### RESEARCH





# Practices for supporting relatives of patients in the agonal phase by an interdisciplinary team in palliative care units. consensus research (PROPAGE 2)

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#### Summary

**Context** In the absence of existing recommendations, the objective of this study was to establish a consensus of the support practices used in an interdisciplinary team in a palliative care unit (PCU) for the relatives of patients in the agonal phase.

Method This is a consensus study using the Delphi technique. 40 French PCUs participated in this study, including 204 professionals (nurses, nursing assistants, doctors, psychologists, social workers), 42 support volunteers and 32 relatives. These experts responded to a questionnaire comprised of a list drawn up from the results of a preliminary study conducted at Bordeaux University Hospital of 55 practices organised around four topics: providing care and ensuring comfort; communicating, informing and explaining; interacting; and mobilising interdisciplinarity skills.

Results Thirty-five practices were approved by the agreement of professionals, volunteers and relatives. 11 were approved only by professionals/volunteers and 6 only by relatives. Three practices were deemed inappropriate by participants.

**Conclusions** These results highlight consensual practices of care during agonal phase in specialized palliative care services and the importance of the quality of care given to patients, of counselling, and the attention paid to the relatives themselves. They will guide and enrich training modules for teams working with relatives.

Keywords Agonal phase, Care practices, Relatives, Interdisciplinarity, Palliative care

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#### Context

Since 2015, the support of relatives called "carers" was one of the actions of the three-year National Plan for the Development of Palliative Care (PC) and End-of-Life Support (2015-2018). Indeed, the support of relatives in palliative situations is an important area of work because of the psychological and social consequences of the patient's evolving situation. This support has been the subject of some non-specific studies in the agonal phase [1-5]. Relatives' ongoing search for balance between their social, family and carer role during the terminal phase. It also addresses the suffering and sometimes "the loneliness of the carer" while providing care and making decisions that continuously burden them, while having trouble admitting that they also need care for themselves [6]. In the absence of recommendations, we can only observe the heterogeneity of the practices even if no research studies report it objectively.

The agonal phase is characterised by the appearance of the first signs of decerebration and the alteration of neurovegetative regulatory functions [7]. It ends irreversibly with death. The agonal phase commonly evokes anxiety and suffering. Testimonies from both healthcare professionals in the Palliative Care Unit (PCU) and relatives show that this is a critical step, experienced intensely, is gruelling and potentially traumatic [8]. Relatives, already often affected by the course of the disease so far, face a major change in communication methods and often the appearance of the body, as well as new symptoms of mechanisms sometimes poorly identified [9-12], then at the time of death. Then, when this carer experience ends with the death of the patient, the relatives express the major impact on their daily life in recent months and more particularly the last moments of life. In the palliative care unit, they describe this period as a "bubble, a suspension of daily life" [6]. Supporting relatives before the death of a patient thus appears to be both a constant and a complex problem.

It has been shown that the conditions of this care and the experience of it can influence the course of the future grief [13]. Studies have shown that support for relatives can prevent psychiatric comorbidities after the death [14, 15] and that insufficiently preparing the relatives for the imminent death is associated with increased complications of grief, depression and anxiety.

However, the burden of grief in our society is significant, with physical, psychological, relational and social consequences (Research Centre for the Study and Observation of Living Conditions [CREDOC]), 2019) and communication that takes into account the clinical, practical, psychosocial and spiritual dimensions seems essential to prepare relatives for the death [16, 17]. Some tools for assessing the needs of carers exist in the context of PC such as the Carer Support Needs Assessment Tool Intervention (CSNAT-I), the Carers' Alert Thermometer (CAT) [18, 19] but currently healthcare professionals cannot refer to consensual practices.

The recommendations concerning PC do not address the last days of life very much and none of them are specific to supporting relatives during the agonal phase. In the United States, a national guide of consensual clinical practices for quality PC has been developed (Clinical Practice Guidelines for Quality Palliative Care by the National Coalition for Hospice and Palliative Care) [20]. It is a guide of evaluation, therapeutic and support practices to be proposed in the physical, psychological, social, spiritual, religious, existential, cultural, ethical and legal fields, part of which concerns patients "approaching the end of life". The need to inform and support loved ones dealing with an imminent death is mentioned. In Europe, the programme OPCARE 9 (a European Collaboration to optimise research for the care of cancer patients in the last days of life), which was developed as part of a European Commission project, aims to optimise research and clinical care in the last days of cancer patients' lives [21]. A significant proportion of the non-pharmacological activities cited deal with body care and contacts with patients and their families (verbal and non-verbal communication). However, no consensus could be established due to the variety of team composition and the loss of nuances when translating into the different languages of the European Union. Furthermore, the agonal phase is not specifically pinpointed in the term "final days of life".

