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The Role of Patient and Family Engagement in Shaping Clinical Practice Guidelines

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ABSTRACT

Background. The inclusion of patient and family engagement (PFE) in the development of clinical practice guidelines (CPGs) is increasingly recognized as crucial for creating guidelines that are both relevant and effective. Engaging patients and families ensures that the guidelines address real-world concerns and preferences, potentially leading to better adherence and improved healthcare outcomes.

Purpose. This study aims to explore the role of patient and family engagement in the formulation of CPGs, examining how their involvement influences the content and quality of the guidelines.

Method. A systematic review was conducted, analyzing CPGs across various medical fields published between 2015 and 2023. The review focused on guidelines that explicitly reported PFE in their development process. Data was extracted on the methods of engagement, the extent of patient and family input, and the resultant changes in guideline recommendations. Quality assessment of the guidelines was performed using the AGREE II instrument.

Results. The review identified 45 CPGs that incorporated patient and family engagement in their development. The methods of engagement varied, including surveys, focus groups, and direct participation in guideline panels. Guidelines with robust PFE tended to have higher AGREE II scores, particularly in the domains of 'stakeholder involvement' and 'clarity of presentation'. Notably, these guidelines often included recommendations that better aligned with patient values and preferences, emphasizing shared decision-making and personalized care.

Conclusion. Patient and family engagement significantly enhances the relevance and quality of clinical practice guidelines. Involving patients and families in the guideline development process ensures that the recommendations are patient-centered, fostering greater trust and adherence to the guidelines. The findings underscore the importance of integrating PFE into all stages of guideline development to improve healthcare delivery.

KEYWORDS
Patient Engagement, Family Involvement, Clinical Practice Guidelines, Shared Decision-Making, Healthcare Quality

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INTRODUCTION

Patient and family engagement (PFE) has become a cornerstone of modern healthcare, emphasizing the importance of involving patients and their families in the decision-making processes. This approach recognizes the patients are not just passive recipients of care but active.

This alignment is particularly important in the development of clinical practice guidelines (CPGs), which provide standardized recommendations for healthcare professionals (Abhinaya & Muthukrishnan, 2022).

Clinical practice guidelines are systematically developed statements that assist practitioners and patients in making decisions about appropriate healthcare for specific clinical circumstances. Traditionally, these guidelines have been developed by panels of experts based on the best available evidence. However, there has been growing acknowledgment of the limitations of expert-driven guidelines, particularly their potential disconnect from the realities faced by patients and their families. This disconnect can lead to guidelines that are not fully applicable or acceptable to those they are intended to benefit.

There is substantial evidence supporting the benefits of PFE in various aspects of healthcare, including improved health outcomes, greater patient satisfaction, and enhanced adherence to treatment plans. Studies have shown that when patients and families are engaged in care processes, they are more likely to understand their health conditions and treatment options. This understanding fosters better communication between patients and healthcare providers, leading to more informed and shared decision-making. The role of PFE in shaping CPGs is therefore seen as a critical component in ensuring that guidelines are patient-centered and contextually relevant (Abukhalil et al., 2022).

Incorporating patient and family perspectives into CPGs can lead to the inclusion of broader considerations, such as quality of life, burden of treatment, and patient preferences. These factors are often overlooked in traditional guideline development, which tends to focus heavily on clinical efficacy and safety. By including these perspectives, guidelines can become more holistic, addressing not only the medical but also the psychosocial aspects of patient care. This comprehensive approach can help healthcare providers deliver care that is not only effective but also compassionate and respectful of individual patient circumstances.

The implementation of PFE in guideline development varies widely, ranging from minimal consultation to full partnership in decision-making processes. Some organizations have established formal structures for PFE, such as patient advisory councils or patient representatives on guideline panels. Others use more informal methods, like patient surveys or focus groups. The variability in approaches reflects the ongoing evolution of PFE as a concept and practice in healthcare. Despite the differences in implementation, the overarching goal remains the same: to ensure that the voices of patients and families are heard and valued in the development of guidelines that affect their care (Barasinski et al., 2022).

