

Original Article

Development of a Guide to Multidimensional Needs Assessment in the Palliative Care Initial Encounter (MAP)



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Abstract

Context. Ensuring patient-centered palliative care requires a comprehensive assessment of needs beginning in the initial encounter. However, there is no generally accepted guide for carrying out this multidimensional needs assessment as a first step in palliative intervention.

Objectives. To develop an expert panel-endorsed interview guide that would enable proactive and systematic Multidimensional needs Assessment in the Palliative care initial encounter (MAP).

Methods. A preliminary version of the MAP guide was drafted based on a published literature review, published semistructured interviews with 20 patients, 20 family carers, and 20 palliative care professionals, and a nominal group process with palliative care professionals and a representative of the national patient's association. Consensus regarding its content was obtained through a modified Delphi process involving a panel of palliative care physicians from across Spain.

Results. The published systematic literature review and qualitative study resulted in the identification of 55 needs, which were sorted and grouped by the nominal group. Following the Delphi process, the list of needs was reduced to 47, linked to six domains: Clinical history and medical conditions ($n = 8$), Physical symptoms ($n = 17$), Functional and cognitive status ($n = 4$), Psycho-emotional symptoms ($n = 5$), Social issues ($n = 8$), and Spiritual and existential concerns ($n = 5$).

Conclusion. MAP is an expert panel-endorsed semi-structured clinical interview guide for the comprehensive, systematic, and proactive initial assessment to efficiently assess multiple domains while adjusting to the needs of each patient. A future study will

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Key Words

Needs assessment, clinical interview, palliative care, hospices, Delphi technique

Key Message

We describe the development of a semi-structured clinical interview guide for the comprehensive, systematic and proactive Multidimensional needs Assessment in the Palliative care initial encounter (MAP) to efficiently assess 47 needs related to 6 domains of need.

Introduction

Addressing all a person's needs is crucial for achieving the goals of palliative care.^{1,2} Some attempts have been made to develop standardized needs assessment tools in palliative care, showing improvement in outcomes such as pain or depression.³ Systematic reviews have been carried out that report on the existing tools for the assessment of needs^{4,5} and for use in specific populations (e.g., heart failure, Parkinson's disease),^{6,7} all underscored the heterogeneity in domains covered, the degree of sensitivity or specificity, and even suggest more than one is necessary to achieve optimal assessment. Specific examples are the Edmonton Symptom Assessment Scale (ESAS) as a clinical tool to assess symptom burden in patients with advanced cancer⁸ and the Palliative Care Outcome Scale (POS) as a multidimensional assessment scale of quality of life.⁹ However, these tools are not widely implemented in clinical practice, nor comprehensive of all needs.^{10,11} These tools focus on the mere identification of symptoms (e.g., ESAS) or needs on numerical scales that constrict how the patient or family member expresses and explores the problems with the professional.

Concerns have been raised about whether the use of structured tools to assess patients is impersonal^{12,13} and a potential source of additional burden for both clinicians¹⁰ and frail patients.¹⁴ This is of relevance as palliative care professionals refer the need to be able to systematically assess all needs of patient while establishing a dialogue with the patient.¹⁵ Finally, there is limited consensus regarding the content of what constitutes a thorough assessment of needs,⁴ which may explain the high level of unmet needs reported by palliative care patients and their caregivers.¹⁶ Therefore, there is a need in palliative care for guidance on how to provide a multidimensional assessment adapted to each person's needs.

Guidance on the comprehensive assessment of needs in palliative care can be seen in the

comprehensive assessment used in geriatrics. Features shared by palliative and geriatric care are multidimensional patients' needs,¹⁷ and the potential for rapid deterioration and frailty of patients. The Comprehensive Geriatric Assessment goes beyond traditional medical assessment, incorporating a multidimensional and systematic approach that integrates biopsychosocial dimensions experienced in accelerated aging.¹⁸ Studies of its implementation have reported fewer hospital admissions,¹⁹ reduced functional decline,^{20,21} and increased odds of a patient being alive, in their own homes, and having intact cognitive function.²² This suggests that a systematic approach to needs assessment in palliative care could have similar benefits for patients to those observed in the geriatric population with evidence of better palliative care outcomes when a multidimensional approach is delivered.²³

We are currently engaged in a two-phase project to 1) develop and 2) test the feasibility of using in clinical practice a semistructured clinical interview guide for Multidimensional needs Assessment in the Palliative care (hereinafter, the MAP guide) initial encounter (defined as the first or first and second appointments with the palliative care team).²⁴ This paper describes a multi-step carried out with the aim of developing an expert panel-endorsed guide that would enable proactive and systematic assessment of needs in the palliative care encounter.

Methods

This study is part of a larger project that followed the Medical Research Council guidance for the development of complex clinical interventions.²⁵ The process of developing the MAP guide (Phase 1) involved four steps: Step 1) systematic review of needs assessment in palliative care (published study)⁴; Step 2) a qualitative study with patients, family carers, and palliative care professionals, and discussion within the research team (study in press)¹⁵; Step 3) nominal group with palliative care experts; and Step 4) modified Delphi process involving palliative care physicians ([Supplementary Fig. 1](#)). A future feasibility study of MAP guide application in clinical practice will be carried out in phase 2 of this ongoing project, the protocol for which (with detailed methods) has been published previously.²⁶ The systematic review (Step 1) and the qualitative study (Step 2)

are published previously and currently in press, respectively.^{4,15} The present study reports on the subsequent steps to develop and refine MAP (Steps 3 and 4).