Because of their mission and expertise, PCUs are structures conducive to a study of reflection and research around the support practices during the agonal phase. A preliminary study (PROPAGE 1) based on the methodology of focus groups has made it possible to characterise a wide range of practices [22]. In total, 214 practices were identified and then categorised according to 4 emerging themes: (1) Informing-Communicating-Explaining, (2) Interacting, (3) Mobilising skills in interdisciplinarity, and (4) Providing care and ensuring comfort.

Following this study, the objective of PROPAGE 2 study is to establish a consensus of the support practices used in an interdisciplinary team in a PCU for the relatives of patients in the agonal phase. For this, a wide range of actors with significant expertise and/or experience in this field (professionals, support volunteers, relatives) was consulted based on a Delphi technique. The purpose of this study is to create a document that can support teams in their missions to support relatives facing this critical agonal phase.

### Population and Method

#### Population

#### **Recruitment of PCUs**

40 PCUs were randomly selected from the 152 French PCUs (available at: https://sfap.org). In the event of refusal to participate or non-response, the random selection was continued until 40 participating PCUs were obtained. 35 PCUs refused to participate in the study and two no longer responded after the first contact. This sample size (40 PCUs) ensures satisfactory statistical power; the number of subjects recommended by the DELPHI methodology range from 15 to 60 participants [23, 24]. In order to guarantee the diversity of the PCUs interviewed, we have taken into account the national distribution, result of the survey carried out in 2013 by the National End-of-Life Observatory on PCUs in France (available at: https://reseaux-sante-ca.org/IMG/pdf/les\_usp\_en\_2013. pdf)] [25], including 62% in the public sector, 26% in the non-profit private sector, 12% in the for-profit private sector, and we ensured that there were no more than 3 PCUs in the same department of the country to prevent one region from being over-represented.

#### Recruitment of support professionals and volunteers

The PCU managers were contacted by email, telephone and/or video call with the necessary documentation (slides, information sheets, support sheet for recruiting relatives). After agreeing to participate, each PCU manager obtained the agreement of their team, then proposed 6 volunteer experts: a doctor (group 1), a nurse (N) (group 2), a nursing assistant (NA) (group 3), a psychologist (group 4), a social worker (SW) (group 5), a volunteer support coordinator (group 6). It was necessary to have worked in their role for at least 2 years, including at least one year in the participating PCU. These were people who did not participate in the PROPAGE 1 study or in the test phase of the questionnaire.

Some teams very eager to participate in the study could not be represented by the participation of an expert in each category. It was approved by the scientific committee of the study, for example, that in the absence of a volunteer, an additional doctor could be included, or that in the absence of a SW a psychomotor specialist could be included. These amendments involved 12 people and required the revision of the protocol.

#### **Recruitment of relatives**

A relative has been defined as the trusted person or person to be notified at the time of death, with their contact details being included in the patient file. They were considered an expert but not in the same way as the contributors from the PCU (professionals and volunteers). Furthermore, only relatives of patients who died in the PCU at least 6 months ago and who visited the unit during the last 3 days of the patient's life were selected. It was also necessary for the relative to understand and speak French sufficiently, have an email address and not be a healthcare professional in order to limit information bias when completing the questionnaire. Each team identified 10 relatives of patients who had died at least 6 months before then selected people at random. If the first person contacted accepted, the other people were not contacted, and if they refused, a new random draw was carried out.

#### **Consensus research method**

Consensus methods are particularly useful in situations where the practices of professionals are not homogeneous, and the data in the literature are insufficient. They consist of a systematic and structured approach. The DELPHI method is undoubtedly one of the most widely used. It is an iterative and interactive procedure. Participants are sampled to create a group of experts representative of current knowledge and/or perceptions.

Based on the list of support practices established during the PROPAGE 1 study [22], a questionnaire consisting of 55 proposals was developed for this study (Additional File 1) and tested with professionals, volunteers and relatives.

The questionnaire was addressed to the 7 categories of experts: 5 groups of professionals (N, doctors, NA, psy-chologists, SW), 1 group of volunteers, 1 group of relatives. Each expert answered the questionnaire.

Everyone received a link to access the online questionnaire via a secure platform. They were given 20 min to complete it. The survey consisted of three rounds.

Each round of voting was completed within 5, 4, and 3 months respectively and the entire procedure lasted 14 months.

The consensus-building procedure was in accordance with the DELPHI methodology [24] and followed the recommendations of the French Health Authority (HAS, 2010).

