Nutrition, quality of life and palliative care: integrative review

Nutrição, qualidade de vida e cuidados paliativos: uma revisão integrativa

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ABSTRACT

BACKGROUND AND OBJECTIVES: Adequate nutritional intervention promotes wellbeing, symptoms control and improved quality of life for patients and their families. This study aimed at evaluating whether nutrition may or may not improve quality of life of patients under palliative care.

CONTENTS: This is an integrative review using Pubmed, Scielo and Medline databases. Guiding question was: "Is nutritional therapy able to improve quality of life of patients under palliative care?" Six articles met pre-established inclusion criteria. Nutritionists were professionals most orienting nutritional therapy, in addition to explaining nutritional strategies to minimize dietrelated discomforts. Adequate therapy should respect dietary and cultural preferences, thus assuring better quality of life.

CONCLUSION: Nutritional approach during palliative care should respect patients and their families' decisions and bioethics principles. Nutritional interventions should give more importance to counseling and support, instead of focusing just on matching nutritional needs. Nutritionists should orient patients and their families about nutritional therapy, in addition to giving further explanations to prolong survival, decrease weight loss and improve quality of life.

Keywords: Bioethics, Nutritional therapy, Nutritionist, Palliative care, Quality of life.

RESUMO

JUSTIFICATIVA E OBJETIVOS: A intervenção nutricional adequada promove bem-estar, controle de sintomas e melhora da qualidade de vida dos pacientes e de seus familiares. O objetivo deste estudo foi verificar se a nutrição pode ou não melhorar a qualidade de vida do paciente em cuidados paliativos.

CONTEÚDO: Trata-se de uma revisão integrativa, utilizando

as bases de dados Pubmed, Scielo e Medline. A pergunta norteadora foi "A terapia nutricional é capaz de melhorar a qualidade de vida dos pacientes em cuidados paliativos?". Seis artigos se enquadravam nos critérios de inclusão pré-estabelecidos. O nutricionista foi o profissional que mais orientou sobre a terapia nutricional em uso, além de fornecer esclarecimentos sobre estratégias nutricionais para redução de desconfortos ligados à alimentação. A terapia adequada deve respeitar as preferências alimentares e culturais, garantindo, assim, melhor qualidade de vida.

CONCLUSÃO: A conduta nutricional em cuidados paliativos deve respeitar as decisões do paciente e de sua família e os princípios bioéticos. As intervenções nutricionais devem dar maior importância à prestação de aconselhamento e de apoio, ao invés de centrar apenas na adequação das necessidades nutricionais. O nutricionista deve orientar o paciente e sua família sobre a terapia nutricional em uso, além de fornecer orientações e esclarecimentos, a fim de prolongar a sobrevida, reduzir a perda de peso e melhorar a qualidade de vida.

Descritores: Bioética, Cuidados paliativos, Nutricionista, Qualidade de vida, Terapia nutricional.

INTRODUCTION

The World Health Organization (WHO) has published in 1990 a definition of palliative care (PC) and this concept was updated in 2002 being internationally accepted: "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"1. In palliative care, when cure is no longer possible, therapeutic strategy should be based on maintaining patients' autonomy preserving the most from their normal lives or helping people enjoy their vitality within their limits². Observing that quality of life (QL) is individuals' perception of their position in life, in the context of the culture and value system within they live, and also considering objectives, expectations, patterns and interests, one may state that PC aims at reaching the best possible QL for patients and their families, without delaying or hastening death, which should be respected for being a constitutive element of the natural process of life³. So, PC should be an alternative for the assistance to patients without therapeutic possibilities of cure to be human, fair and beneficial².

A multiprofessional attention helping pain control and management, but also social, psychological and spiritual aspects, may decrease patients' suffering and promote QL². The most

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important thing for PC is to preserve patients' dignity and to provide comfort and wellbeing, which may be reached by means of minor and simple actions, such as basic hygiene, adequate attention, comfortable furniture and diet⁴. It is critical to use resources preventing nutritional and gastrointestinal manifestations, such as anorexia, nausea, vomiting, wasting, malnutrition and dehydration, in addition to relieving their repercussions and extensions, if already installed⁵.

PC should respect patients' desires and should supply the most possible comfort by means of indicated therapies to minimize distress, but there are controversies whether food could contribute to this process. In general, these patients have some nutritional impairment, but not always this recovery is reached by means of nutritional therapy. Nutritional, caloric, protein and water requirements should be established according to patients' acceptance, tolerance and symptoms, aiming at promoting comfort and better QL and not only assuring adequate nutrients ingestion, preventing in some cases unnecessary invasive nutritional interventions, such as introduction of enteral nutritional therapy (ENT) or parenteral nutritional therapy (PNT)⁶.

