Bridging the Gap Between Social Networks and Healthcare: An Assessment of the Need for Improved Patient-Patient, Patient-Provider, and Provider-Provider Sharing

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Abstract

Health care communication often breaks down at the end of major treatments or procedures and creates divides between patients, their providers, and their support networks. The study investigates how the principles of social networking might bridge these gaps without succumbing to common pitfalls of social media in healthcare. In this review of the literature and in the use of social network analysis, the many communications challenges faced by patients like managing complex medication schedules, coordination among many providers, and keeping up with support for their mental health were identified. Patients reported feeling isolated and overwhelmed once they were discharged from the hospital, struggling to manage their care and stay in touch with their healthcare team. In light of these challenges, using social network theory as a guide, this study considers how a central communication hub might help to connect all members of a patient's care circle without sacrificing privacy and security. This study is not an argument for a specific technical solution but does provide a pragmatic framework for the building of superior healthcare communication tools which put patient needs first.

1. Introduction

Building effective communication between all parties involved in a patient's health care journey is critical to patient success. This literature review aims to assess the need for new tools that facilitate communication between patients, care providers, and health care professionals. This review of the literature aims to explore three key questions, including: Is there a need for better tools to facilitate closer relationships between patients and providers, what are the potential benefits of connecting patients of similar experiences to bridge communication gaps, and what is the value of improved coordination tools for diverse healthcare teams. Using social network analysis methodologies, this research will identify opportunities for strengthening bridges between these disparate teams while avoiding common challenges when it comes to social media, such as the ethical implications and difficulty of adoptions. This paper aims to carefully consider the benefits, as well as the risks associated with building social systems in the health

care process in order to provide a balanced framework to build on. So while the aim of this research is to compile a literature review, it is not in scope to build a practical solution. The goal of this paper is to offer a conceptual framework that lays the groundwork for future investigations into how care circles can improve health outcomes.

2. Methodology

This study will use a literature review and social network analysis to explore how communication in healthcare can be improved, especially after patients undergo major treatments or adopt new health plans. The main goal is to identify key communication issues within their "care circle" (the patient's network of family, care providers, health care institutions, and fellow patients) and see how these connections can be used to have more positive impact on their post-operative outcomes.

2.1. Literature Review

The first part of the study will focus on literature review, where existing research will be gathered and analyzed in two main topics:

- **Post-Treatment Care**: The ways patients and health care providers communicate after their procedure can affect the success of the treatment overall. The challenges and gaps in post-treatment care, such as issues with care coordination between different specialists, will be used to inform strategies for improvement.
- Social Networks in Healthcare: This paper will review how social network analysis, including things like the "small world" effect, can improve communication between patients and their healthcare providers. This includes looking at how stronger connections within a care team and patient's personal support system could improve patient outcomes.

The overall aim of the literature review is to identify patterns, key challenges, and existing solutions in the communication between patients and providers after surgery.

2.2. Social Network Analysis (SNA)

Next, social network analysis (SNA) will be used as a tool to visualize and analyze the information gathered from the literature. Social network analysis modeling will help to show how people involved in post-treatment care (patients, primary care providers, specialists, etc.) are connected and interact with one another. Specifically, this study looks at the following:

- **Optimization of Centrality**: Modelling to help show how directly patients are connected with their healthcare providers prior to and post adopting centrality, and how well do different providers (e.g., surgeons, nurses, specialists) communicate with each other?
- **Small World Effect**: Can the "small world" effect (the idea that everyone is connected through a few steps) be applied to healthcare? In other words, can improving

connections between different people or teams in the care circle lead to better communication and patient outcomes?

• **Building Hubs**: Can introducing a hub node as the source of truth help connect the individuals in a care circle?

Social network analysis will provide a visual map of the relationships within the care circle which will help in identifying areas where communication could be strengthened and nodes connected. The goal for future research would be to make these networks more connected as a possible solution to improve patient outcomes post-treatment.

2.3. Synthesis of Findings

Once the literature review is complete and the social network analysis is done, a framework for building more connected "care circles" can be developed. This involves comparing the insights gathered from the literature with the results of the network analysis to create a clearer understanding of the challenges and opportunities in improving communication within post-operative care.

