

Analyzing Patient Safety Discussions in a Public Facebook Group Community

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Riley B. Wolynn

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This thesis was presented

by

Riley B. Wolynn

It was defended on

April 17, 2024

and approved by

Beth L. Hoffman, PhD, MPH, Assistant Professor in Behavioral and Community Health Sciences

Paul E. Phrampus, MD, MBA, FACEP, FSSH, Vice Chair of Quality and Patient Safety, Department of Emergency Medicine, Professor, Departments of Emergency Medicine and Anesthesiology, Director, Winter Institute of Simulation, Education and Research (WISER), Medical Director for Patient Safety for UPMC

Scotland Huber, MS, Chief Communications Officer for the Jewish Healthcare Foundation

Thesis Advisor: Jaime E. Sidani, PhD, MPH, CHES, Assistant Professor in Behavioral and Community Health Sciences

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Introduction. Medical errors rank as a preventable cause of disability and death in the United States. The emergence of digital platforms such as social media has facilitated patient engagement in this topic and offers new avenues for understanding patient experiences.

Methods. The first chapter of this thesis presents an overview of literature related to patient safety research as well as current challenges and trends with this research. Next, this thesis presents a stand-alone journal article consisting of a study analyzing content posted to a public patient safety Facebook group called the Patient Safety Action Network Community (PSANC) from November 21, 2022, to June 23, 2023. For this study, 200 posts were manually extracted and double-coded using a codebook developed through a grounded theory approach. The analysis involved descriptive statistics, cross-tabulations, and qualitative analysis.

Results: The literature review uncovered a steadily increasing effort to include patient perspectives in patient safety research, but barriers remain. The analysis of Facebook posts revealed that 70.5% (n=141) were directly relevant to patient safety. Of relevant posts, the majority had a link to additional information (85.8%, n=121). Cross-tabulations showed a statistically significant association between posts containing links and discussions on patient empowerment and advocacy, infection-related discussions in the context of vulnerable populations, and between policy and advocacy discussions. Qualitative analysis revealed themes related to the emotional and

physical impacts of medical errors on individuals and families, systemic challenges and advocacy, empowerment through education, and community support and shared experiences.

Conclusions. Findings from the literature search and analysis of Facebook posts affirm persistent safety concerns and the evolving role of patients in healthcare discourse. Findings also suggest the necessity for nuanced policy reforms and the potential of digital engagement in enhancing patient safety and advocacy. These findings are important for public health in that they highlight the possibility of addressing healthcare disparities and managing costs through more inclusive and patient-centered care strategies.

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Preface

As I present this thesis it is imperative to acknowledge the incredible individuals whose guidance, expertise, and support have been instrumental in the completion of this work. First, I extend my deepest gratitude to Dr. Jaime Sidani and Dr. Beth Hoffman. Having the privilege to work alongside them for the past six years has been one of the most enriching experiences of my academic journey. They introduced me to the vibrant field of public health, imparting knowledge and wisdom that I will carry with me throughout my career. Working under their mentorship in the ECHO lab and the committee has been an absolute honor, and for that, I am profoundly thankful.

I also wish to express my sincere appreciation to Scotland Huber, Chief Communications Officer of the Jewish Healthcare Foundation, and the entire Jewish Healthcare Foundation Communications team. My summer practicum in 2023 under their guidance was a pivotal moment in my academic path. It was there that I delved into the critical issue of patient safety, gaining insights and connections that significantly enriched my understanding of public health. Their support and the opportunities they provided were crucial in shaping the direction of my thesis.

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Finally, my deepest thanks to my fiancé Peter Mulholland, for his unparalleled support throughout this journey. Not only did he volunteer as my second data coder and meticulously read every draft of this thesis, but his unwavering support in countless other ways has been a cornerstone of my success. Peter, your belief in me and your constant presence have been a source of comfort and motivation. I could not have achieved this milestone without you.

This thesis not only represents my academic pursuits but also embodies the collective effort and support of everyone mentioned. To all of you, I extend my deepest gratitude. Your contributions have not only made this thesis possible but have also profoundly impacted my personal and professional growth.

Positionality Statement

As a researcher studying patient safety, my journey both academically and personally shapes the lens through which I view this complex field. My educational background in public health, combined with time spent working on patient safety projects during my practicum, has provided me with a foundational understanding of medical errors and the importance of patient safety. I acknowledge the privilege afforded to me through my educational journey and professional affiliations. Access to academic resources, exposure to diverse medical and health perspectives, and the opportunity to engage with mentors in the field have influenced my approach to this research. These privileges necessitate a vigilance against potential blind spots in my analysis and understanding of patient safety from perspectives different from my own.

Additionally, I recognize that my experiences and upbringing may affect my perception and analysis of patient safety issues and can present potential biases in my understanding and interpretation of data. In conducting this research, I am mindful of the potential influence of my background and perspectives on each stage of this thesis, from the formulation of research questions to data collection, analysis, and interpretation. Recognizing this, I have stayed committed to employing methodologies and analytical frameworks that seek to minimize personal biases. Throughout this process I have been continually reflecting on how my positionality influences my approach and findings. I recognize that this thesis is not just an academic exercise, but a contribution to a field that has far-reaching implications for real people's lives and well-being.

1.0 Introduction

Medical errors represent a significant challenge within global healthcare, affecting patient safety and the quality of care. These errors can range from surgical mishaps, diagnostic inaccuracies, and medication issues to broader systems failures, each contributing to adverse events that may harm patients. This thesis adopts a broad definition of medical errors as preventable adverse effects of care, emphasizing the need for systematic approaches to mitigate such errors. The estimation of deaths due to medical errors presents a complex challenge, with conflicting figures indicating both under recognition and significant mortality impact. For example, a 2020 systematic review and meta-analysis examining sixteen studies on preventable mortality in hospitalized patients reported a significantly lower pooled rate of preventable deaths at 3.1%, equating to approximately 22,165 preventable deaths annually in the United States.¹ This finding differs with other estimates, such as those proposed in a 2016 study which suggest as many as 251,454 annual deaths due to medical errors, ranking it as the third leading cause of death in the U.S.^{2,3} This discrepancy underlines the complexity of accurately quantifying the impact of medical errors on mortality, further emphasizing the extensive implications on morbidity, healthcare costs, and the broader socio-economic fabric.

1.1 Terms and Definitions

The term "medical error" lacks a universal definition and encompasses various, often overlapping, interpretations. For the purposes of this thesis, it will be defined as a “preventable adverse effect of care, whether or not it is evident or harmful to the patient.”⁴ Such errors can arise at any stage of the healthcare process, including diagnosis, treatment, or post-treatment care, and are characterized by either a failure to execute an intended plan of care or the execution of an incorrect plan to achieve specific goals.⁴ Furthermore, an adverse event refers to any injury caused or exacerbated by medical management, which encompasses medical errors.⁵ The complexity in understanding these concepts stems from their context-dependent meanings and the influence of regulatory language, which can differ by state.⁶ In general, while medical errors specifically denote mistakes in healthcare practice, adverse events represent a wider range of unintended patient outcomes, extending beyond the consequences of medical errors to include various other forms of harm or complications that may occur during healthcare treatment.⁵

Negligence in the context of healthcare is a key factor contributing to medical errors. It describes situations where healthcare professionals fail to provide the standard of care that a reasonably competent professional would provide under similar circumstances, leading to patient harm.⁷ Negligence occurs due to inadequate care or oversight, such as failing to diagnose a condition correctly, prescribing the wrong medication, or not following up on patient complaints. It is important to distinguish negligence from intentional wrongdoing: negligence involves a lack of due care that a professional would normally exercise.⁷

Quality improvement refers to systematic efforts aimed at enhancing the standard of care delivered to patients. It involves the identification of issues within healthcare processes and the

implementation of changes designed to overcome these issues, thereby closing the quality gap between current and desired healthcare outcomes.⁸ Quality improvement efforts are ongoing and iterative, involving the analysis of performance data, the adoption of best practices, and the evaluation of the impact of changes made.⁹ Interventions in quality improvement are targeted at reducing the discrepancies in care for a representative group of patients encountered in routine practice, with the ultimate goal of achieving optimal outcomes for all patients.¹⁰

Patient-centered care emphasizes the importance of considering the individual needs, preferences, and values of patients in all healthcare decisions and quality measurements.¹¹ This care is based on the belief that healthcare should be tailored to the specific health goals and desired outcomes of each patient, rather than adopting a one-size-fits-all approach.¹¹ Patient-centered care involves engaging patients as active participants in their care, ensuring they are well-informed, respected, and involved in decision-making processes.¹¹ This approach to care recognizes the value of the patient's perspective in achieving health outcomes that matter most to them, facilitating better communication, improving patient satisfaction, and potentially leading to better health outcomes.¹² Patient-centered care is an essential element in the pursuit of quality improvement and the reduction of medical errors, as it encourages a holistic view of patient care that goes beyond treating physical symptoms to address the broader health and well-being of individuals.¹³

1.2 Public Health Significance

Medical errors also have significant public health implications, presenting a complex challenge with far-reaching implications beyond mere statistics of morbidity and mortality. They bring about substantial financial burdens, affecting the healthcare system, patients, and their families across multiple dimensions. The direct medical costs, lost productivity, and income losses are staggering, with medical errors costing the United States \$20 billion, as estimated in one 2024 report.⁵ This figure includes direct medical expenses (\$17 billion), increased mortality (\$1.4 billion), and lost productivity due to short-term disability (\$1.1 billion).¹⁴ Beyond economic impacts, medical errors have profound psychological effects on patients, leading to long-term mental health issues and increased substance use disorders.¹⁵ Additionally, patients' families face disruptions, emotional stress, and caregiving burdens, displaying the extensive and often overlooked ripple effects of medical errors on the social and emotional well-being of those affected.¹⁶ Health disparities further compound these challenges, with studies revealing that medical errors disproportionately impact marginalized racial and ethnic groups, leading to worsened health outcomes and deepening mistrust in the healthcare system.¹⁷ These healthcare outcomes underscore the urgent need for robust preventative measures and equitable healthcare practices to mitigate the effects of medical errors and ensure patient safety across all demographics.

1.3 Thesis Aims

This thesis will have a review of the literature on patient safety research, setting the stage for the significance of this study by tracing the field's development, its present-day challenges, and its broad implications for public health.^{18,19} This is followed by a research study presented as a single, stand-alone journal article that examines patient-generated discourse through analysis of the content of discussions within a public patient safety Facebook group named Patient Safety Action Network Community. By employing a methodical approach to content analysis, this research study quantifies the themes and concerns raised by patients and their families, offering a novel perspective on patient safety issues. The study explores the types of errors discussed, the context in which they occur, and the solutions proposed by patients themselves. This work intends to bridge the gap between the quantitative prevalence of medical errors and the qualitative insights from those most affected by them. In doing so, it aims to contribute to a more holistic understanding of patient safety and foster the development of patient-centered care solutions. This thesis concludes by linking research findings and literature to outline potential strategies for healthcare stakeholders. It emphasizes the untapped value of patient voices in shaping a safer, more patient-centered healthcare system.

2.0 Literature Review

2.1 Overview

Medical errors in healthcare represent a significant global challenge, compromising patient safety and quality of care, with the frequency and type of these errors varying depending on the healthcare system in each country.²⁰ Medical errors encompass a wide range of issues, from surgical and diagnostic errors to complications involving medications, healthcare technology, devices, and equipment.²¹ These errors also include systemic failures, hospital-acquired infections, and patient falls. Among the most prevalent adverse events are infections acquired within the care setting, medication errors, and surgical injuries.⁴ Other significant adverse events arise from miscommunication during staff handoffs between units, failure to rescue, misidentification of patients, pressure ulcers, and falls. The urgency to address these issues was highlighted by the Institute of Medicine's 1999 report "To Err is Human," which catapulted medical errors into the spotlight of healthcare policy and initiated extensive research into understanding and mitigating such errors.²² Despite decades of research, a 2021 report from the National Academies of Sciences, Engineering, and Medicine indicates a stagnation in patient safety improvements, emphasizing the complexity of healthcare systems and the persistent challenge of reducing medical errors through interventions like checklists, electronic health records, and standardized procedures.²³

Estimating the annual death toll from these errors is challenging due to conflicting data, but it is clear that many patients die each year from preventable medical mistakes. This underscores the urgent necessity for more dependable techniques to detect and avert such errors in various

healthcare environments. Reviewing the 2018 US National Vital Statistics mortality data, adverse events are identified as the primary cause in just 0.16% (n=4,620) of total deaths, but are noted as contributing factors in 1.13% (n=32,226) of cases.²⁴ Furthermore, a 2020 systematic review and meta-analysis examining sixteen studies on preventable mortality in hospitalized patients reported a significantly lower pooled rate of preventable deaths at 3.1%, equating to approximately 22,165 preventable deaths annually in the United States.¹ These results differ from other estimates, like a 2016 study that suggests up to 251,454 deaths annually from medical errors, making it the third leading cause of death in the U.S.^{2,3} This variance highlights the difficulty in precisely measuring the toll of medical errors on death rates, underscoring their significant effects on illness, healthcare expenses, and the wider socio-economic landscape. Consequently, these figures underscore the pressing need for an all-encompassing approach to enhance the reporting, comprehension, and prevention of medical errors to reduce their extensive impact.

One aspect persistently noted as underrepresented in patient safety research is the patient perspective.²⁵ Traditional approaches have often positioned patients as passive recipients of care, whose role in the discourse around patient safety was limited to the aftermath of an error.²⁶ There is a growing recognition of the value of active patient engagement and the need to understand patient experiences and insights, particularly as they relate to their own safety within the healthcare system.¹⁸ The rise of digital technology and social media platforms presents a novel opportunity to gather and explore these perspectives. Patients are increasingly turning to online communities to share their experiences, seek support, and advocate for better care.²⁷ Currently, patients lack a formal mechanism to submit patient safety concerns beyond the healthcare providers' internal event reporting system.²⁸ Consequently, social media serves as a public forum, offering a broad platform for examining and discussing patient safety concerns. These platforms hold a wealth of

unstructured data that, when properly analyzed, can provide a rich understanding of patient concerns, experiences, and suggestions for improving safety.²⁷

The social ecological model provides a comprehensive framework to understand and address medical errors by considering multiple levels of influence on patient safety (**Figure 1**). At the individual level, a patient's physical condition and knowledge of the healthcare system can significantly impact their risk of experiencing medical errors, highlighting the need for patient education and empowerment.²⁹ Interpersonal factors, such as patient-provider communication and the availability of family and social support, are critical for ensuring accurate information exchange and adherence to treatment plans.^{30,31} Institutional factors play a pivotal role, with the implementation of Electronic Health Records (EHRs), provider training, standardized care protocols, and the adoption of safety checklists being essential for reducing errors and enhancing patient care quality.³²⁻³⁴ Community-level factors, including the discussion of patient safety issues on social media and public health engagements, contribute to raising awareness and promoting a culture of safety.²⁷ Lastly, at the policy level, legislative actions and initiatives, such as those led by the Agency for Healthcare Research and Quality (AHRQ), aim to establish a safer healthcare environment through regulations, funding, and the promotion of best practices.^{33,35} Together, these levels of the social ecological model underscore the multifaceted approach needed to mitigate medical errors and improve patient safety across the healthcare continuum (**Figure 1**).

