

GENERATING CONSENSUS ON CORE, CLINICAL AND ETHICAL COMPETENCES OF DIETITIANS/NUTRITIONISTS IN PALLIATIVE CARE: A DELPHI STUDY

OBTENÇÃO DE CONSENSO SOBRE COMPETÊNCIAS CENTRAIS, CLÍNICAS E ÉTICAS DOS NUTRICIONISTAS NOS CUIDADOS PALIATIVOS: ESTUDO DELPHI

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ARTIGO ORIGINAL

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ABSTRACT

INTRODUCTION: The professional competences of dietitians/nutritionists in Palliative Care have been inadequately studied. Therefore, for dietitians/nutritionists to develop their work with scientific and technical rigour within an ethical framework, it is essential that their professional competences are clearly defined.

OBJECTIVES: To achieve a consensus on the professional competences required for dietitians/nutritionists in Palliative Care.

METHODOLOGY: This study applied the Delphi Methodology to achieve consensus over two rounds. An expert panel of dietitians/nutritionists with at least three years of professional experience in Palliative Care was established.

RESULTS: Through consensus among dietitians/nutritionists, a very high or high level of consensus was reached in 13 core, 26 clinical, and 18 ethical competences.

CONCLUSIONS: The final set of competences is consistent with those developed under international frameworks. The defined set of competences may enhance the professional practice of dietitians/nutritionists in Palliative Care.

KEYWORDS

Competence, Dietitian, Palliative care

RESUMO

INTRODUÇÃO: O papel dos nutricionistas nos cuidados paliativos tem sido alvo de pouca investigação. Assim, de forma a que os nutricionistas possam desenvolver o seu trabalho com rigor técnico-científico, baseado num ponto de vista ético, é necessário que estes tenham as suas competências profissionais muito bem definidas.

OBJETIVOS: Obter consenso relativamente a um conjunto de competências profissionais dos nutricionistas na área dos Cuidados Paliativos.

METODOLOGIA: Este estudo aplicou o Método Delphi para determinação de consenso em 2 etapas. Foi definido um painel de peritos composto por Nutricionistas que tivessem experiência de, pelo menos, três anos em serviços de cuidados paliativos.

RESULTADOS: Entre nutricionistas, obteve-se consenso elevado ou muito elevado em 13 competências centrais, 26 clínicas e 18 éticas.

CONCLUSÕES: O conjunto de competências finais estão em concordância com o que tem vindo a ser desenvolvido por grupos de trabalho internacionais. As competências definidas poderão contribuir para a melhoria da prática assistencial dos nutricionistas nos cuidados paliativos.

PALAVRAS-CHAVE

Competência, Nutricionista, Cuidados paliativos

INTRODUCTION

Palliative Care (PC) is an ethical, active, coordinated, and holistic approach to caring for individuals of all ages who experience serious health-related suffering due to severe illness, particularly those nearing the end of life. Its purpose is to enhance comfort and the quality of life for patients, their families, and caregivers. PC encompasses prevention, early recognition, comprehensive assessment, setting realistic care goals, and addressing physical issues, including pain, and other distressing symptoms, as well as psychological, spiritual and social needs. It provides support to enable patients to live as fully as possible until death (1).

PC is applicable throughout the course of an illness according to the patients' needs and is intended neither to hasten nor postpone death. It affirms life and acknowledges dying as a natural process. It provides support to the patients' family and caregivers during the illness and in their bereavement. PC is delivered with recognition and respect for the cultural values and beliefs of the patient and their family and it is applicable across all healthcare settings and at all levels of care. PC also requires a multiprofessional team for referral of complex cases (1). According to some authors the nutrition of the PC patients is frequently altered, leading to eating-related distress that arises in all life-limiting illnesses

sooner or later. The inclusion of dietitians/nutritionists in PC teams is strongly recommended to provide the most comprehensive and holistic nutritional care, as food and nutrition issues significantly contribute to the overall burden of total pain experienced by patients (2-12).

There is a scarcity of literature regarding dietitians/nutritionists' in PC and the information available is highly fragmented. For dietitians/nutritionists to perform their roles with greater scientific, technical, and ethical rigor, it is essential that they develop and define their professional competences and skills in PC (13).

OBJECTIVES

To establish consensus among dietitians/nutritionists regarding a defined set of professional competences in the field of PC.

METHODOLOGY

Study Design

The analytical study was developed in two stages, involving the determination, by consensus through the Delphi Method, of a set of competences for dietitians/nutritionists in PC. To this end, a panel of experts comprising dietitians/nutritionists with at least three years of experience in PC was used to form a convenience sample. The 61 competences employed in this study were those previously identified in a systematic review of the literature (9).

