BMC Health Services Research

RESEARCH

Open Access

The family caregiver experience in palliative care pathways: a multidimensional framework

Marzia Cettina Severino[1*], Costanza Galli[2] and Sabina De Rosis[3,4]

Abstract

Background Family caregivers play an essential role across the life course of people, especially in delicate moments as the end-of-life, playing a central role in supporting and caring for terminal patients. Exploring the experience of family caregivers along this pathway is crucial to ensure a respectful, person-centered and high-quality experience with healthcare services, not only for patients but also for their caregivers. This study aimed to develop and validate collaboratively a multidimensional framework to explore the global experience of family caregivers across the palliative care pathways, through a multi-step participatory process involving professionals and caregivers.

Method The study employed a mixed-methods design. A literature exploration was conducted to identify key dimensions of the caregiver experience along the palliative care pathway, which informed the development of a preliminary framework subsequently examined through a Delphi-derived consensus process. A purposive sample of Italian professionals and caregivers participated in the Delphi study and were asked to assess the perceived importance of each dimension of the preliminary framework. Data analysis further examined areas of convergence and divergence between the two groups. The Delphi process resulted in the development of a final framework. Both the preliminary and final frameworks were refined through a workshop involving a group of Italian palliative care experts.

Results As a result of the first phase, our multi-dimensional framework included six key dimensions (namely, 'Needs', 'Responses', 'Clarity and adequacy of information', 'Availability in case of need', 'Responses in the Home Context', 'Communication and involvement'), each with additional sub-dimensions. The Delphi study involved 37 participants, including 19 professionals and 18 caregivers. All dimensions consistently received high ratings already in the first round. Emotional needs, clarity of information, and communication were prioritized by all participants, with differences including caregivers' higher ratings for training and involvement, and professionals' emphasis on communication adequacy. Open-ended comments identified personal, professional, and organizational challenges, such as the emotional burden on caregivers, communication gaps, and a need for enhanced support services. In a follow-up workshop, practitioners discussed the results of the Delphi, proposing to adopt the framework for involving caregivers in a holistic evaluation of services, and in defining person-centered improvements.

Conclusions This study provides a multidimensional framework of the family caregiver experience, developed and refined collaboratively by both professionals and caregivers. The framework represents a conceptual and operational structure that may inform caregiver experience assessment and service evaluation. Given its flexible design, the

*Correspondence:
Marzia Cettina Severino
marziacettina.severino@santannapisa.it

Full list of author information is available at the end of the article

framework may be further examined and adapted in other healthcare systems. These findings provide actionable insights to refine palliative care practices and better align them with the lived experiences and priorities of caregivers and professionals.

Keywords Palliative care pathway, Services experience, Caregiver experience, Delphi method, Multidimensional framework, Participatory research

Background

In a context of rapid demographic, socioeconomic, and familial changes, characterized by an increasing prevalence of advanced chronic conditions and growing long-term care needs [1], palliative care plays a key role in ensuring quality and continuity across care pathways. According to the International Association for Hospice & Palliative Care [2], palliative care encompasses the prevention, identification, assessment, and management of physical symptoms, including pain and other distressing conditions, as well as psychological, social, and spiritual needs. It also provides support to families and caregivers throughout the course of illness and during bereavement. Importantly, palliative care extends beyond healthcare provision, incorporating social care, third-sector involvement, and other supportive services for patients and their families. Palliative care may be delivered across multiple settings. Home-based palliative care refers to specialized services provided in the patient's home, whereas hospice care is typically delivered in dedicated inpatient facilities. These settings differ in organizational structures, care models, intensity of professional support, and the role assigned to informal caregivers [3].

Such care contexts require strong coordination and integration among services and professionals [4–6] with attention directed not only to patients' needs but also to those of caregivers, who often act both as care recipients and as co-providers of care. This perspective aligns with the person-centeredness approach in healthcare. While patient-centered care focuses on individuals as patients with specific conditions, which may sometimes neglect holistic information about the individual, person-centered care addresses not only physical or disease-related needs but also the surrounding context and environment [7]. This includes family, friends and other people taking care of patients. In fact, person-centered care is not tied to hospitals and healthcare institutions, as patient-centered care is often; it involves a network of healthcare providers, social workers, families, communities, and other stakeholders in a coordinated, hybrid model of integrated care [8, 9]. The person-centered care requires a shift from siloed approaches - focused on individual providers or settings - towards multi-setting and multi-provider vision, with health and wellbeing results reflecting contributions from a network of stakeholders working together for the individual's benefit [10].

Healthcare services are highly emotional [11] and strongly relational [12, 13]. Patients and caregivers often face information asymmetry, which can heighten anxiety and fear, making clear communication and a trust-based relationship essential [14].

Older adults are the main users of healthcare services, making the role of caregivers increasingly significant in accessing and navigating healthcare services, as well as in managing health conditions at home. These considerations have two main implications. First, caregivers often act as key communication intermediaries for this population. Second, as directly capturing the experiences of elderly and vulnerable patients can be challenging [15], caregivers can provide valuable information. However, this study seeks to recognize caregivers as subjects of inquiry in their own right, rather than merely as intermediaries for patients' voices. Caregivers are actively engaged in the care pathway of their loved ones and are therefore key actors in the patient journey, with specific information and support needs [16]. Accordingly, professionals should act not only as providers, but also as enablers or facilitators of people who are seen as active agents and co-providers [17, 18]. In fact, co-production does not imply transferring responsibility to service users; rather, it involves sharing responsibilities, redefining roles, and enabling individuals to contribute to value creation for themselves and their communities [19]. According to Pennucci et al. [20], this can happen by developing an approach including education, activation, engagement, and empowerment of people, especially patients and caregivers.

This is particularly relevant in palliative care contexts. On the one hand, it involves higher relational and emotional demands compared to other care settings; on the other hand, it requires more intensive and continuous assistance and, consequently, a strong involvement of informal caregivers [21].

Informal caregivers represent a fundamental resource in many European countries, especially in those in the south, including Italy, characterized by a familistic welfare system [22, 23], commonly referred to as "*countries with strong family ties*" [24]. The caregiver responds to various social and health needs of the person they care for throughout the palliative care path, dealing with symptom management [25], medication administration [26], emotional and social support for the patient, often ensuring the person's continuation in their own living

environment. This latter environment includes both the family and social network or context in which the caregiver acts and lives.

Informal caregiver assistance constitutes a multidimensional caregiving work in practical/organizational, emotional, relational, and ethical terms [27], which may significantly interfere with professional, family, and parental roles [28]. Informal caregiving activities, over time, can wear down the physical and psychological capacities of the caregiver, even leading to a crisis in the choice of home care [29]. The well-being of caregivers has a significant impact on patient outcomes, service functionality, and the overall sustainability of services, affecting the caregivers' productivity, their participation in service delivery, their collaboration in the value creation, and their contribution to service sustainability. A holistic approach is therefore needed, recognizing the person behind the caregiving role [30], including their needs, preferences, role perception, experiences with services, and the value they receive and co-produce with patients and providers [31]. Investigating caregivers' experience along the palliative care path is fundamental to understanding end-of-life services' functioning, better managing them and improving their quality, not only when provided to patients but also to caregivers. In this perspective, the literature recognizes the relevance of the caregivers' health outcomes, wellbeing, and experience with care in the end-of-life care, by highlighting the importance of integrating caregiver experiences among the reported outcome measures of this specific pathway [32].

Despite growing recognition of caregivers' roles, there is limited consensus on the key dimensions that define their experience in palliative care [33]. Existing literature highlights aspects such as access to information, communication with healthcare providers, and practical and emotional support [34, 35]. However, important conceptual and methodological challenges remain, particularly in developing integrative approaches capable of capturing the multidimensional nature of caregiver experience [36].

Moreover, fewer contributions have developed comprehensive models to specifically evaluate the global caregiver experience along palliative care pathways. Some proposed frameworks include psycho-physical dimensions (e.g., pain management), social and relational aspects (e.g., dignity and patient-caregiver relationships), and environmental factors (e.g., home versus hospice care) [37–39].

Several data collection instruments have been developed to assess patient and caregiver experiences, including:

- CAHPS, developed by the Centers for Medicare & Medicaid Services and the Agency for Healthcare Research & Quality [40].
- CANHELP, created by the Canadian Researchers at the End-of-Life Network [41].
- CBI (Caregiving Burden Inventory) [42].
- ZBI (Zarit Burden Inventory), widely used in caregiver burden assessments [43].

However, a recent literature review [44] underscores a critical gap: no existing tool comprehensively captures all dimensions of caregiver experience in palliative care. Many instruments suffer from methodological limitations, often prioritizing quantitative indicators while neglecting qualitative insights. Additionally, caregivers themselves are rarely involved in the development of these tools, leading to a misalignment between what is measured and what actually matters to them. In this study, caregivers are directly engaged, with a specific focus on their lived experience. The unit of analysis is therefore not the patient, nor exclusively the patient–caregiver dyad, but the caregiver's lived experience in their caregiving role. This perspective encompasses emotional, informational, organizational, and relational aspects that characterize the caregiving experience across different phases of the palliative care pathway.

