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CONTROLO SINTOMÁTICO E QUALIDADE DE VIDA EM CUIDADOS PALIATIVOS

Tese submetida à Faculdade de Medicina da Universidade do Porto
para obtenção do grau de Doutor em Cuidados Paliativos



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Trabalho realizado sob a orientação do Professor Doutor Rui Manuel Lopes Nunes (orientador) e Professora Doutora Maria Francisca Melo Pojal da Silva Rego (co-orientadora)

Porto, fevereiro de 2026

DECLARAÇÃO

Tese de candidatura ao grau de Doutor pelo Programa Doutoral em Cuidados Paliativos, submetida à Faculdade de Medicina da Universidade do Porto e elaborada de acordo com os Critérios Curriculares desta Faculdade para Recrutamento na Carreira Académica e Admissão e Classificação de Provas Académicas, em vigor a partir de 21 de julho de 2021, nomeadamente no vertido no ponto III.2 – a respeito dos Critérios de Exigência Mínima para Submissão de Pedido de Admissão a Provas da Tese de Doutoramento.

Decorrendo do antedito contexto, apresenta-se uma dissertação estruturada por artigos científicos de investigação completos e originais, em que a candidata é primeira autora.

Todos os trabalhos aqui englobados não foram submetidos para obtenção de outro grau académico, encontrando-se integralmente reproduzidos ao longo da presente dissertação.

A candidata foi também autora de várias apresentações na forma de comunicações orais ou pósteres, as quais são descritas no currículo vitae.

A presente tese cumpre os pressupostos do artigo 8.º do decreto-lei número 388/1970.

A candidata não escreve segundo o Acordo Ortográfico de 1990.

AGRADECIMENTOS E DEDICATÓRIA

A realização desta dissertação contou com importantes contributos, apoios e incentivos sem os quais a sua concretização não seria possível.

Agradeço ao meu orientador, Professor Doutor Rui Manuel Lopes Nunes, pelo apoio, disponibilidade e estímulo constante que em muito contribuíram para que a presente investigação fosse possível.

Agradeço à minha co-orientadora, Professora Doutora Maria Francisca Melo Pojal da Silva Rego, pela atenção constante e pelo incentivo, pelo exemplo de perseverança e por todo o apoio que sempre me deu ao longo deste percurso.

Agradeço à minha colega e amiga Margarida Gaudêncio por todo o apoio e suporte neste trabalho e pelo seu incentivo contínuo para que este fosse terminado.

Agradeço a todos os profissionais do Serviço de Medicina Interna e Cuidados Paliativos do Instituto Português de Oncologia de Coimbra, Francisco Gentil, E.P.E.

Agradeço a todos os doentes que consentiram em participar no estudo, que com a sua generosidade contribuíram para o avanço da ciência e da medicina.

Agradeço a todos os professores, colegas e amigos que, embora não individualizados, foram tão importantes nestes anos da minha vida pessoal, académica e profissional.

Agradeço ao meu marido e à minha filha, que me dão a força necessária para ultrapassar todos os desafios.

Agradeço à minha irmã, amiga de todos os momentos.

Agradeço aos meus adorados PAIS António da Silva Gonçalves e Isaura Figueiredo dos Santos, por todo o apoio e aconselhamento que me deram ao longo destes anos. Dedico este trabalho a ambos, pelo carinho e dedicação que só o amor pode explicar. Mesmo não estando fisicamente comigo agora neste Mundo, sei o orgulho que sentem ao me verem concluir esta etapa. Bem-hajam!

PUBLICAÇÕES RELACIONADAS COM A DISSERTAÇÃO

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Artigo aceite após defesa pública

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LISTA DE ABREVIATURAS

ASCO - American Society of Clinical Oncology

BSI - Brief Symptom Inventory

CNCP – Comissão Nacional de Cuidados Paliativos

CP – Cuidados Paliativos

CPP – Cuidados Paliativos Pediátricos

ECOG - Eastern Cooperative Oncology Group

EHD – Equipa de Hospitalização Domiciliária

EIHSCP – Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos

EORTC QLQ-C15-PAL - Cancer Quality of Life Questionnaire Core 15 Palliative Care

EORTC QLQ-C30 - European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30

ERPI/D – Estrutura Residencial para Pessoas Idosas/Dependentes

ESAS – Edmonton Scale Assessment Symptoms

EUROQOL EQ-5D - European Quality of Life Five Dimensions Questionnaire

FACT-G - Functional Assessment of Oncology Therapy – General scales

FACIT-PAL - Functional Assessment of Chronic Illness Therapy

GDS - Global Distress Scale

HADS - Hospital Anxiety and Depression Scale

IPOCFG, E.P.E. – Instituto Português de Oncologia de Coimbra Francisco Gentil, E.P.E.

IPOS – Integrated Palliative Outcome Scale

KPS - Karnofsky Performance Status

MMSE - Mini-Mental State

MSAS - Memorial Symptom Assessment Scale

MQOL - McGill Quality of Life Questionnaire

OMS – Organização Mundial de Saúde

PDO - Plano de Desenvolvimento Organizacional

POS – Palliative Outcome Scale

PPS - Palliatie Performance Scale

PRO – Patient Reported Outcome

QdV – Qualidade de Vida

RNCCI – Rede Nacional de Cuidados Continuados Integrados

SF-36 - Medical Outcomes Study Questionaire 36-Item Short Form Health Survey

SICP- Serviço Integrado de Cuidados Paliativos

SNS – Sistema Nacional de Saúde

TE - Termómetro emocional

UCP – Unidade de Cuidados Paliativos

ULS – Unidade Local de Saúde

WHOQOL - World Health Organization Quality of Life

WHOQOL -100 - World Health Organization Quality of Life-100

WHOQOL-Bref - World Health Organization Quality of Life “breve”

RESUMO

Introdução:

Os cuidados paliativos (CP) são cuidados holísticos destinado a aliviar o sofrimento de doentes e famílias que se encontram perante doenças ameaçadoras de vida e cujo principal objetivo é melhorar a sua qualidade de vida (QdV). Atendem às dimensões físicas como a dor ou outros sintomas incómodos, mas também às dimensões emocional, espiritual e social.

O controlo sintomático é um dos pilares dos cuidados paliativos, o qual tem um forte impato na qualidade de vida destes doentes, pelo que nos últimos anos tem havido um uso crescente de medidas de resultados em cuidados paliativos que avaliam simultaneamente a intensidade dos sintomas, a qualidade de cuidados e a qualidade de vida.

Existem vários locais de prestação de cuidados paliativos, dos quais se destacam o acompanhamento em regime de ambulatório e o internamento seja numa Unidade de Cuidados Paliativos (UCP), seja noutras enfermarias hospitalares com o apoio da Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos (EIHSCP).

A referenciação precoce a CP dos doentes com cancro avançado tem um impacto significativo na qualidade de vida destes doentes. No entanto, os critérios para essa referenciação ainda não são consensuais, o que faz com que os doentes sejam encaminhados tardiamente, muitas vezes, já em fase de fim de vida.

Os doentes com cancro avançado metastático apresentam elevados níveis de sofrimento emocional, pelo que a identificação deste tipo de necessidades paliativas é essencial, uma vez que permanece muitas vezes subdiagnosticado e subtratado. A ESAS e a POS são duas escalas de uso comum pelas equipas de cuidados paliativos e que mostram uma fiabilidade razoável na deteção da sintomatologia psico-emocional, podendo servir como métodos de triagem, principalmente da ansiedade e da depressão.

Objetivos:

Principal:

- Avaliar o impato da intensidade dos sintomas na qualidade de vida dos doentes oncológicos em cuidados paliativos à admissão na Unidade de Cuidados Paliativos (UCP).

Secundários:

- Analisar as caraterísticas sociodemográficas e clínicas dos participantes da amostra;

- Analisar a intensidade dos sintomas dos doentes e a perceção da qualidade de vida na admissão da UCP;

- Analisar a intensidade dos sintomas dos doentes e a perceção de qualidade de vida à admissão na UCP de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares);

- Analisar a intensidade dos sintomas dos doentes e a perceção de qualidade de vida à admissão na UCP de acordo com os diferentes tipos de neoplasias

- Avaliar o tempo de referenciação dos doentes para CP na amostra global e de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares);

- Correlacionar o tempo de referenciação para CP com a intensidade sintomática e qualidade de vida dos doentes de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares);

- Analisar as propriedades psicométricas do Edmonton Symptom Assessment System (ESAS) e da Palliative Outcome Scale (POS).

Material e Métodos:

Realizou-se um estudo transversal, descritivo e correlacional, que englobou uma amostra de 60 doentes consecutivamente internados na Unidade de Cuidados Paliativos, provenientes ou da Consulta Externa de Cuidados Paliativos ou de outras enfermarias do hospital em que já tinham acompanhamento pela Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos. A avaliação realizou-se nas primeiras 24 horas da admissão.

O protocolo de avaliação incluiu um questionário sociodemográfico e clínico e dois instrumentos de medida: a Escala de Avaliação de Sintomas de Edmonton (ESAS) e a Palliative Outcome Scale (POS), ambas auto-referidas pelo doente.

A análise estatística foi realizada através do IBM SPSS Statistics versão 25.0 e o nível de significância de 5% ($p < 0,05$).

Resultados:

A maioria dos participantes desta amostra era do género masculino (61,7%) e a mediana da idade de 72 anos. 81,7% eram casados e 65% tinham um ou dois filhos. O local de residência era o domicílio em 83% dos casos e 61,7% tinham os cônjugues

ou ou os filhos como cuidadores. Maioritariamente (81,7%) apresentava como habilitações literárias o nível básico. A maioria dos doentes (71,6%) encontrava-se no estadio IV ao diagnóstico de cancro e 66,6% apresentava um ECOG de 3 ou 4 à admissão na Unidade de Cuidados Paliativos. O tipo de neoplasia mais frequente foi a do foro digestivo (41,7%), seguido pela de cabeça e pescoço (20%). Mais de metade dos doentes internados (n= 34; 56,7%) eram provenientes da Consulta Externa de Cuidados Paliativos.

Encontrou-se uma relação estatisticamente significativa entre a intensidade dos sintomas e a qualidade de vida ($p < 0,01$). Esta associação foi particularmente evidente para os sintomas dor, cansaço, depressão, ansiedade e anorexia auto-aferidos pela ESAS na amostra total. No grupo dos doentes provenientes da Consulta Externa de Cuidados Paliativos, as pontuações mais elevadas verificaram-se na fadiga e dispneia enquanto no grupo dos doentes internados noutras enfermarias do hospital o maior descontrolo verificou-se nos sintomas dor, depressão e ansiedade auto-aferidos pela ESAS. Quanto à avaliação pela POS, verificou-se a presença de diferenças estatisticamente significativas nos itens sentido da vida, sentimentos com o próprio e tempo perdido.

Não se verificou qualquer associação clínica ou social com os scores da ESAS ou da POS, exceto no caso do número de filhos e a pontuação dada pela POS.

Quanto aos tipos de neoplasias mais prevalentes, os doentes com tumores de cabeça e pescoço apresentaram uma mediana da POS de 17 [13;19] e da ESAS de 43,5 [34.25;48]. Já nos doentes com patologia oncológica gastro-intestinal a mediana da ESAS foi de 39 [34.25;48] e da POS de 15 [13;19].

Verificou-se que no grupo dos doentes internados, o tempo que mediou entre o diagnóstico e a referenciação a cuidados paliativos foi superior, mas, no entanto, também foi neste grupo que foi menor o hiato temporal entre a referenciação a cuidados paliativos e a primeira avaliação pela equipa de cuidados paliativos, entre a referenciação e a admissão na UCP e entre a referenciação e o óbito. Não houve qualquer relação estatisticamente significativa entre o tempo de referenciação para CP e a intensidade sintomática (aferida peal ESAS) e a qualidade de vida (aferida pela POS) nos dois tipos de abordagem (cuidados ambulatórios VS hospitalares).

Em relação às medidas das propriedades psicométricas da ESAS e da POS verificou-se que a ansiedade associada à doença e aos tratamentos se correlacionava fortemente com a ansiedade auto-referida ($p < 0,01$), que os doentes que partilhavam menos os seus sentimentos com a família e amigos tinham uma menor perceção do significado da vida ($p < 0,01$), sentiam-se piores consigo próprios ($p <0,05$) e sentiam que a vida não era importante ($p <0,01$). A ansiedade relacionada com a doença ou os

seus tratamentos correlacionavam-se com um aumento da gravidade dos sintomas depressivos ($p < 0,01$).

Discussão e Conclusões:

Este estudo revela uma correlação positiva entre a intensidade dos sintomas e a perceção de qualidade de vida, sendo que quanto mais severos, pior é a sensação de bem-estar psicológico, qualidade de cuidados e qualidade de vida.

Os doentes admitidos na Unidade de Cuidados Paliativos apresentavam uma elevada carga sintomática a qual se refletia numa pior perceção de qualidade de vida. Verificou-se também que a proveniência dos doentes à admissão não influenciava estatisticamente esta tendência e correlação.

Verificou-se que o descontrolo sintomático e a baixa perceção de qualidade de vida satisfatória se associavam com um menor tempo de referenciação a cuidados paliativos, motivado pelo fato dos doentes apenas serem referenciados à equipa de cuidados paliativos quando os tratamentos curativos eram suspensos em definitivo tal como a política da instituição assim o preconizava na época.

A referenciação precoce a cuidados paliativos é essencial não apenas para o alívio sintomático como para a melhoria de resultados e da qualidade de vida de indivíduos com cancro avançado.

Em relação ao sofrimento emocional, existem atualmente vários instrumentos de medida validados para a sua avaliação. Constatou-se que a ESAS e a POS se complementam uma à outra, sendo escalas fáceis de utilizar e usadas de rotina nas equipas de cuidados paliativos. Verificou-se que a ansiedade relacionada à doença e tratamentos, medida pela POS, é preditiva do risco da ansiedade e da depressão auto-referidas identificadas na ESAS. Além disso, os ítems da POS que avaliam a componente emocional demonstraram ter uma correlação interna forte, o que sugere que devem ser usados em conjunto para a sua compreensão completa.

Estudos futuros devem considerar incluir também outras escalas e questionários para avaliação de sintomas e qualidade de cuidados. Além disso, investigações posteriores similares à atual em que doentes com doenças avançadas não oncológicas sejam incluídos podem ser úteis e promissoras nesta linha de investigação.

Palavras-chave:

Ansiedade, Cancro, Cuidados Paliativos, Depressão, Qualidade de Vida, Sintomas

ABSTRACT

Introduction:

Palliative care (PC) is holistic care aimed at alleviating the suffering of patients and families who are facing life-threatening diseases and whose main objective is to improve their quality of life (QoL). They attend to the physical dimensions such as pain or other uncomfortable symptoms, but also to the emotional, spiritual and social dimensions.

Symptomatic control is one of the pillars in palliative care, which has a strong impact on the quality of life of these patients, so in recent years there has been an increasing use of outcome measures in palliative care that simultaneously assess symptom intensity, quality of care and quality of life.

There are several places where palliative care is provided, of which outpatient monitoring and hospitalization either in a Palliative Care Unit (PCU) or in other hospital wards with the support of the Intra-Hospital Palliative Care Support Team (EIHSCP) stand out.

Early referral to PC of patients with advanced cancer has a significant impact on the quality of life of these patients. However, the criteria for this referral are not yet consensual, which means that patients are referred to palliative care, often already at the end of life.

Patients with advanced metastatic cancer have high levels of emotional distress, so the identification of this type of palliative needs is essential, as it often remains underdiagnosed and undertreated. The ESAS and the POS are two scales commonly used in palliative care teams and show reasonable reliability in the detection of psycho-emotional symptoms, and can serve as screening methods, especially for anxiety and depression.

Objectives:

Main:

- To evaluate the impact of symptom intensity on the quality of life of patients in palliative care at admission to the Palliative Care (PCU).

Secondary:

- To analyze the sociodemographic and clinical characteristics of the sample participants;

- To analyze the intensity of patients' symptoms and their perception of quality of life on admission to PCU;

- To analyze the intensity of the patients' symptoms and the perception of quality of life at admission to the PCU according to the different models of approach (outpatient care vs hospital);

- To analyze the intensity of the patients' symptoms and the perception of quality of life at admission to the PCU according to the different types of neoplasms;

- To evaluate the referral time of patients for PC in the global sample and according to the different models of approach (outpatient care vs inpatient);

- Correlate the time of referral to PC with the symptomatic intensity and quality of life of patients according to the different models of approach (outpatient vs inpatient);

- Analyze the psychometric properties of the Edmonton Symptom Assessment System (ESAS) and the Palliative Outcome Scale (POS).

Material and Methods:

A cross-sectional, descriptive and correlational study was carried out, which included a sample of 60 patients consecutively admitted to the Palliative Care Unit from either the Palliative Care Outpatient Clinic or from other wards of the hospital in which they were already monitored by the Intra-Hospital Palliative Care Support Team. The evaluation was carried out within the first 24 hours of admission.

The evaluation protocol included a sociodemographic and clinical questionnaire and two measurement instruments: the Edmonton Symptom Assessment Scale (ESAS) and the Palliative Outcome Scale (POS), both self-reported by the patient.

Statistical analysis was performed using IBM SPSS Statistics, version 25.0, and the significance level was 5% ($p < 0.05$).

Results:

Most participants in this sample were male (61.7%) and the median age was 72 years. 81,7% were married and 65% had one or two children. The place of residence

was the home in 83% of the cases and 61.7% had the spouses or children as caregivers. Most (81.7%) had a basic level of education. Most patients (71.6%) were in stage IV at the diagnosis of cancer and 66.6% had an ECOG of 3 or 4 at admission to the Palliative Care Unit. The most frequent type of neoplasm was digestive neoplasm (41.7%), followed by head and neck neoplasm (20%). More than half of the hospitalized patients (n= 34; 56.7%) were from the Palliative Care Outpatient Consultation.

A statistically significant relationship was found between symptom intensity and quality of life ($p < 0.01$). This association was particularly evident for the symptoms of pain, tiredness, depression, anxiety, and anorexia self-measured by the ESAS in the total sample. In the group of patients coming from the Palliative Care Outpatient Consultation, the highest scores were found in fatigue and dyspnea, while in the group of patients admitted to other wards of the Hospital, the greatest lack of control was found in the symptoms of pain, depression and anxiety self-measured by the ESAS. Regarding the POS evaluation, the presence of statistically significant differences was found in the items meaning of life, feelings with oneself and lost time.

There was no clinical or social association with the ESAS or POS scores, except in the case of the number of children and the score given by the POS. As for the most prevalent types of neoplasms, patients with head and neck tumors had a median POS score of 17 [13; 19] and ESAS 43.5 [34.25; 48]. In patients with gastro-intestinal oncological pathology, the median ESAS was 39 [34.25; 48] and the POS of 15 [13; 19].

It was found that in the group of hospitalized patients, the time between diagnosis and referral to palliative care was longer, but, however, it was also in this group that the temporal gap between referral to palliative care and the first assessment by the palliative care team, between referral and admission to the PCU and between referral and death was shorter. There was no statistically significant relationship between the time of referral to PC and symptomatic intensity (measured by ESAS) and quality of life (measured by POS) in the two types of approach (outpatient vs hospital care).

Regarding the measures of the psychometric properties of the ESAS and the POS, it was found that anxiety associated with the disease and treatments was strongly correlated with self-reported anxiety ($p < 0.01$), that patients who shared their feelings less with family and friends had a lower perception of the meaning of life ($p < 0.01$), felt worse about themselves ($p <0.05$) and felt that life was not important ($p <0.01$). Anxiety related to the disease or its treatments correlated with an increase in the severity of depressive symptoms ($p <0.01$).

Discussion and Conclusions:

This study reveals a positive correlation between the intensity of symptoms and the loss of quality of life, and the more severe, the worse the feeling of psychological well-being, quality of care and quality of life.

Patients admitted to the Palliative Care Unit had a high symptomatic burden, which was reflected in a worse perception of quality of life. It was also found that the origin of the patients at admission did not statistically influence this trend and correlation.

It was found that symptomatic lack of control and low perception of satisfactory quality of life were associated with a shorter time of referral to palliative care, motivated by the fact that patients were only referred to the palliative care team when curative treatments were definitively suspended, as recommended by the Institution's policy.

Early referral to palliative care is essential not only for symptomatic relief but also for improving outcomes and quality of life for individuals with advanced cancer.

Regarding emotional distress, there are currently several validated measurement instruments for its assessment. It was found that ESAS and POS complement each other, being easy-to-use scales and routinely used in palliative care teams. It was found that anxiety related to illness and treatments, as measured by POS, is predictive of the risk of self-reported anxiety and depression identified in the ESAS. In addition, the POS items that assess the emotional component have been shown to have a strong internal correlation, which suggests that they should be used together for their complete understanding.

Future studies should also consider including other scales and questionnaires for symptom assessment and quality of care. In addition, further research similar to the current one in which patients with advanced non-cancer diseases are included may be useful and promising in this line of research.

Key words:

Anxiety, Cancer, Palliative Care, Depression, Quality of Life, Symptoms

CAPÍTULO

1

INTRODUÇÃO

INTRODUÇÃO

A atualidade carateriza-se por mudanças profundas na pirâmide demográfica, em que o desenvolvimento científico-tecnológico permitiu um aumento da esperança de vida com o consequente envelhecimento populacional e aumento da prevalência de doenças crónicas, com destaque para o cancro (Christensen et al., 2009; Connor & Sepulveda Bermedo, 2014).

O cancro é considerado um dos problemas de saúde pública mais importante na atualidade, uma vez que representa uma ameaça à saúde nas dimensões biológica, social e económica e é a segunda causa de morte em muitos países (Sekar & Paulmuruga, 2014).

A perceção cultural da morte e do processo de morrer e as expetativas irrealistas de sobrevivência a qualquer custo podem levar a que os doentes portadores de doenças crónicas, nomeadamente o cancro, sofram desnecessariamente (Cardona-Morrell et al., 2016).

A literatura indica que haverá um aumento substancial do sofrimento associado à saúde (Sleeman et al., 2019), sendo que 87% dos doentes necessitarão de cuidados paliativos até 2060 (Clark et al., 2020)

Segundo a Organização Mundial de Saúde (OMS), os cuidados paliativos definem-se como uma abordagem que visa melhorar a qualidade de vida dos doentes e famílias que enfrentam doenças ameaçadoras de vida através da prevenção e alívio do sofrimento e identificação e tratamento precoce da dor e de outros problemas físicos, psicológicos e espirituais. Afirmam a vida e consideram a morte como um processo natural (World Health Organization, 2015).

Cicely Saunders, pioneira no movimento moderno dos cuidados paliativos, apresentou o conceito de "dor total", que abrange as dimensões física, emocional, social e espiritual dos doentes, dando suporte assim ao cuidado holístico do doente terminal (Saunders, 1996; Clark, 1999; Miccinesi et al., 2019).

Tal como supracitado, o envelhecimento e o desenvolvimento de terapêuticas anti-neoplásicas mais eficazes aumentaram a longevidade dos doentes com cancro, mesmo os progressivos e incuráveis. No entanto, deve acautelar-se que esta melhoria da sobrevida não seja acompanhada de maior sofrimento (Ahmedzai et al., 2004; Jemal, Ward, & Thun, 2010). Sintomas como a ansiedade, a depressão, a dor, a fadiga, a dispneia e a anorexia (Teunissen et al., 2007) podem ter um impacto

negativo na qualidade de vida dos doentes com eventual diminuição da funcionalidade e maior dependência (Tanaka et al., 2002; Deshields et al., 2011; Deshields et al., 2014).

Durante o processo de morrer, há geralmente uma série de relações pessoais e familiares que envolvem despedidas e preocupações, as quais são influenciadas pelo contexto cultural, a biografia pessoal, a vivência espiritual e a ética de cuidado. O doente experiencia ansiedade, depressão, medo, preocupação com a família e a busca de um sentido para a vida na experiência da doença (Lucette et al., 2014; Asgeirsdottir et al., 2014).

Cuidados paliativos de qualidade na doença oncológica envolvem uma gestão eficaz dos sintomas ao longo da trajetória da doença, isto é, desde o diagnóstico até às últimas horas ou dias de vida em que há um agravamento da carga sintomática e do declínio funcional (McCarthy et al., 2000; Rome et al., 2011; Lynn & Adamson, 2003).

O controlo sintomático é um dos pilares básicos dos cuidados paliativos, pelo que a avaliação da presença e intensidade dos principais sintomas e a intervenção precoce no sentido do seu alívio são essenciais para garantir um fim de vida digno e com qualidade de vida (Hui & Bruera, 2017).

A Edmonton Scale Assessment Symptoms (ESAS) é a escala de avaliação de sintomas mais utilizada pelas equipas de cuidados paliativos portuguesas. Trata-se de uma escala numérica, que se completa em 5 minutos e que mede de 0 (sintoma ausente) a 10 (maior intensidade possível) os nove principais sintomas dos doentes que apresentam doença avançada e que são a dor, o cansaço, a náusea, a depressão, a ansiedade, a sonolência, o apetite, a sensação de bem-estar e a dispneia (Bausewein, Dveson, Benalia, Simon & Higginson, 2011).

Qualidade de vida é um conceito multidimensional e subjetivo que se refere à perceção que o indivíduo tem sobre a sua posição na vida, no contexto da cultura e sistema de valores em que está inserido e de acordo com os seus objetivos, expetativas, padrões e preocupações (World Health Organization, 1997).

O objetivo dos cuidados paliativos é proporcionar a melhor qualidade de vida (QdV) aos doentes e suas famílias (Doyle, 2003). No entanto, ainda há poucas evidências na literatura sobre qual é o verdadeiro significado deste conceito no contexto de cuidados paliativos. Há também um interesse crescente sobre a utilização de indicadores que monitorizem a qualidade dos cuidados nesta área, sendo certo que a qualidade de vida pode ser igualmente um indicador da qualidade de cuidados (Treurniet et al., 1997).

A Palliative Outcome Scale (POS) é um instrumento multidimensional que permite avaliar o bem-estar, a qualidade de cuidados e a qualidade de vida nos doentes em cuidados paliativos. Consiste em 10 ítens pontuados numa escala de 0 (nada) a 4 (impossível de pensar em mais alguma coisa), englobando as dimensões física, psicológica, emocional e espiritual do doente e família assim como preocupações práticas e uma pergunta aberta acerca dos principais problemas. A versão self demora cerca de 6,9 minutos a ser preenchida (Bausewein, Daveson, Benalia, Simon & Higginson, 2011).

A Palliative Outcome Scale é um instrumento fiável para medir a qualidade de vida dos doentes com doença avançada, uma vez que avalia os sintomas físicos (dor e outros), psicológicos (ansiedade e sofrimento), o bem-estar emocional e espiritual, as preocupações práticas do dia a dia, a comunicação e o apoio social e familiar. Esta escala vai de encontro ao que é preconizado pelo grupo WHOQOL da Organização Mundial de Saúde (Hearn & Higginson, 1999; Murtagh et al., 2019; World Health Organization Quality of Life Group, 1997).

A pertinência deste tema tem como base a crescente prevalência dos doentes com cancro avançado e em cuidados paliativos e na necessidade de encontrar estratégias que melhorem a carga sintomática e a qualidade de vida destes indivíduos à admissão na UCP. Assim, a investigação ampla nesta área é emergente e um imperativo ético, de modo a que a prática clínica seja compassiva e humanizada, valorizando o cuidado holístico e centrado na pessoa.

O estudo da presente dissertação teve como objetivo principal avaliar o impacto da intensidade dos sintomas na qualidade de vida dos doentes em cuidados paliativos aquando a admissão na Unidade de Cuidados Paliativos (UCP).

Os objetivos secundários pretenderam: 1. analisar as caraterísticas sociodemográficas e clínicas dos participantes da amostra, 2. analisar a intensidade dos sintomas dos doentes e a perceção de qualidade de vida na admissão à UCP, 3. analisar a intensidade dos sintomas dos doentes e a perceção de qualidade de vida na admissão à UCP de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares), 4. analisar a intensidade dos sintomas dos doentes e a perceção de qualidade de vida à admissão na UCP de acordo com os diferentes tipos de neoplasias, 5. avaliar o tempo de referenciação dos doentes para CP na amostra global e de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares), 6. correlacionar o tempo de referenciação para CP com a intensidade sintomática e qualidade de vida dos doentes de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares) e 7. analisar as

propriedades psicométricas do Edmonton Symptom Assessment System (ESAS) e da Palliative Outcome Scale (POS).

Utilizou-se a Edmonton Symptom Assessment *Scale* (ESAS) para a avaliação da presença e intensidade dos sintomas e a Palliative Outcome Scale para avaliar a qualidade de vida. A associação destas duas escalas mostra-se metodologicamente pertinente, uma vez que combina uma medição quantitativa da carga sintomática com a perceção subjetiva do impato global do cancro avançado na qualidade de vida destes doentes.

A presente tese está organizada em oito capítulos, sendo estruturada no formato de compilação de artigos científicos. Em seguida, faz-se uma breve descrição do conteúdo de cada capítulo assim como a integração dos cinco artigos e um capítulo de livro.

No **Capítulo 1 (Introdução),** faz-se uma introdução ao tema e ao contexto da investigação, incluindo a definição dos principais conceitos, a pertinência do tema e os principais objetivos do trabalho.

No **Capítulo 2 (Enquadramento teórico),** explora-se o estado da arte em cuidados paliativos oncológicos com foco no controlo de sintomas e na qualidade de vida e da relação entre ambos. Analisa a história e os princípios dos cuidados paliativos, os instrumentos mais utilizados, os desafios éticos do controlo sintomático em cuidados paliativos e o impacto dos tempos que envolvem o diagnóstico de doença e a referenciação a cuidados paliativos na carga sintomática e na qualidade de vida. Analisa-se igualmente o sofrimento emocional. Este capítulo integra dois artigos e um capítulo de livro: um artigo publicado na revista Current Oncology MDPI e intitulado "*A Review on the Management of Symptoms in Patients with Incurable Cancer",* um artigo aceite para publicação na revista de Bioética intitulado *"Desafios éticos do controle sintomático em cuidados paliativos: reflexão crítica"* e um capítulo da *Encyclopedia of Palliative Care. Coimbra: Almedina; 2023 intitulado "Quality of Life"*

No **Capítulo 3 (Objetivos),** mencionam-se os principais objetivos deste estudo, sendo de destacar o *objetivo principal* - avaliar o impacto da intensidade dos sintomas na qualidade de vida dos doentes em cuidados paliativos aquando da admissão na Unidade de Cuidados Paliativos (UCP).

No **Capítulo 4 (Material e Métodos),** descreve-se a amostra e o desenho geral do estudo, as considerações éticas e o consentimento informado, os critérios de

inclusão e de exclusão, o método de colheita de dados, os instrumentos de recolha de dados (o questionário sociodemográfico e clínico, a Edmonton Symptom Assessment Scale (ESAS), a Palliative Outcome Scale (POS)) e a análise estatística efetuada.