Expert Panel and Recruitment

To assemble an appropriate panel of experts for this research, it was first necessary to establish criteria for selecting the countries in which the experts would be approached. Professional associations in the field of nutrition and PC were identified and subsequently selected based on the level of PC development in their respective countries. The level of development was determined by the World Health Organization, which has classified countries into groups according to the 'Global Atlas of Palliative Care at the End of Life' (10).

According to this document, the countries with the highest level of development in PC are those classified within the following groups: "level 4b – advanced integration" and "level 4a - preliminary integration". Although Portugal was categorized under 'level 3b - generalized provision' it was also included, as this study originated from that country. With reference to the International Confederation of Dietetics Association (11), an online search was conducted to identify professional associations in the field of nutrition in countries classified under levels 4a, 4b and 3b. A total of 59 nutrition associations were identified. Additionally, an online search was carried out using the Global Directory of Palliative Care Institutions and Organizations of the International Association for Hospice & Palliative Care (12), resulting in the identification of 46 PC associations. An email was sent to all these associations in which the researcher outlined the study objectives and methods. In this email, associations were requested to disseminate this research among their members and/or to nominate at least two members who met the inclusion criteria and were available to participate in this research. To broaden the pool of experts, the research was also shared on social networking sites among groups of dietitians/nutritionists and PC practitioners, while maintaining the same inclusion criteria. A link to the informed consent was provided with a field where the experts could enter their email address for the subsequent distribution of questionnaires assessing 61 competences. Statistical data were analysed using the Statistical Package for the Social Sciences (SPSS)[®] version 25. A total of 60 potential experts agreed to participate in this study. However, 10 were excluded for not meeting the inclusion criteria. Ultimately, 50 experts took part in the first round, and in the second round, only 47 experts participated.

Delphi Rounds

In the first round, experts were asked to evaluate each of the 61 competences through an electronic questionnaire using a five-point Likert Scale: 1 - strongly disagree, 2 - disagree, 3 - neither disagree nor agree, 4 - agree and 5 - strongly agree. Additionally, each competence included a field for comments that experts could use. The degree of consensus was assessed using the following criteria (Table 1): the degree of agreement (percentage of experts who agreed and strongly agreed), the median, and the Interquartile Range (IQR) (13). In accordance with the Delphi process, all competences were carried forward to the second round to confirm consensus and provide experts with the opportunity to re-evaluate their own responses as well as those of all other experts. The panel of experts was characterized and analyzed based on the following variables: area of professional activity, age, gender, country, degree-specific training in PC (basic, advanced, and specialized training according to the criteria of the European Association for Palliative Care) (14), and length of professional experience in general and in PC. Descriptive statistics were employed for data analysis. In the second round, the questionnaire from the first round was returned to the 50 participating experts, along with the results of expert evaluations for each competence and the respective comments. The process allowed each expert to reflect on their own responses in light of the answers and comments of other experts, enabling them to reassess the decisions made in the first round.

To assess the level of consensus, the criteria outlined in Table 1 were applied. It was also established that only those achieving a high or very high level of consensus and agreement would be recognized as competence.

RESULTS

Expert Panel

The panel of 50 experts consisted of 58% (n=29) Nutritionists, 38% (n=19) dietitian-nutritionists, and 4% (n=2) of dietitians. In terms of gender, 78% (n=39) were female and 22% (n=11) male. Age ranged from 27 to 61 years old, with a mean of 43.06 ± 9.45 years old and a median of 42.5 years old.

The country with the highest number of participants was Portugal, representing 52% (n=26), followed by the United Kingdom with 10% (n=5), 6% (n=3) from the United States of America, 6% (n=3) from Israel, 6% (n=3) from New Zealand, 4% (n=2) from the Netherlands, 4% (n=2) from Norway, 4% (n=2) from Germany, 2% (n=1) from Switzerland, 2% (n=1) from Sweden, and 2% (n=1) from Canada.

With respect to the place of employment, 54% (n=27) were from hospital settings, 24% (n=12) worked in primary care, 20% (n=10) worked at hospice care, and 2% (n=1) were employed in private practice. Concerning training in PC, 26% (n=13) had no training, 34% (n=17) received basic training, 20% (n=10) had advanced training and 20% (n=10) underwent specialized training.