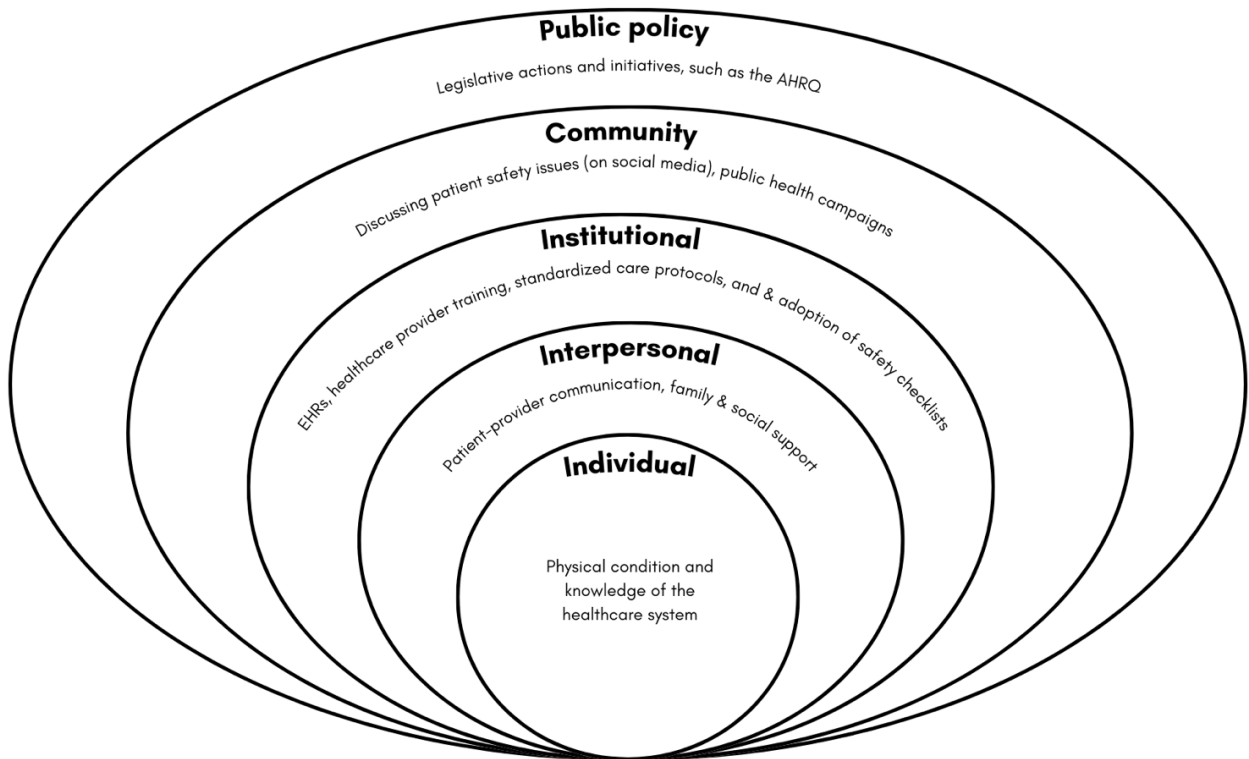


Figure 1. Factors Associated with Medical Errors According to the Social-Ecological Model

Additionally, it is important to acknowledge and address disparities in healthcare that exacerbate the risk and impact of medical errors among marginalized and underserved populations.^{17,36} These disparities highlight the urgent need for targeted interventions to ensure equitable care and safety for all patients, further emphasizing that a multifaceted approach is needed to improve patient safety across the healthcare continuum.

2.2 History of Patient Safety Research

The article “The Harvard Medical Practice Study I” is considered a pivotal piece of research in the history of patient safety. The study, conducted in 1991, reviewed 30,121 randomly selected records from 51 acute care, nonpsychiatric hospitals in New York State in 1984. The study's methodology was rigorous, involving a detailed review process to ensure the reliability of its findings. The review process involved a two-stage sampling and record review of 31,429 hospital records from 1984 to estimate the incidence of adverse events and negligence in New York's nonfederal acute care hospitals.¹⁹ This method included initial screening by nurses and medical records analysts, followed by detailed evaluation by trained physicians, with further validation and reliability testing, adjustments for missing records, and comprehensive statistical analysis to ensure accurate estimation of adverse events and negligence rates.¹⁹ The results indicated that while most adverse events led to disability lasting less than six months, a significant proportion resulted in permanent disability or even death. Additionally, the study revealed that adverse events occurred in 3.7% of hospitalizations, and that approximately 27.6% of these events were attributed to negligence. The study highlighted patient-level factors; for example, it found that the rates of adverse events increased with age. The elderly were particularly vulnerable to negligence, which the study defined as “care that fell below the standard expected of physicians in their community.”¹⁹ This research was instrumental in providing a clearer picture of the nature and scale of medical errors in hospital settings. It displayed the need for systemic changes in healthcare to enhance patient safety, creating the foundation for future reforms and studies. The study's emphasis on the prevalence of adverse events due to negligence also played a crucial role

in shaping policies and practices aimed at reducing adverse events and improving the quality of patient care.³⁷

Patient safety research began gaining significant momentum as a formal discipline in healthcare with the 1999 release of the Institute of Medicine's (IOM) seminal report, *To Err is Human: Building a Safer Health System*. This report marked a critical turning point by revealing alarming rates of medical errors in hospitals and setting a national agenda for improving patient safety. It estimated that between 44,000 to 98,000 people died annually in U.S. hospitals due to preventable medical errors, a figure exceeding death from motor vehicle accidents (41,611 deaths in 1999), breast cancer (41,144 deaths in 1999), or AIDS (just over 16,000 deaths in 1999).³⁸⁻⁴⁰ The authors in this report defined medical error as the “failure of a planned action to be completed as intended or the use of a wrong plan to achieve an aim” and emphasized that these errors were not due to individual negligence but instead systemic issues within healthcare settings. The IOM's report was groundbreaking in its approach as it did not point fingers at healthcare professionals but instead highlighted that “good people” were working within flawed systems.²² The report set a minimum goal of 50% reduction in errors over the five following years, calling for an effort from healthcare providers, government, consumers, and others. It advocated for leadership, improved data collection and analysis, and the development of effective systems at the level of direct patient care.²²

In subsequent years following the report, many specific areas of safety risk were identified and beginning to be researched, such as outpatient care, diagnostic errors, and the use of health information technology (HIT).⁴¹ Moreover, *To Err is Human* sparked legislative actions and initiatives by various organizations and at the policy level.^{41,42} For instance, Congress mandated the Agency for Healthcare Research and Quality (AHRQ) to issue annual reports monitoring

progress in improving care.⁴³ Additionally, the Joint Commission and the Institute for Healthcare Improvement launched programs and campaigns to reduce medical errors and patient harm.⁴⁴ In 2009, the World Health Organization developed a “Surgical Safety Checklist,” which significantly reduced surgical complications and deaths.⁴⁵ Since the checklist’s release, research has found that compliance with the checklist resulted in dramatic improvements in outcomes. For example, one study found a 47% reduction in mortality and a 36% reduction in surgical complications in a cohort of nearly 8,000 patients from eight countries.⁴⁶ However, the impact of these interventions varied due to inconsistent implementation and practice.⁴²

Despite the significance of these efforts, the frequency of preventable adverse events remains high. For example, one study published in 2010 found that 27% of Medicare beneficiaries experienced harm during hospital stays. When the researchers repeated the study 10 years later using the same methodology, they found that the findings were relatively similar, with 25% of Medicare beneficiaries having experienced harm during inpatient hospital stays, almost half of which could have been prevented by better care.⁴⁷ New scientific and policy approaches to medical error prevention are necessary to address both existing and emerging risk areas in patient safety. Still, it is important to recognize how far this field has developed, from the first recognition of the high frequency of medical errors to our present knowledge about patient safety. Researchers and policy makers have progressed from basic tools to more thorough and organized methods of improving patient safety, and various initiatives and programs have had some success in reducing patient harm and improving overall safety in healthcare settings.^{41,42}

2.3 Current Challenges and Trends in Patient Safety

Despite ongoing efforts to improve patient safety, adverse events in medical settings continue to pose significant challenges.⁴⁸ A retrospective cohort study conducted in 2018 across 11 Massachusetts hospitals provides a compelling insight into the persistent barriers to enhancing patient safety.⁴⁹ This study used the trigger tool method to evaluate the frequency, preventability, and severity of patient harm in a random sample of hospital admissions. The trigger tool method is a rigorous approach that identifies potential patient harm through specific "triggers" or indicators within medical records, allowing for a comprehensive review and analysis of patient safety incidents. The study's findings revealed that 29% of patients admitted to the hospital experienced at least one harm, with 12% of these harms being preventable and 7% leading to serious harm, including permanent disability or death.⁴⁹ A substantial proportion of preventable harms highlights the need for a critical assessment of existing safety measures and protocols. By outlining the realities of patient safety today, this study charts a crucial course for future investigations.

Reports from the Office of Inspector General (OIG) give insights that also shape a comprehensive understanding of patient safety. The OIG has been steadfast in its commitment to enhancing patient safety since it was mandated by the Tax Relief and Health Care Act of 2006 to report on adverse events relating to federal programs.⁴⁸ This reporting has been instrumental in revealing the prevalence of adverse events. For example, in 2010 the OIG published the first national incidence rate of adverse events among Medicare patients, revealing that 27% of patients experienced some form of harm.^{50,51} More recent findings from the OIG indicate that there has not been much improvement in this population. A quarter of Medicare patients experienced adverse events during hospital stays in October 2018, with 43% of these events deemed preventable with

better care. Furthermore, nearly a quarter of these patients incurred additional costs to the Medicare program due to the required extended care.⁵² The OIG's work extends beyond hospitals to post-acute care facilities and Indian Health Service hospitals, with harm rates ranging between 13% and 43%.⁴⁸ In these settings, similar patterns emerge, where many harm events are preventable and impose a significant financial burdens. Events commonly linked to substandard or inadequate care provided to the patient, such as failure to follow proper procedures, were preventable. Financial barriers arose from instances of harm to hospitalized Medicare patients. In October 2008, the hospital care necessitated by such harmful events resulted in an estimated \$324 million in costs, including Medicare reimbursements, coinsurance, and deductible payments borne by the patients. Notably, half of these errors were deemed preventable.⁵²

In response to these findings, the Department of Health and Human Services (HHS) has taken steps to enhance patient safety, including refining surveillance of adverse events and adjusting payment incentives.⁴⁸ In 2018, The OIG recommended that HHS reassess its strategies for quality improvement, optimize surveillance tools, and disseminate information about best practices and clinical guidelines more effectively.⁴⁸ Additionally, aligning hospital payment policies to encourage and support quality improvement and providing guidance for hospital compliance in tracking harm events are key areas of focus for the OIG.⁵³ To aid in identifying and measuring patient harm events, the OIG has developed adverse events toolkits. These toolkits comprise two key components: an outline detailing the methodology employed to detect and classify instances of patient harm, and a compilation of clinical guidelines that were applied in determining the occurrence of patient harm.⁴⁸ These resources are designed to be used collectively and can be modified partially or entirely for application in other medical record review initiatives.

These toolkits are designed to assist hospitals, researchers, and healthcare communities in conducting medical record reviews to pinpoint and understand the nature of patient harm.⁵⁴

The current landscape of patient safety, as of 2022, reveals a complex scenario marked by both progress and ongoing challenges. The Pennsylvania Patient Safety Reporting System is the most comprehensive data source in the US, as Pennsylvania is the only state that requires acute care facilities to report all events of harm or potential for harm.⁵⁵ In Pennsylvania acute care facilities there was recently a significant reduction in the overall number of reported safety incidents: a total of 256,679 reports in 2022 marked an 11.1% decrease from the previous year.⁵⁵ However, serious harmful events saw an increase, rising by 7.7% in 2021 to 11.1% in 2022, with adverse drug reactions showing the largest increase among serious event reports.⁵⁵ The researchers were unable to reach a firm conclusion as to why this disparity occurred but speculated that multiple factors were involved, such as changes in reporting practices at individual facilities, enhanced education and guidance provided by regulatory bodies, adjustments in classification criteria for incidents and serious events, and possibly variations in healthcare delivery and patient safety culture within the facilities.⁵⁵ This indicates that while the frequency of incidents may be decreasing, the severity of those that occur remains a significant concern. These incidents primarily included errors related to procedures, treatments, and tests, as well as medication errors, falls, and complications from procedures or treatments.⁵⁵ In terms of reported event rates, there was a noteworthy decrease in hospital incidents, reaching the lowest level since 2016 at 27.5 reports per 1000 patient days.⁵⁵ However, ambulatory surgical facilities showed a slight increase in incidents compared to the previous year, with a reported event rate of 9.4 reports per 1000 surgical encounters.⁵⁵

These trends represent real patient experiences and outcomes, underscoring the need for healthcare systems to refine their safety strategies, foster a culture of safety, and use each incident as a learning opportunity. Although some healthcare systems make efforts to learn from errors occurring within their own operations, a notable gap exists in the sharing of these learnings among different systems. The lack of effective mechanisms for disseminating solutions and best practices contributes to a significant challenge within the broader healthcare landscape. This failure to share knowledge not only stifles innovation but also prevents the collective advancement of patient safety measures across the industry.⁵⁶ Establishing more robust channels for the exchange of insights and solutions could greatly enhance the ability of healthcare systems to mitigate errors and improve care quality on a wider scale. The current state of patient safety demonstrates the need for a dynamic and continuous approach to improving practices, focusing on preventing the most detrimental outcomes and enhancing the overall quality of care.⁵⁵

2.3.1 Organizational and Policy Responses to Patient Safety

In the evolving landscape of healthcare, organizations and policymakers can play a pivotal role in enhancing patient safety. Their efforts and initiatives are characterized by a blend of legal, regulatory, and policy interventions, in addition to strategic organizational approaches aimed at mitigating risks and improving care quality. The legal and policy landscape has been significantly shaped by the introduction of the Patient Safety and Quality Improvement Act (PSQIA) in 2005. The Health and Human Services department (HHS) issued the Patient Safety Rule to implement the Patient Safety Act, with AHRQ overseeing patient safety organizations (PSOs) and Office for Civil Rights within HHS handling confidentiality and disclosure under the Act and Rule.⁵⁷ This

framework, encouraged by the IOM, aims to enhance patient safety and reduce errors by fostering a culture of safety where healthcare providers can voluntarily share patient safety information with PSOs.⁵⁷ These PSOs can then analyze the data to improve practices and prevent future errors, supported by confidentiality protections to encourage reporting.⁵⁷ However, this system also seeks to maintain healthcare providers' accountability and transparency, requiring adherence to external obligations like tracking adverse patient events, as mandated by CMS and state regulations.⁵⁷ The Patient Safety Act balances the dual goals of promoting safety through learning and ensuring provider accountability, without shielding providers from litigation or exempting them from fulfilling external reporting requirements, aligning with broader healthcare quality and legal accountability frameworks.⁵⁸

Additionally, the Center for Medicare and Medicaid Services (CMS) has had a profound impact on certain aspects of patient safety, with initiatives like the Partnership for Patients focusing on reducing hospital-acquired conditions such as infections, pressure ulcers, and adverse drug events.⁵⁹ This partnership, launched by CMS in 2011, is a collaborative effort aimed at enhancing healthcare quality and safety across the United States.⁵⁹ This initiative has brought together healthcare professionals, patients, and various levels of government to reduce Hospital Acquired Conditions (HACs) and hospital readmissions.⁵⁹ Through its Hospital Engagement Networks, the Partnership for Patients has made substantial strides in preventing patient harm and saving healthcare costs, demonstrating significant reductions in HACs and readmission rates. These initiatives have contributed to a reduction in patient deaths from hospital-acquired conditions, driving as a 16.8% decrease in harm events in discharged patients from 2010-2013.⁵⁹ This highlights the effectiveness of policy-driven safety improvements.