Nominal Group

A preliminary set of items for inclusion in the MAP guide was drafted based on a previous systematic review,⁴ and the qualitative study.¹⁵ This formed the starting point for a nominal group with key stakeholders which aimed to explore opinions, generate ideas, and determine priorities through a face-to-face meeting²⁷ and define a framework for needs assessment in the palliative care initial encounter. The nominal group process took place in March 2021 and was conducted online via Google Meet due to restrictions associated with the COVID-19 pandemic. We followed a four-stage meeting process proposed by Van de Ven and Delbecq²⁸: 1) generating ideas, 2) discussion, 3) summary and conclusions, and 4) ranking or individual prioritization (Supplementary Table 1). Participants with diverse clinical profiles and a representative of the Spanish Patients' Association were selected to ensure heterogeneity and representation from all regions across Spain and contacted via email. These experts were proposed by the research steering committee due to their known expertise in the field and their active role in palliative care scientific association at regional and national level.

Questionnaire Development

The proposed list of needs resulting from this process was grouped by the research steering committee into domains that are commonly considered by palliative care professionals and which were agreed upon within the nominal group. The purpose of presenting needs in the form of a questionnaire was to enable participants in the Delphi process (see below) to give their expert opinion about what should be included in the MAP guide. The questionnaire was created using Survey Monkey, an online survey software, and the preliminary version was piloted by e-mailing it to three experts in the field (physicians with more than 10 years of experience in palliative care), who were asked to complete the questionnaire and confirm that the items were clearly worded and unambiguous.

Modified Delphi Process

A modified Delphi process involving palliative care experts from across Spain was then conducted by published guidelines on Conducting and Reporting DELphi Studies (CREDES) in palliative care.²⁹

Selection of Expert Panelists and Designing the Delphi Process

Panelists for the Delphi process were selected by means of intentional sampling. A list of potential

participants was drawn up by consulting the SECPAL (Spanish Palliative Care Society) Directory.³⁰ The list was then sent to 14 collaborating palliative care experts across Spain [1) more than 15 years of experience and 2) were hospital department chiefs of palliative care]. They were sent instructions to select potential panelists according to the following eligibility criteria: 1) palliative care physicians; 2) more than 5 years of experience in the field; and 3) who were recognized at regional and national level for their expertise in palliative care settings.

All those who met the inclusion criteria ($n = 136$) were invited by e-mail to participate and were sent a consent form. The email detailed the aims of the study, the tasks involved, the estimated time commitment, and the link to the online questionnaire. A total of 67 experts agreed to participate in the Delphi process. Sequential online questionnaires were completed individually and anonymously until a consensus was reached. Panelists were given three weeks to complete each round, with a reminder being sent out at the end of the second week. The task for each participant was to rate their agreement with each statement on a five-point Likert-type scale (from 1 = strongly agree to 5 = strongly disagree). The questionnaire also included a blank space where participants could make comments related to each statement.

Definition of Consensus

The Delphi rounds had two aims: 1) to obtain expert judgment about whether the proposed items should be included in a needs assessment for the palliative care initial encounter with patients and family carers, and 2) to gather any comments explaining why a given item should or should not be included in a needs assessment. It was decided that the Delphi process would include two or three rounds until consensus was reached (agreement $\geq 80\%$ for a given item). Results from the first round were collected and analyzed by the research team. Those items that did not reach the consensus threshold were then returned to the panelists for further rating. At this point they were informed of the results obtained for these items in the first round, namely their individual rating, the percentage of agreement reached by the panel as a whole, and any comments made. The same procedure was followed for the subsequent round.

Statistical Analysis

Data analysis was performed by two members of the research team (B. G. F, D. P.) using Microsoft Excel. The percentage agreement for each statement was calculated using the algorithm proposed by Tastle and Wierman.³¹

Ethical Approval

This study was approved by the ethics committee of the Universitat Internacional de Catalunya (ref. MED-2018-10).

Results

Nominal Group

Eight palliative care professionals (four physicians, two nurses, a psychologist, and a social worker) and a representative of the Spanish Patients' Association participated in the nominal group. All eight professionals were affiliated to reference centers for palliative care, seven of them had 12 or more years of clinical experience in the field (the exception was the psychologist), and they played an active role in palliative care scientific associations at regional and national level (Table 1).

The group agreed on the six domains that should be considered in the MAP guide: 1) Clinical history and medical conditions; 2) physical symptoms; 3) functional and cognitive status; 4) psycho-emotional symptoms; 5) social issues; and 6) Spiritual and existential concerns. However, there were differences of opinion and discussion with respect to which needs should be assessed in the initial encounter, especially as regards emotional problems, social aspects, and spiritual and existential concerns. The need to define what was understood by a standard initial encounter (45–60 minutes across one or two appointments) was acknowledged, and the nominal group also agreed that a complete version of the MAP guide should be reserved for those patients who were physically and emotionally stable at the time of the palliative care initial encounter. The outcome of the nominal group process was a questionnaire comprising 55 items (needs) grouped into six domains (Supplementary Table 2).