Table 1

Criteria of level of consensus and agreement (13)

DEGREE OF CONSENSUS	A (%)	X	IQR
Very High	≥ 80	5	0
High	< 80	≥ 4	1
Moderate	60-79	≤ 4	1
Low	< 60	4	> 1

A: Agreement

x: Median

IQR: Interquartile Range

When grouped by periods of professional experience, 12% (n=6) had between 0 and 5 years, 14% (n=7) between 6 and 10 years, 16% (n=8) between 11 and 15 years, 26% (n=13) between 16 and 20 years, 24% (n=12) between 21 and 25 years, 8% (n=16) between 26 and 30 years, 10% (n=5) between 31 and 35 years. Overall, the length of professional experience ranged from 3 to 35 years, with a mean of 17.18 ± 8.91 years, and median of 18.00 years.

When grouped by periods of professional experience in PC, 34% (n=17) had 3 to 5 years of experience, 30% (n=15) had 6 to 10 years, 20% (n=10) had 11 to 15 years, 12% (n=6) had 16 to 20 years, and 2% (n=1) had 21 to 25 years of experience in PC. Regarding the length of professional practice in PC, it ranged from 3 to 25 years, with a mean of 9.48 ± 6.43 years, and median of 8.00 years.

Core, Clinical and Ethical Competences

Regarding Core Competences, in the second round, it was confirmed that competences numbered 1-3,6-11, and 13 achieved a very high level of agreement and consensus. Competences numbered 4, 5 and 12 obtained a high level of agreement and consensus.

In terms of Clinical Competences, during the second round, competences numbered 11-22,25-30 reached a very high level of agreement and consensus. Competences numbered 1-6,9-10 achieved a high level of agreement and consensus while competence number 7 obtained a moderate level of agreement and consensus. Competences numbered 8, 23 and 24 obtained a low level of agreement and consensus.

Regarding Ethical Competences, in the second round all competences reached a very high level of agreement and consensus, except for competence number 5, which obtained a high degree of agreement and consensus (Table 2).

Table 2

Results of core, clinical and ethical competences from the first and second rounds

COMPETENCES/ ROUNDS		FIRST				SECOND			
CORE		A (%)	X	IQR	C	A (%)	X	IQR	C
1	Apply the core constituents of PC in the setting where patients and families are based.	98	5	1	H	100	5	0	VH
2	Demonstrate the ability to use the PC approach as early as is appropriate to facilitate person-centered practice that recognizes the concerns, goals, beliefs and culture of the person and her/his family.	90	5	1	H	100	5	0	VH
3	Enhance physical comfort throughout patients' disease trajectories.	80	4	1	H	97.9	5	0	VH
4	Meet patients' psychological needs.	80	4	1	H	95.7	5	1	H
5	Meet patients' social needs.	84	4	1	H	95.7	5	1	H
6	Meet patients' spiritual needs.	96	5	1	H	100	5	0	VH
7	Respond to the needs of family caregivers in relation to short, medium- and long-term patient care goals.	98	5	1	H	97.5	5	0	VH
8	Respond to the challenges of clinical and ethical decision-making in PC.	100	5	1	H	100	5	0	VH
9	Practice comprehensive care co-ordination and interdisciplinary teamwork across all settings where PC is offered.	100	5	1	H	100	5	0	VH
10	Develop interpersonal and communication skills appropriate to PC.	98	5	1	H	100	5	0	VH
11	Provide empathetic care to individuals with life-limiting conditions and their families, with clear regard to the individuality of each person.	98	5	1	H	100	5	0	VH
12	Practice self-awareness and undergo continuing professional development.	100	5	1	H	100	5	1	H
13	Show a commitment to developing self-care strategies and to attending to any impact that working with people facing life-limiting conditions and their families may have on you.	100	5	1	H	100	5	0	VH
CLINICAL		A (%)	X	IQR	C	A (%)	X	IQR	C
1	Understand and be able to recognize the physical, psychological, social, and spiritual issues that may precipitate dietary concerns for people in PC and their families from diagnosis through death.	90	5	1	H	100	5	1	H
2	Understand, recognize, and address the management of pathological responses to eating-related losses which may impact on behaviour and decision-making of individuals in palliative and end of life care and families.	96	4	1	H	100	5	1	H
3	Understand total pain concept and its relation to food/ nutrition and hydration.	98	5	1	H	97.9	5	1	H
4	Provide education to individuals with life-limiting conditions, their caregivers, and colleagues in the context of your role as a Dietitian/ Nutritionist and at an appropriate level.	84	4	1	H	97.9	5	1	H
5	Demonstrate an advanced knowledge, and understanding of the full spectrum of trajectories of life-limiting conditions and their impact on nutritional management when responding to complex and multidimensional care needs.	74	4	1	M	97.9	5	1	H
6	Develop, facilitate, and provide education, leadership, mentorship and professional support for colleagues, generalist and specialist providers of PC regarding clinical nutrition.	74	4	1	M	97.9	5	1	H
7	Lead, facilitate and engage in further education, research, and audit in palliative care.	72	4	1.25	H	66.0	4	1	M