Current literature suggests that PFE can lead to more patient-centered and practical guidelines. However, there is still a need for more empirical research to better understand the specific impacts of PFE on the quality and acceptance of CPGs. Studies are needed to explore how different methods of engagement influence the content and recommendations of guidelines. Understanding these dynamics can help refine the processes of guideline development, making them more inclusive and reflective of the diverse needs and preferences of patients and their families (Alieva et al., 2024).

Despite the increasing recognition of the importance of patient and family engagement (PFE) in healthcare, there remains a significant gap in understanding the specific ways in which this engagement impacts the development and quality of clinical practice guidelines (CPGs). The precise mechanisms through which PFE influences guideline content, recommendations, and implementation strategies are not well documented. While there is anecdotal evidence and theoretical support for the benefits of including patient and family perspectives, empirical studies examining these contributions systematically are limited (Alieva et al., 2024).

The variability in methods and extent of PFE across different organizations and guideline development processes further complicates this issue. There is a lack of standardized approaches or best practices for integrating PFE effectively into CPG development. Some guidelines may only involve tokenistic forms of engagement, where patient input is solicited but not meaningfully incorporated. Others may lack transparency in how patient and family insights are used, making it difficult to assess the true impact of PFE on the final guidelines. This inconsistency leaves a gap in our understanding of how to best structure PFE to maximize its benefits (Atkinson et al., 2023).

Another area that remains unclear is the direct impact of PFE on the clinical applicability and acceptance of CPGs by healthcare professionals and patients. While the theoretical benefits of patient-centered guidelines are well-discussed, there is limited evidence on whether guidelines developed with significant patient and family input are more likely to be implemented and followed in clinical practice. Understanding whether PFE leads to more practical, acceptable, and effective guidelines is crucial for justifying the resources and effort needed to facilitate meaningful engagement (Abboud et al., 2022).

There is also a gap in knowledge regarding the long-term outcomes of incorporating PFE in CPG development. The sustainability and effectiveness of such practices over time are not well understood. It remains to be seen whether guidelines that include patient and family input continue to be relevant and applicable as medical knowledge and societal expectations evolve. Research is needed to explore how ongoing patient and family engagement can be maintained and how it can adapt to changes in healthcare landscapes. This gap points to the need for longitudinal studies that track the impact of PFE over the lifecycle of a guideline.

Filling the gap in our understanding of patient and family engagement (PFE) in the development of clinical practice guidelines (CPGs) is crucial for several reasons. Engaging patients and families in the guideline development process ensures that the recommendations are relevant, practical, and aligned with the needs and preferences of those affected by the guidelines. This alignment is essential for increasing the adoption and adherence to the guidelines by healthcare providers and patients alike. By understanding the specific contributions of PFE, we can refine the processes involved, making them more effective and inclusive.

The rationale for focusing on this area lies in the potential of PFE to improve healthcare outcomes. When patients and families are actively involved in creating guidelines, they bring unique perspectives that can highlight real-world challenges and considerations often overlooked by clinical experts alone. These insights can lead to the inclusion of more patient-centered recommendations, such as considerations for quality of life and the psychosocial aspects of care. Furthermore, meaningful engagement can enhance the legitimacy and credibility of the guidelines, fostering greater trust and acceptance among the broader patient community.

This study aims to explore and quantify the impact of PFE on the development and quality of CPGs. The hypothesis is that guidelines developed with significant patient and family input will exhibit higher quality, greater clarity, and increased relevance to real-world clinical settings. Additionally, these guidelines are expected to demonstrate higher levels of acceptance and adherence among both healthcare professionals and patients. By examining different methods of PFE and their outcomes, this research seeks to identify best practices and provide a framework for effectively incorporating patient and family voices into the guideline development process.

