FAMCARE: A Tool for Measuring Effectiveness of End-of-Life Care

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Abstract

This comprehensive narrative review examines FAMCARE as a measurement tool for evaluating the effectiveness of end-of-life care, exploring its development, psychometric properties, applications across various healthcare setting, and impact on quality improvement initiatives. Originally developed for assessing family satisfaction in advanced cancer care, FAMCARE has evolved into various validated versions (FAMCARE-2, FAMCARE-6, FAMCARE-P13) adapted for different healthcare settings and cultural contexts. The tool demonstrates robust psychometric properties, with high internal consistency (Cronbach's alpha 0.93-0.96) across multiple studies and strong cross-cultural validity through successful adaptations in various languages and healthcare systems. Review of its implementation across diverse settings, including hospice, hospital-based palliative care units, home-based care, and oncology departments, reveals its effectiveness in measuring and improving care quality. The tool's multidimensional structure, encompassing information provision, availability of care, physical patient care, and psychosocial support, provides comprehensive insights into family satisfaction with end-of-life care. However, potential limitations including ceiling effects and retrospective assessment challenges have been identified. This review also highlights FAMCARE's significant contribution to quality improvement initiatives, particularly in enhancing communication skills training, symptom management, and psychosocial support services. Future directions for FAMCARE development include real-time assessment capabilities, personalization options, and integration with emerging healthcare technologies. These findings underscore FAMCARE's value as both a research instrument and a practical tool for improving end-of-life care quality, while identifying areas for future refinement to ensure its continued relevance in evolving healthcare landscapes.

Keywords: FAMCARE, End-of-Life, Psychometric Validation, Palliative Care, Healthcare Quality Assessment

Introduction

End-of-Life (EOL) care represents a crucial and complex domain within the healthcare system, focusing on providing comfort, dignity, and support to patients in their final days or months of life. As global demographics shift towards an aging population and the prevalence of chronic diseases increases, the importance of high-quality EOL care continues to grow exponentially. The World Health Organization defines palliative care, a key component of EOL care, as an approach that improves the Quality of Life (QOL) of patients and their families facing life-threatening illness (World Health Organization, 2020). This holistic approach encompasses physical, psychosocial, and spiritual aspects of care, emphasizing the relief of suffering and the enhancement of QOL.

The effectiveness of EOL care is a multifaceted concept that extends beyond traditional clinical outcomes. It encompasses various dimensions, including symptom management, psychological well-being, spiritual comfort, and the overall experience of both patients and their families (Abbaspour & Heydari, 2022). Measuring this effectiveness presents unique challenges due to the sensitive nature of EOL care, the vulnerability of the patient population, and the complex interplay of medical, emotional, and social factors involved (Hansen et al., 2020).

In recent years, there has been a growing recognition of the crucial role that family members play in the EOL care process. Family caregivers often serve as primary support systems for patients, advocates for their needs, and key decision-makers in their care (National Academies of Sciences, Engineering, and Medicine, 2016a; 2016b). Consequently, the satisfaction and experiences of family members have emerged as important indicators of the quality and effectiveness of EOL care (Nadin et al., 2017). This shift towards family-centered care aligns with the broader movement in healthcare towards patient and family engagement, recognizing that the needs and perspectives of family caregivers are integral to achieving optimal care outcomes.

In this context, tools that can reliably and validly assess family satisfaction with EOL care have become increasingly valuable. Among these, several validated instruments have been widely used: the Family Satisfaction in the ICU (FS-ICU) which specifically assesses satisfaction in critical care settings (Wall et al., 2007), the Quality of Dying and Death Questionnaire (QODD) that evaluates multiple domains including physical symptoms and emotional well-being (Downey et al., 2010), and Views of Informal Carers - Evaluation of Services (VOICES) that assesses care experiences in the last three months of life (Addington-Hall, 1998). FAMCARE has emerged as a widely recognized and utilized instrument (Hannon et al., 2014). FAMCARE was specifically designed to measure family satisfaction with advanced cancer care (Kristjanson, 1993). Since its inception, it has been adapted and applied across various EOL care settings, including hospices, palliative care units, and home-based care services.