Responses were collected on Likert scales reflecting the degree of agreement with a suggestion (scored between 1 and 9) and/or as free comments. The assessment of the level of agreement between experts was based on the value of the median (i.e. the value obtained by at least 50% of experts). on the one hand and the distribution of quotations on the other hand. (This makes it possible to differentiate between a weak distribution in the direction of a strong agreement and a broader distribution in the direction of a relative agreement).

For each of the practices, the proposal was deemed appropriate with a strong agreement if the median was equal to 9. and the distribution of responses ranged from 7 to 9, with relative agreement if the median was = to 9 and the distribution of responses ranged from 5 to 9. The proposal was judged inappropriate with strong agreement if the median was < or = 3.5 and the distribution of responses ranged from 1 to 3, with relative agreement if the median was < or = 3.5 and the distribution of responses ranged from 1 to 5. The proposal was judged uncertain with indecision if the median was between 4 and 6.5 and the distribution of responses ranged from 1 to 9.

At the end of the first round of voting, the responses were analysed and the summary of the evaluations was sent to the participants.

In the second round of voting, for practices that did not gain consensus, each participant received the aggregated results of the group and a reminder of their own response. The participant could maintain his/her initial degree of agreement with a practice or reassess it in light of the group's response.

In the third round of voting, the same procedure was again applied. In the third round of voting, only those practices not deemed to be consensual with a strong agreement remained.

At the end of the third round, the answers were considered stabilised. The final results are therefore based on the answers obtained at the end of the third round.

#### Results

#### Inclusions and follow-up

Forty PCUs were included: 30 in the public sector (75%), 6 in the for-profit private sector (15%) and 4 in the non-profit private sector (10%).

One department of France is represented 4 times, two departments are represented 3 times and three departments are represented twice.

Two hundred seventy-eight people participated in the first round (246 professionals and volunteers, 32 relatives), and 219 in the third round (21.2% attrition rate from the first to the third round).

## Degree of agreement regarding practices in the different rounds

#### **Responses from relatives**

*Providing care and ensuring comfort* In the first round (R1), two out of 16 practices were considered appropriate with a strong degree of agreement (median 9): practices P18 "Providing comfort care before the relatives enter the room"; and P19 "Allowing relatives a moment of intimacy with the patient". In the second round (R2), the practice P20 "Taking into account the emotional state of relatives before entering the room" was deemed appropriate with a strong agreement.

In the third round (R3), the practice P21 "Ensuring someone can supervise young children in the family to allow the parents to have a moment alone together or facilitate a conversation" was considered appropriate with strong agreement.

Thus, at the end of the 3 rounds, 4 practices out of the 16 gained a consensus. Those that did not are practices P7 to P15 (see Table 1) and the following practices: P53 "Offering relatives the possibility to provide some care by themselves, with professionals (co-care), or to be present during care (taking into account their desire, their feeling of being useful, etc.)", P54 "Offering relatives a massage if the professional is trained", and P55 "Offering relaxation, hypnosis, EMDR (eye movement desensitisation and reprocessing) depending on the situation and if the professional is trained".

*Communicating, Informing, Explaining* Regarding the practices in this topic, from R1 onwards, 19 out of 20 practices were considered appropriate with a strong degree of agreement. The practice P36 "Notifying the relatives of the death in person or by telephone" was deemed appropriate with strong agreement in R3.

Thus, at the end of the 3 rounds, all practices gained a consensus.

*Interacting* With regard to the practices covered by this topic, 9 out of 11 practices were considered appropriate with a strong degree of agreement. The responses remained stable until R3.

Thus, at the end of the 3 rounds, 2 practices did not gain a consensus: P16 "Postponing non-urgent care while relatives are visiting", and P17 "Offering a listening ear or just sitting with them in silence (support volunteers), if the relatives wish".

*Mobilising skills in interdisciplinarity* The 8 practices in this topic were considered appropriate with a strong degree of agreement from R1.

#### Responses from professionals and volunteers

*Providing care and ensuring comfort* Thirteen out of 16 practices were deemed appropriate with a strong degree of agreement in R1. The responses remained stable until R3.