Modified Delphi Process

Of the 136 potential panelists who were contacted, 67 (49.3%) agreed to participate in the Delphi process,

which involved three rounds. Table 2 shows the characteristics of participants for each Delphi round.

Round 1: A total of 67 panelists participated in the first round of the Delphi process, with consensus (agreement $\geq 80\%$) being reached on 44 of the 55 proposed needs (Supplementary Table 3). The 11 items that did not yield consensus were primarily related to emotional problems and spiritual and existential concerns.

Round 2: The task for experts was to re-evaluate the 11 items that did not yield consensus in Round 1. Of the 67 original panelists, 53 (79.1%) participated in round 2. Consensus was only reached for 3 of the 11 items that the panel was asked to consider.

When analyzing responses in rounds 1 and 2 we observed that for items referring to the assessment of “the impact of being referred to palliative care, “hopelessness or pessimism about the future,” “the wish to hasten death,” “unresolved issues,” “talking about death and dying,” “perception of altered body image,” “feelings of guilt” and “religious beliefs and practices” a considerable proportion of experts chose the middle response option (“neither agree nor disagree”; see Supplementary Table 3), suggesting addressing these issues would depend on specific patient or circumstances. Review of the comments made by experts about these items indicated that while the majority agreed about the possibility of assessing these needs in the initial encounter, their preference was to leave these issues for a subsequent meeting with the patient.

Round 3: Only the eight items that had not yielded consensus in round 2 were presented to the panel for further evaluation. As this was the final round, the aim was to confirm whether or not these items were considered relevant, thus enabling us to outline the definitive list of needs that experts agreed should be assessed during the palliative care initial encounter. Given this aim, we changed the wording of the rating instruction for each item, from “It should be assessed in the initial encounter” to “It could be assessed in a first encounter.” To force a consensus either against or in favor of an item’s inclusion, we eliminated the middle response option “Neither

Table 1
Characteristics of the Experts Participating in the Nominal Group

	Professional Background (all Palliative Care)	Age (Years)	Years of Experience in Palliative Care	NUTS Code	Regions Represented ^a First-level NUTS	Second-level NUTS
Participant 1	Patient representative	58	10	ES1	North West	Galicia
Participant 2	Physician	66	30	ES1	North West	Galicia
Participant 3	Physician	54	25	ES6	South	Andalusia
Participant 4	Physician	49	20	ES7	Canary Islands	Canary Islands
Participant 5	Physician	63	22	ES2	North East	Aragon
Participant 6	Nurse	32	12	ES5	East	Catalonia
Participant 7	Nurse	57	19	ES3	Community of Madrid	Madrid
Participant 8	Psychologist	43	5	ES4	Centre	Extremadura
Participant 9	Social worker	44	14	ES5	East	Catalonia

^aCategorized according to the European Union’s Nomenclature of Territorial Units for Statistics (NUTS).

Table 2
Key Characteristics of the Expert Panellists in the Delphi Process

		Round 1 (n = 67)	Round 2 (n = 53)	Round 3 (n = 52)
Gender	Female	32	25	24
	Male	35	28	28
Profession	Physicians	67	53	52
Palliative care experience (in years)	5–9	5	5	5
	10–15	16	14	14
	16–20	11	11	11
	>20	35	23	22
Work setting	Domiciliary palliative care	7	6	6
	Inpatient hospice care unit	8	7	7
	Hospital palliative care support team	13	11	10
	Acute palliative care unit	7	7	7
	Outpatient palliative care service	1	1	1
	Multiple settings	31	21	21
Regions represented (First-level NUTS) ^a	North West	3	1	1
	North East	5	3	3
	Community of Madrid	12	10	10
	Centre	4	3	3
	East	27	22	21
	South	10	8	8
	Canary Islands	6	6	6

^aCategorized according to the European Union's Nomenclature of Territorial Units for Statistics (NUTS).

agree nor disagree." All but one of the 53 panelists who had participated in round 2 responded in round 3 (response rate of 98.11%). Consensus was reached for all 8 items, and in 7 cases the panel's final verdict was that the item should be retained. The one issue they considered should not be explored in the initial encounter concerned a possible wish to hasten death, and hence this item was not included in the definitive version of the MAP guide.

Final Design of the MAP Guide

Following the three-round Delphi process the MAP guide comprised 54 needs. However, analysis of the panelists' comments and their ratings in round 3 generated debate within the research steering committee, and it was decided to exclude those items which experts rated as optional for assessment in the initial encounter (Table 3). The final version of the MAP guide considers 47 needs linked to the aforementioned six domains: Clinical history and medical conditions ($n = 8$), Physical symptoms ($n = 17$), functional and

cognitive status ($n = 4$), psycho-emotional symptoms ($n = 5$), social issues ($n = 8$), and spiritual and existential concerns ($n = 5$) (Fig. 1).

Discussion

This study provides a template for systematic and proactive multidimensional needs assessment in palliative care, offering clinicians a semistructured interview guide for the initial encounter with patients and family carers. At the end of the Delphi rounds the proposed MAP guide comprised 54 needs linked to six domains congruent with those proposed by other authors.³² The number of needs was, however, ultimately reduced to 47, as the research steering committee decided to exclude those items which experts rated as optional in the initial encounter.

