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ARTIGO DE REVISÃO

CORE, CLINICAL AND ETHICAL COMPETENCES OF DIETITIANS/NUTRITIONISTS IN PALLIATIVE CARE

COMPETÊNCIAS CENTRAIS, CLÍNICAS E ÉTICAS DOS NUTRICIONISTAS NOS CUIDADOS PALIATIVOS

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ABSTRACT

INTRODUCTION: Dietitians/nutritionists´ professional competences in Palliative Care have been poorly investigated. Thus, to dietitians/nutritionists develop their jobs with scientific and technical rigour based on an ethical point of view it is necessary that they have their professional competences very well defined.
OBJECTIVES: To identify a set of professional competences of dietitians/nutritionists in the field of Palliative Care.
METHODOLOGY: Systematic literature review in Pubmed, CINAHL, Academic Search Complete, and Web of Science.
RESULTS: A set of 32 publications were found and analysed. From these publications the competence were identified and grouped in the following dominions: 13 core competences, 30 clinical competences, 18 ethical competences.
CONCLUSIONS: Dietitians/nutritionists are the professionals who aggregates knowledge and expands the technical competences of nutritional care and support in Palliative Care.

KEYWORDS
Competence, Dietitian, End of life, Palliative care

RESUMO

INTRODUÇÃO: O papel dos nutricionistas nos cuidados paliativos tem sido alvo de pouca investigação. Assim, de forma 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: Identificar um conjunto de competências profissionais dos nutricionistas nos cuidados paliativos.
METODOLOGIA: Revisão sistemática da literatura na Pubmed, CINAHL, Academic Search Complete e Web of Science.
RESULTADOS: Foi encontrado e analisado um conjunto de 32 publicações. Destas, foram identificadas e agrupadas as competências nos seguintes domínios: 13 competências centrais, 30 competências clínicas e 18 competências éticas.
CONCLUSÕES: Os nutricionistas são os profissionais de saúde que agregam conhecimento e expandem as competências técnicas inerentes a todo o processo de suporte e cuidado alimentar nos cuidados paliativos.

PALAVRAS-CHAVE
Competência, Nutricionista, Fim de vida, Cuidados paliativos

INTRODUCTION

Palliative Care (PC) is the active, coordinated, and holistic care of individuals across all ages with serious health-related suffering due to severe illness, and especially of those near the end of life. It aims to improve the quality of life of patients, their families, and caregivers. It is a care that includes prevention, early identification, comprehensive assessment, and management of physical issues, including pain and other distressing symptoms, psychological and spiritual distress, and social needs. It provides support to help patients live as fully as possible until death by facilitating effective communication, helping patients and their families determine goals of care (1). PC is applicable throughout the course of an illness, according to the patients´ needs and intends neither to hasten nor postpone death. It affirms life and recognizes dying as a natural process. It provides support to the family and the caregivers during the patient's illness, and in their own bereavement. PC is delivered recognizing and respecting the cultural values and beliefs of the patient and the family and it is applicable throughout all health care settings and in all levels. PC also requires specialist PC with a multiprofessional team for referral of complex cases (1). According to some authors the nutrition of the PC patients is usually altered so eating-related distress arises in all life-limiting diseases sooner or later. It is highly recommended the inclusion of dietitians/nutritionists as members of the PC teams or at least that they work closely with the team to

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give the best and the most comprehensive and holistic nutritional care to patients as food and nutrition issues contribute to patients' total pain (2-46). From the literature consulted, dietitians/nutritionists´ roles in PC have been poorly investigated. However, more recently it seems they have been given more attention. Thus, dietitians/nutritionists develop their jobs with more scientific, technical rigour and from a clinical and ethical point of view it is necessary that they develop and define properly their professional competences in PC (2, 14-29).

OBJETIVES

To identify a set of professional competences of dietitians/nutritionists in the field of PC.