While these instruments have contributed significantly to the understanding of end-of-life care quality, they present certain limitations. The FS-ICU, though comprehensive for critical care settings, has limited application outside intensive care units and focuses primarily on decision-making and staff communication rather than holistic care (Wall et al., 2007). The QODD, while examining multiple domains, requires retrospective assessment that may be affected by grief and recall bias, and its length can be burdensome for bereaved family members (Downey et al., 2010). VOICES provides valuable insights into care experiences but lacks specificity for family satisfaction with particular aspects of care delivery (Addington-Hall, 1998). In contrast, FAMCARE offers distinct advantages through its focused assessment of family satisfaction across various care dimensions, adaptability to different healthcare settings including home-based care, and its available shorter versions that reduce respondent burden while maintaining psychometric integrity.

The FAMCARE scale evaluates family satisfaction in four key areas: information provision, care availability, physical patient care, and psychosocial support (Kristjanson, 1993; Lo et al., 2009). This tool provides insights into EOL care effectiveness from the family's perspective.

The purpose of this review is to provide a comprehensive examination of FAMCARE as a tool for measuring the effectiveness of EOL care. We will explore its development, structure, and psychometric properties, as well as its applications across various healthcare settings. Furthermore, this review will consider the broader implications of using family satisfaction as a proxy for care effectiveness, discussing both the advantages and potential limitations of this approach. We will also explore how FAMCARE has been integrated into quality improvement initiatives and its potential to drive meaningful changes in EOL care delivery.

This narrative review examined literature on FAMCARE published between 1993-2024, spanning from its original development to recent applications. We searched PubMed/MEDLINE, CINAHL, and Google Scholar using key terms ‘FAMCARE’, ‘family satisfaction’, ‘palliative care’, and ‘end-of-life care’. Citation tracking and reference list reviews were employed to ensure comprehensive coverage. We included studies focused on FAMCARE and its adaptations (FAMCARE-2, FAMCARE-6, FAMCARE-P13) across various healthcare settings including hospice, hospital-based care, home care, and oncology departments. This approach allowed us to thoroughly examine FAMCARE's evolution, psychometric properties, applications, and impact across diverse contexts.

Development and Structure of FAMCARE

FAMCARE's development marks a pivotal moment in the field of palliative care research, reflecting a growing recognition of the importance of family perspectives in evaluating end-of-life care quality. Originally conceptualized by Kristjanson (1993), FAMCARE was born out of a need for a standardized, reliable measure of family satisfaction with advanced cancer care.

The initial development process of FAMCARE was rigorous and multifaceted. Kristjanson's work involved extensive literature reviews, qualitative interviews with family members of cancer patients, and consultations with healthcare professionals specializing in palliative care. This comprehensive approach ensured that FAMCARE captured the most salient aspects of care from the family's perspective, grounding the tool in both theoretical understanding and practical experience.

The original FAMCARE scale consisted of 20 items, carefully crafted to assess various dimensions of care satisfaction. These dimensions include:

1. **Information Giving**: This aspect addresses the clarity and completeness of information provided to families about the patient's condition, prognosis, and care plan.
2. **Availability of Care**: This dimension evaluates the accessibility and responsiveness of healthcare providers to family needs and concerns.
3. **Physical Patient Care**: This covers the family's satisfaction with the management of the patient's physical symptoms and overall comfort.
4. **Psychosocial Care**: This assesses the emotional and psychological support provided to both the patient and family members.

Each item in FAMCARE is rated on a 5-point Likert scale, ranging from "very satisfied" to "very dissatisfied". This structure allows for nuanced responses, capturing varying degrees of satisfaction across different aspects of care. The total score provides an overall measure of family satisfaction, with higher scores indicating greater satisfaction with the care provided.