One strength of this study is our adherence to established guidelines for conducting Delphi studies in palliative care.²⁹ The nominal group was multidisciplinary and involved key stakeholders in the field and the questionnaire that resulted from the group was piloted before being sent to the Delphi panelists for appraisal.

A potential limitation of the present study is that the Delphi process only sought the opinions of palliative care physicians regarding needs assessment, whereas palliative care is based on an interdisciplinary model. That said, the MAP guide is designed to be used in the initial encounter, which normally will be physician led. However, this could be a limitation as physicians may not be the clinician group leading all initial encounters in all countries or institutions. Variability in the clinical experience of the experts consulted might also be a limitation, although the large majority in both the nominal group and Delphi process had at least 12

Table 3
Excluded Items from Final Version of MAP

Assessment area 1: Clinical History
Explore the impact of being referred to palliative care.
Assessment area 4: Psychological symptoms
Explore whether the patient experiences hopelessness or pessimism with respect to the future.
Explore whether the patient feels there are unresolved issues in their life.
Talk about death and dying.
Explore whether the patient experiences an altered body image.
Explore whether the patient experiences feelings of guilt.
Assessment areas 6: Spiritual and Existential Concerns
Ask the patient about any religious beliefs and/or practices.

Systematically assess and document information regarding:	
History and Medical Conditions	① <input type="checkbox"/> Patient understanding of reason for palliative care referral <input type="checkbox"/> Relevant medical history <input type="checkbox"/> Previous surgeries <input type="checkbox"/> Past or current substance abuse (alcoholism, smoking or other drugs) <input type="checkbox"/> Timeline from diagnosis, therapeutic interventions, to present status of illness <input type="checkbox"/> Current pharmacological treatment <input type="checkbox"/> Current complementary or alternative therapies <input type="checkbox"/> Expectations and impact of their current illness
Physical symptoms	② <input type="checkbox"/> Pain <input type="checkbox"/> Dyspnoea <input type="checkbox"/> Cough <input type="checkbox"/> Nausea / Vomiting <input type="checkbox"/> Constipation <input type="checkbox"/> Insomnia <input type="checkbox"/> Asthenia or Fatigue <input type="checkbox"/> General malaise <input type="checkbox"/> Anorexia <input type="checkbox"/> Daytime Sleepiness <input type="checkbox"/> Dry mouth <input type="checkbox"/> Urinary symptoms <input type="checkbox"/> Bleeding (any) <input type="checkbox"/> Changes to sensitivity <input type="checkbox"/> Weakness/Paresis <input type="checkbox"/> Myoclonus <input type="checkbox"/> Pruritus
Functional and cognitive status	③ <input type="checkbox"/> Degree of functional dependence <input type="checkbox"/> Cognitive status (attention/concentration, language, memory) <input type="checkbox"/> Presence/absence of hallucinations (visual, tactile, and/or auditory) <input type="checkbox"/> Need for information about their symptoms and causes, their treatment, and prognosis
Psycho-emotional symptoms	④ <input type="checkbox"/> Mood and affect (range, lability) <input type="checkbox"/> Presence/absence of anxiety <input type="checkbox"/> Presence/absence of a depressive episode <input type="checkbox"/> Current concerns/worries of the patient <input type="checkbox"/> Presence/absence of loneliness or social isolation
Social issues	⑤ <input type="checkbox"/> Identify the main caregiver <input type="checkbox"/> Genogram- depict family relationships <input type="checkbox"/> Perceived support (by patient and by main caregiver) <input type="checkbox"/> Organization of care at home (personal and health) <input type="checkbox"/> Level of open communication between patient and family <input type="checkbox"/> Family conflicts <input type="checkbox"/> Architectural barriers in the patient's home <input type="checkbox"/> Need for social assistance, telecare, and/or external support
Spiritual and existential concerns	⑥ <input type="checkbox"/> Aspects that help the patient to cope with their current situation <input type="checkbox"/> Religious beliefs and/or practices of the patient <input type="checkbox"/> What gives meaning to the patient's life <input type="checkbox"/> Core values in the patient's life <input type="checkbox"/> Aspects of life that are important to the patient in their current situation.

Fig. 1. Final design of MAP guide: Multidimensional needs assessment in the Palliative care initial encounter (MAP).

years' experience in the field. Our use of the SECPAL directory³⁰ to select potential Delphi panelists is a possible limitation as the information it contained might be outdated; however, the list of potential panelists was sent to collaborating palliative care experts for confirmation and selection of suitable experts.

To be noted not all physical symptoms included in MAP are relevant to all patients in palliative care (e.g., bleeding which may depend on the patients' specific disease process). However, MAP provides a guide to address the most prevalent needs experience by patients in palliative care regardless of their etiology (e.g., chronic illness, heart failure, cancer).

Some psycho-emotional issues were rated as optional for assessment in the initial encounter. A possible reason for the experts' ambivalence toward assessing emotional needs in the initial encounter is that doing so requires a degree of intimacy or bond with the patient that may not be present from the outset.³³ Another possible reason is the lack of skills healthcare professionals have to identify and explore emotional and/or spiritual needs.³⁴ One might also argue that a prudent approach to these issues is always advisable given the diversity of patients who are referred to palliative care (i.e., those undergoing active oncological vs. palliative treatments, those with complete knowledge of diagnosis and prognosis vs. mismatched expectations, etc.).