METHODOLOGY

A systematic literature review, adapted from the PRISMA methodology, was conducted. The identification of publications was initiated through searches in the databases Pubmed, CINAHL, Academic Search Complete, and Web of Science. The keywords used were "nutrition" and "palliative care". By convenience a complementary manual search of publications that did not emerge in previous search was added. Working documents and guidelines from professional associations and working groups in nutrition and PC fields were also searched. Regarding the exclusion criteria, the following types of publications were defined: letter to the editor, comments, editorials, and case studies. The selection of publications presumed, at least, one of the following inclusion criteria: the publication includes core competences in the area of PC; the publication specifically refers to the dietitian/nutritionist competences in PC; the publication describes nutritional interventions in the area of PC in a cross-sectional perspective, including oral feeding, artificial nutrition, assessment of nutritional status, meanings of food, emerging ethical issues; the publication indicates interventions of the nutritional forefield in the area of nutritional support related to PC. The selection process of publications was initiated by reading of the title and abstract, after which, in the selected publications, the document was completely read and subsequently the competences were extracted. A total of 7472 potentially relevant publications were identified initially through research in the databases mentioned above. In addition, to complement the research carried out, 13 more references were included through manual search, relevant to the theme that was intended to be investigated and met the criteria previously defined. Thus, a total of 7485 publications were analysed, excluding 4 publications because they were duplicated. Based on the reading of the title and abstract, 7379 of these publications were excluded, because they did not address the theme that was intended to investigate. Thus, 106 publications initially appeared to meet the selection criteria. However, after their full reading, 32 met at least one of the previously established inclusion criteria. For rejected publications, the justifications are: articles directed only to the nursing area (n=17), articles directed only to the medical area (n=14), brief reference to nutrition (n=8), german language (n=4), nutrition and palliative sedation (n=4), prevalence and impact of artificial nutrition (n=4), home PC with brief reference to nutrition (n=3), parental perceptions (n=3), perceptions of health professionals (n=3), paediatric PC (n=3), neonatal PC (n=2), nutrition for cognitive improvement (n=2), emotional impact of eating on health professionals (n=2), survival and quality of life (n=1), parenteral nutrition (n=1), editorial (n=1), and hastening death (n=1).

RESULTS

From the set of publications were found: 18 literature reviews (2, 3, 5, 7, 10, 14, 16, 17, 22-27, 33, 35-37, 41), 3 original articles (15, 19, 30), 2 book chapters (13, 18), 2 position statement (21, 31), 1 guideline article (34), 2 professional articles (29, 42), 2 books (20, 39), 1 white paper (32), and 1 taskforce document (37). After being identified the competences were written and grouped in three dominions according to the area they were associated with: the core competences mainly defined by the European Association for Palliative Care (EAPC) (32) and by the PC Competence Framework Steering Group of Dublin (37); the clinical competences regarding the area of clinical nutrition; and the ethical competences where all the subjects related to ethical issues were included. After the organisation and writing of competences in these dominions, the results were: 13 core competences, 30 clinical competences, and 18 ethical competences (Table 1).

Table 1

Core, clinical and ethical competences of dietitians/nutritionists in Palliative Care

N.	CORE COMPETENCES
1	Apply the core constituents of PC in the setting where patients and families are based (32)
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 (37)
3	Enhance physical comfort throughout patients' disease trajectories (32)
4	Meet patients' psychological needs (32)
5	Meet patients' social needs (32)
6	Meet patients' spiritual needs (32)
7	Respond to the needs of family caregivers in relation to short, medium- and long-term patient care goals (32)
8	Respond to the challenges of clinical and ethical decision-making in PC (32)
9	Practice comprehensive care co-ordination and interdisciplinary teamwork across all settings where PC is offered (32)
10	Develop interpersonal and communication skills appropriate to PC (32)
11	Provide empathetic care to individuals with life-limiting conditions and their families, with clear regard to the individuality of each person (37)
12	Practice self-awareness and undergo continuing professional development (32)
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 (32)
N.	**CLINICAL COMPETENCES**
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 (37)
2	Understand, recognize, and address the management of pathological responses to eating-related loses which may impact on behaviour and decision-making of individuals in palliative and end of life care and families (37)
3	Understand total pain concept and its relation to food/ nutrition and hydration (37)