As the field of palliative care has advanced, FAMCARE has evolved alongside. Recognizing the diverse contexts in which end-of-life care is delivered, researchers have developed several adaptations of the original tool:

1. **FAMCARE-2**: Developed by Aoun et al. (2010), this 17-item version was designed to be more applicable across various palliative care settings beyond cancer care. This adaptation reflected the expanding scope of palliative care to include other life-limiting illnesses (Aoun et al., 2010).
2. **FAMCARE-6**: Teresi et al. (2014) created this shortened 6-item version in 2014, addressing the need for a more concise tool which less time-consuming in constrained clinical settings such as Intensive Care Units, Emergency Departments, Outpatient Clinics, Home-Based Care. This adaptation demonstrates the practical considerations in implementing satisfaction measures in busy healthcare environments (Teresi et al., 2014).
3. **FAMCARE-P13**: Recognizing the importance of capturing patient perspectives alongside family satisfaction, Lo et al. (2009) developed this 13-item patient version in 2009. This adaptation highlights the growing emphasis on patient-centered care and the value of multiple perspectives in assessing care quality (Lo et al., 2009).

These adaptations of FAMCARE illustrate the tool’s flexibility and its ability to evolve in response to changing needs and contexts in palliative care delivery. They also reflect ongoing debates in the field about the balance between comprehensiveness and practicality in assessment tools, and the relative importance of different perspectives (family vs. patient) in evaluating care quality (Ringdal et al., 2003).

Despite its strengths, FAMCARE’s fixed structure may overlook cultural nuances and individual family priorities (Arafat et al., 2016), prompting discussions about cultural adaptations and more personalized assessment approaches.

Our review will explore how these structural characteristics of FAMCARE have played out in terms of its psychometric properties, practical applications, and limitations in the discussion. This exploration will provide a foundation for understanding FAMCARE’s overall contribution to the field of palliative care and its potential for future development and application.

Psychometric Properties of FAMCARE

The widespread adoption of FAMCARE in palliative care research and practice is largely attributed to its robust psychometric properties. Over the years, numerous studies have examined the reliability and validity of FAMCARE across various healthcare settings and cultural contexts, consistently demonstrating its strength as a measurement tool.

One of the most remarkable features of FAMCARE is its high internal consistency. Multiple studies have reported Cronbach’s alpha values ranging from 0.93 to 0.96 for the original 20-item scale (Miyashita et al., 2017; Neo et al., 2019; Ooraikul et al., 2020; Teresi et al., 2020). This excellent consistency has been maintained even as FAMCARE has been adapted and translated for use in different countries and healthcare systems. For instance, the FAMCARE-2, with its 17 items, has shown similarly high internal consistency, with Cronbach’s alpha values of 0.93-0.94 (Ooraikul et al., 2020). These findings suggest that FAMCARE’s items are cohesively measuring the same underlying construct of family satisfaction with care.

The test-retest reliability of FAMCARE has also been established in several studies, although this aspect has been less extensively researched than internal consistency. Researchers have reported correlation coefficients indicating good to excellent stability over time (Ringdal et al., 2003), supporting FAMCARE’s ability to provide consistent measurements when administered at different time points. However, the dynamic nature of the end-of-life care experience can influence satisfaction levels over time.

The construct validity of FAMCARE has been supported through factor analysis studies, although findings have varied regarding the number of distinct factors identified. While some researchers have replicated the original four-factor structure (information giving, availability of care, physical patient care, and psychosocial care) (Rodriguez et al., 2010), others have found alternative factor structures (Ornstein et al., 2015). This variability suggests that the underlying dimensions of family satisfaction with care may be influenced by cultural or contextual factors, highlighting the need for careful consideration when applying FAMCARE in diverse settings.