Additionally, the Affordable Care Act (ACA) has stimulated improvements to ambulatory care, improving the care quality, patient experience, utilization, and cost management. This has been done through efforts to align financial incentives with patient safety goals, particularly through programs like the Hospital Readmissions Reduction Program (HRRP) and the Hospital-Acquired Condition Reduction Program (HACRP).⁶⁰ The HRRP is a Medicare initiative that aims to reduce avoidable hospital readmissions by incentivizing hospitals to improve patient communication, care coordination, and discharge planning. Established under Section 1886(q) of the Social Security Act, as part of the ACA, HRRP has been reducing payments to hospitals with excessive readmissions since October 2012.⁶¹ This program assesses hospital performance in treating specific conditions like heart failure and COPD, with payment reductions capped at 3%.⁶¹ Additionally, CMS provides hospitals with Hospital-Specific Reports for review and correction, ensuring the accuracy of payment reduction calculations, and publicly reports HRRP data on its website and other CMS platforms.⁶¹ The HACRP is a critical component of Medicare's value-based purchasing initiatives, aimed at enhancing healthcare quality in inpatient settings. Established under Section 1886(p) of the Social Security Act, the HACRP aligns with the broader goals of the ACA by incentivizing higher quality care. Specifically, it mandates reduced Medicare payments to hospitals that rank in the worst-performing quartile for hospital-acquired conditions, embodying the ACA's emphasis on performance-based payment systems to improve patient outcomes and reduce healthcare costs. CMS evaluates hospitals annually, calculating the total HAC Scores from an average of scores on various quality measures, including patient safety and healthcare-associated infections. Hospitals with a Total HAC Score in the top 25% face a 1% reduction in Medicare payments for all fee-for-service discharges in that fiscal year. CMS provides hospitals with confidential reports for review and correction, ensuring accuracy in the evaluation

and scoring process.⁶² Both programs underscore the policy's emphasis on incentivizing improvements in patient safety and care quality by linking reimbursement directly to performance metrics.

On the organizational front, healthcare providers are increasingly adopting Electronic Health Records (EHRs). While EHRs can lead to improved clinical outcomes, such as enhanced quality of care, organizational outcomes, such as financial and operational advantages, and societal outcomes, such as better research capabilities, improved public health, and lower costs, they could also lead to an increase in errors, potentially compromising patient safety.³⁴ Research highlights that EHRs with poor user experience are prone to contributing to alert fatigue and failing to detect critical errors, thereby jeopardizing patient safety.⁶³ Therefore, it is important to conduct additional research to understand how EHRs contribute to patient safety incidents and to identify strategies to reduce these errors. Enhancements aimed at improving EHR usability must prioritize the needs of the physician as the primary user. Moreover, federal bodies should take active steps to promote the rapid uptake of better EHR systems.⁶⁴

Additionally, strategies such as the creation of standardized care protocols and investing in staff training to enhance care delivery can be evaluated for their efficacy in reducing patient harm.⁶⁵ One paper from 2022 indicates that the strategies currently employed have led to a standstill in patient safety progress, comparing unfavorably with safety expectations in other industries such as aviation.⁶⁶ The lack of substantial improvement is attributed to a combination of factors. These include a diluted focus due to competing healthcare priorities, such as COVID-19 and workforce safety, and a general shift away from direct, urgent language surrounding patient safety. The authors of the paper argue for a renewed focus and commitment to patient safety,

advocating for stronger oversight, accountability, and transparency, as well as the active engagement of patients and families in safety efforts.⁶⁶

Due to the standstill in progress made through traditional strategies, there is a growing shift among healthcare organizations toward building cultures of safety and patient-centered care. There is an increase in providers actively engaging patients and their families in care decisions, which recognizes the value of their input in identifying potential safety issues and developing effective safety solutions.⁶⁷ Evidence from research on patient-centered care suggests that it can improve perceptions of safety culture and potentially reduce patient harm. For example, one study from 2019 used a cross-sectional survey that was conducted in 8 different primary care settings.¹² The researchers concluded that organizations that are more patient-centered not only have increased safety and quality of care, but also have other positive outcomes, such as greater satisfaction with care, greater job satisfaction among healthcare professionals, and greater quality of life and well-being of patients.¹² Patient-centered care was also associated positively with the physical and social well-being of patients with multi-morbidity in the primary care setting.¹²

Additionally, a 2019 study offers evidence on the significant enhancement of safety in healthcare settings through patient-centered care and engagement. The researchers sought to understand patients' perceptions of their interactions with healthcare professionals and their beliefs regarding their influence on patient safety.⁶⁸ This study employed a cross-sectional survey methodology to gather data from 1,445 patients within primary and secondary care settings across three county councils in southeast Sweden.⁶⁸ The cohort included both regular patients and individuals who had lodged complaints concerning healthcare-related harm.⁶⁸ The findings reveal a notable consensus among respondents: a substantial majority reported ease in asking physicians and nurses questions (84.9% and 86.6%, respectively) and pointing out concerns in their care

(77.7% and 80.7%).⁶⁸ Importantly, patients who lodged complaints about their care were more likely than those who did not to believe in the potential of patients to contribute to safer care..⁶⁸ Patients who had complaints about their care also reported a higher incidence of harm in healthcare settings over the past decade, with a significant proportion indicating that such harm could have been avoided if healthcare professionals had heeded their input.⁶⁸ These results reveal the critical role of fostering an environment where patients feel empowered to engage in their care and voice concerns about safety. Such engagement not only aligns with the principles of patient-centered care but also serves as a pivotal mechanism for identifying and mitigating safety risks. The study suggests that by encouraging open dialogue and ensuring that patients are active participants in the healthcare process, healthcare professionals can significantly improve patient safety outcomes.

Despite progress in patient safety, challenges remain that hinder the complete achievement of its goals. Disparities in the quality of care, inconsistent application of safety protocols across different healthcare settings, and the inherent complexities of healthcare systems present ongoing obstacles.^{69,70} Moreover, the swift advancement of technology and medical practices calls for a continuous cycle of adaptation and innovation in safety measures.⁶⁴ To summarize, while initiatives at the legal, policy, and organizational levels have driven notable advancements in patient safety, there is a critical need for ongoing diligence and effort to tackle the dynamic challenges present in this domain. The overarching aim is to cultivate healthcare environments that emphasize safety, transparency, and active patient involvement, striving towards a healthcare system that consistently minimizes harm while enhancing the quality of care provided.⁸

2.3.2 The Impact of Technological Advancements on Patient Safety

In the evolving landscape of patient safety, technological advancements have emerged as both facilitators of care quality and as potential sources of new challenges. The integration of HIT into patient care has been a significant development, aiming to improve the quality and safety of healthcare activities.⁶⁴ HIT is being introduced into patient care through electronic health records, telemedicine, patient portals, mobile health apps, and real-time data analytics for better diagnosis and treatment outcomes.⁷¹ However, it is important to recognize that these technologies can also introduce new types of errors, known as technology-induced errors, which can be observed across digital health ecosystems.⁷² An example of a technology-induced error is a patient receiving a medication they are allergic to because of a user's inability to locate patient allergy information in the user interface of an electronic health record.⁷³ Additionally, systems may auto-populate fields with default values that may not be relevant for a specific patient, leading to errors.⁷³ Other reported errors relate to electronic decision support systems, particularly medication alerts, where irrelevant or excessive alerts can lead to alert fatigue and the ignoring of important alerts, potentially resulting in inappropriate medication orders reaching the patient.⁷³

One study from 2017 highlights the dual nature of HIT. The authors argued that it collects data for quality and safety improvements and automates error-prone processes, but also that it might inadvertently lead to new errors.⁶⁴ For example, the implementation of “computerized physician order entry” without clinical decision support systems has been found to not reduce medication errors, indicating that technological solutions without integrated decision support can introduce new types of errors related to oversight or misuse.⁶⁴ The authors of this study stress that while HIT has the potential to significantly enhance patient care, it requires a strategic approach

to implementation with a focus on customizing solutions to fit the unique needs and contexts of different healthcare settings.⁶⁴ Therefore, a critical aspect of technology in healthcare is the need for continuing evolution and improvement, as argued in one study published in 2023.⁷³ This approach extends beyond adopting new technologies; it involves using the data generated by these technologies to enhance healthcare practices. The authors argue that for a health system to evolve effectively, it must not only integrate new technologies but also leverage the insights they provide. This strategy allows healthcare providers to continually adapt and refine their practices based on ongoing feedback, ultimately improving the quality and safety of patient care.⁷⁴

Overall, the integration of technological advancements in healthcare has a complex effect on patient safety. While the potential for improved patient safety and quality of care is significant, it comes with the responsibility to ensure these technologies are implemented thoughtfully and reviewed continuously. Telehealth is a prominent example as it has emerged as a critical tool in extending healthcare access, enabling remote patient monitoring, and facilitating virtual consultations.⁷⁵ Its adoption was accelerated by the COVID-19 pandemic, and recent findings suggest the necessity of integrating telehealth in a manner that complements and enhances traditional care models rather than replacing or complicating them.^{75,76} However, the successful deployment of telehealth services requires addressing challenges related to patient privacy, data security, and the digital divide that may limit access for some populations.⁷⁷ Moreover, it highlights the importance of developing robust frameworks for the evaluation of telehealth outcomes, ensuring that the digital transition in healthcare does not compromise but instead enhances patient safety.^{75,77} This reflective approach to implementing and continuously assessing telehealth and other digital health technologies is essential for advancing patient safety in an increasingly digital healthcare landscape.

2.4 Public Health Implications

Medical errors represent a compelling and multifaceted public health challenge, with far-reaching implications that extend beyond mere statistics of morbidity and mortality. The costs incurred due to medical errors are substantial, impacting not only the healthcare system but also patients and their families on multiple levels. Financially, the burden encompasses direct medical expenses, lost productivity, and lost income, both for individuals and on a national scale. Beyond the physical consequences, being a victim of a medical error can have profound psychological impacts, including long-term mental health issues and an increased risk of substance use disorder. The ripple effects on families are also significant, with disruptions to family dynamics, emotional stress, and the added burden of caregiving responsibilities. Furthermore, medical errors disproportionately affect minoritized groups, exacerbating existing health disparities and often leading to a deepened mistrust in the healthcare system.^{17,36,78} This mistrust can create a vicious cycle, deterring individuals from seeking necessary medical care, which in turn can lead to worsened health outcomes.

2.4.1 Healthcare System Economic Impact

The economic implications of medical errors in the United States are both extensive and multifaceted. An in-depth analysis using medical claims data from 2008 found that the total cost attributed to medical errors in that year amounted to \$19.5 billion. This figure predominantly comprises direct medical expenses (\$17 billion, or about 87% of the total) for inpatient, outpatient, and prescription drug services for those affected by medical errors. The remaining costs include

\$1.4 billion related to increased mortality and approximately \$1.1 billion due to lost productivity from short-term disability claims.¹⁴ These errors also led to over 2,500 excess deaths and resulted in more than 10 million additional days missed from work due to short-term disability.¹⁴ However, these figures likely underestimate the true economic impact of medical errors. Limitations in data collection mean that some costs, such as those related to deaths outside of hospitals or long-term disability claims, are not fully accounted for. Furthermore, medical errors are not explicitly coded in claim databases, complicating their identification and potentially leading to underestimation.⁷⁹

Complementing this analysis, another study used data from the Premier hospital database to estimate the occurrence and costs of medical errors from a hospital perspective.⁸⁰ It identified an estimated 161,655 medical errors in 2008 and 170,201 in 2009.⁸⁰ Extrapolated to the entire U.S. population, this suggests over 1 million unique medical errors annually.⁸⁰ The study estimated the total annual cost of these errors at approximately \$985 million in 2008 and over \$1 billion in 2009. The median cost per error to hospitals was \$892 in 2008, rising to \$939 in 2009.⁸⁰ This analysis emphasizes the direct financial impact of medical errors on hospitals, particularly following Medicare's 2008 decision to stop reimbursing hospitals for certain preventable medical errors. Hospitals are now encouraged to rigorously analyze and implement comprehensive preventative programs to reduce the occurrence of medical errors, as the financial burden increasingly falls on them.⁸⁰

These studies collectively underscore the significant financial burden of medical errors on the healthcare system. The economic impact is not limited to the direct costs of treating medical injuries but extends to the costs associated with increased mortality, lost productivity, and broader societal implications. With Medicare ceasing reimbursements for care related to certain preventable medical errors since 2008, the financial burden increasingly shifts towards hospitals,

emphasizing the need for robust analysis and prevention strategies to mitigate these errors and their associated costs.⁸⁰

2.4.1.1 Financial Implications for Individuals

Medical errors often inflict a profound and lasting financial burden on patients and their families. The repercussions of these errors can persist for extended periods, sometimes stretching over five to ten years or even longer, as revealed by a comprehensive study in 2021.¹⁶ This study interviewed patients who had experienced at least one harmful healthcare event and their families and found that 31% of patients and their families continued to grapple with financial issues long after the medical error event.¹⁶ Many patients described the ongoing financial strain, which included extensive surgeries, therapies, and medications, often without adequate compensation or financial support. Additionally, the toll on employment was significant, with individuals facing difficulties in maintaining regular jobs, or in some cases, being forced to stop working altogether.¹⁶

The intertwining of financial impacts with physical consequences further compounds the challenges faced by affected individuals and families. For instance, physical disabilities resulting from medical errors often lead to the loss of jobs and health insurance coverage, as well as the accumulation of exorbitant medical bills.¹⁶ Many individuals who have experienced medical errors find themselves reliant on Medicaid or Medicare services to cope with escalating healthcare expenses.¹⁶ Patients disabled by medical errors often require expensive long-term care, including ongoing rehabilitation, additional medical procedures and surgeries, costly medications, and specialized equipment and supplies. This financial burden was articulated by one participant from the above study who stated, "I'm in physical therapy the rest of my life because of how he butchered everything up. It threw my whole body off, and so it's costing a fortune... I've spent thousands of

dollars and met with experts and specialists."¹⁶ To alleviate the financial strain imposed by medical errors, many patients and their families seek compensation from the hospital or healthcare worker responsible for the error. This is particularly common when the patient's job was lost or when the patient tragically passed away because of the error.¹⁶ Therefore, financial ramifications of medical errors extend far beyond immediate medical costs, affecting the economic stability and well-being of patients and their families for years to come.

