End-of-life care by specialist palliative care teams: 10-year retrospective satisfaction evaluation

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► Additional supplemental material is published online only. To view, please visit the journal online (https://doi.org/10.1136/spcare-2025-005396).

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Received 18 January 2025
Accepted 12 November 2025

ABSTRACT

Background The Association for Palliative Medicine (APM) ran a national Specialist Palliative Care (SPC) service evaluation from 2013, using the Family Satisfaction with End-of-Life Care (FAMCARE-2) questionnaire to measure the satisfaction of bereaved main caregivers with SPC services.

Aim This feature article reviews ten years of the FAMCARE-2 audit (2013–2022), summarising data from bereaved carers via SPC teams alongside a one-off survey involving the service leads.

Results During the decade, 573 SPC teams across the UK returned 12 573 completed FAMCARE-2 questionnaires, representing 160 SPC services, with a mean of 1048 questionnaires per annum (804–1668). Responses spanned three settings: hospice (48%), home (39%) and hospital (13%). Bereaved caregivers reported highest satisfaction for patients' dignity; 92.2% of respondents were satisfied, while dissatisfaction was highest with the speed deceased patients' symptoms were treated (6.2%). There was no significant difference in satisfaction rate between different SPC teams (home, hospital, hospice) with limited year-to-year variation in responses (Kruskal-Wallis test η2: −0.17).

Participation by community-based home care teams increased during the 10-year period, but reduced for hospital specialist teams. The number of questionnaires returned decreased by 40%.

Notably, of those responding to the one-off survey, 90% of services found FAMCARE-2 valuable for learning, inspection or reflective practice.

Conclusion Bereaved caregivers consistently expressed satisfaction with SPC services across settings over the 10-year period. Despite limited applicability of findings due to annual decline in participation and lack of demographic data, FAMCARE-2 remains the only nationally used tool for evaluating SPC in the UK.

WHAT WAS ALREADY KNOWN?

⇒ Caregivers play a key advocacy role during a patient's final weeks.

⇒ Family Satisfaction with End-of-Life Care (FAMCARE-2) is a validated tool used annually since 2013 by the Association for Palliative Medicine to assess bereaved families' experiences with palliative care in the UK and Ireland.

WHAT ARE THE NEW FINDINGS?

⇒ Over the 10-year period, 12 573 responses showed high overall satisfaction.

⇒ Small but significant increase in dissatisfaction with some aspects of care, with decreasing returned questionnaires.

WHAT IS THEIR SIGNIFICANCE?

a. Clinical: FAMCARE-2 supports clinical evaluation, governance, benchmarking and inspection in Specialist Palliative Care services.
b. Research: Limited uptake, especially in hospital settings, suggests FAMCARE-2 may be outdated and replaced by broader national audits.

INTRODUCTION

Retrospective evaluation of care delivered towards the end of a person's life is a common means of assessing the quality of death and dying.[1] Tools such as the Family Satisfaction with End-of-Life Care (FAMCARE-2), the National Audit of Care at the End of Life (NACEL), the Quality of Dying and Death questionnaire, The National Survey of Bereaved People Views of Informal Carers (VOICES) Evaluation of Services, the Family Perceptions of Care Scale, and the Care of the Dying Evaluation (have been used to explore patient and carer experiences of Specialist Palliative Care (SPC) provided towards the end of life (see online supplemental file).[2–4] Feedback from these tools can shape the delivery

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► https://doi.org/10.1136/spcare-2025-005460

To cite: Karakitsiou D-E, Abarshi E, Grundy A, *et al. BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/spcare-2025-005396

of subsequent care or at least provide assurances as to whether clinical performances correlate with patient or carer satisfaction.

In 1993, the FAMCARE assessment tool was validated[5] as a 20-item questionnaire for care of outpatients receiving oncology treatment. It was successfully used in Australia[6 7] and in parts of North America, Europe and India. Another version, FAMCARE-2, was thereafter validated for bereaved caregiver satisfaction of SPC services until death.[8]

FAMCARE-2 comprises 17 questions with four categories or aspects of care; management of physical symptoms and comfort, patient care and sharing information, symptoms and side effects, and family and patient support (see table 1).

In 2013, the Association for Palliative Medicine of Great Britain and Ireland (APM) offered its members subsidised participation in the FAMCARE-2 annual audit, focusing mainly on service evaluation. The goals of the APM at the time were to;

1. Generate clinically relevant data on the provision of end-of-life care by SPC services
2. Provide data to support consultant appraisal and revalidation and
3. Provide data to support service development and commissioning.