This study aimed at observing whether nutritional orientation may improve QL of PC patients by means, considering that an adequate nutritional intervention promotes wellbeing, symptoms control and better QL of patients and their families.

CONTENTS

This is an integrative review consisting of six stages, where the first stage is to decide the hypothesis or question of the study.

Then, a sample of scientific articles to be reviewed is selected, followed by categorization and evaluation of such studies. Interpretation of results and presentation of the review or of the summary of the knowledge are the last steps of this process. Articles were selected using Pubmed, Scielo and Medline databases, by means of the following keywords: bioethics (bioética); palliative care (cuidados paliativos); nutrition (nutrição); nutritionist (nutricionista).

The following question was developed to guide the study: "Is nutritional therapy able to improve quality of life of patients under palliative care?", complying with the following inclusion criteria: mentioning PC patients' nutrition, being indexed in databases, being published in Portuguese or English between 2005 and 2015 and being available in full. Exclusion criteria were all articles of restricted access and literature reviews.

Articles were selected by reading titles and respective abstracts aiming at checking the matching of the study to the guiding question. At the end of the search, 16 studies were found, however 10 studies were excluded because nutritionist was mentioned by there were no results on nutritional guidance. So, only six have met pre-established inclusion criteria, of which four are quantitative studies and two are qualitative studies. For data extraction identification, characteristics of study methods, evaluation of methodological rigor, studied interventions and results were investigated. Data and discussion were presented in descriptive form, making possible the application of this review to nutrition practice in PC. Included articles are shown in table 1.

Table 1. Information on articles included in the integrative review according to the guiding question. Fortaleza, 2015

Authors	Objectives	Methods	Results	Is nutritional therapy able to improve quality of life of patients under palliative care?
Schirmer, Ferrari & Trindade ⁸	Evaluate the evolution of oral mucositis in cancer patients assisted by the PC service, after medical and nutritional intervention and guidance, in addition to evaluating how mucositis severity interferes with patients' food ingestion.	Qualitative prospective study using interviews and previously structured questionnaire.	Before intervention, mucositis grade I was present in more than half the patients and almost half of them ingested solid food. Few individuals had mucositis grade IV where all ingested liquid food. After intervention, more than half the patients had no mucositis and no restrictions to diet consistency. Oral complaints, such as xerostomia dysgeusia, appetite loss, anorexia and candidiasis were decreased.	Nutritional guidance, such as mouth washing with chamomile tea, avoiding very acid, dry, hard or spicy food, restrict salt, avoid very hot food or preparations may help improving mucositis, thus assuring better QL.
Loyolla, Pessini, Bottoni, et al. ⁹	Analyze, from bioethics point of view, the use of nutritional therapy for cancer patients under PC, observing vision and participation of patients and their families in the decision to use such therapy	Qualitative study with semistructured questionnaire.	Most patients and caregivers were informed about indicated ENT by the nutritionist. When asked about what is and what is the purpose of TNE, most have answered that it served to fortify and feed patients. With regard to the choice by patients or caregivers to start or not TNE, answer was yes for many, but some were in doubt and thought that this should be a physician's decision. As to ENT being a basic care that should always be provided, answers have varied from replacement by other if not bringing benefits or cannot be withdrawn because it is patient's right	ENT is considered a basic care by patients and/or caregivers and is patient's right, which shall be replaced but never withdrawn if not bringing benefit to patients. Although nutritionist was the professional more explaining about ENT, patients and caregivers feel they are unable to decide about using ENT.

Continue...

Table 1. Information on articles included in the integrative review according to the guiding question. Fortaleza, 2015 - continuation