No **Capítulo 5 (Resultados),** apresentam-se os três artigos originais do estudo e que abordam as diferentes dimensões do controlo sintomático e a sua relação com a qualidade de vida:

- ✓ **Artigo I**: Gonçalves F, Gaudêncio M, Paiva I, Semedo VA, Rego F, Nunes R. Impact of Symptom Distress on the Quality of Life of Oncology Palliative Care Patients: A Portuguese Cross- Sectional Study. Healthcare (Basel). 2024 Dec 9;12(23):2487. doi: 10.3390/healthcare12232487
- ✓ **Artigo II**: Gonçalves F, Gaudêncio M, Paiva ICS, Rego F, Nunes R. Intensity of Symptoms and Perception of Quality of Life on Admission to Palliative Care: Reality of a Portuguese Team. Healthcare (Basel). 2024 Aug 1;12(15):1529. doi: 10.3390/healthcare12151529
- ✓ **Artigo III**: Gonçalves F, Gaudêncio M, Paiva I, Rego F, Nunes R. Evaluation of Emotional Distress in Oncology Palliative Patients: Edmonton Symptom Assessment System (ESAS) and Palliative Outcome Scale (POS)-A Portuguese Cross-Sectional Study. Cancers (Basel). 2024 Dec 19;16(24):4232. doi: 10.3390/cancers16244232

No **Capítulo 6 (Discussão),** descrevem-se os resultados deste estudo, que foram correlacionados com a literatura científica atual e as implicações que podem ter para a prática clínica, nomeadamente no que diz respeito à elevada carga sintomática e aos resultados pouco satisfatórios na perceção dos doentes sobre a sua qualidade de vida à admissão na Unidade de Cuidados Paliativos, à referenciação tardia dos doentes que foi maioritariamente realizada na fase terminal da doença e ao facto da ansiedade e as preocupações relacionadas com a doença e os tratamentos medidos pela POS servirem de preditores de risco da ansiedade e da depressão identificadas pela ESAS.

Este estudo apresentou algumas limitações que devem ser tidas em conta na interpretação dos resultados. Apesar destas limitações, os dados obtidos fornecem contributos relevantes para a compreensão do controlo sintomático e da qualidade de

vida dos doentes com cancro avançado à sua admissão na Unidade de Cuidados Paliativos.

No **Capítulo 7 (Conclusões),** apresentam-se as principais conclusões observadas ao longo deste estudo, das quais se destacam: os doentes com cancro avançado seguidos por equipas especializadas nesta área independentemente da tipologia de cuidados prévia apresentavam à admissão na Unidade de Cuidados Paliativos uma elevada carga sintomática tal como foi medida pela ESAS. Verificou-se igualmente que a qualidade de vida dos doentes à admissão apresentava resultados pouco satisfatórios tal como foi aferido pela POS. A referenciação dos doentes a cuidados paliativos foi tardia e já perto do fim de vida. A sintomatologia emocional, mais precisamente a ansiedade e a depressão tiveram uma prevalência expressiva na amostra do estudo. A ansiedade e as preocupações com a doença e tratamentos, conforme aferido pela POS são preditores de risco da ansiedade e depressão identificadas pela ESAS. A ESAS e a POS complementam-se uma à outra como medidas práticas e de fácil uso para avaliar o sofrimento emocional dos doentes admitidos na Unidade de Cuidados Paliativos.

Estes resultados reforçam a necessidade de futuramente a referenciação a cuidados paliativos ser o mais precoce possível na trajetória das neoplasias malignas e não apenas quando o doente se encontra em fase terminal. É igualmente necessário que os sintomas físicos ou emocionais sejam identificados e abordados de forma atempada e personalizada de modo a promover o bem-estar e a qualidade de vida destes doentes que se encontram em situação de extrema vulnerabilidade. Esta investigação permitiu reforçar a teoria de que a ESAS e a POS continuam a ser duas escalas relevantes no contexto dos cuidados paliativos, pelo que devem ser adotadas como instrumentos de monitorização contínua dos sintomas, do bem-estar, da qualidade de cuidados e da qualidade de vida assim como de apoio à decisão clínica.

Por fim, no **Capítulo 8 (Perspetivas futuras),** procura-se desenvolver e apontar algumas linhas de orientação em termos de investigação no futuro, bem como, aspectos a melhorar na prática clínica diária dos cuidados paliativos.

Como necessidades futuras, será essencial realizar estudos de investigação longitudinais e de natureza qualitativa que permitam aprofundar o conhecimento sobre o comportamento evolutivo dos sintomas e da qualidade de vida dos doentes internados. A nível clínico, a implementação de protocolos padrão de abordagem dos sintomas e a integração precoce dos cuidados paliativos na trajetória da doença oncológica devem ser prioritários. A nível educativo, é fundamental investir na formação específica em cuidados paliativos dos profissionais de saúde. O

desenvolvimento de guidelines a nível nacional e internacional sobre controlo sintomático e indicadores de qualidade de vida dos doentes em cuidados paliativos assim como o desenvolvimento de políticas que permitam a equidade no acesso aos cuidados paliativos e a referenciação precoce permitirá diminuir o sofrimento destes doentes e uma abordagem mais humanizada e centrada na pessoa doente.

CAPÍTULO

2

ENQUADRAMENTO TEÓRICO

ENQUADRAMENTO TEÓRICO

Nas últimas décadas tem-se assistido ao envelhecimento populacional, sendo expectável que atualmente a maioria das pessoas viva acima dos 60 anos de idade. Estima-se que em 2030 uma em cada seis pessoas tenha mais de 60 anos e até 2050, a população mundial com mais de 60 anos ascenderá a 2,1 mil milhões de pessoas. O número de pessoas com mais de 80 anos deverá triplicar entre 2020 e 2050, atingindo 426 milhões de habitantes (World Health Organization, 2024).

A 31 de dezembro de 2023, havia 10 639 726 habitantes em Portugal, mais 123 105 do que em 2022. Este aumento populacional verificou-se pelo 5º ano consecutivo. Continuou a verificar-se igualmente um agravamento do envelhecimento no nosso país, cujo índice atingiu em 2023 o valor de 188,1 (em 2022, este índice de envelhecimento era de 184,4). A idade mediana em Portugal aumentou de 46,9 anos em 2022 para 47,1 anos em 2023 (Instituto Nacional de Estatística, 2023).

O envelhecimento populacional e o aumento da longevidade têm sido motivo de pressões profundas a nível político, económico, social e nos serviços de saúde. Por sua vez, o desenvolvimento científico tem aumentado o número de diagnósticos e de novas modalidades terapêuticas que permitem que os indivíduos vivam mais tempo com consequente aumento da prevalência de doenças crónicas. Atualmente, cada indivíduo tem em média duas doenças crónicas, isto é, apresenta multimorbilidade, entre as quais se destaca a diabetes, a hipertensão, as neoplasias e o acidente vascular cerebral (Tinetti, Fried & Boyd, 2012; Fabbri et al., 2015; BMJ, 2023). Em 2017, os óbitos por doenças não comunicáveis representaram 73,4% do total, correspondendo a um aumento de 18,6% em 10 anos (GBD 2017; Causes of Death Collaborators, 2018).

As intervenções em cuidados paliativos têm aumentado em todo o mundo. Como dito anteriormente, prevê-se que haja um aumento global de doenças graves assim como o sofrimento a elas associado e que em 2060, 87% dos doentes necessitarão da intervenção de equipas especializadas em cuidados paliativos (Clark et al., 2020; Sleeman et al., 2019).

Alguns estudos realizados constatam ser previsível que os cuidados paliativos venham a ser necessários para cerca de 20 milhões de pessoas anualmente a nível mundial, sendo que destes 20 milhões, 69% serão adultos com mais de 60 anos de idade e 6% serão crianças (Connor & Sepulveda, 2018).

A intervenção dos cuidados paliativos deverá acontecer em três momentos chave na trajetória da doença: no momento do diagnóstico, no estadio inicial e no início dos sintomas (Howie & Peppercorn, 2013).

Atualmente, o fim de vida na maioria das pessoas ocorre no contexto de doenças crónicas e suas trajetórias. As doenças cardiovasculares e o cancro são as principais causas e as que mais causam dependência antes da morte (Murray et al., 2005). Podem identificar-se várias trajetórias diferentes nas doenças crónicas progressivas como se pode verificar na seguinte figura.

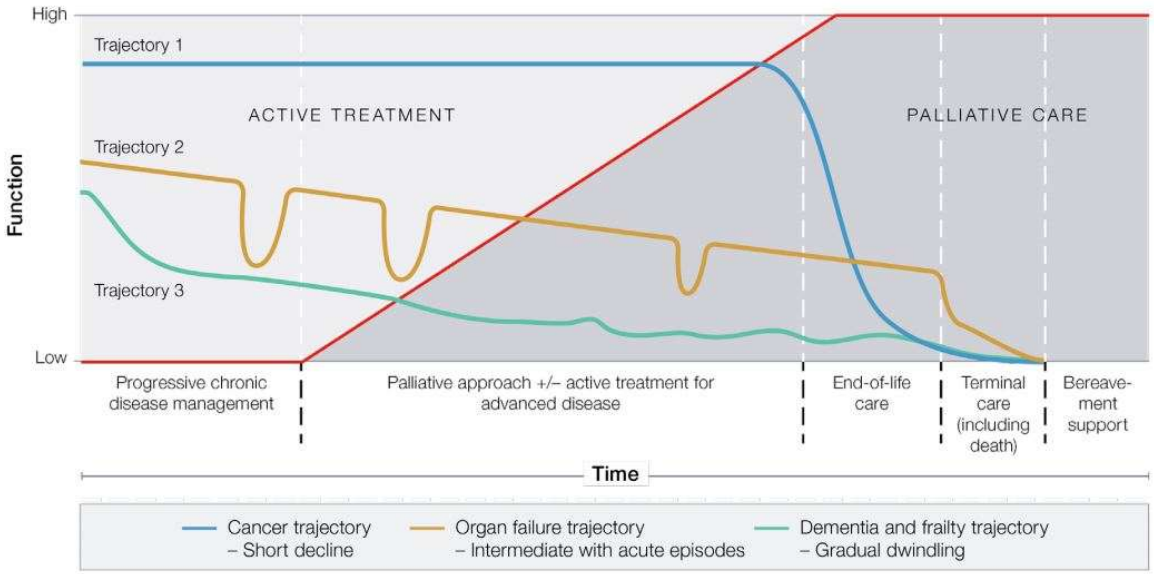


Figura 1: Trajetórias de doença e fases de CP

Reproduced with permission from The Royal Australian College of General Practitioners from: The Royal Australian College of General Practitioners. RACGP aged care clinical guide (Silver Book). 5th edn. East Melbourne, Vic: RACGP, 2019. Available at: https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/silver-book/part-a (Anexo I)

As trajetórias típicas das doenças crónicas ajudam os profissionais de saúde a estimar o prognóstico. Nos casos de morte súbita e cancro terminal a deterioração ocorre instantaneamente ou é rápida, nas falências de órgãos como é o caso da insuficiência cardíaca, insuficiência respiratória crónica, insuficiência renal crónica e falência hepática, há um declínio lento marcado por períodos de exacerbação e recuperação rápida e na síndrome de fragilidade e demências o declíneo é lento com menos episódios agudos (Murray et al., 2024).

Em 1990, a Organização Mundial da Saúde (OMS) referiu-se pela primeira vez aos cuidados paliativos como "Palliative care is the active, total care of patients with progressive, far advanced disease and limited life expectancy whose disease is not responsive to curative treatment. It refers to the control of pain and of other symptoms as well as the treatment of social, psychological, and spiritual problems." (World Health Organization, 1990), mas foi em 2002 que a OMS concebeu a primeira definição dos mesmos como "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." (World Health Organization, 2002). Em 2020, esta definição foi atualizada para "Palliative care: a crucial part of integrated, people-centered health services. Relieving serious health-related suffering, be it physical, psychological, social or spiritual, is a global ethical responsibility. Thus, whether the cause of suffering is cardiovascular disease, cancer, major organ failure, drug-resistant tuberculosis, severe burns, end-stage chronic illness, acute trauma, extreme birth prematurity or extreme frailty of old age, palliative care may be necessary and must be available at all levels of care." (World Health Organization, 2020).

Os cuidados paliativos são uma abordagem holística que visa melhorar a qualidade de vida dos doentes que enfrentam uma doença ameaçadora de vida, assim como a qualidade de vida das suas famílias e cuidadores através da prevenção e alívio da dor e do sofrimento por meio da identificação precoce e avaliação e tratamento adequados da dor e de outros problemas físicos, psicossociais e espirituais, estendendo-se ao luto (Saunders & Sykes, 1993; Beng, 2004).

A condição de doença altera as relações interpessoais do indivíduo como ser único que é. Assim, perante situações de fim de vida, os profissionais de saúde devem garantir um cuidado holístico e humanizado que possibilite a manutenção da autonomia do doente e um controlo sintomático eficaz (Singer, Martin & Kelner, 1999).

1. História dos Cuidados Paliativos

Os cuidados paliativos, na sua perspetiva mais moderna tivaram início em 1959, quando Cicely Saunders, médica e investigadora no St Joseph's Hospice em Hackney, Londres, publicou o seu primeiro artigo científico "The Management of the Terminally Ill" (Saunders, 1960). Naquela época, eram poucos os hospícios no Reino Unido e os que havia eram geridos por fundações religiosas (Humphreys, 2001).

Faziam-se poucas pesquisas sobre os doentes moribundos e o movimento moderno dos cuidados paliativos estava longe de existir (Clark et al., 2005), assim como o termo "cuidados paliativos" (Clark & Seymour, 1999). Além disso, a especialidade de oncologia médica estava focada em curar ou prolongar a vida dos doentes com cancro, e não nos que morriam da doença (Clark, 2007).

Foi apenas em 1999 que o governo britânico nomeou pela primeira vez um diretor nacional, o Professor de medicina paliativa Mike Richards que reformulou e melhorou os centros oncológicos com integração dos serviços de cuidados paliativos a nível nacional (Burke, 2004). Assim, em apenas quatro décadas, o cuidado prestado aos doentes com cancro avançado passou das margens da oncologia para o tratamento moderno das doenças oncológicas em que os cuidados paliativos passaram a fazer parte. O desenvolvimento dos cuidados paliativos ainda decorre atualmente, envolvendo a criação da medicina paliativa como especialidade num número crescente de países. Esse desenvolvimento mundial dos cuidados paliativos está ainda profundamente enraizado na especialidade da oncologia, embora sejam cada vez mais os doentes portadores de doenças não oncológicas a beneficiar também destes cuidados.

1.1. Origens dos Hospices e dos Cuidados Paliativos

Na década de 1950, a abordagem do cancro tinha como principal objetivo o seu potencial tratamento curativo e o doente moribundo ou era ignorado ou era enviado para casa para morrer, alegando-se que "já nada havia mais a fazer".

Foi também nesta década que médicos e assistentes sociais desenvolveram novas pesquisas científicas multidimensionais sobre os doentes oncológicos em fim de vida. Tal foi o caso do estudo de Margaret Bailey com doentes com cancro do pulmão (Bailey, 1959). Nos Estados Unidos da América também se realizavam estudos envolvendo doentes com doença avançada que envolviam questões psicossociais, como dizer a verdade (Brauer, 1960), abordagem da ansiedade e da depressão (Bard, 1960) e luto antecipatório (Lindemann, 1994; Aldrich, 1963). Por

sua vez, Colin Murray Parkes em Londres, realizou uma investigação sobre o luto e a doença mental que ajudou a corroborar os resultados das pesquisas anterioriormente citadas (Parkes, 1964).

Cicely Saunders foi pioneira na dedicação aos doentes com cancro em estado terminal, tal como se pode comprovar nesta conversa que teve com um colega de trabalho" Carcinoma of cervix I think is the most diffi cult both from the point of view of pain and of general distress; and I think that carcinoma of breast with bone secondaries probably comes second to that. In both these groups it is the patients between 40 and 60 years who tax our skill." (Saunders, 2001). Passou a focar-se nos doentes oncológicos em fase terminal, quando esgotadas todas as terapêuticas curativas possíveis, tornando-se numa referência em cuiadados paliativos. Os seus artigos baseavam-se em relatos de casos individuais que recolhia. Em 1960 apresentou uma série de 340 casos (Saunders, 1960) e em 1967 este número já foi de 1100 (Saunders, 1967).

Uma caraterística marcante de seus artigos era sua articulação entre o sofrimento físico e mental, em que um afetava o outro. Esta relação ficou bem explícita com o conceito de "dor total" que englobava no seu todo as dimensões física, psicológica e social do sofrimento (Clark, 1999). Cicely Saunders também era uma clínica com ideias muito concretas em relação à dor: "dor constante necessita de controlo constante", defendendo a administração regular de analgésicos, o seu escalamento de acordo com a intensidade da dor e a sua prevenção atempada. Para ela, a morte fazia parte da vida e deveria ocorrer naturalmente, opondo-se incansavelmente à eutanásia (Saunders, 1975).

1.2. St Christopher's Hospice

Em 1967, Cicely Saunders abriu o primeiro hospice em Londres, onde conjugava a clínica com o ensino e a investigação. Este centro rapidamente se transformou numa referência nos cuidados paliativos, particularmente na investigação sobre o controlo da dor, farmacocinética e mecanismos de ação dos opioides. Os estudos incidiram inicialmente nos primeiros métodos conhecidos para alívio da dor com o conhecido "coktail de Brompton" utilizado em hospices antigos (Clark, 2003). O coktail de Brompton consistia numa mistura de morfina, cocaína, álcool, clorofórmio e xarope de mel para facilitar a sua ingestão. No entanto, Robert Twycross, igualmente investigador do St Christopher's Hospice, concluiu que esta mistura não era mais do que a simples administração oral de morfina em doentes

oncológicos com dor, pelo que foi da opinião de que o antigo coktail deveria ser abandonado (Twycross, 1979).

Assim, a investigação e o ensino de outros profissionais de saúde sobre as ações da morfina e novas vias de administração em conjunto com a utilização de outros analgésicos e adjuvantes permitiram o desenvolvimento científico da área dos cuidados paliativos. Estes estudos começaram mesmo antes da admissão do primeiro doente no Hospice, quando Parkes analizou uma amostra de 276 doentes que morreram com cancro em Londres, sendo que 49 ainda estavam em tratamento oncológico ativo no momento da morte. Descobriu que uma percentagem muito significativa deles tinha morrido com dor não aliviada e que à medida que novos doentes entravam no estudo e eram admitidos no Hospice o nível de dor diminuía consideravelmente (Parkes, 1978).

O sucesso do St Christopher's Hospice foi tal que na década de 1980 eram abertos cerca de 10 novos hospices por ano no Reino Unido. Em 1976, o St Thomas's Hospital cria a primeira equipa para doentes terminais, marcando o início das equipas hospitalares, sendo que entre 1982 e 1986 o número de hospitais com equipas multidisciplinares de cuidados paliativos cresceu de cinco para 275 (Clark & Seymour, 1999), constituindo a primeira ligação entre oncologistas e especialistas em cuidados paliativos.

A partir da década de 1980, os primeiros paliativistas disseminaram os seus conhecimentos, promovendo e denvolvendo os cuidados paliativos noutros países (Clark, 2004).

A história dos cuidados paliativos tem pouco mais de cinco décadas de existência, com uma aceitação inegável na área das doenças oncológicas. O acesso aos cuidados paliativos nos doentes em fim de vida com doenças não oncológicas é igualmente uma realidade crescente.

2. Cuidados Paliativos em Portugal

2.1. História

Em Portugal, os efeitos cumulativos da redução da mortalidade e do número de nascimentos transformou a sociedade numa polulação envelhecida, com consequências dramáticas a curto-médio prazo. Com o aumento da esperança de vida, o cuidado de doenças crónicas exige atualmente o recrutamento de uma importante parcela de recursos humanos com competências específicas em geriatria e cuidados paliativos (da Cruz & Nunes, 2016).

Enquanto antes os serviços de saúde estavam apenas focados no tratamento curativo das doenças crónicas, nomeadamente o cancro, hoje em dia faz-se um esforço para que os cuidados paliativos integrem o mais precocemente a trajetória destas doenças (Gonçalves, 2011; da Cruz & Nunes, 2016).

Foi na década de 90 que os cuidados paliativos iniciaram o seu percurso em Portugal (Marques et al. 2009), quando em 1992 o hospital do Fundão passou a ter um internamento dedicado aos doentes em cuidados paliativos integrados na sua Unidade de Dor. Em 1996 foi criada a primeira equipa de cuidados paliativos domiciliários pelo Centro de Saúde de Odivelas (Marques et al., 2009).

Em 1995 surgiu a Associação Nacional de Cuidados Paliativos que em 2007 passou a chamar-se de Associação Portuguesa de Cuidados Paliativos (Nunes, Rego & Rego, 2018).

A competência em cuidados paliativos foi criada pela Ordem dos Médicos em 2003 e em 2004 o Ministério da Saúde publicou pela primeira vez o programa nacional de cuidados paliativos (da Cruz & Nunes, 2016; Direção-Geral da Saúde, 2004). Em junho de 2006 foi criada a Rede Nacional de Cuidados Continuados Integrados destinada a doentes com patologia crónica e em cuidados paliativos (Ministério da Saúde, 2006).

Em 2012 foi finalmente publicada em Portugal a Lei de Beses dos Cuidados Paliativos, Lei n.º 52/2012, de 5 de setembro que consagrou a Rede Nacional de Cuidados Paliativos sob a responsabilidade do Ministério da Saúde (Assembleia da República Portuguesa, 2012).

2.2. Modelos de Organização dos Cuidados Paliativos

O plano Nacional de Cuidados Paliativos recomenda a sua divisão em vários níveis de cuidados para poder haver resposta às necessidades paliativas (da Cruz & Nunes, 2016; Capelas & Coelho, 2014):

- Unidades de Cuidados Paliativos: serviços especialmente concebidos para doentes em cuidados paliativos com necessidades complexas, sendo consideradas maioritariamente unidades de agudos. Geralmente fazem parte do sistema hospitalar, embora algumas integrem a Rede nacional de Cuidados Continuados Integrados;
- Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos: a equipa multidisciplinar de cuidados paliativos desloca-se às enfermarias onde estão identificados doentes com necessidades paliativas, dá suporte à família e cuidadores e atua habitualmente em regime de consultadoria;
- Equipas Comunitárias de Suporte em Cuidados Paliativos: as equipas deslocam-se ao domicílio dos doentes onde fazem ações paliativos e dão suporte à Unidade doente-família;
- Hospitais de Dia de Cuidados Paliativos: permitem que os doentes recebam os cuidados necessários da equipa inter-disciplinar durante o dia, regressando ao domicílio cumpridas as necessidades paliativas.

Mais de 50% dos doentes em cuidados paliativos desejavam morrer no seu domicílio, mas apenas 33% deles vêem este desejo ser cumprido (Beauchamp & Childress, 2001). Ainda que se preconize que os cuidados paliativos devam ser iniciados o mais precocemente possível, desejavelmente aquando do diagnóstico de uma doença ameaçadora de vida, a verdade é que na maioria dos casos só acontece no último mês de vida em contexto de internamento hospitalar (Kozlov et al., 2018). Segundo o estudo realizado por Sarmento et al, estima-se que em 2030, 75% das mortes em Portugal ocorra em ambiente hospitalar (Sarmento et al., 2015).

Os profissionais de saúde têm o dever ético de respeitar a autonomia do doente, oferecer o tipo de tratamento que querem ou não receber e respeitar o local de morte onde desejam que esta aconteça (da Cruz & Nunes, 2016; Burlá, Rego & Nunes, 2014).

O Plano Estratégico para o Desenvolvimento dos Cuidados Paliativos em Portugal Continental – Biénio 2023-2024 de 29-12-2023 reformulou a "estratégia de organização e coesão de cuidados num novo paradigma de desempenho do SNS, em

resultado da generalização do modelo das Unidades Locais de Saúde." (Ministério da Saúde, 2023). Este plano refere o seguinte: "As pessoas com necessidades de saúde complexas necessitam de cuidados de múltiplos prestadores em vários ambientes de saúde, pelo que o risco de receberem cuidados fragmentados é elevado. No processo atual de reorganização do SNS, é imprescindível a agregação das Equipas de Cuidados Paliativos nos SICP das ULS garantindo a prestação de cuidados de forma integrada à pessoa com necessidades paliativas e sua família, centrados nas suas necessidades, com inclusão dos mesmos nas tomadas de decisão, perspetivando a simplificação de processos, a qualificação das respostas e melhoria dos resultados. No caso particular dos Cuidados Paliativos Pediátricos, será mais lógica e produtiva a sua permanência na dependência dos Serviços de Pediatria, em estreita articulação com o SICP da mesma ULS.

A CNCP determina que se concretize, de forma faseada e com cronograma bem estabelecido pela gestão de cada ULS, com tradução no respetivo Plano de Desenvolvimento Organizacional (PDO):

- Integração de todas as valências de CP em cada ULS;
- Dotação das equipas com profissionais com formação especializada em CP, nomeadamente assegurando que sempre que se verifiquem saídas de profissionais, sejam substituídos por outros com formação adequada;
- Avaliação das necessidades de recursos humanos para as equipas em formação e nas equipas existentes, para promover a composição adequada ao definido ou ao seu reforço e expansão, respetivamente;
- Estabelecimento de circuitos de comunicação entre equipas de CP e CPP e destas com as outras estruturas do SNS e parceiros, nomeadamente com a RNCCI, ERPI/D e EHD;
- Disponibilidade de infraestruturas adequadas para a prestação de Cuidados Paliativos especializados;
- Sistemas de informação que permitam fácil acessibilidade a dados dos SICP;
- Identificação e definição dos itens de informação relevante e válida, capazes de permitir medir e monitorizar a qualidade dos cuidados nos SICP" (Ministério da Saúde, 2023).

3. Princípios dos Cuidados Paliativos

Os cuidados paliativos representam uma área fundamental da prática médica, focando-se não só na doença, mas essencialmente na qualidade de vida daqueles que sofrem de patologias ameaçadoras de vida. Priorizam o alívio do sofrimento e a preservação da dignidade do doente. A definição consensual da International Association for Hospice and Palliative Care, apoiada pela Lancet Commission on Global Access to Palliative Care and Pain Relief, realça que os cuidados paliativos devem abordar o doente e família de modo holístico através de uma equipa multidisciplinar constituída por médicos, enfermeiros, psicólogos, assistentes sociais e assistentes espirituais e independentemente da doença ou do local onde se encontra o doente.

Assim, os cuidados paliativos são a resposta ética aos limites curativos da medicina, oferecendo cuidados centrados no doente (WHS, 2015; WHS, 2018; Roth; Canedo, 2019; Radbruch et al., 2021).

Os princípios fundamentais dos cuidados paliativos abordam os aspetos físicos, emocionais, sociais e espirituais dos doentes, não se limitando aos cuidados em fim de vida, podendo integrar a trajetória da doença desde o seu diagnóstico, ao longo da progressão da doença e até à morte, estendendo-se ao luto.

Duas grandes organizações criaram e adaptaram os princípios dos cuidados paliativos, a Organização Mundial de Saúde (OMS) e a *International Association for Hospice and Palliative Care*.

Descrevem-se a seguir os nove principais princípios dos cuidados paliativos da Organização Mundial de Saúde (2002):

- Proporcionam o alívio da dor e de outros sintomas incómodos;
- Afirmam a vida e consideram a morte como um processo normal;
- Não prolongam nem antecipam a morte;
- Integram os aspetos psicológicos e espirituais dos doentes;
- Oferecem um sistema de apoio para ajudarem os doentes a viverem tão ativamente quanto possível;
- Oferecem suporte à família, ajudando-a a lidar com a doença e com o próprio luto;
- A abordagem é através de uma equipa multidisciplinar que atua interdisciplinarmente;
- O objetivo é maximizar a qualidade de vida doe doente e família, podendo influenciar positivamente o curso da doença;

- Iniciam-se ao diagnóstico da doença juntamente com os cuidados curativos e intervêem nas crises.

A *International Association for Hospice and Palliative Care* organizou os princípios dos cuidados paliativos em quatro grandes áreas:

1. Atitudes perante o cuidado: compassiva, de compromisso, holística e com decisões partilhadas com o doente;
2. Comunicação: clara e empática, permitindo a gestão de expetativas e construto de confiança;
3. Cuidado: adequado à fase da doença, prognóstico e valores, multidisciplinar e direcionado aos melhores interesses do doente e cuidador, contínuo e antecipatório de crises associadas aos sintomas;
4. Plano antecipado de cuidados: inclui conferências familiares, em que se discute o prognóstico, locais de cuidados e objetivos terapêuticos, com participação ativa do doente e família e respeito pela cultura de valores.

Os princípios dos cuidados paliativos representam um compromisso individual com o doente e família de que os seus valores e desejos sejam cumpridos, promovendo o princípio da autonomia ao longo da trajetória da doença.

4. Controlo sintomático em Cuidados Paliativos

A correta gestão dos sintomas é uma das pedras angulares dos cuidados paliativos (Souza, Jaramillo and Borges, 2021).

Em cuidados paliativos, os sintomas são múltiplos e encontram-se habitualmente associados. Encontram-se em constante mutação, possuem caráter multidimensional e múltiplas causas. A sua elevada prevalência influencia negativamente a qualidade de vida dos doentes e suas famílias (Freire, 2017; Coelho et al., 2022).

Em alguns estudos, os sintomas mais comuns em fim de vida são a dor, a dispneia, o delírio e as secreções das vias áereas superiores (Mularski et al., 2007; Hudson et al., 2016; Tapp et al., 2019). No entanto, outros sintomas igualmente prevalentes não têm sido foco de tanta atenção tanto na investigação como na prática clínica, ou porque o doente não os refere ou porque as opções de tratamento são limitadas. Estes sintomas podem ter um impato negativo na qualidade de vida remanescente, pelo que devem ser abordados (Gleeson, 2022). A boa gestão destes sintomas pode ajudar a minimizar o sofrimento e a proporcionar conforto não só ao doente, mas também aos seus familiares (Freire, 2017).

A literatura mostra-nos que a dor e os outros sintomas não são adequadamente abordados no fim de vida, levando a sofrimento inevitável (Wilkie and Ezenwa, 2012).

Os doentes com cancro avançado apresentam muita sintomatologia relacionada com a doença ou com os tratamentos. Uma revisão sistemática de 2007 que incluiu 25074 doentes oncológicos em fase avançada da doença em 44 estudos diferentes concluiu que os sintomas mais frequentemente avaliados por instrumentos ou entrevistas padrão foram fadiga (74%), dor (71%), astenia (60%), e anorexia (53%) (Teunissen et al., 2007). Duas outras revisões sistemáticas baseadas em 64 e 57 estudos, respetivamente, compararam a prevalência dos sintomas entre doentes oncológicos e não oncológicos e concluíram que a dor, a fadiga, a anorexia, a dispneia e a ansiedade foram as queixas mais frequentes nos doentes com cancro avançado (Solano, Gomes, & Higginson, 2006; Moens et al., 2014). Em relação aos sintomas psicológicos vários estudos em que foi utilizada a HADS (score» 11) relataram uma prevalência de ansiedade que variou entre 22 a 28% e de depressão entre 25 a 47% em doentes oncológicos paliativos que se encontravam internados (Holtom & Barraclough, 2000; Lloyd-Williams, Friedman, & Rudd, 2001; Smith, Gomm, & Dickens, 2003; Strömgren et al., 2002).

4.1. Abordagem à avaliação de sintomas em cuidados paliativos

Todos os profissionais de saúde estarão alguma vez perante doentes com doenças oncológicas ou não oncológicas terminais, cujo objetivo será proporcionar cuidados de conforto e não a cura.

Assim, compreender os princípios da gestão de sintomas em cuidados paliativos deve ser transversal a todas as especialidades médicas.

O controlo da dor e outros sintomas físicos assim como dos sintomas psicológicos, sociais e espirituais é assim prioritário em cuidados paliativos, de modo a alcançar a melhor qualidade de vida possível.

