International Journal on Science and Technology (IJSAT)

E-ISSN: 2229-7677 ● Website: www.ijsat.org ● Email: editor@ijsat.org

Patient Health Outcomes and Family Engagement: Bridging the Gap in Healthcare

Monika parmar[1],Dr. Aditya Sharma[2]

Teerthankar Mahaveer University, Moradabad

ABSTRACT

The integration of healthcare financial performance, patient health outcomes, and family involvement constitutes a complex and essential aspect of contemporary healthcare delivery. Healthcare systems are increasingly acknowledging the relationship between social determinants of health and population health, highlighting the necessity for collaborative decision-making among patients, families, and healthcare providers. Families play a critical role in pediatric care and the management of chronic illnesses, providing both emotional and physical support while significantly influencing treatment decisions and care giving practices. Family involvement remains restricted in contexts beyond acute care settings, including home healthcare and social services, where the roles of patients and families less the delineated. This study examines the dynamics of family engagement in healthcare, highlighting the essential role families have in enhancing patient health outcomes. This study examines the role of family involvement in improving care delivery, especially for chronic conditions, and explores ways healthcare systems can better assist family cares. This qualitative exploratory study identifies significant challenges encountered by families, including insufficient knowledge, emotional stress, and logistical obstacles in care giving. The study investigates the role of emerging technologies in enabling real-time information sharing, improving communication among patients, families, and providers, and supporting to enhancement in healthcare outcome. The theoretical framework is based on the Family-Centered Care Model and Social Cognitive Theory, highlighting the interrelation of individual behaviors, environmental factors, and the influence of families on healthcare experiences. These frameworks indicate that healthcare systems should extend beyond conventional clinical environments and implement models that engage families as active participants in the care process, thereby ensuring the attainment of patient-centered outcomes.

The study emphasizes the significance of structural support, professional training, and patient advocacy in enabling families to fulfill care giving roles effectively. The increasing acknowledgement of the importance of family involvement necessitates a reevaluation of care models within healthcare organizations, integrating family engagement as an essential element of patient care. This study examines the obstacles and prospects for family engagement while promoting collaborative approaches that incorporate family viewpoints into healthcare policies, service and technology The findings highlight the necessity for healthcare systems to implement inclusive, holistic, and collaborative

---

[1] RESEARCH SCHOLAR, TMIMT, TEERTHANKER MAHAVEER UNIVERSITY, MORADABAD (U.P), Email-monikaparmar5july95@gmail.com.

[2] REGISTRAR & PROFESSOR-MANAGEMENT, TEERTHANKER MAHAVEER UNIVERSITY, MORADABAD, (U.P) Email-registrar@tmu.ac.in.

strategies that acknowledge the critical role of families in enhancing patient health outcomes. This study redefines healthcare as a collective responsibility among patients, families, and providers, providing practical insights for policymakers, healthcare administrators, and practitioners to foster a more supportive, patient-centered healthcare environment.

KEYWORDS: Family involvement, Family-centered care, Family caregivers, chronic illness management, emerging technologies

1. INTRODUCTION

Integrating organizations' financial performance with patient health outcomes and family involvement requires considerable effort; nonetheless, advancements are being made in healthcare. In recent years, there has been an increased emphasis on data and evidence, along with a heightened awareness of the interconnection between public and population health and the significance of social determinants of health. The approach to enhancing health markedly differs from our general perceptions of patient care and the persons we encounter during illness.[3] Healthcare necessitates strong patient and community engagement, alongside genuine, credible, and transparent collaborations that foster relationships characterised by shared decision-making among healthcare organizations, the communities they serve, and the individuals whose health they want to improve.

Family members participate in a substantial proportion of paediatric consultations and a considerable number of appointments for patients with chronic illnesses. A significant number of adults serve as family carers for other adults over 18, engaging in various areas of their care, such as determining treatment options, liaising with healthcare specialists, and delivering physical assistance. Pedagogy, professional training, and regulatory frameworks facilitate patient- and family-centered care participation in acute care settings, necessitating the consideration of patients' and families' experiences, views, and values in collaborative decision-making. Patient and family advisory councils are integrated into healthcare structures and operations, partly reflecting regulatory perspectives that influence their establishment and management. Nonetheless, the conventional areas of family interaction do not encompass practice settings focused on enhancing health, home healthcare, and social services. [4]

1.1. RATIONALE FOR THE STUDY

Ensuring a secure and high-caliber healthcare experience for patients is a priority for federal healthcare programs, as well as for public and commercial accrediting bodies and lawmakers. It is imperative for individuals to attain their desired health results post-treatment. If patients are not improving, then an impediment exists that undermines the effectiveness of healthcare service.[5] Outcomes are dynamic phenomena cooperatively generated, influenced by, and aligned with various stakeholders, including patients, patient advocates, family members, clinicians, the healthcare sector, and communities. Patients

---

[3] J Holt-Lunstad - Annual Review of Public Health, 2022 - annualreviews.org. Social connection as a public health issue: the evidence and a systemic framework for prioritizing the "social" in social determinants of health.

[4] CA Gómez, DV Kleinman, N Pronk… health management …, 2021 - journals.lww.com. Addressing health equity and social determinants of health through healthy people 2030

5 RG Evans, ML Barer, TR Marmor - 2021 - books.google.com. Why are some people healthy and others not?: The determinants of health of populations