2.4. Limitations

This study has a few limitations:

- **Scope**: The research focuses specifically on post-treatment care (particularly post-operative and other large procedures), so the findings may not apply to all areas of healthcare. The scope is also affected by the amount of time given to complete the project as well as it is being done by a single person.
- No Direct Patient Input: The study will not include interviews or surveys with patients or healthcare providers, so it will rely on existing research. This is primary due to the difficulty and time constraints in receiving ethics approvals. While this offers a broad perspective, it might miss out on real-life details and more specific patient or provider challenges.
- **Time Constraints**: Due to time limitations, the study will not include surveys or other data collection methods that could have provided additional insights. However, the findings from the literature and social network analysis will still provide a solid foundation for understanding communication issues in healthcare.

3. Post-Treatment Challenges

3.1. Long-term Treatment

Patients are not in the clear once their procedure is over or their treatment plan is set. Once finished, there is often a rigorous schedule of medications, tests, and appointments to ensure they are recovering. Patients with conditions that are incurable will encounter no shortage of

physical, mental, and social challenges that can last their lifetime and require careful navigation and support. We are going to focus on a few specific challenges this research aims to address:

3.2. Medication Management Challenges

Patients are often required to maintain a strict medication schedule that is vital for continuity of care. This is particularly important since missing even a single dose can have severe consequences on their treatment in the future. Patients will often need to take multiple medications at specific times throughout the day. Many of these medications including things like immunosuppressants can trigger many side effects ranging from increased chance of infections to significant changes in appearance and weight[1]. This is not simply an issue of remembering to take pills. It is primarily about understanding drug interactions, managing side effects, and maintaining a consistent schedule. There are other factors impacting adherence to medication schedules. In a study by Localio et al., participants including patient advocates, patients, and providers cited communication, logistical, and financial barriers impacting adherence[2] such as the cost of medication, patient misconceptions regarding their medications, and long insurance approval processes.

3.3. Healthcare Navigation Challenges

Managing a patient with complex healthcare needs is like conducting an orchestra where each musician plays a key role, but they're all in different rooms. Patients aren't just following doctor's orders - they're juggling a complex set of medical tasks that can quickly feel overwhelming.

Patients struggle with a seemingly endless list of responsibilities. Aside from medications, they coordinate with multiple healthcare providers, manage complex treatment plans, and manage multiple appointments. Many patients feel they didn't receive enough clear information before leaving appointments with their primary healthcare provider, which makes everything harder to manage. In fact, six studies referenced by Yang et al. showed that patients need better education and support to assist in the navigation of life post life-altering treatments like organ transplantation[1]. The study by Localio et al. communication issues were rampant and were often due to language barriers and failure to follow up correctly on both the provider and patient sides. Furthermore, providers noted that they were unsure whether they explained medical information to their patients at the appropriate literacy level, and whether patients understood what was said during the short visits. There also seemed to be a number of providers concerned that patients did not always communicate issues outside of a medical visit, which mirrored the patient's concerns that long wait times made accessing their providers tedious with long gaps between visits[2].

3.4. Mental Health and Social Challenges

Patients encounter a wide range of mental health and social challenges post-operation. Yang et al. highlighted eleven studies where psychological difficulties were actually the most common challenges patients faced[1].

Here's what they found:

- Transplant Patients often experience anxiety and depression linked to fears about organ rejection and infection[1]
- Many struggle with mood swings that mirror their physical condition[1]
- The stress of maintaining medical schedules can feel overwhelming[1]

But it's not just about emotional health - it's also about how patients fit back into their social life. Six more studies discovered that many patients feel socially isolated because of their condition[1]. This isolation can negatively impact everything from self-image to relationships with friends and family. Some patients even need to completely alter their social roles and lifestyle to accommodate their new health requirements.

As well it is often possible for patients to feel a sense of distrust towards their providers. This can result in information given to the provider that is not entirely truthful, which inhibits the ability to provide proper care. As one provider mentioned in the study by Localio et al., "I think a lot of patients are afraid when things aren't going well because they think they're going to be judged."[2]. This fundamental distrust can come from a history of poor care, or may even stem from an altered emotional state due to symptoms the patient may be experiencing from treatment. Either way, building that trust both ways is critical to patient success. In a study by Greene and Ramos, they found the following: "What builds their trust is a combination of the health provider communicating effectively, caring about them and their health, and demonstrating competence. For communication, participants stressed the importance of being listened to and having detailed and honest explanations about their health issues"[3]. This reinforces that trust is critical to the mental well-being of patients needing long-term care, and will often come down to feeling heard and maintaining open communication.