Our study addresses the abovementioned gaps by adopting a mixed methods approach that combines qualitative and quantitative methodologies, through a participatory research design to ensure rigor and participation. By actively involving caregivers and professionals, we aim to develop a framework adaptable to different healthcare systems, grounded in their experiences and priorities. This framework is intended to support both research and practice by promoting more inclusive, integrated, and person-centered approaches to service improvement.

Method

Study design

The study was conducted between March 2023 and May 2024 in the Tuscany Region (Italy), in collaboration with the Palliative Care Functional Unit (PCFU) of Livorno. The research was initially designed by a team of three researchers: a lecturer with expertise in palliative care, a lecturer with expertise in patient experience, and a junior researcher with experience in community and social care. The study design was further refined through close collaboration between the research team and practitioners working in the above-mentioned palliative care and end-of-life setting.

We adopted a mixed methods approach by combining qualitative and quantitative methodologies. The collaborative team working on this research took great care in choosing and combining methods that align with

the complex phenomenon to investigate and with the research aims, and that raise the robustness of the outcome [45, 46]. This approach minimizes bias, improves consistency, and ensures precision through triangulation [47], thereby enhancing the reliability of the data [48]. A participatory design was also employed, actively involving not only practitioners, but primarily caregivers.

Within this design, rather than proposing a standardized psychometric instrument, this study aims at advancing a structured, multidimensional conceptual framework grounded in literature synthesis and consolidated through participatory stakeholder consensus. Its value lies in providing a theoretically informed foundation upon which further research can finalize the validation process, and future measurement and evaluation tools can be developed as well.

Research process

The research process was defined through a collaboration between the research team and the practitioners, and followed a two-phase approach: first, in an exploratory phase we identified key dimensions relevant to understanding caregivers' experiences along the end-of-life care pathway; then, we employed a Delphi study to reach a consensus on the dimensions identified in the first phase through expert consultation (professionals and caregivers). The comparison between caregivers' and professionals' ratings was theoretically motivated by the assumption that different stakeholder groups may attribute different levels of relevance to dimensions of caregiver experience. Examining convergence and divergence between these perspectives was considered important to identify potential misalignments in perceived priorities, and to inform the development, interpretation, and potential application of the framework in service evaluation and organizational decision-making.

Phase 1: Identification of key dimensions

In the first phase, we examined relevant studies and existing assessment tools to identify the dimensions that enable the exploration of caregivers' experiences in end-of-life care. The final step of this phase involved synthesizing the key findings and presenting them during a workshop with a purposive sample of five practitioners from the PCFU of Livorno. These professionals included three psychologists and two practitioners with managerial roles, one operating at the unit and local health authority level, and the other at the regional coordination level. These experts could contribute to discussing, refining, and potentially expanding the identified dimensions.

Phase 2: Delphi study

Based on the findings from the first phase of the study, a Delphi study was conducted in collaboration with a purposive sample of caregivers and professionals involved in the palliative care services in Tuscany Region. Recruiting a representative sample of patients or caregivers in end-of-life research is both methodologically demanding and contextually sensitive. For this reason, recruitment procedures were jointly defined by researchers and practitioners, including the development of shared guidelines, to ensure methodological rigor [49]. At the same time, given the sensitivity of the setting, caregivers were identified and enrolled by professionals of the above-mentioned PCFU, selecting only individuals who had already experienced bereavement, for ethical and practical reasons. They were selected among people who cared for patients both at home (home care) and in the hospice. There were no selection criteria in terms of age and sex, but the suggestion was to include as much as possible caregivers with diverse socio-demographic characteristics.

While the literature does not identify a fixed minimum number of participants for a Delphi process, some studies suggest that panels of around 15–20 experts may be sufficient to ensure meaningful contributions [50]. Taking potential dropouts into account, the research team therefore invited approximately 50 participants in order to obtain a minimum of 20 effective panel members. The aim was to investigate the perspective of professionals and caregivers regarding the relevant dimensions of experience emerged from the previous literature analysis. The data was used to understand any differences and similarities in the responses provided by the two groups of participants. The Delphi process was carried out through the distribution of an online questionnaire. The questionnaire included both open-ended and closed-ended questions. Respondents were asked to rate each dimension and sub-dimension on a scale from 1 (not important) to 10 (very important). Additionally, they were asked to prioritize the dimensions from most to least important. The open-ended questions, which were optional, allowed participants to provide suggestions regarding each dimension or sub-dimension, and researchers to gather qualitative data. The complete questionnaire used in the Delphi study, including both the original Italian version (Appendix 1) and the English translation (Appendix 2), is provided in the Supplementary Materials.

Eventually, the results of the second phase of the study were presented during a second workshop with the above-mentioned PCFU's professionals for a final revision and consolidation of the framework. This process can be considered the first step of a validation study.

Data collection and analysis

The panel members received via e-mail the invitation to participate in each round of the Delphi study. Participants received one or more subsequent follow-up

e-mails, as reminders, when necessary. Two Delphi rounds were expected. The high level of convergence and response stability achieved in Round 1 suggested that further rounds would be unlikely to produce meaningful changes in prioritization.

Quantitative data from the closed-ended questions of the Delphi study were analysed using SAS software for descriptive statistical analyses and t-tests. The consensus of the Delphi was defined according to the kind of measure adopted: (i) a mean score of 7 out of 10, for the 1 to 10 scales, (ii) greater than 75% of Delphi participants for the ranking position. The statistical significance was set at a minimum p value < 0.05 [51].

The qualitative comments left in the open-ended questions were analyzed using two flexible and open qualitative methods [52]: bottom-up content analysis [53] and polarity analysis of comments in positive, negative, neutral, and mixed categories. The first method allows for the discovery of new categories and exploration of the data in detail, identifying themes and categories during the analysis phase, without any preconceptions. Therefore, content analysis enables the identification of categories to deepen the data analysis and report the results. The other method, on the other hand, allows for the identification of comment polarization based on the words and expressions used in the text. This thematic analysis identified key themes that were integrated into the Delphi results.

Results

The first phase of the study enabled the identification of caregiver experience dimensions and sub-dimensions derived from the literature exploration and subsequently refined through professional insights. Five main dimensions of caregiver experience were identified. Most dimensions were related to needs and responses. While physical, psychological and social needs refer to the lived experience of caregivers, responses are related to activities, that concern caregivers' experiences in managing symptoms and coping, for instance, with stress-related manifestations (not patient outcomes). These aspects require assessment, personalization, and adaptation. In contrast, the dimensions "Clarity and adequacy of information" and "Communication and involvement" implied a more active participation of caregivers, with different shades, from the one-way information provision to two-way communication, involvement in decision-making, and engagement [54].

These findings were presented and discussed with healthcare professionals. The online workshop, lasting approximately one hour, revealed strong practitioner interest. Participants confirmed the relevance of the identified dimensions by comparing them with their professional experience. Additionally, they suggested integrating the dimension "Availability in case of need" (including its sub-dimensions). For the dimension "Clarity and adequacy of information", professionals proposed exploring not only different care phases (diagnosis, planning and actions, prognosis), but also caregivers' emotional responses when receiving information, as well as their perceptions of how such information was communicated. Participants also emphasized the importance of incorporating caregivers' perspectives into the next phases of framework development. A visual representation of the multidimensional framework is provided in Fig. 1, while the details of dimensions and sub-dimensions are reported in Appendix 3.

Delphi

47 informants were invited to the Delphi study. We obtained an overall response rate of 78.7%, corresponding to 37 participants. Table 1 presents the number of respondents per category. The number of participants was considered sufficient for the planned analyses, both considering all the respondents together and the two sub-groups of participants [50].

Respondents had an average age of 55 years (min 38 – max 76) and were predominantly female in both the groups (83%, $N = 31$, summing both professionals and caregiver). Educational attainment was only queried from caregivers. In total, 13 caregivers responded to this question, with mostly a medium-low level of education (76%, $N = 10$). Table 2 presents the sociodemographic characteristics of respondents by category.

The results of the Delphi study showed an overall high rating across all dimensions considered. Given the strong convergence observed in the first round of the Delphi, further rounds were not conducted. Dimensions related to 'Needs', 'Responses', 'Clarity of information', and 'Availability in case of need' received very high scores, with averages exceeding 9 on a scale from 1 to 10. The results do not present statistically significant differences between the responses of caregivers and professionals. Table 3 below is the summary of responses to the question "*In evaluating the end-of-life path, how important do you consider exploring the following dimensions of the caregiver's experience?*" with details for respondent groups.

Although the perceived importance of the dimensions was generally slightly lower for caregivers, this difference was not statistically significant. Just two dimensions reached a p-value close to 0.05, namely 'Clarity and adequacy of information' and 'Availability in case of need'.