2.4.1.2 Physical Implications

A study conducted by Harvard School of Public Health in 2013 unveiled the global burden of injury from unsafe medical care.⁸¹ The study harnessed a comprehensive dataset comprising over 4,000 articles published over several decades⁸¹. These sources were leveraged to investigate seven distinct adverse outcomes associated with hospitalization, including medication-related injuries, catheter-related infections, hospital-acquired pneumonia, blood clots in veins, falls, and bedsores. To gauge the impact of these adverse events, researchers employed the "disability-adjusted life years" (DALYs) metric, which measures the number of years of healthy life lost due to illness, disability, or premature death. The researchers found that more than 43 million individuals worldwide experience injuries each year due to medical error, leading to the loss of 22.6 million years of "healthy" life.⁸¹ This study marked the first concerted effort to quantify the human suffering resulting from medical errors and adverse health events, shedding light on an urgent global health issue that demands attention. Moreover, the implications extend beyond morbidity and mortality. According to the authors of the 2013 Harvard study, unsafe medical care can cause resource consumption, prolonged hospital stays, loss of wages and productivity, and

even the potential discouragement of patients, especially in low-income countries, from seeking formal healthcare services.⁸¹

2.4.1.3 Psychological Implications

While there is limited research on the psychological impact of medical errors, one notable study provides valuable insights.¹⁵ This study, conducted in Massachusetts and published in 2020, focused on the association between open communication following a medical error and its emotional and behavioral impact on patients and families. The researchers employed a cross-sectional survey methodology to gather data from patients and families affected by medical errors about their experiences and emotional responses. Key elements assessed included the level of communication from healthcare providers post-error, feelings of emotional distress like sadness or depression, and behavioral changes such as avoidance of medical care or specific healthcare providers. The survey had a 41% response rate and included 253 respondents who perceived a medical error.¹⁵ Notably, 87% reported initial emotional impacts like sadness or anger, and 43% experienced significant physical impacts or death.¹⁵ Over time, these emotional impacts persisted, with 56% still experiencing them years later.¹⁵ This study also revealed that open communication was crucial: higher levels of it were associated with fewer long-term emotional and healthcare avoidance impacts.¹⁵ However, it also revealed that such communication strategies do not fully restore trust in healthcare or prevent general avoidance of medical care, highlighting the need for not only immediate error acknowledgment and apology but also the long-term emotional and behavioral consequences of medical errors.¹⁵ The study emphasized the need for multifaceted interventions to support patients and families comprehensively and restore trust in the healthcare

system.¹⁵ The lack of research examining the psychological impact of medical errors also underscores the need for additional research into this topic.

2.4.2 Health Disparities in Patient Safety

In recent years, the intersection of health disparities and patient safety has emerged as a critical area of concern in healthcare research and policy. The growing recognition that patient safety incidents disproportionately affect marginalized racial and ethnic groups, as well as individuals enrolled in Medicare, has catalyzed a re-examination of healthcare practices and policies. This section of the literature review delves into a collection of studies that scrutinize the extent, causes, and potential solutions to these disparities. This understanding is vital for informing more equitable healthcare practices and policies, ensuring that patient safety is a right afforded to all regardless of racial or ethnic background, or Medicare status.

As noted earlier, there is a clear health disparity among patients insured by Medicare compared to those with other forms of medical insurance. Medicare serves as a federal health insurance program in the United States, catering to individuals aged 65 and above, as well as younger persons who have disabilities.⁸² In 2015, a comprehensive study spanning across 11 states, analyzing hospital discharge data, found that Medicare and Medicaid patients experienced significantly more adverse safety events compared to private pay patients within the same hospitals.⁸³ This was particularly evident across 12 of the 13 Patient Safety Indicators defined by the AHRQ, where Medicare patients consistently faced higher rates of adverse events.⁸³ Such disparities underscore the systemic challenges in ensuring equitable care quality across different patient groups within the same hospital settings.

In 2010 the OIG published the first national incidence rate of adverse events among Medicare patients, revealing that 27% of patients experienced some form of harm.^{50,51} More recent findings from the OIG indicate that there has not been much improvement in this population. For instance, a quarter of Medicare patients experienced adverse events during hospital stays in October 2018, with 43% of these events deemed preventable with better care.⁵² Furthermore, nearly a quarter of these patients incurred additional costs to the Medicare program due to the required extended care.⁵² Financial barriers arose from instances of harm to hospitalized Medicare patients. In October 2008, the hospital care necessitated by such harmful events resulted in an estimated \$324 million in costs, including Medicare reimbursements, coinsurance, and deductible payments borne by the patients. Notably, half of these errors were deemed preventable.⁵²

The Medicare Patient Safety Monitoring System (MPSMS) was created in 2001 in response to the *To Err Is Human* report and has been at the forefront of measuring and improving patient safety in U.S. hospitals. MPSMS has emerged as the only system capable of providing reliable national-level estimates of a wide array of adverse events, highlighting its crucial role in the healthcare system.⁸⁴ Data utilized by the Department of Health and Human Services for the Partnership for Patients program, as of 2013 and 2014, indicated a promising 17% reduction in hospital-acquired conditions compared to the baseline year of 2010.⁸⁴ This success underscores the effectiveness of MPSMS in identifying safety issues and guiding improvements. In 2015, there was a transition where the MPSMS became the Quality and Safety Review System (QSRS), which marked a significant evolution in the approach to enhancing patient safety and healthcare quality. This transformation, spearheaded by the AHRQ, was motivated by the need to address the limitations of MPSMS and to adapt to the changing healthcare environment, particularly the widespread adoption of EHRs.⁸⁴ This evolution reflects a systematic approach to understanding

safety issues, pinpointing areas needing enhancement, and measuring the impact of interventions. Despite the progress made, the ongoing challenges in patient safety underscore the need for further development and integration of such systems to ensure a safer healthcare environment for all patients.

A study published in 2017 presents a comprehensive examination of the disparities in patient safety across different racial and ethnic groups within the U.S. healthcare system.¹⁷ This study was conducted to delve into the complexities and nuances of how race and ethnicity are reported in patient safety studies. It also aimed to assess the role of socioeconomic status, comorbidity, and disease severity in these disparities, and offer recommendations for the inclusion of these factors in future adverse event research. This study involved a thorough review of published studies on racial and ethnic disparities in patient safety in the United States, spanning a period from 1991 to 2013.¹⁷ The data extraction focused on aspects such as study design, outcomes, patient demographics, and the inclusion or consideration of race and ethnicity in these studies. The findings of this analysis revealed mixed evidence regarding the existence of disparities in adverse events based on race and ethnicity.¹⁷ One of the key observations was the variation in reporting these disparities, coupled with geographic and hospital-level differences, which were identified as significant factors contributing to these inconsistent results.¹⁷ This variation underscores the complexity of analyzing patient safety across different racial and ethnic groups. Based on these findings, the study put forth several recommendations. It advocated for improved reporting practices and the need for stratification by race and ethnicity in patient safety research. Additionally, it emphasized the importance of adjusting for comorbidities and hospital-level factors to ensure a more accurate and representative analysis. The study underlined the necessity

of employing appropriate study designs that can effectively capture and analyze racial and ethnic disparities in patient safety.¹⁷

A paper published in 2018 adds another layer to the understanding of disparities in patient safety, particularly in the context of primary care.⁸⁵ This review extends the discussion beyond racial and ethnic disparities to encompass a broader range of social disparities—including gender, income, and education—and their impact on patient safety.⁸⁵ Similar to the methodology in the 2017 study on racial and ethnic disparities, this review employed a systematic approach to identify and synthesize publications from January 1st, 2006, and January 31st, 2017.⁸⁵ However, its focus was distinctly on patient safety events in primary care, examining a range of error types such as administrative, diagnostic, medication, and transition of care errors. The researchers found that the likelihood of experiencing patient safety events in primary care varies with the type of disease, treatment, and healthcare service, though it is notably higher among women and Black patients.⁸⁵ These findings from this review can be seen as complementary to those of the study on racial and ethnic disparities. While the former highlights mixed evidence on disparities in adverse events based on race and ethnicity, the latter expands this scope to include how gender, income, and educational background also play significant roles in patient safety within primary care settings. The emphasis on socioeconomic status in this review resonates with the recommendations from the racial and ethnic disparities study, which calls for adjustments for socioeconomic factors in patient safety research.⁸⁵

Moreover, another study published in 2010 provides a critical perspective on ethnic disparities in patient safety, adding depth to the discussions presented in the previous two studies on disparities in patient harm.³⁶ This qualitative analysis dove into the specific processes underlying these disparities, utilizing semi-structured interviews with healthcare providers to

examine patient safety events involving immigrant patients.³⁶ Three key patterns emerged from the analysis. The first was inappropriate responses by healthcare providers to objective characteristics of immigrant patients, such as language proficiency and insurance status.³⁶ The second was misunderstandings due to differences in illness perceptions and care expectations. The third was inadequate care resulting from providers' prejudices or stereotypes.³⁶ These findings suggest that both organizational practices and individual healthcare professional behaviors contribute significantly to the higher risk of patient safety events in immigrant populations.³⁶

When considering patient harm in marginalized groups, trust and trustworthiness must be a key focus as these groups face compounded trust and credibility issues due to systemic disparities and historical injustices that uniquely exacerbate their healthcare experiences beyond individual incidents of harm. Building and maintaining trust in healthcare systems is paramount to addressing the disparities and vulnerabilities experienced by these communities. In the work titled *Medical Error and Vulnerable Communities*, published in 2022, the authors focus on the erosion of trust within healthcare systems, especially among marginalized groups.⁷⁸ This trust deficit often arises from medical errors, which are frequently a byproduct of systemic biases. The section in this study discussing women as a vulnerable community highlights the pervasive gender bias deeply rooted in medical research and practice. Throughout history, medical research has primarily centered on the white, cis-gendered male population, leading to substantial gaps in understanding women's unique health needs. This bias has resulted in misdiagnoses of conditions like heart attacks in women and the failure to provide equitable and unbiased medical care.⁷⁸ Despite the strides made by the Affordable Care Act in improving women's healthcare access and quality, disparities persist. Women's health concerns are often dismissed as emotional or mental health issues, resulting in misdiagnoses and neglect of their actual medical needs.⁷⁸ Addressing this gender bias necessitates

a fundamental reevaluation of medical practices and research to better cater to the distinct health requirements of women.⁷⁸

This same paper also underlines the unique challenges and disparities faced by the LGBTQ+ community in the realm of healthcare. It points out the persistent anti-gay and anti-transgender attitudes prevalent in medicine, which create barriers to healthcare access for transgender individuals, primarily due to the fear of discrimination. These barriers contribute to poorer health outcomes within the LGBTQ+ community. The same section of *Medical Error and Vulnerable Communities* also delves into the specific health and healthcare disparities experienced by sexual and gender minorities, including a higher incidence of diseases like HIV, certain cancers, and mental health disorders. The lack of inclusion of LGBTQ+ people in clinical trials further impedes our understanding and efforts to address these disparities. Although the ACA has made significant strides in improving healthcare coverage for the LGBTQ+ community like it did for women, challenges remain, including discrimination and the absence of coverage for gender-affirming care. Consequently, transgender individuals, especially those of color, bear a disproportionate burden of health issues like HIV. This paper underscores the pressing need for more inclusive and equitable healthcare practices to enhance the health outcomes of these communities.⁷⁸

Consequently, addressing these disparities requires more than merely enhancing medical accuracy. It necessitates a concerted effort by the medical community to improve its trustworthiness. Such an effort must begin with acknowledging past shortcomings and actively working to eliminate systemic biases. Additionally, it involves creating an environment where every patient, irrespective of gender or background, feels confident that their healthcare needs will be addressed with fairness and respect. This multifaceted approach is vital for building and

maintaining trust within our healthcare systems, ensuring that all communities receive the equitable care they deserve.⁷⁸

Furthermore, *Medical Error and Vulnerable Communities* highlights the critical impact of implicit bias on the erosion of trust in the physician-patient relationship, with a specific focus on Black populations. Implicit bias significantly influences the healthcare-seeking behavior, medication adherence, and long-term relationships with healthcare providers among members of the Black community, which in turn negatively impacts health outcomes.⁷⁸ Racial and ethnic minorities consistently report lower satisfaction with healthcare services compared to their white counterparts, with studies indicating that Latinos and Asian-Americans rate physician accessibility unfavorably.⁷⁸ These disparities in trust can be attributed to differing cultural experiences and expectations within the healthcare system.⁷⁸

These four studies collectively illuminate the pervasive and persistent disparities in patient safety experienced by marginalized communities. These disparities are deeply rooted and affect racial and ethnic minorities, women, the LGBTQ+ community, and immigrant populations. They encompass issues of access, trust, implicit bias, and healthcare practices. These studies collectively underscore the urgent need for a reevaluation of healthcare systems to ensure equity for all patients, regardless of their background or identity. Addressing disparities in patient safety requires a multifaceted approach that includes improving reporting practices, adjusting for socioeconomic factors in research studies, and acknowledging the role of systemic and implicit biases. Moreover, building and maintaining trust within healthcare systems is paramount in addressing the vulnerabilities experienced by members of these communities. The findings from these studies emphasize that achieving equitable healthcare is not only a matter of policy but also a moral imperative. It is essential to recognize the unique challenges faced by marginalized groups and

work toward a healthcare system that respects their rights, experiences, and diverse needs. Only through concerted efforts to eliminate disparities in patient safety can we hope to provide truly universal and inclusive healthcare.

2.5 The Patient Perspective

The exploration of patient perspectives on patient safety reveals a crucial yet often overlooked aspect of healthcare research. Despite the limited focus in this area, some studies provide valuable insights and demonstrate the importance of incorporating patient viewpoints in healthcare safety measures. One notable study in 2020 emphasized the significance of communication issues, patient knowledge, and the impact of healthcare system factors on medication safety.⁸⁶ This study collected data from 18 focus groups involving 106 participants.⁸⁶ The participants were grouped by demographics or specific conditions, such as various ethnic elder groups, patients and parents of children with long-term conditions, transgender individuals, and those with heart disease, renal disease, mental health issues, substance misuse recovery, deafness, and visual impairment.⁸⁶ The study revealed that participants were aware of their medication-related issues, and they could identify factors contributing to medication errors in primary care and transitions into primary care, including actual medication errors they had experienced.⁸⁶ Common issues identified included communication problems, difficulties with medication and appliance supplies, patient- and caregiver-related factors (e.g. patient knowledge), healthcare professional factors, and problems with computer systems and programs.⁸⁶ Communication issues were particularly prominent, encompassing both communication among healthcare professionals and

between healthcare professionals and patients.⁸⁶ Problems included ineffective communication about medication supplies, changes in doses, lack of information about medication use, and failure to listen to patients' concerns.⁸⁶ Patient and caregiver factors encompassed patient knowledge, responsibility, physical and cognitive challenges, and patient involvement in their care. The study highlighted barriers to taking responsibility and managing one's own condition. For example, some participants spoke about how “new system implementations” are different from what they have experienced in the past.⁸⁶ The Patient Medication Safety (P-MEDS) framework and checklist were developed by the study’s authors, with public collaboration.⁸⁶ This tool aims to capture the patient's perspective on medication safety and complement existing tools to understand medication safety issues in primary care. P-MEDS stands out for its patient-centered approach, highlighting factors like “access to services” and “continuity of care” that are not typically emphasized in other models.⁸⁶ This tool was pivotal in this research by assisting in understanding the unique factors contributing to these incidents from a patient's perspective.⁸⁶

A study from 2012, on acute care consumer perceptions, delved into patient perspectives and identified key concerns in communication, staffing, and medication administration.²⁵ Through group interviews with patients who had received acute care (also known as inpatient care) and their family members, this study provided insights into how patients and their families view and experience safety in the healthcare setting. Patients in the study emphasized the importance of clear, prompt, and precise communication regarding their health status, as well as the need for efficient access to health information, sufficient hospital staffing, and effective management and distribution of medication.²⁵

This study was complemented by a 2017 study that developed the Patients' Perceptions of Safety Culture (PaPSC) scale to assess patient views on safety-relevant aspects of care in

hospitals.⁸⁷ The PaPSC scale was designed to be patient-centric, offering a more comprehensive view of patients' experience of healthcare and a balanced approach to safety culture measurement. This 11-item scale measures patients' perceptions of safety and quality of care during a hospital stay. It evaluates the effectiveness of communication among healthcare professionals, the level of knowledge healthcare providers have about the patient's medical history and current condition, the coordination between different hospital services, the clarity of responsibility for patient care, the willingness of staff to address potential issues, and the availability of qualified healthcare personnel. An online survey was conducted with 112,814 insured persons participating—a response rate of 19.7%.⁸⁷ The findings showed that the most frequent category describing the experience of safety culture concerned communication; this was followed by safety systems.⁸⁷ By highlighting the importance of patient-centric tools and patients' views on safety-relevant aspects of their care, this study outlined crucial inputs for patient safety improvement.⁸⁷ Together, both studies highlight the necessity of considering patient experiences in enhancing healthcare safety in hospitals.