O controlo sintomático é um dos pilares dos cuidados paliativos em doentes portadores de doenças avançadas oncológicas ou não oncológicas. De notar de que os doentes com doenças não oncológicas terminais apresentam tantos sintomas como aqueles portadores de neoplasias (Gore, Brophy and Greenstone, 2000; McKinley et al., 2004). Os sintomas físicos mais comuns incluem a dor, as náuseas e os vómitos, a dispneia enquanto a ansiedade, a depressão são os sintomas psicológicos mais comuns.

Os princípios gerais do controlo sintomático são (Cherny et al., 2015):

1. História clínica e Exame Objetivo e pedido de exames complementares de diagnóstico se for o caso;
2. Identificar potenciais causas reversíveis: os sintomas podem estar diretamente relacionados com o cancro, com o seu tratamento ou indiretamente relacionados (por exemplo, dor por úlcera de pressão devido ao alectuamento prolongado) ou não relacionados (por exemplo, dor no contexto de osteoartrite prévia);
3. Reverter qualquer causa reversível e cuja reversibilidade não coloque em causa a qualidade de vida do doente;
4. Paliar o que é irreversível.

Os sintomas em oncologia e cuidados paliativos são os mesmos independentemente do diagnóstico, especialmente no fim de vida (Dong et al., 2014). Habitualmente, os sintomas são múltiplos e embora tradicionalmente sejam avaliados isoladamente, mais recentemente já há tendência para a sua avaliação conjunta (Dong et al., 2014). Optimiza-se o controlo sintomático em cuidados paliativos quando se abordam os sintomas por clusteres (Dong et al., 2014).

A literatura mostra-nos que os sintomas físicos e emocionais ocorrem simultaneamente (Laird et al., 2011). Por exemplo, ao melhorar a dispneia, reduz-se o cansaço, a tristeza e a angústia existencial (Laird et al., 2011).

O controlo sintomático tem um forte impato na qualidade de vida dos doentes em cuidados paliativos, pelo que é imperativo que estes sintomas sejam adequadamente aferidos ou pelo doente, ou pelos profissionais de saúde e cuidadores, quando aquele não se encontra competente para tal (Gleeson, 2022). Há maior acurácia na medição dos sintomas físicos pela família do que os psicológicos, dado o caráter subjetivo destes (Gleeson, 2022).

Os sintomas têm várias dimensões como a intensidade, a frequência, o grau de interferência com a funcionalidade e o grau de sofrimento associado (Gleeson, 2022). Alguns sintomas, como a dispneia, são inclusivamente marcadores de prognóstico e de sobrevida (Gleeson, 2022).

A monitorização continua da severidade dos sintomas assim como do possível aparecimento de outros é essencial para um bom controlo sintomático e eventuais ajustes terapêuticos (Gleeson, 2022).

Assim, é necessário a atuação interdisciplinar de uma equipa multidisciplinar que tenha total disponibilidade para ouvir o doente/ família, tornando a trajetória da doença crónica menos dolorosa (Gleeson, 2022; Larson et al., 1994).

4.2. Instrumentos de medida dos sintomas em Cuidados Paliativos

A medição de sintomas em cuidados paliativos é essencial para uma correta abordagem dos mesmos (Larson et al., 1994). A sua avaliação sistemática em cuidados paliativos contribui para melhorar a qualidade de vida destes doentes (World Health Organization, 2002; Osman *et al.*, 2018). Esta avaliação pode ser realizada através de instrumentos de avaliação de resultados preenchidos pelos próprios doentes que podem ter ajuda ou não dos seus cuidadores ou do staff de profissionais de saúde (Patient Reported Outcome - PRO), aferindo tanto a sintomatologia como a qualidade de vida sem interferência de terceiros (U.S. Department of Health and Human Services, FDA Center for Drug Evaluation and Research, 2006).

Os instrumentos PRO validados e mais frequentemente utilizados em cuidados paliativos são a Escala de Avaliação de Sintomas de Edmonton (ESAS) de 9 itens que mede sintomas físicos e psicológicos (Bruera *et al.*, 1991), a Functional Assessment of Chronic Illness Therapy (FACIT-PAL) (Lyons *et al.*, 2009), com 19 itens, que avalia o bem-estar físico, social, emocional e funcional dos doentes e é

muitas vezes utilizada como medida de qualidade de vida; a Memorial Symptom Assessment Scale (MSAS) (Portenoy *et al.*, 1994) que avalia a frequência, a gravidade e o sofrimento de 24 sintomas físicos e psicológicos; a Palliative Outcome Scale (POS) (Hearn and Higginson, 1999) com 10 itens, que identifica os principais sintomas e preocupações que os doentes mais priorizam e que é também muitas vezes utilizada como medida de qualidade de vida em cuidados paliativos e a sua recente versão integrada, a Integrated Palliative care Outcome Scale (IPOS) (Murtagh *et al.*, 2019) que incorpora tanto questões em relação aos sintomas, como em relação a necessidades espirituais, de informação, preocupações práticas, questões familiares, entre outros.

Para o rastreio de sintomas psicológicos, os instrumentos validados mais utilizados são a Escala Hospitalar de Ansiedade e Depressão (HADS) (Zigmond and Snaith, 1983) de 14 itens e o termómetro emocional; para o rastreio do défice cognitivo temos o Mini-Mental State (MMSE) (Folstein, 1975, p. 192), que é bastante utilizado.

Outro instrumento de avaliação dos sintomas é o European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 Palliative Care (EORTC QLQ-C15-PAL). Este questionário é uma versão abreviada do EORTC QLQ C30, que é um dos instrumentos PRO mais validados e amplamente utilizados em Oncologia (Fayers and Bottomley, 2002, Velikova et al., 2012). O EORTC QLQ-C30 foi reduzido de 30 para 15 itens, eliminando itens identificados como menos relevantes para os cuidados paliativos.

Quando avaliamos sintomas, é essencial obter a sua intensidade durante um determinado período de tempo, como por exemplo, nas últimas 24 horas (Larson et al., 1994), sendo que outras versões consideram da ESAS se reportam à intensidade sentida no momento da avaliação. Tal sucede quando utilizamos a Escala de Avaliação de Sintomas de Edmonton (ESAS), a qual mede de 0 a 10 a intensidade dos nove principais sintomas presentes nos doentes em cuidados paliativos (Larson et al., 1994). Já a Palliative Outcome Scale (POS) avalia a intensidade da dor e outros sintomas nos últimos três dias numa escala tipo Likert que varia entre 0 e 4 (Hearn and Higginson, 1999). Esta escala é diferente da ESAS, dado que as suas questões permitem avaliar outras dimensões além da física e emocional em cuidados paliativos, como a psicológica, social e espiritual. Daí que em muitos estudos, esta escala é considerada uma medida de qualidade de vida, de resultados e de bem-estar em cuidados paliativos (Hearn and Higginson, 1999).

Deve-se ter presente que muitos doentes não têm a capacidade de transmitir a severidade dos sintomas numa escala numérica dada a sua baixa literacia em saúde ou alteração do estado cognitivo (Sze et al., 1998). Uma alternativa viável é perguntar ao doente como classifica o sofrimento associado ao sintoma em causa (por exemplo, nada, um pouco, muito, bastante) em vez de tentar obter uma resposta acerca da sua intensidade numérica (Kuehner et al., 2021). Alguns sintomas como a fadiga podem ser relatados como moderados em intensidade, mas severos em sofrimento (Kuehner et al., 2021). Os despertares noturnos e o tipo de interferência com as atividades básicas da vida diária causados por um sintoma são também ilustrativos da sua severidade (Kuehner et al., 2021).

Assim, é de suma importância a avaliação cuidada centrada no doente e família, identificando os "triggers" que podem interferir na qualidade de vida de ambos. Os cuidados paliativos dão humanismo e dignidade à abordagem terapêutica dos sintomas.

A propósito da temática do controlo sintomático em cuidados paliativos e dado ser um dos pilares básicos que norteia a medicina paliativa, decidiu-se fazer uma revisão narrativa da literatura sobre o tema, redigindo o artigo intitulado "A Review on the Management of Symptoms in Patients with Incurable Cancer" publicado na revista Current Oncology MDPI (Anexo II).

4.3. A Review on the Management of Symptoms in Patients with Incurable Cancer

Gonçalves F, Gaudêncio M, Rocha A, Paiva I, Rego F, Nunes R. A Review on the Management of Symptoms in Patients with Incurable Cancer. Curr Oncol. 2025 Jul 31;32(8):433. doi: 10.3390/curroncol32080433. PMID: 40862802; PMCID: PMC12384594.

Current Oncology

MDPI

Review

A Review on the Management of Symptoms in Patients with Incurable Cancer

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Simple Summary

Symptomatic control is one of the main principles of palliative care. Its correct approach includes continuous monitoring of symptom progression and the implementation of pharmacological and non-pharmacological therapies. Updates on the relevance of cannabinoid use for certain symptoms and the applicability and reasonableness of palliative sedation are some of the topics to be addressed. In this review, the authors summarize the management of common symptoms in patients in palliative oncology care, as well as present a brief reflection on quality of life in this context.

Abstract

Palliative care aims to alleviate suffering and prioritize the quality of life of patients facing serious and fatal diseases, such as cancer. Cancer patients, especially in advanced stages, often have many difficult-to-control symptoms, such as pain, fatigue, dyspnea, anxiety, and depression, requiring the attention of a multidisciplinary team highly trained in palliative care and end-of-life management. Pain, dyspnea, nausea, and vomiting are the focus of symptomatic assessment in palliative care, but patients experience other equally important symptoms that do not receive as much attention and are often overlooked, which negatively impacts the quality of life of these patients. One of the main aims of palliative care is to provide patients with the best possible quality of life through adequate symptom control, teamwork, and psychosocial support based on the principles, values, and wishes of the patient and family. In this review, the authors summarize the management of common symptoms in patients in oncology and palliative care, as well as present a brief reflection on quality of life in this context.

Keywords: dyspnea; nausea; pain; palliative care; palliative medicine; psychological distress; quality of life; symptom assessment; symptom burden; vomiting

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Received: 23 June 2025
Revised: 22 July 2025
Accepted: 29 July 2025
Published: 31 July 2025

Citation: Gonçalves, F.; Gaudêncio, M.; Rocha, A.; Paiva, I.; Rego, F.; Nunes, R. A Review on the Management of Symptoms in Patients with Incurable Cancer. *Curr. Oncol.* **2025**, *32*, 433. https://doi.org/10.3390/curroncol32080433

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1. Introduction

With the aging population and increasing survival rates, chronic diseases such as cancer, often diagnosed at advanced stages of the disease, are increasingly prevalent, as are palliative needs [1]. Cancer patients receiving palliative care tend to have many difficult-to-control symptoms, such as pain, fatigue, dyspnea, anxiety, and depression, requiring the attention of a multidisciplinary team highly trained in end-of-life management [1].

If the exponentially increasing need for palliative care teams cannot be met by available human resources, the situation is at risk of becoming a public health crisis [2].

Palliative care consists of a multidisciplinary approach whose objective is to alleviate suffering and prioritize the quality of life of patients facing serious and life-threatening diseases [3]. Palliative care differs from end-of-life care in that the former can begin at any stage in the trajectory of a life-threatening illness, including the diagnosis, while the latter is intended for patients whose estimated prognosis is less than six months of life [4].

Palliative care is based on a series of basic principles [5]: Care objectives should be defined on the basis of the known disease trajectory, the degree of reversibility, and the patient's values [6]. Symptom control should be attempted early and be intensive. Working in palliative care means working as a team [6]. Palliative care neither accelerates nor postpones death [6]. Finally, the patient's family should always be involved in care [6].

Immunotherapy has changed the traditional trajectory of cancer, leading to greater success in many incurable tumors, but also to greater unpredictability [7]. The survival of patients undergoing immunotherapy can be longer in those who are responders, and even after its suspension, the periods of remission are also longer. Palliative care should support these new anti-neoplastic therapies by providing support in the control of physical, emotional, social, and spiritual symptoms [7].

Effective symptom control is a basic pillar of palliative care [7]. Pain, nausea and vomiting, and dyspnea are the focus of symptomatic assessment in palliative care, but patients experience other equally important symptoms that do not receive as much attention and are often overlooked, which negatively impacts the quality of life of these patients [7]. This may be because the patient does not mention them or because they are difficult to address by the team [7].

A symptom can be defined as a "subjective experience resulting from changes in the biopsychosocial, sensory, or cognitive profile of an individual" [8].

The proper management of pain and other symptoms is an essential component of palliative care [9,10], with the aim of maximizing comfort and quality of life for patients and their families [9,10]. The performance of palliative care is associated with a lower symptomatic burden and less suffering [9,10].

2. Methodology

In this work, the authors intend to present a narrative review article on approaches to managing the main symptoms of patients in oncology and palliative care while also emphasizing the importance of their impact on quality of life.

This article presents a brief description of the main symptoms in advanced cancer, aimed at oncologists, palliative care specialists, and other healthcare professionals who deal with patients with incurable cancer.

The authors conducted a bibliographical research in the PUBMED, CINAHL, and Web of Science databases (literature over the last 10 years), complemented by books and websites on the topic presented. The research was based on the following keywords: "Dyspnea", "Nausea", "Pain", "Palliative care", "Palliative medicine", "Psychological distress", "Quality of life", "Symptom assessment", "Symptom burden", "Vomiting". However, the authors decided to keep some essential articles on this topic, exceptionally, regardless of the publication date.

After the search was complete and all duplicates were thrown out, the authors reviewed the abstracts and articles to ensure that they addressed the objectives. So, the articles were chosen in order to develop each topic.

3. Symptom Management

3.1. Principles of Symptom Management in Oncology and Palliative Care

The symptoms of patients in oncology and palliative care are generally the same regardless of the diagnosis, especially at the end of life [11]. Most patients in these settings have multiple symptoms, and although they are traditionally addressed in isolation, more recent studies show a tendency to evaluate them as symptom groups [11]. An opportunity to optimize symptom control is to analyze clusters of symptoms described by the patient [11].

The literature shows that physical and psychological symptoms occur simultaneously [12]. For example, improving dyspnea reduces tiredness but also sadness and existential anguish [12,13].

Symptom control impacts the quality of life of patients in palliative care, so it is imperative that symptoms be accurately evaluated by either the patient or the caregiver when the patient is unable to do so [8]. Physical symptoms are better scored by the family than psychological symptoms, given their subjective nature [8].

Symptoms have several dimensions, including intensity, frequency, the degree of interference with basic activities of daily living, and the degree of associated suffering [8]. Some symptoms, such as dyspnea, can even be predictors of prognosis and survival [8].

Correctly and continuously monitoring the severity of symptoms, as well as the possible appearance of others, is essential for effective symptom control and for making necessary therapeutic adjustments [8]. To this end, an interdisciplinary team is needed that, in sum, has the ability to listen, monitor, and develop a chronic disease management strategy that minimizes pain and suffering [8,9].

In palliative care, evaluating symptoms is essential for making the approach to their management as effective as possible [14]. When assessing symptoms, it is essential to obtain the classification of their intensity over a certain period of time, such as the last 24 h [14]. Such is the case for the Edmonton Symptom Assessment System (ESAS), which evaluates the intensity of the nine main symptoms in patients receiving palliative care from 0 to 10 [14].

The ESAS-r is an adaptation of the original version of the visual analog scale ESAS, developed in 1991 in Edmonton with the aim of assessing the most common symptoms in palliative care [15]. Subsequently, it was classified numerically with a 24-h assessment period [15]. The ESAS-r was created in 2011, and the assessment period changed from 24 h to now [15].

Another instrument widely used in palliative care to measure the symptomatic burden is the Palliative Outcome Scale (POS), which evaluates the intensity of pain and other symptoms experienced in the last 3 days on a Likert scale scored from 0 to 4 [16]. This is a more comprehensive scale, since it has questions that also allow the psychological, social, and spiritual dimensions to be measured, and it is often used as an instrument to assess the quality of life and the care and well-being of patients in palliative care [16].

Some patients are unable to rate the severity of their symptoms on a numerical scale because of poor health literacy or altered cognitive status [17]. An alternative is to ask patients how they rate their symptom distress rather than how intense the symptoms are and provide them with a range of possible responses (e.g., not at all, a little, a lot, or very much) [18]. Some symptoms, such as fatigue, may be rated by patients as mild in intensity but severe in suffering/distress [18]. Information on symptom duration, nocturnal awakening, and interference with activities of daily living can also help assess symptom severity [18].

Thus, it is important to conduct a careful evaluation centered on the patient and family and identify triggers that may interfere with the quality of life of both. Palliative care gives humanity and dignity to the therapeutic approach to these symptoms.

3.2. Pain

Pain is defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage". This concept was revised by the International Association for the Study of Pain (IASP) in 2020 [19]. Pain is a personal experience influenced by the physical, psychological, emotional, social, and spiritual factors of the affected person and by their life experiences [17,19].

Recently, increasing importance has been given to the concept of "Total Pain", first described by Cicely Saunders in 1964, which refers to the pain felt by patients with life-threatening diseases who do not respond to standard analgesic therapy, given its multidimensional character (physical and non-physical dimensions) (Figure 1) [20,21]. It is known that emotional pain is a form of spiritual coping, in which hope is associated more with the psycho-emotional component of pain than with its intensity [20,21]. The concept of "Total Pain", created several decades ago, remains the gold standard concept for a symptoms approach in palliative care.

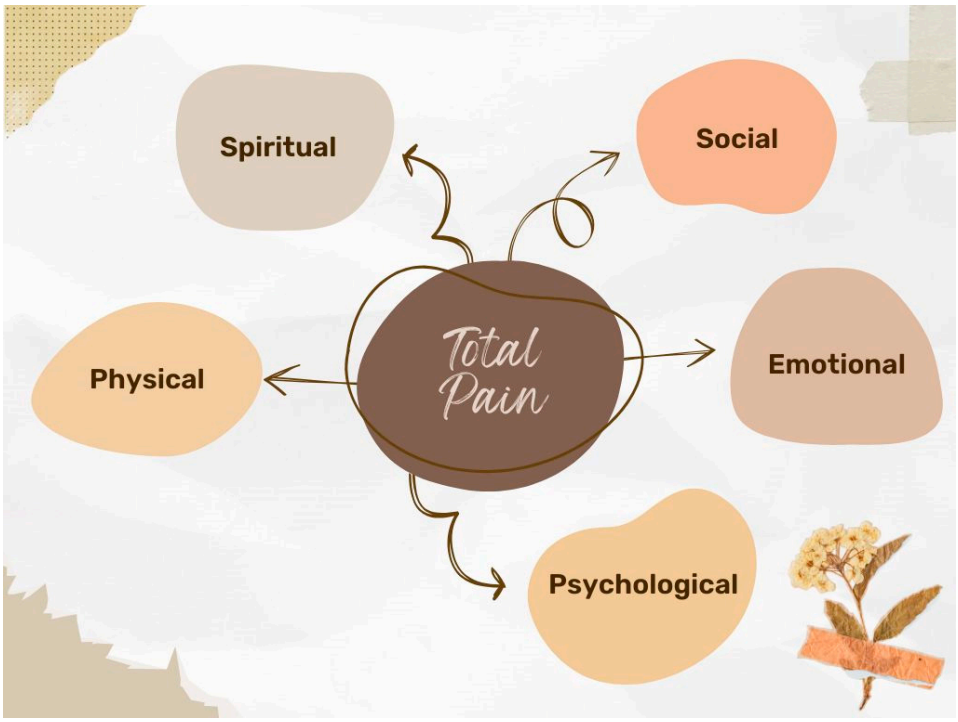


Figure 1. Total Pain dimensions according to Dame Cicely Saunders.

Chronic pain negatively affects the quality of life of cancer patients [22]. Its prevalence is high, being present in about 39.3% of cancer survivors, in 55% of patients undergoing curative treatment of the disease, and in 66.4% of those with advanced, metastatic, or terminal cancer [22]. In more than one-third of patients (38%), the score given was >5 on the numerical pain scale, meaning they experienced moderate to severe pain [22].

Although the prevalence of cancer is increasing worldwide, it is also true that the survival of patients is longer thanks to new therapies [23]. Pain is the symptom that affects cancer patients the most, which can tend towards chronicity [23]. Despite its high prevalence, chronic pain is not described in the current International Classification of Diseases (ICD-10) [23]. Cancer-related chronic pain is characterized by its association with

cancer or its treatment [23]. The new classification of chronic oncological pain (lasting more than three months) in the ICD-11 aims to assist in the individualization of care and in the understanding of these painful syndromes [23].

Since pain is considered the 5th vital sign, its assessment should be a routine part of daily clinical practice [24]. The evaluation, treatment, and monitoring of pain should be conducted whenever there is a recurrence of cancer or a second neoplasm appears [24]. The initial approach to oncological chronic pain involves the use of non-opioid analgesics or adjuvants, whether for symptomatic relief or for improvement of functionality [24]. Whenever this strategy is ineffective and there is suffering, opioid analgesics should be carefully considered in cancer patients, taking into account the potential appearance of adverse effects [24]. Healthcare professionals should be familiar with terms such as tolerance, dependence, and abuse, and adopt measures that minimize the potential for addiction [24].

The correct approach to managing pain involves evaluating and measuring it [20,25]. There are several measurement tools, such as the Brief Pain Inventory, the Palliative Outcomes Scale (POS), the Edmonton Symptom Assessment System (ESAS), and the Visual Analog Scale (VAS) [20,25]. Visual Analogic Scale (VAS) can be used carefully in patients with cognitive impairments [26]. For example, a review showed that the VAS is used in about 16% of studies addressing pain assessment in dementia and that the results are unreliable when cognitive impairment is moderate to severe [26].

Individuals with dementia or cognitive impairment may not be able to verbally convey the level of pain they are experiencing, leading to undertreatment [27]. For this reason, the literature suggests using the Pain Assessment in Advanced Dementia (PAINAD) scale [27].

In the oncological context, pain may be caused by the direct effect of the neoplasm (invasion/progression to viscera, bone, and/or soft tissue, raised intracranial pressure, nerve injury, or a combination of these) [28]. On the other hand, some pain may be related to the side effects of oncological treatment (e.g., nerve injury during surgery, chemotherapy-induced peripheral neuropathy, lymphoedema, muscle spasms, pressure ulcers, or constipation) [28].

Thus, cancer pain can be classified as nociceptive (visceral and somatic), neuropathic (nerve compression, nerve injury, and sympathetically maintained), or mixed. Its correct identification is essential in analgesic guidance [28].

Pain treatment with drugs alone is insufficient. Non-pharmacological measures are also needed to target the multiple dimensions of pain as the "total" symptom that it is [20]. A correct pharmacological approach to managing cancer pain consists of multimodal analgesia, in which several classes of analgesics are combined to reduce adverse effects and control pain more effectively [29,30].

Therefore, in addition to pharmacological interventions, cancer pain treatment must be based on an approach that includes social, spiritual, psychological, neurosurgical, radiotherapeutic, physiotherapeutic, and anesthetic interventions [28].

In 1986, the World Health Organization (WHO) first published the three-step analgesic ladder, in which drugs and the potency of analgesic drugs accompanied the severity of the pain (Figure 2) [28–30]. Recent studies suggest an analgesic ladder of only two steps, in which the second is eliminated [31,32].

When controlling pain, it is important to follow some basic principles [28]. Whenever possible, the oral route should be used because it is the least invasive ("by mouth"); the schedule should be regular ("by clock"); medications should be administered at the lowest effective dose; and those with the least adverse effects should be chosen ("for the individual"; "with attention to detail") [28]. It is important to pay attention to the details and particularities of each patient [28].

Opioids still remain the gold standard of treatment for moderate to severe cancer pain [22]. Consequently, the appropriate use of opioids is very important for effective pain relief, taking into account the benefits and risks of these drugs [28,29]. Opioids are safe and potent drugs with important side effects [28,29] and can be administered by almost any route [28,29]. When choosing an opioid, we must take into account the individual characteristics of each patient and the associated comorbidities [28,29].

Weak opioids (such as tramadol and codeine) are recommended for initiation when pain intensity is reported to be mild or moderate, particularly in opioid-naïve patients [28,29,33–36]. These drugs are usually combined with acetaminophen/paracetamol and/or non-steroidal anti-inflammatory drugs (NSAIDs) [28,29,33–36].

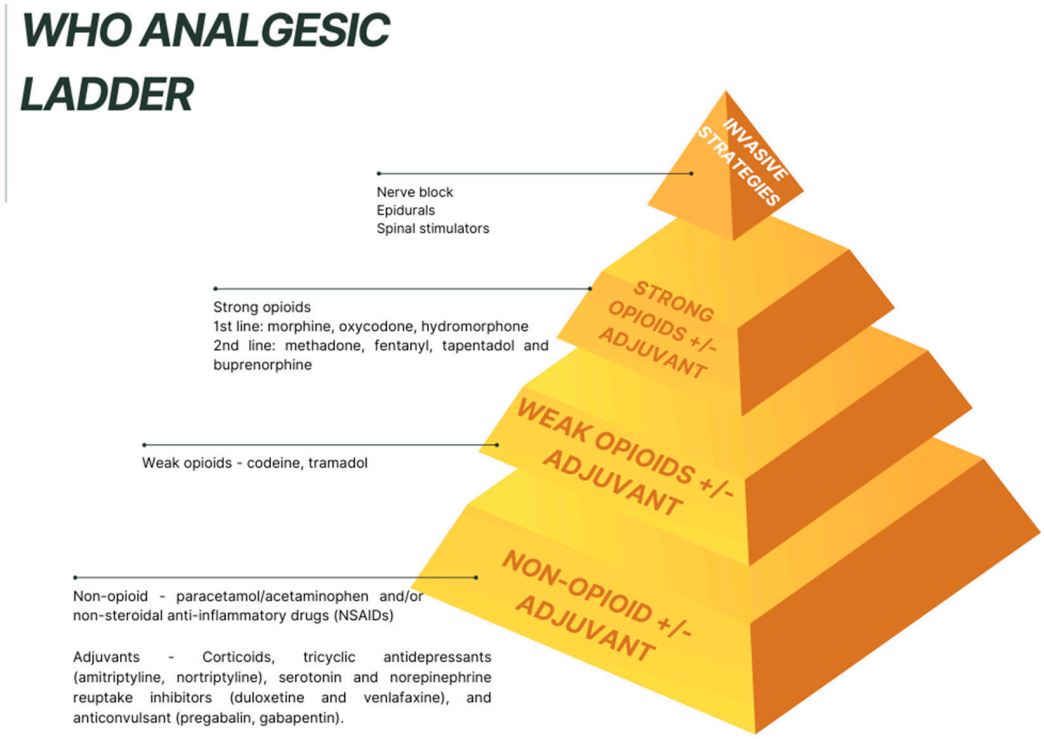


Figure 2. WHO analgesic ladder for cancer pain management (with suggested 4th step). Based on WHO Guidelines and Vargas-Schaffer et al. [37].

On the other hand, strong opioids (first line: morphine, hydromorphone, and oxycodone; second line: methadone, buprenorphine, and fentanyl) are recommended when pain intensity is moderate or severe [28,29,33–36]. It is important to start with a low dose and titrate up in order to ensure adequate analgesia and tolerable side effects [28,29,33–36].

No studies have shown that one opioid is superior to another, and morphine continues to be the most prescribed opioid because it is the best known, effective, and low-cost [28,29,33–36]. Fentanyl and buprenorphine are reserved for cases where renal failure is present, especially when creatinine clearance is less than 30 [22,29–31]. Fast-acting formulations, such as fentanyl administered sublingually, transmucosally, or nasally, are excellent drugs for breakthrough pain [28,29,33–36].

Approximately 26% of patients respond poorly or not at all to opioids [37–39]. There are many possible causes of this phenomenon, including breakthrough pain, disease/cancer progression, negative psychological conditions, and the presence of a neuropathic mechanism [37–39].

About 20–40% of cancer patients will experience neuropathic pain, defined by the IASP as pain "caused by a lesion or disease of the somatosensory nervous system" [40].

In these patients, the nervous system (peripheral or central) may be affected by the tumor itself or by its treatment (chemotherapy, surgery, and radiotherapy) [40,41].

The NeuPSIG (Neuropathic Pain Special Interest Group) grading system was updated in 2016 with the aim of improving the degree of certainty that pain is neuropathic in nature, classifying it into three levels: possible (compatible clinical history and location), probable (when associated with neurological dysfunction), and definite (when complementary diagnostic tests confirm the presence of somatosensory injury) [42].

The medications used to treat neuropathic pain include anticonvulsants (pregabalin, gabapentin), tricyclic antidepressants (nortriptyline, amitriptyline), and serotonin and norepinephrine reuptake inhibitors (venlafaxine, duloxetine) [43]. These drugs have also been called adjuvant medications because they are used to treat nociceptive pain (with an additive effect when used in combination with opioids and non-opioids) [44].

As with opioids, clinicians must balance the benefits and adverse effects of adjuvant medications [45,46]. Tricyclic antidepressants have anticholinergic properties and can induce blurred vision, dry mouth, sedation, dry urinary retention, orthostatic hypotension, and tachycardia [45,46]. On the other hand, serotonin and norepinephrine reuptake inhibitors can induce headaches, dizziness, nausea, sweating, and arterial hypertension [45,46]. Finally, patients on anticonvulsants can experience somnolence and dizziness and are at risk of respiratory depression when taking opioids as well [45,46].

Cannabinoids have increasingly gained attention [47,48]. However, their use in pain management is still controversial [47,48]. The legalization of medical cannabinoids in 40 countries has increased interest in their use in cancer symptom management, especially in pain control [47–49]. In fact, cancer patients use cannabis regularly [50]. A study carried out in Canada revealed that 18% of cancer patients admitted to having used cannabis in the last 6 months, with 46% of these doing so to control pain [50]. In fact, most studies conducted on cancer patients in palliative care do not show that adding cannabis to opioids reduces pain [48,51].

In the literature, there are several proposed updated versions of the WHO analgesic ladder [37,52,53]. In these new versions, the concept of integrative medicine (which can be implemented at every step) is proposed, along with a fourth step, which includes interventional/invasive treatments [37,52,53].

Interventional/invasive treatments may be considered at any point in the cancer trajectory but may be proposed particularly when patients have uncontrolled pain and/or analgesics have "intolerable adverse effects" [44]. The two main categories are intrathecal/epidural analgesics and nerve blocks [44]. Intrathecal/epidural procedures can be used to simultaneously administer different classes of analgesic drugs, as well as allow the use of medications that are not available in oral/transdermal formulations [44]. Deciding whether to use these interventions requires an assessment of prognosis, risks, contraindications, and benefits [44]. Nerve blocks are traditionally considered the last step in the analgesic ladder; however, evidence has shown their action to be more effective when applied in the early stages of cancer [44].

Finally, more recently, the European Society of Medical Oncology (ESMO) recommended an integrative strategy for the treatment of pain in cancer patients [32]. The suggested strategy included an approach based on disease-directed treatments (primary anticancer treatments such as surgery, hormonotherapy, chemotherapy, and radiotherapy) and classical and interventional analgesic therapies, combined with a variety of non-invasive and non-pharmacological therapies [32]. Therefore, it is important to highlight the role of non-pharmacological approaches that are part of the integrative medicine strategy proposed for pain relief [54,55]. The objective of these strategies is to reinforce the intervention of pharmacological measures and improve the comfort and quality of life of patients [54,55].

To this end, several approaches have been developed, including tai chi, hypnosis, meditation, yoga, mindfulness, cognitive behavioral strategies and pain coping, music therapy, acupuncture, and massage therapy [54,55]. These therapies have demonstrated benefits in controlling anxiety, pain, depression, and fatigue and providing a sense of well-being through a personalized strategy according to patients' preferences [54,55].

Pain management in the context of oncology faces daily challenges, which are more evident in the advanced stages of the cancer trajectory, highlighting the importance of a multidisciplinary team with the aim of minimizing the impact of this symptom on the patient's life.