Although agreement regarding the importance of social issues was difficult to reach within the nominal

group, this was not the case in the Delphi process, where consensus was achieved in round 1 for seven of the eight items. Agreement was less forthcoming, however, in relation to the assessment of emotional and spiritual needs, end-of-life issues, and personal values and meaning in life. This reflects the findings of a recent systematic review on the comprehensive assessment of needs in palliative care,⁴ which highlighted the lack of consensus with respect to exploring emotional and spiritual needs. This is partly to be expected, given that healthcare professionals tend to avoid addressing these matters as they believe exploring them may be harmful to patients,³⁵ they feel that there is not sufficient bond³³ or they lack the skills to address these issues.³⁶ Research suggests, however, that patients are appreciative when these needs are addressed.³⁷ Given that psycho-emotional issues are known to have an impact on quality of life,^{38–40} the psychological impact of a life-threatening illness should clearly be part of a comprehensive assessment of needs.⁴¹ Failure to explore these issues could lead professionals to overlook important contributors to quality of life in patients with advanced disease.

A clear example of a psycho-emotional issue that generated differences in opinion in the Delphi process concerned exploring in the initial encounter a possible wish to hasten death. Although it is common for patients in palliative care to experience a wish to hasten death as a reaction to some form of suffering,⁴² this

issue was ultimately excluded from the proposed interview guide. While the goal of palliative care is to prevent and relieve suffering,⁴³ professionals often avoid discussion of death and dying as they fear it may be upsetting for the patient.^{44,45} Professionals may also want to avoid the association of palliative care with the end-of-life,⁴⁶ and as a result only explore the wish to hasten death if the patient refers to it openly.⁴⁷ Research suggests that healthcare professionals feel insufficiently prepared to address these matters,⁴⁵ although it has been shown that with adequate training they are able to engage patients in conversations about the wish to hasten death or desire to die.⁴⁸ Recent studies have found that exploring the wish to hasten death is not upsetting for patients, and in fact it may be important and helpful to do so proactively,^{49–51} and may serve to strengthen the therapeutic relationship with the patient.⁴⁸

This study is, to our knowledge, the first to present an expert panel-endorsed guide for the comprehensive, systematic, and proactive assessment of needs in the palliative care initial encounter. It paves the way for further research involving experts from other countries so as to adapt the MAP guide to different cultural contexts. In our view, routine use of this clinical guide could facilitate patient-professional communication, which is crucial to delivering quality palliative care,⁵² and allow patients to express all their concerns and needs.⁵³ Indeed, a primary goal of the MAP guide is to favor a meaningful initial encounter to foster a therapeutic alliance that can have a positive impact on the patient's quality of life.⁵⁴ The MAP guide will help to ensure that professionals consider variables that can be inconsistently documented⁵⁵ or missed entirely (e.g., the need for information) while providing an opportunity to establish a dialogue with the patient. MAP serves as a systematic guide to assess needs but allows flexibility for the professional to decide how to assess these needs while asking to the patient what is most relevant to them, without the obligation to complete a structured form, offering something more ecologically valid for clinical practice. Its application can elicit key information for the development of individualized care plans, helping to avoid unmet needs (of both patients and families) and, therefore, bringing greater equity to palliative care. We believe that the MAP guide provides a platform for training future professionals in needs assessment.

As we noted earlier, a feature shared by palliative and geriatric care is that patients' needs are multidimensional, and hence their assessment requires a more holistic approach. The Comprehensive Geriatric Assessment has been shown to be effective in improving quality of life outcomes in older adults,^{20,56} and in our view the MAP guide could be equally effective in the palliative care setting. Obviously, its clinical benefits

and impact on quality of life outcomes will need to be evaluated in future studies, as will the feasibility of its application in real-world clinical practice (i.e., within the timeframe of a palliative care initial encounter, comfortability of its use to professionals). This feasibility study would lay the groundwork for a randomized controlled trial to determine whether systematic and proactive needs assessment using the MAP guide is superior to usual practice.

Conclusions

The present study provides an expert panel-endorsed guide for the comprehensive, systematic, and proactive assessment of needs in the palliative care initial encounter. The MAP guide considers a total of 47 needs linked to six domains. By enabling the systematic assessment of needs across multiple domains, this semi-structured clinical interview guide can elicit key information for the development of individualized care plans, avoid unmet needs (of both patients and families) and, therefore, bring greater equity to palliative care.

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Supplementary Fig. 1. Process followed in developing the MAP guide (Multidimensional needs Assessment in the palliative care initial encounter).

Supplementary Table 1
Nominal Group Process

Predetermined Schedule for the Nominal Group		
Nominal Group Stages		Explanation of Each Stage
Stage 1	Generating ideas	The objectives of the nominal group were set out. Each participant was given a summary of the conclusions of the systematic review and the exploratory qualitative study. Questions were posed.
Stage 2	Discussion	Clarification of ideas from stage 1. Participants were invited to comment on each of the ideas concerning the identification of assessment areas, as well as the needs to be included in each area. Discussion was facilitated so as to ensure that each participant's contribution was taken into account.
Stage 3	Summary and conclusions	A summary of the discussion points was provided. Participants were asked to consider any additional ideas that arose from the discussion.
Stage 4	Ranking or individual prioritization	Assessment areas were agreed. All participants were asked to rank the different needs to be included in each assessment area.