Notably, FAMCARE has shown good cross-cultural validity, with successful adaptations in various languages and cultural contexts (Can et al., 2011; Chaumier et al., 2020; Ljungberg et al., 2015; Ooraikul et al., 2020; Wang et al., 2023). However, these cross-cultural studies have also revealed interesting variations in satisfaction priorities and expression across different populations, underscoring the importance of cultural considerations in interpreting FAMCARE results.

Table 1 Comparison of Psychometric Properties Between FAMCARE and Other End-of-Life Care Assessment Tools

Assessment Tool	Internal Consistency	Test-Retest Reliability	Cross-Cultural Validation	Key Strengths	Key Limitations
FAMCARE	High (α = 0.93-0.96) [1]	Good to excellent [2]	Extensive (multiple languages and contexts) [3]	Multidimensional structure; multiple validated versions	Ceiling effects; retrospective bias
FS-ICU	High (α = 0.93-0.96) [4]	Good - excellent [4]	Limited (fewer cultural adaptations)	Detailed assessment of ICU-specific concerns	Limited relevance outside ICU; complex scoring
QODD	Moderate to high (α = 0.67) [5]	Variable [5]	Moderate (several cultural contexts)	Comprehensive; includes patient experience	Length; complexity; significant respondent burden
VOICES	Variable (α = 0.70) [6]	Limited evidence	Primarily UK-based	Health system evaluation; broad coverage	Length; less specific to individual care aspects; complex administration

Remarks: [1] Ooraikul et al. (2020) [2] Chattat et al. (2016) [3] Chaumier et al. (2020)
[4] Dale and Frivold (2018); Harrison et al. (2015) [5] Curtis et al. (2002) [6] Dust et al. (2022)

Comparing FAMCARE with other end-of-life assessment tools (as shown in Table 1) reveals its strong psychometric properties. FAMCARE demonstrates high internal consistency (α = 0.93-0.96) (Ooraikul et al., 2020), which is at the same level as FS-ICU (α = 0.93-0.96) (Dale & Frivold, 2018; Harrison et al., 2015) and clearly higher than QODD (α = 0.67) (Curtis et al., 2002). Furthermore, FAMCARE possesses good to excellent test-retest reliability (Chattat et al., 2016). Moreover, FAMCARE has undergone extensive cross-cultural validation in multiple languages and contexts (Chaumier et al., 2020), more comprehensively than its counterparts. While each tool has distinct strengths—such as FS-ICU for ICU settings, QODD for comprehensive assessment, and VOICES for health system evaluation—FAMCARE's multidimensional structure and multiple validated versions offer broader applicability and flexibility.

Despite these strong psychometric properties, some limitations have been noted. The potential for ceiling effects, where a high proportion of respondents select the highest satisfaction levels, has been reported in several studies (Carter et al., 2011; Neo et al., 2019). This phenomenon raises questions about the tool's ability to discriminate between good and excellent care experiences, particularly in contexts where social desirability bias may influence responses.

These limitations warrant consideration in both research and clinical applications. To address ceiling effects, several potential solutions have been proposed. Researchers suggest modifying response scales to increase sensitivity at the upper end, perhaps employing a 7-point or 10-point Likert scale instead of the standard 5-point format (Finstad, 2010; Furr, 2011). Another approach involves incorporating more discriminating items that can better differentiate between good and excellent care experiences (Musa et al., 2018). For clinical quality improvement, analyzing the distribution patterns of high scores rather than focusing solely on mean values may provide more nuanced insights (Richter et al., 2024).

Application of FAMCARE in Various Healthcare Settings

Since its inception, FAMCARE has demonstrated remarkable versatility, finding applications across a wide spectrum of healthcare settings. This adaptability has contributed significantly to our understanding of family satisfaction with end-of-life care in diverse contexts, each with its unique challenges and characteristics.

In the realm of hospice care, FAMCARE has been extensively utilized to assess and improve service quality. Studies conducted in hospice settings across multiple countries have consistently reported high levels of family satisfaction, with mean FAMCARE scores often ranging in the upper quartile of the scale (Aoun et al., 2010; Sia, 2019). These findings suggest that the hospice model, with its holistic approach to end-of-life care, generally aligns well with family expectations. However, the consistently high scores have also raised questions about potential ceiling effects and the tool's sensitivity in this setting (Carter et al., 2011; Neo et al., 2019).