After a decade of use, the APM undertook this review to determine how effective the annual FAMCARE-2 service evaluation had been in achieving its initial goals, to identify patterns in responses across the years (and across settings), and to highlight and overcome challenges encountered with running the process.

METHODS

The APM FAMCARE-2 audit process

APM's FAMCARE-2 audit was advertised via social media and via the APM bulletin at approximately the same time (usually April), every year. SPC services wishing to participate were registered via a designated audit Lead, who required APM membership. The leads were sent guidance on the audit process and blank FAMCARE-2 questionnaires, alongside pre-addressed stamped envelopes for their return on completion. Within a SPC, the audit may have been completed by either a community Home Care (HC) team, a Hospital Support Team (HST) and/or a Hospice Inpatient Unit (IU).

Participating teams sent out the FAMCARE-2 questionnaire to a list of all bereaved carers, henceforth referred to as carers, of patients who had benefitted from SPC input during a 3 month period prior to their death. This was typically 4–8 weeks after the patient had died. Consent was assumed or implied if the sent questionnaire was filled and returned back to the APM secretariat. Respondents were asked to rank different aspects of the deceased patient's care leading up to death, using a 6-item Likert scale of 'very satisfied', 'satisfied', 'neither satisfied nor dissatisfied', 'dissatisfied', 'very dissatisfied' or 'not relevant'. Identifiable data for both the deceased patients and the bereaved carers were not collected, although the APM secretariat held data on services and organisations that provided SPC across the country. Responses were analysed annually. The response rate was the number

Table 1 A compilation of 'very satisfied' and 'very dissatisfied' percentage responses per 17 questions of the FAMCARE-2 questionnaire over 10 years

FAMCARE-2 question and aspect of care	Very satisfied scores		Very dissatisfied scores	
	Lowest	Highest	Lowest	Highest
1. The patient's comfort	67.1%	72.2%	1.0%	5.7%
2. The way in which the patient's condition and likely progress has been explained by the palliative care team	59.8%	69.4%	1.7%	5.2%
3. Information given about side effects of treatment	40.8%	47.2%	1.3%	4.4%
4. The way in which the palliative care team respected the patient's dignity	79.4%	84.0%	0.8%	5%
5. Meetings with the palliative care team to discuss the patient's condition and plan of care	58.9%	66.5%	2%	6.1%
6. Speed with which symptoms were treated	57.5%	65.2%	1.7%	5.8%
7. Palliative care team's attention to the patient's description of symptoms	57.3%	63.9%	1.0%	5.5%
8. The way in which the patient's physical needs for comfort were met	66.5%	74.6%	1.2%	5.6%
9. Availability of the palliative care team to the family	61.5%	70.0%	2.0%	6.3%
10. Emotional support provided to family members by the palliative care team	61.0%	67.5%	2.0%	5.5%
11. The practical assistance provided by the palliative care team (eg, bathing, home care, respite)	50.2%	53.6%	1.1%	5.1%
12. The doctors' attention to the patient's symptoms	53.4%	61.9%	1.9%	5.4%
13. The way the family was included in treatment and care decisions	59.5%	68.7%	1.9%	6.0%
14. Information given about how to manage the patient's symptoms (eg, pain, constipation)	49.4%	57.7%	1.6%	5.2%
15. How effectively the palliative care team managed the patient's symptoms	61.0%	70.8%	1.5%	5.8%
16. The palliative care team's response to changes in the patient's care needs	63.6%	71.1%	1.9%	6.3%
17. Emotional support provided to the patient by the palliative care team	59.5%	67.4%	2.0%	5.9%

of completed questionnaires returned before the deadline, divided by the number of questionnaires each service sent out. Figure 1 shows the timeline for the annual FAMCARE-2 audit.

At the outset, FAMCARE-2 questionnaires were made available to participating services at no cost. However, due to the rising cost of administering the audit (overall postage cost, secretariat time, data computing services and so forth), a standard administration fee was later applied for participation.

The National Research Ethics Committee deemed the FAMCARE-2 audit was primarily for service evaluation; hence, local research ethics committee approval was not required. That said, services were expected to seek organisational approval as per routine practice.