Table 1

Core, clinical and ethical competences of dietitians/nutritionists in Palliative Care (continuation)

N.	CLINICAL COMPETENCES
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 (37)
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 (37)
6	Develop, facilitate, and provide education, leadership, mentorship and professional support for colleagues, generalist and specialist providers of PC regarding to clinical nutrition (37)
7	Lead, facilitate and engage in further education, research, and audit in palliative care (37)
8	Design research projects in line with PC service needs, collaborating with all relevant stakeholders in respect of research issues (37)
9	Act as an expert resource providing and advising on undergraduate and postgraduate education in the domain of dietetics/ clinical nutrition in PC (2, 13, 14, 18, 21, 29-31, 34, 37)
10	Training of other health professionals in the areas of nutrition science in palliative and end-of-life care (2, 13, 14, 18, 21, 29-31, 34, 37)
11	Assessment of nutritional status at the individual level (2, 13, 14, 16-20, 23, 24, 26, 27-30, 34-37, 39, 40-42)
12	Assessment of food history and dietary intake (2, 13, 14, 16-20, 23, 24, 26, 27, 29, 30, 34-37, 39, 40-42)
13	Assessment of eating-related symptoms (2, 13, 14, 16-20, 23, 24, 26, 27, 29, 30, 34-39, 40-42)
14	Interpretation of biochemical data (2, 13, 14, 16-20, 23, 24, 26, 27, 29, 30, 34-37, 39, 40-42)
15	Individual nutritional care provision, developing nutritional diagnosis based on clinical, biochemical, anthropometric, and dietary data (2, 13, 14, 16-20, 23, 24, 26, 27-30, 34-37, 40-42)
16	Assessment of needs and wishes for food with relatives and family (2, 13, 14, 16-20, 23, 24, 26, 27, 29, 30, 34-37, 39-42)
17	Prescription, planning, analysis, monitoring and evaluation of therapeutic food plans (2, 13, 14, 16-20, 23, 24, 26, 27, 29, 30, 34-37, 39-42)
18	Modification of food texture to personalize dietary plans and meals (2, 13, 14, 16-20, 23, 24, 26, 27, 29, 30, 34-37, 39-42)
19	Management of eating-related symptoms (2, 13, 14, 16-20, 23, 24, 26, 27-30, 34-38, 39-42)
20	Enteral and parenteral nutrition prescription and adapted staples, used for special purposes (2, 13, 14, 16-20, 23, 24, 26, 27-30, 34-37, 39-42)
21	Prescription of nutritional supplements (2, 13, 14, 16-20, 23, 24, 26, 27, 29, 30, 34-42)
22	Interface with the food service and the hospital kitchen to personalize meals (2, 29, 30)
23	Being present in family reunions, as other health care team members, in order to discuss nutritional support by oral or artificial route and clarify myths and doubts surrounding feeding and hydration in the end of life (37)
24	Being present near families in the last days or hours of life to clarify doubts, fears and myths surrounding nutrition and hydration (37)
25	Demonstrate deep knowledge about the meaning of food and fluids in the context of palliative and end-of-life care (2, 3, 13, 14, 16, 17, 36, 37, 39)
26	Demonstrate deep knowledge about the social meaning of food and fluids (2, 3, 13, 14, 36, 37)
27	Demonstrate deep knowledge about the psychological meaning of food and fluids (2, 3, 13, 14, 36, 37)
28	Demonstrate deep knowledge about the spiritual meaning of food and fluids (2, 3, 13, 14, 36, 37)
29	Demonstrate deep knowledge about the meaning of oral feeding and drinking (2, 3, 13, 14, 36, 37)
30	Demonstrate deep knowledge about the meaning of artificial nutrition and hydration (2, 3, 13, 14, 36, 37)
N.	**ETHICAL COMPETENCES**
1	Work within your current Code of Professional Conduct and engage ethically, knowledgably, and respectfully with other healthcare areas (2,13,14,18,21,31,34,37,41)
2	Recognize the limits of the dietitian/ nutritionist intervention (2,13,14, 18, 21,31,34,37)
3	Apply an advanced understanding of contemporary legal, ethical, and professional standards to the provision of quality PC therapy services (13, 14, 20, 21, 31, 34, 37)
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 (13, 22, 37)
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 (2, 13, 14, 16, 21, 22, 31, 34, 36 37, 41, 42)
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 (2, 13-17, 21, 31, 34, 36, 37, 41, 42)
7	Respecting advance care plans made by people where the decision is an informed choice and relates to the situation that has arisen (13-16, 20, 21, 31, 34, 36, 37, 41, 42)
8	Demonstrate a commitment to engage in anti-discriminatory practice in relation to end of life care and service deliver (13, 21, 31, 34, 37)
9	Be aware of ethical and legal issues that may arise regarding artificial nutrition support in the palliative and end of life care (13-16, 21, 25, 31, 34, 36, 37)
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 (37)
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 (13-15, 21, 31, 34, 36, 37)
12	Demonstrate deeply understanding about the ethical principles of autonomy, beneficence, non-maleficence and justice (2, 5, 7, 13, 16, 21-27, 31, 36, 37, 41)
13	Demonstrate deeply understanding about the principles of integrity, dignity and vulnerability (2, 5, 13, 20-22, 37)
14	Demonstrate deeply understanding about the distinction of basic human care and medical treatment regarding to the use of artificial nutrition and hydration (2, 3, 7, 13, 21, 31, 36, 37, 41, 42)
15	Demonstrate deeply understanding about proportionate versus disproportionate feeding and hydration (2, 7, 13, 21, 22, 31, 37)
16	To deeply understand and distinguish withhold or withdrawn artificial nutrition and hydration from the concepts of euthanasia and assisted suicide (2, 7, 13, 21, 31, 37)
17	Act collaboratively in the multidisciplinary team in the cases of voluntary cessation of eating and drinking (13, 21, 31, 37)
18	Demonstrate knowledge about the implications of advanced directives by proxys or living will in nutritional support (7, 13, 14, 21, 31, 36, 37, 41)

