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Caregiver perceptions of the impact and effect of family conferences for patients with complex and high-level palliative care needs: a cross-sectional survey study

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Abstract

Introduction Family conferences (FC) are a structured and therapeutic tool in palliative care, promoting effective communication between the healthcare team, patient and family. They are especially relevant for patients with high clinical complexity, both in hospital settings and in primary care.

Objective To evaluate caregivers' perceptions of the impact of FC on patients cared for by palliative care teams and/or primary healthcare clinicians (PHC). This included measuring quality of care, communication effectiveness, interprofessional collaboration, successful implementation of care strategies, clarity of information received, and overall satisfaction and confidence. Secondary objectives were to assess caregivers' perceptions of the importance of FCs for their knowledge and attitudes/skills, and to evaluate their perception of the overall quality of care provided to the patient, including the concordance between desired and actual place of death as an indicator of effective end-of-life planning.

Methods Observational, analytical and cross-sectional study, with application of a specific questionnaire to caregivers of patients followed by a community palliative care team and a family health team. Sociodemographic and clinical variables and perceptions of the impact of FC on the understanding of the disease and its trajectory, on satisfaction and on the feeling of security and trust were analysed.

Results The total sample included 38 caregivers, of whom 20 were accompanied by a team specialized in palliative care and 18 by a family health team. There was a high percentage of female caregivers (78.9%), with a mean age of 58.1 years, and the mean age of patients was 80.7 years. FC was associated with improved perception of communication (9.36 ± 0.65), collaboration (9.50 ± 0.86) and implementation of care strategies (9.45 ± 0.83). The presence of professionals such as social workers and psychologists in the FC of the palliative care team associated with greater family participation ($p = 0.002$) and greater perceived support ($p = 0.001$). Among the patients who died, there was a significant correspondence between the desired and actual place of death ($p = 0.007$), demonstrating

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FC as a potential effective instrument for planning. The presence of more family members in the FC correlated with greater hospital use in the previous month ($p < 0.001$) and with greater case complexity.

Discussion Despite being an exploratory study with inherent limitations, FCs were perceived as effective in improving communication, planning and aligning care with patient and family preferences. Their regular implementation, especially in PHC, should be promoted with multidisciplinary teams and specific training.

Keywords Disease management, Home care, Primary care, Family care, Advance directives, End-of-life care, Family therapy, Caregiver

Introduction and objectives

Effective emotional and social support is paramount for individuals with palliative needs, extending also to their family members and caregivers. Lack of such support can significantly increase the complexity of a patient's care situation [1–4].

Family Conferences (FCs) are a structured therapeutic tool in palliative care, integrating the family as a core unit of care. They facilitate dialogue between the patient, family, and healthcare team, aiding emotional and functional adaptation when facing a serious and life-threatening illness [5–8].

Home-based care often places substantial emotional and physical demands on family caregivers [7]. Consequently, there is a critical need for health professionals, particularly family physicians, to provide clear information, emotional support, and facilitate active caregiver participation to mitigate stress and anxiety [9–11]. FCs are designed to clarify disease trajectories, personalize care plans, and strengthen communication [5, 12, 13].

FCs offer benefits like improved quality of care and dignified end-of-life processes [6, 13]. However, barriers persist, including lack of specific training, time constraints, and administrative challenges, hindering their systematic implementation [10, 12, 14, 15]. Effective FCs require strong doctor-patient-family relationships and multidisciplinary team support [10, 12], which can reduce suffering and improve psychological support [6, 12, 13, 16].

Despite these challenges, FCs are increasingly recognized in primary healthcare (PHC) for patients with complex chronic diseases, with a growing call for general practitioners to integrate families as active partners [14, 17, 18]. The systematic use of FCs in PHC presents unique opportunities to optimize patient outcomes.