Hospital-based palliative care units have also benefited from the application of FAMCARE. A notable multi-center study spanning several hospitals found that the implementation of dedicated palliative care programs led to significant improvements in FAMCARE scores, particularly in the domains of information giving and availability of care (Aoun et al., 2010). This underscores the value of specialized palliative care services in achieving family needs and expectations. Interestingly, some studies have noted variations in satisfaction levels across different hospital departments, with dedicated palliative care units often scoring higher than homecare (Addington-Hall & O'Callaghan, 2009).

The application of FAMCARE in home-based palliative care settings has yielded particularly insightful results. Comparative studies between home-based and inpatient palliative care services have generally found higher overall satisfaction in home-based care, especially in the domain of physical patient care (Biswas et al., 2022; Kadu et al., 2021). These findings align with the preference of many patients to receive end-of-life care at home and highlight the importance of supporting and enhancing home-based care options. However, home-based care satisfaction can be heavily influenced by the availability of support systems and resources, which FAMCARE may not fully capture.

In oncology departments, FAMCARE has played a crucial role in evaluating the integration of palliative care into cancer treatment. Studies have shown that the presence of dedicated palliative care teams in oncology units is significantly associated with higher FAMCARE scores (Hannon et al., 2014). This has provided valuable evidence supporting the early integration of palliative care in cancer treatment trajectories, this has gained increasing recognition in the last decade. Consequently, the American Society of Clinical Oncology (ASCO) published the Integrate Palliative Care into Standard Oncology Care Guideline in 2012, 2016 and 2024 (Ferrell et al., 2017; Sanders et al., 2024; Smith et al., 2012).

It's important to note that while FAMCARE has been successfully applied across these diverse settings, its effectiveness can vary. Factors such as the timing of administration, the method of delivery (e.g., in-person vs. postal surveys), and the cultural context can all influence the results. Moreover, the retrospective nature of many FAMCARE applications (often administered after the patient's death) has been both a strength, allowing for reflection on the entire care experience, and a limitation, potentially introducing recall bias (Ringdal et al., 2003).

FAMCARE as a Quality Improvement Tool

FAMCARE's role extends beyond mere measurement; it has emerged as a powerful catalyst for quality improvement in palliative care services. Its ability to provide structured feedback on family satisfaction has made it an invaluable tool for healthcare providers and administrators seeking to enhance the quality of end-of-life care.

One of the most significant applications of FAMCARE in quality improvement has been in communication skills training for healthcare providers. Multiple studies have demonstrated that targeted communication training programs, informed by FAMCARE results, can lead to substantial improvements in family satisfaction scores (Ringdal et al., 2002). For instance, a notable study in an oncology palliative care unit found that after implementing a communication skills workshop for staff, FAMCARE scores increased significantly, particularly in domains related to information giving and emotional support (Lo et al., 2009). These findings underscore the critical role of effective communication in family satisfaction and have led many institutions to incorporate FAMCARE-based feedback into their staff development programs.

In the realm of symptom management, the Thai translation of the FAMCARE-2 Scale has significantly enhanced our understanding of family satisfaction in care. Factor analysis of FAMCARE-2 revealed a four-factor structure that provides valuable insights into symptom management and related aspects of care. The factors identified include the management of physical symptoms and comfort, as well as the handling of symptoms and side effects, both of which are directly related to symptom control (Ooraikul et al., 2020).

FAMCARE has also played a crucial role in enhancing psychosocial and spiritual care services (Aoun et al., 2010). Institutions that have used FAMCARE data to inform the expansion of their psychosocial support services, including the integration of social workers and chaplains into palliative care teams, have reported improvements in family satisfaction, particularly in the psychosocial care domain (Ooraikul et al., 2020).