Table 2

Results of core, clinical and ethical competences from the first and second rounds (continuation)

8	Design research projects in line with PC service needs, collaborating with all relevant stakeholders in respect of research issues.	86	5	1	<i>H</i>	49.0	3	0	VH
9	Act as an expert resource providing and advising on undergraduate and postgraduate education in the domain of dietetics/ clinical nutrition in PC.	92	4.5	1	<i>H</i>	100	5	1	H
10	Training of other health professionals in the areas of nutrition science in palliative and end-of-life care.	94	5	1	<i>H</i>	97.9	5	1	H
11	Assessment of nutritional status at the individual level.	98	5	0	<i>VH</i>	100	5	0	VH
12	Assessment of food history and dietary intake.	100	5	0	<i>VH</i>	100	5	0	VH
13	Assessment of eating-related symptoms.	96	5	0	<i>VH</i>	100	5	0	VH
14	Interpretation of biochemical data.	96	5	0	<i>VH</i>	100	5	0	VH
15	Individual nutritional care provision, developing nutritional diagnosis based on clinical, biochemical, anthropometric, and dietary data.	100	5	0	<i>VH</i>	100	5	0	VH
16	Assessment of needs and wishes for food with relatives and family.	96	5	0	<i>VH</i>	100	5	0	VH
17	Prescription, planning, analysis, monitoring and evaluation of therapeutic food plans.	100	5	0	<i>VH</i>	100	5	0	VH
18	Modification of food texture to personalize dietary plans and meals.	98	5	0	<i>VH</i>	100	5	0	VH
19	Management of eating-related symptoms.	98	5	0	<i>VH</i>	100	5	0	VH
20	Enteral and parenteral nutrition prescription and adapted staples, used for special purposes.	94	5	1	<i>H</i>	100	5	0	VH
21	Prescription of nutritional supplements.	96	5	1	<i>H</i>	100	5	0	VH
22	Interface with the food service and the hospital kitchen to personalize meals.	94	5	1	<i>H</i>	100	5	0	VH
23	Being present in family reunions, as long as other health care team members, in order to discuss nutritional support by oral or artificial route and clarify myths, doubts and myths surrounding feeding and hydration in the end of life.	24	3	0.25	<i>L</i>	31.9	3	2	L
24	Being present near families in the last days or hours of life to clarify doubts, fears and myths surrounding nutrition and hydration.	32	3	2	<i>L</i>	57.4	4	2	L
25	Demonstrate deep knowledge about the meaning of food and fluids in the context of palliative and end-of-life care.	94	5	1	<i>H</i>	97.9	5	0	VH
26	Demonstrate deep knowledge about the social meaning of food and fluids.	94	5	1	<i>H</i>	100	5	0	VH
27	Demonstrate deep knowledge about the psychological meaning of food and fluids.	96	5	1	<i>H</i>	100	5	0	VH
28	Demonstrate deep knowledge about the spiritual meaning of food and fluids.	86	5	1	<i>H</i>	100	5	0	ME
29	Demonstrate deep knowledge about the meaning of oral feeding and drinking.	96	5	1	<i>H</i>	100	5	0	VH
30	Demonstrate deep knowledge about the meaning of artificial nutrition and hydration.	98	5	1	<i>H</i>	100	5	0	VH
ETHICAL		A (%)	X	IQR	C	A (%)	X	IQR	C
1	Work within your current Code of Professional Conduct and engage ethically, knowledgeably, and respectfully with other healthcare areas.	100	5	0	<i>VH</i>	100	5	0	VH
2	Recognize the limits of the dietitian/ nutritionist intervention.	100	5	1	<i>H</i>	100	5	0	VH
3	Apply an advanced understanding of contemporary legal, ethical, and professional standards to the provision of quality PC therapy services.	100	5	0	<i>VH</i>	95.7	5	0	VH
4	Recognize and respect your professional responsibility to care for people with life-limiting conditions and their families to ensure their comfort and dignity from diagnosis through death.	98	5	1	<i>H</i>	97.8	5	0	VH
5	In the context of professional scope of practice and/ or role, anticipate and demonstrate the ability to address potential ethical issues such as withdrawal and withholding of artificial hydration and feeding.	96	5	1	<i>H</i>	95.7	5	1	H
6	Be able to establish and respect people's wishes about their care and options/ preferences. This includes recognizing people's right to make informed decisions to refuse additional treatments of artificial nutrition and hydration.	96	5	1	<i>H</i>	97.9	5	0	VH
7	Respecting advance care plans made by people where the decision is an informed choice and relates to the situation that has arisen.	92	5	1	<i>H</i>	97.9	5	0	VH
8	Demonstrate a commitment to engage in anti-discriminatory practice in relation to end of life care and service delivery.	94	5	1	<i>H</i>	93.6	5	0	VH
9	Be aware of ethical and legal issues that may arise regarding artificial nutrition support in the palliative and end of life care.	92	5	1	<i>H</i>	97.9	5	0	VH