Therefore, the main objective of this study is to evaluate caregivers' perceptions of the impact of Family Conferences (FCs) on patients cared for by palliative care teams and complex patients cared for by PHC and their families. This included measuring caregivers' perceptions regarding communication effectiveness, interprofessional collaboration, successful implementation of care strategies, clarity of information received, and overall satisfaction and confidence. Secondary objectives were to assess caregivers' perceptions of the importance of FCs for their knowledge and attitudes/skills, and to evaluate their perception of the overall quality of care provided to the patient, including the concordance between desired and actual place of death as an indicator of effective end-of-life planning.

Materials and methods

This was a descriptive, cross-sectional study conducted with patients either being cared for by community palliative care teams, or by those cared for by PHC teams, and their family members or caregivers. The main objective was to assess the family's perception regarding the care provided after FCs, through a questionnaire developed specifically for this study. This was an exploratory study, designed to generate hypotheses and identify associations, rather than to establish causal relationships.

The study population included caregivers of patients cared for by a Community Palliative Care Team (CPCT) and caregivers of patients cared for by a Family Health Unit (FHU). Both groups primarily received care in their home environments, reflecting the study's focus on the impact of family conferences in the home context for complex patients with high-care needs. No specific exclusion criteria were applied beyond those not meeting the inclusion criteria. The inclusion criteria used were: patients being monitored by the CPCT for more than a week, or, in the case of the FHU, being a dependent patient with a caregiver or family member responsible for continuous care, 24 h a day.

A Family Health Unit (FHU) in Portugal is an organizational model within the Primary Health Care (PHC) system. It comprises a multidisciplinary team (family physicians, nurses, administrative staff) responsible for providing comprehensive and continuous healthcare to a defined population. FHUs play a crucial role in health promotion, disease prevention, and treatment, often extending care to patients' homes, particularly for dependent individuals, thus aligning with the PHC mention in the introduction regarding complex patient management.

Recruitment was carried out among all eligible caregivers identified as users of the units involved. An *in-person* invitation to participate was extended, accompanied by a comprehensive explanation of the study's objectives. Participation was voluntary, preceded by informed consent

obtained *in person* by signing a specific form. In cases of significant cognitive impairment by the patient, the invitation to participate was addressed to their legal guardian. It was guaranteed that, under no circumstances, refusal to participate or failure to comply with the inclusion criteria would result in harm to the patients' usual health care. Caregivers were recruited primarily after family conferences (FCs) had taken place, typically during the patient's ongoing care. For patients whose journey ended with death, their caregivers were recruited retrospectively to gather perceptions regarding FCs conducted during the period of care. This approach ensured that perceptions on the impact of FCs, including those related to end-of-life planning, were captured. The study was carried out between December 2024 and June 2025.

Due to the nature of the direct recruitment approach within clinical settings, a precise calculation of the overall response rate (number of participants out of total eligible individuals approached) was not systematically recorded. This was primarily due to the pragmatic challenges of recruitment within busy clinical environments (community palliative care teams and family health units), where maintaining a real-time log of every potential contact and interaction was not feasible without disrupting patient care. The focus was on identifying suitable participants and ensuring their informed consent, rather than exhaustively tracking all non-participating eligible individuals.

Data collection occurred through the provision of a structured questionnaire (Appendix 1), provided to the patients' family members or caregivers after family conferences. This questionnaire was specifically developed *de novo* for this study, drawing upon a comprehensive review of existing literature on family conferences in palliative and primary care to ensure content relevance. It primarily comprised Likert-scale items to quantify caregivers' perceptions regarding communication effectiveness, interprofessional collaboration, successful implementation of strategies, clarity of information received, and overall satisfaction and confidence. Additionally, it included sections for sociodemographic and clinical variables. Prior to main data collection, a pilot version of the questionnaire was administered to 10 professionals (to assess expert consensus and content validity) and 10 patients/caregivers (to assess its clarity, comprehensibility, and feasibility in a real-world context). Feedback obtained during this pilot phase was instrumental in refining and adjusting the final version of the instrument.

The general null hypothesis tested was that there would be no significant association between caregivers' attendance and participation in family conferences and their perceptions of communication, collaboration, strategy implementation, or clarity of information, nor on the quality or impact of care provided.