3.3. Dyspnea

Dyspnea is defined by the American Thoracic Society as "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity" [56,57].

Thus, dyspnea is a complex symptom that potentially poses a critical threat to homeostasis and, therefore, often prompts adaptive responses [57].

Dyspnea can be potentiated by other symptoms present in cancer patients in palliative care, such as fatigue, depression, and anxiety, limiting their quality of life and causing great apprehension to family members [57–59]. The presence of dyspnea is a marker of poor prognosis [57–59]. Prolonged or intractable dyspnea causes distress and suffering and compromises performance and quality of life [57].

It is important to emphasize that physiological measures (e.g., heart rate, oxygen saturation, and respiratory rate) have little relationship to the patient's experience of dyspnea [58–63]. The patient's subjective rating remains the standard for assessing symptom burden, notably when evaluating the benefits of any therapeutic strategies provided [58–63].

The interaction between dyspnea and other symptoms highlights the multidimensional nature of the distress and suffering that a patient experiences [58–63].

Dyspnea is present in 10 to 70% of patients with advanced cancer. The approach to its treatment should be performed in a hierarchical manner, starting with the investigation of potentially reversible causes whose reversal does not have disproportionate adverse effects on the patient's well-being [58–63].

Pharmacological treatment is multimodal. In terms of drugs, corticosteroids and bronchodilators may be indicated, as well as antibiotics, whose objective is symptom control [63,64]. Studies on the possible benefits of inhaled furosemide, antidepressants, or neuroleptics have produced conflicting results [63,64].

There may be a need to move on to respiratory sedatives for dyspnea control, such as opioids (morphine, methadone, fentanyl, oxycodone, or codeine) and benzodiazepines (midazolam, diazepam, or lorazepam), the latter of which are used when there is associated anxiety or a need to increase doses of opioids [63,64]. Continuous palliative sedation should be considered in patients who have dyspnea refractory to standard treatment and whose life expectancy is short [64].

In addition to pharmacological treatment, the palliative care team will offer non-pharmacological measures, such as a fan or an open window, and pharmacological measures that include oxygen supplementation to increase comfort [64].

Patients with dyspnea often report that cool air movement reduces dyspnea/breathlessness, and studies have shown that air directed at the face decreases induced dyspnea. For this purpose, the use of fans and/or cold airflow for the relief of dyspnea is suggested (the air movement across the face stimulates the trigeminal nerve) [57]. Exercise and pulmonary rehabilitation programs may reduce dyspnea scores and improve quality of life [60].

High-flow oxygen therapy and non-invasive ventilation may be indicated at the end of life to control dyspnea or to prolong life for short-term goals, such as the arrival of a family member or to allow a farewell [60,65].

In any case, the use of oxygen therapy as a palliative measure is sometimes controversial.

Oxygen is a therapeutic measure in clear clinical situations, and therefore, oxygen therapy must be prescribed and appropriately administered [65]. The administration of oxygen through the various available interfaces (nasal cannula, face mask, high-flow mask) is based on the principle that increasing the fraction of inspired oxygen (FiO_2) will increase alveolar oxygen pressure and, consequently, will increase arterial oxygen pressure, improving tissue oxygenation [65].

However, there are some risks associated with the use of oxygen, namely, cerebral and coronary vasoconstriction, hypercapnia, increased peripheral vascular resistance, pulmonary atelectasis, the production of reactive oxygen species with cytotoxic effects, decreased cardiac output, discomfort, and airway damage [65].

Over the years, researchers have hypothesized that oxygen therapy has a beneficial effect in the management of dyspnea in patients receiving palliative care [65]. Its systematic administration to these patients was based on a personal intuition that it could be beneficial and on a certain belief that, in view of such threatening conditions, it would have an almost miraculous power [65]. The possible symptomatic improvement would be due to contact of the face with fresh air, which would stimulate the trigeminal/vagal nerve and reduce dyspnea [65].

Thus, the use of oxygen therapy in palliative care should be reserved for patients with persistent peripheral saturation < 90% (after identifying and optimizing therapeutic interventions in the various possible causes) or for patients whose dyspnea significantly improves after a course of oxygen therapy [65,66]. In non-hypoxemic patients, non-pharmacological interventions and opioid drugs should be tried first, simultaneously [65,66]. Oxygen therapy should be discontinued in the absence of clinical benefit or when disadvantages (for example, marked discomfort caused by masks or nasal cannulas, dryness of mucous membranes) outweigh the benefits [65,66]. When all other strategies have been optimized, a therapeutic trial for non-hypoxemic patients can be considered, with a recommended duration of 72 h, with adequate and systematic clinical reassessment. In the absence of a benefit, this therapeutic trial must be suspended [65,66].

The effectiveness of the palliation of dyspnea depends on the availability of a specialized palliative care team that, with its knowledge in multiple fields, knows how to minimize the impact of this symptom on the quality of life of the patient and the patient's family.

3.4. Nausea and Vomiting

Nausea and vomiting are symptoms that palliative care patients describe as very unpleasant and are present in about 68% of cancer patients [67]. In the last 6 weeks of life, nausea and vomiting are present in more than 40% of patients [67,68].

Uncontrolled nausea and vomiting often affect the cognitive and psychosocial dimensions of the patient, with a negative impact on their quality of life and contributing to a fear of death by hunger or thirst [69].

Nausea is the subjective sensation of vomiting accompanied by symptoms of dysautonomia, while vomiting is the expulsion of gastric contents through the oral cavity [70].

The literature has little evidence and information about the mechanisms involved in triggering nausea and vomiting in advanced cancer [70]. Thus, an etiological approach based on a detailed clinical history and objective examination is strongly recommended so that the most appropriate antiemetic is chosen based on the receptors implicated [70].

Nausea and vomiting are common and distressing symptoms affecting the majority of patients in oncology and palliative care settings [70,71]. Assessment and treatment have been based on understanding the physiopathology and neurotransmitters involved in this process [70,71].

In advanced metastatic cancer, the most common causes of nausea and vomiting are metabolic and hydroelectrolytic disorders, among which hypercalcemia, liver and kidney failure, opioids, and intestinal occlusion stand out [71].

Antiemetics should be administered at fixed times, with progressive dose titration, and preferably parenterally [72–74]. If ineffective, a combination of antiemetics should be attempted, given the multifactorial nature of these symptoms and the frequent involvement of several neurotransmitters [72–74]. Corticosteroids, olanzapine, and cannabinoids are promising drugs in the treatment of nausea and vomiting, although haloperidol and metoclopramide continue to be used [72–74].

Nutritional counseling and acupuncture are non-pharmacological measures that should be used concomitantly with prescribed drugs [72–74]. It is recommended to avoid environmental stimuli (such as smells, sounds, or sights) that may trigger nausea [75]. In terms of diet, spicy, fatty, and salted food should also be avoided [75]. Behavioral approaches, such as distraction and relaxation, can decrease psychological stress by redirecting the patient's attention elsewhere and increasing the patient's feelings of well-being [75].

In Table 1, the authors present an overview of nausea and vomiting mechanisms, the involved receptors, and the main drugs used according to etiology, because antiemetic drugs are predominately neurotransmitter-blocking agents [70,75].

3.5. Anorexia–Cachexia Syndrome

Cancer anorexia–cachexia syndrome (CACS) is a metabolic syndrome associated with oncological disease and "characterized by loss of muscle mass with or without loss of fat mass that occurs involuntarily" [76].

Anorexia–cachexia syndrome associated with advanced cancer is present in up to 80% of patients [77]. Its incidence ranges from 20 to 40% in early stages (diagnosis) and 70–80% in advanced cancer. The prevalences described in the literature, according to the primary tumor site, are approximately 80% (gastric and pancreatic neoplasms), 54–60% (prostate, lung, and colon cancers), and 32–48% (sarcoma, lymphomas, breast cancer, and leukemias) [76].

Anorexia–cachexia syndrome in cancer has been of interest to the scientific community in recent decades, resulting in the development of promising drugs and non-pharmacological measures [78]. However, no drugs have yet been approved for its treatment [78].

Anorexia–cachexia syndrome's physiopathology is based on a combination of metabolic mechanisms and tumor anatomical and cancer treatment factors [76].

One of the main mechanisms is the excessive production and secretion of cancer-related cytokines, particularly tumor necrosis factor alpha (TNF-α), interleukin-6 (IL-6), interleukin-1 (IL-1), and C-reactive protein (CRP) [76]. These cytokines lead to a pro-inflammatory state that causes a catabolic and anorectic effect, resulting in lean mass and weight loss [76].

Most solid tumors, particularly gastrointestinal and head/neck neoplasms, can cause mechanical nutritional problems [76]. Gastric reflux, abdominal pain, and/or dysphagia may lead to a decline in food intake [76]. Some tumors can cause early satiety due to abdominal occupancy (e.g., hepatomegaly and ascites) [69]. Other cancers affect gastrointestinal motility (as a result of peritoneal and/or intestinal infiltration) and nutritional malabsorption (particularly in pancreatic cancer) [76].

Table 1. Antiemetic prescribing guide based on etiology.

Nausea/Vomiting Etiology	Mechanisms Implicated	Receptors Involved	Main Drug Options
Chemical/metabolic	Stimulation of chemoreceptor trigger zone	Dopamine type 2 receptor (D2) Serotonin type 3 receptor (5HT3) Neurokinin 1 receptors (NK1)	Dopamine antagonists: • Chlorpromazine; • Domperidone; • Haloperidol; • Levomepromazine; • Metoclopramide; • Promethazine. Serotonin type 3 and 4 antagonists: • Ondansetron; • Granisetron; • Cisapride. Neurokinin antagonists: • Aprepitant. Acetylcholine (muscarinic) antagonists: • Butylscopolamine; • Scopolamine. Histamine antagonists: • Cyclizine; • Dimenhydrinate; • Meclizine; • Promethazine. Corticosteroids could be used for cranial causes: • Dexamethasone; • Prednisolone. Other agents: • Benzodiazepines (used in nausea and vomiting associated with anxiety); • Octreotide (malignant bowel obstruction); • Cannabinoids.
Drugs	Stimulation of chemoreceptor trigger zone (dopamine type 2 receptor)		
	Delayed gastrointestinal transit (e.g., opioids)		
Impaired gastric emptying/ gastric stasis	Gastroparesis	Dopamine type 2 receptor (D2) Serotonin type 4 receptor (5HT4)	
Visceral/serosal causes of delayed gastrointestinal transit	Malignant bowel obstruction (stimulation of chemoreceptor trigger zone and/or stimulation of peripheral pathways)	Dopamine type 2 receptor (D2) Acetylcholine receptor (Ach) Serotonin type 3 receptor (5HT3)	
Cranial causes	Meningeal mechanoreceptor activation secondary to meningeal irritation with or without increased intracranial pressure	Histamine type 1 receptor (H1)	
Vestibular causes	Stimulation via vestibulocochlear nerve (muscarinic acetylcholine receptors, histamine type 1)	Acetylcholine receptor (Ach) Histamine type 1 receptor (H1)	
Cortical causes		Gamma-aminobutyric acid receptor (GABA) Histamine type 1 receptor (H1)	

Note: Prescribe the most appropriate first-line antiemetic; review at least every 24 h and consider parenteral administration if oral absorption is uncertain. Based on Henson et al. [70].

On the other hand, oncological treatments can cause cachexia [76]. Surgery can alter swallowing, absorption, and/or digestive functions and thus lead to malnutrition [76], and chemo- and radiotherapy can lead to xerostomia, appetite loss, oral mucositis, nausea, vomiting, dysgeusia, and enteritis [76]. These effects make it difficult to eat and, as a result, cause a reduction in caloric intake, which exacerbates nutrient loss [76].

Three phases are recognized in anorexia–cachexia syndrome: pre-cachexia, cachexia, and refractory/advanced cachexia. The stage depends on the degree of weight loss and the reversibility of the condition with nutritional intake [79]. Pre-cachexia is characterized by systemic inflammation with weight loss of <5% of the patient's body weight [76,80].

Patients in the cachexia stage present with systemic inflammation, weight loss of >5% (or BMI < 20 kg/m^2 or weight loss > 2% if sarcopenic), and the loss of cell mass [76,80]. Finally, refractory or advanced cachexia is characterized by irreversible catabolism, resulting in poor functional status [69,73]. In this phase, the cancer also progresses, sometimes with an expected survival < 3 months, corresponding to the end-of-life phase [76,80].

Simple measures such as the Edmonton Symptom Rating Scale (ESAS) and the Subjective Patient-Generated Global Assessment (PG-SGA), together with nutritional assessment and a weight loss of more than 5% in the last 6 months, are used to identify patients with anorexia–cachexia syndrome [76,80].

The treatment of cancer cachexia is multimodal and includes a nutritional approach and pharmacological measures [76,80].

Nutritional support includes dietary counseling, particularly in patients who are able to eat [76]. This counseling consists of guiding the patient and/or family by promoting frequent and small meals according to the patient's taste, with adjustments to the consistency, as well as choosing high-energy and high-protein foods, enriching their diet [76]. Nutrition plays an important role in the psychosocial well-being of advanced cancer patients, affecting their quality of life [81,82].

In addition to nutritional advice, patients can enrich their diet with the help of oral nutritional supplements [76,80]. These products are a balanced mixture of macro- and micronutrients available on the market in the form of liquid foods, puddings, and powder formulations that can be reconstituted with water or milk [76,80]. According to the literature and main guidelines in this area, these supplements are best used as adjuncts to the diet, because their use alone, without changes in the diet, is not effective [76,80]. Some studies have reported positive effects of using these supplements on energy intake, weight gain, and some aspects of quality of life (e.g., emotional functioning, appetite loss, and global quality of life) in cancer patients [76,80].

In patients expected to survive for more than several months and in those receiving anticancer therapy, nutrition should be intensified as needed through enteral and parenteral routes [76,80]. Enteral nutrition may be used in cases of dysphagia if the small bowel function is preserved (using tube feeding) [76,80]. Parenteral nutrition should be used if oral intake and tube feeding are not tolerated or considered inadequate [69,73]. Artificial nutrition is rarely indicated in palliative care, and prognosis and the possibility of complications should be taken into account [81,82].

The literature lacks sufficient evidence to support any drug to treat this syndrome [76,80]. Pharmacological treatment depends on the patient's preferences but also on the degree of anorexia/weight loss, the risk of side effects, comorbidities, prognosis, and treatment goals [76,80]. The main benefits associated with pharmacological treatment are increased appetite and weight gain [76,80].

The two main important drugs used in the pharmacological treatment of anorexia–cachexia syndrome are corticosteroids and progesterone analogs (megestrol acetate) [82–84].

Corticoids improve appetite in a manner similar to that observed with progesterone analogs [76,80]. Given their adverse effects and the decline in their efficacy (with long-term use), their role is often limited to those with an estimated life expectancy of weeks to a few months [76,80]. In oncology and palliative care, the most commonly used corticosteroids are dexamethasone, prednisolone, and methylprednisolone [76,80]. No corticosteroid is superior to another, but dexamethasone is preferred due to its lower mineralocorticoid effects [76,80].

On the other hand, megestrol acetate improves appetite and body weight in cancer-related cachexia, but the weight gained is mainly in the form of adipose tissue [76,80]. Its

possible complications include thromboembolic events, edema, and adrenal suppression, especially when the dosage exceeds 800 mg per day [76,80].

In the literature, other drugs for cachexia treatment are described, although the evidence regarding their benefits is inconclusive [76,80]. The drugs in question are olanzapine, anamorelin, thalinomide, omega-3 fatty acids, vitamins, minerals, cyproheptadine, non-steroidal anti-inflammatory drugs, mirtazapine, hydrazine sulfate, TNF inhibitors, melatonin, insulin, and cannabinoids [76,80].

Thus, the goal of cachexia treatment is to stabilize or increase protein–caloric ingestion, reduce inflammation, optimize the person's nutritional status, and prevent negative effects related to malnutrition [76,80]. This goal is particularly important in the early stages of cancer and cachexia [76,80]. However, as the end of life approaches, the goal of care turns more toward quality of life than nutritional adequacy [85]. This is where the great dilemma arises between reconciling nutritional intervention with offering comfort and helping to control symptoms [85].

3.6. Psychological Distress

Optimizing the symptom control of patients in palliative care requires that the respective team be attentive to their emotional suffering [86].

Psychological distress is highly prevalent in the oncology context [87]. Although its identification, assessment, and management are supported by the literature, there is still no universal concept of distress and suffering [87]. For example, psychological distress could include anxiety, sadness, depression, fear, and negative affect [86].

According to the National Comprehensive Cancer Network (NCCN), distress in cancer is defined as "a multifactorial unpleasant experience of a psychological (cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with one's ability to cope effectively with cancer, its physical symptoms, and its treatment" [88].

In other words, psychological distress can be defined as the "unique discomfort and emotional state experienced by an individual in response to a specific stressor or demand that results in temporary or permanent harm caused to the person" [86]. Emotional suffering can encompass several dimensions, such as psychological, social, and spiritual [89].

The instruments that allow the measurement of psychological distress can be routinely used and include symptom assessment scales, as well as more specific tools and structured interviews for this purpose [90]. The Edmonton Symptom Assessment System (ESAS) and the Palliative Outcome Scale (POS) are generic instruments commonly used by palliative care teams to screen for symptoms, including anxiety, depression, well-being, meaning in life, and sharing feelings [90]. When the scores of these symptoms are high, patients should be referred for psychology or psychiatry consultations in which more specific instruments will be used, such as the Distress thermometer (DT), the Hospital Anxiety and Depression Scale (HADS), and the Brief Symptom Inventory (BSI) [90].

Depression and anxiety are the most common psychiatric disorders in palliative care [91]. It is estimated that 24 to 70% of these patients may experience depression, leading to a significant decline in their quality of life and even suicidal ideation [91].

Methylphenidate and antidepressants may also be beneficial in the treatment of depressive symptoms in this subpopulation of patients [92,93]. The combination of these drugs with non-pharmacological measures, such as music therapy, has been shown to be more effective than the use of pharmacological therapies alone [92,93].

Anxiety is very common in patients who are in palliative care and, like depression, has a strong impact on their quality of life. Anxiety is present in about 20% to 50% of patients with advanced cancer [93]. Some physical symptoms, such as nausea and anorexia, are more prevalent when patients do not feel well emotionally [94]. By reducing anxiety, the

palliative care team is providing patients with holistic and humanized care that is attentive to the symptoms as a whole [94].

The correct approach to treating anxiety is an area that is still little studied and with little training [95]. The literature shows that screening scales are rarely used, and the use of benzodiazepines is often inadequate, being prescribed in patients with survival expectations of months [95]. Access to psychology and psychiatry consultations is also very deficient [95].

Cancer patients can benefit physically and psychologically from personalized distress interventions [96]. Patients who were routinely assessed for distress showed improvements in psychological and physical symptoms, as well as in well-being [96].

Nowels et al. conducted a systematic review that demonstrated the need to consider improvements in psychological symptoms as realistic outcomes of palliative care interventions [97]. However, non-worsening emotional symptoms may be a more reasonable goal for patients in end-of-life care [97]. This review further demonstrated that, for patients in the late stages of their disease trajectory, reducing psychological suffering was the most difficult, since distress tends to increase as the end of life approaches (especially in diseases with high symptom burden such as cancer) [97].

Paley et al. performed a systematic review that showed a wide range of therapeutic approaches to managing distress in cancer patients [98]. There was no consensus on any intervention method, although mindfulness was the most frequently researched with some evidence, followed by communication and group therapies [98].

Mindfulness appears to be effective for cancer patients, particularly those in the terminal stages of the disease [98]. This technique is easy to teach and can be self-administered outside medical settings by patients and/or caregivers [98]. They can be taught in person or online and practiced at home. Brief mindfulness may also be appropriate for use in end-of-life care [98].

Palliative care teams should make an effort to identify emotional distress so that patients can take advantage of targeted psychotherapeutic and pharmacological interventions and thus improve their quality of life.

3.7. Palliative Sedation

Throughout the disease process and especially in the last days of life, patients can present with symptoms that cannot be controlled, despite appropriate treatment, and may interfere with the process of a peaceful death [99]. As a result, some authors deem it a medical and moral imperative to use sedative drugs to control these symptoms [99].

According to the European Association of Palliative Care (EAPC), palliative sedation is a therapeutic measure of the last resort for the treatment of refractory symptoms. It entails the monitored use of sedative medication with the intention of inducing a state of decreased consciousness to alleviate otherwise intractable suffering in a manner acceptable to the patient, family, and health professionals [100].

A refractory symptom is a symptom that cannot be adequately controlled, despite exhaustive and tolerable pharmacological and non-pharmacological interventions that do not compromise the patient's degree of consciousness [100]. The most common refractory symptoms are pain, dyspnea, anxiety, seizures, delirium, and psychomotor agitation, with an overall prevalence of 10–50% [93]. Refractory symptoms often increase as the patient gets closer to death and may interfere with a peaceful death [100].

The objective of palliative sedation is to control symptoms that cause severe discomfort and are refractory to conventional palliative treatment, relieving the suffering of patients in the final phase of the disease, improving their comfort, and maintaining the dignity of human life until its end [100].

According to the EAPC, sedation is used in palliative care within different contexts: to perform more invasive procedures, in end-of-life patients on ventilatory support, in the presence of refractory symptoms, in cases of emergent sedation, in respite sedation, and in cases of refractory psychological and existential suffering (2009 and 2023 recommendations) [100,101].

Emergent sedation is indicated in irreversible clinical situations in terminal patients who require immediate relief, such as catastrophic hemorrhages, asphyxia and suffocation, uncontrollable pain or dyspnea, and delirium with intense psychomotor agitation [100].

In the 2009 EAPC recommendations, there is no consensus on end-of-life sedation for severe non-physical symptoms (existential or psychological) such as depression, anxiety, demoralization, or existential suffering [100]. The lack of clear consensus on these issues is a barrier to the optimal treatment of patients with existential distress, particularly at the end of life, as well as a source of misunderstanding and controversy [102]. Many authors have raised concerns about the subjectivity and ambiguity inherent in the assessment of existential distress [102].

However, the 2023 EAPC guidelines recognize that existential distress is an indication for palliative sedation and includes a number of distinguishable non-physical components [101]. Existential suffering should only be considered refractory "after a comprehensive assessment by specialists in palliative care, considering the psychological, social and spiritual suffering" [101].

In summary, most guidelines and experts define the following criteria for palliative sedation: terminal illness (life expectancy of less than 6 months), imminent death (hours or days, maximum 2 weeks), intolerable suffering, refractory symptoms, the involvement of a palliative care specialist or an interdisciplinary team, and informed consent obtained from the patient or their legal representative [100,101].

This decision must be in accordance with the wishes of the patient, family, or legal representative and be the consensus of the medical team [100,101].

The level of sedation can be classified according to degree (light or deep) and duration (intermittent/respite sedation or continuous) [103]. When defining the level of sedation, there are some principles to consider: the level of sedation should always be the minimum necessary for the adequate relief of symptoms, and intermittent sedation should be the first option considered [103]. According to most authors, deep sedation should only be considered in the terminal phase of the disease, with an expected prognosis of hours at most [103].

The scale most commonly used to assess the state of consciousness/level of sedation is the Richmond Agitation Sedation Scale (RASS), which assesses the patient's level of agitation and sedation, with a score ranging from +4 (combative patient) to −5 (unresponsive patient) [100,104]. It is an observational scale and validated for the intensive care context [100,104]. However, it has been modified and adapted to the context of palliative care and is being studied for its use in the monitoring of palliative sedation (Richmond Agitation Sedation Scale—Palliative Version (RASS-PAL)) [100,104].

The use of sedation to relieve the suffering of the patient can cause distress and stress among the family and health professionals involved in care [105]. One of the apparent reasons behind this stress is the fear that death is accelerated by palliative sedation [105]. In general, the evidence indicated that palliative sedation did not accelerate death, which was a concern of physicians when prescribing treatment, as well as of family members [105].

The ideal drugs for palliative sedation should have a rapid and short onset of action to facilitate dose titration to the desired effect [101,104,106,107]. These drugs should induce sedation reliably and, if necessary, a state of reduced consciousness with minimal side effects [101,104,106,107].

With regard to pharmacological therapy, a multiplicity of drugs can be used in the practice of palliative sedation [101,104,106,107]. The most frequently used drugs are benzodiazepines (midazolam, diazepam, lorazepam), neuroleptics (haloperidol, chlorpromazine, levomepromazine), barbiturates (phenobarbital), and other drugs such as anesthetics (propofol, ketamine, dexmedetomidine) (Figure 3) [101,104,106,107].

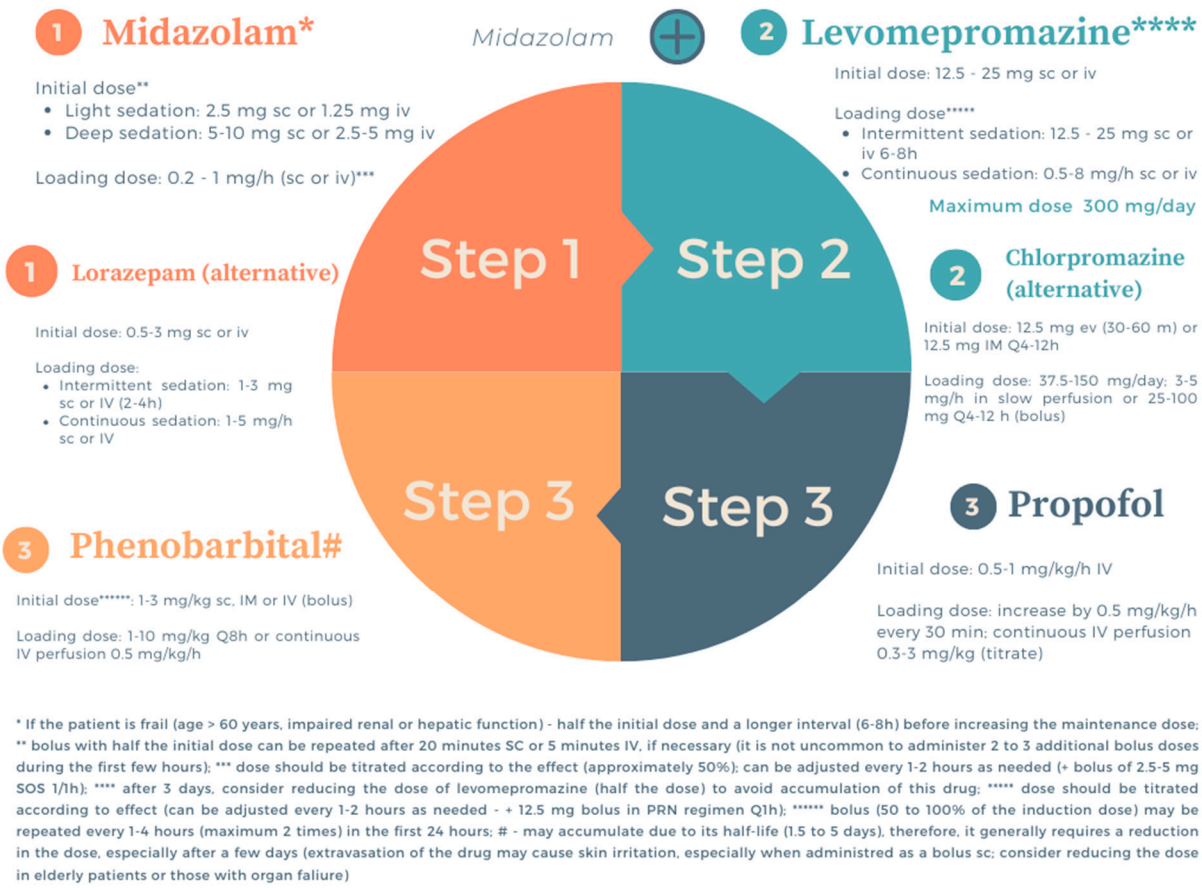


Figure 3. Drugs and pharmacological combinations used in palliative sedation. Based on the Palliative Sedation Protocol (Hospice and Palliative Care Federation of Massachusetts 2004 [106]), the Waterloo Wellington Palliative Sedation Therapy Protocol (Waterloo Wellington Interdisciplinary HPC Education Committee—PST Task Force 2022 [107]), Inter-professional Palliative Symptom Management Guidelines—Refractory symptoms and palliative sedation (BC Centre for Palliative Care 2017 [104]), and 2023 EAPC Guidelines [101].

One of the novelties in this area is the use of dexmedetomidine (DEX) for symptom control and sedation. DEX is approved for use in the adult population for anesthesia care during mechanical ventilation [108]. However, clinical experience supports the application of this drug in palliative care [108]. DEX can not only induce sedation with a low risk of delirium but also minimize the side effects of other drugs [108]. DEX has a different mechanism of action, providing a type of sedation that is distinct from that induced by barbiturates, benzodiazepines, and propofol [108]. With less delirium, DEX also controls anxiety and agitation, allowing patients to remain oriented and conscious, maximizing their ability to interact with loved ones, which is a primary goal in end-of-life care [108].

According to the literature, DEX can be used in the context of palliative care, particularly in cases of hyperactive delirium or agitation; severe opioid-refractory pain; severe opioid- and benzodiazepine-refractory dyspnea; and dyskinesia, nausea, insomnia, shivering, and sedation [109]. The use of this drug should be avoided in patients with severe

cardiac comorbidities. In the case of hepatic and renal failure, dose reductions are necessary [109].

4. Quality of Life

Assessing the quality of life (QoL) of patients in palliative care is essential [110]. The main goal of palliative care is to provide patients with the best possible quality of life [110]. The WHO defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" [110].

This concept highlights six fundamental domains: physical well-being, psychological well-being, functional autonomy, relational quality, environment, and personal beliefs or spirituality [110].

"Health-related quality of life" is a concept used to assess how an individual's health affects how they feel physically, socially, and emotionally [111]. It is a subjective concept, as different individuals with the same disease and severity have different perceptions of their quality of life [112].

The need to assess the quality of life in cancer patients is currently undisputable, and it is no longer appropriate for the success of cancer treatment to be limited to response rates, survival time, disease-free interval, or mortality rate [113].

Cicely Saunders pioneered the modern palliative care and hospice movement by creating the first hospice and launching the concept of "Total Pain" or suffering [114,115]. Some authors studied how caregivers of patients defined quality of life or a "good death". They concluded that this concept depends on each individual's unique experiences but that it encompasses several dimensions, such as physical, psychosocial, and spiritual [115].

According to Higgison and Carr, measuring quality of life in oncology and palliative care is appropriate in several scenarios, such as identifying and prioritizing problems, ensuring effective communication with the patient and family, preventing any symptoms that may arise, engaging in shared decision-making, and monitoring possible changes in health and response to the treatments instituted [116].

Bernard et al. conducted a study that showed that meaning in life, especially relevant to social interactions and spirituality, had a great impact on the quality of life of patients in palliative care [117]. This study is in line with the most recent literature that shows that, at the end of life, the aspects that most contribute to the quality of life are the presence of family, relationships, and spirituality or religion, leaving the physical aspects in second place [117].

Measures to assess quality of life in palliative care are, for the most part, multidimensional [118,119].

There are currently several instruments that can be used to measure quality of life in palliative care [118,119]. The most commonly administered questionnaires were the European Organization for Research and Treatment of Cancer Quality of Life questionnaire (EORTC-QLQ), Short Form Health Survey 36 (SF-36), McGill Quality of Life Questionnaire (MQOL), and European Quality of Life Five Dimensions Questionnaire (EUROQOL EQ-5D) [118,119]. Conrad et al. found that the simple question "How satisfied are you currently with your physique and emotional well-being?" had the same validity as the Functional Assessment of Oncology Therapy—General scales (FACT-G) and the Palliative Outcomes Scale (POS) in the assessment of quality of life [120]. In other studies, simple questionnaires such as the Edmonton Symptom Assessment Scale (ESAS) and Palliative Outcome Scale (POS) are widely used due to their ease of implementation and frequent use in the routines of palliative care teams.