In 2018, following the introduction of the Data Protection Act in the UK, the APM requested advice from a compliance team (Crimson Crab) on how to best implement the General Data Protection Regulation (GDPR) with the ongoing data collection. The annual audit passed the legitimate interest test given its perceived benefit to patients, and non-inclusion of bereaved carer details for the audit was thought permissible at the time. A GDPR privacy notice was sent to all participating services, along with registration documents, and further guidance was uploaded on the APM website. In addition, services were advised to provide protection of privacy information and fair hearing processes on their websites, thereby offering bereaved carers the opportunity to opt out if they wanted to.

The FAMCARE-2 10-year review process

The team evaluated 10 years' worth of FAMCARE-2 questionnaire responses made by bereaved family carers, identifying emerging themes and trends. From each FAMCARE-2 question, the percentages of responses were calculated, ranked from 'very satisfied' to 'very dissatisfied', and analysed across the 10-year period using Microsoft Excel.

In 2023, a one-off survey was conducted to list audit leads who themselves had served as links between the carers and the APM secretariat, to determine how their services had used FAMCARE-2 results annually, and to explore their perception of the audit's strength, weakness and future direction.

Statistical analysis

Kruskal-Wallis H-test was used to establish the presence of statistically significant differences between the three different service types or settings (IU, HC, HST) and the independent variables.

Kruskal-Wallis H-test is a non-parametric statistical test, used to determine the presence of statistically significant differences between medians of three or more independent groups, or between data that is ordinal and not normally distributed. It was conducted on combined datasets and on the 17 FAMCARE-2 questions and compared differences per service type (Hospice, Hospital, Community), and per year of the audit.

RESULTS

Participating specialist palliative care teams and services organisation

A total of 573 SPC teams participated in APM's FAMCARE-2 annual audit, via 160 different SPC services. The teams comprised 222 at home (39%), 274 in hospices (48%) and 77 in a hospital setting (13%)—see figure 2. Some services participated in more than one audit within the 10-year period, but no single team participated in all of the ten audits.

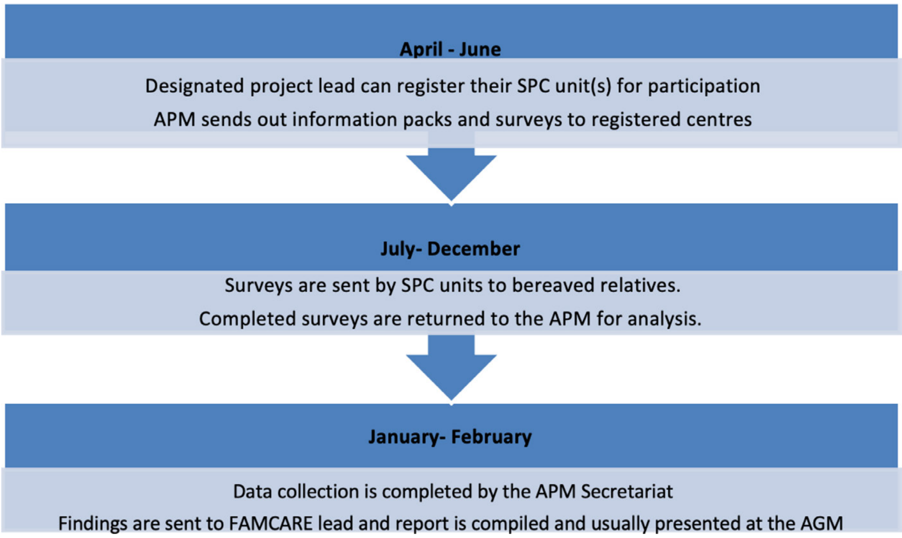

Figure 1 Estimated timeline for the annual FAMCARE-2 service evaluation. APM, Association for Palliative Medicine; FAMCARE, Family Satisfaction with End-of-Life Care; SPC, specialist palliative care.