At the end of the 3 rounds, 3 practices did not gain consensus: P53 "Offering relatives the possibility to provide

	Number of	Number of complete questionnaires					
	Round 1 ( <i>n</i> = 278)		Round 2 ( <i>n</i> = 254)		Round 3 (n = 219)		
	n	%	n	%	n	%	
Relatives	32	11.5	29	11.4	22	10.1	
Volunteers	42	15.1	32	12.6	27	12.3	
Professionals	204	73.4	193	76.0	170	77.6	
Doctor	42	15.1	38	15.0	34	15.5	
Nurse	40	14.4	38	15.0	34	15.5	
Social worker	31	11.2	28	11.0	25	11.4	
Nursing assistant	42	15.1	40	15.6	36	16.5	
Psychologist	34	12.2	33	13.0	29	13.2	
Occupational therapist	1	0.4	1	0.4	1	0.5	
Psychomotor specialist	2	0.7	2	0.8	2	0.9	
Chaplain	2	0.7	2	0.8	2	0.9	
Social Worker	2	0.7	3	1,2	1	0.5	
Secretary	2	0.7	2	0.8	2	0.9	
Other (healthcare manager, physi- otherapist, etc.)	6	2.2	6	2.4	4	1.8	

#### Table 1 Number and distribution of responding participants

some care by themselves, with professionals (co-care), or to be present during care (taking into account their desire, their feeling of being useful, etc.)", P54 "Offering relatives a massage if the professional is trained", and P55 "Offering relaxation, hypnosis, EMDR (Eye movement desensitisation and reprocessing) depending on the situation and if the professional is trained".

*Communicating, informing, explaining* Fifteen out of 20 practices were deemed appropriate with a strong degree of agreement in R1.

The responses remained stable until R3.

At the end of the 3 rounds, 5 practices did not gain consensus: P1 "Informing relatives about what they can see in the room before entering it, and describing the medical devices and equipment once inside", P2 "Helping relatives spot the signs of the agonal phase that may appear", P3 "Providing explanations to relatives about the patient's condition, while touching and speaking to the patient", P4 "Making physical contact with relatives when the situation arises (hugging them, taking their hand)" and P5 "Talking to the relative about something other than the patient's situation".

*Interacting* All practices were deemed appropriate with a strong degree of agreement in R1.

*Mobilising skills in interdisciplinarity* Seve out of 8 practices were deemed appropriate with a strong degree of agreement in R1.

At the end of the 3 rounds, the practice P6 "Designing a project to support relatives in interdisciplinarity (using the genosociogram in particular)" still did not gain consensus.

The results are summarised in 3 tables: practices that gained consensus among relatives (Table 2), practices that gained consensus among professionals and volunteers (Table 3), and practices that gain consensus among professionals, volunteers and relatives (Table 4).

#### Discussion

In this survey, based on a wide range of practices, 35 of them obtained consensus among professionals, support volunteers and relatives with strong agreement, and 17 practices received relative agreement from some participants (professionals only or relatives only).

For the 35 consensual practices, even if the consensus is widely and strongly shared by experts, the relevance of each of these practices requires verification on a caseby-case basis, such as offering relatives to participate in certain care or anticipating the steps after death. They cannot be considered as practices to be adopted systematically. The palliative clinic retains this requirement Table 2 Practices deemed appropriate with strong agreement by relatives (value 9 for more than 50% of participants)

#### 1. Communicating, informing, explaining

P1. Informing relatives about what they can see in the room before entering it, and describing the medical devices and equipment once inside

- P2. Helping loved ones spot the signs of the agonal phase that may appear
- P3 Providing explanations to relatives about the patient's condition, while touching and speaking to the patient
- P4. Making physical contact with relatives when the situation arises (hugging them, taking their hand)

P5. Talking to the relative about something other than the patient's situation

2. Mobilising skills in interdisciplinarity

P6. Designing a project to support relatives in interdisciplinarity (using the genosociogram in particular)

of adaptation to the context, as well as adapting to situations. Rather, these are possible orientations of care to consider.

This study is part of the dynamics of one of the forms of intervention with carers considering them as "partners who have a voice in the definition and monitoring of aid plans, and who can be involved in obtaining informed consent" [26].

The distribution of PCUs across the country (75% in the public sector, 15% in the for-profit private sector and 10% in the non-profit private sector) is close to that from the surveys available. The survey conducted in 2013 by the National End of Life Observatory on PCUs in France reported 62% for the first category, 26% for the second and 12% for the third (available at: https://reseaux-santeca.org/IMG/pdf/lesuspen2013.pdf) [25], whereas the annual statistical survey of healthcare institutions carried out by the DREES (Direction de la Recherche, des Études, de l'Évaluation et des Statistiques [Board for Research, Studies, Assessment and Statistics]) in 2021 reported 70%, 20% and 10%, respectively (available at: https:// drees.solidarites-sante.gouv.fr/sites/default/files/2021-07/ES2021.pdf) [27]. The intention that there would be no more than 3 PCUs in the same department to prevent one geographical area from being over-represented was respected with one exception.