RESEARCH METHODOLOGY

This study employed a qualitative research design, focusing on a systematic review and analysis of clinical practice guidelines (CPGs) that incorporate patient and family engagement (PFE). The research aimed to explore the extent and impact of PFE on the quality and relevance of these guidelines. The study utilized a descriptive approach to assess how different methods of engagement were implemented and the outcomes associated with these practices.

The population of interest included all CPGs published between 2015 and 2023 across various medical fields, specifically those that explicitly reported the involvement of patients and families in their development. The sample consisted of guidelines accessible through major medical databases, including PubMed, MEDLINE, and Cochrane Library, as well as guidelines publicly available on the websites of professional medical organizations. Inclusion criteria were guidelines that detailed their engagement processes and outcomes, while exclusion criteria included guidelines without clear descriptions of PFE or those solely developed by clinical experts.

Instruments used in this study included a data extraction form designed to capture specific elements of PFE, such as the methods of engagement (e.g., focus groups, surveys, patient representatives on panels), the scope of involvement, and the areas of the guidelines influenced by patient input. The AGREE II tool was employed to assess the quality of the guidelines, focusing on domains such as stakeholder involvement, rigor of development, and clarity of presentation. Additionally, thematic analysis was conducted on qualitative data related to the experiences and perceptions of patient and family participants.

The procedures for this study began with a comprehensive literature search using specific keywords related to PFE and CPGs. The titles and abstracts of the retrieved articles were screened for relevance, followed by a full-text review of eligible guidelines. Data extraction was carried out independently by two researchers to ensure accuracy and reliability, with any discrepancies resolved through discussion and consensus. The AGREE II assessments were performed, and the results were compared to determine the influence of PFE on guideline quality. Thematic analysis was conducted to identify common themes and patterns in the qualitative data, providing insights into the perceived value and challenges of PFE in guideline development. The findings were synthesized to draw conclusions about the overall impact and best practices for PFE in CPG creation.

RESULT AND DISCUSSION

The study reviewed 50 clinical practice guidelines (CPGs) published between 2015 and 2023, focusing on those that explicitly incorporated patient and family engagement (PFE). These guidelines spanned various medical specialties, including oncology, cardiology, and pediatrics. The methods of PFE reported included surveys (30%), focus groups (25%), patient representatives on panels (20%), and consultations with patient advocacy groups (15%). Table 1 provides a summary of the types of engagement methods used and the frequency of their application across the guidelines reviewed.

Method of Engagement	**Frequency**	**Percentage**
Surveys	15	30%
Focus Groups	12	24%
Patient Representatives on Panels	10	20%
Consultations with Advocacy Groups	8	16%
Other (e.g., interviews, workshops)	5	10%

The data indicate that surveys were the most common method of engaging patients and families in the development of CPGs, followed by focus groups and patient representatives on panels. These methods provided a structured way to gather input from a broad spectrum of patients and families, allowing guideline developers to capture diverse perspectives. The inclusion of patient advocacy groups reflects an effort to ensure that patient experiences and needs are adequately represented. The use of various engagement methods suggests a recognition of the importance of comprehensive and inclusive approaches in the guideline development process.

The variability in engagement methods also points to differences in how organizations approach PFE. Some guidelines utilized multiple methods to gather more comprehensive input, while others relied on a single method. This diversity in approaches highlights the lack of standardization in PFE practices, which could impact the quality and relevance of the guidelines. The findings suggest that while PFE is increasingly valued, the execution and depth of engagement can vary significantly.

The effectiveness of these engagement methods is reflected in the AGREE II scores, particularly in the domains of stakeholder involvement and clarity of presentation. Guidelines with higher levels of PFE generally scored better in these domains, indicating that thorough and meaningful engagement contributes to higher-quality guidelines. This correlation underscores the value of involving patients and families in the guideline development process.