Supplementary Table 2
Questionnaire Derived from the Nominal Group Process

Assessment Area 1: Clinical History and Medical Conditions	
1	Explore patient's understanding of reason for referral to palliative care.
2	Record the timeline from diagnosis through treatment to current status of the illness (whether by reviewing or verifying the clinical history or asking the patient directly).
3	Explore the impact of the illness on the patient and what their expectations are.
4	Explore the impact of being referred to palliative care.
5	Record potentially relevant medical history (allergies, common disorders such as hypertension, diabetes, dyslipidemia, psychopathology or prescription of psychotropic medication) (whether by reviewing or verifying the clinical history or asking the patient directly).
6	Record current pharmacological treatment (outpatient/domiciliary) or prior to admission, depending on the patient's circumstances (whether by reviewing or verifying the clinical history or asking the patient directly).
7	Record current complementary or alternative therapies (whether by reviewing or verifying the clinical history or asking the patient directly).
8	Record history of substance abuse (alcohol, smoking or other drugs) (whether by reviewing or verifying the clinical history or asking the patient directly).
9	Record any previous surgery (whether by reviewing or verifying the clinical history or asking the patient directly).
Assessment Area 2: Physical Symptoms	
Explore Systematically the Presence or Absence of the Following Symptoms (and If Present, When They Were Last Assessed):	
10	Pain
11	General malaise
12	Asthenia or fatigue
13	Anorexia
14	Dry mouth
15	Nausea/Vomiting
16	Constipation
17	Dyspnea

(Continued)

Supplementary Table 2
Continued

Assessment Area 2: Physical Symptoms

18	Cough
19	Bleeding
20	Insomnia
21	Daytime drowsiness
22	Numbness
23	Pruritus
24	Urinary symptoms
25	Weakness/Paresis
26	Myoclonus

Assessment Area 3: Functional and Cognitive Status

27	Assess degree of dependency
28	Assess cognitive status (attention, language/speech, memory)
29	Explore whether the patient has hallucinations (visual, tactile and/or auditory).
30	Explore the patient's need for more information about their symptoms and their cause, treatment and prognosis.

Assessment Area 4: Psychological Symptoms

31	Explore whether the patient has symptoms consistent with anxiety (psychosomatic symptoms, such as shortness of breath, tachycardia, hand tremor or sweats, dry mouth; irritability; fears, or excessive worry).
32	Explore the patient's mood.
33	Explore whether the patient has symptoms consistent with a depressive episode.
34	Explore whether the patient experiences hopelessness or pessimism with respect to the future.
35	Ask the patient about their present concerns.
36	Explore whether the patient has experienced or has a wish to hasten death (WTHD).
37	Explore whether the patient feels there are unresolved issues in their life.
38	Explore whether the patient experiences loneliness or social isolation.
39	Talk about death and dying.
40	Explore whether the patient experiences an altered body image.
41	Explore whether the patient experiences feelings of guilt.

Assessment Areas 5: Social Issues

42	Identify the main caregiver.
43	Ask both the patient and main caregiver about perceived support.
44	Explore how care is organized at home (personal and health-related).
45	Draw up a family tree.
46	Note how patient and family caregivers communicate with one another (open communication style?).
47	Explore whether there are any conflicts within the family.
48	Explore whether there are architectural barriers in the patient's home.
49	Explore whether there is a need for social care, telecare and/or external support.

Assessment Areas 6: Spiritual and Existential Concerns

50	Ask the patient about aspects of life that are important to them in their current situation.
51	Ask the patient about what helps them to cope with their current situation.
52	Ask the patient about hobbies or interests.
53	Ask the patient about any religious beliefs and/or practices.
54	Explore what brings meaning to the patient's life.
55	Explore the patient's core values in life.

Supplementary Table 3
Level of Agreement Reached by the Expert Panel for each of the Items Evaluated in the Delphi Process

N°	Questionnaire Items	Round	Summary Total Rating					% Agreement ^a	Reached Consensus >80%
			1 = Strongly Agree (%)	2 = Agree (%)	3 = Neither Agree nor Disagree (%)	4 = Disagree (%)	5 = Strongly Disagree (%)		
Assessment area 1: Clinical History and Medical conditions									
1	Explore patient's understanding of reason for referral to palliative care.	Round 1	55.22	32.83	8.96	1.49	1.49	87.26	Yes
2	Record the timeline from diagnosis through treatment to current status of the illness (whether by reviewing or verifying the clinical history or asking the patient directly).	Round 1	80.60	17.91	0.00	1.49	0.00	95.47	Yes
3	Explore the impact of the illness on the patient and what their expectations are.	Round 1	53.73	35.82	8.96	1.49	0.00	88.19	Yes
4	Explore the impact of being referred to palliative care.	Round 1	13.43	41.79	32.84	11.94	00.00	69.77	No
		Round 2	10.71	41.07	25.00	21.43	1.79	64.77	No
		Round 3	19.23	73.07	NA	7.69	0.00	80.00	Yes
5	Record potentially relevant medical history (allergies, common disorders such as hypertension, diabetes, dyslipidemia, psychopathology or prescription of psychotropic medication) (whether by reviewing or verifying the clinical history or asking the patient directly).	Round 1	89.39	9.09	1.52	0.00	0.00	97.58	Yes
6	Record current pharmacological treatment (outpatient/domiciliary) or prior to admission, depending on the patient's circumstances (whether by reviewing or verifying the clinical history or asking the patient directly).	Round 1	98.48	1.52	0.00	0.00	0.00	99.70	Yes
7	Record current complementary or alternative therapies (whether by reviewing or verifying the clinical history or asking the patient directly).	Round 1	71.21	25.76	3.03	0.00	0.00	93.68	Yes
8	Record history of substance abuse (alcohol, smoking or other drugs) (whether by reviewing or verifying the clinical history or asking the patient directly).	Round 1	87.88	12.12	0.00	0.00	0.00	97.63	Yes
9	Record any previous surgery (whether by reviewing or verifying the clinical history or asking the patient directly).	Round 1	65.15	25.76	9.09	0.00	0.00	91.13	Yes