One of the goals of palliative care is to provide patients with the best possible quality of life, although it is true that information on the self-perception of quality of life at this stage of the disease is still scarce. The difficulty in interpreting and collecting data obtained through the various measurement instruments used contributes to this.

Although there is much talk about quality of life in palliative care due to its usefulness in evaluating the results of care provided to patients and their families, the truth is that this topic remains understudied [121]. Most studies do not address quality of life as a primary objective [121]. The best studies that assessed health-related quality of life in end-of-life patients were those carried out with patients followed only by palliative care teams, compared to control groups, in which patients received palliative anti-neoplastic treatment, whose main focus was to prolong life with clear advantages for the former [121].

End-of-life patients who have some type of religious belief have a better quality of life, as well as a lower risk of depression or suicide [122].

Evidence shows that the early integration of palliative care into the trajectory of chronic diseases improves the quality of life of patients, especially from a psychological and functional point of view.

5. Future Directions

Global policies have sought to strengthen access to palliative care [123]. However, their implementation has been difficult [123].

One of the major challenges for the future is the integration and financing of palliative care as part of general/usual clinical care [123]. According to the literature, the main future challenges for palliative care include universal access to medications such as opioids; access to universal coverage for this care; the integration of palliative care into general/usual clinical care; the development of skills among health professionals; the promotion of shared decision-making; the development of home care; and the implementation of palliative care based on the best evidence and the assessment of aspects that are significant for patients and their families [123].

More research on home-based palliative care needs to be performed in the near future. Home-based care can improve overall health outcomes and reduce healthcare costs by employing personalized quality metrics, expanding the range of services available outside the hospital, tailoring approaches to the patient and family, and improving quality of life [124]. End-of-life care, particularly in situations with high symptom burden, appears to be challenging in the home setting, requiring additional staff and teams, as well as further research to identify these challenges [124].

Regarding symptom control, it seems to us that the role of cannabinoids in cancer symptom control (particularly in advanced cancer) needs more evidence and will be the subject of more studies in the near future.

Currently, in Portugal, Law No. 33/2018, of July 18, establishes the legal framework for the use of cannabis-based drugs for medicinal purposes [125]. The use of cannabinoids has been approved for the following pathologies/symptoms: appetite stimulation in palliative care (AIDS or cancer patients undergoing treatment); chronic pain (associated with cancer or the nervous system); Gilles de la Tourette syndrome; nausea and vomiting (resulting from cancer, HIV, or hepatitis C therapy); spasticity due to multiple sclerosis or spinal cord injuries; epilepsy and severe seizure disorders in childhood; and therapy-resistant glaucoma [126].

According to the American Society of Clinical Oncology (ASCO), the use of cannabis in cancer patients is indicated for the treatment of chemotherapy-induced nausea and vomiting, total symptom burden in adults with advanced cancer, cancer pain, sleep (in

patients with chronic cancer pain), low weight or poor appetite, and anxiety/depression. In addition, its use is recommended to improve quality of life [127].

6. Conclusions

Palliative care aims to reduce the suffering of patients, their families, and their significant others, providing them with a quality of life that would not be possible otherwise. Proper assessment and appropriate interventions to control symptoms are fundamental aspects of providing palliative care.

The multifactorial nature of these patients' symptoms requires an initial evaluation and the monitoring of their evolution, including their intensity, impact on activities of daily living, emotional impact, and likelihood of being controlled.

Palliative care provides specific treatments for certain symptoms, which should be practical and non-invasive, including non-pharmacological and prophylactic treatments. After implementing a therapeutic plan, it is essential to adjust the medication, as undesirable side effects may occur and/or the progression of the disease may lead to the exacerbation of symptoms or the emergence of new ones.

Clinical procedures in palliative care are the same as other clinical practices, but the objective is the well-being and comfort of the patient, prioritizing the best possible quality of life.

Author Contributions: Conceptualization, F.G. and M.G.; methodology, F.G. and M.G.; resources, M.G.; data curation, F.G.; writing—original draft preparation, F.G. and M.G.; writing—review and editing, A.R., I.P., F.R. and R.N.; visualization, M.G., A.R. and I.P.; supervision, F.R. and R.N. All authors have read and agreed to the published version of the manuscript.

Funding: The research received no external funding.

Acknowledgments: The authors would like to acknowledge the support of the Portuguese Institute of Oncology Francisco Gentil Coimbra and the University of Porto.

Conflicts of Interest: The authors declare no conflicts of interest.

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4.4. Desafios éticos no controlo sintomático em Cuidados Paliativos

As questões relacionadas com o início e o fim de vida representam um imenso desafio para os profissionais de saúde, envolvendo domínios da ciência, da espiritualidade, do humanismo e os domínios social, legal, moral e bioético (Alcântara, 2020).

Os avanços da medicina moderna e tecnológica têm levado ao aumento da esperança de vida, alterando as antigas trajetórias das doenças crónicas e a própria morte. Embora muitas destas inovações tecnológicas não curem as doenças avançadas, as intervenções médicas como a imunoterapia, a nutrição artificial, a hemodiálise e o suporte respiratório podem prolongar a sobrevida destes doentes; no entanto, este "aumento da quantidade de vida" é muitas vezes associado a sofrimento desnecessário e encarniçamento terapêutico (Karnik & Kanekar, 2016).

As decisões no fim de vida devem ser tomadas de modo a minimizar impactos negativos nos princípios da bioética. A aplicação da bioética à medicina paliativa envolve quatro imperativos morais: respeito pela autonomia, não maleficiência, beneficência e justiça (Beauchamp & Childress, 2009; Barker; 2017).

O princípio do duplo efeito é outro dos dilemas éticos em fim de vida. Este princípio justifica o uso da sedação paliativa quando estamos perante sintomas refratários e em que a administração de fármacos sedativos para aliviar os sintomas pode eventualmente encurtar a vida, não obstante o objetivo principal seja o alívio do sofrimento (Schofield *et al.*, 2021; Guevara-López, Altamirano-Bustamante and Viesca Treviño, 2015; Walker and Breitsameter, 2015).

Os dilemas éticos em cuidados paliativos colocam-se em diversos cenários clínicos que a seguir se descrevem (Quill & Bower, 2014):

- Uso apropriado de antibióticos, particularmente no fim de vida;
- Desafios na implementação de diretivas antecipadas de vontade, principalmente quando a família solicita atitudes fúteis e desproporcionadas;
- Transfusão consensual de concentrados eritrocitários;
- Altura temporal apropriada de desativação de pacemakers;
- Decisão de não-ressuscitação;
- Decisão clínica da melhor abordagem de distúrbios hidro-eletrolíticos;
- Desafios relacionados com a abstenção de alimentação e hidratação;

- Tomada de decisões quanto à adequação da realização de exames complementares de diagnóstico;
- Dilemas éticos com o uso de sedativos para o controlo de sintomas refratários/ sedação contínua até à finitude;
- Escolha do melhor agente farmacológico e dose adequada tendo em conta o equilíbrio alívio do sintoma/ efeitos secundários indesejáveis;
- Cuidar de doentes que optam pelas terapêuticas alternativas, recusando a medicação prescrita pelos clínicos;
- Dilemas relacionados com o uso de opioides/ lidar com a opioidofobia.

A aplicação dos princípios da bioética em cuidados paliativos reflete-se na tomada de decisões, em conseguir em pleno que os doentes tenham "uma boa morte" e com o controlo sintomático otimizado e numa comunicação aberta e honesta. Tal como disse Cicely Saunders: *"We will do all we can not only to help you die peace fully, but also to live until you die"*.

A aluna, ciente da importância dos dilemas éticos em fim de vida, escreveu o artigo intitulado "Desafios éticos do controle sintomático em cuidados paliativos - reflexão crítica", aceite na Revista "Bioética" a 15 de dezembro de 2025 (Anexo III).

4.4.1. Desafios éticos do controle sintomático em Cuidados Paliativos – reflexão crítica

Gonçalves F, Gaudêncio M, Rocha A, Paiva I, Rego MF, Nunes R. Desafios éticos do controlo sintomático em Cuidados Paliativos - reflexão crítica – artigo aceite na Revista Bioética

Desafios éticos do controle sintomático em cuidados paliativos: reflexão crítica

Resumo

Introdução: Em cuidados paliativos, os sintomas são múltiplos, complexos e multidimensionais, estando em constante mutação. A sua elevada prevalência influencia negativamente a qualidade de vida dos doentes e suas famílias. Os cuidados paliativos representam uma área de conhecimento capaz de contribuir para uma boa gestão do controlo sintomático. No entanto, representam igualmente um desafio ético em áreas sensíveis com a obstinação terapêutica, a abstenção de alimentação e hidratação e a sedação paliativa.

Métodos: Revisão narrativa/reflexão crítica com base numa pesquisa bibliográfica nas bases de dados PUBMED, CINAHL e Web of Science, complementadas por alguns artigos, livros e websites considerados pertinentes pelos autores. Após a conclusão da pesquisa e eliminação dos duplicados, os autores fizeram a revisão dos artigos, inicialmente com base no título e abstract, e posteriormente após leitura integral. Assim, os artigos foram seleccionados de forma a desenvolver cada tópico dos resultados/discussão.

Resultados: Da pesquisa realizada, os autores chegaram a 69 artigos que servem de bibliografia ao artigo em análise. Com este trabalho, pretende-se fazer uma reflexão crítica sobre os dilemas éticos em cuidados paliativos, com particular foco no controlo sintomático. A reflexão foi organizada em dois grandes temas: princípios éticos a considerar no controlo sintomático (beneficência, não maleficência, autonomia, duplo efeito, dignidade, justiça e vulnerabilidade) e dilemas éticos em situações de fim de vida (uso compassivo de terapêuticas dirigidas, sedação paliativa e cuidados em fim de vida).

Discussão e conclusão: O controlo sintomático é um pilar dos cuidados paliativos. O melhor cuidado ao doente em cuidados paliativos é aquele que é centrado na pessoa e não na doença, evitando o prolongamento artificial da vida a qualquer custo. O doente deve ser reconhecido como protagonista da sua própria vida, respeitando o seu direito à autodeterminação e privacidade. A prática clínica baseada em princípios éticos é fundamental no cotidiano de uma equipa de cuidados paliativos.

Palavras-chave: Avaliação de sintomas. Bioética. Cuidados paliativos. Medicina paliativa.

Desafíos éticos del control sintomático en cuidados paliativos: reflexión crítica

Resumen

Introducción: En los cuidados paliativos, los síntomas son múltiples, complejos y multidimensionales, y están en constante cambio. Su alta prevalencia influye negativamente en la calidad de vida de los pacientes y sus familias. Los cuidados paliativos representan un área del conocimiento capaz de contribuir a un buen manejo del control sintomático. Sin embargo, también representan un desafío ético en áreas sensibles como la obstinación terapéutica, la abstención de alimentación e hidratación, y la sedación paliativa.

Métodos: Revisión narrativa/reflexión crítica basada en una búsqueda bibliográfica en las bases de datos PUBMED, CINAHL y Web of Science, complementada con artículos, libros y sitios web considerados relevantes por los autores. Tras completar la búsqueda y eliminar duplicados, los autores revisaron los artículos, inicialmente basándose en el título y el resumen, y posteriormente tras su lectura completa. De esta forma, se seleccionaron los artículos para desarrollar cada tema de los resultados/discusión.

Resultados: A partir de la investigación realizada, los autores identificaron 69 artículos que sirven como bibliografía para el artículo en análisis. Este trabajo busca reflexionar críticamente sobre los dilemas éticos en cuidados paliativos, con especial atención al manejo sintomático. La reflexión se organizó en dos grandes temas: principios éticos a considerar en el manejo sintomático (beneficencia, no maleficencia, autonomía, doble efecto, dignidad, justicia y vulnerabilidad) y dilemas éticos en situaciones de fin de vida (uso compasivo de terapias dirigidas, sedación paliativa y cuidados paliativos).

Discusión y conclusión: El manejo sintomático es un pilar de los cuidados paliativos. Los mejores cuidados paliativos se centran en la persona, no en la enfermedad, evitando la prolongación artificial de la vida a cualquier precio. El paciente debe ser reconocido como protagonista de su propia vida, respetando su derecho a la autodeterminación y a la privacidad. La práctica clínica basada en principios éticos es esencial en la rutina diaria de un equipo de cuidados paliativos.

Palabras clave: Evaluación de síntomas. Bioética. Cuidados paliativos. Medicina paliativa.

Ethical challenges of symptomatic control in palliative care: critical reflection

Abstract

Background: In palliative care, the symptoms are multiple, complex and multidimensional, and are constantly changing. Its high prevalence negatively influences the quality of life of patients and their families. Pain, dyspnea and fatigue are some of the symptoms that are difficult to control in patients with advanced diseases. Palliative care represents an area of knowledge capable of contributing to a good management of symptomatic control. However, they also represent an ethical challenge in sensitive areas such as therapeutic obstinacy, abstention from feeding and hydration, and palliative sedation.

Methods: Narrative review/critical reflection based on a literature search of the PUBMED, CINAHL, and Web of Science databases, supplemented by articles, books, and websites considered relevant by the authors. After completing the search and eliminating duplicates, the authors reviewed the articles, initially based on the title and abstract, and then after reading them in full. Thus, the articles were selected to develop each topic of the results/discussion.

Results: From the research conducted, the authors identified 69 articles that serve as the bibliography for the article under analysis. This work aims to critically reflect on ethical dilemmas in palliative care, with a particular focus on symptomatic management. The reflection was organized into two major themes: ethical principles to consider in symptomatic management (beneficence, non-maleficence, autonomy, double effect, dignity, justice, and vulnerability) and ethical dilemmas in end-of-life situations (compassionate use of targeted therapies, palliative sedation, and end-of-life care).

Discussion and conclusion: Symptomatic management is a pillar of palliative care. The best palliative care is person-centered, not disease-centered, avoiding artificial prolongation of life at any cost. The patient must be recognized as the protagonist of their own life, respecting their right to self-determination and privacy. Clinical practice based on ethical principles is essential in the daily routine of a palliative care team.

Keywords: Symptom assessment. Bioethics. Palliative care. Palliative medicine.

Declaram não haver conflito de interesse.

Introdução

A Organização Mundial da Saúde (OMS) define cuidados paliativos como *uma abordagem que melhora a qualidade de vida de pacientes e familiares que enfrentam problemas associados a doenças ameaçadoras da vida, por meio da prevenção e alívio do sofrimento, identificando precocemente, avaliando e tratando a dor e outros problemas físicos, psicossociais e espirituais* [1].

Apesar da história dos cuidados paliativos ter décadas de existência, ainda persistem dúvidas acerca do que são exatamente estes cuidados, qual o seu interesse e para que doentes estão indicados [2]. Estas dúvidas são transversais, envolvendo profissionais de saúde, cidadãos e até os próprios doentes, criando desigualdades no acesso aos cuidados paliativos, considerados hoje um direito universal [2].

De acordo com a Associação Portuguesa de Cuidados Paliativos, mais de 70% dos doentes em Portugal não têm acesso atempado a estes cuidados, sendo que, no caso das crianças, este número aumenta para uma percentagem alarmante de 90% [3].

Os cuidados paliativos são cuidados holísticos e humanizados, que têm como principal objetivo melhorar a qualidade de vida dos seus doentes e famílias quando confrontados com doença crónica e limitante de vida (cancro, insuficiência de órgão, demência, entre outras) [4].

A progressão da doença crónica avançada, nomeadamente o cancro metastático, é normalmente acompanhada por múltiplos sintomas físicos, psicológicos, espirituais e sociais, resultantes da própria doença, do seu tratamento e/ou de outras comorbilidades associadas [5].

No contexto de cuidados paliativos, o controlo dos sintomas é um pilar básico, através da sua identificação, avaliação e tratamento precoce [6]. O termo paliativo deriva do latim "*pallium*" que significa manto ou capa, ou seja, estes cuidados têm como objetivo "encobrir" os sintomas, nas suas várias dimensões, com o intuito de promover o bem-estar e a qualidade de vida [6]. Um sintoma pode ser definido como uma *experiência subjetiva que afeta a esfera biopsicossocial e cognitiva de um indivíduo* [7].

De acordo com Twycross, a abordagem do controlo sintomático engloba sempre cinco categorias: avaliação dos sintomas, explicação da causa dos mesmos, tratamento individualizado, monitorização contínua e atenção aos detalhes, sem nunca fazer juízo de valores [6,8].

Como já referido anteriormente, um dos principais objetivos dos cuidados paliativos é otimizar a gestão de sintomas não controlados que tenham impacto na qualidade de vida dos doentes [7]. A importância de uma abordagem eficiente e ajustada dos sintomas é um indicador de qualidade dos serviços de cuidados paliativos [9]. Assim, é fundamental uniformizar as melhores práticas clínicas no controlo sintomático, de modo a proporcionar o maior conforto e qualidade de vida possível aos doentes em fim de vida [9].

Esta temática está bem expressa em múltiplos estudos que provam que o controlo adequado da dor e de outros sintomas é uma peça fundamental na promoção da dignidade e bem-estar nos doentes paliativos [9]. Desta forma, o controlo inadequado dos sintomas influencia negativamente a trajetória de doença, induzindo sofrimento e encurtando a própria sobrevida do doente [10].

A partilha de decisões dos profissionais de saúde com os doentes e suas famílias e a coordenação por uma equipa multidisciplinar são peças fundamentais para a prestação de cuidados paliativos de qualidade [11].

Os cuidados paliativos valorizam a vida e consideram a morte um processo normal na trajetória da doença, não atrasando nem antecipando que ela aconteça, sendo que o seu foco está na promoção da máxima qualidade de vida possível [1]. Um controlo de sintomas de excelência só é conseguido quando estamos perante uma equipa de cuidados paliativos multidisciplinar altamente motivada e flexível para responder às exigentes necessidades paliativas dos doentes [11]. O trabalho em equipa interdisciplinar é a única forma de responder de modo humanizado às caraterísticas individuais de cada doente único na sua essência [11].

Por outro lado, *a bioética é uma área do pensamento humano e da intervenção social que aborda a ética das ciências da vida, incluindo a ética não humana e a prática profissional da saúde, numa perspetiva multi e transdisciplinar* [12]. Desta forma, a prática clínica baseada nos princípios da bioética é essencial na área dos cuidados paliativos.

São vários os imperativos éticos em cuidados paliativos: o compromisso de não abandono do doente e família, o tratamento intensivo dos sintomas, a evicção de tratamentos desproporcionais ou fúteis e inúteis e iniciar sedação paliativa quando estamos perante sintomas refratários e o doente assim o consinta. Assim, é eticamente inaceitável não tratar intensivamente qualquer sintoma que provoque sofrimento a um doente em cuidados paliativos, uma vez que representa uma ameaça à sua qualidade de vida [13].

Neste artigo, os autores pretendem promover uma reflexão ética sobre o controlo sintomático e as suas implicações nos doentes e família, com base nos princípios da bioética.

Material e métodos

Com este trabalho, os autores pretendem apresentar um artigo de reflexão crítica/revisão narrativa sobre os desafios éticos do controlo sintomático em Cuidados Paliativos.

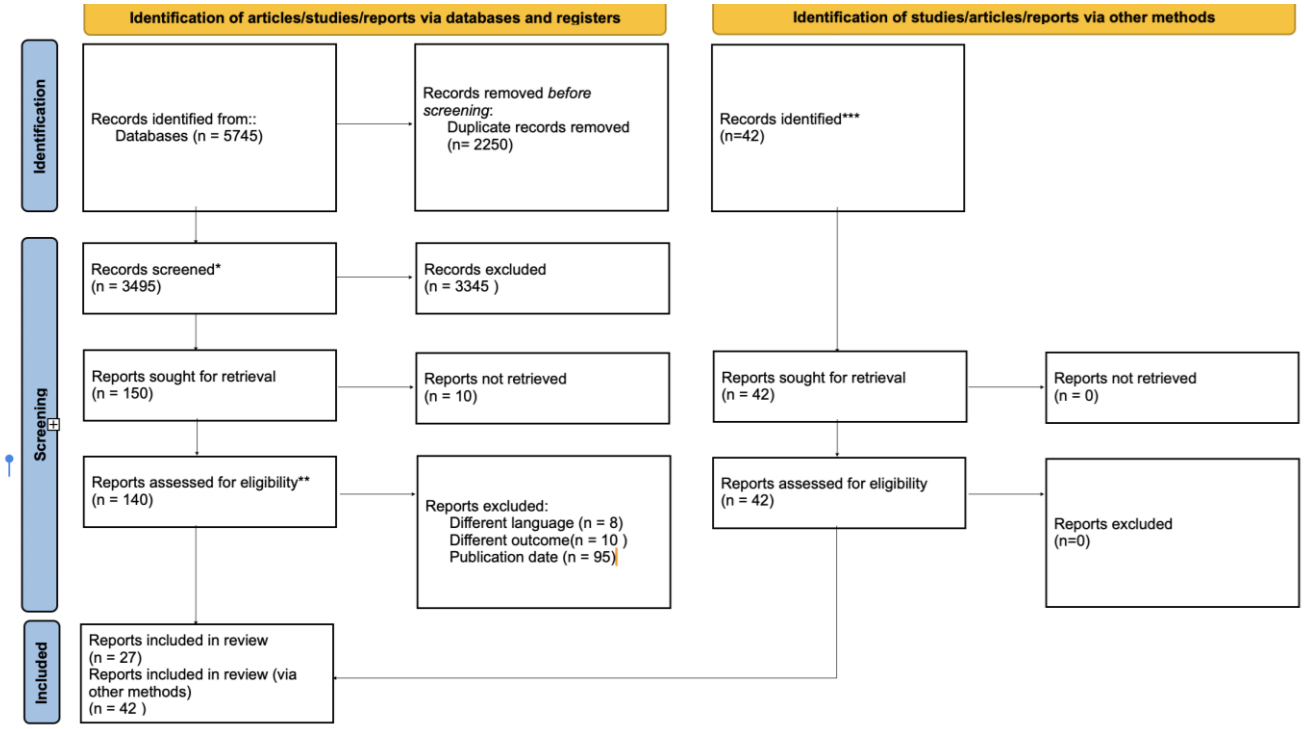
Os autores realizaram uma pesquisa bibliográfica nas bases de dados PUBMED, CINAHL e Web of Science, complementada por alguns artigos, livros e websites sobre o tema que consideraram pertinentes e igualmente encontrados na literatura. A pesquisa baseou-se nos seguintes termos MESH: “Palliative Care”, “ Palliative Medicine”, “Bioethics”, “Symptom Assessment”, “Symptom Burden”.

Foram definidos os seguintes critérios de inclusão: artigos que abordem questões/desafios/dilemas/princípios éticos do controlo sintomático em cuidados paliativos (em qualquer contexto); apenas foram considerados artigos em português, inglês e espanhol, com um limite temporal de 10 anos (ou seja, publicações de 2015 a 2025). Como critérios de exclusão, consideraram-se publicações que abordem a população com idade < 18 anos. No entanto, os autores decidiram incluir alguns artigos essenciais sobre esta temática, excepcionalmente, independentemente da data de publicação.

Após a conclusão da pesquisa e eliminação dos duplicados, os autores fizeram a revisão dos artigos, inicialmente com base no título e abstract, e posteriormente após leitura integral. Assim, os artigos foram seleccionados de forma a desenvolver cada tópico dos resultados/discussão.

Na Figura 1, os autores apresentam o fluxograma de seleção de artigos para revisão narrativa/reflexão crítica, com base na metodologia PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis).

Figura 1: Fluxograma de seleção de artigos para a revisão narrativa/reflexão crítica com base na



metodologia PRISMA

* Records screened at title and abstract; ** Full-text articles assessed for eligibility; *** Artigos seleccionados pelos autores (e considerados essenciais para o desenvolvimento do tema)

Adaptado de: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, Shamseer L, Tetzlaff JM, Akl EA, Brennan SE, Chou R, Glanville J, Grimshaw JM, Hróbjartsson A, Lalu MM, Li T, Loder EW, Mayo-Wilson E, McDonald S, McGuinness LA, Stewart LA, Thomas J, Tricco AC, Welch VA, Whiting P, Moher D. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ. 2021 Mar 29;372:n71. doi: 10.1136/bmj.n71

Resultados e discussão

O avanço do conhecimento científico nas últimas décadas levou ao aumento exponencial da longevidade e consequentemente, da prevalência das doenças crónicas [4].

Desta forma, os cuidados paliativos com a sua abordagem holística do doente e família, procurando atender às várias necessidades, afirmam-se como essenciais nos sistemas de saúde [4].

Embora os cuidados paliativos representem uma área clínica diferenciada, exigindo formação e competências próprias para uma correta abordagem dos doentes e suas famílias, as ações paliativas básicas devem ser do domínio de qualquer profissional de saúde [14]. Os cuidados paliativos não se limitam aos doentes em fim de vida, devendo ser iniciados em simultâneo com os cuidados curativos e sempre que se identifique uma doença crónica e progressiva ou qualquer outra condição ameaçadora de vida. De salientar também que não são incompatíveis com o prolongamento da sobrevida, desde que este não se traduza em aumento do sofrimento [14].

Os serviços de cuidados paliativos, através da gestão sintomática adequada, comunicação eficaz sobre os desejos dos doentes em relação aos cuidados de fim de vida, reforço do apoio emocional às famílias, nomeadamente no luto e atenção às necessidades ao longo do continuum de cuidados desde o domicílio até ao hospital, desempenham um papel significativo na prática clínica baseada em princípios éticos. No entanto, as questões de futilidade, o uso apropriado da sedação paliativa, o papel da hidratação e nutrição artificiais em fim de vida e a tomada de decisões adequadas em doentes vulneráveis continuam a ser áreas de potencial conflito, com implicações práticas e morais [15,16].

Para o desenvolvimento destes cuidados, deve-se procurar proporcionar compaixão, respeito e dignidade, bem como, oferecer cuidado, tratamento, apoio e atendimento coordenados e personalizados. Desta forma, incorporar todos estes princípios é essencial para a prestação de cuidados de elevada qualidade [15,17].

Desta forma, os profissionais de saúde frequentemente enfrentam situações eticamente difíceis no decorrer do seu trabalho, e essas questões abrangem uma ampla gama de áreas, como é o caso dos cuidados paliativos[18,19,20]. Como tal, é necessário promover discussões e deliberações de casos clínicos com questões éticas complexas, bem como, reforçar a importância da consulta às comissões de ética para apoiar as decisões tomadas pelos profissionais[18,19,20].

Partindo deste tema, os autores vão desenvolver uma reflexão ética sobre o controlo sintomático em cuidados paliativos, utilizando os vários princípios da bioética: beneficência, não maleficência, autonomia, duplo efeito, dignidade, justiça e vulnerabilidade[15].

Princípios éticos a considerar no controlo sintomático em Cuidados Paliativos

Princípios da beneficência, não maleficência e duplo efeito

O princípio da beneficência refere-se à obrigação de agir em benefício da pessoa, sendo apoiado por uma série de regras morais para proteger e defender o direito do outro, prevenindo e eliminando condições que possam causar danos. Este princípio exige não apenas evitar danos, mas também beneficiar os doentes e promover o seu bem-estar, o que está em concordância com os objetivos dos cuidados paliativos [21,22].

Por outro lado, o princípio da não maleficência refere-se à obrigatoriedade moral de não provocar dano à pessoa[21,23,24]. Este princípio diz respeito a uma máxima básica da boa assistência médica *Primum non nocere* [24]. A aplicação prática deste princípio consiste em o profissional de saúde pesar os benefícios e os riscos de todas as intervenções e tratamentos, evitando aqueles que são inadequados e escolhendo o melhor curso de ação para o doente. Isto é particularmente importante e pertinente nos cuidados de fim de vida, em que o profissional é confrontado com decisões de suspensão ou início de tratamentos, com vista ao controlo sintomático [24].

O princípio de duplo efeito consiste na ponderação entre os efeitos negativos e positivos causados por uma ação, privilegiando os efeitos negativos, o que em situações específicas pode ser legítimo. Este princípio pressupõe que haja uma boa intencionalidade de quem o aplica [23].

Desta forma, os princípios da beneficência, não maleficência e duplo efeito estão interligados entre si [21,23].

Para a gestão adequada dos sintomas dos doentes em cuidados paliativos, a equipa responsável deve socorrer-se destes princípios para justificar as suas ações.

A dor é um dos sintomas mais frequentes em doentes paliativos, particularmente no contexto da oncologia e um dos que mais dilemas condiciona[25]. A dor pode deixar o doente com medo, retraído e agitado, sendo que o controlo inadequado da dor pode condicionar um enorme sofrimento ao doente, mas igualmente à sua família[25].

Assim, a analgesia representa um imperativo ético[25]. O doente tem direito a que a sua dor seja aliviada e o médico tem o dever deontológico de saber fazê-lo. Assim, não devemos permitir que alguém sofra de dor por falta de conhecimentos e competências na avaliação da dor, medicação inadequada, indisponibilidade de morfina e mitos infundados sobre a dependência de opióides e sedação[25].

Na maioria dos países, o alívio da dor é reconhecido como direito ético e legal e a disponibilidade de morfina constitui uma responsabilidade social. Por razões éticas, o correto seria encarar a dor como uma crise de saúde pública. No entanto, a sociedade parece ainda temer que medicamentos como os opióides e sedativos prescritos na fase terminal, acelerem o processo de morte. Desta forma, é ético prescrever este tipo de medicamentos para controlo da dor refratária, mesmo com a possibilidade de sedação. Esta prescrição assenta nos princípios éticos da autonomia (obtido o consentimento informado), da beneficência e do duplo efeito, devendo a equipa responsável explicar este aspecto aos familiares[25].

Em suma, a responsabilidade da equipa de cuidados paliativos é defender a melhor abordagem no controlo sintomático, com vista à prestação do melhor cuidado possível ao doente. Idealmente, esta prestação de cuidados deve ter em conta os desejos e vontade do doente, atendendo aos seus valores, ideais e cultura[24,26].

Princípio da justiça

Os aspectos jurídicos e os direitos humanos proporcionam as proteções fundamentais que permitem a participação igualitária e a justiça individual numa sociedade[15]. No século XX, o direito aos cuidados de saúde está bem estabelecido, abrangendo não só a prestação de serviços clínicos básicos, mas também um ambiente que permite o florescimento de cuidados especializados, com os cuidados paliativos[15]. O princípio da justiça é geralmente interpretado como um tratamento justo, equitativo e apropriado das pessoas. No entanto, das diversas categorias de justiça, a que é mais pertinente para a ética clínica é a justiça distributiva[24].

A justiça distributiva procura conceder equidade de distribuição de recursos, para igualar as oportunidades de acesso a todos aqueles que têm as mesmas necessidades e se encontram nas mesmas circunstâncias [22,27].

Desta forma, o princípio da justiça visa garantir uma distribuição justa dos recursos de saúde e exige imparcialidade na prestação de cuidados[15]. Os recursos médicos são frequentemente limitados e devem ser distribuídos de forma equitativa[15]. Por isso, existe a necessidade de avaliar a alocação da terapêutica médica para evitar o uso desnecessário de recursos limitados[15]. Por isso, os profissionais de saúde têm a obrigação ética de defender um tratamento apropriado e justo aos doentes, em todas as fases da sua vida e doença[15,28].