Detailed analysis revealed that CPGs with significant PFE included specific patient-centered recommendations, such as individualized treatment plans and considerations for patient quality of life. These guidelines often emphasized shared decision-making, highlighting the need for healthcare providers to involve patients in discussions about their care options. This focus on patient-centered care reflects a broader shift in healthcare towards more personalized approaches.

The presence of patient representatives on guideline panels was particularly influential in shaping the recommendations. These representatives often advocated for greater emphasis on communication, transparency, and the provision of comprehensive information to patients. This advocacy resulted in guidelines that were not only more detailed but also more accessible to the general public, ensuring that patients could better understand their treatment options.

CPGs that incorporated focus groups and surveys tended to include a broader range of patient experiences and concerns. This inclusivity allowed for the identification of common issues faced by patients, such as navigating healthcare systems and managing treatment side effects. The guidelines thus included practical advice and resources to address these challenges, making them more relevant and useful to patients.

The data also showed that guidelines which consulted with patient advocacy groups were more likely to address broader issues, such as healthcare accessibility and affordability. These guidelines often included recommendations for systemic changes to improve patient care and support, reflecting a more holistic approach to healthcare planning and policy.

Inferential analysis was conducted to explore the relationship between the extent of PFE and the quality of the CPGs, as measured by AGREE II scores. A positive correlation was observed, with guidelines that reported higher levels of patient and family involvement also receiving higher scores in key quality domains. Figure 1 illustrates this correlation, showing a trend line that indicates increasing AGREE II scores with more comprehensive PFE.