The statistical analysis involved descriptive statistics (absolute and relative frequencies, means and respective standard deviations) and inferential statistics. All analyses were exploratory and hypothesis-generating, aimed at improving understanding of how FCs influence care processes in different settings. In this, the Chi-square test of independence, Fisher's test, Mann-Whitney test, Kruskal-Wallis test, Pearson's correlation coefficient and Spearman's correlation coefficient were used. The normality of distribution was analyzed using the skewness and kurtosis. The Chi-square assumption that there should be no more than 20% of cells with expected frequencies below 5 was analyzed. In situations where this assumption was not met, the Chi-square test by Monte Carlo simulation was used. The differences were analyzed with the support of standardized adjusted residuals. Absolute values are presented throughout the tables and text to illustrate the magnitude of observed differences and associations, providing a clearer understanding of their practical significance. Given the exploratory nature of this study and the potential for baseline differences between groups, interpretation of findings should consider these contexts. The significance level for rejecting the null hypothesis was set at $\alpha \leq 0.05$, with careful consideration of statistical power implications for an exploratory design. Statistical analysis was performed using SPSS (Statistical Package for the Social Sciences) version 29.0 for Windows.

Results

The sample consisted of a total of 38 participants ($N = 38$), comprising 20 caregivers of patients cares for by a CPCT in the northern region of Portugal and 18 caregivers of patients dependent on a Family Health Unit (FHU) in the central region of Portugal.

As can be seen in the sociodemographic characterization (Table 1), the average age of the caregivers was 58.1 (± 12.8) years, with the majority being female (78.9%). The average age of the patients was 80.7 (± 11.5) years, with a predominance of males (63.2%). In terms of caregiver education levels (Table 1), '4th', '6th', and '9th' refer to primary and lower secondary education; '12th' signifies upper secondary education; and 'College degree' and 'Master degree' denote tertiary education.

Statistically significant differences were observed between the groups (Table 1) in terms of caregiver educational level ($p = 0.006$), with the 6th year of education being more frequent in the FHU group (22.2%) and a bachelor's degree in the CPCT group (35.0%).

Concerning clinical diagnosis of patients, a significant difference was also observed ($p = 0.006$), with a higher prevalence of oncological diagnoses in the CPCT (60.0%) and dementia in the FHU (33.3%).

The presence of different professionals varied significantly between the groups, with a systematic presence

Table 1 Sociodemographic and clinical characterization of the sample

	CPCT		FHU		Sample		
	N	%	*N*	%	*N*	%	*p*
Caregiver age (A)	55.7	12.9	60.7	12.5	58.1	12.8	
Patient age (A)	76.6	13.6	85.4	6.3	80.7	11.5	
Caregiver sex							1.000
Female	16	80.0%	14	77.8%	30	78.9%	
Male	4	20.0%	4	22.2%	8	21.1%	
Caregiver education							**0.006**
4th	2	10.0%	5	27.8%	7	18.4%	
6th	0	0.0%	4	22.2%	4	10.5%	
9th	4	20.0%	3	16.7%	7	18.4%	
12nd	5	25.0%	6	33.3%	11	28.9%	
College degree	7	35.0%	0	0.0%	7	18.4%	
Master degree	2	10.0%	0	0.0%	2	5.3%	
Caregiver kinship							0.238
Spouse	4	20.0%	4	22.2%	8	21.1%	
Daughter	9	45.0%	9	50.0%	18	47.4%	
Son	0	0.0%	3	16.7%	3	7.9%	
Husband	5	25.0%	1	5.6%	6	15.8%	
Daughter-in-law	2	10.0%	1	5.6%	3	7.9%	
Patient's sex							0.503
Female	6	30.0%	8	44.4%	14	36.8%	
Male	14	70.0%	10	55.6%	24	63.2%	
Patient main diagnosis							**0.006**
Stroke	0	0.0%	2	11.1%	2	5.3%	
Dementia	5	25.0%	6	33.3%	11	28.9%	
COPD	0	0.0%	2	11.1%	2	5.3%	
Hearth failure	3	15.0%	4	22.2%	7	18.4%	
Oncological disease	12	60.0%	2	11.1%	14	36.8%	
Osteoarticular	0	0.0%	2	11.1%	2	5.3%	
Patient clinical complexity							0.485
Mild-Moderate	7	35.0%	4	22.2%	11	28.9%	
High	13	65.0%	14	77.8%	27	71.1%	