#### Global care approach and support for relatives

Four practices gained consensus for professionals, support volunteers and relatives regarding the topic "Providing care and ensuring comfort". This survey thus made it possible to refine the results of the PROPAGE 1 pilot study [22], since only 25% of the proposed practices were retained.

These practices are related to the comfort of the patient, the time spent privately with him/her or the team supervising the children while the relatives are talking or in the room. These are patient-centred practices either directly (P18) or indirectly (P19, P20, P21). Relatives give less strong agreement for practices more focused on them: offering a coffee, asking about their sleep, checking they are supported by others, etc. These practices seem suitable for them but with lesser agreement, while they are strongly highlighted by professionals and support volunteers. Relatives seem to express the idea that

**Table 3** Practices deemed appropriate with strong agreement by professionals/support volunteers (value 9 for more than 50% of participants)

#### 1. Providing care and ensuring comfort

P7. Caring for relatives by providing comfort care to the patient (washing, putting on perfume, doing hair and make-up, mobilising them, talking to them, putting on music, giving a manicure)

- P8. Paying attention to the physiological needs of relatives: "Are you eating and sleeping okay?"
- P9. Ensuring the comfort of relatives in the unit (offering a coffee, breakfast, snack, etc.)
- P10. Inviting relatives to leave the room, to use the family room so that they can have some time for themselves
- P11. Inviting relatives to take time for themselves (rest, enjoy a moment of pleasure)
- P12. Asking about absent relatives depending on the context (are they aware of the situation? Do they need support? etc.)
- P13. Ensuring that relatives have people around them to support them
- P14. Accepting a request from the family to put make-up on the patient after their death

P15. Personalising the support conversations according to the objectives set and the content (advance directives, family dynamics, experience of relatives, period after death)

#### 2. Interacting

P16. Postponing non-urgent care while relatives are visiting

P17. Offering a listening ear or just sitting with them in silence (support volunteers), if the relatives wish it

**Table 4** Practices deemed appropriate with strong agreement by professionals/supporting volunteers and relatives (value 9 for more than 50% of participants)

#### 1.Providing care and ensuring comfort

P18. Providing comfort care to the patient before relatives enter the room

P19. Allowing relatives a moment alone with the patient

P20. Taking into account the emotional state of relatives before entering the room

P21. Ensuring someone can supervise young children in the family to allow the parents to have a moment alone together or facilitate a conversation

#### 2. Communicating, informing, explaining:

P22. Answering questions about pain

P23. Explaining the care and its impact on the patient's well-being and their next steps

P24. Informing [relatives] that the patient is entering the agonal stage

P25. Explaining the patient's condition and visible symptoms

P26. Answering questions from relatives about how the patient perceives his/her condition

P27. Checking whether the answers provided are satisfactory to relatives

P28. Informing the relatives that carers will go into the room more often since the patient can no longer call

P29. Pre-empting by warning relatives that they will not necessarily be there at the time of death for those who wish to be

P30. Allowing relatives to express the wish not to be present at the moment of death

P31. Informing relatives that they can phone the department whenever they wish, even at night

P32. Anticipating steps that must be taken after death (clothing, paperwork, funeral, bereavement follow-up)

P33. Receiving a request for euthanasia from relatives (reminder of the ethical and legal framework, advance directives, trusted person, sedation, aim of treatment)

P34. Informing relatives of imminent death

P35. Respecting the wishes of relatives regarding the notification of death (Who to call? Call 24 h a day?)

P36. Notifying the relatives of the death in person or by telephone (time of silence, beginning of sentence, etc.) provided that the nurse is trained (institutional or on-the-job training)

#### 3. Interacting

P37. Greeting, approaching the relatives, and calling them in the corridor if you do not know them, demonstrating your availability non-verbally (with a look, a smile, an attitude), establishing a climate of trust

P38. Offering relatives an informal conversation in the corridor or in the room

P39. Offering a formal conversation, in a specific place (put up a sign or presence if the interview takes place in the room), with one or more relatives, to one or more professionals

P40. Offering a formal telephone conversation if the relative is far away or unable to travel

P41. Accompanying relatives to the room upon arrival if there has been a change in the patient's condition

P42. Taking into account the patient's socio-cultural and religious practices (treatment of the body, representatives from religious community)

P43. Supervising young children while the relatives are visiting (games suggested by the support volunteers)

P44. Offering relatives the possibility of staying overnight

P45. Encouraging the relatives to call on the doctors and team members

#### 4. Mobilising skills in interdisciplinarity

P46. Working in nurse-nursing assistant pairs (safety of care, availability for relatives)