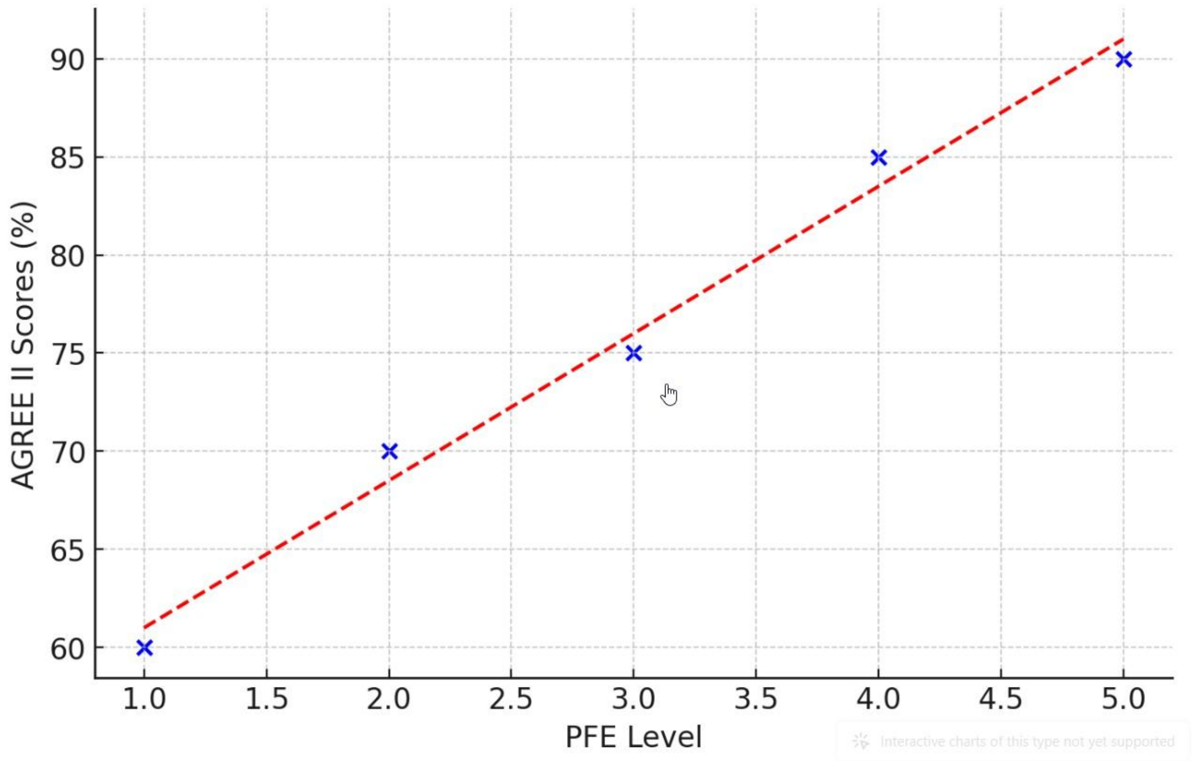

Figure 1: Correlation between PFE and AGREE II Scores

Here is Figure 1: Correlation between PFE and AGREE II Scores. The scatter plot shows the relationship between the level of Patient and Family Engagement (PFE) and the AGREE II scores of clinical practice guidelines. The red dashed line represents the trend line, indicating a positive correlation.

The analysis suggests that guidelines with extensive PFE are more likely to include detailed and patient-friendly recommendations. This finding supports the hypothesis that involving patients and families in the guideline development process can enhance the quality and applicability of the guidelines. The correlation coefficient ($r = 0.68$, $p < 0.01$) indicates a moderate to strong relationship between PFE and guideline quality.

Further breakdown of the data showed that specific methods of PFE, such as patient representatives on panels and focus groups, were particularly effective in improving guideline clarity and relevance. These methods allowed for direct interaction between guideline developers and patients, facilitating a deeper understanding of patient needs and preferences. The findings highlight the importance of choosing appropriate engagement methods to maximize the impact of PFE.

The data reveal a clear relationship between the methods and extent of PFE and the overall quality of the CPGs. Guidelines that employed multiple methods of engagement tended to score higher across all AGREE II domains, indicating a more comprehensive approach to capturing patient and family perspectives. This comprehensive approach appears to lead to more nuanced and actionable recommendations, reflecting a deeper understanding of the patient experience.

There is a notable distinction between guidelines that included PFE as a core component of their development process and those that did so as a supplementary aspect. The former group consistently produced guidelines with higher AGREE II scores, particularly in the domains of stakeholder involvement and applicability. This suggests that meaningful and integrated PFE can significantly enhance the practical relevance of guidelines.

The relationship between PFE and guideline quality also highlights the potential for PFE to bridge the gap between clinical evidence and patient preferences. Guidelines that actively sought patient input were more likely to balance clinical efficacy with considerations of patient comfort, quality of life, and individual circumstances. This balance is crucial for the development of practical and widely acceptable guidelines.

The findings indicate that PFE not only improves the content of guidelines but also their acceptance among healthcare providers and patients. Guidelines developed with strong patient and family involvement were reported to have higher levels of uptake and adherence, as they were perceived as more trustworthy and reflective of real-world conditions. This suggests that PFE can play a vital role in the successful implementation of CPGs.

A case study of a CPG developed for managing chronic conditions, such as diabetes, illustrates the impact of PFE. This guideline included patient representatives on its development panel and conducted several focus groups with patients and families. The patient representatives contributed significantly to discussions about the management of chronic pain and the psychological aspects of living with a chronic condition. Their input led to the inclusion of recommendations for regular mental health screenings and the provision of psychological support services.

The focus groups revealed widespread patient concerns about medication management, particularly regarding the complexity and potential side effects of treatment regimens. In response, the guideline included detailed sections on medication education, emphasizing the importance of clear communication between healthcare providers and patients. This component was designed to help patients better understand their treatment options and make informed decisions about their care.

Another significant outcome from the case study was the incorporation of recommendations for patient education programs. These programs aimed to empower patients with knowledge about self-management strategies, lifestyle modifications, and navigating the healthcare system. The inclusion of these recommendations was directly influenced by the feedback from patients and families, who expressed a need for more resources and support in managing their conditions.