Patient engagement and advocacy are also increasingly recognized as central themes in healthcare research. Research in a surgical oncology setting, utilizing patient interview transcripts, revealed that patients view safety as a shared responsibility and assert their right to be involved in safety measures. This 2017 study utilized a grounded theory qualitative descriptive approach to analyze the interviews and found three major themes: the potentially confusing use of the term 'patient' due to patients' unfamiliarity with the term paired with 'safety', the concept of safety as a shared responsibility, and the idea that involvement in safety is a right for patients.⁸⁸ The authors concluded that the complex interrelations and interdependencies between people, resources, information, and technology need to be more clearly defined if successful interventions are to be

developed. This study emphasized the growing trend of patients asserting their role and rights in healthcare processes.

Similarly, the importance of patient autonomy was suggested by a study on a harm reduction-oriented addiction medicine consultation team in Western Canada. The study clinicians empowered the patient's autonomy by giving them care options, explaining things carefully, and creating care plans that reflected the patients' preferences and priorities. Through semi-structured patient interviews, the study explored the importance of non-judgmental care, and examined the patient perspective on Addiction Medicine Consultation Teams (AMCTs).⁸⁹ These teams included a rotating group of physicians with addiction medicine expertise, a full-time equivalent nurse practitioner, a social worker, and an addiction counselor. Results suggested that AMCTs had a positive impact on patients overall and created better hospital experiences and perceived outcomes for patients. However, further efforts are needed to ensure adequate post-discharge follow-up and a consistent approach to substance use disorder care amongst all hospital staff.⁸⁹ This shift towards patient-centered care displays the evolving dynamics of patient engagement and advocacy in the healthcare sector.

A 2020 study used a patient-centered approach to examine medication safety in primary care.⁹⁰ This study, conducted in Sweden, utilized structured questionnaires with free text answers to explore the perspectives of patients who experienced preventable harm from medication. The authors performed a content analysis and found that patients emphasized the importance of continuity, communication, and competence among healthcare providers in their questionnaire responses. The researchers concluded that safety in primary care is primarily influenced by three factors: continuity of care, communication, and competence. Both patients and primary care providers identified that deficiencies in these areas could increase risks, whereas improvements

could enhance safety. Patients often felt neglected when these elements were lacking, citing experiences of inadequate examination as an example. For primary care providers and practice managers, the lack of continuity in care was a significant concern. The authors suggested that focusing on enhancing these three key categories could lead to a reduction in patient safety risks and contribute to safer primary healthcare practices.⁹⁰

Another study that occurred in 2018 conducted interviews to examine inpatient perspectives on fall prevention in an acute care setting and revealed the need for more patient-centric strategies. Results from 12 interviews found two categories for falls: those caused by a need to use the restroom and those caused by a loss of balance or unexpected weakness. The interviews found that patients often perceived discrepancies between their own views and clinicians' assessments of fall risks and interventions' effectiveness. This reveals a mismatch in perceptions that is a barrier to effective fall prevention. The study concluded that patients did not know their risk of falling, and those who were told of their risk received inconsistent messages regarding their risk from different nurses. It also found that patients wanted to be informed of why they were at risk, what specific activities the nurse wanted them to do to reduce their risk, and the role of the healthcare team in their fall prevention. This study highlights the need for fall prevention programs to be more patient-centric and consider patient perspectives in planning and implementation.⁹¹

In conclusion, studies to date collectively illustrate the indispensable role of patient perspectives in understanding and improving patient safety. Across studies, findings support the need for more inclusive, patient-centered approaches in healthcare, enhancing communication between patients and providers, increasing patient engagement, and considering specialized areas like medication safety and addiction medicine. By incorporating patient viewpoints, healthcare

policies and practices can be better aligned with the needs and experiences of those they serve, ultimately leading to improved safety and quality of care.

2.6 Social Media Discussions About Patient Safety

To date, only two studies have examined social media discussions from patients focused on safety. Both studies used Twitter (now known as X) as a data source for patient safety discussions and revealed significant insights as well as notable gaps in the research. The first study from 2019 focused on assessing Twitter's utility in gathering patient perspectives on medical errors.⁹² The authors analyzed 1,006 Twitter messages (i.e. “tweets”), predominantly identifying various types of medical errors such as procedural, medication, diagnostic, and surgical errors.⁹² Most of the tweets were posted by patients or their family members, expressing a range of emotions including anger, humor, or sadness, with a small portion mentioning litigation intent.⁹² The authors found that most of the tweets came from unique Twitter users, while a smaller fraction came from nonunique users, meaning that one of multiple tweets in the dataset was by the same author⁹². This observation does not invalidate the findings, as the authors adequately address the "uniformity of Twitter users" in their abstract, suggesting that the presence of multiple tweets per person signifies a heightened level of engagement and passion about the issue, which in turn can amplify the reach and impact of the discussed topics.⁹²

Furthermore, a small percentage of tweets mentioned an intent or desire to pursue a malpractice lawsuit, a finding that is consistent with existing literature.^{92,93} In terms of the dimensions and characteristics of the tweets, most harmful events were reported by patients

themselves. Over half of the tweet authors placed blame on physicians. Procedural errors were the most common type of error mentioned.⁹² A significant portion of tweets expressed anger or frustration. This study demonstrated Twitter's relevance as a source for discussions related to medical errors and threats to patient safety, capturing the often-overlooked patient perspective on medical errors. However, it also highlighted limitations, including the uniformity of the Twitter user population and potential inaccuracies in patient-reported errors among patients. The study called for further research to validate the accuracy and meaningfulness of this patient-reported Twitter data.⁹²

The second study, "Patient Safety Discourse in a Pandemic: A Twitter Hashtag Analysis Study on #PatientSafety," analyzed over 358,000 tweets under the #PatientSafety hashtag during the COVID-19 pandemic.⁹⁴ It is important to note that not all of the tweets examined were from patients: physicians contributed 18.65% of all tweets, and other healthcare professionals contributed 14.31%. This study found more than a third of tweets (60.90%) were published in the United States.⁹⁴ Three of the most frequently discussed topics within the global Twitter community using the hashtag #PatientSafety are patients, practicing doctors, and healthcare safety management or pharmacovigilance (defined as the science and activities relating to the detection, assessment, understanding and prevention of adverse effects or any other medicine/vaccine related problems).⁹⁴ This study highlighted the role of Twitter as a platform for rapid exchange of medical information among diverse stakeholders, including healthcare providers, patient advocates, and other individuals. It also emphasized Twitter's potential in pharmacovigilance and monitoring of medical errors, identifying the need for a systematic approach to patient safety that includes digital technologies and social media platforms.⁹⁴

These studies collectively demonstrate Twitter's potential as a valuable source of patient safety information, particularly in engaging patients and healthcare professionals in discussions about medical errors and experiences. However, they also reveal limitations and highlight the need for further research using social media data for patient safety research. Additionally, the findings from these studies underscore the critical need to expand research beyond Twitter to include other social media platforms, such as Facebook. This expansion is important because each social media platform has its unique user demographics, interaction styles, and content dissemination methods.⁹⁵ Another reason for the importance of utilizing Facebook is because of the size of the platform: in 2021, 69% of Americans reported that they use the site, with seven-in-ten Facebook users claiming to use the site daily, including 49% who say they use the Facebook multiple times a day.⁹⁶ The ubiquity of its usage means that expanding research to Facebook has the potential to reveal even more valuable data regarding patient perspectives on safety.

**3.0 Journal Article: “Tirelessly striving towards the challenging goal of patient safety”: A
Content Analysis of Patient Advocacy Dialogues on Facebook**

Riley Wolynn, MPH^a, Beth L. Hoffman, PhD MPH^a, Paul E. Phrampus, MD, MBA, FACEP,
FSSH^b, Scotland Huber, MS^c, Jaime E. Sidani PhD, MPH, CHES^a

- a) University of Pittsburgh School of Public Health, Department of Behavioral and
Community Health Sciences
- b) University of Pittsburgh Departments of Emergency Medicine and Anesthesiology
- c) Jewish Healthcare Foundation

3.1 Abstract

Introduction. With medical errors ranking as a major cause of mortality and morbidity in the United States, patient-centered care and patient engagement have become focal points in healthcare discourse. However, meaningful engagement still faces challenges such as communication gaps and limited exploration of patient viewpoints. The advent of digital platforms, especially social media, offers new avenues for understanding patient experiences. Therefore, this study sought to understand patient perspectives from posts made to a public Facebook group, Patient Safety Action Network Community (PSANC), which is focused on patient safety.

Methods. A total of 200 posts that were posted to PSANC from November 21, 2022 to June 23, 2023 were manually extracted and double-coded by two independent human coders using a systematically developed codebook. Chi square tests were performed to analyze associations between codes. Finally, a grounded theory approach was used to qualitatively analyze the data to explore key themes that emerged.

Results: Of the 141 posts relevant to patient safety (71% of the total), the majority (85.8%, n=121) contained links to further information. Discussions predominantly focused on surgical or procedural errors (27.7%, n=39), infections (17.1%, n=24), and medication-related issues (14.2%, n=20). Key themes included patient empowerment and advocacy (33.3%, n=47) and the necessity for reporting and transparency (21.3%, n=30). There was a statistically significant association between posts containing links and those discussing empowerment and advocacy ($p=0.001$), those discussing infections in vulnerable populations ($p= 0.018$), and posts discussing both policy and advocacy ($p=0.000$). Qualitative analysis uncovered several overarching themes, including the

personal impact of medical errors, systemic challenges, the importance of empowerment through education, and the role of community support.

Conclusions. This study highlights the pivotal role of online patient communities in providing information to other patients and shaping the discourse on patient safety. The findings emphasize the need for healthcare systems to actively involve patients in discussions and decisions affecting their care. The study contributes to the ongoing conversation about patient safety, offering unique insights into the concerns and advocacy efforts of patients themselves.

3.2 Introduction

Medical errors in healthcare pose a significant global challenge, undermining patient safety and the quality of care. Despite variations in their frequency and nature across different healthcare systems, these errors encompass a range of incidents, including surgical mistakes, medication errors, diagnostic inaccuracies, and failures in healthcare technology.¹ These incidents not only result in adverse events such as infections, surgical injuries, and medication errors but also highlight systemic issues within healthcare settings, such as miscommunication, failure to rescue, and falls.¹ The definition of a medical error is broad and encompasses any preventable adverse effect of care, whether or not it immediately harms the patient.¹ An adverse effect is any unfavorable and unintended sign, symptom, or disease associated with the care or treatment, which does not necessarily result from an error. It's important to distinguish that while all medical errors can lead to adverse effects, not all adverse effects stem from errors; some may occur despite the provision of appropriate and error-free care.

The estimation of deaths attributable to these errors is complex and contested, with figures suggesting that a substantial number of patients die annually due to preventable medical errors, highlighting the critical need for more reliable methods to identify and prevent these errors across healthcare settings. The analysis of the United States (U.S.) National Vital Statistics 2018 mortality data reveals that adverse events are cited as the underlying cause in a mere 0.16% (n=4,620) of total deaths, yet they appear among multiple causes in 1.13% (n=32,226) of cases.² Additionally, a 2020 systematic review and meta-analysis examining sixteen studies on preventable mortality in hospitalized patients reported a pooled rate of preventable deaths at 3.1%, equating to approximately 22,165 preventable deaths annually in the U.S.³ These findings starkly contrast with other estimates, such as those proposed in a 2016 study which suggest as many as 251,454 annual deaths due to medical errors, ranking it as the third leading cause of death in the U.S.^{4,5} This discrepancy underlines the complexity of accurately quantifying the impact of medical errors on mortality, further emphasizing the extensive implications on morbidity, healthcare costs, and the broader socio-economic fabric.

The investigation into patient safety gained prominence with the Harvard Medical Practice Study in 1991, which uncovered a high incidence of medical errors in hospitals and propelled further safety-centered research and systemic reforms.⁶ This movement gained momentum with the Institute of Medicine's 1999 landmark report "To Err is Human," which cast light on preventable medical errors in U.S. hospitals and argued for systemic solutions to this widespread issue.⁷ Despite concerted efforts by policymakers, healthcare organizations, and international bodies like the World Health Organization (WHO), studies indicate that hospital errors remain a stubborn challenge, with recent evidence pointing to their continuous prevalence.^{8,9} Beyond the inherent risks to patient health, these errors impose a substantial economic burden, with direct and

indirect costs—including lost income and productivity—amounting to \$20 billion per year in the U.S. alone.^{1,10} The psychological toll on patients and their families is also considerable, contributing to long-term mental health problems, substance use disorders, and emotional stress.¹¹ Medical errors have a more pronounced impact on marginalized racial and ethnic groups, exacerbating health disparities and the erosion of trust in healthcare systems.^{12,13} Considering the vast economic and societal implications of adverse events, which extend from direct treatment costs to increased mortality and lost productivity, a comprehensive and multifaceted strategy is crucial. This strategy should include both the empowerment of individual patients and systemic institutional reforms, such as the implementation of Electronic Health Records and standardized care protocols, to ensure equitable improvements in patient safety and a reduction in medical errors.¹⁴

Patient perspectives on safety have become increasingly central in healthcare research, with the current rise of a focus on patient-centered care.¹⁵ Patient-centered care can be defined as care where “an individual’s specific health needs and desired health outcomes are the driving force behind all healthcare decisions and quality measurements.”¹⁴ Traditionally, patient engagement has focused on the patient-provider relationship for care decisions and self-management. Currently, the healthcare community increasingly acknowledges that patient-centered care and an understanding of patients' experiences are fundamental aspects of care quality and safety.¹ As such, there is a growing push to gain a deeper understanding of the patient's perspective to not only improve overall quality of care, but also patient safety. Patient narratives and experiences offer invaluable insights that can lead to significant improvements in safety protocols and treatment approaches.¹⁴ Studies exploring patient views in various settings, from primary care to acute and surgical care, underscore the need for more inclusive, patient-centered approaches.^{15–17} These

perspectives reveal crucial insights into the challenges patients face, such as communication barriers, medication safety issues, and the need for greater involvement in safety measures.¹⁸ By integrating patient viewpoints, healthcare policies and practices can be more effectively aligned with the needs and experiences of those they serve, leading to improved safety and quality of care.

However, engaging patients meaningfully remains a complex endeavor. Barriers such as communication gaps, health literacy levels, and systemic healthcare issues often hinder patient-centered care.¹⁹ Thus, while patient engagement is championed by current healthcare agencies, patient perspectives on safety remain underexplored, emphasizing the necessity of new approaches to obtaining these perspectives. Digital platforms may be one such approach, as these tools have enabled patients to share their experiences on a broader scale. Social media in particular has emerged as an important tool for understanding patient perspectives, especially in the context of improving and reshaping service delivery.²⁰ However, limited research has been conducted using social media to understand patient perspectives on safety. Specifically, two key studies have delved into patient safety discussions on Twitter (now known as X), uncovering significant insights and research gaps. The first, analyzing 1,006 Twitter messages (i.e. tweets), found them rich in patient and family experiences of medical errors, marked by a broad spectrum of emotions and occasional litigation intentions, therefore affirming Twitter/X's utility in capturing patient perspectives on safety issues.²¹ The second study examined over 358,000 #PatientSafety tweets during the COVID-19 pandemic, identifying a wide engagement from healthcare professionals and highlighting the platform's role in facilitating rapid information exchange across diverse stakeholders.²² These investigations found that Twitter/X has the potential to revolutionize patient empowerment and advocacy, marking a significant shift towards more inclusive and participatory healthcare conversations.^{21,22}

However, to date there has been no examination of patient perspectives using data from Facebook. Facebook, with its vast and diverse user base, presents an untapped opportunity to capture a wider array of patient experiences and insights. Facebook is the second most used social media platform by Americans, with 69% of Americans reporting use of the site.²⁴ Furthermore, 70% of Facebook users claim to use the site daily, including 49% who say they use the platform multiple times a day, according to a 2021 study.^{24,25} Expanding patient safety research to use data from Facebook can provide valuable insights for healthcare providers and policymakers in creating more effective patient engagement and safety strategies.