Em Portugal, o acesso aos cuidados paliativos é considerado um direito universal, estando regulado na *Lei de Bases da Saúde* aprovada em 2012 [29]. De acordo com esta lei, os cuidados paliativos *devem respeitar a autonomia, a vontade, a individualidade, a dignidade da pessoa e a inviolabilidade da vida humana* [29].

De forma a divulgar e promover os cuidados paliativos nos sistemas de saúde, a European Association for Palliative Care (EAPC) recomenda dois níveis de cuidados: abordagem paliativa/cuidados generalistas e cuidados paliativos especializados[30,31]. A abordagem paliativa deverá estar presente em todo o serviço de cuidados, sendo consagrada como um direito básico de acesso a cuidados mínimos[30,31]. Por outro lado, os cuidados especializados devem ser prestados por equipas multidisciplinares, com competências específicas e avançadas, com vista a otimização dos cuidados prestados, sobretudo em situações de maior complexidade[30,31].

Deste modo, a Comissão Nacional de Cuidados Paliativos, em Portugal, procura desenvolver estratégias para disponibilizar cuidados paliativos de forma universal no Serviço Nacional de Saúde, dado tratar-se de um direito inerente à condição humana e à justiça social[31].

Em suma, todas as pessoas têm direito ao acesso a cuidados paliativos de qualidade e que lhe permitam apoio e dignidade no fim de vida[28].

Princípio da autonomia

O princípio da autonomia refere-se ao direito da pessoa à sua autodeterminação. Desta forma, a pessoa tem o direito de decidir sobre si, de forma livre, racional e consciente[27]. Todas as pessoas têm o direito de decidir que tipo de cuidados devem receber e ver as suas decisões respeitadas[27].

O respeito a este princípio obriga o profissional de saúde a partilhar informações médicas e opções de tratamento necessárias para que o doente exerça a autodeterminação e apoia o consentimento informado, a verdade e a confidencialidade [24,32,33,34,35].

Para além disso, este princípio enfatiza a proteção dos médicos ao direito dos seus doentes à autodeterminação, mesmo para aqueles que perderam a capacidade de tomada de decisões [15,32]. Esta proteção pode ser alcançada com recurso às diretivas antecipadas de vontade[15,32,36].

As diretivas antecipadas de vontade correspondem a instruções orais e/ou escritas sobre os cuidados médicos futuros de um doente, caso ele ou ela se torne incapaz de comunicar e perca a capacidade de tomar decisões por qualquer motivo[22]. Normalmente, as diretivas antecipadas de vontade escritas incluem um "testamento" (em Portugal, designado de testamento vital) e nomeação de procuradores de cuidados de saúde[22]. O testamento vital é um documento escrito, no qual uma pessoa competente, fornece instruções sobre preferências de cuidados de saúde e intervenções médicas a realizar num contexto de fim de vida[22]. Por outro lado, o procurador de cuidados de saúde corresponde a uma pessoa nomeada pelo doente para tomar decisões em seu nome, quando o doente perder a capacidade para tal[15,22]. Desta forma, o procurador de cuidados é considerado o representante legal do doente numa situação de doença grave, sendo a sua responsabilidade, decidir o que o doente deseja[22].

Assim, os sintomas e os cuidados centrados no doente devem ter em conta este princípio[37]. No entanto, é preciso não esquecer que se deve realizar uma avaliação prévia e cuidadosa dos sintomas, nomeadamente do estado mental do doente, uma vez que, os doentes em fim de vida apresentam frequentemente grande dificuldade em responder a perguntas, mesmo as mais simples ou apresentar quadros de confusão ou *delirium,* que dificultam a identificação e a avaliação precisas dos sintomas[38]. Nestes casos, o doente não se encontra competente para exercer em pleno o seu direito à autonomia, pelo que, a equipa deve basear-se nas diretivas antecipadas de vontade escritas ou relatadas por familiares ou amigos próximos, que expressem o que o doente quereria para si no contexto em causa[38]. Na ausência destas premissas, existe risco de incorrer em terapêuticas inadequadas e desajustadas à situação clínica e à vontade do doente[38]. Desta forma, os familiares/cuidadores podem ser uma fonte de informação muito útil na identificação, avaliação e tratamento sintomático dos seus entes queridos[38,39].

Princípios da dignidade e vulnerabilidade

O conceito de dignidade é vasto, com várias definições disponíveis, dependentes do contexto sociocultural [40,41].

Embora a dignidade seja aceite como uma necessidade universal que é fundamental para o bem-estar de cada indivíduo em todas as sociedades, o verdadeiro significado permanece complexo e pouco claro, porque é um conceito multidimensional. Os conceitos de respeito, autonomia, empoderamento e comunicação foram identificados na literatura como os principais atributos definidores de dignidade. Por sua vez, cada um destes atributos é multidimensional, contribuindo para a natureza ambígua e complexa deste conceito[42].

Segundo Chochinov, a dignidade é composta por três elementos: fatores físicos e psicológicos (relacionados com a doença/fragilidade), fatores espirituais (perceção individual) e fatores sociais (contexto envolvente)[40,41].

Desta forma, um dos objetivos dos cuidados paliativos foca-se na preservação da dignidade no final de vida[42]. A maioria das intervenções nesta fase centra-se predominantemente no controlo sintomático, sendo que é útil considerar as necessidades físicas, emocionais e espirituais dos doentes nesta fase[42]. No que diz respeito às necessidades físicas, a boa gestão dos sintomas físicos oferece oportunidade para trabalhar questões emocionais, psicológicas e espirituais inacabadas, promovendo a sensação de encerramento no final de vida e desta forma, a dignidade do doente e família[42]. Em relação às necessidades emocionais, os profissionais de saúde que prestam cuidados de fim de vida devem saber comunicar, ouvir, transmitir empatia e envolver os doentes e suas famílias na tomada de decisões[42,43]. Além disso, deve ser promovida uma boa comunicação entre o doente e família sobre os seus sentimentos [42,43].

Por fim, as necessidades espirituais também devem ser abordadas, de forma a garantir a dignidade da pessoa[42]. A necessidade de ser reconhecido como pessoa até ao fim da vida, sem perder a identidade e saber a verdade sobre a sua doença são aspetos essenciais e promotores de dignidade[42]. Outras medidas encontradas para promover a dignidade nesta fase incluem a construção do legado, a possibilidade de gestão das finanças, permitir que o doente passe tempo com a sua família, proporcionar escolhas quanto ao local de morte, lembrar a dignidade da família após a morte do ente querido e oferecer apoio emocional[42].

Fatores religiosos e culturais também podem influenciar a forma como se pensa a dignidade nos cuidados de fim de vida[42]. Como a dignidade é um conceito carregado de valores que abrange um amplo espectro de questões físicas, psicossociais, espirituais, familiares e culturais, é necessária uma consciência da diversidade étnica por parte de todos os profissionais de saúde[42]. Em suma, apesar de ser visto como um conceito abstrato, a importância da dignidade do doente nos cuidados paliativos não pode ser negada[42]. Como a dignidade é vivenciada subjetivamente e cada doente é único nas suas necessidades, é importante utilizar uma abordagem aberta para avaliar as necessidades de cada pessoa e procurar atendê-las adequadamente[42,43].

Por isso, não há um conceito definido de "morrer com dignidade". No entanto, para a maioria dos autores e doentes, considera-se que a ausência de sintomas físicos, respeito pelos valores, desejos, crenças do doente e família, bem como o direito à privacidade são alguns dos atributos para este processo[40,41].

A vulnerabilidade deriva do latim *vulnus* que significa ferida, como tal, define-se como a suscetibilidade de ser ferido[44]. A Declaração de Barcelona (1998)[45] e a Declaração Universal sobre Bioética e Direitos Humanos (2005)[46] reconheceram a vulnerabilidade como princípio ético essencial. Todo o ser humano pode ser vulnerável ao longo da sua vida[43].

Os cuidados paliativos sempre incluíram uma perspetiva existencial, de que é vital também cuidar das necessidades existenciais dos doentes e famílias[43,47]. Reconhecer a própria vulnerabilidade como ser humano e que a vida é vulnerável à morte, doença, sofrimento, pode ser reivindicado como uma experiência existencial compartilhada entre doentes, famílias e profissionais da equipa de cuidados paliativos, uma vez que, a finitude e a fragilidade da vida são evidentes nestes cuidados[43,47].

Em relação à pesquisa sobre a vulnerabilidade na ética de cuidados paliativos, vários estudos têm sido desenvolvidos sobre a identificação de grupos vulneráveis, numa perspetiva social [47, 48,49]. Esta pesquisa demonstrou que grupos marginalizados e com vulnerabilidade estrutural, têm acesso desigual aos a estes cuidados[47, 48,49]. Esta realidade exige estratégias e políticas para garantir o direito igual a cuidados paliativos, sendo que, as equipas dedicadas a estes cuidados têm desenvolvido um importante trabalho no sentido de oferecer cuidados inclusivos e um acesso igual e justo a todos os indivíduos, independentemente de pertencerem a grupos de vulnerabilidade social[47, 48,49].

No campo da bioética, a vulnerabilidade tem sido um ponto central de discussão, nomeadamente na ética de investigação. A boa prática médica exige provas de eficácia para resolver os défices de cuidados. Existem oportunidades substanciais para melhorar os cuidados paliativos, que podem passar pela investigação nesta área, nomeadamente no controlo sintomático. No entanto, os profissionais de saúde enfrentam dilemas éticos no desenvolvimento de estudos na área de cuidados paliativos, porque a investigação que envolve doentes em fim de vida cria vários desafios, nomeadamente pela vulnerabilidade desta população, pela dificuldade na aquisição do consentimento informado adequado e pela dificuldade em equilibrar a investigação e as funções clínicas (no seio da equipa de cuidados paliativos)[15,50].

Na prática, a morte de um doente terminal é clinicamente reconhecida como um processo natural. O doente pode experimentar mudanças dinâmicas nos sintomas físicos e psicossociais. Muito progresso foi feito na compreensão e no cuidado da maioria dos sintomas observados em cuidados paliativos, mas ainda é necessário um maior foco de pesquisa em muitas áreas. Idealmente, deveria ser possível equilibrar os princípios éticos em termos de proteção do doente vulnerável contra danos e, ao mesmo tempo, realizar estudos cientificamente concebidos, para melhorar a prestação de cuidados[15,39,50].

Dilemas éticos em situações de fim de vida (controlo sintomático)

Uso compassivo de terapêuticas dirigidas

Apesar dos múltiplos tratamentos disponíveis, principalmente na área da oncologia, os doentes em situação terminal podem esgotar as suas opções terapêuticas sem resultados satisfatórios [51,52]. Nesses casos, os medicamentos experimentais podem representar uma oportunidade de tratamento, podendo ser acedidos através de ensaios clínicos (medicamentos experimentais em fase II ou III) [51,52]. O acesso a medicamentos não aprovados por doentes em situação terminal parece gozar de apoio público considerável [51,52]. O acesso a este tipo de medicamentos tem sido designado na literatura como uso compassivo de medicamentos [51,52].

O esforço terapêutico no controlo dos sintomas deve ser incansável [51,52]. Esta premissa pode justificar o uso compassivo de fármacos experimentais pelo efeito benéfico que podem ter no alívio do sofrimento[51,52]. Kasper Raus identificou os três princípios da bioética que justificam o uso de drogas compassivas: a beneficência, a autonomia e a justiça[52].

Em relação à beneficência, o uso compassivo de fármacos experimentais é atualmente limitado pelo dano potencial aos doentes, ausência de monitorização rigorosa e pelo risco de exploração financeira e de pesquisa[52]. Desta forma, é essencial garantir uma avaliação cuidadosa dos riscos e benefícios deste tipo de terapêutica, de forma a evitar que o seu uso, condicione um agravamento do estado clínico do doente e da sua qualidade de vida[52]. Embora o uso compassivo possa ser eticamente justificado, devem ser feitos esforços para garantir uma distribuição equitativa, maximizar os benefícios para os doentes, minimizar os riscos e garantir um consentimento informado em plena consciência[52].

Sedação paliativa

Ao longo do processo de doença e principalmente nos últimos dias de vida, podem surgir sintomas que não são susceptíveis de controlo, apesar da terapêutica adequada, podendo interferir no processo de uma morte tranquila[53]. Desta forma, constitui um imperativo médico e moral aliviar o sofrimento, sendo que, pode ser necessário usar fármacos sedativos titulados para o controlo destes sintomas[53].

Segundo a EAPC (2009), a sedação paliativa é uma medida terapêutica de último recurso para tratamento de sintomas refratários, que consiste no uso monitorizado de medicação sedativa com o intuito de induzir um estado de diminuição da consciência com o objetivo de aliviar o sofrimento, de outro modo intratável, e de forma eticamente aceitável pelo doente, família e profissionais de saúde[54]. Por outro lado, a Sociedade Espanhola de Cuidados Paliativos (SECPAL) define sedação paliativa como a administração deliberada de fármacos, com dose e em combinações adequadas, para reduzir o grau de consciência de um doente com doença avançada e terminal, tanto quanto seja necessário para aliviar de forma adequada, um ou mais sintomas refratários com o seu consentimento explícito, implícito ou delegado[55].

Desta forma, a sedação paliativa tem como objetivo controlar sintomas causadores de grave desconforto, refratários ao tratamento paliativo convencional, aliviando o sofrimento de doentes em fase final de doença grave, progressiva e incurável, bem como, melhorar o conforto e manter a dignidade da vida humana até o seu final [54,56].

Em relação às indicações para sedação paliativa, a maioria das linhas diretrizes e especialistas define os seguintes critérios: doença terminal (esperança de vida inferior a 6 meses); morte iminente (horas ou dias, máximo 2 semanas); sofrimento intolerável; sintomas refratários; envolvimento de especialista em cuidados paliativos ou equipa interdisciplinar; obtenção de consentimento informado pelo doente ou seu representante legal; esta decisão deve estar de acordo com a vontade do doente, família ou representante legal e em consenso com a equipa médica [57,58,59].

Apesar da vasta discussão sobre este assunto na literatura, muitas questões continuam sem ter resposta devido à falta de definições e orientações[60]. Nesse sentido, surge frequentemente alguma confusão entre o conceito de sedação terminal, sedação paliativa e eutanásia/suicídio medicamente assistido[54,57,59,60].

O termo "sedação terminal" é frequentemente usado como sinónimo de "sedação paliativa", no entanto, o primeiro pode ser interpretado como se a intenção da sedação fosse "terminar" a vida, e não o alívio dos sintomas, como sugere o segundo[54,57].

A sedação paliativa do doente terminal deve ser distinguida da eutanásia/suicídio medicamente assistido. No suicídio medicamente assistido e eutanásia, a morte não é iminente mas sim resultado de uma dose letal de medicação intencional administrada [54,57,60]. Na sedação paliativa, a intenção do médico é apenas aliviar o sofrimento refratário grave, utilizando a sedação como último recurso [54,57,60]. O objetivo não é terminar com a vida do paciente como na eutanásia e no suicídio assistido, mas sim administrar e titular medicamentos até que o paciente fique aliviado [54,57,60]. O médico administra apenas a dose necessária para induzir a sedação adequada e assim obter conforto [54,57,60]. Uma vez alcançado o alívio do doente, doses mais baixas são usadas para manter esse alívio [54,57,60]. Na eutanásia e no suicídio assistido por médico, não se considera a titulação, o cálculo ou a manutenção das doses mínimas necessárias para o conforto, porque o objetivo é a morte [54,57,60]. Na sedação paliativa, a intervenção é proporcional à intensidade dos sintomas e aos objetivos terapêuticos [54,57,60]. Assim, quando corretamente indicada, não constitui uma "estratégia" para se atingir o mesmo objetivo da eutanásia [54,57,60]. No entanto, de acordo com a literatura mais recente, os princípios da intencionalidade, proporcionalidade e duplo efeito são os mais utilizados para distinguir entre a sedação paliativa e a eutanásia/suicídio medicamente assistido[54,57,58,60].

O princípio da proporcionalidade pressupõe que o risco de causar dano está diretamente relacionado com a gravidade da situação clínica do doente e o benefício esperado pela intervenção. Isto é, na sedação paliativa, a gravidade de sedar um doente até à inconsciência, prevalece sobre o sofrimento severo quando as outras intervenções falharam[57,58,59,60]. Por outro lado, o princípio do duplo efeito pressupõe que, desde que a intenção da intervenção seja atingir um resultado benéfico, as consequências nefastas são justificadas[57,58,59,60]. Em suma, a ação em si mesma da sedação paliativa é boa (aliviar o sofrimento), não se pretendendo mal para o doente; isto é, a boa consequência não é obtida através da má (o alívio do sofrimento não implica a morte do doente)[57,58,59,60]. Por fim, existe uma proporcionalidade entre o bem atingido e o mal efetuado, ao abrigo do princípio da dignidade humana, de não prolongar a vida para além do razoável e providenciar cuidados de conforto e qualidade de vida ao doente [57,58,59,60].

De forma a cautelar eventuais conflitos éticos, todas as recomendações internacionais e mesmo a Associação Portuguesa de Bioética recomendam, sempre que possível, a obtenção de consentimento livre e esclarecido junto do doente, pressupondo que o mesmo está no pleno uso das suas capacidades mentais[61]. Desta forma, a sedação paliativa é fundamental para garantir a dignidade do doente na sua fase final de vida, nomeadamente quando existe dificuldade no controlo sintomático e perante sofrimento intolerável[62]. Porque, tal como a Dame Cicely Saunders, a criadora dos Cuidados Paliativos, referiu *o sofrimento humano só é intolerável quando ninguém cuida* [62].

Cuidados em fim de vida

Os cuidados de fim de vida constituem um desafio clínico e ético. Os doentes e familiares podem enfrentar diversas incertezas. Na fase final de vida, com múltiplos sintomas angustiantes, infeção, anorexia-caquexia, fadiga, delírio, colocam-se várias questões controversas como o local de cuidados, uso de antibióticos, realização de transfusões sanguíneas, nutrição parentérica, colocação de sonda nasogástrica, entre outras[13,15]. No fim de vida, a decisão entre implementar medidas que prolonguem a vida ou cuidados de conforto é extremamente difícil, tanto para o médico como para a restante equipa, doente e/ou família [13,63].

A tomada de decisões nesta fase é desafiante, particularmente, em diversos cenários como o de paragem cardiorrespiratória, necessidade de ventilação mecânica, nutrição e hidratação artificiais, início de sedação paliativa e/ou início/suspensão de tratamentos considerados fúteis e inúteis (ex: hemodiálise)[13,63]. Como tal, a adequação terapêutica representa um imperativo ético em cuidados paliativos[64]. Nos doentes portadores de condições clínicas irreversíveis, o princípio *primum non nocere* obriga a repensar os objetivos de cuidados, de modo a proporcionar um fim de vida digno e compassivo[64]. De modo algum, a limitação do esforço terapêutico deve ser vista como abandono, uma vez que, se trata de proporcionar conforto e alívio de sofrimento[64]. É este contexto ético-clínico que justifica o foco no tratamento de sintomas, estando sempre subjacente os desejos e valores do doente[64]. Os tratamentos devem ser sempre proporcionados à condição clínica presente, à fase da trajetória da doença em que o doente se encontra e tendo sempre como principal objetivo alcançar a melhor qualidade de vida possível[13,64,65,66].

Outro dos assuntos que levanta diversas questões éticas é a nutrição e hidratação artificiais no contexto de fim de vida [67]. A nutrição e a hidratação são consideradas essenciais à sobrevivência humana [67]. Quando a situação clínica do doente se deteriora, pode ocorrer alteração do estado de consciência, perdendo-se o reflexo de deglutição, o que dificulta a manutenção da nutrição e hidratação com segurança [67]. A nutrição e hidratação artificial pode ser administrada por via entérica através de sonda ou através de via parentérica [67].

A abstenção de alimentação e hidratação em doentes em estado vegetativo persistente ou em doentes em cuidados paliativos terminais é um dos maiores desafios nos cuidados em fim de vida, pelo significado que pode representar tanto para o profissional de saúde como para o doente e família [67]. O doente e a família devem ser informados cuidadosamente de que não é por não comer que a morte vai acontecer, mas sim que é o processo de morte que induz a recusa alimentar [67].

Geralmente, doentes terminais que não conseguem comer, recusam nutrição e hidratação artificiais[68,69]. Iniciar estas intervenções contra a vontade do paciente não só viola a sua autonomia, uma vez que estas intervenções também podem causar danos ao prolongar o processo de morrer ou agravar o edema pulmonar, o derrame pleural, as secreções respiratórias, ascite ou anasarca, resultando em dispneia ou dor, gerando riscos que violam o princípio da não maleficência[68,69]. Doentes, familiares e profissionais podem considerar a continuação da hidratação/nutrição como uma intervenção de apoio humana e não onerosa que representa (e pode realmente constituir) um meio de reduzir o sofrimento[68,69]. Muitas vezes, o doente solicitará alívio do sofrimento e não dará orientação quanto à hidratação e nutrição[68,69]. Nestas circunstâncias, os familiares e os prestadores de cuidados de saúde devem trabalhar para chegar a um consenso sobre o que constitui um plano moralmente aceitável, baseado nos melhores interesses do doente[68,69].

Considerações finais

O controlo de sintomas constitui um pilar essencial dos cuidados paliativos. A boa prática em Medicina exige que a avaliação e tratamento dos sintomas em fim de vida, com o objetivo de aliviar o sofrimento, seja feito de modo irrepreensível, representando igualmente um padrão de qualidade dos cuidados prestados. Os cuidados paliativos apresentam-se como cuidados holísticos que procuram olhar para o doente como um todo, sendo que, a avaliação de cada sintoma, procura atender não só à dimensão física, mas também às dimensões psicológica, social e espiritual.

O melhor cuidado ao doente em cuidados paliativos é aquele que é centrado na pessoa e não na doença, evitando o prolongamento artificial da vida a qualquer custo. O doente deve ser reconhecido como protagonista da sua própria vida, respeitando o seu direito à autodeterminação e privacidade. A prática clínica baseada em princípios éticos é fundamental no cotidiano de uma equipa de cuidados paliativos.

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5. Qualidade de Vida

A qualidade de vida (QdV) tem sido, e continua a ser, uma importante área de investigação que envolve vários contextos disciplinares como a medicina, a psicologia, a economia, a sociologia e o ambiente (Estoque *et al.*, 2019).

De acordo com a Organização Mundial de Saúde (OMS), qualidade de vida é definida pela "Perceção que um indivíduo tem sobre a sua posição na vida, no contexto da cultura e sistema de valores nos quais está inserido e em relação aos seus objetivos, expetativas, padrões e preocupações" (World Health Organization, 1997). Trata-se de um conceito subjetivo e multidimensional, que envolve vários domínios como o físico, o psicológico, o nível de autonomia funcional, o contexto social e ambiental.

O conceito de qualidade de vida da Organização Mundial de Saúde foi pela primeira vez desenvolvido em 1990 pelo grupo WHOQOL (World Health Organization Quality of Life) constituído por vários especialistas que se associaram para avaliar e medir de um modo padronizado a qualidade de vida nos diversos campos culturais e de valores.

O conceito de QdV é usado em diferentes situações e contextos, estendendo-se a todos os setores da sociedade (Haraldstad *et al.*, 2019). A QdV não possui uma definição concreta e definida, uma vez que o conceito e significado variam muito de indivíduo para indivíduo. Sendo multidimensional, procura abordar o ser humano de um modo holístico segundo o modelo biopsicossocial (Canavarro & Serra, 2010). As suas dimensões tanto podem ser objetivas (condições de vida, situação laboral, salário auferido) como subjetivas (sensação de bem-estar, relacionamentos amorosos, realização pessoal).

A falta de consenso sobre o que é a qualidade de vida leva a que conceitos como saúde e bem-estar sejam considerados erradamente seus sinónimos (Pereira, Teixeira and Santos, 2012).

Dependendo da área de estudo, o conceito é também, muitas vezes confundido com felicidade, satisfação pessoal (Renwick & Brown, 1996), condições de vida (Buss, 2000), estilo de vida (Nahas, 2003), entre outros.

Os instrumentos de medida da QdV divergem de acordo com o objetivo do estudo em causa. No entanto, identificam-se dois questionários mais comumente utilizados:

- ✓ **WHOQOL-100 e WHOQOL-Bref:** O grupo WHOQOL desenvolveu o questionário WHOQOL-100 (World Health Organization Quality of Life-100) que avalia seis facetas da QdV: física, psicológica, nível de

independência, relações sociais, ambiente e aspectos espirituais, religiosos ou crenças pessoais. Mais tarde, este questionário foi transformado na sua forma reduzida, o WHOQOL-Bref, que consiste num instrumento utilizado à escala mundial para medir a qualidade de vida (The WHOQOL Group, 1998). O WHOQOL-Bref é um questionário subjetivo e multi-dimensional desenhado para avaliar a qualidade de vida de indivíduos saudáveis e não saudáveis. Consiste em 26 questões (2 relacionadas com aspetos gerais da qualidade de vida; 24 relacionadas a aspetos específicos e organizadas em quatro domínios: físico, psicológico, social e relacionado ao ambiente) (Canavarro and Serra, 2010). Para cada domínio, a pontuação varia entre 0 e 100, ou entre 4 e 20, sendo que quanto maior for a pontuação maior é a perceção de melhor qualidade de vida (Canavarro and Serra, 2010; Gonçalves and Gaudêncio, 2023).

- ✓ **Medical Outcomes Study Questionaire 36-Item Short Form Health Survey (SF-36):** Questionário genérico que avalia a qualidade de vida relacionada à saúde. Originalmente concebido por Ware e Sherbourne, consiste em 36 questões divididas em oito dimensões (capacidade funcional, limitação por aspectos físicos, dor, estado geral de saúde, vitalidade, aspetos sociais, aspetos emocionais e saúde mental). A pontuação varia entre 0 (pior qualidade de vida) e 100 (melhor qualidade de vida)

Tem sido dada grande relevância ao tema da qualidade de vida tanto ao nível das ciências sociais como humanas. Apesar disso, o tema ainda apresenta muitas lacunas a nível concetual, sobrepondo-se muitas vezes com questões relacionadas com o estado de saúde. Apesar de o estado de saúde ser muito importante na vida das pessoas e constituindo uma parcela significativa da sua qualidade de vida, esta não se resume a tal. As visões mais holísticas e multidimensionais, com caráter dinâmico e individual em que valorizam caraterísticas como os valores e os interesses de cada um devem ser consideradas.

Finalmente, deve ser realçado que a qualidade de vida é fundamental para se ter uma boa saúde e não o oposto.

5.1. Qualidade de Vida em Cuidados Paliativos

A abordagem da qualidade de vida em cuidados paliativos é essencial, sendo que estes têm como principal missão proporcionar aos seus doentes a melhor qualidade de vida possível.

A "Qualidade de Vida relacionada à saúde" é um conceito que pretende determinar de que modo a saúde afeta o bem-estar físico, social e emocional (Dulaney et al., 2017). Trata-se de um conceito subjetivo, uma vez que diferentes indivíduos com a mesma doença têm diferentes perceções da sua qualidade de vida (Brozek, Guyatt, & Schünemann, 2006).

A avaliação da qualidade de vida nos doentes com cancro é indiscutível, não sendo mais aceitável que o sucesso do tratamento do cancro se baseie apenas nas taxas de resposta aos tratamentos, tempo de sobrevida, intervalo livre de doença ou taxa de mortalidade (Lopes Ferreira & Pinto Barros, 2008).

Cicely Saunders foi pioneira no movimento moderno dos cuidados paliativos, tendo criado o primeiro hospice e o conceito de "dor total" ou sofrimento (Richmond, 2005).

Steinhauser et al. realizaram estudos com cuidadores dos doentes e avaliaram como estes definiam qualidade de vida ou "boa morte". Concluiram que este conceito dependia das experiências únicas de cada indivíduo, incluindo várias dimensões, tais como física, psicossocial e espiritual (Steinhauser et al., 2000).

De acordo com Higgison e Carr, a qualidade de vida em oncologia e cuidados paliativos envolve vários cenários como a identificação e a priorização de problemas, a comunicação eficaz com o doente e família, a prevenção de sintomas, a tomada de decisões partilhadas, a monitorização de possíveis alterações na saúde e a resposta aos tratamentos instituídos (Higginson & Carr, 2001).

Bernard et al. realizaram um estudo que revelou que o significado da vida, com especial destaque para as interações sociais e espiritualidade, tinha um grande impacto na qualidade de vida dos doentes em cuidados paliativos (Bernard et al., 2017).

Este estudo vai de acordo ao que está descrito na literatura mais recente que nos mostra que no fim de vida, os aspetos que mais contribuem para a qualidade de vida são a presença da família, os relacionamentos e a espiritualidade ou religião, delegando para segundo plano os aspetos físicos (Bernard et al., 2017).

Os doentes em fim de vida que acreditem em algum tipo de religião apresentam uma melhor qualidade de vida e menor risco de depressão ou suicídio (Burlacu et al., 2019).

A evidência mostra-nos que a integração precoce dos cuidados paliativos na trajetória das doenças crónicas melhora a qualidade de vida dos doentes, especialmente do ponto de vista psicológico e funcional.

5.2. Instrumentos de medida da Qualidade de Vida em Cuidados Paliativos

Os instrumentos utilizados para medir a qualidade de vida em cuidados paliativos são, na sua maioria, instrumentos multidimensionais (Albers et al., 2010).

Atualmente, existem várias escalas que podem ser usadas para medir a qualidade de vida no fim de vida (Demuro et al., 2024).

Uma meta-análise realizada por Demuro et al. demonstrou que os questionários mais utilizados foram o European Organization for Research and Treatment of Cancer Quality of Life questionnaire (EORTC-QLQ), o Short Form Health Survey 36 (SF-36), o McGill Quality of Life Questionnaire (MQOL), e o European Quality of Life Five Dimensions Questionnaire (EUROQOL EQ-5D) (Demuro et al., 2024).

Conrad et al. descobriram que uma simples questão como "Em que medida se sente satisfeito atualmente com o seu bem-estar físico e emocional?" tinha a mesma validade qua a Functional Assessment of Oncology Therapy – General scales (FACT-G) e a Palliative Outcome Scale (POS) na avaliação da qualidade de vida (Conrad et al., 2017).

Outros estudos utilizaram questionários mais simples como a Edmonton Symptom Assessment Scale (ESAS) e a Palliative Outcome Scale (POS), as quais são amplamente difundidas dado o seu uso comum e facilidade de preenchimento na rotina das equipas de cuidados paliativos.

Um dos objetivos dos cuidados paliativos é proporcionar aos doentes a melhor qualidade de vida possível. No entanto, ainda são escassos os estudos que avaliam a auto-perceção da qualidade de vida nesta fase da doença. A dificuldade que existe na interpretação e colheita de dados obtidos através da utilização destes instrumentos pode ser um dos motivos qua contribui para tal.

Embora muito se fale da importância da medição da qualidade de vida em cuidados paliativos na avaliação dos cuidados prestados aos doentes e suas famílias, a verdade é que este tópico ainda permanece sub-estudado (Kassianos et al., 2018).

A maioria dos estudos não têm como principal objetivo avaliar a qualidade de vida. (Kassianos et al., 2018). Os melhores estudos que avaliaram a qualidade de vida relacionada à saúde nos doentes em fim de vida foram aqueles realizados com doentes seguidos exclusivamente por equipas de cuidados paliativos em comparação com

grupos controlo em que o foco era apenas os tratamentos curativos com clara vantagem para os primeiros (Kassianos et al., 2018).