PC: Palliative Care

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DISCUSSION OF THE RESULTS

Core Competences

Some authors state that to work in PC, dietitians/nutritionists must have a combination of multiple attributes, including aptitude and technical competence which allows them to comply with philosophy and principles of PC and understand the total pain (32, 36). The empathy, interest in PC, the willing to work in this area within a multidisciplinary context and a good communication capacity were also allocated as essential personal characteristics to work in such a complex area of human care as long as taking care and cope with themselves because of their contact with complex and emotional clinical cases (30, 32, 37).

Clinical Competences

The following competences were identified: nutritional assessment, diagnosis, intervention, and monitoring. However, the first fundamental clinical competence is the ability to understand the food phenomenon as multidimensional and a part in the total pain concept, recognizing food has a social, cultural, emotional, religious, and spiritual meaning, and changes during the trajectory of the disease can be a factor of eating--related distress for patients, family members and caregivers. It is their competence to assess unique dietary needs for each patient considering the social determinants of health, ethnicity, culture, gender, sexual orientation, language, religion, age, and their respective preferences. Also in this context, the dietitians/nutritionists assess the patients and family members/carers capacities and needs in relation to food education for specific purposes with dietitians/nutritionists as a source of credible information (2, 3, 13, 14, 16-21, 28-31, 36,37, 41-43).

The literature states that it is the dietitians/nutritionists' responsibility to define objectives and to establish realistic nutritional goals and treatment plans, making appropriate adjustments in the nutrition care process, collaborating in the discharge plans, establishing comfort feeding, or prescribing oral nutritional supplements or artificial nutrition, when appropriate (21, 29, 30, 37). It is also pointed out as a competence the advice on ways of preparation, supplementation, and flexibilization of food routine and previous dietary restrictions (36). Another clinical competence is the articulation with the hospital kitchen. Thus, regarding the area of cooking and distribution of meals, dietitians/nutritionists can modify eating routines and schedules where meals can be customized appropriately (29, 30).