Therefore, this study aims to examine patient discussions within an online community to better understand the patient perspective on safety-related issues. Specifically, this study analyzes content from a public Facebook group related to patient safety, called the Patient Safety Action Network Community (PSANC). By analyzing the content of these discussions, this study seeks to contribute to the enhancement of safety and quality in healthcare delivery, ensuring that patient voices are not only heard but are integral to the evolution of patient safety standards.

Community engagement in research, particularly at the intersection of social media and patient safety, represents a novel approach that is understudied.²¹ This study has aimed to involve the PSANC in every step of the research process. Engaging community members not only enriches the research with diverse patient perspectives but also enhances the relevance and applicability of the findings.²¹ These collaborative efforts are important for advancing patient safety initiatives and ensure that the voices of those most affected are heard and valued in the research that aims to protect them.

3.3 Methods

3.3.1 Sample Selection

We collected all posts (n=200) that were posted to PSANC from Nov 21, 2022, to June 23, 2023. This entailed manual extraction of the original content text, comments, and links associated with each post. We determined *a priori* to collect and analyze 200 posts, a decision informed by the capacity of human coders to conduct a thorough and comprehensive analysis of the content. Data were manually extracted on June 23, 2023 starting with most recent posts; the 200th post was from Nov 21, 2022. This sample size is consistent with other research leveraging Facebook group data.²⁶

We collected and analyzed the data in the summer and fall of 2023. No privately identifiable information was collected; the names of post authors were not recorded with the post content. Researchers did not interact with post authors, nor did they post content to the group. All study procedures were exempted by the University of Pittsburgh Institutional Review Board (Appendix B).

3.3.2 Community Engagement Procedures

In an effort to secure support from the community, demonstrate respect for the community's privacy, and ensure transparency, we contacted the moderators of the PSANC Facebook group prior to any data collection. The moderators have requested for their group to be named in this research. Moderators play a crucial role in maintaining the integrity and relevance

of discussions within Facebook groups.²¹ The primary role of a moderator in this specific Facebook group encompasses ensuring that all discussions align with the group's purpose and guidelines, moderating content to prevent violations of community standards, and guiding conversations to stay on topic. By fostering a respectful and constructive environment, moderators significantly influence the shaping of discussions.

The moderators were informed about the objectives and methods of the research, emphasizing the observational nature of the study and the commitment to maintaining the confidentiality and anonymity of the group members. Moderators often have a vested interest in the group's topic, whether from personal passion, professional engagement, or both, which drives their commitment to cultivating a vibrant and focused community. Considering this, as well as that the moderators for this Facebook group have a deep understanding of the community dynamics, we invited them to provide feedback on the research aims and methods. Specifically, they reviewed the preliminary codebook and offered insights that ensured the coding process was aligned with the context and nuances of the discussions of the group. Lastly, the moderators posted in the group to inform PSANC community members about this research.

3.3.3 Coding Procedures

Codebook development began with two researchers conducting an initial review of the 200 collected Facebook posts to identify key concepts, themes, and patterns. All 200 posts, along with their comments and links, were examined by each researcher. This inductive approach allowed the data itself to guide the establishment of the codebook. Then, we developed a preliminary codebook with 8 different codes for error type and 9 different content codes. Each code in the codebook

contained a clear and specific definition and an exemplary quote or text from the posts to serve as an example. This codebook underwent 3 revisions before a final codebook was codified, with each revision undertaken after two researchers double coded a small sample of posts (20 posts for each of the 3 preliminary rounds). In developing and refining our codebook, we employed a thorough and collaborative process. Initially, the two researchers convened to meticulously review the coded data, allowing any discrepancies in interpretations to be identified and discussed. These discussions were critical, as they enabled the two researchers to achieve a higher level of consistency and reliability in their coding approach. Following this review, the two researchers made several edits to codebook definitions to ensure they were clear, precise, and accurately reflective of the data's nuances. Based on the collective analysis of emerging themes from the data, the two researchers found it necessary to both add new codes and delete others that were no longer relevant or were overly redundant. This iterative process of review, discussion, and modification was essential in developing a robust and effective codebook that served as a foundational tool for this research. A coding hierarchy was developed to structure these codes, with similar codes grouped under broader categories (**Table 1**). The two researchers made modifications to the exemplary quotes and texts before including them in the codebook. For example, the researchers removed names and locations, changed words to others with the same meaning, and made other modifications. These edits were made to ensure that the quotes were not searchable on Facebook and could not be linked back to the original author. However, it is important to emphasize that the meaning of the original quotes was not changed in this process.

The codebook included a binary coding system (0 for 'no', 1 for 'yes') for all variables. Following the codebook development, all posts (including the 60 posts used for codebook development) were double-coded by a trained research assistant and the primary first author, by

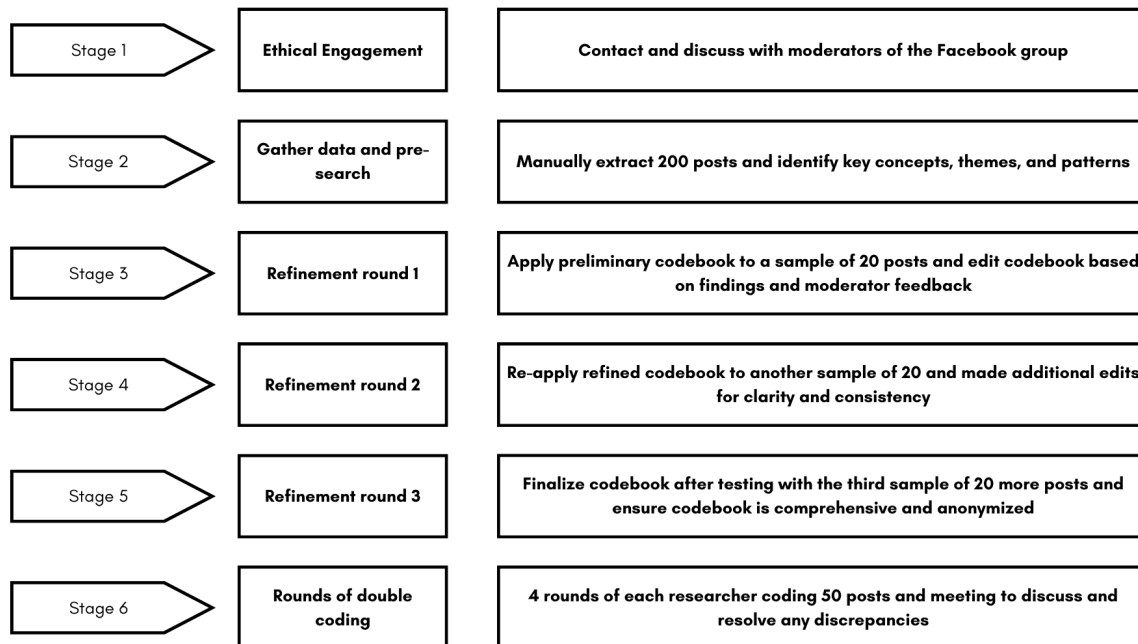


Figure 2. Codebook Development Process

categorizing each post according to the codebook. This was done on a spreadsheet housed within a secure drive. The spreadsheet included the posts’ texts in rows and all the variables from the codebook in the columns along the top. None of the codes were mutually exclusive.

Coders individually coded 50 posts and then met to adjudicate; this was done four times, thus double-coding all 200 posts and ensuring that a consensus was reached on all coded items. This double-coding method mitigated the need for a measure of inter-coder reliability, as there was a full consensus reached for each variable. While coding posts, the researchers took in-depth notes on emerging themes to utilize for qualitative analysis (**Figure 2**).

Figure adapted from “Qualitative and Mixed Methods Social Media Research: A Review of the Literature”.²⁷

3.3.4 Coding Categories

All posts were first assessed for *relevance*, which was defined as, “The main topic of the post is patient safety.” If a post was not deemed relevant to patient safety, it was not coded further. Irrelevant topics included discussions of unrelated incidents, personal or administrative announcements, and broader health policy issues without a direct link to patient safety. The relevance code helped to ensure this analysis focused strictly on content discussing patient safety. The presence and accessibility of external links in posts, such as links directing readers to news articles, were also coded. These links often served to further support the points or arguments made in the original post.

The *source of the post* was another coding category, categorized based on the author of the post’s relationship to the patient. This included codes for the patient, family members, friends, and other relations (e.g. ‘A friend’s niece’).

The codebook also included non-mutually exclusive codes for *error types*. These include medication errors, medical device or implant errors, diagnostic or missed diagnosis errors, surgical or procedural errors, infections caused by medical errors, technology or equipment errors, errors caused by neglect, and other errors.

In addition to coding the types of errors, the codebook included a range of content codes to capture the broad range of discussion topics. These included *communication and information sharing*, indicating discussions about healthcare providers sharing medical information to the patient and to other providers that were part of the care team. Other content categories included *patient empowerment and advocacy*, *healthcare provider practices*, *reporting and transparency*, *systemic and organizational factors*, *policy and regulatory issues*, *ethnic and racial minorities*,

vulnerable populations, understaffing issues, and the presence of personal photos. None of the codes were mutually exclusive, and they were all applied to comments, images, and links (which were opened and reviewed for their content) in addition to the main content of the posts. The final codebook, with all coding categories, is shown in **Table 1**.

3.3.5 Analysis

Descriptive statistics and cross-tabulations were calculated using StataSE to describe the data.²⁸ Chi-square tests were used to determine the statistical significance of associations between coded content. Additionally, an in-depth qualitative analysis using a grounded theory approach was conducted to identify and synthesize emergent themes related to patient safety by utilizing notes from the coders. This process began with open coding, where each Facebook post was examined to identify basic ideas and themes, which were then labeled in simple terms. This was followed by axial coding, where these identified ideas were connected, effectively creating a map of how they relate to each other. The final step involved selective coding, where the most prominent theme that emerged from the analysis was chosen and all other themes were organized around it. This systematic approach allowed for a comprehensive understanding of the key issues within the patient safety discussions. No software was used during this process.

Table 1. Codebook for Analyzing Patient Safety Facebook Posts

| Variable | Definition | Example |
|---|---|---|
| Relevance | The main topic of the post is patient safety | |
| Link | The post contains a link to an article or website | |
| Access | The link can be accessed (still available, not blocked by a paywall, etc) | |
| Source Patient, family member, friend of patient, other relation to patient | How the user identifies in the post IF taking about a personal/proximal experience | Patient: "I had surgery..." Family: "my sister..." Friend: "my friend..." |
| Error types | | |
| Medication error | Conversations related to medication errors or adverse drug reactions. Includes concern about under or over medicating | -“A 2019 clinical trial... found that the drug... failed to reduce the risk of preterm births or produce better health outcomes for newborns.” -“Too many medicines, in the wrong combination, killed him” |
| Medical Device or Implant error | Conversations related to Medical Device or implant error | -Unknown dental allergies led to failing implants, multiple sessions to remove and install new fillings, along with pain and discomfort” -“As the number of permissible changes to high-risk medical devices increases, so does the frequency of following recalls of these devices” |
| Diagnostic or missed diagnosis error | Conversations related to diagnostic error | -“Jury awards \$23 million to man who lost an arm after hospital missed blood clot” -“She acknowledged her medical negligence by not seeing the cancer cells in the pathology slides” -“HIV test creator said that it mistakenly sent letters to about 200 patients falsely suggesting they may have HIV” |
| Surgical or procedural errors | Conversations related to Surgical or procedural errors | -“Chicago surgeon found guilty of manslaughter in death of a 20 year old patient” -“Dr. Smith continued to disable other patients with the same surgery after he harmed me” |
| Infection caused by medical error | Conversations related to infection caused by medical error | -“Four babies perished from non-sterile equipment” -“In 2017 he went in for a surgery and walked out with a life-threatening MRSA infection” |
| Technology or equipment error | Conversations related to technology or equipment error | -“A computer error and poor monitoring” |

| | | |
|---------------------------------------|---|--|
| | | -“While new technology can save lives...adverse events can lead to pain, disability, and death” |
| Error caused by neglect | Harm or error to the patient is caused by neglect of healthcare worker | -“This organization calls all to raise awareness about elder neglect” -“Deaths Linked to Neglect, Error Raise Concerns About Quality of Care at This Dallas Hospital” |
| Other error | Conversations related to other errors | |
| Content codes | | |
| Communication and Information Sharing | Discussion about communication between healthcare providers or between patients and providers | -“FDA Seeks to Improve Patient Communication on Laser Eye Suregry Benefits and Risks Through Issuance of Draft Guidance” -“Very careless and utter lack of communication” |
| Patient Empowerment and Advocacy | Discussions on patient empowerment and involvement in their own care. Asking for or sharing strategies and resources for patients to advocate for their safety. Experiences of patients advocating for safer care or better practices | -“So thankful for the work of group member in teaching individuals how to protect themselves from MRSA and other healthcare acquired infections” -“In March I filed a medical board complaint against the surgeon...” |
| Healthcare Provider Practices | Conversations about healthcare provider behavior and practices related to safety, sharing experiences with healthcare providers. Personal or proximal experiences only | -“In May I was referred to a Gynecologist” -“My shoulder surgeon has started abusing and harming me” |
| Reporting and Transparency | Discussions about healthcare workers or systems reporting errors and discussions about healthcare workers not being transparent with patients | -“He also blamed the company for not developing the proper reporting procedures” -“Great info to get hospitals to do the right thing when harm occurs is just to simply be transparent” -“A medical assistant was requested to fill out an anonymous report. So, she did, but it turned out to not be anonymous and was reprimanded” |
| Systems and Organizational Factors | Discussions on systemic factors contributing to patient safety issues. Conversations about the role of healthcare organizations in promoting safety. Includes administrative factors | -“That’s how privatized and protected our system of care is.” -“The healthcare system is a scam” |
| Policy and Regulatory Issues | -Conversations about policies or regulations related to patient safety | -“A new Ohio law taking effect on June 14th is very anti-patient” -“Federal lawmakers push for a policy that would let hospitals get away with unsafe and harmful practices” |
| Ethnic and racial minorities | -Mention of racial disparities in patient safety | - “African-Latina people are 10x times more likely than whites to be diagnosed as bipolar, but a recent study shows this is nothing to do with biology.” |

| | | |
|------------------------|---|---|
| | | -“Her research suggests they can affect the health of Asian patients down the line” |
| Vulnerable populations | Mention of the elderly, those on Medicare/Medicaid, children, and other vulnerable populations. | -“The medical system over prescribes the elderly with medications and procedures” -“Medicare Advantage Enrollees with Dual Eligibility, Including Those in Nursing Facilities, Experienced Inferior Clinical Care” |
| Understaffing | Discussion about understaffing in healthcare settings | -“This hospital was under staffing of as much as 38% the National Average” -“Under-Staffing Leads to More MRSA and Other Hospital Acquired Infections” |
| Photos | Personal photos of a patient injury (not from a website or article) are shared in the group | |

3.4 Results

3.4.1 Descriptive

A substantial proportion of the analyzed posts, (n=141, 70.5%), were found to be *relevant* to patient safety issues. Of the relevant posts, a majority, 85.8% (n=121) contained *links to further resources or information*, with 74.7% (n=105) featuring links that were accessible to the researchers. The majority of links directed readers to news articles that supported the points or arguments made in the original post.