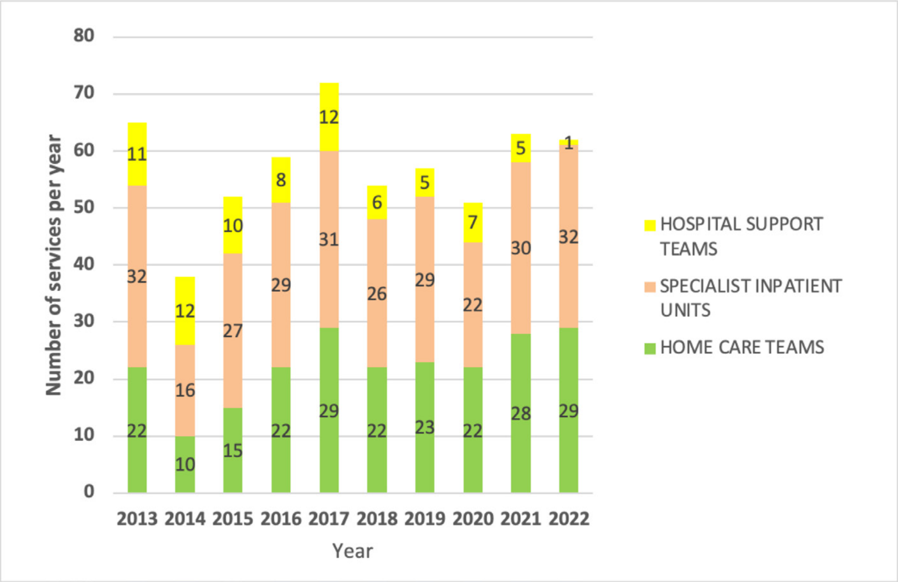

Figure 2 Numbers and settings of participating specialist palliative care services by year.

The highest participation recorded was by Hospice Units and the lowest by HSTs (see figure 2), with a mean of 27 IU, 22 HC and 7 HST teams per year.

In 2014 and 2020, the total number of participating SPC teams dropped to 38 and 51 respectively. Overall, the data showed an increase in the number of HC services that participated over the 10-year period, showcasing a steady pattern of Hospice IUs participation and a gradual decline in HSTs participation. Participation by Hospital Teams reduced markedly after 2018.

Participating bereaved carers

Of the 12 573 FAMCARE-2 returned questionnaires, with a mean of 1048 questionnaires per annum (804–1668). The highest number of completed questionnaires was recorded in 2017 (1668) and the lowest in 2014 (806)—see figure 3.

Service evaluation results

Over the audit period, we observed a gradual decline in response rates across all three service types, marking a 40% decrease in the number of questionnaires from IU and HC, and a 50% decrease from HST. Higher response rates were more often recorded by the IU teams (mean: 48.5 %, range: 34%–72.4%)—see figure 4.

Responses which were ‘very satisfied’ and ‘very dissatisfied’ are shown below—see table 1.

Care dimensions for which the carers reportedly were ‘very satisfied’ included (in >70% of cases); patient’s comfort (Q1), symptom management

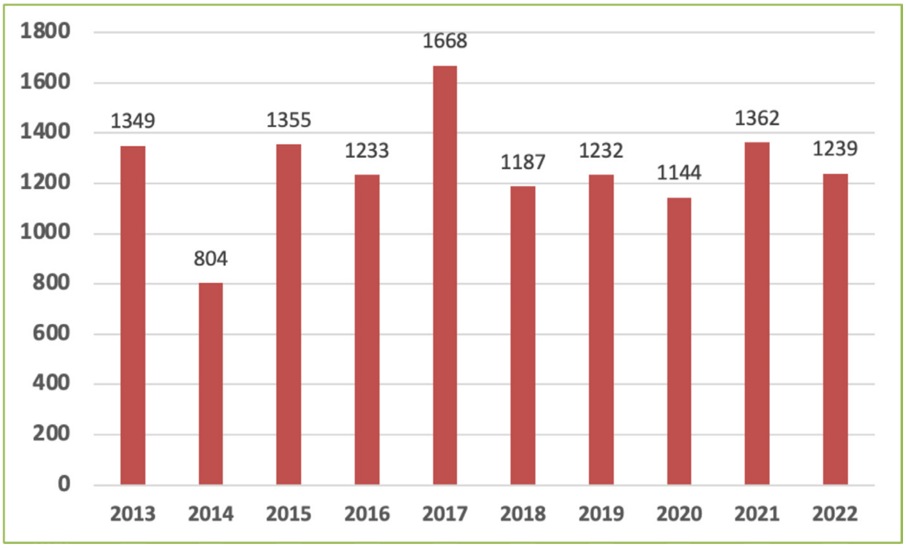

Figure 3 Number of Bereaved Carer responses returned by year.