Dietitians/nutritionists also have as competences the participation and promotion of research and audit within the service (29, 30, 37). Also in the training aspect, dietitians/nutritionists are capable to train colleagues in the nutrition service as well as other health professionals (29, 30, 37). Within the last hours and days of life, dietitians/nutritionists have as specific clinical competence the ability to support the wishes of patients and clarify any doubts and myths regarding nutrition in the end-of-life and agonic phase that family members and caregivers may have (37).

Ethical Competences

The literature points out that dietitians/nutritionists who deal with PC patients and family members have skills at a level of patient-centered care adding the ethical dimension to their clinical nutrition practice and applying the principles of autonomy, beneficence, non-maleficence, justice, integrity, vulnerability and dignity according to patients' proxys, values, religion, spirituality, and culture perspective of their own quality of life and goals (2, 5, 7, 13-15, 31, 32, 34, 37, 41).

Dietitians/nutritionists have the competence to work respecting their code of ethics and considering the limits of their intervention and respect for the other professional areas of the multidisiciplinary team. In addition, they should be able to define and at the same time respect the wishes of the patient related to food choices and preferences, and in this context, they should recognise the importance of properly informed consent and decision-making (2, 5, 37).

Dietitians/nutritionists have the duty to protect life so they must participate and collaborate in the ethical deliberation process of issues related to food and nutrition support (31). As ethical competences, they must develop several essential dimensions: the dimension of knowledge in the area of clinical nutrition, moral reasoning, legislation, involving possible emerging ethical issues, religious, and cultural values, to the policies of the institution where PC takes place; the dimension of practical knowledge: the analysis and evaluation of the ethical issues, critical thinking, ability to negotiate and to communicate, being a facilitator of ethical discussion and deliberation and ethical decision-making capacity; the dimension of attitudes: empathy, patient, ability to approach the team, to comfort despite the uncertainty of clinical situations and comfort despite possible negative feelings of the patient and family members regarding to the dietitian as an healthcare professional; the virtues dimension: integrity, respect and compassion (21, 31).Other authors also state that dietitians/nutritionists have a responsible and active role in ethics deliberation of issues related to voluntary cessation of eating and drinking and with issues surrounding the withholding and withdrawing of artificial nutrition and hydration (21, 31, 32, 34, 37, 41). Some authors also affirm that dietitians/nutritionists have a fundamental role not only in promoting the use of advanced directives and referring patients to a competent professional area to elaborate them (37).

Limitations

The fact that a blind evaluation methodology was not used by more than one reviewer of the publications to be included in this review and in the identification of competences could represent a limitation, because this would allow a more accurate assessment, limiting the investigators' biases. The review was not carried out in all existing databases and languages may also have interfered with the results of this review, as other relevant articles could possibly have been found. It is also important to highlight the difficulties experienced in the process of systematic literature review. These difficulties consisted of the scarcity of publications that addressed, identified, and described exclusively professional roles and competences of nutritionists/dietitians in PC. In addition, the fragmentation and poor development of this theme among the literature was also a limitation.

CONCLUSIONS

Although the nutrition care process is a responsibility from many healthcare professionals, it is only enhanced through the action of dietitians/nutritionists since they are the professionals who aggregate knowledge and expand the technical competence of nutritional care and support offered by the multidisciplinary team. An interesting future research would consist in submitting the competences found to an expert panel of nutritionists/dietitians and obtaining consensus about this issue by the Delphi Method.

CONFLICTS OF INTEREST

None of the authors reported a conflict of interest.

AUTHORS' CONTRIBUTIONS

CP-R: Contributed to the articles' search and analyses, to the conception, the design, the draft, the writing of the manuscript; AS, MLC: Contributed to article analyses and the critical review of the manuscript and the final approval of the version to be published.

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