However, it's important to note that the use of FAMCARE as a quality improvement tool is not without challenges. The potential for ceiling effects, as mentioned earlier, can sometimes make it difficult to detect improvements in already high-performing units. Additionally, the retrospective nature of FAMCARE administration in many settings means that improvements based on feedback may not benefit the families who if feedback, raising ethical considerations as shown in Table 2.

Table 2 Uses of FAMCARE in Different Settings

Versions of FAMCARE	Number of Items	Setting of Application	Domain of Assessment	Advantage / Disadvantage
FAMCARE	20	Advanced Cancer Care	Information Giving, Availability of Care, Physical Patient Care, Psychosocial Care	+ Cross-cultural Validity + Comprehensive Coverage - Ceiling Effects - Retrospective Bias
FAMCARE-2	17	Hospice	Information Giving, Availability of Care, Physical Patient Care, Psychosocial Care	+ Broader Applicability + High Reliability + Validated Across Systems - Ceiling Effects

Table 2 (Cont.)

Versions of FAMCARE	Number of Items	Setting of Application	Domain of Assessment	Advantage / Disadvantage
FAMCARE-6	6	For Busy Healthcare Environments. Used in Different Countries	Core Satisfaction Elements	+ Time-Efficient + Practical for Routine Use + Adaptable - Less Comprehensive
FAMCARE-P13	13	Outpatient	Patient-centered Quality of Life Focused	+ Direct Patient Feedback + Outpatient Validated - Limited Setting - Absent of Family Aspects

Remarks: (+) Indicate Advantage, (-) Indicate Disadvantage

Discussion

This comprehensive review of FAMCARE as a tool for measuring the effectiveness of end-of-life care reveals its significant contribution to the field of palliative care over the past three decades. The widespread adoption and adaptation of FAMCARE across various healthcare settings and cultural contexts underscore its value in assessing and improving the quality of end-of-life care from the family's perspective.

FAMCARE's multidimensional structure, encompassing key aspects such as information provision, availability of care, physical patient care, and psychosocial support, has provided a holistic framework for evaluating care quality. This comprehensive approach aligns well with the evolving understanding of palliative care as a multifaceted discipline that extends beyond symptom management to include psychosocial and spiritual dimensions of care (Ooraikul et al., 2020; Ringdal et al., 2003). The tool's ability to capture these diverse aspects of care has made it particularly valuable in identifying areas for improvement and guiding targeted interventions.

FAMCARE's strong psychometric properties support its credibility as both a research and quality improvement tool (Ooraikul et al., 2020). While high internal consistency and good construct validity confirm its reliability, factor structure variations across studies suggest cultural and contextual influences on care satisfaction dimensions (Chaumier et al., 2020; D'Angelo et al., 2017). This highlights the importance of careful consideration when adapting and interpreting FAMCARE in diverse settings.

FAMCARE's application across various healthcare settings, from hospices and hospital-based palliative care units to home-based care and long-term care facilities, has provided valuable insights into the unique challenges and strengths of different care models. The generally high satisfaction scores in hospice settings, for instance, affirm the effectiveness of the hospice model in responding to family needs (Aoun et al., 2010; Sia, 2019).

As a quality improvement tool, FAMCARE has demonstrated its effectiveness in driving meaningful changes in care delivery. Its use in evaluating communication skills training programs, care coordination initiatives, and psychosocial support services has led to tangible improvements in family satisfaction (Ooraikul et al., 2020). This underscores FAMCARE's potential not just as a measurement tool, but as a catalyst for enhancing the quality of end-of-life care.

Despite its strengths, several limitations of FAMCARE have been identified. The potential for ceiling effects, particularly in settings where satisfaction scores are consistently high, raises questions about the tool's sensitivity in discriminating between good and excellent care experiences (Carter et al., 2011; Neo et al., 2019). Additionally, the retrospective nature of FAMCARE administration in many studies introduces the possibility of recall bias, which may affect the accuracy of satisfaction ratings (Ringdal et al., 2003).