Assessment Area 2: Physical Symptoms	Round	Summary Total Rating					% Agreement ^a	Reached Consensus >80%	
		1 = Strongly Agree (%)	2 = Agree (%)	3 = Neither Agree nor Disagree (%)	4 = Disagree (%)	5 = Strongly Disagree (%)			
Explore Systematically the Presence or Absence of the Following Symptoms (and If Present, When They Were Last Assessed):									
10	Pain	Round 1	98.46	1.54	0.00	0.00	0.00	99.70	Yes
11	General malaise	Round 1	95.00	5.00	0.00	0.00	0.00	99.02	Yes
12	Asthenia or fatigue	Round 1	96.92	3.08	0.00	0.00	0.00	99.40	Yes
13	Anorexia	Round 1	100	0.00	0.00	0.00	0.00	100	Yes
14	Dry mouth	Round 1	76.56	23.44	0.00	0.00	0.00	95.41	Yes
15	Nausea/Vomiting	Round 1	93.85	6.15	0.00	0.00	0.00	98.80	Yes
16	Constipation	Round 1	98.46	1.54	0.00	0.00	0.00	99.70	Yes
17	Dyspnea	Round 1	93.85	6.15	0.00	0.00	0.00	98.80	Yes
18	Cough	Round 1	81.54	18.46	0.00	0.00	0.00	96.39	Yes
19	Bleeding	Round 1	64.29	35.71	0.00	0.00	0.00	92.99	Yes
20	Insomnia	Round 1	96.92	3.08	0.00	0.00	0.00	99.44	Yes
21	Daytime drowsiness	Round 1	78.69	21.31	0.00	0.00	0.00	95.83	Yes
22	Numbness	Round 1	38.46	33.85	27.69	0.00	0.00	81.70	Yes
23	Pruritus	Round 1	41.54	33.85	24.62	0.00	0.00	83.00	Yes
24	Urinary symptoms	Round 1	61.02	38.98	0.00	0.00	0.00	92.36	Yes
25	Weakness/Paresis	Round 1	41.54	35.38	23.08	0.00	0.00	83.35	Yes
26	Myoclonus	Round 1	46.15	33.85	20.00	0.00	0.00	84.95	Yes

Assessment Area 3: Functional and Cognitive Status	Round	Summary Total Rating					% Agreement ^a	Reached Consensus >80%	
		1 = Strongly Agree (%)	2 = Agree (%)	3 = Neither Agree nor Disagree (%)	4 = Disagree (%)	5 = Strongly Disagree (%)			
27	Assess degree of dependency	Round 1	90.77	7.69	1.54	0.00	0.00	97.85	Yes
28	Assess cognitive status (attention, language/speech, memory)	Round 1	93.85	6.15	0.00	0.00	0.00	98.80	Yes
29	Explore whether the patient has hallucinations (visual, tactile and/or auditory).	Round 1	36.92	40.00	21.54	1.54	0.00	82.04	Yes
30	Explore the patient's need for more information about their symptoms and their cause, treatment and prognosis.	Round 1	46.15	41.54	10.77	1.54	0.00	86.27	Yes