Table 2

Results of core, clinical and ethical competences from the first and second rounds (continuation)

10	Demonstrate an understanding of the difference between managing a life-limiting condition and providing end of life care to an individual with a life-limiting condition.	98	5	1	H	97.9	5	0	VH
11	Be able to facilitate discussion and resolution of ethical and legal issues with the multidisciplinary team, individuals with life-limiting conditions and families that may arise in relation to artificial nutrition support.	98	5	0	VH	100	5	0	VH
12	Demonstrate deeply understanding about the ethical principles of autonomy, beneficence, non-maleficence and justice.	100	5	0	VH	100	5	0	VH
13	Demonstrate a deep understanding about the principles of integrity, dignity and vulnerability.	100	5	0	VH	100	5	0	VH
14	Demonstrate a deep understanding about the distinction of basic human care and medical treatment regarding the use of artificial nutrition and hydration.	100	5	0	VH	100	5	0	VH
15	Demonstrate deeply understanding about proportionate versus disproportionate feeding and hydration.	100	5	0	VH	100	5	0	VH
16	To deeply understand and distinguish withhold or withdrawn artificial nutrition and hydration from the concepts of euthanasia and assisted suicide.	90	5	0	VH	100	5	0	VH
17	Act collaboratively in the multidisciplinary team in the cases of voluntary cessation of eating and drinking.	92	5	1	H	100	5	0	VH
18	Demonstrate knowledge about the implications of advanced directives by proxies or living will in nutritional support.	92	4.5	01	H	100	5	0	VH

x̄ : Median
 A: Agreement
 C: Consensus

H: High
 IQR: Interquartile Range
 L: Low

M: Moderate
 PC: Palliative Care
 VH: Very High

DISCUSSION OF THE RESULTS

This study represents the first attempt in Portugal to define, through consensus, a set of professional competences of dietitians/nutritionists in PC. The consensus was established by a panel of dietitians/nutritionists with at least three years of professional experience in PC, ensuring their familiarity with the strengths and limitations of working in PC wards. Furthermore, the experts demonstrated a strong commitment to this study, as indicated by the low drop-out rate between rounds (6%) (15).

Consensus generated through expert opinion contributes to solutions for real-world problems with direct and practical results. However, the Delphi Process by itself, has certain limitations and disadvantages: the non-universality of consensus criteria, the method of selecting experts, the non-generalizability of results, the inability for joint reflection, the possibility of altering initial positions as well as the lack of value assigned to opinions outside the consensus. Among the various consensus criteria suggested by different authors, a combination of strict, sensitive and selective criteria was chosen, enabling both consensus and agreement to be achieved (15-20).

By integrating the level of agreement with the competence, the median, and the IQR, the authors believe they have established a fair and conservative system. As with the agreement and consensus criteria, there is no unanimity among the authors regarding the experts' characteristics (13). The number of experts in both rounds exceeded the minimum required for this type of study (15-50 experts) (20). Overall, of the 61 competences initially submitted for evaluation, 93% (n=57) met the pre-established consensus criteria for selection, and no additional competences were added by the experts during the Delphi process.

Clinical competences numbered 23 and 24 received a low degree of agreement and consensus, since it is uncommon for dietitians/nutritionists to be involved at such a terminal stage of the disease, given that their potential role is typically fulfilled in earlier stages. Nevertheless, dietitians'/nutritionists' interventions and expertise during the final

days or hours of life may highlight impending death cases, supporting patients' last wishes and assisting families with their needs, concerns, doubts and misconceptions surrounding nutritional issues in the end of life and agonic phase.

CONCLUSIONS

The results of this study offer dietitians/nutritionists globally a tool that can guide and enhance clinical practice in PC.

CONFLICTS OF INTEREST

None of the authors reported a conflict of interest.

AUTHORS' CONTRIBUTIONS

CP-R, MLC, AS: Contributed to the conception, the design and the writing of the manuscript.

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