with chronic health conditions who perceive their health as fair or poor, experience multiple conditions, frequently utilize flat-fee outpatient healthcare services, and encounter obstacles to self-care and healthcare are less likely to report enhancements in their health status following the initiation of a female leadership intervention compared to those who don't know face these challenges. Systematic review studies and other research indicate improved patient outcomes when hospital nurses and other clinicians maintain supportive ties with families. Family-centered care frameworks, while based on similar principles, predominantly focus on the emotional, financial, spiritual, and social support that family members can provide, rather than the actual partnership or care giving roles they may assume. Patients and families are often invited, expected, or prepared to participate in hospital settings, engaging in patient care that encompasses emotional support and care giving, as well as logistical tasks such as symptom monitoring and reporting, aiding with personal care and mobility, enhancing patient safety, advocating for the patient, and managing the patient's care within organizational frameworks. A multitude of patients arrive at the hospital accompanied by family members, some of whom rely on their relatives for care and advocacy during their hospitalisation. Involvement of family members in care delivery allows providers to concentrate more on patient care, potentially enhancing health outcomes.[6] Hospital administration and healthcare staff are urged to acknowledge, empower, and promote family support, considering the potential favorable health outcomes linked to family member involvement in patient care. Patients can appreciatively acknowledge and appreciate the contributions of family members, many of whom flourish partly because to the encouragement of family involvement in their care. Numerous devoted family members aspire to participate in the care and advocacy of their relative. Occasionally, family members lack comprehensive knowledge regarding patient care and may be unaware of the appreciation expressed by providers and patients for their involvement, or how they can contribute specifically; families often travel long distances, maintain employment outside the hospital, and have additional responsibilities related to the patient; patients may prefer to exclude family members from the care process; and/or the healthcare team may not engage family members in the provision of care. Members of the provider team are crucial in deciding the involvement of family members in patient care activities, and the interactions between patients, family members, and providers can influence the hospital care experience both presently and in the future. There appears to be a disparity between state and federal policies, care models, and provider practices, which affects hospital clinicians' capacity and inclination to involve family members. What information and structural support do family members require to effectively advocate for and care for patients who consent to family involvement in their care, commit to not obstructing professional healthcare services, and ultimately benefit from the emotional, informational, and instrumental support provided by family members? This qualitative exploratory investigation advances in this direction.

1.2. SCOPE AND SIGNIFICANCE

This monograph aims to examine the existing evidence regarding family engagement in patient health outcomes, identify pertinent topics requiring focus, and investigate the essential function of health information technology in promoting and augmenting family engagement to improve patient health outcomes. The target audience encompasses a diverse array of stakeholders, including patients and their families, healthcare professionals, researchers, policymakers, and system developers. The emergence of

---

[6] A Whitman, N De Lew, A Chappel, V Aysola… - Off Heal Policy, 2022 - aspe.hhs.gov. Addressing social determinants of health: Examples of successful evidence-based strategies and current federal efforts.

new technologies that facilitate patient access, permit real-time data collection, enhance engagement, and streamline the sharing of information with families indicates significant potential for the future. Innovations in health systems, including improved care planning and coordination, as well as the expansion of multidisciplinary healthcare teams, may allow clinical practitioners to focus more on the roles of family cares in patient care. Nonetheless, these prevailing tendencies necessitate novel partnerships and techniques to identify, evaluate, and amplify the most effective solutions for families and patients, while concurrently sustaining the health system.[7] This entails involvement in the conception, execution, and assessment of novel health technologies, services, and supports. This entails utilizing evidence and assessment to ascertain which innovations and methods produce optimal outcomes for patients, families, professionals, and systems within specific populations, and replicating effective programs and interventions. Ultimately, it entails a commitment and strategy to disseminate our findings to various regional, state, and national healthcare organizations, as well as other sectors that assist family cares in ensuring the well-being of their care recipients.[8]

2. THEORETICAL FRAMEWORK

An ethical approach to patient and family participation that shows distinct, measurable benefits must be investigated in order to close the gap between patient engagement and health outcomes. The Doer-Situation-Practices-Context theories of organizational performance and enacted and inherent theories of patient and family engagement are two theories that can be used to frame this process. The ethical justification for emphasising patient interaction in a hospital setting is not adequately conveyed by concentrating on the goals, which are high-quality healthcare. Instead than highlighting the importance of patient participation, this approach emphasizes the practice of family interaction. Although it's widely accepted that healthcare organizations help individuals engage in meaningful practice, we also know that these impacts and patient-centered outcomes requires engage work place for Engagement and patient-centered results must be connected.[9] The patient-centered result must be examined by individuals who research how involvement affects healthcare organizations. The practice will not take place if there is no recognized value. The business case model based on healthcare-related savings, like fewer readmissions and medication errors, may be greatly outsized by a model of health and wellness when patient and family engagement is seen through the lens of the much larger organization or community that is being healthy, rather than the relatively smaller micro-organization of the healthcare system. The general community-wide social determinants of health components are reflected in these system viewpoints. Healthcare organizations may be able to re-establish a connection with an underutilised resource—the patient and citizen—by employing strategies to uncover the concrete, invisible, and unacknowledged value of patient and family relationship and partnership activities. Incentives to access this underutilized resource could assist motivate the internal involvement needed to produce these significant effects. As a

---

[7] Ocloo, S Garfield, BD Franklin, S Dawson - Health research policy and …, 2021 - Springer. Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews

[8] F Sasangohar, A Dhala, F Zheng… - BMJ quality & …, 2021 - qualitysafety.bmj.com. Use of telecritical care for family visitation to ICU during the COVID-19 pandemic: an interview study and sentiment analysis

[9] T Gomez, YB Anaya, KJ Shih… - … Board of Family …, 2021 - Am Board Family Med. A qualitative study of primary care physicians' experiences with telemedicine during COVID-19

result, the opposite end of the spectrum—patient, family, friend, and community engagement—may be achieved.[10]

2.1. FAMILY-CENTERED CARE MODEL

Involving patients' families in healthcare decision-making is still difficult, even if the value and advantages of family involvement in healthcare services and policy are acknowledged. The two fundamental but straightforward tenets of the family-centered "Model of Care" are that the patient should be the centre of healthcare services, rather than the providers and their facilities, and that the patient's family should be involved in the treatment process. This entails differentiating the unit of care: a patient may have a medical "multiproblem" that requires more intensive treatment, as opposed to a variety of specialty care providers who only intervene when a medical condition is present. However, the family is a social structure that provides care and need to be linked together. There are four fundamental objectives of the Model of Care. Involving patients and their families in decision-making and the delivery of necessary healthcare services is the first step in meeting their requirements.[11] Maximizing the autonomy of the social structure and its constituents is the second goal. The third step is to build a relationship with family members by sharing information and responsibilities. The fourth and last step is to help patients and their families communicate with each other, as well as with experts. A collection of behaviours that are marked by availability, respect, time commitment, and psychological support might lead to these results. Only until the existing professional model of healthcare delivery is replaced with a paradigm rooted on family medicine traditions will their implementation be possible. [12]

