient brings up or other input irrelevant to the EHR's information from them. In addition, physicians relying on information from EHRs when making treatment decisions encourage nurses to prioritize gathering data over patient care. Patient-nurse relationships and interactions between healthcare professionals are affected by innovative HITs (Campbell and Rankin, 2016).

Disruptive HITs have also led to strained relationships between patients and doctors. Cupit et al. (2019) showed that doctors refer to risk-scoring technology to classify the severity of cardiovascular disease and to judge treatment decisions despite concerns a patient has, such as taking statin medications, which help lower cholesterol levels to prevent cardiovascular disease. Physicians also found that describing such a complicated situation is difficult for patients to comprehend and decided not to create a discussion out of it. Since patients are not familiar with the judgments considered in the risk-scoring technology due to a lack of clarification from doctors, patients are less willing to be open about their opinions with healthcare professionals.

However, HITs that succeed in communication have been shown to improve patient relations with physicians. With the increase in ways available for patients to retrieve their information, patients and doctors appear to have improved communications with HITs. Unintended risks like increased worry were minimal and benefits such as increased trust between doctors and improved medical knowledge in patients, was evident. Improved medical understanding also correlated with patients making fewer appointments. One motivator was that patients began to self-address problems potentially due to expensive healthcare costs. (Ross and Lin, 2003). Clearer explanations and allowing patients greater access to their health records can

provide greater trust and effective dialogue regarding patient treatment; however, there will always be unintended consequences that are difficult to mitigate.

To better understand the socio-technical dynamics behind HIT, the Interactive Sociotechnical Analysis (STA) model will be used to further examine them (Harrison et al, 2007). Analysis of the feedback on interactions between social groups with introductions to new HITs or disruptive technologies will be addressed. The sociotechnical interactions and unintended consequences can be viewed via the feedback loops addressed in the model to explain phenomena in healthcare and hospital systems. The main feedback loops that will be addressed are the technical and physical infrastructures mediate HIT use, social systems mediating HIT use, and HIT-in-use changes in the social system. One goal is to examine how unintended consequences come about due to difficulties with implementing new HITs within existing physical and technical infrastructures. Identifying how healthcare professionals work around these challenges and how the purpose of HITs has deviated from their original intensions. For the loop observing how social systems mediate HITs, understanding how these interactions have affected their work allows us to understand the behavioral changes that affect standard practices and collaboration between healthcare professionals. This feedback also leads to the need to examine HIT-in-use changes in the social system, which helps us understand how overdependence on technology changes how healthcare professionals make decisions and their roles. This framework will provide a better understanding on how these interactions between HITs, practitioners, and patients will change the way social entities communicate with one another.

Research Question and Methods

The research question being asked is: How has advanced technology affected communication/interactions between doctors, healthcare workers, coordinators, and patients? Medical misinformation has begun to spread through social media and groups of people who disbelieve the evidence behind vaccines and diseases. Although actions have been taken to combat it, there are still tensions between medical professionals and doubtful social groups (Murthy, 2021). In addition, awareness of historical medical mistreatment against minorities has become an issue when trying to encourage them to receive Covid-19 vaccinations. Addressing medical mistrust in communities of color and establishing trust between healthcare professionals and these groups is vital to continue this effort (Hostetter, 2021). The roles of healthcare professionals have also greatly evolved where doctors rely on others for support. For example, nurses have moved away from solely following instructions from the doctors to performing educated patient-care, allowing them to answer patient questions and discuss with doctors about patient health (Maryville University, 2020). As such, with the growth of technological advancements in the healthcare field, it is important to ensure that healthcare professionals can efficiently utilize the tools provided and address concerns that may come from changes over time, considering both the benefits and unintended consequences.

To explore this question, I will be conducting interviews and surveys as well as looking through case studies and other interviews with healthcare professionals done previously. Interviews will be with various healthcare professionals, such as pharmacists and nurses, to gain a better understanding of their experiences with HITs and their relations with other healthcare professionals. These interviews will provide a better understanding of how HITs are changing the relations between actors in the healthcare system and the potential issues and unforeseen

consequences that have arisen. It can also help pinpoint some of the specific areas that developers could address, or the healthcare system and hospitals can mitigate through different measures. Responses can support some of the specified feedback loops between HITs and healthcare professionals observed in ISTA that we want to pinpoint. The survey will be conducted on the Charlottesville population who have visited doctors or have been treated in a hospital at UVA Health in order to keep consistency with results. Please see the Appendix for prototypes of these questions. The survey will provide answers on how effective technological communication has been used for patients and healthcare professionals to communicate and how behavior has changed with it. It will also be used to analyze the effects of the specified feedback loops the ISTA framework has on patients. The survey will be posted on social media groups where the Charlottesville community interacts, and door-to-door visits will be made to gain a better response rate. With this evidence, a clearer picture of the social and technical interactions with HITs can be discovered.

Conclusion

Advancements in medical technologies have provided more immediate and efficient ways to treat patients and assist healthcare professionals with their work. It has also changed how they communicate, and thus how they interact with one another. Understanding the changes and effects that disruptive HITs have in these systems will provide solutions and mitigating measures to address the concerns each of the social groups' faces. Through my research, I will address and identify the issues faced by patients and healthcare professionals and understand how HITs have affected communication between these social groups

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Appendix

Here is a draft list of questions that will be asked in the survey for patients. This will be later refined with more research and feedback from peers who will be screening the questions before it is sent out. More questions will be added later, and some will be removed based on

feedback from peers. Each question will have different options people can select from as well as a field where they can put their own answers.

General questions confirming that they are someone who lives in Charlottesville and assessing their age will be asked first to assess the demographic

1. How often do you visit a doctor or similar healthcare professional?
2. How many doctors do you typically see?
3. As best as you can, select the reasons you usually have when visiting a doctor.
4. Did you get vaccinated for Covid-19?
    a. Was your doctor or other healthcare professionals a factor in your decision? Please select the relevant choices from the following options
5. How do you feel about your relationship with your doctor(s)?
6. If comfortable, why do you feel this way? What are some things that help you feel so?
7. If uncomfortable, what are the issues preventing you from feeling more comfortable?
8. How do(es) your doctor(s) communicate with you? Please select any of the following options
    a. This will have options ranging from different software to traditional ways via phone call, paper, and other modes of communication
9. (Based on which modes they select): Rate XXX way of communication.
    a. Optional: Why did you give it this rating?
    b. Do you use this communication often when you visit or communicate with your doctor(s)?
        i. If yes: Select the following reasons you do not use it
        ii. If no: Select the following reasons you do not use it

c. Have you felt like this has helped or hindered your relationship with your doctor(s)?

10. How would you rate the interactions between you and nurses? (1-10)
    a. If < 7: What are your interactions typically like? What are some of the issues that lower your rating?
    b. If >=7: What are your interactions typically like?