Thus, the research team analyzed the sub-dimensions to identify potential differences at a more granular level of the multi-dimensional framework.

The analysis of the dimension 'Needs' highlights the central role of 'Emotional support for caregivers', who rated this aspect with an exceptionally high score,

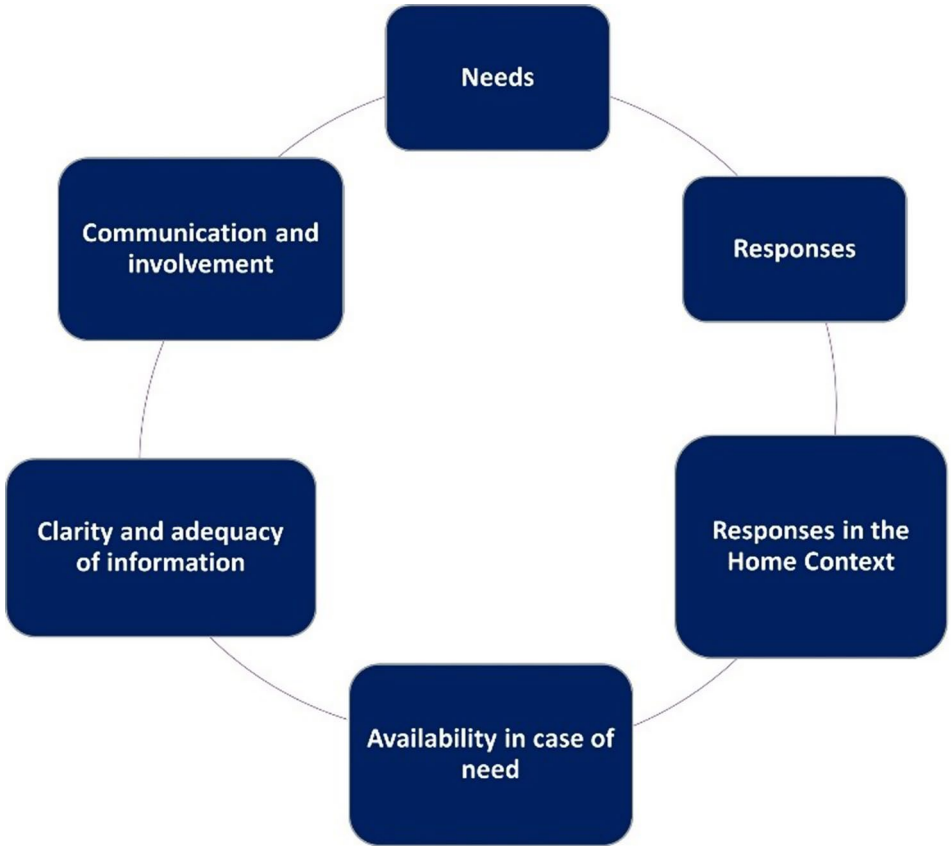

Fig. 1 A visual representation of the multidimensional framework

Table 1 Participants (partial and total numbers) and response rates in the Delphi study by category

	Invited people (*n.*)	Respondents (*n.*)	Response rate (%)
Caregiver (CG)	27	18	66.6%
Provider (PR)	22	19	83.4%
Total n.	47	37	78.7%

averaging over 9. Among the various sub-dimensions, 'Information and training' stood out as particularly significant for caregivers, receiving a statistically higher score compared to professionals (CG: mean 9.67, SD 0.69; PR: mean 9.11, SD 1.2; p = 0.026).

When examining the dimension 'Responses', both caregivers and professionals expressed a consistently high appreciation across all sub-dimensions, with average ratings exceeding 9 out of 10. Within the 'Responses in the home context' dimension, the 'Quality of assistance received' was particularly valued, with scores surpassing 9.5. However, aspects related to the frequency and timing of visits were rated slightly lower, though still remaining within a high range. Notably, no significant differences emerged between the two groups in these evaluations.

Table 2 Participants' characteristics by category (partial and total numbers of participants, percentages and means of characteristics)

Variable	Type of respondent	Category	*N.*	% or mean
Sex	Caregiver	Females	16	89%
		Males	2	11%
	Professional	Females	15	79%
		Males	4	21%
Age	Caregiver		18	55.72 (min 43-max 76)
	Professional		19	55.97 (min 38-max 67)
Educational level	Caregiver	Low	4	30.8%
		Medium	6	46.2%
		High	3	23%
Professional Background	Professional	Doctor	14	73.7%
		Psychologist	3	15.7%
		Nurse	1	5.3%
		Socio-Health Assistant	1	5.3%
		Social Worker	0	0%

Table 3 Results (n., mean, SD, min, max, t-test p value) for the question "How important do you consider it in evaluating the end-of-life path to explore the following dimensions of the caregiver's experience?" with details for respondent groups (CG= Caregivers – PR= Provider)

Perceived importance of the dimension		*N.*	Mean	SD	Min	Max	T-test *p*-value
Needs	CG	18	9.33	1.03	7	10	0.706
	PR	19	9.05	1.13	7	10	
	Tot	37	9.19	1.08	7	10	
Responses	CG	18	9.39	1.09	6	10	0.376
	PR	19	8.79	1.36	6	10	
	Tot	37	9.08	1.26	6	10	
Clarity and adequacy of information	CG	18	9.44	1.34	5	10	0.052
	PR	19	9.37	0.83	8	10	
	Tot	37	9.41	1.09	5	10	
Availability in case of need	CG	18	9.56	0.78	8	10	0.064
	PR	19	9.11	1.24	6	10	
	Tot	37	9.32	1.06	6	10	
Responses in the Home Context	CG	18	9.17	0.78	8	10	0.357
	PR	19	8.53	1.24	6	10	
	Tot	37	8.84	1.54	5	10	
Communication and involvement	CG	18	9.67	0.69	8	10	0.611
	PR	19	9.58	0.61	8	10	
	Tot	37	9.62	0.64	8	10	

* p-value < 0.05

** p-value < 0.01

*** p-value < 0.001

The 'Ability of services to respond promptly in times of need' was another crucial factor, receiving high ratings from both groups. In particular, '24-hour availability' was perceived as more important by professionals than by caregivers, with a statistically significant difference (CG: mean 9.22, SD 2.13; PR: mean 9.26, SD 0.99; $p = 0.002$).

Similarly, 'Clarity and adequacy of information' were widely recognized as fundamental, with both groups emphasizing the importance of clear communication regarding available services and care plans. While no significant discrepancies emerged between caregivers and professionals in this area, the need for structured and accessible information remains evident.

'Communication and involvement' also played a pivotal role in shaping perceptions of care quality. Both groups assigned high importance to the 'Adequacy and coherence of communication', though professionals placed greater emphasis on these aspects than caregivers did. The same pattern was observed regarding 'Caregiver involvement', where professionals attributed significantly higher importance to ensuring caregivers are actively included in decision-making processes (CG: mean 8.44, SD 1.92; PR: mean 9.26, SD 0.81; $p = 0.0006$).

The ranking of dimensions according to perceived priority further underscores these findings. The 'Needs' dimension emerged as a primary concern for both caregivers and professionals, receiving 24.32% of the total responses. In contrast, 'Responses' was considered a lower priority compared to other dimensions.

The dimension of 'Clarity and Adequacy of Information,' although ranked lower by caregivers compared to professionals, still represented a significant priority, accounting for 18.92% of responses. Meanwhile, 'Communication and Engagement' emerged as the second most prioritized aspect, receiving 21.62% of total votes. Interestingly, caregivers assigned it an even greater importance than professionals. Appendix 4 includes the Tables reporting the detailed analyses of sub-dimensions.

All comments left in the open-ended questions were read in detail by two researchers, aiming to capture their meaning and lived experience, and at identifying key influencing aspects. There were 28 comments left by respondents, 17 from caregivers and 11 from professionals. From an initial reading of the comments, we identified three broad categories to classify both professionals' and caregivers' comments. These categories relate to personal, professional, and organizational aspects, defined as in the following lines:

1. Personal aspects are related to the emotional, social, and psychological challenges faced by caregivers, emphasizing the complexity of balancing physical and emotional caregiving demands. They highlight the need for empathy, emotional support, and resilience.

2. Professional aspects focus on the technical and communicative skills essential in palliative care, such as clear and effective communication, adequate information sharing, and resolving language barriers, reflecting the hard skills required for quality care.
3. Organizational aspects pertain to the structural and systemic elements of care, including the availability of specialized professionals (e.g., psychologists), resource allocation, and teamwork among providers, stressing the importance of coordinated systems and strong support networks for patients and caregivers.

About the personal aspects, caregivers highlighted the emotional and social impact of their role, emphasizing the complexity of managing the emotional and physical aspects associated with their loved ones' illness. The importance of psychological support in addressing these difficulties has emerged.

With regard to the professional aspects, the main criticisms concern communication, with language barriers and inadequate information about the state of the illness. There was highlighted a contrast of information between palliative care specialists and other professionals, along with a lack of coordination among them.