P47. Offering a multi-professional conversation (range of viewpoints and skills)

P48. Offering a conversation for young children (with or without parents) in pairs of one psychologist and one other professional

P49. Tag team between peers (same role) in the event of a difficult situation

P50. Handing over to other members of the team (hospital professionals, doctors, psychologist, support volunteer, etc.) so that relatives meet representatives who can meet their needs

P51. Ensuring a mediator role between the team and relatives, to help them build or manage their relationships

P52. Providing opportunities for the healthcare team to speak (transmissions, multi-disciplinary meeting, analysis of professional practices with an external representative, discussion groups, etc.)

they are not the priority; care must be centred on the patient. These results are consistent with studies on the needs of relatives at home in which they prioritise patient care [17, 28], even if other results report the expectation

by relatives of recognition of their own needs [29]. One relative participating in this study told us: "I didn't want the staff to have too much work to do". Relatives seem to rely on the skills and expertise of the team that provides patient care to support them. Their main expectations, in this period marked by uncertainty, remain focused on humane patient care and a need for security and information [30]. This common expectation of relatives is fed by a need to feel safe for oneself and one's relative at the end of life following a prolonged care journey. It seems that during the agonal phase, some relatives express: "I'll be taken care of later, I am not the priority!", in a form of reluctance to be helped.

Supporting professionals and volunteers, for their part, position themselves as being responsible for supporting relatives with several objectives: to allow relatives to be more available to the patient after recharging their batteries, to think about the future when they will need to continue to take care of themselves and to live without the patient after his/her death [5, 31, 32].

Although relatives do not openly ask for these practices focused on them, these "little things" are valued in the literature [22, 33] as well as in the oral or written feedback of relatives after the patient's death: "A smile, a word, a gesture, silence, a moment of life... everything to do with considering the other person, attention paid to the other, *caring for them* as care" "[...] these little things illustrate: "the 'non-scientific' part that includes all professional action since, when someone else is present, the intuition of the action to be taken often precedes its conceptualisation and rationalisation. [...] It is there, in the "little things", that the theoretical and practical knowledge forged elsewhere is combined. With no fuss or frills" [34]. We can then think that these are practices not highlighted here by relatives yet still being important. Through the proposal of this care, professionals and volunteers seek to make this period as pain-free as possible. As a relative wrote in the comments section of the guestionnaire: "After that, only the memories remain".

Only professionals and support volunteers approve practices to postpone non-urgent care while relatives are visiting (P16) and support volunteers offering a listening ear or to sit with the relative in silence (P17). Relatives moderately subscribe to these practices, probably always in order to prioritise the needs of patients.

Several practices were not considered appropriate by all participants, professionals, volunteers and relatives: Offering relatives to provide care by themselves or along with a staff member, to attend care (taking into account their desire, their sense of usefulness...). (P53); massages for relatives (P54); relaxation, hypnosis, EMDR offered to relatives (P55), depending on the situation, if the professional is trained.

The professionals who took part in the research believe that offering relatives to participate in care can be considered but can also put them in a difficult position and cause "emotional overload". They recommend that relatives take time for themselves, that they allow themselves to get out of the role of carer that they may have had at home for weeks or months, or even years, to rest and to prioritise being a relative rather than a carer.

From the perspective of the relatives who took part in the research, care is the role of the care staff. They do not necessarily feel comfortable in this role, contrary to what can be found in the literature at other stages of the illness [35, 36]. These results confirm that "professionals must be cautious and can co-create care activities with family members" [29], with the palliative situation requiring adaptation to the situations and people encountered. Some relatives expressed "I am not a carer but I am present and ready to communicate and interact".

The practice of massage is commonly considered an ultimate care practice, leading to relaxation. This practice offered to relatives can increase well-being and can lead to a feeling of guilt for having it during the critical period for the patient who is passing from life to death. Practices relating to approaches of relaxation, hypnosis and EMDR are more conceivable by responders in extra-hospital follow-up, with the involvement of private-practice staff. Moreover, it should also be noted that the non-medicinal approaches developed in PCUs are not yet known by relatives.

#### Relationship dimension and support of relatives

Fifteen out of 20 practices have gained consensus from all participants in the topic "Communicating, Informing, Explaining". The expression of relatives, the information given on care, the possibility of contacting care staff at night, etc. are practices deemed relevant by all experts. Thus, there is a broad consensus on the methods of supporting relatives and the proposal of conversations.