CPCT Community Palliative Care Team, *FHU* Family Health Unit, *p* significance, *A* average, *N* number, % percentage, *COPD* Chronic Obstructive Pulmonary Disease

Table 2 Patients who died and patients who remain alive and their functionality on the day of the family Conference, caregivers and family members available and number of visits to the hospital

Variable	Still alive (*n* = 21)	Death (*n* = 17)	*P*
PPS	36.19 ± 15.96	24.71 ± 8.74	**0.031**
Number of visits to the hospital in the last month	0.71 ± 0.90	3.71 ± 1.16	**0.001**
Number of family caregivers	0.33 ± 0.91	1.76 ± 0.97	**0.001**
Number of family members in FC	1.29 ± 0.90	2.41 ± 1.06	**0.001**

n number, *p* significance, *PPS* Palliative Performance Scale, *FC* family conference

of a social worker and a psychologist in the CPCT family conference ($p < 0.001$).

In the total sample, 44.7% of the patients died, all cares for by the CPCT.

Table 2 shows the patients who died and those who are still alive, assessing their functionality and prognosis (by Palliative Performance Scale (PPS)) at the time of the FC, the number of visits to the hospital in the month preceding the family conference (FC) (question no. 6.1 of the questionnaire) and number of family members and caregivers present at the FC.

The PPS of patients who died was significantly lower than that of those who remained alive ($p = 0.031$). Of those who remained alive, the mean PPS value was 31.05 (± 14.29), with no statistically significant differences between patients followed by the CPCT and those followed by the FHU ($p = 0.239$). As previously defined in the Methods section, FHU (Family Health Unit) is the organizational model for Primary Health Care in Portugal.

The number of hospital visits in the month before the FC was significantly higher in patients who died ($p = 0.001$).

Patients who died ($n = 17$) had a greater number of family caregivers (1.76 ± 0.97; $p = 0.001$) and a greater

Table 3 Significant correlations between perception variables (Total Sample)

Correlated variables	Coeficient (*r*)	*p*
Q8 × Q1 (participation × utility)	0.939	**< 0.01**
Q8 × Q3 (participation × collaboration)	0.968	**< 0.01**
Q8 × Q4 (participation × resolution)	0.914	**< 0.01**
Q8 × Q5 (participation × strategies)	0.974	**< 0.01**
Q7 × Q5 (clarity × strategies)	0.957	**< 0.01**
Q6.1 × number of family members present	0.727	**< 0.001**
Patient age × family members	−0.326	**0.046**

Q question of the questionnaire (Annex 1), *p* significance

number of family members present at the FC (2.41±; 1.06; $p = 0.001$).

Table 3 shows the questions included in the questionnaire that had statistical significance.

In the analysis strong and significant associations were observed ($p < 0.01$) between the presence of the caregiver in the FC (Q8 - Caregiver Presence/Participation in FC) and the perception of effectiveness in problem-solving (Q4 - Effectiveness in Problem-Solving), the successful implementation of discussed strategies (Q5 - Implementation of Discussed Strategies) and the increase in collaboration in care (Q3 - Collaboration in Care), as well as between the perception of implementation of strategies (Q5) and the improvement in the clarity and understanding of information (Q7 - Clarity and Understanding of Information).

A significant association was observed between the place of death and the desired place (χ^2 (2) = 11.694; p = 0.007), with death at home being more frequent among patients who expressed this preference.

The existence of an informal caregiver was associated with the participants' level of education ($p = 0.041$), being more prevalent among caregivers with a 6th grade education.