Some professional aspects related to technical and communicative skills present blurred boundaries with personal ones, such as those related to the respect and dignity, and the emotional status of the caregivers, including additional ethical implications.

Regarding the organizational aspects, professionals emphasized the need to increase the services offered, particularly the presence of professionals such as psychologists in palliative care. There was also a need highlighted to enhance support for caregivers and improve teamwork among the various professionals involved.

The need for consistency among the kind of information given by all the professionals emerged as crucial, also in the words of the same professionals. The need for being prepared to address the personal aspects of care, as here defined, appeared an important skill for all professionals, regardless of professional background and discipline.

Some comments categorized into the organizational aspects showed the importance of establishing roles and responsibilities among the caring actors, including the informal caregiver considered as a part of the team. The Table 4 below provides representative quotes organized by thematic category and respondent group.

The results of the Delphi study were presented and discussed with professionals in a second workshop. The workshop was conducted online. It lasted around one hour. The five professionals from the above-mentioned PCFU of Livorno participated in the workshop.

They expressed again their interest in the results with some novel aspects with respect to their daily life experience on the field. In particular, they gave great value to the importance given by caregivers to the involvement, an aspect often underestimated in professional practice but considered by participants as deserving greater attention. A surprising result for practitioners was the difference in the relevance given to the '24-hour availability' (slightly more important for providers than caregivers). They explained the result in terms of need to focus on quality and promptness of the professionals' presence, rather than quantity. Professionals proposed to discuss the final framework by involving caregivers in another future step of the research study.

Discussion

The caregiver plays an essential role in palliative care pathways, providing crucial support and assistance to patients in the terminal phase of life. However, behind the caregiving role, there is a person, a relational actor whose experience, health and wellbeing directly shapes patient outcomes, service functioning, and the broader sustainability of care systems.

According to Bjørnelv and colleagues [6], more settings are involved in the end-of-life journey, with a substitution effect: "more care in one care setting (e.g., the secondary care) is associated with less care in other settings (primary- and home- and community-based care setting)". This supports the need for multi-setting analyses in end-of-life research [55]. Thus, a strength of our study was the inclusion in the Delphi study of caregivers of patients cared in home and hospice settings.

A first point to discuss concerns the family caregivers who participated in the study. The majority were women, particularly wives, reinforcing the well-documented gender disparities in informal caregiving. This finding aligns with previous research highlighting how caregiving responsibilities disproportionately fall on women, leading to structural inequalities in access to the labor market, financial stability, and social participation [56]. The unequal burden of caregiving exacerbates gender imbalances in career progression, income, and social inclusion, as caregiving often leads to career interruptions, reduced work hours, and increased emotional and financial stress. Additionally, caregiving is often undertaken informally, which has long-term economic consequences for women, including lower lifetime earnings and reduced pension contributions [57]. Marital status also represents a relevant lens through which to analyse the phenomenon under study. A previous study showed that married patients, compared to those who never married, spent more time at home, relied less on home- and community-based care, but made greater use of primary and secondary health care services [58]. These findings

Table 4 Representative quotes by thematic category and respondent group

Category	Respondent	Representative quote
Personal aspects	CG	*« (…) The social aspect, however, plays a crucial role because if a caregiver is truly present and wants to be, balancing everything while maintaining emotional stability is truly challenging. »* *«In my opinion, the priority, even for the caregiver, is to manage the patient's physical needs. The emotional sphere remains fundamental, as the predominant feeling is often one of helplessness, not knowing what to do».* *«In my opinion, it is necessary to strengthen and create dedicated support for the caregiver—not only for the physical care of the patient but also for their spiritual and psychological well-being, as well as that of the caregiver and the entire family unit».*
Professional aspects	CG	*«Considering the situation at the beginning of the journey, (…) the technical terms were used that prevented me from fully understanding, leading to a superficial approach in this regard. »* *«It is appropriate to explore the communication and information provided by the specialists who follow the patient before the palliative care physician. In fact, not only patients but also family members are absolutely unaware of the prognosis».*
	CG	*«The clarity of the diagnosis, however important, is secondary to the other two aspects, because if the patient is in palliative care, the diagnosis is already clear, unfortunately. Communicating the proximity of death is essential, as it is difficult to assess and, above all, to accept that the person you love more than anyone else in the world is leaving. But it is also of primary importance for healthcare professionals to convey (and ensure that the caregiver fully understands) the care plan».*
	CG	*"I lost my mother almost four months ago, and I still live with the regret of not having said goodbye to her, because when she was sedated, I was not told that she would never wake up again. And she, too, said that she wanted to sleep, not die… I think there is a big difference. »*
Organizational aspects	PR	*«I need to say that, despite the clear importance of these needs, they cannot always be met due to the lack of a psychologist specifically dedicated to palliative care in my area. On the other hand, a social worker is present but not dedicated to palliative care. As for informational and educational needs, there is a shortage of human resources, and the area has a very low population density, making it highly dispersed. Everything is done, but with great difficulty. Telemedicine support would also be of great help».*
	PR	*«To assist a patient and their family and support the caregiver, teamwork is essential from the very beginning of the patient's home care. Clear communication and the involvement of all professionals are crucial, they must talk to each other and work in close coordination. The caregiver immediately senses if we are not aligned».*
	PR	*«Colleagues from other disciplines mostly share only clinical information, and many palliative care professionals are not trained to identify crucial aspects of family dynamics (e.g., dysfunctional, enmeshed…) or their needs. This makes it difficult to provide high-quality care. »*
	PR	*« When entering the home of a patient to be taken into palliative care, communication is crucial, as well as assessing who the caregiver is. Without a caregiver, it is not possible to take a patient into home palliative care. Think about the stress, anxiety, and burden of managing all this. That's why it takes a lot of time, sometimes even two hours. It is essential to work as a team: palliative care physician, family nurse, social worker, psychologist, physiotherapist, dietitian, specialists and spiritual caregiver, ensuring comprehensive coverage of the needs of both the patient and their family. However, the most critical aspect is supporting the caregiver. We are there, but then we leave».*

emphasize the urgent need for policy interventions to mitigate the economic and social costs of informal caregiving, such as flexible work arrangements, financial support, and formal recognition of caregiving roles within social security systems. From a theoretical perspective, this gendered distribution reinforces the need to conceptualize caregiver experience as socially embedded rather than purely individual.

Given the high level of convergence observed in the first round of the Delphi study, further rounds were not conducted. In line with methodological discussions describing flexible and reduced-round Delphi applications, this participatory process may be classified as a Mini-Delphi [59, 60]. The early convergence observed among participants strengthens the robustness of the identified dimensions and supports the internal coherence of the proposed framework. By conceptualizing caregivers as subjects of inquiry in their own right, the study contributes to refining the theoretical understanding of caregiver experience and clarifies its internal dimensions and subdimensions. In fact, our findings confirm that caregiver experience in end-of-life pathways is inherently multidimensional, encompassing psychological, relational, informational, and organizational components. The first key contribution of our study is, therefore, the development of a multidimensional framework that reflects this holistic and person-centered understanding of caregivers' experiences. In this holistic framework, in fact, caregiver needs are not reduced to clinical or logistical dimensions but are considered dynamically interconnected. Our findings situate the caregiver experience within a broader conceptual distinction between patient- and person-centered care. While the former refers to a multidimensional clinical focus on the individual physical, psychological, social, and spiritual needs, the latter expands the locus of care to include relational and family system dimensions. Our results suggest that end-of-life care cannot be fully understood within a patient-centered framework alone, as caregivers emerge not merely as support actors but as integral components of the care unit itself [61]. This holistic approach to the caregivers' experience with the end-of-life path highlights the complex interplay between

professional competencies and personal, emotional, and ethical dimensions in end-of-life care. However, future studies about end-of-life should include the longitudinal perspective in a more focused way, in order to explore whether these different dimensions change in meaning and/or in relevance along the path.

Evaluating end-of-life journeys from the caregiver's perspective therefore requires an approach that captures interconnected needs and experiences across different stages of the pathway and translates them into appropriate service availability and provision. This includes psychological support [50], which emerged as key service in our study, especially in the home-setting.

The perceived quality of home-based care emerged as particularly relevant. Caregivers expressed a strong preference for maintaining patients within familiar environments, consistent with evidence suggesting that the home setting may sustain family cohesion and togetherness [62]. However, 'dying at home' can be difficult for people coming from rural and remote communities, so pushing healthcare practitioners, managers, and decision-makers to discuss the definition of 'home place', in order to assure a respectful, person-centered and family-bonding end-of-life to all people, equally [63].

An important theme emerging from our findings concerns communicative and relational aspects of the end-of-life pathway. Caregivers consistently highlighted issues related not only to the clarity of information received, but also to the quality of interactions, coordination among professionals, and their own positioning within the care process. These elements indicate that communication is not merely a technical component of care delivery, but a structural and relational dimension shaping the overall caregiving experience.