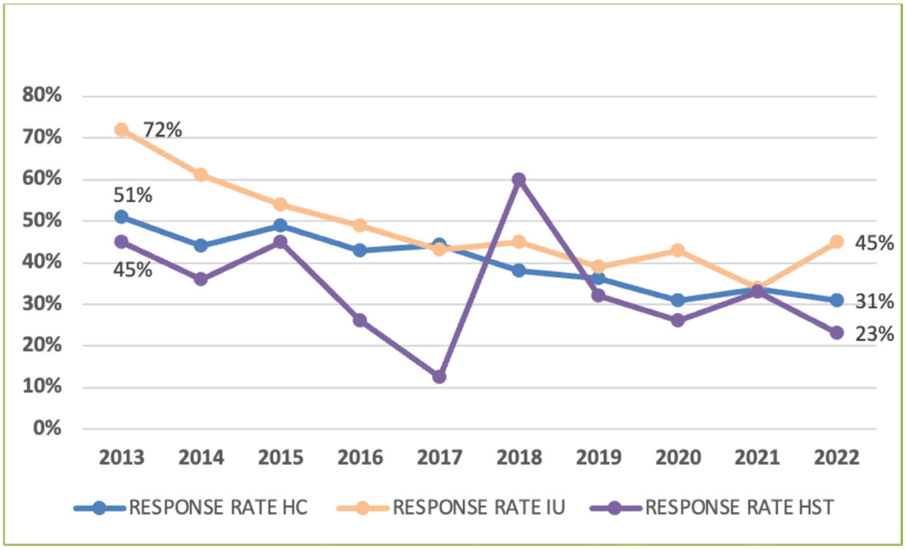

Figure 4 Response rate by setting of participating specialist palliative care teams by year. HC, HC; HST, Hospital Support Team; IU, Inpatient Unit.

(Q8), communication with SPC team (Q2), inclusion (Q13) and respect of patient's dignity (Q4)—see table 1.

The aspects of care that generated higher 'very dissatisfied' scores included the SPC team's response to the changes in the patient's care needs (Q16), family inclusion in treatment and care decisions (Q13), availability of SPC teams to the family (Q9) and meetings to discuss the patient's condition and plan care (Q5)—see table 1.

Overall, 'satisfaction' by the availability of SPC teams (Q9) remained high over the ten-year period (average 85.7% across all settings). Notable is the year-to-year variation and perception of SPC availability, with an increase in 'very dissatisfied' responses: from 2.6% in 2013 to 6.3% in 2022.

Overall, 'dissatisfaction' increased in patients' care needs (Q16) from 3.9% in 2013 to 7.9% in 2022, alongside dissatisfaction with practical assistance (Q11) from 2.14% to 6.3% during the decade.

Most carers found the FAMCARE-2 questions 'relevant' to them, although 9% reported 'not relevant' (across all settings, across the 10-year period). And 26% reported 'provision of practical assistance' (Q11) 'not relevant' to them with the following breakdown across settings: 17% (IU), 40% (HST) and 21% (HC).

In addition, 19% of carers (range: 16.4%–21.9%) reported the 'information about treatment side-effects' (Q3) 'not relevant'—with a similar pattern across services, over the 10 years.

There were subtle changes in how well patients' physical needs for comfort were met (Q8) and a gradual rise in 'very dissatisfied' responses for Q8, from 1.2% in 2013 to 5.1% in 2022.

Results from the one-off survey of FAMCARE-2 service users

From the 40 services that received surveys regarding their experience with FAMCARE-2, 20 audit leads responded to the survey; that is, 50% response rate. Of these, 18 respondents (90%) had registered an Inpatient Hospice Unit, 15 respondents (75%) had registered a HC team, and one respondent (5%) had registered a HST for participation in FAMCARE-2.

A similar pattern of FAMCARE-2 uptake was observed across SPC services as a whole.

Approximately 90% reported they had found the FAMCARE-2 annual audit 'valuable', 5% reported 'limited value' and 5% were unsure—stating it was their 'first year of participation'.

Although most services (90%) wanted to continue with the FAMCARE-2 annual audit, 5% reported they had 'considered stopping', and 5% were 'unsure'.

Responding services acknowledged participation in NACEL (50%), other national audits (30%) and internal audits such as Race inequalities, VOICES, National EOLC survey (Ireland) and the Marie Curie audit (40%). In the open-ended question section, 3 of the 20 respondents reported the FAMCARE-2 questionnaire had been 'repetitive', 'overlapping' and 'outdated'. Further exploration was not possible, as characteristics of the carers, the SPC practitioners and the audit leads were not collected.

DISCUSSION

Services need a validated assessment for clinical results, to monitor care provided across medical, nursing and allied healthcare streams. The APM started the annual FAMCARE-2 audit with the aim of producing data on the quality of end-of-life care by SPC services, support consultant appraisal and revalidation, and encouraging service development and commissioning. This audit remains the only UK-wide nationally run SPC service evaluation tool that has explored patient experiences of SPC services, using bereaved carers, who are often family members, as proxies.