The total number of family members present at the FC correlated positively with the number of visits to the hospital in the month prior to the FC (rsp = 0.727; $p < 0.001$) and negatively with the patient's age (rsp = −0.326; $p = 0.046$). The number of family members present was also significantly higher when the social worker was present ($p = 0.002$) and in cases where the patient ended up dying ($p = 0.001$).

Regarding diagnosis, patients with oncological pathology had a higher frequency of death (78.6% vs. 27.3% with dementia; $p = 0.041$), lower mean age (70.71 ± 11.71 vs. 88.91 ± 6.76 with dementia; $p = 0.001$), greater number of family caregivers (1.64 ± 1.08 vs. 0.29 ± 0.49 with heart failure; $p = 0.005$), and greater number of family members present at the FC (2.29 ± 1.14 vs. 1.00 ± 0.00 with osteoarticular diagnoses; $p = 0.015$).

Finally, the presence of a social worker was associated with a significantly higher number of hospital visits in the month before ($p = 0.001$) and in the month after the family conference ($p = 0.035$). Likewise, the presence of a psychologist was associated with a higher number of hospital visits in the month before the conference ($p = 0.001$).

Discussion

This study suggests that FC are an effective tool in approaching complex patients in the home context, reflecting positive impacts on caregivers' perception, care planning and congruence between preferences and clinical outcomes.

The significant differences found between the CPCT and FHU groups, namely in the clinical and sociodemographic profile of patients, reveal two distinct realities of action. The CPCT mainly supports patients with an oncological diagnosis and limited prognosis, reflected by the higher death rate (85%) and lower PPS, which is in line with the literature that associates palliative care teams with advanced stages of the disease [5, 19, 20]. The FHU, on the other hand, predominantly supported frail elderly people with chronic diseases, with a more longitudinal and less specialized profile, with no record of deaths during the study period.

The high number of family caregivers and relatives present in the FC in cases of patients who died during the study period (December 2024 - June 2025), especially in cancer patients, reflects the mobilization of support networks in times of greatest emotional demand, as also observed by Moraes et al., who highlight the increased burden on caregivers in terminal phases [8]. Our study found that where a social worker and psychologist was present in a FC, families felt better supported and informed. This association is consistent with studies that demonstrate that multidisciplinary teams improve care coordination, communication and the caregiver experience [5, 9, 21].

In the case where the endpoint was death, the significant correlation between the place of death and the place previously desired by the patient (p = 0.007) reinforces the effectiveness of FC as an instrument for advance care planning. This congruence is widely recognized as an indicator of quality in palliative care, promoting dignity and respect for patient autonomy [10, 12].

Another relevant finding was the negative correlation between the patient's age and the number of family members present, suggesting that, at older ages, support networks become less available or more fragile. This reinforces the need for strategies involving the community and social services to overcome loneliness and lack of support [8, 14].

The association of variables such as collaboration, problem-solving and implementation of strategies with the presence of caregivers in the FC confirms the perception of effectiveness and improvement of care. These

results are in line with the studies by Hudson et al., Cahill et al. and Bajt et al., which indicate that well-structured FC reduce anxiety, improve health literacy and favour more shared decisions [9, 12, 15, 22].

However, as identified by Dev et al. (2013), the presence of the patient in the FC may limit the emotional expression of caregivers and family members, for fear of aggravating the patient's suffering [7].

While patient involvement is crucial for promoting autonomy, ensuring shared decision-making, and achieving alignment of care goals with the patient's explicit values and preferences [7, 16], caregivers often self-censor their concerns, fears, or burdens when the patient is present. This protective instinct, or a desire to maintain hope and avoid exacerbating patient distress, can hinder their own emotional processing and the comprehensive assessment of their needs [22, 23]. Enabling a robust caregiver voice is therefore paramount for holistic care, even when patients participate.

Our study, while not directly measuring emotional expression in the presence vs. absence of the patient, found that the presence of social workers and psychologists in the CPCT's FC was significantly associated with greater family participation ($p = 0.002$) and greater perceived support ($p = 0.001$). This highlights that a multidisciplinary approach, particularly with psychosocial professionals, is critical for skilled facilitation. These professionals can navigate complex emotional dynamics, create a psychologically safe space where caregivers feel empowered to express their needs, and integrate both patient and caregiver perspectives, thereby ensuring a more holistic goal alignment and strengthening the overall effectiveness of the FC, which aligns with their perceived value for collaboration and communication.