From an analytical perspective, it is necessary to distinguish between information, communication, involvement, and engagement. Information refers to one-way content transmission, whereas communication is a relational and bi-directional process involving feedback and shared meaning-making. Similarly, in line with Carman et al. [54], involvement and engagement should not be conflated: involvement concerns participation in decision-making, while engagement represents a broader psychosocial process of activation. Importantly, information and communication alone are insufficient to produce activation; genuine engagement and empowerment require educational and relational processes that enable individuals to assume an active role.

Starting from what we can consider the most basic communicative level, caregivers reported a lack of clarity and consistency in the information received. This emphasizes the need for clear and timely information.

When healthcare professionals fail to clearly inform about what to expect, caregivers may experience lasting distress and ethical concerns related to informed decision-making. For instance, the distinction between "sleeping" and "dying," though medically implicit, holds immense emotional weight for both patients and their families. Previous research revealed that communication, understood as information transfer, feedback loops, and processes for enabling communication, is a crucial aspect for all stakeholders [64]. While technical and communicative skills are core aspects of professional practice, they often intersect with deeply personal elements such as respect, dignity, and the emotional well-being of caregivers. These blurred boundaries raise ethical considerations. These findings suggest that training in palliative care should place greater emphasis not just on technical and communicative skills but also on the ability to navigate difficult conversations with transparency, empathy, and a deep respect for the emotional states of caregivers and patients. This case highlights the need for professionals to move beyond procedural expertise and develop sensitivity to the emotional and ethical dimensions of their role. Of course, professional training alone cannot address the structural dimensions underlying these challenges. Ensuring dignity in end-of-life care requires balancing professional detachment with human connection, supported by ethical reflection and organizational backing.

At a more relational level, caregivers also reported a lack of coordination among the various professionals involved in palliative care and an insufficient continuity of information across professionals, including inconsistencies and limited feedback mechanisms and poor coordination between services. This implies the need for coherent information across different settings, disciplines, and phases of care pathway. For severe conditions, in fact, coordination may surpass relational continuity, in terms of preference and relevance of people [65]. This is also in line with Landers and colleagues [64], where participants highlighted the need for care integration, by proposing changes to improve communication, including information continuity among all health professionals, real-time visibility of relevant clinical information, and robust feedback mechanisms after referral to another service.

Moving further along the communicative-relational continuum, the theme of involvement emerges. Caregivers expressed the need to be actively involved in patient care and decision-making processes, as well as to feel recognized in their role. Differences between caregivers and professionals in the perceived relevance of the "Communication and involvement" dimension suggest distinct interpretative frames: while professionals emphasize communication as a formal dimension of care, caregivers focus on the experiential consequences of its absence, particularly in terms of coordination, shared

decision-making and recognition, but also in terms of training and education. On the one hand, these differences suggest different interpretative frames through which caregivers and professionals conceptualize communication and involvement.

On the other hand, some analytically distinct implications emerge.

First, in the caregivers' perspective, the lack of clarity, consistency, and coordination among professionals may affect the education and activation process of all actors involved in the pathway, including caregivers. This led to the second implication, related to the fact that education is one of the four key principles of the framework of Pennucci et al. [20], which builds on the crucial role of providers, individuals and communities for producing activation, engagement, and empowerment.

Second, the findings highlight the role of communication in training and in engaging caregivers. Education should be designed to go beyond passive information delivery [20], and is strictly related to the construct of the health literacy, health knowledge and health consciousness. Indeed, it is key to recognize that information and communication alone are not able to produce the activation of individuals [66]. Our results suggest that caregivers feel a stronger need for clear guidance, skills, and education to navigate their role effectively. This aligns with findings by Nysaeter et al. [57], who identified key caregiver support preferences, including maintaining a sense of control, being actively involved in patient care, feeling recognized, and having access to respite opportunities. Similarly, Xu et al. [67] emphasize the importance of structured guidance on symptom management, emotional coping strategies, and respite care options to sustain caregivers in their roles.

Third, this result is also an important aspect to be addressed in terms of educational needs of professionals in the palliative care setting [55], to increase their awareness by providing specific training. Our results both reinforce the idea that effective communication and active involvement are essential for a supportive care experience, and also suggest that professionals from different backgrounds, all involved in this care pathway, should be prepared to address the holistic experiences of both patients and caregivers. It is crucial not to take for granted the multifaceted factors influencing end-of-life outcomes for caregivers, ensuring a dignified and compassionate approach.

At the highest level of communicative and relational intensity lies engagement and empowerment, which emerge, within our framework as key dimensions for supporting individuals in becoming co-producers of care. However, prior literature has often used the terms engagement, activation, and involvement interchangeably [68], despite their conceptual differences. Clarifying these distinctions is necessary to avoid analytical ambiguity. Engagement represents a broader "umbrella" construct that extends beyond individual participation in decision-making or behavioral activation. It also encompasses the contextual, relational, and organizational conditions that enable healthcare service users to be meaningfully positioned at the center of their care [69]. In this sense, engagement captures the dynamic relationship between healthcare supply and demand across different levels and settings. Person engagement in healthcare has been conceptualized as a "*multi-dimensional psychosocial process*", involving cognitive, emotional, and behavioral components enacted in managing health conditions [69, 70]. The behavioral dimension concerns the concrete actions undertaken in dealing with illness and treatments. The cognitive dimension refers to knowledge, understanding, and interpretation of the disease, its progression, and monitoring. The emotional dimension encompasses the psychological reactions and affective adaptation required when facing illness and related life changes. From this perspective, engagement goes beyond mere adherence to medical prescriptions and implies an active, reflexive, and integrated role in care. Building on this conceptualization, engagement becomes a necessary condition for effective co-production. A well-defined and transparent co-production process, based on the joint sharing of knowledge and legitimacy, including a rebalancing of power between providers and users, can foster engagement, sustain caregivers in their role, and contribute to improved health and well-being [71]. Co-production thus requires the voluntary and intentional engagement of users, whose contributions are essential for shaping and improving healthcare services [71]. Our findings suggest that this transition toward co-production is not automatic. The more positive perception of the involvement and training dimension by caregivers (enablers of real engagement), compared to professionals' stronger emphasis on information provision, indicates a potential misalignment. While professionals may prioritize informational aspects, caregivers appear to particularly value some relational and participatory dimensions more strongly. This gap suggests that healthcare professionals may require further guidance, support, and training to fully embrace their role as enablers and facilitators of co-production processes. In other words, professionals themselves need to be activated and engaged in order to actively engage caregivers, recognizing them not as passive recipients of information and care, but as co-producers of knowledge, services, and outcomes.

Finally, our results emphasize caregivers' needs with respect to services provided after the patient's death. Consistent with public health approaches to palliative care, death should be understood not solely as a biomedical event but as a social and relational process embedded

in families and communities. Conceptualizing caregivers as potential "second-order patients" further reinforces this systemic perspective [72]. Earlier studies highlighted that the primary needs of chronic patients in the end-of-life path and their families are not related to health [73]. Our findings confirm this, highlighting that caregivers also value comprehensive emotional, informational, and psychological support. The lack of dedicated resources, such as psychologists specialized in palliative care, emerged as a significant gap in current services. This finding may reflect a professional focus on the quantitative dimension of care provision, ensuring continuity and constant availability, rather than on its qualitative impact. In other words, services may be organized according to a "high volume" logic, prioritizing the amount and continuity of provision (e.g., 24/7 coverage), rather than a "high value" logic centered on the appropriateness, timing, and meaningfulness of support for caregivers. The higher relevance attributed by professionals to service presence, compared to caregivers, may therefore be interpreted through this lens. Professionals may equate quality with constant availability, whereas caregivers appear to value a specialized, responsive, and phase-sensitive presence aligned with their evolving needs along the end-of-life trajectory and in bereavement. From the caregivers' perspective, professional presence is not merely a matter of being continuously reachable, but of receiving competent, empathetic, and timely support at critical moments. Caregivers and patients need emotional, psychological, and informational support delivered when it is most meaningful. A model oriented toward high value rather than high volume, emphasizing timely, specialized, and tailored interventions, would be better suited to address these multidimensional needs and to ensure that resources generate relational and experiential impact, not only service continuity.

Research limitations

The data presented in this article are from a group of purposively selected professionals and caregivers in Italy; in addition, this study is a participatory validation within a specific regional context, not a psychometric or cross-national validation. The results may not be generalizable. Therefore, they should be considered as a stimulus to further research and expand the available evidence, particularly regarding the role that research both on caregivers and on palliative care services could play in promoting evidence-based support policies for vulnerable groups and delicate moments of the people's life.

Further research, particularly with a longitudinal and pathway-oriented design, is needed to apply the framework across diverse settings and inform the development of evidence-based policies aimed at supporting caregiver wellbeing and enhancing service quality. In this perspective, including the caregiver experience is essential to advancing more equitable, integrated, and person-centered long-term care systems.