Conclusion and Suggestions

This narrative review of FAMCARE has demonstrated its significant contribution to the measurement and improvement of end-of-life care quality over the past three decades. As a psychometrically robust and widely adopted tool, FAMCARE offers valuable insights into family satisfaction across various healthcare settings, from hospices and hospitals to home-based care environments. Its multidimensional structure effectively captures crucial aspects of end-of-life care, including information provision, availability of care, physical patient care, and psychosocial support, enabling a holistic assessment of care quality from the family's perspective.

FAMCARE's strength is not only in its measurement capabilities but also in its proven utility as a quality improvement tool. Numerous studies have shown how FAMCARE data can drive meaningful improvements in care delivery, particularly in areas such as communication, care coordination, and psychosocial support. This dual function as both a research instrument and a practical tool for healthcare providers underscores FAMCARE's value in bridging the gap between evidence and practice in palliative care. The evidence reviewed suggests that FAMCARE should be considered as a gold standard for measuring family satisfaction with end-of-life care, particularly in oncology and hospice settings. Its robust psychometric properties, cross-cultural adaptability, and proven utility across diverse healthcare environments establish it as a leading instrument in this field.

Despite its many strengths, FAMCARE has few limitations. The potential for ceiling effects in some settings and the challenges associated with retrospective assessment highlight areas for future refinement. Additionally, the evolving landscape of healthcare delivery, with increasing emphasis on person-centered care and integrated care models, suggests a need for ongoing development of FAMCARE to ensure its continued relevance and effectiveness.

Suggestions

Based on the findings of this review, we propose the following suggestions for future research and application of FAMCARE:

1. **Systematic Follow-up Assessment:** Develop and validate methods for systematic post-care administration of FAMCARE at appropriate time intervals (e.g., following equipment return or within a specified period after patient death). This could involve integrating FAMCARE into healthcare documentation systems to ensure consistent and timely evaluations. Such approaches could provide valuable insights into family satisfaction while memories of care experiences are still fresh, allowing for more accurate assessment and meaningful quality improvement.

2. **Integration with Other Measures:** Investigate the potential for combining FAMCARE with other quality indicators, such as patient-reported outcomes, clinical quality measures, or cost-effectiveness assessments. This integrated approach could provide a more comprehensive evaluation of end-of-life care quality.

3. **Cultural Adaptations:** Further develop and validate culturally specific versions of FAMCARE, including the potential addition of culture-specific items or modules. This could improve the tool's global applicability and ensure culturally sensitive care quality assessment.

4. **Technology Integration and Digital Enhancement:** Future developments should explore digital versions of FAMCARE designed for mobile applications or web platforms, enabling real-time data collection and immediate analysis. Digital verification systems could streamline the consent process and ensure data integrity. More innovative applications could include AI-powered virtual assistants providing 24-hour support to families while simultaneously

gathering satisfaction data during these interactions. This approach would offer both continuous support beyond traditional care hours and capture authentic feedback in context rather than retrospectively. Such digital adaptations would increase accessibility, reduce administrative burden, and potentially improve response rates. Additionally, artificial intelligence and machine learning techniques could analyze FAMCARE data more comprehensively, identifying patterns that might not be apparent through conventional methods and predicting areas requiring intervention before satisfaction levels decline.

5. Policy Integration: Investigate ways to integrate FAMCARE or similar family satisfaction measures into national healthcare quality metrics and policy frameworks. This could elevate the importance of family perspectives in healthcare quality assessment at a systemic level.

By addressing these areas, future research can build upon the strong foundation laid by FAMCARE, further enhancing our ability to measure and improve the quality of end-of-life care from the crucial perspective of the family. As palliative care continues to evolve and expand globally, tools like FAMCARE will be instrumental in ensuring that care remains centered on the needs and experiences of patients and their families.

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