3.5. Support System Needs

Eight studies highlighted by a literature review by Yang et al. emphasized that psychological support needs were at the top of patients' priority lists, especially when they found themselves alone after the initial wave of post-surgery attention faded[1].

The research highlighted three key areas where support is critical:

- **Emotional and Spiritual Support**: Studies show that emotional support becomes particularly crucial for patients' mental well-being, especially when they're dealing with negative emotions and physical pain simultaneously[1].
- **Social Support Network**: Five studies found that patients actively sought support from a trio of sources: family, friends, and other transplant recipients[1]. Some of these studies noted that helping patients maintain these connections was crucial for their quality of life.
- **Practical Support**: Research by both Yang et al. and Localio et al. revealed that many patients need tangible assistance, including financial and physical support. The studies found that the considerable costs of medical procedures and ongoing care often become a family burden, highlighting the need for both emotional and practical support

systems[1], [2]. Practical support is vital to improve patient outcomes but financial support will not be addressed in this review.

The concerns of patient support are echoed by Culp et al. in their study, when respondents showed a sizable lack of confidence in their dialysis clinic's ability to support patients in the long term[4]. Their concerns primarily came down to a lack of guidelines to help with decision making in seriously ill patients: "It is noteworthy that respondents identified 'guidelines to help with decision-making in seriously ill patients' as the one change that would most improve supportive care in their centers. The majority were unaware that such a guideline already exists.[4]"

3.6. Where Technology Comes In

Analysis of the study results referenced above reveals several critical needs that warrant consideration in developing social connectivity features. These needs emerged consistently across patient experiences, providing clear direction for potential solutions.

The research highlighted four fundamental areas where enhanced social features could meaningfully impact patient outcomes:

- 1. **Information Gap:** Studies demonstrated that patients consistently encountered an information deficit upon discharge, finding themselves inadequately equipped with the knowledge needed for optimal recovery. This gap in understanding frequently led to uncertainty and anxiety during a critical recovery period[1], [4].
- 2. Lack of Care: Further analysis revealed a pronounced decline in perceived care following procedures. Patients reported feeling deprioritized once their treatment concluded, suggesting a critical need for sustained engagement mechanisms. This sentiment of abandonment during recovery emerged as a consistent theme across patient experiences[1].
- 3. **Social Isolation:** Social isolation emerged as another significant challenge, with patients reporting disconnection from their support networks during recovery. This separation from friends and family appeared to have substantial implications for their emotional well-being and recovery trajectory. The research indicated that this isolation often compounds other recovery challenges, highlighting the importance of maintaining social connections[1].
- 4. **Overwhelming Medication Regimen:** Additionally, patients consistently reported struggling with medication management, finding their prescribed regimens overwhelming and complex. This challenge frequently led to anxiety and concerns about recovery outcomes, suggesting an opportunity for socially-enhanced support mechanisms[1], [2].

While these identified needs represent only a portion of the post-treatment experience, they provide a strong basis for building a social analysis framework. This framework can guide future development efforts, ensuring that proposed solutions directly address documented patient needs while maintaining flexibility for various implementation approaches.

4. Social Healthcare

4.1. Current Benefits

The use of social networks in the healthcare field is not an entirely new concept. Telehealth is the act of transitioning health care interactions that are usually done in person to a digital space, thereby transforming traditional face-to-face medical consultations into virtual interactions accessible from almost anywhere. Instead of going to your physician's office, it's often possible to meet your doctor remotely using a web browser or mobile app, saving you travel and reducing the time commitment usually required for medical consultations. Some of these applications even allow the sending of documents to health professionals, besides the sending of requisitions to patients, therefore creating a smooth digital flow of medical information and necessary documentation. This feature is particularly important for populations that are considered at higher risk, especially those who face important barriers to accessing traditional healthcare services. In a paper by Bailey et al., they state that "Telehealth modalities have great potential to help overcome geographic, socioeconomic, cultural, and language barriers related to the social determinants of health and enhance access to essential health services for high-risk populations"[5]. Their results demonstrate that telehealth systems can effectively reach underserved populations in their own communities[5], making healthcare more accessible to those who might otherwise struggle to receive regular medical attention due to various social, economic, or geographical constraints.