This study has some potential limitations related to recruitment pathways and pre-existing professional relationships between researchers and participants, which could have introduced elements of selection bias or social desirability. However, several design features reduce the likelihood that these dynamics substantially affected the findings. The Delphi process was fully anonymized, and responses were collected through an online questionnaire completed individually, allowing participants to respond in a setting of their choice and without direct interaction with other panel members or the research team. Feedback was provided only in aggregated form. These procedures helped limit interpersonal influence, minimize hierarchical pressures, and reduce potential power imbalances, particularly between caregivers and professionals, thereby supporting independent expression of views.

Potential limitations also relate to recruitment procedures. Caregivers were approached through healthcare professionals and professionals were invited by the research team, which may have introduced some degree of selection bias or gatekeeping. To mitigate these risks, predefined and transparent inclusion criteria were applied, and recruitment aimed to ensure heterogeneity in terms of roles, settings, and experiences. Invitations clearly emphasized the voluntary nature of participation and the independence of responses. Given the anonymized and online format of the Delphi rounds, recruitment pathways are unlikely to have influenced how participants expressed their views within the study.

Managerial implications

In this study, the key to evaluation lies in understanding the dimensions relevant to the caregiver to develop tools capable of capturing the overall quality of services in their perspective. Given the crucial role of caregivers in palliative care pathways, it is necessary to understand their experience in order to improve the quality of care and responses provided not only to the patient but also to family caregivers. This is even more necessary in light of the transformative pressures stemming in several countries, including Italy from the National Recovery and Resilience Plan (PNRR) and Ministerial Degree No 77/2022. One useful tool for defining, measuring, and evaluating interventions could be a structured system for capturing caregivers' voices and experiences. There are very structured and systematic experiences of patient-voice collection at national and international level, including good practices in the same regional system of our study [74–76], but only a few specific and non-continuous experiences of collecting Caregiver-Reported

Experience Measures [77], even if these tools are capable of generating evidence for improving care and supporting initiatives for caregivers. Such surveys could also be useful for reconstructing the actual healthcare and social network that supports both the patient and the caregiver, in order to identify best practices for integration. Our framework can be used to inform such a system for systematically collecting, reporting and up-taking caregivers' voice into clinical and managerial decision-making.

In addition, the preliminary results of this study have clear managerial implications since they highlight important differences in the perspective of providers and caregivers, which are also related to the organization of end-of-life services: they regard the caregivers' preferences for domiciliary services and the lower importance attributed to 24-hours services with respect to coordinated and high-quality services in structured moments. Although these results are context-specific for the region of Tuscany, they can inspire reflections in other healthcare systems where this research can be easily replicated.

Originality of the paper

This is one of the first studies exploring the caregivers' experience with end-of-life services, by directly involving both caregivers themselves and professionals in a collaborative research process. It contributes to the literature by advancing a structured, multidimensional conceptual framework of the caregiver experience in palliative care. Grounded in a synthesis of prior research and iteratively consolidated through participatory stakeholder consensus, the framework extends existing approaches that often position caregivers primarily as proxies for patients, or that do not encompass a holistic approach to the lived experience of caregivers as persons. Rather than proposing a finalized psychometric instrument, the framework should be interpreted as a theoretically informed and context-sensitive model that provides a foundation for future construct operationalization and validation. Moreover, it provides insights for future applied studies for measuring the caregiver experience with palliative care, and initial suggestions on potential changes in organizational models to better address caregivers' preferences and needs, increase their involvement and participation, and improve their wellbeing in this critical phase of life.

Conclusions

The findings of this study support the relevance of adopting a multidimensional perspective to understand and evaluate the global experience of family caregivers in palliative care pathways. Through a participatory process involving both caregivers and professionals, this research developed and consolidated a framework that captures key emotional, informational, organizational, and communicative dimensions of caregiving.

The high level of consensus observed across stakeholder groups indicates that caregiver experience represents a critical domain for assessing the quality, coordination, and responsiveness of end-of-life care services. The framework provides a structured and flexible foundation to guide the development of evaluation tools, inform service design, and support organizational and policy decisions aimed at strengthening person-centered care models.

Integrating caregiver-reported experiences into routine evaluation practices may enhance care alignment with caregivers' needs, improve service integration, and contribute to more inclusive, equitable, and responsive palliative care systems.

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12913-026-14531-0.

Supplementary Material 1: Appendix_1_Questionnaire_Italian_Validated

Supplementary Material 2: Appendix_2_Questionnaire_English_Translation

Supplementary Material 3: Appendix_3_Tables reporting Dimensions and sub-dimensions of the caregiver experience framework derived from the literature and refined through professional insights

Supplementary Material 4: Appendix_4_Tables reporting the detailed analyses of sub-dimensions

Acknowledgements

The authors thank all the panel members, as well as professionals and caregivers who took part in the study. A particular acknowledgment is extended to Professor Milena Vainieri and Professor Sabina Nuti for their vision and scientific contribution, and to Dr. Francesca Ferré who was involved in the preliminary phases of conceptualization of the study. The authors are also grateful to the researchers of the Management and Healthcare Laboratory (MeS) of Sant'Anna School for their continued support.

Author contributions

Conceptualization and methodology, SDR; data collection, MS; formal analysis, MS; writing - original draft preparation, MS and SDR; writing - review and editing, SDR, MS, and CG. All authors have read and agreed the final version of the manuscript.

Funding

The study was funded by the Region of Tuscany, under a scientific agreement coordinated by the Management and Health Laboratory (MeS) of Scuola Superiore Sant'Anna of Pisa (Italy), with the scientific responsibility of Prof. Milena Vainieri. The funding bodies contributed to discussions on the aims and research design and to the interpretation of the preliminary results.

Data availability

Data and statistical procedures are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

Based on the current Italian laws (*January 26, 2023, Ministerial Decree and EU Regulation 536/2014*), ethics committee approval is required for clinical research or studies involving direct interventions with and on human beings. The present study does not fall under clinical studies, as it does not entail experimental treatments. Rather, this study relies on the Delphi method and gathers the views of experts on a conceptual model. The study was

conducted in accordance with the principles outlined in the Declaration of Helsinki. All participants were fully informed about the study objectives, confidentiality, and their rights. Informed consent was obtained from all participants before completing the first round of the Delphi survey and before participating in the workshops.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

Author details
[1]Interdisciplinary Center in Health Science, Sant'Anna School of Advanced Studies, Pisa, Italy
[2]Palliative Care Unit, Azienda USL Toscana Nord-Ovest, Tuscany Region, Italy
[3]Department of Law, Economics, and Human Sciences, University Mediterranea of Reggio Calabria, Reggio Calabria, Italy
[4]Management and Health Laboratory & Interdisciplinary Center in Health Science, Sant'Anna School of Advanced Studies, Pisa, Italy