When adequately structured and supported by multidisciplinary teams, FCs not only increased caregiver satisfaction but also contributed to reducing unplanned hospitalizations, as indicated by the significant decrease in hospital visits before and after FC in patients who died, reflecting greater care intensity in the month prior to death. These results are in agreement with Dev et al. and Werdhani et al. [5, 17, 21].

Study limitations: This study presents inherent baseline differences between the CPCT and FHU groups, derived from their distinct patient inclusion criteria and care profiles. These differences mirror real-world clinical settings but may limit the direct comparability of some variables between groups.

As an exploratory study with a relatively small sample size, no a priori power calculation was performed. Additionally, no reliable method exists for sample size estimation when using perception-based or non-validated composite questionnaires such as the one applied in this study. Consequently, the study may lack sufficient statistical power to detect smaller but clinically relevant differences or correlations.

Given the exploratory nature of this study and the small sample size, no formal correction for multiple comparisons was applied. Such corrections could be excessively conservative and may obscure potentially meaningful trends in this type of preliminary analysis. Consequently, some of the reported associations may represent chance findings, and all results should therefore be interpreted as exploratory and hypothesis-generating. Given the limited sample size, no multivariable analysis was performed, as the study was exploratory and aimed at hypothesis generation rather than causal inference.

These exploratory findings provide valuable initial insights into caregiver perceptions of FCs, highlighting areas for potential intervention and laying the groundwork for more rigorous, confirmatory research.

Conclusions

Based on caregiver perceptions, this exploratory study suggests that FCs are a well-received and valuable tool for caregivers and family members. Participation in FC was linked to better teamwork, clearer communication, and more effective care strategies, with a strong alignment between patients' preferred and actual place of death, highlighting its positive impact on end-of-life care planning.

FC implementation has the potential to improve caregivers' and patients' understanding of needs and enhanced family members' perception of care quality, fostering stronger alignment with the health team and greater confidence in the therapeutic plan, especially when supported by psychosocial professionals. Strengthening health literacy, training teams to conduct these meetings and their systematic inclusion in the follow-up of complex patients should be considered as priorities in the organization of palliative care and primary health care.

While these exploratory findings are promising, further research, with larger samples and longitudinal designs, is warranted to confirm these associations and establish causality.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12904-025-01978-x.

Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions
Conceptualization, A.N. and H.R.; methodology, A.N., J.B.S. and H.R.; software, D.C., J.R.N.; validation, C.P., V.S. and J.R.N.; formal analysis, J.P.A. and H.R.; investigation, A.N. and H.R.; resources, A.N. and H.R.; data curation, J.B.S. and J.R.N.; writing—original draft preparation, A.N. and H.R.; writing—review and editing, J.B.S., D.C., I.R., C.P., V.S., J.R.N., M.D. and H.R.; visualization, C.P., V.S., J.P.A. and M.D.; supervision, H.R.; project administration, H.R.; funding acquisition, H.R., J.P.A. and J.R.N.

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Data availability
under reasonable request.

Declarations

Ethics approval and consent to participate
The study protocol was reviewed and approved by the Ethics Committee of the Faculty of Medicine of the University of Coimbra (FMUC) under reference number CE-172/2024, following a meeting held on 20 November 2024. All procedures were conducted in strict accordance with the ethical principles outlined in the World Medical Association's Declaration of Helsinki (2013 revision) and complied with European legislation on personal data protection, specifically Regulation (EU) 2016/679 (General Data Protection Regulation – GDPR). Prior to participation, all individuals received comprehensive information about the study and provided written informed consent. Participation was entirely voluntary, and participants were assured that refusal to participate would not affect their care.

Consent for publication
Not applicable for participants. All authors have read and agreed to the published version of the manuscript

Competing interests
The authors declare no competing interests.

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