A propósito da temática Qualidade de Vida em cuidados paliativos, a aluna escreveu o capítulo "*Gonçalves F. Quality of Life. In: Nunes R, Rego F, Rego G, editors. Encyclopedia of Palliative Care. Coimbra: Almedina; 2023.*"

5.3. Quality of life

Gonçalves F. Quality of Life. In: Nunes R, Rego F, Rego G, editors. Encyclopedia of Palliative Care. Coimbra: Almedina; 2023

Quality of Life

FLORBELA GONÇALVES

1. Introduction

The last few years have been marked, in the area of medicine, by an important technical-scientific advance, which, together with the improved socioeconomic conditions, translated into a decrease in mortality from infectious diseases and an increase in the average life expectancy. The increase in average life expectancy and the low birth rate have resulted in an aging population and a higher prevalence of chronic and oncological diseases.

The inversion of the demographic pyramid has not, however, implied a better quality of life or wellbeing. The end-of-life has become medicalised and associated, at times, with intense suffering.

Palliative care seeks to respond to these needs. The World Health Organization's definition of palliative care in 1990 refers to the need to offer the maximum quality of life possible to the individual with advanced, incurable and progressive disease and to his family members in the process of confronting life-threatening diseases, through early identification, prevention and relief of suffering, adequate evaluation and treatment of pain, as well as other physical, psychosocial and spiritual problems.

Also, according to this organisation, quality of life may be defined as an individual's perception of their position in life, in the context of the culture and value systems in which they live, in accordance with their goals, expectations, standards and concerns.

Various aspects are defined, including the systems associated with illness and treatment, physical function, psychological aspects, social aspects, family or work-related aspects and economic aspects.

Measuring outcomes in palliative care, however, requires the assessment of more specific dimensions, such as improved quality of life before death, control of symptoms, family support and satisfaction, as well as patient perceptions of the purpose and meaning of life.

This chapter aims to make a careful review of the quality of life in palliative care.

2. Historical Background and Development

The term palliative has its origin in the Latin word *palliare* which means to welcome, to shelter, to protect. Palliation is, therefore, defined as the relief of suffering of the patient and of those with whom the patient lives affectively. The origin of Palliative Care goes back to the Greek Civilization, to the 4th century BC, in which some of the social activity was called *xenodochium*, i.e., hospitality. During the Roman Empire the term *xenodochium*, was translated into Latin as *hospitium*. During the Middle Ages many hospices were built to accommodate pilgrims, with the aim of feeding them and providing them with medical care. However, hospices were extinguished and only in the second half of the 19th century, in France, namely in Lyon, did the movement to support the terminally ill resurge.

In the 1960s, in London, Cicely Saunders, disturbed by the suffering and scarcity of care provided to patients at the end-of-life, dedicated herself to the study, care and relief of pain in terminally ill patients, with the objective of alerting to the need to offer rigorous, scientific and quality care to an increasingly large group of people with incurable, progressive and advanced diseases. In 1967 she founded the famous "Le Saint Christopher's Hospital" where she maintained the tradition of compassion for end-of-life suffering, but at the same time introduced a realistic philosophy of symptom relief, namely pain.

The Cicely Saunders movement spread to other hospices and hospitals leading to its rapid implementation in the United States, Canada and only later in the rest of Europe.

Quality of life has been a running theme of the last century and has been recognised as an important area in several sciences. The concept first

appeared in 1920 to refer to the consequences of working conditions on the wellbeing of the worker. Nevertheless, it was from the 1960s onwards that it began to have practical applicability. Since then, several definitions have emerged and given the complexity that the variables involved may mean for each person, there is still no universal concept.

The concept of quality of life may be defined in various ways and have different meanings for different people. There is no resoundingly accepted definition, since it is multidimensional and seeks to meet the biopsychosocial nature of human beings from a holistic perspective. Therefore, it involves objective dimensions such as living conditions, professional situation or salary and subjective dimensions such as wellbeing, love and personal fulfilment.

In order to clarify the concept of quality of life, a panel of experts appointed by the World Health Organization and known as the WHOQOL Group, discussed this issue and defined quality of life as "*an individual's perception of their position in life, within the context of cultures and values in which they live and in relation to their goals, expectations, standards and concerns*" (WHOQOL Group). This definition is multidimensional and covers different domains such as health, physical, psychological, social relationships, personal beliefs...

The assessment of the quality of life of patients in palliative care is an important procedure for identifying their overall condition, as well as for evaluating the quality of the services offered. Thus, it became necessary to create measurement tools to assess the quality of life in this specific group of patients.

3. Conceptual Definition and Clarification

3.1. Palliative Care

Palliative care emerged from the need verified by some health professionals to continue to treat oncology patients.

Although the objective at this stage is not the cure of the pathology, much should be done for their wellbeing.

The World Health Organisation (WHO) defines palliative care as a holistic approach that aims to improve the quality of life of patients with problems associated with life-threatening diseases and their families, using

prevention and relief of suffering through early identification, adequate assessment and treatment of the various problems, whether physical, psychological, social or spiritual.

The principles of palliative care are:

- to provide relief from pain and other symptoms;
- to affirm life and see death as a natural process;
- not to aim to hasten or postpone death;
- to integrate psychological and spiritual aspects into patient care;
- to offer a support system to help patients live as actively as possible until death;
- to use a multidisciplinary approach to meet the needs of patients and their families, including bereavement support;
- to improve quality of life.

3.2. Quality of Life in Palliative Care

The use of standardised and validated scales for different cultures is of great use in identifying needs and assessing the care provided to palliative patients.

Given the pertinence of the theme, several measuring instruments have been developed, however we will address here only a few that seem more relevant.

The first instrument to assess cancer patients was a performance scale proposed in 1948 by Karnofsky. Its score ranges from 0 to 100, these extremes representing, respectively, death and the capacity to carry out all normal activities.

Another important scale is the Eastern Cooperative Oncology Group Performance Status Scale (ECOG) in which a single question assesses the functional status of cancer patients.

The QLQ-C30 is a measurement instrument designed by the European Organisation for Research and Treatment of Cancer (EORTC) and is also intended for cancer patients.

The Functional Assessment of Chronic Illness Therapy Measurement System (FACT) is a system intended to assess the quality of life of cancer patients.

The Hospice Quality of Life Index (HQLI) is a questionnaire designed to assess the quality of life of hospice patients and contains 28 questions measuring physical, psychological and social wellbeing.

The McGill Quality of Life Questionnaire (MQOL) is a relevant questionnaire for all stages of the disease trajectory in life-threatening situations and four main dimensions are measured: physical symptoms, psychological symptoms, outlook on life and meaning of existence.

The Edmonton Symptom Assessment System (ESAS) is a questionnaire designed to monitor nine of the most frequent symptoms of cancer patients in terminal care. These symptoms are pain, fatigue, nausea, depression, anxiety, dizziness, lack of appetite, sense of wellbeing, dyspnoea and others.

The Support Team Assessment Schedule (STAS) is an instrument aimed at support teams for cancer patients in palliative care. It has nine key questions (covering pain and other symptom control, patient and family anxiety, patient and family judgment, communication between patient and family, among health professionals and between health professionals and patient or family) and seven questions on planning, practical aids, funding, lost time, spirituality, professional anxiety, and patient counselling.

The Palliative Care Assessment (PACA) is a questionnaire that assesses the effectiveness of a palliative care hospital team. It consists of 12 questions and addresses three dimensions: symptom control (pain, nausea, vomiting, constipation, anorexia, dyspnoea, immobility, insomnia), the insight of patients and families into the diagnosis and prognosis and patient positioning.

The Assessment of Quality of Life at the End of Life (AQEL) is a questionnaire directed to terminally ill cancer patients. It contains 19 questions addressing the physical, psychological, social, existential and medical care domains, in addition to a global dimension.

The Palliative Outcomes Scale (POS) was designed by Irene Higginson of the Department of Palliative Care and Policy at King's College, in London, and is a specific instrument to assess the quality of life of palliative care patients. It is a questionnaire composed of ten questions reflecting the main domains of palliative care and using a time window referring to the three days prior to its application. These questions relate to the physical, social, psychological and spiritual aspects of people's lives and the provision of palliative care.

Therefore, quality of life is difficult to assess, since several variables may affect it; due to its complex nature, there is no way to assign reference values

that say what is an adequate value or not. In palliative care its measurement becomes essential, as quality of life is in itself the main focus of this care.

4. Conclusion

Palliative care as active and global care, centred on the patient, aim to promote the quality of life of the patient and his/her family, therefore, it is increasingly important to measure health outcomes in order to analyse the usefulness of different forms of treatment or different interventions.

5. Keywords

End-of-Life; Palliative Care; Quality of Life; Scales; Terminally Ill.

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6. Impacto do controlo sintomático na qualidade de vida dos doentes em cuidados paliativos

O cancro representa atualmente um problema de saúde pública. A morbilidade e a mortalidade associadas apresentam uma tendência crescente à escala mundial, sendo que em 2021 se previa que em 2024 houvesse 16 milhões de mortes relacionados com o cancro (World Health Organization, 2021).

Os cuidados paliativos em doentes com doenças oncológicas avançadas devem ser iniciados no momento do diagnóstico e continuados ao longo da trajetória da doença, priorizando-se a qualidade de vida e a otimização do controlo sintomático (Bausewein et al., 2015).

Os cuidados paliativos são cuidados holísticos e humanizados que têm como objetivo principal a melhoria da qualidade de vida dos doentes e famílias que enfrentam doenças ameaçadoras de vida (Wantonoro et al., 2022; Bryk et al., 2022). Os doentes que apresentam sintomas de elevada complexidade são aqueles que mais beneficiam de cuidados paliativos especializados. Sabe-se que os doentes com cancro apresentam habitualmente uma pior qualidade de vida em relação à população em geral (Quinten et al., 2015; Gayatri et al., 2020). A literatura mostra-nos que a presença de sintomas descontrolados tem um efeito negativo na perceção de qualidade de vida e na satisfação dos doentes (Tuna et al., 2018; ElMokhallalati et al., 2022). Os componentes essenciais da abordagem dos sintomas são a sua correta identificação, avaliação e tratamento apropriado (Bruera et al., 1991).

Para assegurar uma boa qualidade de vida, é essencial documentar a eficácia das intervenções instituídas com o objetivo de reduzir o sofrimento físico e emocional (Bausewein et al., 2015). Além disso, é também necessário avaliar e monitorizar estas intervenções ao longo do tempo. (Bausewein et al., 2015). Vários instrumentos têm sido desenvolvidos para a avaliar o controlo sintomático (ElMokhallalati et al., 2022).

Alguns questionários multidimensionais são, por vezes, demasiados complexos para doentes debilitados, enquanto outros, tais com as escalas visuais analógicas e numéricas são mais eficazes (ElMokhallalati et al., 2022). Medir a qualidade de vida em doentes com cancro nos vários estadios da sua doença é fundamental (Ferreira, Barros, & Brito, 2008).

No passado, os indicadores do sucesso ou falência terapêutica consistiam nas taxas de resposta, intervalos livres de doença ou taxas de mortalidade (Ferreira, Barros, & Brito, 2008). Em 1996, a American Society of Clinical Oncology (ASCO) adotou guidelines clínicas para os cancros metastáticos, em que foi pela primeira vez referido que os tratamentos que melhorassem a qualidade de vida deveriam ser

recomendados, independentemente da ausência de benefícios em termos de sobrevida (American Society of Clinical Oncology, 1996).

Karnofsky et al. introduziu o primeiro instrumento de avaliação dos níveis de funcionalidade dos doentes com cancro, o Karnofsky Performance Status (KPS) (Karnofsky & Burchenal, 1949). O score desta escala varia entre 0 (morte) e 100 (autonomia total) (Karnofsky & Burchenal, 1949). Posteriormente, em 1982, o Eastern Cooperative Oncology Group (ECOG) desenvolveu uma escala similar conhecida como Performance Status Scale cujo objetivo era igualmente avaliar o nível de funcionalidade (Oken et al., 1982), seguido do Quality of Life Questionnaire (QLQ-C30) do European Organization for Research and Treatment of Cancer (EORTC) (Aaronson et al., 1993). Em 1996, Romayne Gallagher no Canadá concebeu a Palliative Performance Scale (PPS) (Anderson, Downing, Hill, Casorso, & Lerch, 1996), uma adatação do instrumento de medida Karnofsky Performance Status, dirigida aos doentes em cuidados paliativos e em que aspetos como a funcionalidade, o nível de consciência e a capacidade de deglutição são tidos em conta na pontuação da escala.

Medir resultados em cuidados paliativos requer a avaliação de dimensões mais específicas, tais como o controlo sintomático, a melhoria da qualidade de vida antes da morte, o suporte à família e a satisfação e o sentido de vida.

A Escala de Avaliação de Sintomas de Edmonton (Edmonton Symptom Assessment Scale (ESAS)) é um instrumento desenvolvido por Bruera em 1991 numa Unidade de Cuidados Paliativos do Hospital Geral de Edmonton no Canadá (Wong et al., 2021). Esta escala foi desenhada para identificar e medir os sintomas mais comuns em cuidados paliativos, tanto físicos como psicológicos (Wong et al., 2021). Avalia dez sintomas no total: seis relativos à dimensão física (dor, fadiga, náuseas, sonolência, dispneia e apetite), dois relativos à dimensão psicológica (depressão e ansiedade), um que avalia o bem-estar e um sintoma opcional considerado relevante (Wong et al., 2021).

O Global Distress Scale (GDS) é um subtipo da Edmonton Symptom Assessment Scale (ESAS) que avalia a presença e a intensidade dos nove primeiros sintomas identificados na ESAS (Subbiah et al., 2021).

A Palliative Outcome Scale (POS) (na sua versão self) avalia o bem-estar, a qualidade de cuidados e a qualidade de vida dos indivíduos em cuidados paliativos, sendo as suas questões e dimensões adequadas aos doentes oncológicos em fim de vida (Hearn & Higginson, 1999). A Palliative Outcome Scale (POS) foi originalmente concebida para avaliar a qualidade cuidados e o bem-estar psicológico dos doentes em cuidados paliativos (Hearn & Higginson, 1999; Stevens et al., 2005). Dada a sua

natureza multidimensional, também é considerada uma medida de qualidade de vida, uma vez que engloba aspetos físicos, psicológicos, emocionais e espirituais dos doentes e suas famílias. (Ferreira, Barros, & Brito, 2008; Rugno & De Carlo, 2016; Conrad et al., 2017).

A Edmonton Symptom Assessment Scale (ESAS), mais especificamente a Global Distress Scale (GDS), é atualmente mais usada para avaliar a intensidade dos sintomas em cuidados paliativos (Hui & Bruera, 2017), embora possa também ser considerada uma medida de avaliação da qualidade de vida, dado que identifica sintomas físicos e emocionais e inclui um ítem mais geral que é o "bem-estar". Contudo, não avalia as componentes social e spiritual em detalhe. (Hui & Bruera, 2017).

7. Impacto do tempo de referenciação no controlo sintomático e na qualidade de vida em cuidados paliativos

A Organização Mundial de Saúde (OMS) define Cuidados Paliativos (CP) como uma abordagem de cuidados que melhora a qualidade de vida dos doentes e suas famílias que enfrentam doenças ameaçadoras de vida, através da identificação e tratamento precoce da dor e de outros sintomas físicos, psicossociais e espirituais (World Health Organization, 2022).

Em Portugal, o acesso aos cuidados paliativos é considerado um direito básico universal, o qual está bem regulamentado na Lei de Bases dos Cuidados Paliativos aprovada em 2012 (Diário da República, 2012). De acordo com esta Lei, os cuidados paliativos "devem respeitar a autonomia, a doença, a individualidade, a dignidade da pessoa e a inviolabilidade da vida humana" (Diário da República, 2012). Esta foi a lei que definiu a criação das equipas de cuidados paliativos em Portugal, organizadas em unidades de cuidados paliativos, equipas intra-hospitalares de suporte em cuidados paliativos e equipas comunitárias de suporte em cuidados paliativos (Diário da República, 2012).

Wiencek et al. descreveu vários modelos de cuidados paliativos baseado na realidade dos Estados Unidos da América – cuidados paliativos em ambulatório, cuidados paliativos domiciliários, unidades de cuidados paliativos e equipas intra-hospitalares de cuidados paliativos (Wiencek & Coyne, 2014).

Embora haja benefícios individuais tanto na modalidade de internamento como na modalidade de ambulatório, as vantagens relativas de uma em relação à outra ainda não estão bem esclarecidas (Temel et al., 2010; Bakitas et al., 2015; Dionne-Odom et al., 2015; Zimmermann et al., 2014; Grudzen et al., 2016). Os dois tipos de abordagens são caraterizados por diferenças importantes no tipo de cuidados. (Temel et al., 2010; Bakitas et al., 2015; Dionne-Odom et al., 2015; Zimmermann et al., 2014; Grudzen et al., 2016). Um estudo recente mostrou que o modelo de cuidados paliativos em regime de ambulatório reduz as admissões hospitalares, melhora a qualidade de vida e prolonga a sobrevida. (Temel et al., 2010; Bakitas et al., 2015; Dionne-Odom et al., 2015; Zimmermann et al., 2014; Grudzen et al., 2016).

Tradicionalmente, os cuidados paliativos nos doentes com cancro são apenas iniciados quando terminam os tratamentos curativos. (Hui et al., 2012). Contudo, há evidências de que a referenciação precoce destes doentes não apenas melhora a sua qualidade de vida como pode até prolongar a sobrevida simultaneamente (Temel et al., 2010). A referenciação precoce a cuidados paliativos dos doentes diagnosticados

com cancro avançado melhora significativamente a sua qualidade de vida (Pigni et al., 2022).

Embora a definição de referenciação precoce ainda não esteja totalmente esclarecida, alguns estudos randomizados utilizam como critérios de referenciação precoce os seguintes: 2 a 3 meses depois do diagnóstico de doença avançada e Eastern Cooperative Oncology Group (ECOG) inferior ou igual a 2 (Hui, Heung, & Bruera, 2022). Outros autores são da opinião que a definição da referenciação precoce a cuidados paliativos depende do tempo que decorreu até à morte do doente: se a referenciação a cuidados paliativos ocorreu mais de um ano antes da morte é considerada "precoce"; referenciações entre 3 e 12 meses antes da morte são consideradas "intermédias"; referenciações realizadas menos de três meses antes da morte são consideradas "tardias" (Wadhwa et al., 2018).

Os critérios de referenciação são controversos. (Hui et al., 2012). Sintomas severos, baixo nível de funcionalidade, comorbilidades e prognóstico estão entre os critérios mais comuns (Hui et al., 2012). A dificuldade na referenciação precoce dos doentes com cancro a cuidados paliativos está muitas vezes relacionada com a dificuldade em estabelecer um prognóstico correto (Pigni et al., 2022). Estudos realizados mostram que, de fato, os oncologistas admitem dificuldades em estimar a sobrevida de 3, 6 ou 12 meses (Pigni et al., 2022). Outros motivos que levam à referenciação tardia são a escassez de tempo durante as consultas para falar sobre os princípios e filosofia dos cuidados paliativos e falhas na abordagem das necessidades psicológicas, espirituais e sociais. (Hui, Heung, & Bruera, 2022).

A referenciação tardia de doentes a cuidados paliativos tem um impacto negativo no controlo sintomático e na qualidade de vida destes doentes (Hausner et al., 2021). Vários estudos têm mostrado que a introdução precoce dos cuidados paliativos ao longo da trajetória da doença melhora a qualidade de vida dos doentes com cancro avançado se iniciados simultaneamente com os tratamentos oncológicos standard. (Hausner et al., 2021).

Humphreys et al. concluiram que as referenciações tardias a cuidados paliativos podem ter um impacto negativo nos resultados em saúde (Humphreys & Harman, 2014). Assim, é importante implementar políticas hospitalares que encoragem a referenciação precoce a cuidados paliativos, particularmente nos casos de doentes com cancro avançado (Humphreys & Harman, 2014). Os doentes que são referenciados a cuidados paliativos logo na primeira semana após a admissão hospitalar apresentam menos tempo de internamento, e menores taxas de mortalidade intra-hospitalar quando comparados com aqueles que foram referenciados após uma semana (Humphreys & Harman, 2014).

Com já mencionado, um dos objetivos dos cuidados paliativos é promover qualidade de vida aos doentes e suas famílias. Contudo, a perceção de qualidade de vida é muito subjetiva, sendo a definição mais consensual a da OMS que a define como a perceção do indivíduo sobre a sua posição na vida, de acordo com a sua cultura de valores, expetativas e objetivos (World Health Organization, 1990).

Várias escalas são utilizadas para medir a qualidade de vida no contexto de doentes com cancro e em cuidados paliativos, incluindo Eastern Cooperative Oncology Group Performance Status Scale (ECOG) e a QLQ-C30 desenhadas pelo European Organization for Research and Treatment of Cancer (EORTC) (Ferreira & Barros, 2008). Reconhece-se que abordar a qualidade de vida dos doentes oncológicos em cuidados paliativos requer medições cuidadosas e abrangentes e não apenas o alívio da dor e outros sintomas (Ferreira & Barros, 2008). É igualmente importante abordar os aspetos emocional, social, psicológico e spiritual, assim como o suporte e a comunicação compassiva com a família do doente (Ferreira & Barros, 2008). A Palliative Care Outcome Scale (POS) aborda todas estas três dimensões, tendo sido originalmente concebida para doentes oncológicos em cuidados paliativos (Ferreira & Barros, 2008; Hearn & Higginson, 1999).

8. Sofrimento emocional dos doentes com cancro em cuidados paliativos

O cancro e a sua trajetória desde o diagnóstico até à morte estão associados a elevada angústia existencial. De acordo com o National Comprehensive Cancer Network (NCCN), a angústia existencial pode ser definida como "an unpleasant, multifactorial experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with a person's ability to cope effectively with cancer, their physical symptoms and their treatment; extending along a continuum from normal feelings of vulnerability, sadness, and fear of problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis" (Cutillo et al., 2017).

Os doentes com cancro avançado apresentam frequentemente elevados níveis de sofrimento, pelo que é necessário identificar as suas necessidades paliativas e abordá-las eficazmente. Os sintomas que mais afetam a qualidade de vida dos doentes em cuidados paliativos, reduzindo inclusivamente a sua sobrevida, são a dor, a astenia e os sintomas emocionais como a ansiedade e a depressão (Basch et al., 2016; Huertas, Pérez, & Nieves, 2023; Thekkumpurath et al., 2008).

Embora o sofrimento emocional seja muito prevalente nos doentes em cuidados paliativos, estudos nesta área indicam que ainda permanence subdiagnosticado e subtratado (Murillo & Holland, 2004; Kristeller, Zumbrun, & Schilling, 1999). A identificação precoce dos sintomas psico-emocionais nos doentes em cuidados paliativos é crucial para a referenciação atempada para consultas de psiquiatria ou psicologia (Feldstain, 2024; Michel et al., 2023).

Numerosos instrumentos validados têm sido descritos na literatura para medir o sofrimento emocional; contudo, não há consenso sobre qual o que melhor o avalia. Exemplos destes instrumentos são o termómetro emocional (TE) (Roth et al., 1998), a Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) e o Brief Symptom Inventory (BSI) (Derogatis & Melisaratos, 1983), entre outros. Estes instrumentos são utilizados para identificar e medir os principais sintomas associados ao sofrimento, assim como a presença de depressão, ansiedade, angústia existencial, espiritualidade, esperança e desesperança (Kelly, McClement, & Chochinov, 2006).

O termómetro emocional é considerado o instrumento de medida de standard dos sintomas psicológicos; contudo, não se trata de um questionário usado por rotina pelas equipas de cuidados paliativos.

Na prática, a Edmonton Symptom Assessment System (ESAS) e a Palliative Outcome Scale (POS) são os isntrumentos mais utilizados para avaliar sintomas

nestes doentes (Stewart-Knight et al., 2012). A Edmonton Symptom Assessment Scale (ESAS) (Bruera et al., 1991) é uma das escalas mais utilizadas para identificar e avaliar a intensidade dos sintomas mais comuns em cuidados paliativos (Bakitas et al., 2009). Contudo, é sabido que os sintomas psicológicos avaliados pela ESAS, nomeadamente a ansiedade e a depressão, são frequentemente sobre-estimadas pelos doentes, uma vez que esta escala se refere às últimas 24 horas (Hui & Bruera, 2016; Mercadante et al., 2019).

Hearn e Higginson foram pioneiras no desenvolvimento da POS, uma escala inicialmente desenhada para medir resultados em cuidados paliativos (Hearn & Higginson, 1999). Esta escala inclui 10 ítens que avaliam o bem-estar físico, psicológico, social e spiritual dos doentes com doenças avançadas (Hearn & Higginson, 1999). Os ítens 3, 6, 7 e 8 da POS estão correlacionados e devem ser avaliados em conjunto, uma vez que se referem ao bem-estar emocional dos doentes em cuidados paliativos (Siegert et al., 2010). Quando o score destes ítens é elevado, deve ser considerada a possibilidade da presença de patologia depressiva, distúrbios da ansiedade ou sofrimento espiritual (Siegert et al., 2010). Dado o papel relevante de instrumentos como a ESAS e a POS na prática clínica diária em cuidados paliativos, documentar a sua validade é igualmente importante.

CAPÍTULO

3

OBJETIVOS

OBJETIVOS

O **objetivo principal** desta dissertação é avaliar o impato da intensidade dos sintomas na qualidade de vida dos doentes em cuidados paliativos aquando a admissão na Unidade de Cuidados Paliativos (UCP).

Os **objetivos secundários** do estudo são os seguintes:

- Analisar as caraterísticas sociodemográficas e clínicas dos participantes da amostra;
- Analisar a intensidade dos sintomas dos doentes e a perceção de qualidade de vida na admissão à UCP;
- Analisar a intensidade dos sintomas dos doentes e a perceção de qualidade de vida na admissão à UCP de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares);
- Analisar a intensidade dos sintomas dos doentes e a perceção de qualidade de vida à admissão na UCP de acordo com os diferentes tipos de neoplasias;
- Avaliar o tempo de referenciação dos doentes para CP na amostra global e de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares);
- Correlacionar o tempo de referenciação para CP com a intensidade sintomática e qualidade de vida dos doentes de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares);
- Analisar as propriedades psicométricas do Edmonton Symptom Assessment System (ESAS) e da Palliative Outcome Scale (POS).

CAPÍTULO

4

MATERIAL E MÉTODOS

MATERIAL E MÉTODOS

1. Amostra e desenho do estudo

Foi desenvolvido um estudo transversal descritivo e correlacional, realizado numa Unidade de Cuidados Paliativos (UCP) de um hospital oncológico terciário português.

O estudo foi realizado com uma amostra de 60 doentes consecutivamente internados pela primeira vez entre janeiro e março de 2021 na UCP. Estes doentes já eram seguidos previamente pela equipa de cuidados paliativos, fosse em regime de ambulatório, através da consulta externa de cuidados paliativos ou em regime de internamento noutras enfermarias, em que eram acompanhados pela equipa intra-hospitalar de suporte em cuidados paliativos.

Os **critérios de inclusão** foram os seguintes:

- Doentes oncológicos adultos em cuidados paliativos exclusivos (em que os tratamentos curativos já haviam sido suspensos);
- Doentes que deram o seu consentimento voluntário para participar no estudo;
- Doentes que eram capazes de compreender os objetivos do estudo.

Os **critérios de exclusão** foram os seguintes:

- Doentes com idade inferior a 18 anos de idade;
- Doentes que não falavam a língua portuguesa;
- Doentes com dificuldades na comunicação, incapazes de compreender os objetivos do estudo;
- Doentes em estado terminal.

2. Considerações éticas e Consentimento Informado

O estudo respeitou as regras da Declaração de Helsínquia (World Medical Association, 2013) e da Convenção de Oviedo (Harmon, 2006) e decorreu após a aprovação da Comissão Ética da instituição onde o estudo foi realizado (parecer nº. TI 17/2020) (Anexo IV)

Todos os participantes receberam dois envelopes fechados. Um envelope continha uma carta de explicação da natureza e objetivos do estudo e o termo de consentimento informado livre e esclarecido para assinatura e o segundo envelope continha os instrumentos de medida (Anexo V e VI). Após a obtenção da autorização através do consentimento informado, os dados foram recolhidos, utilizando um protocolo especificamente concebido para o efeito. A confidencialidade dos dados foi garantida através da recolha separada dos envelopes selados, tendo sido atribuído um código numérico ordenado para registo na base de dados criada para o efeito.

Os participantes não estiveram diretos ou indiretamente envolvidos na conceção, implementação, elaboração de relatórios ou divulgação do estudo.

3. Colheita de dados

O protocolo desenhado foi aplicado nas primeiras 24 horas após a admissão na Unidade de Cuidados Paliativos e incluiu as seguintes ferramentas:

1. Um questionário sociodemográfico (idade, género, escolaridade, estado civil, número de filhos, local de residência, presença ou não de cuidadores) e clínico (serviço de origem prévio à admição na UCP, tipo de cancro, estadio ao diagnóstico e funcionalidade – avaliada através do Eastern Cooperative Oncology Group (ECOG);
2. A Escala de Avaliação de Sintomas de Edmonton (ESAS);
3. A Palliative Outcome Scale (POS).

3.1. Instrumentos de recolha de dados

3.1.1. Questionário sociodemográfico e clínico (Anexo VII)

A aluna desenvolveu um questionário socio-demográfico e clínico que incluiu variáveis como a idade, o género, as habilitações literárias, o estado civil, o número de filhos, o local de residência, a presença ou não de cuidadores, o tipo de neoplasia, o estadio ao diagnóstico e o ECOG.

3.1.2. Eastern Cooperative Oncology Group (ECOG)

A escala ECOG é usada para avaliar o nível de funcionalidade dos doentes, cujos scores variam entre 0 (completamente ativo) a 4 (incapaz de realizar qualquer atividade da vida diária.) (Gehan & Freireich, 1974).

3.1.3. Edmonton Symptom Assessment Scale (ESAS)

A Edmonton Symptom Assessment Scale (ESAS) foi desenvolvida por Bruera em 1991 com o objetivo de identificar e medir a gravidade dos sintomas mais comuns nos doentes com cancro.

Trata-se de um instrumento de medida que pode ser autorreferido e que inclui avaliações visuais e numéricas (Bruera et al., 1991; Donlan et al., 2024). É uma ferramenta fácil de utilizar tanto por doentes como por profissionais de saúde, demorando cerca de 1 a 2 minutos a ser concluída mesmo nos casos em que a literacia em saúde é baixa e encontra-se traduzida e validada em mais de 20 línguas (Wong et al., 2020). É uma escala de uso mundial tanto para fins clínicos como de de investigação, o mesmo acontecendo no nosso país (Wong et al., 2020). Em Portugal, esta escala foi traduzida e adaptada para português em 2016 (Barbosa et al., 2016). É amplamente utilizada como ferramenta de uso clínico no nosso país assim como na investigação. Neste último caso, há vários exemplos de estudos em que foi utilizada como nos seguintes casos: a tese de mestrado intitulada "Controlo de sintomas em cuidados paliativos num serviço de medicina interna" (Santos, 2012) e o estudo "Associação da Intensidade de Dor no Tempo Até à Morte dos Doentes Oncológicos Referenciados aos Cuidados Paliativos" publicado na Acta Médica Portuguesa (Figueiredo and Almeida, 2015).

A ESAS consiste numa escala numérica que avalia de 0 (ausência de sintoma) a 10 (pior intensidade possível) os dez sintomas mais comuns dos doentes com cancro, seis relacionados com a dimensão física (dor, fadiga, náuseas, sonolência, dispneia e apetite), dois que abordam a dimensão psicológica (depressão e

ansiedade), um que avalia o bem-estar geral e um sintoma opcional considerado relevante. Permite assim medir o sofrimento associado tanto aos sintomas físicos como aos sintomas psicológicos nas últimas 24 horas (Wong et al., 2020).