Received: 1 April 2025 / Accepted: 6 April 2026
Published online: 16 June 2026

References

1. OECD. Health at a Glance 2021 OECD indicators. Paris; 2021.
2. IAHPC. Global consensus based palliative care definition [Internet]. 2018. https://iahpc.org/what-we-do/research/consensus-based-definition-of-palliative-care/definition/.
3. Lin CP, Chu WM. Home-Based Palliative Care: Benefits, Challenges, Opportunities and Future Directions in a Super-Aged Society. J Hospice Palliat Care. 2025;28(3):81–8. https://doi.org/10.14475/jhpc.2025.28.3.81.
4. Higginson IJ, Sen-Gupta GJA. Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences. J Palliat Med. 2000;3(3):287–300. https://doi.org/10.1089/jpm.2000.3.287.
5. Wilson DM, Cohen J, Deliens L, Hewitt JA, Houttekier D. The Preferred Place of Last Days: Results of a Representative Population-Based Public Survey. J Palliat Med. 2013;16(5):502–8. https://doi.org/10.1089/jpm.2012.0262.
6. Bjørnelv G, Hagen TP, Forma L, Aas E. Care pathways at end-of-life for cancer decedents: registry based analyses of the living situation, healthcare utilization and costs for all cancer decedents in Norway in 2009–2013 during their last 6 months of life. BMC Health Serv Res. 2022;22(1):1221. https://doi.org/10.1186/s12913-022-08526-w.
7. Starfield B. Is Patient-Centered Care the Same As Person-Focused Care? Perm J. 2011;15(2):63–9. https://doi.org/10.7812/TPP/10-148.
8. Håkansson Eklund J, Holmström IK, Kumlin T, Kaminsky E, Skoglund K, Höglander J, et al. Same same or different? A review of reviews of person-centered and patient-centered care. Patient Educ Couns. 2019;102(1):3–11. https://doi.org/10.1016/j.pec.2018.08.029.
9. Slater L. Person-centredness: A concept analysis. Contemp Nurse. 2006;23(1):135–44. https://doi.org/10.5172/conu.2006.23.1.135.
10. Nuti S, De Rosis S, Bonciani M, Murante A. Rethinking Healthcare Performance Evaluation Systems towards the People-Centredness Approach: Their Pathways, their Experience, their Evaluation. Healthc Pap. 2017;17(2):56–64. https://doi.org/10.12927/hcpap.2017.25408.
11. Berry LL. Revisiting big ideas in services marketing 30 years later. J Serv Mark. 2016;30(1):3–6. https://doi.org/10.1108/JSM-10-2015-0318.
12. Sweeney JC, Danaher TS, McColl-Kennedy JR. Customer Effort in Value Cocreation Activities. J Serv Res. 2015;18(3):318–35. https://doi.org/10.1177/1094670515572128.
13. Berry LL, Parish JT, Dikec A. Creating value through quality service. Organ Dyn. 2020;49(3):100716. https://doi.org/10.1016/j.orgdyn.2019.04.002.
14. Karlsson S, Bleijlevens M, Roe B, Saks K, Martin MS, Stephan A, et al. Dementia care in European countries, from the perspective of people with dementia and their caregivers. J Adv Nurs. 2015;71(6):1405–16. https://doi.org/10.1111/jan.12581.
15. Harmon JR, Higgins I, Summons P, Bellchambers H. Efficacy of the use of evidence-based algorithmic guidelines in the acute care setting for pain assessment and management in older people: a critical review of the literature. Int J Older People Nurs. 2012;7(2):127–40. https://doi.org/10.1111/j.1748-3743.2010.00261.x.
16. Partinico M, Corà A, Ghisi M, Ouimet AJ, Visentin M. A New Italian Questionnaire to Assess Caregivers of Cancer Patients' Satisfaction With Palliative Care: Multicenter Validation of the Post Mortem Questionnaire-Short Form. J Pain Symptom Manage. 2014;47(2):298–306. https://doi.org/10.1016/j.jpainsymman.2013.03.018.
17. Needham C. Realising the Potential of Co-production: Negotiating Improvements in Public Services. Social Policy Soc. 2008;7(2):221–31. https://doi.org/10.1017/S1474746407004174.
18. Ryan B. Co-production: Option or Obligation? Australian J Public Adm. 2012;71(3):314–24. https://doi.org/10.1111/j.1467-8500.2012.00780.x.
19. Batalden M, Batalden P, Margolis P, Seid M, Armstrong G, Opipari-Arrigan L, et al. Coproduction of healthcare service. BMJ Qual Saf. 2016;25(7):509–17. https://doi.org/10.1136/bmjqs-2015-004315.
20. PENNUCCI F, DE ROSIS S, MURANTE AM. Behavioural and social sciences to enhance the efficacy of health promotion interventions: redesigning the role of professionals and people. Behav Public Policy. 2022;6(1):13–33. https://doi.org/10.1017/bpp.2019.19.
21. Kim KA, Park JS, Seo KW, Choi EY, Ahn JA. Factors affecting the quality of life of family caregivers of patients with heart failure: A cross-sectional study. Medicine. 2022;101(35):e30042. https://doi.org/10.1097/MD.0000000000030042.
22. Saraceno C. The ambivalent familism of the Italian welfare state. Soc Polit. 1994;1(1):60–82. https://doi.org/10.1093/sp/1.1.60.
23. Naldini M. The family in the Mediterranean welfare states. Routledge; 2004. https://doi.org/10.4324/9780203009468.
24. Saraceno C, Keck W. Can we identify intergenerational, policy regimes in Europe? Eur Soc. 2010;12(5):675–96. https://doi.org/10.1080/14616696.2010.483006.
25. Funk LM, Stajduhar KI, Outcalt L. What family caregivers learn when providing care at the end of life: A qualitative secondary analysis of multiple datasets. Palliat Support Care. 2015;13(3):425–33. https://doi.org/10.1017/S1478951513001168.
26. Wilson E, Caswell G, Turner N, Pollock K. Managing Medicines for Patients Dying at Home: A Review of Family Caregivers' Experiences. J Pain Symptom Manage. 2018;56(6):962–74. https://doi.org/10.1016/j.jpainsymman.2018.08.019.
27. Brenna E, Di Novi C. Is caring for older parents detrimental to women's mental health? The role of the European North–South gradient. Rev Econ Househ. 2016;14(4):745–78. https://doi.org/10.1007/s11150-015-9296-7.
28. Fahle S, McGarry K. Caregiving and work: the relationship between labor market attachment and parental caregiving. Innov Aging. 2018;2(suppl1):580–580. https://doi.org/10.1093/geroni/igy023.2150.
29. Vellone E, Riegel B, Alvaro RA, Situation-Specific. Theory of Caregiver Contributions to Heart Failure Self-care. J Cardiovasc Nurs. 2019;34(2):166–73. https://doi.org/10.1097/JCN.0000000000000549.
30. Hudson P. A conceptual model and key variables for guiding supportive interventions for family caregivers of people receiving palliative care. Palliat Support Care. 2003;1(4):353–65. https://doi.org/10.1017/S1478951503030426.
31. Kristjanson LJ, Aoun S. Palliative Care for Families: Remembering the Hidden Patients. Can J Psychiatry. 2004;49(6):359–65. https://doi.org/10.1177/070674370404900604.
32. Mularski RA, Dy SM, Shugarman LR, Wilkinson AM, Lynn J, Shekelle PG, et al. A Systematic Review of Measures of End-of-Life Care and Its Outcomes. Health Serv Res. 2007;42(5):1848–70. https://doi.org/10.1111/j.1475-6773.2007.00721.x.
33. Ringdal GI, Jordhøy MS, Kaasa S. Family Satisfaction with End-of-Life Care for Cancer Patients in a Cluster Randomized Trial. J Pain Symptom Manage. 2002;24(1):53–63. https://doi.org/10.1016/S0885-3924(02)00417-7.
34. Lorenz KA, Lynn J, Dy SM, Shugarman LR, Wilkinson A, Mularski RA, et al. Evidence for Improving Palliative Care at the End of Life: A Systematic Review. Ann Intern Med. 2008;148(2):147–59. https://doi.org/10.7326/0003-4819-148-2-200801150-00010.
35. Grunfeld E, Folkes A, Urquhart R. Do Available Questionnaires Measure the Communication Factors That Patients and Families Consider Important at End of Life? J Clin Oncol. 2008;26(23):3874–8. https://doi.org/10.1200/JCO.2007.15.8006.
36. Payne S, Hudson P, Grande G. Family carers research: What progress has been made? Palliat Med. 2022;36(3):NP9–10. https://doi.org/10.1177/02692163211037855.