In terms of medical errors discussed, *surgical or procedural errors* were the most frequently mentioned (27.7%, n=39; **Table 2**). *Infections* resulting from medical errors were discussed in 17.1% (n=24) of posts, while *negligence* was discussed in 17.1% (n=24) of posts. *Medication-related errors* and issues with *medical devices or implants* were also prevalent, appearing in 14.2% (n=20) and 10.64% (n=15) of posts, respectively. *Diagnostic or missed diagnosis errors* were discussed in 10% (n=7.1) of posts. Other types of errors, which included *categories not specified elsewhere*, were mentioned in 3.6% (n=5) of posts, and *technology or equipment errors* were the least discussed, in only 2.1% (n=3) of posts.

The content code *patient empowerment and advocacy* was the most prominent, with 33.3% (n=47) of posts discussing this. Posts under this category discussed topics such as harmed patients taking legal action and public awareness campaigns. *Reporting and transparency* within the healthcare system were discussed in 21.3% (n=30) posts. *Communication and information sharing* were topics of discussion in 7.8% (n=11) of the posts.

The complex interplay of *systemic and organizational factors* affecting patient safety was addressed in 24.1% (n=34) of posts. *Policy and regulatory issues* were discussed in 34.8% (n=49) of posts. The needs of *ethnic and racial minorities* were specifically mentioned in 3.6% (n=5) of posts, and *vulnerable populations* more broadly were mentioned in 26.2% (n=37) of posts, highlighting the community's sensitivity to diverse patient groups. *Understaffing issues* were highlighted in 9.2% (n=13) of posts (**Table 2**).

3.4.2 Cross-Tabulation Analysis of Key Themes

Chi square tests revealed a statistically significant association specifically between posts containing links and those discussing patient empowerment and advocacy. Specifically, of the 94 posts that included links, 87 (71.9%) were found to engage in topics related to patient empowerment and advocacy ($p=0.001$). Furthermore, posts discussing infections caused by medical errors were statistically significantly associated with the mention of vulnerable populations ($p=0.018$). Of the 24 posts that engaged with topics of infection, 11 posts (45.83%) specifically mentioned vulnerable populations. Finally, there was a significant association between posts that discussed policy and those that discussed advocacy ($p<0.000$), underscoring a significant intersection of these topics within the discourse. Specifically, within the subset of 49 posts that mentioned policy, more than half (n=27; 55.10%) also engaged in advocacy discussions.

Table 2. Frequency of 141 Relevant Patient Safety Posts by Category

| Variable | Frequency | |
|---------------------------------------|-----------|------|
| | N | % |
| Link | 121 | 82.8 |
| Link access | 105 | 74.5 |
| Error Types | | |
| Surgical or procedural errors | 39 | 27.7 |
| Infection caused by medical error | 24 | 17.1 |
| Negligence | 24 | 17.0 |
| Medication error | 20 | 14.2 |
| Medical device or implant error | 15 | 10.6 |
| Diagnostic or missed diagnosis | 10 | 7.1 |
| Other Error | 5 | 3.6 |
| Technology or equipment error | 3 | 2.13 |
| Content Codes | | |
| Policy and regulatory issues | 49 | 34.8 |
| Patient empowerment and advocacy | 47 | 33.3 |
| Vulnerable populations | 37 | 26.2 |
| Systems and organizational factors | 34 | 24.1 |
| Reporting and transparency | 30 | 21.3 |
| Understaffed | 13 | 9.22 |
| Communication and information sharing | 11 | 7.8 |
| Ethnic and racial minorities | 5 | 3.6 |

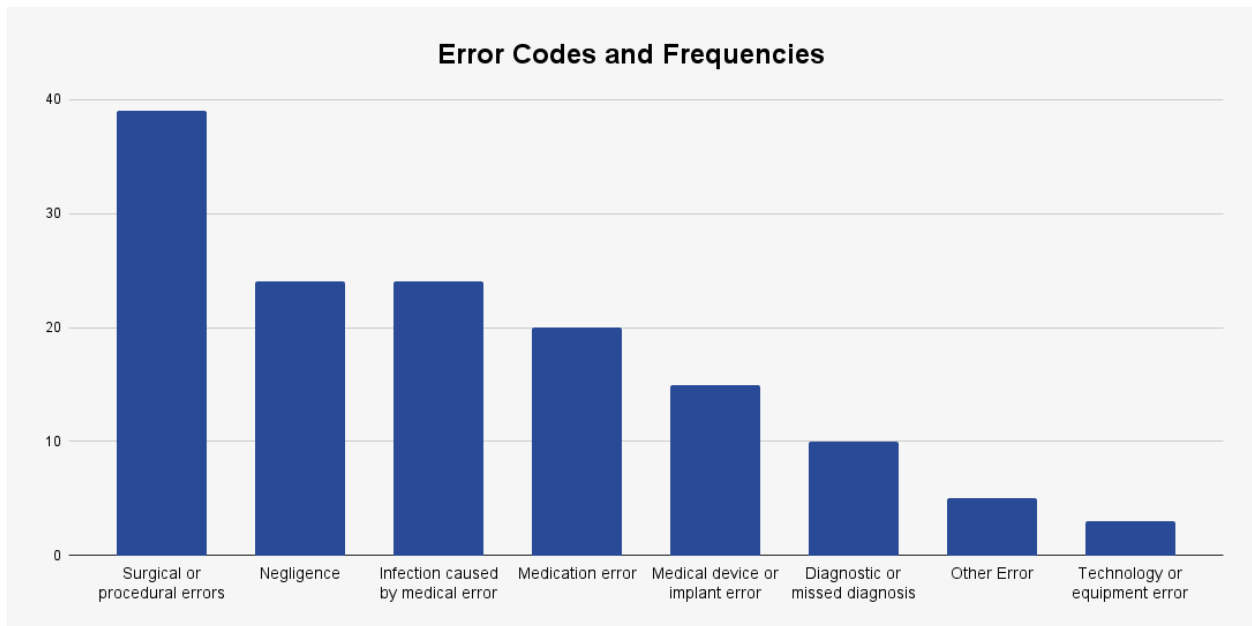


Figure 3. Error Codes and Frequencies

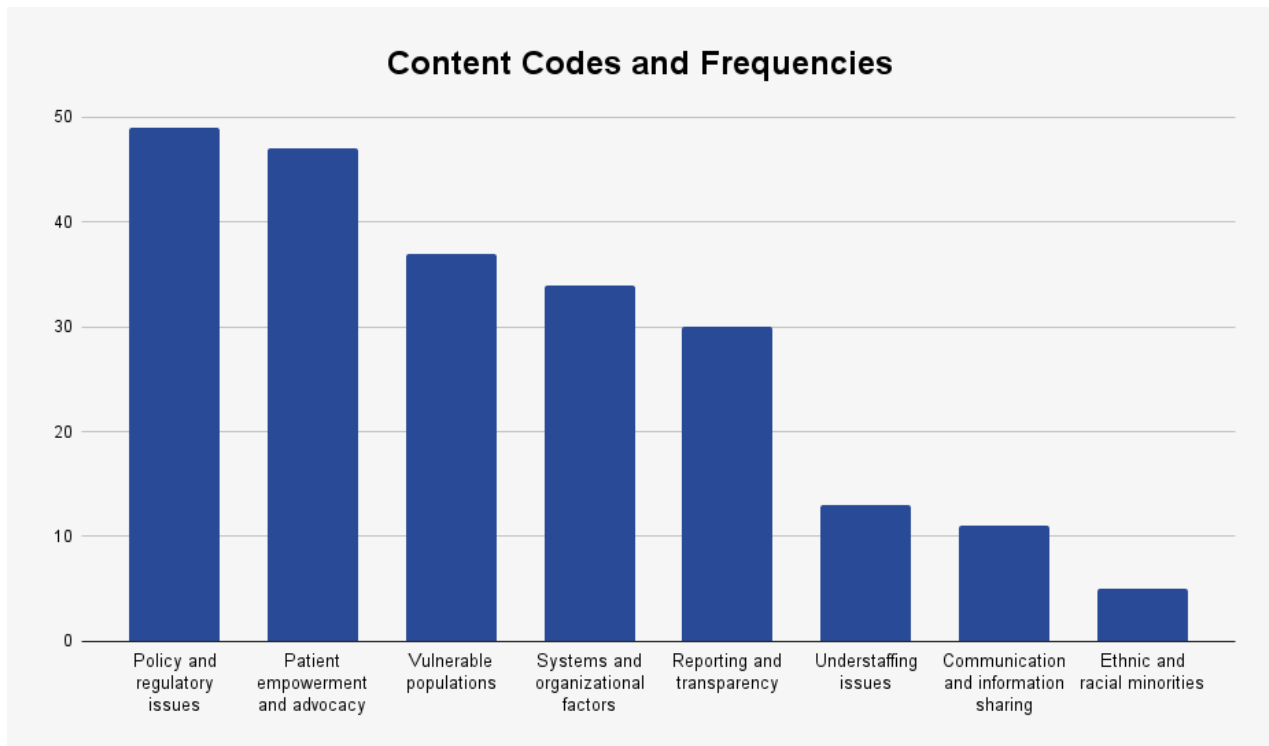


Figure 4. Content Codes and Frequencies

3.4.3 Qualitative Analysis

Qualitative analysis revealed four overarching themes. One overarching theme was the *personal and proximal impact of medical errors*. Many posts contained narratives detailing the emotional and physical toll of medical errors on patients and their families. For example, one group member wrote, “Despite the passage of several years since my surgery, the experience remains deeply distressing, dramatic, and triggering for me. I find myself feeling isolated, as those around me seem unable to grasp the full impact of what happened. When I try to convey how the injuries from that surgery continue to disrupt my life, I'm often met with indifference, almost as if they think I am lazy.” These stories often highlighted the long-term consequences of such errors, including chronic pain, psychological trauma, and financial burdens.

Another overarching theme was *systemic challenges and advocacy*. Posts within this theme often addressed broader systemic issues, such as understaffing and inadequate policies, which were perceived as contributing factors to patient safety risks. For example, one person wrote, “In this group, we're tirelessly striving towards the challenging goal of Patient Safety. Despite our efforts and hard work, the sad reality is that our efforts won't bring our physically lost loved ones back. This deep sorrow underlines the need for eliminating harmful policies.”

Empowerment through education emerged as another overarching theme. There was a clear desire among community members for more accessible information about patient rights, safe practices, and the healthcare system at large. Many posts included or requested resources for self-advocacy, emphasizing the role of informed patients in promoting safety and accountability in healthcare. For example, one person wrote, “A detective has been appointed by the state medical board to look at my complaint about my doctor. Can anyone shed light on what this entails? Does anyone have insights or knowledge about how medical board investigations typically proceed?”

Finally, a recurring theme involved the importance of *community support and shared experiences*. The online community network served as a platform for individuals to find solace and solidarity with others who have encountered similar challenges. For example, one person wrote, “I'm in need of someone who gets it and can offer sympathy to talk to.”

3.5 Discussion

This study analyzed 200 posts in the Facebook group Patient Safety Action Network Community (PSANC) and identified key content codes that included patient empowerment and advocacy, reporting and transparency in healthcare, systemic and organizational factors, and the specific needs of ethnic, racial, and vulnerable groups. There were also significant associations between posts containing further information resources and those discussing patient advocacy and empowerment. Qualitative analysis revealed personal narratives highlighting the impact of medical errors, systemic challenges, the importance of education for patient empowerment, and the value of community support in navigating healthcare challenges.

One surprising finding was the intersection of discussions about vulnerable populations with various types of medical errors. The focus on infections and negligence in the context of vulnerable groups highlights a community sensitive to the unique challenges faced by these populations. This is important because research reveals there are significant health disparities, particularly pertaining to preventable hospital or care home acquired infections in elderly populations.⁴ This awareness is crucial for healthcare providers and policymakers, as it underscores the need for tailored approaches to patient safety that consider the specific needs and vulnerabilities of different patient groups.

Furthermore, this study revealed a strong connection between advocacy discussions and policy matters, indicating a community actively engaged in influencing healthcare policies. This suggests that patient communities can be instrumental in driving policy changes and advocating for systemic improvements in healthcare. The moderate association between reporting, transparency, and advocacy suggests the community has a desire for more open communication

and accountability in healthcare systems. Moreover, the growing traction of online platforms in fostering patient-led advocacy further underscores the vital role these communities play in pushing for greater accountability and inclusive policy-making processes in healthcare.²¹

The qualitative analysis of posts adds another dimension to these findings, pairing heartfelt narratives with statistics often associated with research on medical errors. These narratives illuminate the profound impact of medical errors on individuals and families and call for more compassionate and patient-centered care. Additionally, the discussions around systemic challenges and the need for policy reform reflect a sophisticated understanding of the complexities of healthcare systems and the factors that contribute to patient safety risks.

This study found that technology or equipment errors were the least discussed type of error, in only 2.1% (n=3) of posts. This observation suggests a possible gap in how patients perceive the role of Health Information Technology (HIT) in ensuring safety. Given the significant focus in existing literature on the potential of HIT to enhance patient safety, the limited mention of technology errors by patients could be viewed in a positive light.¹ It may indicate that, from the patient's perspective, technology errors are not a major concern, possibly reflecting well on the reliability and effectiveness of current HIT systems. This perspective aligns with studies highlighting HIT's benefits, such as improved information access and reduced medication errors. However, the limited mention of technology may also indicate that patients are not aware of the potential for HIT to enhance patient safety. This nuanced view encourages further exploration of HIT's effectiveness from both a patient safety and technology reliability standpoint.

In summary, this study highlights the potential of patient communities as vital contributors to the discourse on patient safety. The perspectives of members of the PSANC Facebook group offered a unique and necessary dimension that can inform and enhance healthcare practices and

policies. In the evolving landscape of healthcare, it is essential that the voices of patients, especially those from vulnerable groups, play a central role in shaping a healthcare system that is safer, more responsive, and centered around patient needs. These perspectives are crucial in driving the development of healthcare practices that truly address the diverse needs of all patient populations.

3.5.1 Integration of Findings with Existing Literature

The results of this study serve as a complement to existing patient safety research, highlighting the ongoing challenge of medical errors such as surgical mistakes and infections, while also identifying emerging trends in patient empowerment through digital platforms.^{19,22,23,29} It builds on the historical foundations set by seminal works, emphasizing the role of social media in bolstering patient-centered advocacy and engagement.^{6,7,30} The analysis reveals systemic issues like understaffing as significant challenges, advocating for comprehensive, strategic responses. Furthermore, it sheds light on the disproportionate impact of adverse events on vulnerable populations, urging targeted interventions.^{12,13,31,32} The importance of social media as a rich source for capturing patient perspectives is acknowledged, underscoring its potential to refine patient safety practices.^{22,23} This integration of new insights with traditional concerns reveals the necessity for continuous policy evolution and the inclusion of diverse patient voices in creating a healthcare environment focused on safety, transparency, and patient engagement.