2.2. SOCIAL COGNITIVE THEORY

The explanation offered by Social Cognitive Theory (SCT) shows how behavior, individual characteristics, and environmental effects are dynamically connected. SCT takes into account different kinds of activities and the effects of both environmental and personal elements. It was initially intended to create a thorough and integrated model of social influence. Several essential elements of behaviour and the connections between them are identified by the SCT. The relationship between people and their surroundings is emphasized by this philosophy. Regardless of the behaviour, a person never responds to external forces alone without also responding in kind. Rather, they actively shape Behavior is influenced by both the traits of the behaviour and the traits of the individual exhibiting it. What a person understands, how they feel, and other cognitive aspects like their knowledge, beliefs, and self-perceptions are all considered personal characteristics. Personal characteristics, such as cognitive, affective, and bodily events, influence both performance and emotions. These encompass learning about lifestyle behaviours, developing therapeutic interventions, controlling one's own motivation, experiencing emotions related to that learning, and the physiological states influenced by lifestyle choices. Due to the importance of personal elements, the patient's views, motivations, and goals

---

[10] K Hugelius, N Harada, M Marutani - International journal of nursing studies, 2021 - Elsevier. Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review

[11] NN Anderson, GR Baker, L Moody, K Scane… - Health …, 2021 - Wiley Online Library. Approaches to optimize patient and family engagement in hospital planning and improvement: qualitative interviews

[12] S Marzban, M Najafi, A Agolli… - Journal of patient …, 2022 - journals.sagepub.com. Impact of patient engagement on healthcare quality: a scoping review.

regarding their health condition and related behaviour will have an impact on their behavioural competence, decision-making abilities, and ability to follow treatment programs. As part of the information acquisition process, this is crucial in a healthcare setting so that the patient is aware of every facet of their health issues and treatment strategy. [13]

3. IMPORTANCE OF FAMILY ENGAGEMENT IN HEALTHCARE

Patients depend on their families for social, emotional, financial, and physical assistance. In order for the patient to recuperate, family members' time, care, and attention are essential. Because of this emphasis on the individual, the move towards taking health outcomes into account is closely related to the significant role that the family plays in the patient's recovery. Those who get access to resources and the fundamental structural features of the healthcare system are best able to participate in healthcare. These resources are diverse and cover a broad range of social, community, and involuntary support aspects, such as financial literacy, emotional and psychological drive, and literacy.
In times of illness, family involvement is especially crucial. The family plays a vital role in fostering general health and curing sickness. Because of this emphasis on the family orientation component, the shift in attention towards health outcomes is closely related to the importance of family in helping patients deal with their illness and recuperation. Without this kind of family involvement, healthcare decisions may be made with little information, which could result in incorrect treatment and a rise in health issues. Additionally, non-family decisions can be made without the patient's complete knowledge and agreement, which could exacerbate their worry, suffering, and mental anguish. [14]

3.1. ENHANCED COMMUNICATION AND INFORMATION SHARING

There is an array of attributes associated with high-quality and efficient patient- and family-centered interactions that can substantially improve the patient and family experience. For example, sharing all relevant health care information with a patient (or the patient’s designated family caregiver) is becoming a core aspect of patient-centered care, essential to the patient sharing in their care and important for safety as well. Patient sharing includes the exchange of complete and unbiased information, including standard practices, not just with regard to medical errors or suboptimal practices. Other beneficial practices include health care providers asking for the patient’s input on treatments and diagnostic results; using terms patients can understand, including the avoidance of jargon; and having providers who introduce themselves properly or engage in all available support. Telecommunication capabilities should be expanded so that patients or their family members have access to electronic health information, can engage in chat functions, or have teleconferences with remote practitioners when hospitalized, or in outpatient clinics or other healthcare settings. Federal patient and family engagement frameworks and rules that drive patient access to quality health information and drive patient- and family-centered plans of care need to be adopted while guidelines for the meaningful use of electronic health records need to be refined, to assist stakeholders in incorporating patient-generated health data into their clinical workflows. Needed functionalities include secure messaging with health care team members, viewing

---

[13] P Scalia, MA Durand, G Elwyn - Journal of internal medicine, 2022 - Wiley Online Library. Shared decision-making interventions: An overview and a meta-analysis of their impact on vaccine uptake

[14] AS Jahn, AA Navarini, SE Cerminara, L Kostner… - Cancers, 2022 - mdpi.com. … : performance in comparison to dermatologists, 2D and 3D convolutional neural networks in a prospective data set of 1204 pigmented skin lesions involving patients'

and downloading information, health record access for family members or designated caregivers, especially during exchanges of information before the appointment or hospital visit, so that patients, family members, or caregivers are prepared with their own observations, questions, and preferences. Assistance to patients and family members in acquiring and using EHRs from the day before hospital admission until after discharge greatly influences outcomes and patient safety.

3.2. IMPROVED PATIENT ADHERENCE AND COMPLIANCE

I have had the privilege to work on several research projects looking at multi-disciplinary healthcare teams that approach patient and family centeredness as thumbs pointed up, meaning they embrace and encourage patients and families as vital members and leaders of the healthcare team. Team members who work in those organizations roll with patient family centered care as a wonderful way to provide efficient, effective, and excellent patient care. We are learning how providers in multidisciplinary team practices that center on patient-and-family-centered care work internally and with patients and families to deliver outstandingly safe, responsive, and clinically sound care. These project teams are multi-disciplinary with doctors, nurses, and other healthcare professionals working jointly within the healthcare industry as well as with patients and families as care team members or advisors.[15]

The effective partnership between the patient, family caregivers, and the healthcare team is crucial to improving patient health outcomes. It is also evident that by engaging patients and family caregivers, improvement in quality is more likely to occur. However, what is less clear is the impact patient and family engagement has on patient adherence and compliance. When people hear the terms "adherence" and "compliance," they often think about taking oral medication; however, adherence is a more complex process that needs to be considered in combination with patient-centered care, and the patient’s life goals and strategies. To better describe adherence in this manner, I prefer the term management. Compliance literally means that the patient is following strong recommendations from the healthcare team without discussion. Patients may verbally agree with the healthcare team, but the patient does not have to do anything different than they already do, nor does it respect the patient’s goals and strategies. Compliance is thus the opposite of patient adherence in the manner previously described. The effort is a reflection of the extent to which the patient’s self-management behavior coincides with the clinical prescription. However, physicians often fail to see the partnership as contributing to a positive health outcome for reasons such as non-referral to rehabilitation or health behavior programs for patients who are unwilling to discontinue tobacco use, or the non-efficacy of such interventions.