37. Daly D, Matzel SC. Building a Transdisciplinary Approach to Palliative Care in an Acute Care Setting. OMEGA - J Death Dying. 2013;67(1–2):43–51. https://doi.org/10.2190/OM.67.1-2.e.
38. Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leighl N, Oza A, et al. Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. Lancet. 2014;383(9930):1721–30. https://doi.org/10.1016/S0140-6736(13)62416-2.
39. Zhang B, Nilsson ME, Prigerson HG. Factors important to patients' quality of life at the end of life. Arch Intern Med. 2012;172(15). https://doi.org/10.1001/archinternmed.2012.2364.
40. Anhang Price R, Stucky B, Parast L, Elliott MN, Haas A, Bradley M, et al. Development of Valid and Reliable Measures of Patient and Family Experiences of Hospice Care for Public Reporting. J Palliat Med. 2018;21(7):924–32. https://doi.org/10.1089/jpm.2017.0594.
41. Heyland DK, Cook DJ, Rocker GM, Dodek PM, Kutsogiannis DJ, Skrobik Y, et al. The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: the Canadian Health Care Evaluation Project (CANHELP) Questionnaire. Palliat Med. 2010;24(7):682–95. https://doi.org/10.1177/0269216310373168.
42. Novak M, Guest C. Application of a Multidimensional Caregiver Burden Inventory. Gerontologist. 1989;29(6):798–803. https://doi.org/10.1093/geront/29.6.798.
43. Chattat R, Cortesi V, Izzicupo F, Del Re ML, Sgarbi C, Fabbo A, et al. The Italian version of the Zarit Burden Interview: a validation study. Int Psychogeriatr. 2011;23(5):797–805. https://doi.org/10.1017/S1041610210002218.
44. Cheng Q, Xu B, Ng MSN, Zheng H, So WKW. Needs assessment instruments for family caregivers of cancer patients receiving palliative care: a systematic review. Support Care Cancer. 2022;30(10):8441–53. https://doi.org/10.1007/s00520-022-07122-2.
45. Creswell JW. Research design: qualitative, quantitative and mixed methods approaches. SAGE; 2013.
46. Morgan DL. Integrating qualitative and quantitative methods: a pragmatic approach. 1 Oliver's Yard, 55 City Road London EC1Y 1SP. SAGE Publications, Inc.; 2014. https://doi.org/10.4135/9781544304533.
47. Greene JC, Caracelli VJ, Graham WF. Toward a Conceptual Framework for Mixed-Method Evaluation Designs. Educ Eval Policy Anal. 1989;11(3):255–74. https://doi.org/10.3102/01623737011003255.
48. Denzin NK. Triangulation 2.0. J Mix Methods Res. 2012;6(2):80–8. https://doi.org/10.1177/1558689812437186.
49. Hanratty B, Lowson E, Holmes L, Addington-Hall J, Arthur A, Grande G, et al. A comparison of strategies to recruit older patients and carers to end-of-life research in primary care. BMC Health Serv Res. 2012;12(1):342. https://doi.org/10.1186/1472-6963-12-342.
50. Hasson F, Keeney S, McKenna H. Research guidelines for the Delphi survey technique. J Adv Nurs. 2000;32(4):1008–15. https://doi.org/10.1046/j.1365-2648.2000.t01-1-01567.x.
51. Wasserstein RL, Lazar NA. The ASA Statement on *p* -Values: Context, Process, and Purpose. Am Stat. 2016;70(2):129–33. https://doi.org/10.1080/00031305.2016.1154108.
52. Silverman D. Come fare ricerca qualitativa. Roma: Carocci; 2002.
53. Krippendorff K. Content analysis: an introduction to its methodology. 2455 Teller Road, Thousand Oaks (CA): SAGE Publications; 2019. https://doi.org/10.4135/9781071878781.
54. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. Health Aff. 2013;32(2):223–31. https://doi.org/10.1377/hlthaff.2012.1133.
55. Edwards RL, Bakitas M, Li P, Spence D, Kahwa E, Stoltenberg M, et al. Adaptation and psychometric testing of the end-of-life professional caregiver survey in Jamaica. BMC Health Serv Res. 2023;23(1):498. https://doi.org/10.1186/s12913-023-09497-2.
56. Samtleben C, Müller KU. Care and careers: Gender (in)equality in unpaid care, housework and employment. Res Soc Stratif Mobil. 2022;77:100659. https://doi.org/10.1016/j.rssm.2021.100659.
57. Nysaeter TM, Olsson C, Sandsdalen T, Hov R, Larsson M. Family caregivers' preferences for support when caring for a family member with cancer in late palliative phase who wish to die at home – a grounded theory study. BMC Palliat Care. 2024;23(1):15. https://doi.org/10.1186/s12904-024-01350-5.
58. Bjørnelv GMW, Edwin B, Fretland ÅA, Deb P, Aas E. Till death do us part: the effect of marital status on health care utilization and costs at end-of-life. A register study on all colorectal cancer decedents in Norway between 2009 and 2013. BMC Health Serv Res. 2020;20(1):115. https://doi.org/10.1186/s12913-019-4794-6.
59. Strasser A. HomeSearchBrowsePublishFAQ Delphi Method Variants in Information Systems Research: Taxonomy Development and Application. Electron J Bus Res Methods. 2017;15(2):120–32.
60. Hasson F, Keeney S, McKenna H. Revisiting the Delphi technique - research thinking and practice: a discussion paper. Int J Nurs Stud. 2025;168:105119. https://doi.org/10.1016/j.ijnurstu.2025.105119.
61. Kuipers SJ, Cramm JM, Nieboer AP. The importance of patient-centered care and co-creation of care for satisfaction with care and physical and social well-being of patients with multi-morbidity in the primary care setting. BMC Health Serv Res. 2019;19(1):13. https://doi.org/10.1186/s12913-018-3818-y.
62. Thaqi Q, Riguzzi M, Blum D, Peng-Keller S, Lorch A, Naef R. End-of-life and bereavement support to families in cancer care: a cross-sectional survey with bereaved family members. BMC Health Serv Res. 2024;24(1):155. https://doi.org/10.1186/s12913-024-10575-2.
63. Ervik B, Dønnem T, Johansen ML. Dying at home - a qualitative study of end-of-life care in rural Northern Norway from the perspective of health care professionals. BMC Health Serv Res. 2023;23(1):1359. https://doi.org/10.1186/s12913-023-10329-6.
64. Landers A, Pitama SG, Palmer SC, Beckert L. People that suffer or have been through it know the answers': stakeholders' perspectives on improving healthcare systems for end-of-life care in chronic obstructive pulmonary disease. BMC Health Serv Res. 2023;23(1):1443. https://doi.org/10.1186/s12913-023-10431-9.
65. Vainieri M, Spataro V, De Rosis S, Quattrone F, Nuti S. What matters most to the population in case of chronic conditions? Results from a discrete choice experiment in Italy. Health Policy (New York). 2025;161:105420. https://doi.org/10.1016/j.healthpol.2025.105420.
66. Jayanti RK, Burns AC. The Antecedents of Preventive Health Care Behavior: An Empirical Study. J Acad Mark Sci. 1998;26(1):6–15. https://doi.org/10.1177/0092070398261002.
67. Xu Y, Liu Y, Kang Y, Wang D, Zhou Y, Wu L, et al. Experiences of family caregivers of patients with end-of-life cancer during the transition from hospital to home palliative care: a qualitative study. BMC Palliat Care. 2024;23(1):230. https://doi.org/10.1186/s12904-024-01559-4.
68. Barello S, Graffigna G, Vegni E. Patient Engagement as an Emerging Challenge for Healthcare Services: Mapping the Literature. Nurs Res Pract. 2012;2012:1–7. https://doi.org/10.1155/2012/905934.
69. Graffigna G, Barello S, Bonanomi A, Lozza E. Measuring patient engagement: development and psychometric properties of the Patient Health Engagement (PHE) Scale. Front Psychol. 2015;6. https://doi.org/10.3389/fpsyg.2015.00274.
70. Graffigna G, Barello S, Riva G. How to Make Health Information Technology Effective: The Challenge of Patient Engagement. Arch Phys Med Rehabil. 2013;94(10):2034–5. https://doi.org/10.1016/j.apmr.2013.04.024.
71. Osborne SP, Radnor Z, Strokosch K. Co-Production and the Co-Creation of Value in Public Services: A suitable case for treatment? Public Manage Rev. 2016;18(5):639–53. https://doi.org/10.1080/14719037.2015.1111927.
72. Sherman DW. A Review of the Complex Role of Family Caregivers as Health Team Members and Second-Order Patients. Healthcare. 2019;7(2):63. https://doi.org/10.3390/healthcare7020063.
73. Valleggi A, Passino C, Emdin M, Murante AM. Differences in family caregiver experiences and expectations of end-of-life heart failure care across providers and settings: a systematic literature review. BMC Health Serv Res. 2023;23(1):429. https://doi.org/10.1186/s12913-023-09241-w.
74. De Rosis S, Cerasuolo D, Nuti S. Using patient-reported measures to drive change in healthcare: The experience of the digital, continuous and systematic PREMs observatory in Italy. BMC Health Serv Res. 2020;20(1):1–17. https://doi.org/10.1186/s12913-020-05099-4. PubMed PMID: 32299440.
75. De Rosis S, Bonciani M, Spataro V, Corazza I, Conti E, Sibbles B, et al. Value of Including the Children's Experience for Improving Their Rights During Hospitalization: Protocol for the VoiCEs Project. JMIR Res Protoc. 2023;12:e42804. https://doi.org/10.2196/42804.
76. Spezia N, Quattrone F, De Rosis S, Nuti S. The population experience observatory: a community-based approach to health in rural Tuscany, Italy. Eur J Public Health. 2025;35(Suppl4). https://doi.org/10.1093/eurpub/ckaf161.500.
77. Desai AD, Jacob-Files EA, Lowry SJ, Opel DJ, Mangione-Smith R, Britto MT, et al. Development of a Caregiver-Reported Experience Measure for Pediatric Hospital-to-Home Transitions. Health Serv Res. 2018;53(S1):3084–106. https://doi.org/10.1111/1475-6773.12864.

78. Palliative Care Definition. IAHPC. https://iahpc.org/research/consensus-based-definition-of-palliative-care/

Publisher's note

Marzia C. Severino PhD, is a post-doctoral researcher at the Interdisciplinary Center for Health Science of the Sant'Anna School of Advanced Studies. Her research focuses on the comparative analysis of long-term care systems and the evaluation of integrated socio-health services, with particular attention to the person-centered approach and the engagement of persons and communities. She explores how the experience and perspective of persons can be used as key tools for assessing and improving the quality of care, assistance, and service integration.

Costanza Galli MD, is Director of the Corporate Coordination of Palliative Care at "Azienda USL Toscana Nord-Ovest" and Director of the Palliative Care Unit (Zona Livornese), Livorno, Tuscany Region, Italy.

Sabina De Rosis PhD, works as Senior Assistant Professor in Management at the Department of Law, Economics and Human Science, at "Mediterranean" University of Reggio Calabria (Italy), and is affiliate researcher at Scuola Superiore Sant'Anna. Her research focuses on strategies to enhance personal, public and social value measurement, assessment and integration into the public and healthcare service definition, provision and evaluation.