The integration of insights from this study with findings from the two studies which explored perspectives of patient safety on Twitter enriches our understanding of patient safety challenges and innovations.^{21,22} This addition underscores the necessity for healthcare policies to evolve continuously, embracing social media insights to foster a safer, more transparent, and

inclusive healthcare environment. Both the Twitter studies and our Facebook study utilize social media to explore patient perspectives on safety, revealing diverse and emotional responses to medical errors. The difference lies in the data depth, with Facebook providing more extensive narratives and Twitter capturing succinct, immediate reactions, suggesting varied applicability depending on the research goals.

3.5.2 Policy and Future Research Implications

This research underscores the potential of leveraging patient insights from social media to inform nuanced reforms in patient safety policies. It specifically sheds light on the significance of including the patient's voice in targeting persistent safety issues. Results from this study support the need for policies that not only tackle technical and systemic hurdles, such as understaffing and specific patient group vulnerabilities, but also strengthen patient empowerment and advocacy. The findings suggest that enhancing patient involvement and ensuring healthcare transparency can be achieved by being responsive to community concerns raised in online discussions. Furthermore, the active sharing of information among patients on social media suggests a readiness for greater inclusion on advisory boards and implies that their insights could be instrumental when designing interventions and shaping patient-centered policy reforms.

Additionally, the study points to the potential use of digital platforms in fostering patient education and engagement, which could have positive implications for the emotional and psychological wellbeing of patients dealing with medical errors. Results from this study support the need for policies that enhance patient involvement. The research does not expressly advocate for targeted interventions but highlights the potential benefits of incorporating patient-derived

social media insights into healthcare policies. Future research is advised to focus on evaluating the impact of these insights on patient safety practices and exploring supportive interventions for patients affected by medical errors. This approach aims to contribute to the development of responsive, equitable healthcare systems by integrating the patient perspective into the fabric of healthcare policy and practice.

3.5.3 Limitations

This study has several limitations that warrant consideration. First, the analysis was conducted on a single Facebook group, limiting the generalizability of the findings to the broader population. Additionally, the motivation and characteristics of individuals who join a Facebook group specifically for discussing patient safety concerns may inherently differ from those who do not. This specific focus could potentially not capture the full spectrum of patient experiences and discussions about medical errors occurring across various social platforms or offline contexts.

Another key limitation is the reliance on publicly available information. Only content accessible on the public PSANC Facebook group was coded, excluding potentially relevant discussions and perspectives shared within private networks or restricted to select groups of Facebook friends. Furthermore, the rules and regulations set by Facebook and those set by the group moderators may restrict access to certain types of content. This exclusion could lead to an incomplete understanding of the range and depth of patient experiences and perceptions related to medical errors.

Moreover, while this study centers on patient experiences, it's important to note that these experiences are subjective and can vary widely. Patients' descriptions of their experiences,

including any harm or injuries following healthcare encounters, are based on their personal understanding and perspective, which might not always align with medical assessments. However, these accounts are valuable and provide crucial insights into the patient perspective, contributing significantly to patient safety and quality of care research. Additionally, the linked sources were not assessed for the source or quality, although the moderators assess and approve each post for relevancy to patient safety and credibility.

Finally, despite efforts to minimize subjectivity, such as double coding and multiple rounds of analysis, the use of qualitative analysis methods inherently involves subjective interpretation. The researchers' perspectives and judgments could have influenced the analysis and findings. This highlights the importance of approaching the analytical process with awareness and caution, ensuring that the voices and experiences of patients remain central and respected throughout the study.

3.6 Conclusions

The active engagement in discussions related to patient safety, as evidenced by the content and nature of the posts in the PSANC Facebook group, reflects a community deeply committed to advocating for safer healthcare. This commitment is particularly significant in the realm of patient empowerment and advocacy. The frequent inclusion of external resources in these discussions indicates this online community values informed dialogue. The association between information sharing and advocacy highlights the potential of empowering patients with knowledge as a tool for representing the voices of patients and their families in the broader dialogue on enhancing patient

safety and quality of care. The qualitative analysis revealed a deeply interconnected web of personal stories, systemic critiques, and advocacy efforts that together create a powerful narrative of the need for change within healthcare systems. These themes show that the community serves as a space for sharing individual experiences and collectively calling for improvements in patient safety. While the efficacy of social media discussions as a direct mechanism for improving healthcare outcomes remains to be fully substantiated, the argument can be made that these platforms could serve as significant channels for patient and family advocacy in the discourse on healthcare improvement.

3.7 Acknowledgements

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4.0 Thesis Conclusions

This thesis included a thorough examination of 200 Facebook posts on patient safety within the Patient Safety Action Network online community, uncovering significant insights into the dynamics, consequences, and conversations about medical errors and patient advocacy. This research delved into discussions around surgical mishaps, infections, negligence, medication issues, and complications related to medical devices, highlighting a trend toward community-led sharing of information and resources. A key discovery of the research undertaken as part of this thesis is the statistically significant association between resource-sharing posts and enhanced discussions on patient empowerment, underscoring the critical role digital platforms play in enabling patients to actively participate in healthcare conversations.

The analysis of Facebook posts revealed a deep concern by post authors for systemic challenges such as understaffing and policy deficiencies, pointing to the intricate nature of patient safety as a problem that necessitates a holistic and strategic approach. Personal stories within the community elucidate the devastating impact of medical errors, including psychological and financial distress, advocating for a healthcare system that is more empathetic and centered around patient needs.

The study also uncovered a statistically significant association between advocacy and policy discussions within the community, suggesting an active role for patient groups in spearheading healthcare reform. The moderate association between calls for transparency, reporting, and advocacy highlighted a collective yearning for more accountable healthcare systems.

Exploring the statistically significant association of the intersection of medical errors with vulnerable populations revealed a community attuned to the unique challenges these groups face, stressing the importance of customized safety measures. The personal narratives shared added a human element to the data, supporting the need for a healthcare approach that is compassionate and patient focused.

This research emphasized the importance of patient communities in the dialogue on patient safety and posited these communities as crucial influencers in advancing healthcare practices and policies. As the healthcare landscape continues to evolve, it is imperative that the insights and needs of patients, particularly those from vulnerable demographics, are at the forefront of shaping a healthcare system that prioritizes safety, transparency, and inclusivity. The study sets the stage for further research into the effectiveness of patient safety policies, the role of social media, and post-medical-error support mechanisms, offering a comprehensive perspective on the complexities of patient safety and the transformative potential of patient advocacy.

4.1 Integration of Findings with Existing Literature

The research conducted for this thesis resonates with findings from the literature review presented in Chapter 2 of this thesis. The analysis of Facebook discussions on patient safety not only echoes historical concerns identified in seminal studies, but also supports emerging trends in patient-centric advocacy and the utilization of digital platforms. Historically, the Harvard Medical Practice Study and the Institute of Medicine's report *To Err is Human* laid the groundwork for understanding the prevalence and nature of medical errors in healthcare settings.^{19,22} The original

research findings, which highlighted the continued prevalence of specific types of adverse harm events such as surgical errors and infections through Facebook discussions, suggest a persistent challenge in these areas. This continuity in the types of medical errors indicates that, despite advancements in patient safety protocols and healthcare technologies, certain types of errors remain as significant concerns, mirroring the early revelations of the 1991 study.¹⁹

The findings of this research illuminate the growing trend of patient empowerment and advocacy within online communities, resonating with the patient-centered care approach as portrayed by *To Err is Human*.²² This finding also complements the discoveries made by the two studies examining patient safety discussions on Twitter.^{92,94} The first study demonstrated how Twitter enabled patients to voice their experiences and concerns about patient safety, signifying a surge in patient empowerment and advocacy online.⁹² The second study amplified this by showing how discussions, especially during the COVID-19 pandemic, further engaged patients in advocating for safety, reinforcing the critical role of social media in patient-centered advocacy.⁹⁴ Together, they exemplified how Twitter could be pivotal in advancing patient empowerment, underlining a transformative shift towards more inclusive and participatory healthcare dialogues. As the first study to examine patient safety discussions on Facebook, this research supports the use of Facebook for similar purposes, supporting the notion that social media could be used more broadly for active engagement of patients on digital platforms, where patients are not just seeking information but are actively sharing resources and participating in discussions related to their healthcare. This occurrence represents a transformative shift in the patient-care paradigm, where the role of patients has evolved from passive recipients of healthcare information to active, informed participants.^{11,12} The prominence of such interactions in online communities signifies a fundamental change in how patients engage with healthcare systems, highlighting an era where

digital means are increasingly central to patient empowerment. This evolution in patient engagement reflects a significant move towards more collaborative and transparent interactions in healthcare, fundamentally reshaping the traditional dynamics between patients and healthcare providers.

This thesis provides valuable insights into the critical role of systemic factors such as understaffing in healthcare facilities, a concern that is prominently echoed in the ongoing discourse within contemporary patient safety literature.⁸⁷ The identification of understaffing as a key issue not only aligns with, but also reinforces, the recognized need for systemic improvements in the healthcare sector. These findings showcase the complex and multifaceted nature of patient safety challenges, which demand strategic responses at both policy and organizational levels. The findings in the literature review and the original research suggest the need for a holistic view of healthcare systems, where responses go beyond short-term fixes and involve long-term strategic planning and implementation. This includes re-evaluating workforce strategies, enhancing support systems for healthcare professionals, and ensuring that healthcare organizations have the resources and frameworks necessary to provide safe, effective, and high-quality care.⁸ In doing so, the insights from this thesis resonate with and contribute to the ongoing efforts of various healthcare policies and initiatives, which are focused on mitigating risks and enhancing the overall quality of care in healthcare settings. This comprehensive approach is essential for addressing the systemic issues that continue to challenge patient safety and for ensuring sustainable improvements in healthcare delivery.

Furthermore, the original research findings regarding the intersection of discussions about vulnerable populations with various types of medical errors adds another perspective to the literature on health disparities in patient safety. It highlights the enduring challenge of ensuring

equitable healthcare and the need for focused attention on vulnerable groups, reinforcing the call for targeted policies and interventions to address these disparities. Additionally, the original research finding of compelling personal narratives corroborates findings from the literature review regarding the psychological and physical toll of medical errors on patients. These narratives underscore the need for a holistic approach to patient safety, one that encompasses not only the prevention of errors but also the emotional well-being and long-term care of patients affected by medical errors. Taken together, these findings emphasize that because vulnerable populations experience medical errors at a disproportionate rate, these groups are subject to an increased psychological and physical impact from such errors.^{17,36}

Lastly, the original research conducted as part of this thesis contributes insights into the use of social media for discussing patient safety issues. This study aligns with the emerging trend in patient safety literature of recognizing social media as a valuable source of patient safety information.^{92,94} It emphasizes the potential of these platforms for capturing patient perspectives and experiences, offering a rich and untapped resource for understanding and improving patient safety practices.

In summary, the original research findings, situated within the context of existing patient safety literature, reveal a dynamic and evolving field. The findings affirm some of the established concerns in patient safety while bringing to light new insights regarding the role of social media and digital engagement in patient safety discourse. This integration highlights the importance of continuous assessment, policy evolution, and the inclusion of diverse patient voices in shaping a healthcare environment that prioritizes safety, transparency, and patient engagement.

4.2 Policy and Research Implications

The study's findings, alongside insights from the literature review, highlight potential areas for policy evolution in patient safety. These areas, particularly those concerning the technical and systemic aspects of medical errors, underscore the complexity of healthcare systems and the need for ongoing research to fully understand the best paths for policy adaptation.^{35,97} The persistence of these issues calls for a nuanced exploration of both the problems and potential solutions, factoring in complexities like understaffing and the vulnerabilities of certain patient groups. However, it is crucial to approach the idea of policy reforms with caution, recognizing the preliminary nature of these findings.

Additionally, the role of patient empowerment and advocacy, as identified in this study, points to the value of further exploring patient narratives and experiences through novel platforms, including social media. This exploration could enrich researchers' understanding of patient safety concerns without prematurely advocating for specific policy changes. Discussions around policy and advocacy in online communities have indeed highlighted a public interest in these topics.^{27,92,94} This interest suggests areas for future policy discussion and research, providing a compass for where policy might eventually need to adapt, rather than dictating immediate policy shifts.

The study also suggests considerations for healthcare practices, particularly that they move towards more patient-centered approaches and explore the potential for engaging digital platforms for patient education and support.^{18,27} While the high percentage of online community posts sharing resources reflects an opportunity for healthcare providers to engage with and utilize digital platforms, this should be seen as an area for potential development rather than an immediate directive for healthcare practices.

Furthermore, the focus on vulnerable populations in the research, especially regarding medical errors and infections, aligns with the literature's emphasis on health disparities in patient safety.^{12,36} This alignment suggests the exploration of targeted interventions and culturally tailored health communication as crucial areas for further research to ensure equitable and inclusive patient safety measures.

4.3 Future Directions

This thesis opens several avenues for future research. One key area is assessing the effectiveness of different patient safety policies and practices in reducing the types of medical errors frequently discussed in online communities. Future studies could explore the impact of specific policy changes or interventions on the prevalence of surgical errors, infections, and other issues. Additionally, the role of social media in patient safety presents a pressing field of interest. Future research could examine how these platforms can be effectively used for patient education, support, and engagement by analyzing different social media platforms to understand their user demographics, interaction styles, and potential for disseminating health information related to patient safety. Lastly, given the significance of the emotional and psychological impacts of medical errors, future research could investigate interventions aimed at supporting patients and families after an adverse event. This could include examining the effectiveness of communication strategies, psychological support services, and long-term care approaches to mitigate the emotional toll of medical errors.

In summary, the original research study conducted for this thesis, coupled with findings from an examination of the existing literature, offers a comprehensive understanding of patient safety issues and opens pathways for policy reforms, practice enhancements, and future research. These implications are crucial for evolving patient safety measures and ensuring that healthcare systems are responsive, equitable, and effectively meet all patients' needs.

Appendix A Terms and Definitions

Adverse Event – An injury resulting from or contributed to by medical management, including medical error.

Medical Error – A preventable adverse effect of care, whether it is evident or harmful to the patient. This error can occur at any point in the healthcare process, whether from diagnosis, treatment, or aftercare, and it often involves a plan of care that does not achieve its intended outcome or implements the wrong plan to achieve certain goals.

Negligence – Descriptions for events that happen when inadequate care or oversight leads to patient harm.

Quality Improvement – Any intervention aimed at reducing the quality gap for a group of patient's representatives of those encountered in routine practice⁸

Patient Centered Care – An individual's specific health needs and desired health outcomes are the driving force behind all healthcare decisions and quality measurements¹¹

Appendix B IRB Exemption Notice

Discussion Today about Project

Ries, John William <jwr22@pitt.edu>

Tue 6/6/2023 2:25 PM

To: Wolyynn, Riley <RIW22@pitt.edu>

Good afternoon,

Thanks again for taking the time to discuss your upcoming research plan with me today. As we discussed, you will be accessing public Facebook data which you will collect and qualitatively analyze. As we discussed, all of the data you plan to record will be recorded in a de-identified manner and no private identifiable information will be accessed or recorded. You also have never interacted or intervened, for research purposes, with the individuals' whose data will be studied. Given these points, your research study does not meet the criteria of involving human subjects and therefore does not require IRB oversight. Please let me know if any of this information is inaccurate, otherwise best of luck with your research.

Have a great day,

John

John W. Ries, MPH
Research Review Analyst, Exempt/Expedited
Institutional Review Board / Human Research Protection
Office of Research Protections
University of Pittsburgh
Telephone: 412-383-7446
Email: jwr22@pitt.edu
Pronouns: he/him/his

Mailing Address:
Suite 401, Hieber Building
3500 Fifth Avenue
Pittsburgh, PA 15213

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