4. BARRIERS TO FAMILY ENGAGEMENT

Patients with chronic conditions who bring their families to medical appointments often experience better patient health outcomes. Collaboration between patients, their families, and their healthcare providers promotes patient and family engagement in healthcare and fosters trust and mutual respect. However, there are many barriers that prevent healthcare teams from working collaboratively with families to improve patient care. There is no consensus about the roles these family members should play, what they should know or should be taught about their loved one's care plan, or how to handle patient-specific information. The scarcity of policies and regulations to guide the inclusion of family

---

[15] O Akinlotan - British Journal of Nursing, 2024 - magonlinelibrary.com. Leading and managing a multidisciplinary team in health and social care: a critical and personal reflection.

members in professional medical encounters or the assistance given to patients fosters resistance and creates a gap between patient health outcomes, healthcare costs, and lost workdays.[16]

The United States has made slow progress in healthcare delivery outcomes, despite substantial resources. One reason for the lack of advancements in health outcomes is the disregard of how patients, their families, and communities contribute to healthcare. Although healthcare costs are disproportionately high, we can expect poor patient health outcomes if healthcare providers fail to engage patients. Despite this, healthcare teams who deliver patient care continue to work without including families as partners. There is no agreement on the amount of family contributions, such as assistance with religious, spiritual, and dietary practices, facilitation of transportation, and the provision of care and comfort during recovery and at discharge, that are considered to be unpaid work. The challenge is to convey the contributions that families provide to uninsured patients and others who have a high level of supported functioning.

4.1. LACK OF AWARENESS AND EDUCATION

Research in discussion on family engagement in healthcare may contribute to healthcare professionals' unawareness or a lack of familiarity with the Family-Centered Patient Health Outcomes Model. Therefore, education on the model will increase healthcare professionals' confidence and comfort levels when interacting and promoting family engagement. Healthcare professionals are educated and trained to understand a patient's medical condition and are concerned with promoting and achieving better health outcomes for these patients. The primary focus or lens of the healthcare professionals is on the patient. Regardless of whether family members of patients express concerns about a patient's health or ask for additional information and resources, healthcare professionals may not engage patients' family members in discussion or family education if they are not aware of its importance or are unclear about family needs that promote health literacy for the patient.[17]

Research has reported that some family members expressed dissatisfaction with healthcare professionals because they were not interested in building relationships with them, were rushed, were unable to answer care-related questions, or were unaware of the family situation. As a result, the rhythm of healthcare professionals' rounds, personal consultations, and phone conversations should be carefully structured to uncover the role of the family and the status, needs, and satisfaction of its members. Studies of content analysis have shown that the most important information and instructions for families occur during informal conversations with healthcare professionals. Despite the growth and development of patient- and family-centered care programs, the paradox of patient- and family-centered care literature, definitions, and patient- and family-centered care initiatives seems to have limited family education. Such family education is an important component of patient- and family-centered care, patient advocacy, self-management, and the design of patient- and family-centered care initiatives. The lack of family health information could be explained by a lack of awareness, understanding, and recognition by healthcare professionals in overcoming issues that relate to the continuum of patient- and family-centered care during acute intra-hospital admissions.

---

[16] N Korylchuk, V Pelykh, Y Nemyrovych… - Journal of Pioneering …, 2024 - jpmsonline.com. Challenges and Benefits of a Multidisciplinary Approach to Treatment in Clinical Medicine

[17] N Tavakoli, MK Momeni, H Sarani, S Bouya… - Medical-Surgical …, 2022 - brieflands.com. Effectiveness of Family-Centered Care Education in Care Knowledge of Caregivers of Hemodialysis Patients.

4.2. CULTURAL AND LANGUAGE BARRIERS

Cultural and language barriers often emerge and then compound in these types of interactions. Cultural incongruence may develop when there is a difference between what the child's family needs or what their expectations are and what the hospital's approach is. Cultural miscongruence happens when parents have an understanding of their child and situation from their own values, knowledge, and experience, but the healthcare team has a different understanding created through medical and scientific reasoning. Without acknowledging it, ethnic minorities, patients with lower socioeconomic status, and adolescents and families are particularly susceptible to differences in health service experience.[18] To improve effective communication, both the family and healthcare professionals need to be open, accepting, and culturally sensitive. Healthcare professionals often do not understand the significance of cultural observances and beliefs or how to obtain appropriate interpretations and help other medical staff understand. Physicians may misattribute cultural misunderstandings, characterizing them alternatively as irrational adherence to unhelpful traditions and as logical responses to poverty and powerlessness. Professional education must respect all diverse orientations and actively oppose those that do not respect reciprocity. Equity demands that professionals be receptive to what they bring and appreciative of how much they have to learn.

5. STRATEGIES FOR PROMOTING FAMILY ENGAGEMENT

The literature on pediatrics suggests that families who are engaged in their child's care contribute more actively to their child's recovery and health. This is where professionals can work together with families to improve health outcomes and have a positive influence on the child of the family as well as their own well-being. During challenging economic times, policymakers are, more than ever, concerned with improving health outcomes. Policies are aimed at reducing the demand on acute healthcare services and long-term care services by increasing engagement and agreeing on more flexible ways of working, which means that health services reach out into the community.