4.2. Criticisms

While the paper by Bailey et al. highlights all of the ways telehealth can be helpful, there are some very valid criticisms of any social approach to healthcare that leverages internet based social technologies, particularly when considering the complex interplay between digital connectivity and medical privacy. One such paper by Denecke et al. highlights a set of concerns about internet based social media for patient-patient and patient-provider communications, delving into the nuanced challenges that arise when healthcare interactions move into the digital sphere[6]. Social platforms inherently introduce a different dynamic when it comes to what people share and when they share it, and it all comes down to the question of ethics and data privacy - a consideration that becomes increasingly complex in the age of digital footprints and permanent online records. They state physicians would potentially have access to online patient information that may otherwise not be available in the healthcare setting[6], creating a scenario where the boundaries between professional medical knowledge and incidental social media discoveries become blurred. This is not inherently dangerous, but does ask for increased sensitivity in safeguarding patient privacy on the side of the provider[6], as providers in this complex balance must navigate harnessing available useful data to improve quality of care, respecting the accepted boundaries of the physician-patient relationship, while sustaining strict ethical and professional standards about patient confidentiality and privacy. The challenge is not only how to protect the data itself, but to develop clear guidelines for the handling of inadvertently received information in the context of professional medical practice.

The critiques extend beyond the realm of patient-provider confidentiality; they also encompass situations in which an individual seeks contact with others facing analogous health challenges. Such peer-to-peer engagement, although it may offer advantages in terms of emotional support and shared narratives, brings forth a distinct array of intricate privacy and safety issues. The paper of Denecke et al. asserts that "social networking communities and data sharing platforms support sharing experiences with conditions, symptoms, and treatment outcomes, but also enable to track personal health and be actively involved in one's own care coordination"[6].

While these platforms hold promise in the areas of improving health research and practice, mobilizing social action, and facilitating offline health-related services and events[7], they also present unique challenges. The dual nature of social health platforms—both an empowering force and a potential contributor to risk—makes for a particularly complex situation that calls for detailed exploration. This can be particularly troublesome for pediatric patients, who may lack the experience to know what information should be kept private and what can be shared, even in online patient support forums. The vulnerability of younger users in these digital spaces causes great concern about their ability to make adequately informed decisions about the sharing of personal health information. The authors go on to claim that "increasingly, social networks are being used to investigate adolescent and young adult behaviors and personality traits, as well as for data collection and education purposes"[6], further supporting the idea that such sites serve not only as places of communication and support but also as a source of data that could have important implications for younger users who might not fully understand the permanence of their presence in health-related social networks.

5. SNA (Social Network Analysis)

5.1. Setting the Stage

To begin analyzing how a social network platform or framework can be used to optimize patient care, we must first look at the participants in the existing patient care circle. Generally speaking, we can split the care circle into the following components:

- 1. The Patient
- 2. Healthcare Provider Primary Care
- 3. Healthcare Provider Urgent Care
- 4. Healthcare Provider Specialist(s)
- 5. Family
- 6. Friends
- 7. Similar Patients

We can group these different participants into four broad categories like so:

- 1. Patient
- 2. Provider
- 3. Family & Friends

4. Similar Patients

Once we have these groups, it becomes easy to see the possible lines of communication. Every participant in this circle needs to have their communication with the others optimized to improve outcomes for patients. The core issue here is that the onus falls on those parties to reach out and to be aware of the other members. It is best now to put a pin in that, and move on to a few basics of network theory that will prove helpful.

5.2. Network Theory and Centrality

Social Network Theory is based on two basic building blocks: the concepts of nodes and edges. Nodes are members of the network and correspond to individual actors or entities within the system, while edges correspond to links between two nodes, which represent relationships or interactions amongst those members. With that in mind, one can notice that a network can be made up of several nodes linked to one another by means of edges with complicated patterns of interconnectedness, which could represent real-life social structures and sets of relationships. Another important concept to bring into view is that of the notions of bridges and hubs. Bridges are edges in a network that connect large parts of a network, essential connections between otherwise disconnected or poorly connected groups. A hub, on the other hand, is a node with a huge number of edges emanating from it, serving as a centerpiece of connection among many other nodes in the network. The Calgary or Vancouver airports in Canada could be called examples of hub nodes, acting for international connections to and from the country.