Authors	Objectives	Methods	Results	Is nutritional therapy able to improve quality of life of patients under palliative care?
Silva, Lopes, Trindade, et al. ¹⁰	Analyze, by means of previously validated questionnaire, how nutritional intervention and symptoms control have interfered with QL of cancer patients.	Quantitative prospective study. Tools: three previously structured questionnaires on QL, socioeconomic aspects and food questionnaire ¹¹ .	Most patients were under oral diet and were classified as lacking more intensive care. After medical and nutritional interventions and discussion of cases, the use of food supplements and gastrointestinal symptoms have decreased and appetite was improved, in addition to better QL of patients.	Giving diet and therapy guidance contemplating dietary indication, diet consistency, possible associated comorbidities, respecting food and cultural preferences, minimizing food-related discomfort, thus assuring better QL.
Orrevall, Tishelman, Permert, et al. ¹¹	Investigate the nutritio- nal risk status and the use of nutritional therapy among cancer patients enrolled in home PC ser- vices.	Quantitative study using phone interview and a questionnaire	Most studied patients were diagnosed as at nutritional risk. As to nutritional therapy, most used common oral nutritional supplements, while the minority used artificial nutrition, especially PNT. Common oral supplements were related to low BMI and severe weight loss.	Evaluate the nutritional risk of PC patients helps improving nutritional approach, however the use of nutritional therapy should consider life expectancy and patients' psychosocial aspects.
Muir & Linklater ¹²	Explore the meaning of food, food ingestion and body weight of PC patients, investigating the impact of such changes on such patients, in addition to determining whether nutritional recommendations were followed ¹³ .	Qualitative study using semistructured interviews.	A recurrent theme was change and uncertainty. Four major areas subject to variation were: disease status, symptoms, oral ingestion and weight. Each change could control or be controlled by patients. When patients were unable to control they accepted the change, be it voluntarily or not ¹³ .	The article shows that nutritional guidance given to palliative care patients by means of standar-dized nutritional requirements may fail by not addressing the real meaning of nutritional care for such patients. So, nutritional interventions with these patients should give more importance to offering counseling and support instead of focusing on calculated nutritional requirements.
Hasenberg, Essenbreis, Herold, et al. ¹³	Evaluate the effect of parenteral nutrition supplementation on body composition, QL, secondary effects associated to chemotherapy and survival in patients with advanced colorectal cancer.	Quantitative retrospective randomized study.	Groups receiving parenteral supplementation or oral nutrition have improved gastrointestinal symptoms, resulting in significantly increased appetite.	Nutritional therapy as oral or parenteral supplementation improves QL, prolongs survival and decreases weight loss.

QL = quality of life; PC = palliative care; ENT = enteral nutritional therapy; PNT = parenteral nutritional therapy. BMI = body mass index.

DISCUSSION

Untreated mucositis may interfere with nutritional status and even interfere with the choice of anti-cancer therapy, in addition to impairing patients' QL¹⁴. According to Schirmer, Ferrari and Trindade³, nutritional therapy may prevent severe oral mucositis³. According to Boligon and Huth¹⁵, supplementation with 20g/day glutamine for head and neck cancer patients under anti-cancer therapy has helped the maintenance of nutritional status and has prevented mucositis, especially grades III and IV. In case of moderate to severe mucositis, enteral nutrition with nasogastric/nasoenteric probe, or even parenteral nutrition, should be indicated in cases of weight loss above 5%. So, medical and nutritional care is needed to contribute to anti-cancer therapy maintenance, as well as to patients' weight maintenance and hydration¹⁶.

Multiprofessional action is mandatory for the efficient management of PC patients, helping improving complications, QL and their autonomy⁹. This should be achieved by means

of better interaction among professionals, considering the individualized choice of pharmacological and dietary therapy, in addition to minimizing drug-related adverse effects¹⁰.

Loyolla et al.⁹ have observed that patients and caregivers were informed about nutritional therapy and knew how to define its function and importance. However, it was observed that information given by professionals was not enough or was not clear for most patients and caregivers. This transfers ENT responsibility to the physician aiming at assuring patients' benefit. In addition, physician, patient and caregiver relationship still follows the old paternalist pattern, an asymmetric relationship where the only decision-maker on therapy is the physician.

According to Cardoso et al.¹⁷ the multiprofessional team identifies weaknesses and challenges, such as the need to qualify communication and team work. The nutritionist is one professional responsible for providing nutritional guidance to patients and their families. So, nutritionist must have communication skills, being this as important as technical knowledge regarding nu-

tritional requirements. Dietary prescription should, above all, offer pleasure and comfort to patients, in addition to respecting their will². So, it is clear that patients' autonomy, while being conscious and able to decide, should be respected, otherwise, family should determine what is best⁹.

Silva et al.¹⁰ have shown that nutritional and medical interventions have indirectly reflected on socialization and have allowed patients' participation in meals together with relatives and friends, in addition to implying comfort and self-care. This has shown that nutritional aspects are not only those related to nutritional status, but also those related to family relations, pleasure, wellbeing and autonomy. Seredynskyj et al. 18 have observed that autonomy should be preserved for the maintenance of better patients' health status. In addition, simultaneous medical and nutritional intervention has also resulted in improved symptoms such as appetite loss, dysgeusia, oral candidiasis, mucositis, nausea and constipation, similarly to Durval et al.19 findings, who have shown improved wasting, thus contributing to better QL. When strategies to favor food ingestion are obtained, results portray patients' clinical and social approach, improving their life condition¹⁰.