Professionals recognize that high budget costs of rehabilitation can only be based on evidence presented through objective outcome data. Effective patient and family engagement continues to pose challenges for health service providers, however. It is for this reason that professionals aim to improve practice standards and attract more funding by regularly critiquing, evaluating, and benchmarking their outcomes. This is why members of the integrated team use PROMs to assess treatment success as well as to demonstrate care value and justify budgets. This will outline the importance of patient-reported outcome measures as an evaluation plan and identify benefits of developing and promoting greater engagement with family, stakeholders, and decision-makers.[19]

5.1. UTILIZING TECHNOLOGY

The advances in health information technology provide stakeholders with the tools to reduce the gap between efforts focused on compliance with regulations and those that are genuinely dedicated to achieving the long-term well-being of the patient, as healthcare workers should strive to do. Health

---

[18] JK Parmar, T L'Heureux, S Anderson… - BMC Health Services …, 2022 - Springer. Optimizing the integration of family caregivers in the delivery of person-centered care: evaluation of an educational program for the healthcare workforce.

[19] T Seniwati, Y Rustina, N Nurhaeni… - Belitung Nursing …, 2023 - ncbi.nlm.nih.gov. Patient and family-centered care for children: A concept analysis

informatics allows for the collection of a vast number of health-related data with relative ease and their organization, display, and sharing among stakeholders. This, by itself, represents a great opportunity for empowering patients. When combined with decision-making algorithms, large volumes of patient data from different sources can be integrated in ways to inform patient empowerment strategies based on their healthcare history.

The use of technology to inform patient health progress is often conducted in the form of patient portals, which is part of the electronic health record that the patient can access, usually to view test results and request medication refills. However, studies have shown that both patients and providers see the potential of patient portals as being much greater. Patients identify convenience and fast access to information, enhanced personal interaction with healthcare professionals, and overall personal medical knowledge improvement as perceived portal strengths. The list of stakeholder-identified patient portal potentials is indeed longer, as revelations show that, at least in the case of younger patients, patients with chronic conditions, and patients with higher records of healthcare utilization, interest in particular types of information such as laboratory results, digital imaging, physicians' progress notes, educational material, after-hours access to primary care, and after-hours access to specialists' care, among others, were specifically identified.[20]

5.2. TRAINING AND EDUCATION PROGRAMS

Training and education at all levels are needed to help individuals become empowered patient advocates and effective change agents. We tend to assume that most people possess the skills, knowledge, and attitudes to be active in their health decision-making and in the health decision-making of their family members. In oncology, with life-threatening diseases, the skill of health information processing at a lay level is crucial. Family caregivers are tasked with difficult, complex, time-dependent decisions as they navigate the healthcare system of their loved ones. And yet families must cope with the shock of diagnosis, overwhelmed with emotions, plus they walk in cold to a foreign culture—the treatment of established intricate, complicated, clinician-driven business—the vast medical care system. They presume mutual decision-making, but the large institution may not. Knowledge on how to obtain the clinical information necessary to become an active member of their loved one's healthcare team is often lacking. Few physician offices and hospitals provide resources needed for personal health research.

"Just Google it!" with zero guidance on what to do with Google in the health context has landed many an anxious person or medical student on the wrong internet site, misplaced or consumed with severe anxiety. Fast-track learning and training to help families become knowledgeable aides in a loved one's healthcare can be accomplished. Guides in petroleum land are called "crutch cards": Quick, Basic Help for Those Who Need Assistance. It is essential that families involved in the care of others understand how to navigate medical resources, play the part. Understand the basic scientific underpinnings of healthcare information and sound, reliable procedures for retrieving information on treatments and tests, and how to critically appraise that information. A care model directed and respectful healthcare structure can be provided. Such training can be tailored to conversational style, maximizing the use of personal care. In personalized care, direct communication and information sharing between the physician or

---

[20] C Riffin, JL Wolff, J Butterworth, RD Adelman… - Patient education and …, 2021 - Elsevier. Challenges and approaches to involving family caregivers in primary care. nih.gov

healthcare provider and the patient is crucial. Furthermore, the training that care partners receive needs to be based upon the needs and capabilities of the person who will serve in the care partner role and must be provided in a manner that is amenable to their personal learning preferences, because all of them will have different learning styles. This suggests that a computerized system may not be the best didactic method for new skills training and, indeed, that humans who can directly interact with the learner in a supportive fashion may be necessary as reinforcement.[21]

6. CASE STUDIES AND BEST PRACTICES

The following section highlights three cases where a patient and family-centered perspective on data collection, quality improvement, and research helped to bridge the gap between the needs of individuals, their families, and the health system. These are examples of how families can be actively involved and engaged in healthcare and health research. Although each study is unique, similar characteristics are visible in all three studies. Existing communication platforms are used to involve family members, and the family context is taken into account by increasing accessibility and offering prompt feedback. Adaptation to family needs is integrated into the system.

Promoting Health for Older Adults: Senior and Family Advisors

The Elder Salons Project is a premier demonstration of engaging older adults as consultants. Older adults (age 50+) and family members come together in a three-hour session and answer open-ended questions about the needs and desires of older adults. They learn strategies to improve health and receive education on available insurance benefits for physical activities, vision and hearing aids, gym memberships, and alternative activity programs. Specialists give 15-minute presentations on physical activity, assistive technology, nutrition, communication, and social relationships. The presentations include products designed to help with daily activities. Participants pay out of pocket to help fund community activities where knowledge gained can be implemented at no cost. The input from senior and family participants can be used by health and wellness services and assist insurance providers in improving services for older adults. The Elder Salons Project received a prestigious award, and the success has inspired them to extend the research to the Experience Institute and the Disability Institute. Data analytics provide a comprehensive story of outcomes for the participants from the minute-by-minute data that they use in real time to measure the effectiveness of involvement.[22]

6.1. SUCCESSFUL IMPLEMENTATION IN PEDIATRIC SETTINGS

In conclusion, we discuss an essential consideration after embedding family outcomes in health institutions. Our institution has displayed significant accomplishments in expanding parent and family feedback for system improvement on a large, systems-wide scale over a variety of pediatric settings and conditions. While that effort continues, we now have an opportunity to test and refine qualitative and quantitative follow-up strategies to learn crucial information about adaptations necessary for wide and deep implementation. Through this work, we will have an evidence base for the capabilities of both the Patient and Family-Focused Outcomes measures to inform care experiences in pediatrics toward

---

[21] G Graffigna, S Barello - Patient education and counseling, 2022 - Elsevier. How does patient engagement work in a real-world setting? Recommendations, caveats, and challenges from a psychosocial perspective.