Another basic concept is that of Centrality. Centrality, in terms of social network analysis, designates the degree of influence a node has either by its position or by its links, mapping the relative importance and power relations inside the structure of the network. Centrality can be sub-classified into three categories: degree, betweenness, and closeness[8]. It defines the degree centrality, which is the number of links a node has, showing directly the connections and, therefore, the influence of each node in the network. Nodes with high degree centrality have more social contacts and, therefore, enjoy more chances of receiving and diffusing information[8]; hence, they are very likely to be the key actors of information flow and social influence inside the network. Betweenness centrality measures how often a node lies in the shortest path between two other nodes and is thus an indicator of its role as an intermediary in network communications. High betweenness centrality indicates that a node may serve as a bridging node between two or more parts of the network structure[8], hence, to a certain extent, controlling and influencing the flow of information between other parts of the network structure. Closeness centrality can lastly be defined as the measure of the average distance from a node to all the other nodes within the architecture of the network. It has been given that nodes with high closeness centrality are well linked and require relatively fewer steps to reach other nodes across the network[8]. This property makes them well placed for speedy dissemination of information across the entire network.

5.3. Building the Network

Communication was mentioned as a major obstacle to patient success in previous chapters, which can be illustrated by mapping the relationships between the stakeholders in 5.1. When mapped as a network, each stakeholder shown in Figure 1 is a node that needs to keep information current and timely with several other parties:





The following examples highlight some of the issues that stem from such a network structure. The relationships between people in a patient's care network are quite complex, with a high variability in the availability of information at each node. The dissemination of information across this distributed system requires multiple hops, leading to delays and inconsistencies. This is particularly true for family and friends, who must receive all updates exclusively via the patient node. Without the central hub, maintaining consistency of information across the network is very difficult, thus leading to different versions of the same events existing in different parts of the network. However, the addition of a hub would now provide direct communication between all nodes and the hub, which hence allows for centralized management of information:



Figure 3: Adding a Hub

Incorporating a hub exploits the centrality property described in section 5.2 by providing a single authoritative source that all nodes can refer to and update, commonly implemented as a website or application. However, this comes with inherent risks. A highly connected hub, as depicted in Figure 3, is a severe vulnerability; if it is compromised then it could potentially cut the connectivity of the whole network. Consolidating information to a single node means only one point has to be exploited to have an effect on patient care. Further, there are issues of privacy, as all information has to go through this hub node, requiring strong security and established trust. Inherent in such a centralized architecture is, therefore, a basic trade-off between accessibility and security, which must be attentively balanced. While this approach offers clear benefits in terms of information consistency and ease of coordination across the network, it requires rigid access control to ensure nodes are authorized to access only the specific information they need, nothing more.

We can also apply the small world principle, where nodes can be connected in surprisingly few intermediary steps. In a small world network, even distant nodes could quickly communicate through strategic shortcuts, much like people can often be connected through merely six degrees of separation[9]. While this could improve efficiency in information sharing across a healthcare network, it further amplifies the security issues already discussed. If malicious actors

gain access to even a peripheral node, they might be able to traverse the network and access the more vital parts through these shortcut paths. This problem is even more critical in healthcare networks since every additional link between nodes represents not just a communication channel but also an additional vulnerability for the private data of patients. The small-world property, while making the network more efficient to traverse with fewer intermediary steps, requires that each connection be very carefully weighted between accessibility and security. Especially, the implementation of strong authentication protocols and encrypted communication channels becomes even more imperative when the average path length between nodes is lowered. Ultimately, it seems that this approach of adding a hub node for all members in a patient's care circle would allow for more seamless communication and coordination, so long as the risks are appropriately managed.

6. Conclusion

Communication breakdowns in health care pose real problems for patients, especially after they have left the hospital. The research shows that patients struggle with everything from managing their medications to coordinating between different doctors, largely because there's no easy way for everyone involved in their care to stay connected and informed. While social networking technology has the potential to help solve these problems, any solution will need to carefully balance making communication easier with protecting patient privacy.

Social network analyses are suggestive in this research of the creation of a communicational hub which might just work: imagine a locked, secure platform where patients and doctors, family members, other care providers can all know and stay updated. This would serve as one source of truth that would help with the confusion when different people each have different information about a person's care. However, such a system is not without its challenges. Such a platform needs to be secure enough to keep medical information private, accessible even to the least technologically capable, sensitive in what data is shared with whom, and reliable enough for doctors and other healthcare professionals to trust and use it.

Although this research will not provide the complete solution, it lays the groundwork for constructing much better healthcare communication tools. Next would be to take those ideas and build real systems that could help patients and their care teams stay better connected-and ultimately lead to better health outcomes.

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