The annual audit reflects voices of bereaved family carers across three core SPC settings in the UK. Ten years and over 12 500 FAMCARE-2 questionnaires were returned by 573 participating SPC teams (from 160 SPC services). While no single team participated every year, many came back repeatedly—suggesting a commitment to knowing what worked and what was not potentially working.

Of the 3 categories of care settings, the hospice-based teams participated most frequently, averaging 27 SPC teams per year, an equivalent of more than 200 hospices in the UK.[9] The uptake of FAMCARE-2 by SPC teams was consistent, though reducing over time, with an average of 57 participating services per year (ranging 38–72). The reduction, since 2017, coincided with the introduction of NACEL. But even if a good uptake was to be guaranteed across the hospital palliative care services, in general SPC teams are unlikely to participate in more than one national audit per year, given their increasing workload across the country.

Limitations of the annual audit

Undoubtedly, inability to explore demographics of deceased patients and bereaved participants who engaged in the FAMCARE-2 audit from the onset was a limitation, just as with the national VOICES bereaved family survey.[10] And although this had been due to the need for anonymity and confidentiality, simply not knowing the characteristics of the bereaved carers meant that patient characteristics of those who took part versus those who declined were also unknown. Hence, the generalisability of the results, or comparability with similar patient and carer groups, could not happen.

Meanwhile, the level of overall dissatisfaction responses for the 10-year was consistently low (below 8%) across all years and settings. A notable trend was the small but steady increase in the number of 'very dissatisfied' ratings, and a corresponding reduction in 'satisfied' ratings. This shift may again be due to an increase in public dissatisfaction with the NHS since 2014.[11 12]

With regard to the tool, the questions themselves have not been updated to reflect a change in the composition of SPC teams (ie, increasing specialist nurse-led input), and it is not possible to amend its current form being a validated tool. Now, other tools used to assess family/caregiver grief, family attendance in hospital and in-patient units are likewise varied and one could speculate their role in the assessment of HC deaths. However, Kupeli and colleagues argue that the accuracy of even the best tools can be distorted by grief.[13] Hence, for clinicians involved in end-of-life care, assessing family caregiver issues during the dying process may be the pragmatic option.[13] That said, FAMCARE-2 can improve by reasonable adjustments to ensure greater accessibility, that is, digitally, over the phone or with an interpreter.

Now, the retrospective nature of proxy feedback on care has inbuilt biases, including the potential for recall bias of patient symptoms. Also, snapshot surveys may not aptly capture the complexities of respondents' grief.[14] One could ask, is feedback from family/caregivers 4–8 weeks after a patient's death the best way to assess patient comfort during the dying process? And so, while 90% of services that responded to the survey found the FAMCARE-2 tool valuable, there is an obvious need for more research into this dimension of SPC.

Non-specific barriers to participation were staff time and cost, which understandably were not explored in any detail. For instance, would the team leads representing the audit themselves have had enough 'protected time', away from their clinical duties, to identify carers, and thereafter, to manually process incoming questionnaires. And regarding cost, it is unclear whether the need for mandatory APM membership affected participation in any way.

Themes and trends

What went well?

Across the 17 questions on the FAMCARE-2 questionnaire, satisfaction was consistently high (see figure 5). Three areas stood out, year after year:

1. **Respect for patient dignity (Q4):** this was the highest-rated item across settings. On average, around 82% of carers were 'very satisfied', and fewer than 3% were *very dissatisfied*, which perhaps points to the quality that underpins the SPC culture.
2. **Comfort and symptom management (Q1 and Q8):** the questions about patient comfort and physical needs regularly scored in the high 60s to low 70s for *very satisfied* responses.
3. **Communication and inclusion (Q2 and Q13):** overall, satisfaction by carers was high—though some subtle dips were reported over time.
4. **Relevance of the FAMCARE-2 questions (Q1–17):** about 1 in 10 carers reported questions were 'not relevant' across settings, and across the 10-year period. And most responded in the affirmative, suggesting the content was more often than not relevant. Unsurprisingly, 26% carers reported 'provision of practical assistance' (Q11) as 'not relevant', with a breakdown of 40% (HST), 21% (HC) and 17% (IU) per SPC team—showcasing differences in priorities across care sites, and most likely across regions (though not explored). Meanwhile, the issue of relevance was highlighted by a small fraction in the one-off survey.
5. **Overall satisfaction (Q1–17):** above 90% of the participating carers were reportedly satisfied with the care of the patients towards the end of life, and this was a sizeable proportion, particularly across such a wide and potentially diverse set of SPC teams.