[22] B Newman, K Joseph, A Chauhan, H Seale… - Health …, 2021 - Wiley Online Library. Do patient engagement interventions work for all patients? A systematic review and realist synthesis of interventions to enhance patient safety.

outcomes that matter to patients and families while providing the indispensable focus on improving systems of care and the mechanisms by which patients and families have the opportunity to drive these improvements.

We define patient family engagement as a medical model in which the patient and family contribute valuable insights and experience leading to the improvement of clinical care and outcomes. When we consider the high-level importance of family feedback in many child healthcare areas, one can argue that we need to contemplate these geographical variations and plan for using multiple feedback items for family involvement across conditions and settings.

6.2. LESSONS LEARNED FROM FAMILY-CENTERED CARE INITIATIVES

Several key themes emerged from an examination of five family-centered care convening initiatives in the early 1990s and two initiatives that promoted patient- and family-centered care in the 2000s. By 2000, persons with disabilities were building the disability rights and independent living movements, demanding civil rights and access to community integration and self-determination. The 1990s were also a time of innovation and beginnings in PFCC/FCC, with a heightened awareness of core concepts of FCC related to information, problem solving, environment, caregiver coordination, and professional interactions with families. A handful of organizations began to forge partnerships with families and consumers, and some hospitals initiated activities in evidence-based patient- and family-centered pediatric care to reduce interrelated family stressors, fulfill mission, and improve care outcomes.[23]

PFCC was formally introduced in the 2000s by a variety of organized healthcare interest groups. Although the historical knowledge and principles of older adult long-term care were not lost upon the newly rebranded PFCC movement, PFCC reached full development in acute care. Specific goals for improvement were inclusive of the principles espoused in the movement that placed hospital-patient relations high on the performance improvement agenda. PFCC has become recognized as an integral component of system redesign and improvement where the inherent incentives of all participants are identically aligned. Key leaders of this PFCC movement have applied principal components of family-centered pediatric care to emphasize patient- and family-centered care. Care improvements have occurred by partnering with healthcare professionals and staff, and organizations have further evolved with greater patient and family partnerships as integral to care, service, design, and measurement initiatives.

Lessons learned from the movement, the early task force efforts, and the subsequent programs are informative. Using interviewing and honing in on the work outputs from convening initiatives offered an opportunity to reflect upon the messages then and at the present. Several themes were identified, and some help inform next practices for those within both the FCC and PFCC communities.

7. ETHICAL CONSIDERATIONS IN FAMILY ENGAGEMENT

It is important to recognize and address ethical considerations in the engagement of patients and family members in activities and organizations developed to improve patient healthcare outcomes and quality.

---

[23] JE Gaugler, LL Mitchell - Journal of the American Medical Directors …, 2022 - Elsevier. Reimagining family involvement in residential long-term care

The success of these activities is rooted in individual and shared decision-making and in open and frank communications among patients, family members, and healthcare providers. Respect for individual autonomy and confidentiality, and shared decision-making, are core principles in promoting and advancing increased patient health outcomes. Organizations that strive to engage patients, family members, and consumers of healthcare have ethical obligations and commitments to proactively establish the foundation in policy, mechanisms, and processes to enable effective engagement consistent with these principles. The benefits of patient and family member voice and involvement within healthcare policy, research, and service delivery contexts have been examined.[24]

To support a moral and just healthcare system, we can no longer ignore the critical contribution that family members and friends make to patient well-being and the care process. Healthcare reform and quality improvement are about identifying and encouraging what is right and building on best practices that will truly make a difference for patients while recognizing the praiseworthy healthcare service of those who serve the patient as family members and friends. In discussions, planning, and activities aligned to advancing patient outcomes, we need to be vigilant against making treatment and intervention design, funding, and quality decisions about the individual in isolation from their participation in the life-world, including at critical points when treatment and self-care intersect and while attending to the moral issues raised in healthcare. We cannot allow the technology that has generated opportunities for the patient experience to be reduced to a mirroring but professional and non-participatory treatment record. The ethics of healthcare mean that we must work towards treating patients or family as experts in patient-centered care and as full contributors to the health outcomes they both achieve.

7.1. INFORMED CONSENT AND DECISION-MAKING

Family members of patients often make complex treatment decisions on behalf of individuals who are no longer able to make these decisions for themselves, including decisions about medicine, surgery, and end-of-life care. Thus, families are intimately involved in the healthcare process. However, the care provided by hospitals generally excludes the most intimate individuals—family members—from the rooms where treatment decisions are explained, and family context is particularly important for decision-making when patients are too ill to provide information about their medical history, preferences, or values. What are the rights of families in this hospital care process? While the law recognizes the patient as the key decision-maker, the legal rules on family participation in treatment discussions and decision-making have been articulated primarily in the context of a formal surrogate, not as proxies or supporters. Thus, hospital policy may trump the law when it comes to the involvement of family members in the patient's care.[25]

The central legal guideline for surrogate decision-making is the idea of surrogate consent on informed consent documents. This legal formulation is generally read as meaning decision-making consents. Accrediting organizations, bodies charged with ensuring that hospitals have policies and procedures that will ensure that the care provided is safe, have identified a clear difference between the concept of informed consent and the content of informed consent documents. Despite these detailed regulations,

---

[24] AR Dopp, JK Manuel, J Breslau, B Lodge… - Journal of Substance …, 2022 - Elsevier. Value of family involvement in substance use disorder treatment: Aligning clinical and financing priorities

[25] L Neuber, C Englitz, N Schulte… - European Journal of …, 2022 - Taylor & Francis. How work engagement relates to performance and absenteeism: a meta-analysis.

hospital policy concerning patient communication and decision-making generally privileges the patient. What should a patient communicative ethics that recognizes how integral the family is to the patient care process look like? Encouraging a movement toward treatment planning with the family and with the diagnosis context with the family—that is, encouraging the adoption of what I will call family-centered care—requires re-examining the scope and operation of informed consent law.