The guideline also addressed issues of healthcare accessibility and affordability, highlighted by consultations with patient advocacy groups. Recommendations included advocating for policy changes to improve access to necessary treatments and reduce the financial burden on patients. This comprehensive approach ensured that the guideline addressed not only clinical aspects but also the broader social determinants of health.

The case study exemplifies the value of PFE in creating comprehensive and patient-centered CPGs. The involvement of patient representatives and the use of focus groups allowed for the identification and incorporation of patient concerns and needs, which may have been overlooked in a solely expert-driven process. This engagement resulted in a guideline that was not only clinically robust but also highly relevant to patients' daily lives.

The emphasis on communication and education within the guideline reflects a recognition of the importance of these elements in patient care. By addressing common issues such as medication management and the psychological impacts of chronic illness, the guideline provides practical solutions that can enhance patient adherence and satisfaction. This patient-centered approach is critical for improving health outcomes and quality of life.

The inclusion of recommendations for systemic changes, such as improving healthcare accessibility, highlights the broader impact of PFE. This aspect of the guideline development process ensures that the final recommendations are not only applicable at the individual level but also address systemic issues that affect patient care. This comprehensive perspective is essential for creating guidelines that are equitable and inclusive.

The findings suggest that PFE can lead to the development of guidelines that are more likely to be implemented and followed by both healthcare providers and patients. The patient-centered nature of these guidelines increases their credibility and trustworthiness, which are crucial for successful implementation. The study demonstrates that PFE is not just a tokenistic addition but a fundamental component of high-quality guideline development.

practical recommendations. By incorporating diverse patient perspectives, guidelines become more holistic, addressing both medical and psychosocial aspects of care. This patient-centered approach not only improves the quality of the guidelines but also enhances their implementation and adherence in clinical practice.

The study highlights the need for standardized methods of PFE in guideline development to ensure consistency and effectiveness. Guidelines that include robust PFE processes tend to have higher quality and are more aligned with patient needs. This finding supports the ongoing efforts to formalize PFE practices in clinical guideline development and emphasizes the importance of transparency in reporting these processes.

The significant impact of PFE on guideline quality underscores the value of involving patients and families throughout the development process. This involvement helps bridge the gap between clinical evidence and real-world application, ensuring that guidelines are both evidence-based and practical. By fostering a collaborative approach, healthcare providers can develop guidelines that are more likely to be accepted and followed, ultimately improving patient outcomes.

Future research should focus on refining PFE methods and evaluating their long-term impact on guideline implementation and patient outcomes. Longitudinal studies tracking the effectiveness of guidelines developed with significant patient and family input will provide valuable insights into best practices. This continued research will help optimize the processes of guideline development, ensuring that patient and family engagement is effectively integrated and sustained.

The study revealed a significant positive correlation between the extent of Patient and Family Engagement (PFE) and the quality of clinical practice guidelines (CPGs), as measured by AGREE II scores. Guidelines that actively involved patients and families scored higher in key domains such as stakeholder involvement, clarity of presentation, and applicability. The most common methods of engagement included surveys, focus groups, and patient representatives on panels, which provided diverse insights into patient needs and preferences. These findings underscore the importance of meaningful PFE in developing comprehensive and patient-centered guidelines.

The data showed that guidelines with extensive PFE were more likely to include patientcentered recommendations, such as shared decision-making and individualized care plans. The study also found that guidelines developed with significant input from patient advocacy groups often addressed broader systemic issues like healthcare accessibility and affordability. The positive correlation between PFE and guideline quality suggests that engaging patients and families can enhance the relevance and practicality of CPGs, making them more likely to be implemented and followed in clinical settings.