Relatives present stronger agreement for more practices resulting from the topic "Communicating, Informing, Explaining" than professionals and support volunteers. Indeed, they value the information provided on the material used with the patient (P1), and are requesting information on the signs of the agonal phase (P2), while professionals mention their fear of increasing their anxiety by giving too much information about it. They stress the importance of checking what relatives wish to know. This request for information corroborates the results of the PROPAGE 1 study in which "relatives seem very sensitive to the possibility of saying goodbye to the patient and being present for the death [37], they are requesting information on the disease and on the future course [38]". In addition, time for sharing and information with families is valued in the literature as a factor reducing the stress of relatives and supporting their

relationship with team members who derive satisfaction from them [39]. Finally, relatives value being able to talk about something other than the illness (P5), which some find especially with friends and the chaplain. Professionals and support volunteers stress that it is of course necessary to check if this is what the relatives want, but it is possible to initiate it and desirable not to avoid such an exchange.

Relatives emphasise that they are in favour of physical touch from care staff, a non-verbal method of communication: touching the patient (P3) and them (P4). As Le Breton writes: "In certain circumstances, tactile communication no longer requires language, it brings people together in a profound way when words are lacking because of pain or emotion" [40]. Professionals are more reluctant when it comes to physical touch, questioning its purpose, mentioning their difficulties in this regard, sometimes finding this practice intrusive towards relatives.

The topic "Communicating, Informing, Explaining" also includes practices related to the upcoming death.

Anticipation of the steps to be taken after death (P32) is valued, but relatives specify that it is not necessary to anticipate too much, and professionals and volunteers add that it is a practice to be adapted to each individual relative.

The notification of death, in person or by telephone (P36), has raised many comments from carers. Some professionals mention that the person should not be alone when the death is announced, that they should be sitting down in a quiet place. As such, notifying the relative by telephone seems difficult for them, not being sure that the setting is suitable to break the news. Others believe that relatives should be notified of the patient deteriorating by phone if necessary, followed by recommending that they come in to see the patient. Finally, some professional carers say that relatives can be notified of the death by phone if they have already been informed that the patient is in the agonal phase and if the relative has decided not to travel. Some of the professionals emphasise that notifying relatives by phone is not their preferred method, and that they will ensure, if necessary, not to share anything if the person is driving and not to leave a voicemail message. We address the issue of training in notifying relatives of the death, particularly by phone: is there training and is it recommended? Are staff trained via sharing with peers, personal reading? Indeed, there is a legislative framework (Art. R1112 - 69), without specifying the methods of breaking the news [41], as well as recommendations (HAS, C.CLIN Paris-Nord, IGAS, etc.), publications [42, 43].

## Place of relatives in the support of patients in the agonal phase

Experts adhered to the majority of practices related to the topic of Interacting and Mobilising Skills in Interdisciplinarity.

They require interview times. One of the peculiarities of the agonal phase lies in the modification of the type of link within the triangle of the patient, the relative and the team members [44]. Some relatives who can no longer interact with the patient seem to find a role as the patient's spokesperson in the exchanges with the various team members, and a role in relaying information to family members, thus continuing to invest their role as a carer.

Although relatives do not always have precise knowledge about the PCUs and the care provided, they have their own perceptions about the agonal phase. As a primary carer, throughout the care journey they played a role in caring for and supporting the patient, relaying information to the healthcare teams. At this final stage, these roles and functions as carers need to be redefined [30]. We hold on to their request to be considered, if the situation permits, as full partners in what is being prepared for the patient and to be as close as possible to the progression of the disease.

Understanding the needs of loved ones and responding to them remains an adaptation challenge for care teams in PCUs.

They also consider it crucial for carers to share with each other. They value teamwork and times of sharing between the different actors [17, 45]. Different types of spaces for sharing dedicated to professionals were discussed: team transmissions, multi-disciplinary meetings, analysis of practices, discussion groups. Here we see the diversity of time offered to the teams according to the objectives and the dynamics in place. Indeed, such spaces allow teams to adjust the support as best they can [46, 47].

Relatives strongly approve the design of the project to support relatives (P6). Several professionals and support volunteers comment on the use of the genosociogram and some are not familiar with it. This tool, to be used with tact, confidentiality and no judgement, can be a helpful tool to find out who the patient's loved ones are [48]. Some participants wonder what the point of this tool is, how useful it is. They mention that it is potentially intrusive. This raises the question: "of how far to go in caring for the family?" One participant highlights the possible use of the genosociogram as a "projection weapon" by carers and volunteers according to their representations and what they would read through it. It is clear that the idea of a support project can take place with or without a genosociogram to help. Each team will have its own way of supporting relatives, the essential point remaining interdisciplinarity.