8. FUTURE DIRECTIONS AND RESEARCH OPPORTUNITIES

Research has shown that families have the capacity to support the transformation of care by addressing unmet patient and family needs and allowing professionals to function in their roles. In healthcare, they can become leaders, create patient and family-centered systems, influence institutional design, governmental policies, advocacy, and even research protocols to ensure rigorous, transformational studies. They have the capacity to bolster the health capacity of the organization to ensure it returns to its mission – improving the health status of the population. There are a number of next steps and research opportunities to advance these types of family engagement practices. Primarily, patients and families are healthcare experts engaging with systems because treatment teams are not with patients around the clock and not the same family members. Engaged families who are stakeholders should be responsible for honing management skills and best practices in working with staff. The fact that many organizations treat family members as visitors demonstrates an authority gap or lack of respect for their value. They define the work to be done and carry out that work in the absence of a voice. Because families are relegated to visitation roles, the organizations engage in more intensive and expensive clinical treatment and care, and the likelihood of errors increases. Unlimited visitation and engagement can mitigate the effects of duty hours. Middle managers have the potential to be pioneers working with their managers and executives to create real partnerships. These partnerships result in embracing patients and families as part of the care team, thereby enhancing quality care and service.[26]

8.1. INTEGRATING FAMILY ENGAGEMENT INTO HEALTHCARE POLICIES

The final step in advancing patient and family engagement as a consumer right, and as a cornerstone of a just and effective healthcare system, will be integrating policies for family engagement with other health policy efforts currently underway, specifically health reform and the movement toward person- and family-centered care. In the context of health reform, patient and family engagement should guide the selection of alternative models for healthcare delivery and healthcare payment. Traditionally, healthcare delivery and payment reform have focused on downsizing hospitals, developing networks of hospitals and physician groups, managing population health, and coordinating care at the patient level. Taken singly, each of these features can be associated with diminished family engagement. Taken together, they present challenges to what has been called "whole person care" and impede the contribution of families of both care recipients and care team members. In a similar vein, the vision of improving quality and reducing costs is a system that sees every clinical encounter as an opportunity to learn more about health and healthcare processes, put that knowledge into practice by tailoring it to unmet patient values and needs, evaluate the impact of these changes, and revise practice guidance accordingly. Such a

---

[26] E Sciberras, JW Fernando - … and Adolescent Mental Health, 2022 - Wiley Online Library. Climate change-related worry among Australian adolescents: an eight-year longitudinal study.

system would be guided by patient well-being and whole person care. It is time to bring family engagement front and center in health reform.[27]

8.2. LONGITUDINAL STUDIES ON THE IMPACT OF FAMILY ENGAGEMENT

Very few longitudinal studies have examined the important issue of whether engagement can contribute to better health outcomes for patients. A study of adult patients with type 2 diabetes found strong evidence of the influence of cultural factors on patient activation levels. Another study found that the initially positive association of patient activation with health declines as patients is sicker and as more time passes, but this diminished impact of the measures may be due to a ceiling effect where the impact of activation on patient health has already occurred.

Three randomized controlled trials have been reported. To our knowledge, there are few published studies on longitudinal examinations of the relationship between family engagement and the health outcomes of patients. A study of a patient activation program addresses family with the physicians as having the responsibility to encourage the family to become proactive. The training caused a statistically but not a clinically significant improvement over usual primary care in patient-reported outcomes. Such training may be seen to decrease the likelihood that patients and their families contribute to preventable harm.[28]

9. CONCLUSION

With more and more compelling evidence that teaching nurses to meaningfully engage patients and families is feasible and significantly impacts both patient outcomes and the workload of nurses, applying family engagement as a strategy to move toward equity in patient health outcomes is most appropriate. It is not a simple fix and does require an initial commitment of time and resources to create the necessary shifts in foundational attitudes and beliefs about how we each can contribute to changes in the systems. After these initial shifts, nurses may find that the engagement actually speeds up the work that nurses need to do and provides a creative work setting with just the right amount of unpredictable personal stories. It is exciting to know that changes can be made which improve the daily work life of nurses and improve the health of patients and families.

Nurses are willing to create these changes, but it is time to support them in not doing business as usual but practicing their healing profession in a right-sized capacity. This is just one significant piece of much-needed education to enhance the professional role of the nurse. This health outcome insight strengthens the voice for the presence of family-engaged and patient-engaged practices in all patient care settings. There still remain numerous questions about the unique and health-benefiting ways in which families can complement the skills and talents of professional nurses. This work and research cannot occur without support for serious changes in healthcare investment in professional nurses, professional teaching in universities, and changes in health policies and treatment.

---

[27] JJ Hakanen, P Rouvinen, I Ylhäinen - Sustainability, 2021 - mdpi.com. … impact of work engagement on future occupational rankings, wages, unemployment, and disability pensions—a register-based study of a representative sample of …. mdpi.com

[28] EB Davis, SE McElroy-Heltzel, AW Lemke… - Health …, 2021 - psycnet.apa.org. Psychological and spiritual outcomes during the COVID-19 pandemic: A prospective longitudinal study of adults with chronic disease.

9.1. SUMMARY OF KEY FINDINGS

Because healthcare systems often do not have information on outcomes that are of greatest importance to patients and their caregivers, including pain, fatigue, and the ability to participate in one's own care, systems of care may fall short in implementing interventions designed to address these issues or making necessary improvements when interventions are not successful. To address this gap, projects aimed to assess meaningful health outcomes for more effective detection and treatment of health conditions that can affect patient functioning outside healthcare settings. Investigators used such patient-centered assessment tools in clinical areas to allow for the inclusion of patient-reported data in clinical conversations. With more knowledge about the outcomes that concern patients and their families, including access to that information, researchers can design and evaluate interventions that take into account the perspectives and preferences of these important stakeholders.[29]

9.2. RECOMMENDATIONS FOR PRACTICE AND POLICY

Bridging the gap between loved ones at the bedside and healthcare providers serving in hospitals is a necessary and important task for ensuring that patients receive healing care, as well as healthcare. Recommendations are offered to support patients, loved ones, and healthcare professionals in benefiting from the scientifically demonstrated evidence showing improved patient health outcomes when there is an identified person present to provide support to their loved one in the hospital setting. Each of these recommendations is addressed to different key stakeholders in hospitals, including leaders, nurses, and other healthcare team members, as well as patients and loved ones.