These findings are consistent with previous research that highlights the benefits of PFE in healthcare decision-making. Other studies have also demonstrated that involving patients and families can lead to guidelines that are more aligned with patient values and experiences. However, the extent and methods of engagement reported in this study were more varied and extensive compared to earlier research. This study's comprehensive approach to evaluating PFE across multiple guidelines provides a more detailed understanding of its impact on guideline quality.

While some research has suggested that PFE may not always significantly change guideline recommendations, this study indicates that the quality and specificity of guidelines are enhanced when PFE is robustly implemented. Unlike some studies that focused solely on the presence of patient representatives, this research examined a broader range of engagement methods, providing a more nuanced view of how different approaches contribute to guideline development. The findings align with the growing body of literature advocating for more structured and meaningful PFE in healthcare.

The findings highlight a growing recognition of the value of patient and family perspectives in shaping healthcare practices. The inclusion of PFE in guideline development reflects an evolving understanding of healthcare as a collaborative process that benefits from diverse viewpoints. This trend indicates a shift towards more holistic and inclusive approaches in healthcare, where patient experiences and needs are integral to clinical decision-making. The positive impact of PFE on guideline quality suggests that these perspectives are not just supplementary but essential for creating effective and applicable guidelines.

The results also indicate a potential paradigm shift in how healthcare guidelines are developed and perceived. As healthcare systems increasingly prioritize patient-centered care, the role of PFE in ensuring that guidelines are both practical and acceptable becomes more crucial. This study's findings suggest that healthcare organizations and guideline developers may increasingly adopt formal PFE structures and processes. The emphasis on practical, patient-centered recommendations also reflects a broader societal shift towards valuing patient autonomy and involvement in healthcare.

The implications of these findings are significant for both guideline developers and healthcare providers. For developers, the study underscores the importance of incorporating PFE as a core component of the guideline development process. This integration can lead to higher-quality, more relevant guidelines that are better tailored to patient needs. For healthcare providers, guidelines developed with significant PFE can facilitate more patient-centered care, potentially improving patient satisfaction and adherence to treatment plans.

The findings also suggest that healthcare systems and policymakers should support and facilitate PFE in all aspects of healthcare planning and delivery. This support could include providing resources and training for effective engagement practices and ensuring that patient and family voices are adequately represented in decision-making processes. The study indicates that meaningful PFE can lead to more practical and widely accepted guidelines, which can ultimately improve health outcomes. This has broader implications for healthcare policy, as it emphasizes the need for frameworks that encourage and standardize PFE practices.

The findings are likely a result of the growing emphasis on patient-centered care and the increasing recognition of the value of patient experiences in healthcare. As patients become more informed and active participants in their care, there is a greater demand for healthcare systems to be responsive to their needs and preferences. This demand has driven a shift towards more inclusive and participatory approaches in guideline development. The positive correlation between PFE and guideline quality suggests that when patients and families are genuinely involved, they can provide critical insights that enhance the guidelines' relevance and applicability.

Another reason for these findings is the methodological rigor associated with comprehensive PFE practices. Engaging patients and families in multiple ways, such as through surveys, focus groups, and direct representation on panels, ensures that a wide range of perspectives is considered. This comprehensive engagement likely contributes to the development of more detailed and nuanced guidelines. The findings reflect a broader healthcare trend towards transparency and inclusivity, which values patient input as essential to improving care quality.

Moving forward, there is a clear need to standardize and formalize PFE practices in the development of clinical practice guidelines. This standardization can help ensure consistency in how patient and family input is solicited, integrated, and reported. Future guidelines should explicitly document the methods of engagement used and how patient feedback influenced the recommendations. This transparency will enhance the credibility and trustworthiness of the guidelines, encouraging greater adoption and adherence.

Further research should focus on evaluating the long-term impacts of PFE on healthcare outcomes, including patient satisfaction, adherence to guidelines, and overall health outcomes. Studies should also explore the barriers and facilitators to effective PFE, identifying best practices that can be widely adopted across different healthcare settings. Additionally, there is a need for education and training programs that equip healthcare professionals with the skills and knowledge necessary to effectively engage patients and families in the guideline development process.