Orrevall et al.¹¹ have observed that more than two thirds of patients were at nutritional risk, which was associated to precancer low body mass index (BMI). However, an association between pre-cancer BMI indicating overweight and nutritional risk was also found, being indicated that nutritional problems may not be easily identified without nutritional tracking, even after severe weight loss. This study has shown the need for a structured approach to early identify and evaluate cancer patients on nutritional risk. However, any evaluation tool which may generate physical or emotional discomfort should not be used in this stage.

Incurable cancer is associated to high prevalence of nutritional problems and weight loss, leading to physical and psychological impairment. Nutritional implications should be identified and treated as early as possible during disease progression, however, in later stages, nutritional therapy is still controversial²⁰.

Nutritional therapy is part of integral oncological support and may significantly contribute to improve QL^{21} . However, ENT or PNT should only be started in individuals with better life expectance and/or if there are psychosocial aspects favoring such process, to assure better life condition to patients, sparing those with no indication from unnecessary interventions²².

Muir and Linklater¹² have observed the testimony of patients, allowing a broad understanding of their concerns. For them, food goes beyond nutritional objectives; it is reflected on motivation, control along disease progression, care and compassion expressions, and death acceptance. Health worsening may be often identified by not being able to eat²².

With regard to meaning, foods are physical substances necessary as energy source to feed the body and continue to fight against disease, which is source of frustration and anxiety, in addition to showing the sensation of patients' care and inter-

est. Changes in food ingestion have followed the trend of decline, characterized by decreased appetite, oral ingestion and weight loss. Decreased consumption has induced physical and psychological changes in such patients. As to weight, loss was fearsome and stressing because death process was coming close. So, most of them have felt that weight monitoring could be noxious or even useless¹².

Malnutrition is mentioned by studied patients not only as physical malnutrition, but also as psychological and sociological malnutrition. Weight loss may be identified by many as symbol of disease progression, loss of control of their own body and physical and emotional weakness, and may also represent the proximity of death. Many times it is related to weakness, fatigue and decreased QL23. Nutritional care strategies with holistic approach should be developed to meet the broad meanings that food or eating may have, because already defined protocols and standards may not meet individual requirements and even overload patients with unfeasible targets, such as weight gain and adequate nutritional ingestion¹². So, sensitivity and creativity will make the difference during nutritional evaluation and guidance²². Aiming at improving QL, the real meaning of PC nutritional care should be addressed, especially by means of assuring patients' counseling and support¹².

Hasenberg et al.¹³ have observed that early nutritional therapy may maintain body composition, improve life condition and even prolong survival of cancer patients under PC13. It is necessary to stress that unintentional weight loss and changes in body composition are related to unfavorable clinical evolution, psychological, socioeconomic and QL impairment²¹. This article has observed the effects of parenteral and oral nutrition supplementation. Group receiving PNT and oral nutrition have stabilized albumin levels, in addition to improving gastrointestinal symptoms related to chemotherapy, thus improving QL. Patients receiving oral supplementation have reported improved symptoms, such as early satiation, constipation, nausea, vomiting, abdominal pain and diarrhea, resulting in significant appetite improvement in this group¹³. So, nutritional intervention has positively impacted clinical and social aspects, improving individuals' life condition.

Anti-cancer therapies may produce additional symptoms, negatively affecting nutritional status, depending on treatment type and duration, dose and individual patients' response²¹. Nutritional therapy helps decreasing treatment-related symptoms and disease evolution, as well as weight loss, prolonging survival and improving QL¹³.

In light of the above, dietary approach should, above all, offer pleasure and comfort, respecting patients and their families' autonomy. So, together with other therapeutic measures, it may contribute to promote QL of patients without clinical possibilities of cure.

CONCLUSION

Nutritional approach in PC should respect patients and their families' decisions, as well as bioethics principles: autonomy,

beneficence, non malfeasance and justice. Nutritional therapy may prolong survival, decrease weight loss and improve QL of PC patients, by means of decreasing adverse effects of treatments and/or diseases. Considering the importance of this article, there is need for further nutrition studies involving PC patients, not only in the oncologic area, but also in all different situations involving this theme.

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