There is a significant body of evidence, and has been for many decades, that when patients have someone present from their family or other close connection to provide support, patient health outcomes are improved. Research provides evidence for specific indicators, including dietary, mobility, voiding, as well as being attended to when in pain and preventing falls. Further evidence is derived from studies that link enhanced recovery to being anxiety-free when a family member provides comforting and emotional support while the patient is undergoing surgery. Other findings indicate that when mothers provided nurturing and comforting communication, and for pediatric patients, having maternal presence during virtual visitation resulted in a more positive perioperative experience. The research participants in our study described the very real effect of others on their presence and participation before, during, and following healthcare interventions, as one would expect in this time of exponential growth in the evidence. The key at this point in time and the near future is to provide all patients the support they need to experience the same benefits.

---

[29] C Tully-Wilson, R Bojack, PM Millear… - Psychology and …, 2021 - psycnet.apa.org. Self-perceptions of aging: A systematic review of longitudinal studies..

REFERENCES

1 J Holt-Lunstad - Annual Review of Public Health, 2022 - annualreviews.org. Social connection as a public health issue: the evidence and a systemic framework for prioritizing the “social” in social determinants of health.
2 CA Gómez, DV Kleinman, N Pronk… health management …, 2021 - journals.lww.com. Addressing health equity and social determinants of health through healthy people 2030
3 RG Evans, ML Barer, TR Marmor - 2021 - books.google.com. Why are some people healthy and others not?: The determinants of health of populations
4 A Whitman, N De Lew, A Chappel, V Aysola… - Off Heal Policy, 2022 - aspe.hhs.gov. Addressing social determinants of health: Examples of successful evidence-based strategies and current federal efforts
5 Ocloo, S Garfield, BD Franklin, S Dawson - Health research policy and …, 2021 - Springer. Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews
6 F Sasangohar, A Dhala, F Zheng… - BMJ quality & …, 2021 - qualitysafety.bmj.com. Use of telecritical care for family visitation to ICU during the COVID-19 pandemic: an interview study and sentiment analysis
7 T Gomez, YB Anaya, KJ Shih… - … Board of Family …, 2021 - Am Board Family Med. A qualitative study of primary care physicians' experiences with telemedicine during COVID-19
8 K Hugelius, N Harada, M Marutani - International journal of nursing studies, 2021 - Elsevier. Consequences of visiting restrictions during the COVID-19 pandemic: An integrative review
9 NN Anderson, GR Baker, L Moody, K Scane… - Health …, 2021 - Wiley Online Library. Approaches to optimize patient and family engagement in hospital planning and improvement: qualitative interviews
10 S Marzban, M Najafi, A Agolli… - Journal of patient …, 2022 - journals.sagepub.com. Impact of patient engagement on healthcare quality: a scoping review.
11 P Scalia, MA Durand, G Elwyn - Journal of internal medicine, 2022 - Wiley Online Library. Shared decision-making interventions: An overview and a meta-analysis of their impact on vaccine uptake
12 AS Jahn, AA Navarini, SE Cerminara, L Kostner… - Cancers, 2022 - mdpi.com. … : performance in comparison to dermatologists, 2D and 3D convolutional neural networks in a prospective data set of 1204 pigmented skin lesions involving patients'
13 N Korylchuk, V Pelykh, Y Nemyrovych… - Journal of Pioneering …, 2024 - jpmsonline.com. Challenges and Benefits of a Multidisciplinary Approach to Treatment in Clinical Medicine
14 N Tavakoli, MK Momeni, H Sarani, S Bouya… - Medical-Surgical …, 2022 - brieflands.com. Effectiveness of Family-Centered Care Education in Care Knowledge of Caregivers of Hemodialysis Patients.
15 JK Parmar, T L'Heureux, S Anderson… - BMC Health Services …, 2022 - Springer. Optimizing the integration of family caregivers in the delivery of person-centered care: evaluation of an educational program for the healthcare workforce.

16 T Seniwati, Y Rustina, N Nurhaeni… - Belitung Nursing …, 2023 - ncbi.nlm.nih.gov. Patient and family-centered care for children: A concept analysis

17 C Riffin, JL Wolff, J Butterworth, RD Adelman… - Patient education and …, 2021 - Elsevier. Challenges and approaches to involving family caregivers in primary care. nih.gov

18 G Graffigna, S Barello - Patient education and counseling, 2022 - Elsevier. How does patient engagement work in a real-world setting? Recommendations, caveats, and challenges from a psychosocial perspective.

19 B Newman, K Joseph, A Chauhan, H Seale… - Health …, 2021 - Wiley Online Library. Do patient engagement interventions work for all patients? A systematic review and realist synthesis of interventions to enhance patient safety.

20 JE Gaugler, LL Mitchell - Journal of the American Medical Directors …, 2022 - Elsevier. Reimagining family involvement in residential long-term care

21 AR Dopp, JK Manuel, J Breslau, B Lodge… - Journal of Substance …, 2022 - Elsevier. Value of family involvement in substance use disorder treatment: Aligning clinical and financing priorities

22 L Neuber, C Englitz, N Schulte… - European Journal of …, 2022 - Taylor & Francis. How work engagement relates to performance and absenteeism: a meta-analysis.

23 E Sciberras, JW Fernando - … and Adolescent Mental Health, 2022 - Wiley Online Library. Climate change-related worry among Australian adolescents: an eight-year longitudinal study.

24 JJ Hakanen, P Rouvinen, I Ylhäinen - Sustainability, 2021 - mdpi.com. … impact of work engagement on future occupational rankings, wages, unemployment, and disability pensions—a register-based study of a representative sample of …. mdpi.com

25 EB Davis, SE McElroy-Heltzel, AW Lemke… - Health …, 2021 - psycnet.apa.org. Psychological and spiritual outcomes during the COVID-19 pandemic: A prospective longitudinal study of adults with chronic disease.

26 C Tully-Wilson, R Bojack, PM Millear… - Psychology and …, 2021 - psycnet.apa.org. Self-perceptions of aging: A systematic review of longitudinal studies..