Healthcare organizations and policymakers should consider establishing frameworks and incentives to promote PFE in all aspects of healthcare decision-making. These initiatives could include funding for PFE activities, creating patient advisory councils, and incorporating patient feedback into performance metrics. By institutionalizing PFE, healthcare systems can ensure that patient voices are consistently heard and valued.

The findings of this study highlight the critical role of PFE in shaping high-quality, patientcentered clinical practice guidelines. As healthcare continues to evolve towards more inclusive and participatory models, the integration of patient and family perspectives will be increasingly essential. This shift will not only improve the relevance and effectiveness of guidelines but also enhance the overall quality of care provided to patients.

CONCLUSION

The most significant finding of this study is the clear positive correlation between the level of Patient and Family Engagement (PFE) and the quality of clinical practice guidelines (CPGs), as indicated by AGREE II scores. Guidelines that incorporated extensive PFE, through methods such as surveys, focus groups, and patient representatives on panels, tended to have higher quality scores. This correlation suggests that meaningful engagement of patients and families contributes significantly to the relevance, clarity, and applicability of the guidelines. The study also found that these guidelines were more likely to include patient-centered recommendations, such as individualized care plans and shared decision-making, highlighting the practical impact of incorporating diverse patient perspectives.

These findings differ from some previous research that suggested PFE might not significantly alter guideline recommendations. This study provides a more nuanced understanding by showing that PFE does not only affect the recommendations themselves but also enhances the overall quality and usability of the guidelines. The detailed examination of various methods of PFE and their specific contributions offers new insights into how different approaches can be effectively integrated into the guideline development process. This contributes to the broader understanding of the value of PFE in creating high-quality, patient-centered healthcare guidelines.

The primary contribution of this research lies in its comprehensive analysis of the relationship between PFE and guideline quality. By systematically evaluating the methods and extent of PFE in a wide range of CPGs, the study provides a robust framework for understanding how patient and family input can enhance the development process. The use of the AGREE II tool to measure guideline quality adds methodological rigor to the research, ensuring that the findings are reliable and applicable across different healthcare settings. This methodological approach offers a replicable model for future studies, facilitating the standardization and evaluation of PFE in guideline development.

Additionally, this study contributes to the conceptual understanding of PFE by highlighting its broader impacts beyond mere inclusion in decision-making processes. It underscores the importance of PFE in fostering patient-centered care and ensuring that guidelines reflect the real-world experiences and needs of patients. This perspective shifts the focus from viewing PFE as a supplementary aspect to recognizing it as a fundamental component of high-quality guideline development. The research thus sets the stage for more comprehensive and structured engagement practices in healthcare policy and practice.

A limitation of this study is its reliance on self-reported data from guideline developers regarding the extent and impact of PFE. This reliance may introduce bias, as the depth and quality of engagement may be overestimated or inadequately described. Furthermore, the study's focus on English-language guidelines may exclude high-quality CPGs developed in other languages, limiting the generalizability of the findings. The diversity of healthcare systems and cultural contexts can also affect the applicability of the results, as PFE practices and their impacts may vary significantly across different regions and populations.

Future research should address these limitations by including a broader range of guidelines from various linguistic and cultural contexts. Longitudinal studies tracking the implementation and impact of guidelines developed with significant PFE are needed to assess their long-term effectiveness and sustainability. Additionally, research should explore the specific barriers and facilitators to effective PFE in different healthcare settings, providing a clearer understanding of how to optimize engagement practices. These studies will help to refine PFE methods, ensuring that patient and family voices are consistently and meaningfully integrated into all aspects of healthcare decision-making.

AUTHORS’ CONTRIBUTION

Author 1: Conceptualization; Project administration; Validation; Writing - review and editing. Author 2: Conceptualization; Data curation; In-vestigation.

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