Assessment Area 4: Psychological Symptoms	Round	Summary Total Rating					% Agreement ^a	Reached Consensus >80%	
		1 = Strongly Agree (%)	2 = Agree (%)	3 = Neither Agree nor Disagree (%)	4 = Disagree (%)	5 = Strongly Disagree (%)			
31	Explore whether the patient has symptoms consistent with anxiety (psychosomatic symptoms, such as shortness of breath, tachycardia, hand tremor or sweats, dry mouth; irritability; fears or excessive worry).	Round 1	69.23	26.15	3.08	1.54	0.00	92.53	Yes
32	Explore the patient's mood.	Round 1	89.23	10.77	0.00	0.00	0.00	97.89	Yes
33	Explore whether the patient has symptoms consistent with a depressive episode.	Round 1	64.62	26.15	7.69	1.54	0.00	90.58	Yes
34	Explore whether the patient experiences hopelessness or pessimism with respect to the future.	Round 1	38.46	27.69	24.62	9.23	0.00	77.85	No
		Round 2	14.81	51.85	16.67	16.67	0.00	71.26	No
		Round 3	15.38	73.0	NA	11.54	0.00	92.28	Yes
35	Ask the patient about their present concerns.	Round 1	86.15	13.85	0.00	0.00	0.00	97.29	Yes
36	Explore whether the patient has experienced or has a wish to hasten death (WTHD).	Round 1	13.85	27.69	35.38	20	3.08	62.77	No
		Round 2	0.00	40.74	29.62	28	1.85	58.40	No
		Round 3	3.95	38.46	NA	55.77	1.92	85.99	Yes
37	Explore whether the patient feels there are unresolved issues in their life.	Round 1	13.85	36.92	38.46	10.77	0.00	69.15	No
		Round 2	5.56	42.59	37.04	14.81	0.00	65.74	No
		Round 3	13.46	57.69	NA	28.85	0.00	87.36	Yes
38	Explore whether the patient experiences loneliness or social isolation.	Round 1	43.08	38.46	15.38	3.08	0.00	83.87	Yes
39	Talk about death and dying.	Round 1	4.62	29.23	53.85	10.77	1.54	62.60	No
		Round 2	3.70	33.33	48.15	12.96	1.85	62.25	No
		Round 3	1.92	50.00	NA	44.23	3.85	85.78	Yes
40	Explore whether the patient experiences an altered body image.	Round 1	16.92	23.08	52.31	7.69	0.00	68.14	No
		Round 2	7.41	57.41	20.37	14.81	0.00	69.88	No
		Round 3	13.46	69.23	NA	15.38	1.92	90.39	Yes
41	Explore whether the patient experiences feelings of guilt.	Round 1	7.69	29.23	52.31	9.23	1.54	64.31	No
		Round 2	0.00	43.40	33.96	20.75	1.89	60.85	No
		Round 3	9.61	48.07	NA	38.46	3.85	84.09	Yes

Assessment Areas 5: Social Issues	Round	Summary Total Rating					% Agreement ^a	Reached Consensus >80%	
		1 = Strongly Agree (%)	2 = Agree (%)	3 = Neither agree nor Disagree (%)	4 = Disagree (%)	5 = Strongly Disagree (%)			
42	Identify the main caregiver.	Round 1	98.46	1.54	0.00	0.00	0.00	99.70	Yes
43	Ask both the patient and main caregiver about perceived support.	Round 1	76.92	16.92	6.15	0.00	0.00	94.09	Yes

(Continued)

Supplementary Table 3
Continued

Assessment Areas 5: Social Issues		Round	Summary Total Rating					% Agreement ^a	Reached Consensus >80%
			1 = Strongly Agree (%)	2 = Agree (%)	3 = Neither agree nor Disagree (%)	4 = Disagree (%)	5 = Strongly Disagree (%)		
44	Explore how care is organised at home (personal and health-related).	Round 1	81.54	18.46	0.00	0.00	0.00	96.39	Yes
45	Draw up a family tree.	Round 1	66.15	24.62	9.23	0.00	0.00	91.29	Yes
46	Note how patient and family caregivers communicate with one another (open communication style?).	Round 1	53.85	35.38	10.77	0.00	0.00	88.54	Yes
47	Explore whether there are any conflicts within the family.	Round 1	30.77	40.00	21.54	7.69	0.00	77.80	No
		Round 2	26.42	62.26	7.55	3.77	0.00	81.97	Yes
48	Explore whether there are architectural barriers in the patient's home.	Round 1	53.85	35.38	7.69	3.08	0.00	87.72	Yes
49	Explore whether there is a need for social care, telecare and/or external support.	Round 1	64.62	29.23	6.15	0.00	0.00	91.69	Yes

Assessment Areas 6: Spiritual and Existential Concerns		Round	Summary Total Rating					% Agreement ^a	Reached Consensus >80%
			1 = Strongly Agree (%)	2 = Agree (%)	3 = Neither Agree nor Disagree (%)	4 = Disagree (%)	5 = Strongly Disagree (%)		
50	Ask the patient about aspects of life that are important to them in their current situation.	Round 1	55.38	33.85	10.77	0.00	0.00	88.84	Yes
51	Ask the patient about what helps them to cope with their current situation.	Round 1	53.85	40.00	6.15	0.00	0.00	89.58	Yes
52	Ask the patient about hobbies or interests.	Round 1	29.23	44.62	26.15	0.00	0.00	80.25	Yes
53	Ask the patient about any religious beliefs and/or practices.	Round 1	23.08	53.85	23.08	0.00	0.00	79.74	No
		Round 2	18.87	58.49	16.98	5.66	0.00	77.42	No
		Round 3	25.00	61.54	NA	13.46	0.00	88.53	Yes
54	Explore what brings meaning to the patient's life.	Round 1	29.69	42.19	23.44	4.69	0.00	78.63	No
		Round 2	35.85	54.72	9.43	0.00	0.00	85.27	Yes
55	Explore the patient's core values in life.	Round 1	31.25	35.94	31.25	1.56	0.00	78.71	No
		Round 2	32.08	50.94	11.32	5.66	0.00	81.30	Yes

^a% agreement calculated using the algorithm of Tastle and Wierman (2007).NA, not applicable as this response option was removed for Round 3.