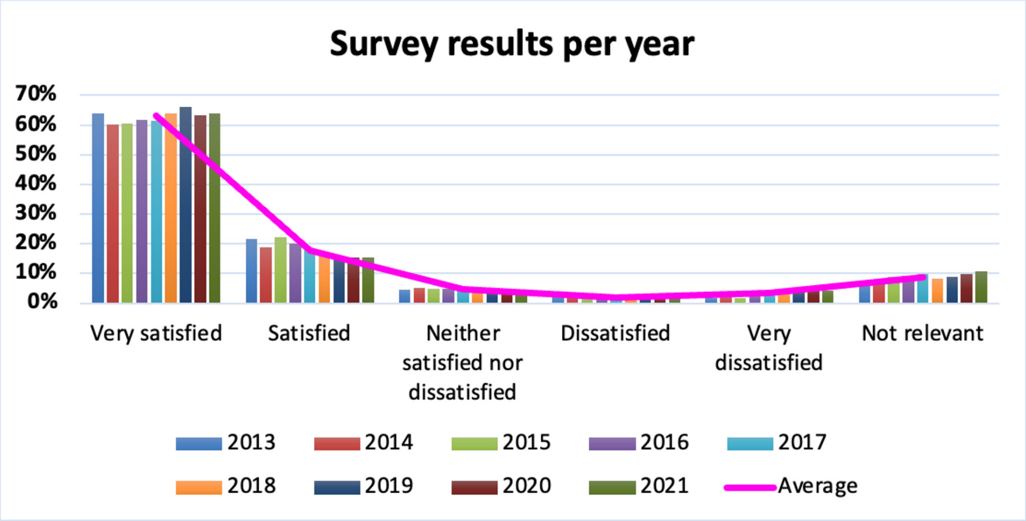

Figure 5 Average of all questions for each of the five Likert scale responses by year.

What did not go so well?

While dissatisfaction remained low overall (typically below 8%), some trends gradually emerged from the analyses.

1. **Speed of symptom management (Q6):**
   Up to 6.2% of carers were 'dissatisfied' or 'very dissatisfied' with how quickly symptoms were treated. Although this is a small number, towards the end-of-life care, time can be everything.
2. **Practical support and responsiveness (Q11 and Q16):**
   Dissatisfaction apparently increased in these areas over the decade. For example, dissatisfaction with practical help rose from 2.1% in 2013 to 6.3% in 2022. Similarly, dissatisfaction with how SPC services responded to changes in patient needs doubled.
3. **Availability of SPC teams (Q9):**
   While over 85% were satisfied, the proportion of 'very dissatisfied' carers increased from 2.6% to 6.3% over the decade. This perhaps reflects service pressures, staff shortages or changing expectations.

Changing patterns over the decade

The number of questionnaires returned dropped by 40% over the 10 years, and the steepest drop occurred after 2017. Also, there were observable changes among the SPC teams, with the Hospice IUs teams being consistently the most involved over the decade, averaging 27 teams per year. The HC teams increased participation, perhaps reflecting a shift toward community-based care. Conversely, the HST participation declined sharply from 2018, partly due to the roll-out of NACEL and increasing NHS staff pressures.

Likewise, in 2018, the European Union GDPRs likewise came into force, and there was an interval during which organisations were reluctant to participate in ongoing audits. Also, the GDPR commencement did affect the smooth running of SPC teams, owing to concerns about confidentiality and the protection of patients and their carers from unsolicited contacts. To ensure the APM acted in good stead and in alignment with the new and incoming regulations, it took advice from a compliance team. After a series of meetings and a legitimacy test for FAMCARE-2 with regards to the Data Protection Act (2018), a GDPR privacy notice was issued to relevant organisations, along with registration documents and further guidance—some of which are currently available on the APM's website.