#### Strengths and limitations of the study

One of the strengths of the study is that it was carried out in two steps: the first step (PROPAGE 1) was able to identify a large number of practices, which allowed this survey to start from a very wide range of practices. Another strength lies in the sample size and the representation of different categories of actors in PCUs, including relatives. This study includes 40 participating PCUs and 278 respondents, which ensures satisfactory statistical power. The distribution of PCUs across the country is close to that reported by the available surveys.

The DELPHI methodology has several advantages, including limiting the effects of leadership or lack of assurance of some, with the answer to the questionnaire being individual. The interdisciplinary panel of participants can reconsider their response to each round and share their practices.

Last but not least, this is the first study seeking to objectively monitor the practices to support relatives during the agonal phase.

Regarding the limitations of the study, the study began before the end of the pandemic. Indeed, re-organisation of several units as well as the absence and unavailability of staff were observed. Then, some PCUs that wished to participate did not have one representative per category.

Furthermore, some participants did not understand the purpose of answering the questionnaire 3 times despite the explanations or did not answer certain parts as the situation described did not concern them. These limits may explain the attrition between round 1 and round 3, which, although acceptable, would probably have been less in another context.

Finally, we did not collect demographic data on the participants, such as age, ethnic origin or disability... These elements cannot therefore be taken into account when formulating recommendations for the next stages of the research design.

#### **Conclusion and perspectives**

This study highlighted consensual practices in PCUs regarding supporting relatives during the agonal phase. 35 practices were deemed appropriate by professionals, support volunteers and relatives. These practices should not be applied systematically but must be considered on a case-by-case basis, taking into account the specificities of the professional (adherence to the practice, skills, status in the team), the patient (wishes, perceptions, trauma, family context), and relatives (relationship to the patient, life context concerning physical, psychological, social aspects, etc.)

This scientifically approved list of practices can be used as a tool for reflection within care teams on their practices in agonal situations. It can also contribute to a better visibility of practices by professionals and volunteers, to highlight the needs of relatives, or to highlight innovative practices. Better support for relatives during the critical agonal phase could contribute to preventing difficult or even pathological grief. It can also help to change perceptions of the agonal phase. Disseminating this list will help promote quality of life at work and can help to welcome newcomers or contribute to creating a training programme for professionals and support volunteers.

From this study, the research perspectives are diverse. Implementing an interventional study would make it possible to assess the role of the list of practices in the refection of teams and the evolution of practices. These practices may also be researched in the various contexts of PC practice, through clinical trials (feasibility of transferring these practices to HAD (Hospitalisation à Domicile [home-based hospitalization services]), EHPAD (Etablissements d'hébergement pour personnes agées dépendantes [nursing homes]), LISP (lits identifiés de soins palliatifs [beds dedicated to palliative care]), EMSP (équipes mobiles de soins palliatifs [palliative care mobile teams]).

The results of this study may also contribute to improving support practices in other care settings that should benefit from such experience (medicine and intensive care departments where the frequency of death can be high and the feeling of failure and impotence of carers can be commonplace).

This is a "list of practices" that professionals can use and not "recommendations". Making recommendations could also be the subject of future work.

#### Supplementary Information

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Supplementary Material 1.

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#### Authors' contributions

M.M., C.R, V.B., H.H., B.P., N.S., V.B., H.A, B.B. participated to the conception of the research. M.M., C.R, M.F., V.B., H.H., B.P., N.S., O.P., V.B., H.A, B.B. contributed to the analyse and the interpretation of the results. M.M., C.R., H.A., B.B. wrote the main manuscript text. H.A. prepared Tables 1. and M.M., C.R. prepared Tables 2, 3 and 4. All authors (M.M., C.R, M.F., V.B., H.H., B.P., N.S., O.P., V.B., H.A, B.B.) reviewed the manuscript and have approved the submitted version (and any substantially modified version that involves the author's contribution to the study).

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Data availability

The data that support the findings of this study are available on request from the corresponding authors, [MM, CR]. The data are not publicly available due to restrictions their containing information that could compromise the privacy of research participants.

#### Declarations

#### Ethics approval and consent to participate

In accordance with French and European regulations, the opinion of an ethics committee is not required. The data processing has been registered with the data protection officer and the institution Bordeaux University Hospital (Bordeaux, France) has undertaken to comply with reference methodology 004 in accordance with the French Data Protection Act. The trial is also listed on the public portal clinicaltrials.gov under NCT04818684. All these steps are in line with our legal obligations.

#### **Consent for publication**

Not applicable.

#### **Competing interest**

The authors declare no competing interests.

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