On a positive note, the audit's response rates were good in the first years of running, with an average of 56% across all settings. This compares closely with response rates from similar national surveys. For instance, the response rate for the National Bereavement Survey (VOICES) was 43%,[10] while that for the National Care of the Dying audit 2014 was 37%.[4] However, the FAMCARE-2 rates have fallen significantly over the 10-year period, to 32.7% in 2022. The observed drop is somewhat akin to that reported in similar healthcare-related postal surveys, which apparently have themselves fallen over time, in the past decade or so.[15]

Another event that most likely affected the response rate was the COVID-19 pandemic of 2020, although FAMCARE-2 did thrive despite the worldwide challenge. Unsurprisingly, the number of returned questionnaires, especially from community teams, increased somewhat, although a reduction in SPC teams registering to the audit across all settings was implied, thereby implying that more SPC team activity occurred within the community. This outcome may have occurred as a logical response or reluctance of especially the frail and elderly to visit acute hospitals and even inpatient hospices at the time. Unfortunately, we do not have access to the demographic data of those who were or were not supported by these teams during and immediately after COVID-19.

Lastly, the cost of delivering the annual audit needs careful consideration, particularly in the light of limited SPC access, depleting numbers of experienced staff and a general diminishing return from non-clinical or non-mainstream activities. Some services and bereaved carer respondents found the historic use of paper forms cumbersome, and some questions even were tagged 'not relevant'. That said, a recent provider survey demonstrated the FAMCARE-2 tool remains valued by many, for service evaluation, audit and clinical governance, benchmarking, reflection and feedback processes and to support external inspection. However, no mention was made of its use in championing consultant appraisals and revalidation processes. It may be possible to switch to a hybrid model, encompassing the known FAMCARE-2 'paper forms' and an electronic version, to ultimately increase response rates and reduce APM administration time and costs.

In summary, this cumulative review of ten annual audits identified themes, trends and evolving patterns as identified by bereaved family carers via SPC teams across the UK and Ireland. It shows FAMCARE-2 achieved, to a large extent, its main goals and objectives. The authors have acknowledged strengths of existing national audits, such as NACEL[16] and SEECare[17] vis-à-vis FAMCARE-2, but these tools assessed generalist palliative care and often were setting-specific (ie, hospital-focused), unlike FAMCARE-2 which was able to evaluate SPC across the three main settings where planned end-of-life care occurs. In addition, they have acknowledged FAMCARE-2 in its current form may be fast approaching its natural shelf life, in the absence of a timely intervention, and that the tool runs the risk of being superseded by a more nuanced and bespoke national audit.

Looking ahead, the fate of FAMCARE-2 waits to be seen. But given its uniqueness, there is an opportunity to rebrand, without necessarily altering its format, and perhaps to update sections of the questionnaire to reflect a change in the current composition of SPC teams (which are increasingly nurse-led), without necessarily losing its overall validity. Should the APM decide to continue offering the annual FAMCARE-2 audit, a hybrid model should at least be considered, alongside equality monitoring and adequate support to enable equitable completion—especially if the tool would be made available for use in other countries. That said, participation in the annual APM FAMCARE-2 service evaluation is but one option—in the absence of a successful national evaluation programme like the national Palliative Care Outcomes Collaborative programme in Australia.[8]

CONCLUSION

FAMCARE-2 is a validated tool adopted by the APM to deliver an annual audit on end-of-life care satisfaction, that 90% of participating services have found valuable. It has been used to support service evaluation, audit and clinical governance, benchmarking, reflection and feedback processes, and to support external inspection. Responses of bereaved carers reveal a high level of satisfaction with SPC services in different settings over the last 10-year period.

However, due to the limited participation rates and lack of demographic information, the power of the data to support benchmarking is weak, and the applicability of findings is limited. Some items now appear dated with recent developments in care delivery. It remains unclear whether hospice inpatient teams will continue with FAMCARE-2 in its current form, particularly if the APM were to withdraw its current annual subsidy, and if other audits were to extend participation to the hospice setting.

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Acknowledgements Special thanks to all the bereaved main caregivers who kindly represented the patients who had been cared for by the participating specialist palliative care service teams in their lifetime. Also, huge thanks to the APM Office, in particular to Georgina Bulla, for exceptional administrative support and continuity over the period of the collection. We are very grateful to Fernando Cado (Barts Health) for specialist statistical testing and analyses of relevant data.

Contributors SC conceived the idea of a report. VK and D-EK oversaw data collation over the 10 years, via the APM Office, and D-EK analysed the combined data. FC was responsible for statistical testing and interpretation. EA provided a survey and draft for the script. SC, SK, EA, D-EK, AG, VK and later ES commented on successive drafts. Guarantor: SC is the guarantor for the manuscript.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants, but an ethics approval was not identified as being required, as this was a service evaluation report, not requiring local ethics committee approval.

Provenance and peer review Not commissioned; externally peer reviewed.

and is not responsible for any error and/or omissions arising from translation and adaptation or otherwise.

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