Neste estudo, utilizou-se uma subescala da ESAS, o Global Distress Score (GDS), que consiste na soma dos primeiros nove sintomas físicos e psicológicos (Hui et al., 2012). O GDS apresenta três níveis de intensidade consoante o score obtido: alto (GDS ≥ 35), moderado (16 ≥ GDS > 34) e baixo (GDS < 15) (Subbiah et al., 2021).

A escala de avaliação de sintomas (ESAS) é uma ferramenta pragmática, centrada na avaliação de sintomas do doente, fácil de administrar e interpretar (Hui & Bruera, 2017). Permite identificar diferenças mínimas, mas clinicamente importantes e avaliação de sintomas por clusteres.

3.1.4. Palliative Outcome Scale (POS) (Anexo VIII)

A Palliative Outcome Scale (POS), desenvolvida por Irene Higginson no Departmento de Cuidados Paliativos do King's College em Londres, é uma escala multidimensional que contém um questionário de 10 itens (Albers et al., 2009). Permite medir sintomas físicos, psicológicos, emocionais e espirituais dos doentes, assim como necessidades de suporte e de apoio tanto dos doentes como dos familiares.

Trata-se de uma escala validada, utilizada na clínica, em processos de auditoria e investigação.

Esta escala foi concebida para dar resposta a doentes em cuidados paliativos devido a doenças crónicas como o cancro, as insuficiências crónicas de órgãos (insuficiência cardíaca, renal, hepática) ou demências.

Trata-se de uma escala amplamente utilizada à escala mundial, incluindo a Europa, a Austrália, a Ásia, áfrica e Estados Unidos da América.

A pontuação varia entre 0 e 4 e avalia vários aspetos como a dor e outros sintomas físicos, a ansiedade do doente e da família, o bem-estar emocional, a qualidade de informação fornecida e o suporte social nos três dias prévios (Albers et al., 2009).

Fácil de utilizar, demora cerca de 10 minutos a ser preenchida, dando informações importantes sobre o bem-estar, qualidade de cuidados e qualidade de vida dos doentes que se encontram em cuidados paliativos.

A POS possui duas versões: a versão self para o doente e a versão proxy para os profissionais de saúde. Neste estudo, utilizou-se a versão self, por se acreditar que a resposta do doente é sempre mais fidedigna na informação fornecida (Albers et al., 2009).

4. Análise estatística

O Microsoft® Excel 2016 foi utilizado para criar a base de dados e o SPSS versão 25® foi utilizado para realizar a análise estatística.

As variáveis da amostra foram caraterizadas segundo o método estatístico mais adequado. As frequências absolutas e relativas (N e %) foram utilizadas para descrever as variáveis categóricas e qualitativas enquanto a mediana, mínimo, máximos e quartis foram usadas para descrever as variáveis contínuas.

As correlações entre as variáveis qualitiativas foram realizadas através do coeficiente de Spearman, sendo considerado valores < 0,05 estatisticamente significativos (nível de significância de 95%). As variáveis quantitativas e qualitativas foram comparadas através do teste de Mann-Whitney.

O teste de Kruskal-Wallis foi utilizado para avaliar possíveis associações entre as caraterísticas sociodemográficas (género, escolaridade, estado civil, número de filhos, cuidadores e local de residência) ou associadas à doença (tipo de neoplasia, ECOG) com o score das ESAS e da POS.

O coeficiente de Spearman foi aplicado para avaliar as correlações entre os scores da ECOG e da POS.

CAPÍTULO

5

RESULTADOS

RESULTADOS

Os doentes em cuidados paliativos são frequentemente referenciados tardiamente, o que eleva a carga sintomática com franco prejuízo da sua qualidade de vida.

Nesse contexto, foram publicados três artigos originais, em que se procurou responder aos objetivos da tese propostos.

Um dos artigos visa o impato do controlo sintomático na qualidade de vida dos doentes oncológicos em cuidados paliativos na sua qualidade de vida: "Gonçalves F, Gaudêncio M, Paiva I, Semedo VA, Rego F, Nunes R. Impact of Symptom Distress on the Quality of Life of Oncology Palliative Care Patients: A Portuguese Cross-Sectional Study. Healthcare (Basel). 2024 Dec 9;12(23):2487. doi: 10.3390/healthcare12232487. PMID: 39685109; PMCID: PMC11641344."

O segundo artigo aborda o tempo de referenciação a cuidados paliativos e o tempo que decorreu entre o diagnóstico e a avaliação pela equipa de cuidados paliativos/ admissão na UCP de acordo com o tipo de abordagem (ambulatório VS internamento) e o seu impato no controlo sintomático e na qualidade de vida nos doentes com cancro em cuidados paliativos: "Gonçalves F, Gaudêncio M, Paiva ICS, Rego F, Nunes R. Intensity of Symptoms and Perception of Quality of Life on Admission to Palliative Care: Reality of a Portuguese Team. Healthcare (Basel). 2024 Aug 1;12(15):1529. doi: 10.3390/healthcare12151529. PMID: 39120232; PMCID: PMC11312417."

O terceiro artigo aborda o sofrimento emocional dos doentes em cuidados paliativos comparando as propriedades psicométricas da ESAS e da POS: "Gonçalves F, Gaudêncio M, Paiva I, Rego F, Nunes R. Evaluation of Emotional Distress in Oncology Palliative Patients: Edmonton Symptom Assessment System (ESAS) and Palliative Outcome Scale (POS)-A Portuguese Cross-Sectional Study. Cancers (Basel). 2024 Dec 19 ;16(24) :4232. doi: 10.3390/cancers16244232. PMID : 39766131 ; PMCID : PMC11674550."

1. IMPACT OF SYMPTOM DISTRESS ON THE QUALITY OF LIFE OF ONCOLOGY PALLIATIVE CARE PATIENTS

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Impact of Symptom Distress on the Quality of Life of Oncology Palliative Care Patients: A Portuguese Cross-Sectional Study

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Abstract: Introduction: Uncontrolled symptoms are widely recognized as one of the main challenges in oncology palliative care patients. The central aim of palliative care is to improve the patient's quality of life. In recent years, there has been a growing use of patient-reported outcome measures in palliative care, particularly to evaluate symptoms, quality of care, and well-being. Aim: To evaluate the sociodemographic and clinical profile, symptom distress, and perceived quality of life in oncology palliative care patients admitted to a specialized palliative care unit in Portugal. Methods: This study was cross-sectional, descriptive, and correlational, carried out in the inpatient setting of the palliative care unit at a tertiary oncology hospital (at admission). The evaluated protocol included a sociodemographic and clinical questionnaire, as well as two measurement instruments: the Edmonton Symptom Assessment Scale (ESAS) and the Palliative Care Outcome Scale (POS), both filled out by the patients. Data analysis was conducted using IBM SPSS® Statistics version 25.0, with a significance level set at 5% ($p < 0.05$). Results: The majority of participants in this sample were male (61.7%), with a mean age of around 72 years. More than half of the patients admitted (n = 34; 56.7%) were being monitored in outpatient care. Digestive and head and neck cancers were the most commonly found in the sample (41.7% and 20%, respectively). A significant correlation was found between high symptom intensity and poorer quality of life and care ($p < 0.01$). This association was particularly pronounced for symptoms such as pain, weakness, depression, anxiety, and anorexia. Conclusions: This study revealed a positive correlation between overall symptom severity and a perceived deterioration in quality of life, well-being, and quality of care. Future studies should consider utilizing alternative assessment tools for evaluating symptoms and quality of care. Additionally, including non-cancer palliative patients in similar studies may provide further valuable insights.

Keywords: hospice; palliative care; palliative medicine; patient care; quality of healthcare; quality of life; symptom assessment

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Citation: Gonçalves, F.; Gaudêncio, M.; Paiva, I.; Semedo, V.A.; Rego, F.; Nunes, R. Impact of Symptom Distress on the Quality of Life of Oncology Palliative Care Patients: A Portuguese Cross-Sectional Study. *Healthcare* **2024**, *12*, 2487. https://doi.org/10.3390/healthcare12232487

Academic Editor: Paolo Cotogni

Received: 25 October 2024
Revised: 24 November 2024
Accepted: 5 December 2024
Published: 9 December 2024

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1. Introduction

Cancer represents a significant global public health issue. Both cancer morbidity and mortality are on the rise worldwide, with an estimated 16 million global cancer-related deaths projected by 2024 [1].

Palliative care for cancer patients should be initiated at the onset of the disease and continue through to the bereavement period, prioritizing quality of life and achieving optimal symptomatic control [2,3].

Palliative care is a holistic and humanized approach that aims to improve the quality of life for patients and families facing life-threatening illnesses [4,5]. Patients with highly

complex symptoms are the ones who benefit most from specialized palliative care. It is well established that cancer patients generally experience a lower quality of life compared to the general population [6,7].

The literature demonstrates that the presence of uncontrolled symptoms has a detrimental effect on the quality of life and overall satisfaction of these patients [8,9]. Therefore, the essential components of symptom management are accurate identification, thorough evaluation, and appropriate treatment [10]. To ensure a good quality of life, it is essential to document the effectiveness of interventions carried out to reduce physical and psychological suffering [2]. Furthermore, it is also necessary to evaluate and monitor these interventions over time [2].

Several assessment and measurement instruments have been developed to evaluate symptom distress [9]. Some multidimensional questionnaires are overly complex for debilitated patients, while others, such as the visual analog scale and numerical rating scale, are simple and highly effective [9].

According to the World Health Organization (WHO), quality of life is defined as "an individual's perception of their position in life, within the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" [11].

Measuring the quality of life of cancer patients at various stages of their illness is considered a fundamental clinical practice [12]. In the past, indicators of the success or failure of therapeutic interventions were largely confined to response rates, disease-free survival intervals, or mortality rates [12].

In 1996, the American Society of Clinical Oncology (ASCO) adopted clinical guidelines for metastatic cancers, stating that treatment may be recommended based on its potential to improve quality of life, even in the absence of survival benefits [13].

Higginson and Carr proposed that quality of life measures serve several clinical purposes, including identifying problems, enhancing communication skills, screening for hidden issues, facilitating shared decision-making, and monitoring health changes or treatment effects [14].

In 1949, Karnofsky et al. introduced the first instrument to assess functional levels in cancer patients [15]. This performance scale ranged from 0 (indicating death) to 100 (indicating complete autonomy) [15]. Subsequently, in 1982, the Eastern Cooperative Oncology Group (ECOG) developed a similar scale known as the Performance Status Scale to assess functional levels [16], along with the Quality of Life Questionnaire (QLQ-C30) from the European Organization for Research and Treatment of Cancer (EORTC) [17].

Measuring outcomes in palliative care requires the assessment of more specific dimensions, such as symptom control, improvement of quality of life before death, family support, and the satisfaction and meaning of life.

The Edmonton Symptom Assessment Scale (ESAS) is a multidimensional instrument developed by Bruera in 1991 at the palliative care unit of Edmonton General Hospital in Canada [18]. This tool is designed to track and measure the most common symptoms experienced in palliative care, both physical and psychological [18]. It evaluates ten symptoms in total: six related to the physical dimension (pain, fatigue, nausea, drowsiness, dyspnea, and appetite), two addressing the psychological dimension (depression and anxiety), one assessing overall well-being, and an optional symptom [18].

In this investigation, the Global Distress Scale (GDS) was used. This scale is a subtype of the Edmonton Symptom Assessment Scale (ESAS), designed to assess the presence and intensity of the first nine symptoms identified in the ESAS [19].

Additionally, the authors employed the Palliative Outcome Scale (POS) (patient self-report) to evaluate the well-being and quality of life of these individuals, as its questions and dimensions are well-suited for a population composed of cancer patients in palliative care [15].

The Palliative Outcome Scale (POS) was originally developed to assess the quality of care and well-being in palliative care patients [20,21]. Due to its multidimensional nature,

it also serves as a measure of quality of life in palliative care, encompassing physical, psychological, emotional, and spiritual aspects of patients [12,22,23].

The authors recognize that the Edmonton Symptom Assessment Scale (ESAS), specifically the Global Distress Scale (GDS), is now commonly used to assess symptom intensity in patients undergoing palliative care [24]. The ESAS can be considered an instrument for evaluating quality of life, as it identifies physical and emotional symptoms and includes a nonspecific general item that assesses "well-being." However, it does not assess the social and spiritual dimensions of quality of life in detail [24].

Although the Palliative Outcome Scale (POS) was originally designed as a tool to measure the quality of care and psychological well-being, several studies have utilized it to evaluate the quality of life of patients and their families in palliative care. This is due to the fact that its questions facilitate the assessment of physical, psychological, social, and spiritual dimensions [12,22,23].

So, with this study, the authors intend to analyze the sociodemographic and clinical profile of oncology palliative care patients admitted to a specialized palliative care unit in Portugal. Additionally, the study will evaluate symptom intensity and the perception of quality of life at admission, utilizing the Edmonton Symptom Assessment Scale (ESAS) and the Palliative Outcome Scale (POS) as measurement instruments.

2. Material and Methods

2.1. Sample and Design

This was a cross-sectional, descriptive, and correlational study conducted in the palliative care unit of a Portuguese oncology hospital. The study included a sample of 60 consecutive patients admitted to the unit for the first time.

The inclusion criteria were adult cancer patients undergoing palliative/supportive treatment at the hospital (who have suspended chemotherapy and radiotherapy), admitted to the palliative care ward between January and March 2021, who provided informed consent to participate and were able to comprehend the study's objectives.

The authors excluded all patients under 18 years of age, as well as those who did not speak Portuguese, had communication difficulties, were terminally ill, or were unable to comprehend the study and/or provide written consent.

2.2. Ethical Approval, Informed Consent and Data Collection

The procedures followed were in accordance with the regulations of the Helsinki Protocol [25] and the Oviedo Convention [26] and obtained approval from the institution's Ethics Committee (Opinion No. TI 17/2020).

All participants were provided with two sealed envelopes. One envelope contained a letter explaining the research and the informed consent form for them to sign, while the second envelope contained the measurement instruments.

Data confidentiality was guaranteed through the separate collection of sealed envelopes, having been assigned an alphanumeric code ordered by registration in the database created for this purpose. The data collection period took place between January and March 2021.

2.3. Social and Clinical Demographic Assessment and Measuring Instruments

The sociodemographic and clinical questionnaire, along with the measurement instruments, was provided to participants within the first 24 h of their admission to the palliative care ward and was completed by the participants themselves.

The sociodemographic and clinical questionnaire included variables such as age, sex, place of origin, type of neoplasm, and Eastern Cooperative Oncology Group performance status (ECOG). The ECOG scale (Boston, USA) assesses the functional status of patients, with scores ranging from 0 (fully active) to 4 (completely unable to perform self-care activities) [16].

Two measurement instruments were used to assess the patients in this study: the Edmonton Symptom Assessment Scale (ESAS), translated into Portuguese, aimed at iden-

tifying and rating the severity of the most common symptoms in palliative care, and the Palliative Care Outcome Scale (POS), also in its Portuguese version, which measures quality of life and well-being.

The Edmonton Symptom Assessment Scale (ESAS) evaluates ten symptoms in total: six related to the physical dimension (pain, fatigue, nausea, drowsiness, dyspnea, and appetite), two addressing the psychological dimension (depression and anxiety), one assessing overall well-being, and an optional symptom [18]. The ESAS allows patients to self-report the severity of their symptoms in their daily routine. It is a numerical scale ranging from 0 (absence of the symptom) to 10 (maximum possible intensity) [27].

The authors chose to use the Global Distress Scale (GDS), which consists of the first nine symptoms from the ESAS. Studies indicate that the GDS is correlated with patient survival rates [19]. The GDS was categorized into three levels: high (GDS $\geq$ 35), moderate (16–34), and low (0–15) [19].

The Palliative Outcome Scale (POS) consists of 11 questions scored on a Likert scale from 0 to 4, with both numerical and descriptive labels [21,28]. It is considered a valuable tool for assessing quality of life, as it addresses not only practical and psychosocial needs but also takes into account the patient–family dynamic as a whole [12,22,23]. The total POS score is calculated from the first 10 questions, ranging from 0 to 40 points, with higher scores indicating poorer quality of life and care [29].

2.4. Statistical Analysis

SPSS version 25 (IBM; Chicago; USA) was employed for statistical analysis.

Each variable was characterized using the most appropriate statistical tests. Absolute and relative frequencies (N and %) were used to describe categorical and qualitative variables, while means, minimum, maximum, and quartiles were used for continuous variables.

The authors performed Kruskal–Wallis tests to assess possible associations between demographic (gender, education level, marital status, number of children, companion and residence) or disease-related characteristics (type of neoplasm, ECOG) with ESAS and POS total score.

Spearman's coefficient was applied to assess correlations between variables (ECOG and POS score).

A p-value of <0.05 was considered statistically significant for all comparisons.

3. Results

3.1. Sociodemographic Characteristics and Disease-Related Data of the Sample

During the 3-month study period, 60 patients were included for analysis. None of the patients declined participation and no other participants were excluded.

In the study sample, the prevalence of men was higher than that of women (n = 37; 61.7% vs. n = 23; 38.3%). The average age of participants was approximately 72 years. Most patients were married and had one or two children. Eighty-three percent were living at home. Most patients were accompanied by their family members (spouse and/or children). Most patients had elementary education (81.7%). Epidemiological and social characteristics are further detailed in Table 1.

Table 1. Sociodemographic characteristics of the sample (n = 60).

Variables		Sample
Gender, n (%)	Male	37 (61.7)
	Female	23 (38.3)
Age (years)	Median [Q1; Q3]	72 [58, 25; 79]
	Minimum	43
	Maximum	94

Table 1. *Cont.*

Variables		Sample
Education level, n (%)	Elementary school	49 (81.7)
	High school	5 (8.3)
	Graduation	4 (6.7)
	Absent	2 (3.3)
Marital status, n (%)	Married	49
	Single	9 (15)
	Divorced	4 (6.6)
	Widow	16 (26.7)
Number of children, n (%)	0	13 (21.7)
	1	21 (35)
	2	18 (30)
	≥3	8 (13.3)
Residence, n (%)	Home	50 (83.3)
	Nursing home	10 (16.7)
Companions, n (%)	Spouse	30 (50)
	Son/daughter	7 (11.7)
	Siblings	1 (1.6)
	Father/mather/parents	3 (5)
	Without companion	12 (20)
	Other caregivers (eg nursing home)	7 (11.7)

Q1—first quartile; Q3—third quartile.

More than half of the patients (n = 34; 56.7%) were referred from the external palliative care consultation, while the remaining patients (n = 26; 43.3%) were transferred from other services within the institution where they had been hospitalized. Regarding the type of neoplasm, the most frequently observed were digestive cancers, followed by head and neck cancers (41.7% and 20%, respectively) (Table 2).

Table 2. Disease-related data and POS and ESAS scores of the sample (n = 60).

Variables		Sample
Origin service prior to admission, n (%)	Ambulatory/outpatient	34 (56.7)
	Hospitalization	26 (43.3)
Type of neoplasm, n (%)	Head and neck	12 (20)
	Cutaneous	3 (5)
	Digestive	25 (41.7)
	Gynecological	5 (8.3)
	Hematologic	1 (1.7)
	Breast	6 (10)
	Prostate	2 (3.3)
	Lung	6 (10)

Table 2. *Cont.*

Variables		Sample
POS Score *	Median [Q1; Q3]	15 [13; 19]
	Minimum	7
	Maximum	25
ESAS Score (GDS) *	Median [Q1; Q3]	42.5 [34.25; 48]
	Minimum	15
	Maximum	62
ECOG performance status at admission	0	4 (6.6%)
	1	6 (10%)
	2	10 (16.6%)
	3	25 (41.6%)
	4	15 (25%)

Q1—first quartile; Q3—third quartile; * Total score was obtained by adding the items.

Approximately one-third of the cases had an ECOG performance status of 3 or 4 upon admission (Table 2).

On the Global Distress Scale (GDS), the median score was 42.5, with a minimum of 15 and a maximum of 62 (Table 2).

3.2. Edmonton Symptom Assessment Scale Results

Most patients reported experiencing no pain upon admission (n = 22; 36.7%) or indicated severe pain, scoring greater than 7 on a scale from 0 to 10 (n = 19; 31.7%) (Table 3 and Figure 1).

Table 3. Frequencies of the patients' answers to the ESAS (N (%)).

	ESAS										
	0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Pain	22 (36.7)	1 (1.7)	0 (0)	1 (1.7)	4 (6.7)	6 (10)	7 (11.7)	14 (23.3)	4 (6.7)	1 (1.7)	0 (0)
Fatigue	2 (3.3)	0 (0)	1 (1.7)	2 (3.3)	2 (3.3)	16 (26.7)	6 (10)	18 (30)	12 (20)	1 (1.7)	0 (0)
Nausea *	34 (57.6)	0 (0)	0 (0)	4 (6.8)	2 (3.4)	6 (10.2)	6 (10.2)	6 (10.2)	1 (1.7)	0 (0)	0 (0)
Depression	3 (5)	0 (0)	1 (1.7)	6 (10)	8 (13.3)	12 (20)	19 (31.7)	7 (11.7)	3 (5)	1 (1.7)	0 (0)
Anxiety *	1 (1.7)	0 (0)	0 (0)	6 (10.2)	3 (5.1)	14 (23.7)	19 (32.2)	10 (16.9)	5 (8.5)	1 (1.7)	0 (0)
Drowsiness **	8 (14)	1 (1.8)	4 (7)	5 (8.8)	0 (0)	24 (42.1)	7 (12.3)	1 (1.8)	5 (8.8)	2 (3.5)	0 (0)
Appetite	2 (3.3)	1 (1.7)	1 (1.7)	3 (5)	5 (8.3)	16 (26.7)	7 (11.7)	11 (18.3)	9 (15)	5 (8.3)	0 (0)
Dyspnea	27 (45)	0 (0)	2 (3.3)	5 (8.3)	2 (3.3)	10 (16.7)	3 (5)	6 (10)	2 (3.3)	3 (5)	0 (0)
Well-being	8 (13.3)	0 (0)	0 (0)	1 (1.7)	0 (0)	8 (13.3)	20 (33.3)	15 (25)	7 (11.7)	1 (1.7)	0 (0)

* 1 missing; ** 3 missing.

The majority of patients reported feelings of fatigue (n = 31; 51.7%), with scores exceeding 7 out of 10 (Table 3 and Figure 2). Only a few patients did not report fatigue (n = 2; 3.3%). More than half of the patients denied experiencing nausea (n = 34; 57.6%), with a mean nausea score of 2.30 (± 1.84).

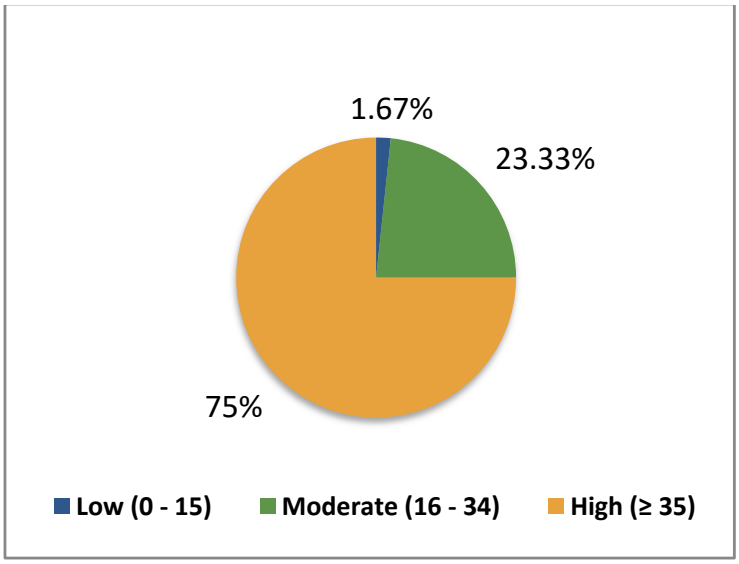


Figure 1. The Global Distress Scale cohorts based on the total sum of the answers to ESAS (%).

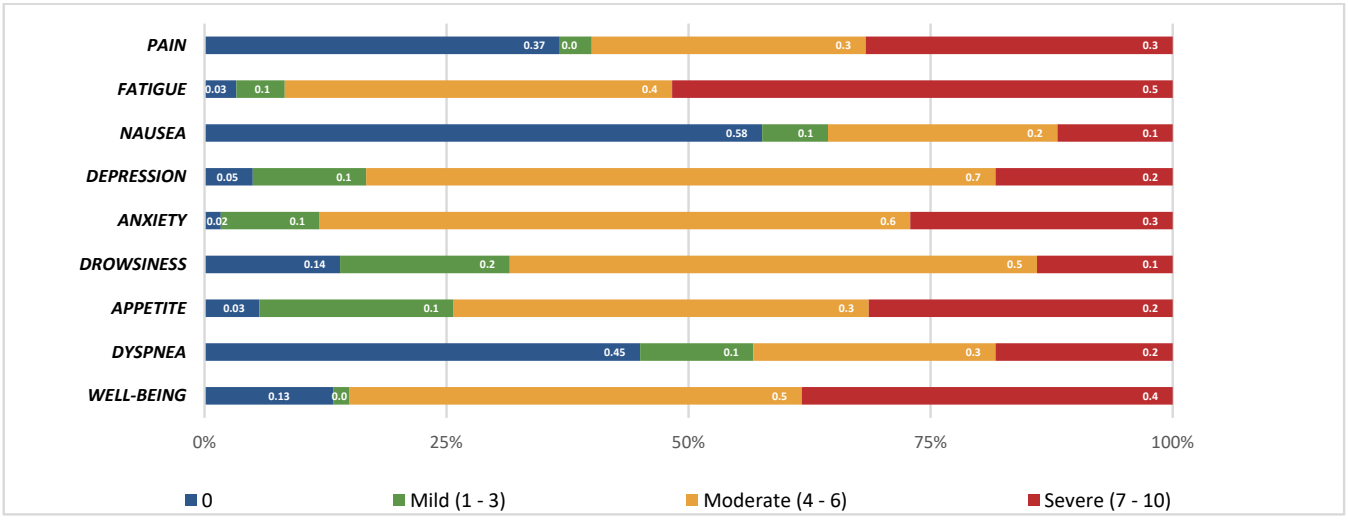


Figure 2. Frequencies of the patients' answers to the ESAS (%) according to severity.

Depression was absent in a minority of patients (n = 3; 5%), while some patients reported a score of 6 out of 10 for depression (n = 19; 31.7%) (Table 3).

Drowsiness was absent in a small number of patients (n = 8; 14%). Conversely, the majority of patients reported a score higher than 5 out of 10 for drowsiness (n = 39; 68.4%) (Table 3).

Loss of appetite was prevalent in most of the sample (n = 58; 96.6%), with some patients reporting a score of 5 out of 10 (n = 16; 26.7%) (Table 3).

A significant number of patients (n = 27; 45%) denied experiencing dyspnea upon admission, while a few patients reported a score of 5 out of 10 (n = 10; 16.7%) (Table 3).

Regarding overall well-being, some patients (n = 8; 13.35%) scored 0 on well-being (no well-being) and others (n = 20; 33.3%) reported 6/10, with a mean of 5.55 (+/−2.37), indicating a moderate presence of well-being in this sample.

3.3. Palliative Outcome Scale (POS) Results

The scores from the Palliative Outcome Scale (POS) are presented in Tables 4 and 5, where the main topic of each question is identified.

Table 4. Frequencies of the patients' answers to the first 10 questions of the POS (N (%)).

	POS				
Items/Score	**0**	**1**	**2**	**3**	**4**
1. Have you been affected by PAIN?	20 (33.3)	4 (6.7)	11 (18.3)	23 (38.3)	2 (3.3)
2. Have OTHER SYMPTOMS (nausea, cough, constipation) seemed to be affecting how you feel?	8 (13.3)	2 (3.3)	19 (31.7)	29 (48.3)	2 (3.3)
3. Have you been feeling ANXIETY ABOUT DISEASE or treatment?	1 (1.7)	6 (10)	13 (21.7)	36 (60)	4 (6.7)
4. Have any of your FAMILY been ANXIOUS about you? *	0 (0)	2 (3.4)	12 (20.3)	43 (72.9)	2 (3.4)
5. How much INFORMATION have you and your family been given? *	9 (15.3)	20 (33.9)	27 (45.8)	1 (1.7)	2 (3.4)
6. Have you been able to SHARE how you are feeling? *	5 (8.5)	29 (49.2)	21 (35.6)	4 (6.8)	0 (0)
7. Have you felt that life was worthwhile (MEANING OF LIFE)?	7 (11.7)	38 (63.3)	13 (21.7)	2 (3.3)	0 (0)
8. Have you felt good about yourself as a person (SELF-FEELINGS)?	7 (11.7)	35 (58.3)	16 (26.7)	2 (3.3)	0 (0)
9. How much TIME do you feel has been wasted on appointments relating to your healthcare (LOST TIME)?	50 (83.3)	-	9 (15)	-	1 (1.7)
10. Have any PRACTICAL matters resulting from your disease, either financial or personal, been addressed?	41 (68.3)	-	11 (18.3)	-	8 (13.3)

* 1 missing. Question 1, 2: 0—no; 1—slightly; 2—moderately; 3—severely; 4—overwhelmingly. Question 3, 4: 0—no; 1—Occasionally; 2—Sometimes; 3—Most of the time; 4—always. Question 5: 0—Full information or as much as wanted; 1: Information given but hard to understand; 2—Information given on request but would have liked more; 3—Very little given and some questions were avoided; 4—None at all. Question 6, 7, 8: 0—always; 1—Most of the time; 2—Sometimes; 3—Occasionally; 4—never. Question 9: 0—None at all; 2—Up to half a day wasted; 4—More than half a day wasted. Question 10: 0—I have had no practical problems; 2—Practical problems are in the process of being addressed; 4—Practical problems exist which were not addressed.

Table 5. Frequencies of the patients' answers to the last question of the POS, which does not enter in the final score (N (%)).

	Alone (0)	**With Help of Family or Friend (1)**	**With Help of Palliative Care Staff (2)**
How did you complete this questionnaire?	49 (81.7)	6 (10)	5 (8.3)

In this study, the question "If so, what were your main problems in the last 3 days?" was not included in the analysis.

It was found that some patients felt that pain had a minimal impact on their daily lives (n = 20; 33.3%). However, the majority of patients (n = 25; 41.6%) reported that pain significantly impacted their daily activities.

For other symptoms, such as nausea, coughing, or constipation, there was a predominance of moderate (n = 19; 31.7%) and severe (n = 29; 48.3%) impacts.

Most patients reported feeling anxious and worried about disease progress and treatment. Specifically, some patients (n = 13; 21.7%) responded with "Sometimes—it affects my concentration now and then," while others (n = 36; 60%) indicated "Most of the time—it often affects my concentration."

Regarding the worry and anxiety of family members or friends, no patients selected the response "No, not at all." Most patients perceived that their families were anxious and worried about them (n = 43; 72.9%).

Only a few patients reported having complete information or as much information as they desired (n = 9; 15.3%). Conversely, some patients (n = 20; 33.9%) acknowledged

having access to information but faced difficulties in understanding it. The majority of patients expressed a desire for more information (n = 27; 45.8%), while a minority of the sample population indicated that they had no information about their disease (n = 3; 5.1%).

Additionally, it was found that most patients believed they were able to share their feelings most of the time or sometimes (n = 50; 84.8%).

Most patients felt that their lives were worthwhile, with 38 patients (63.3%) responding "Most of the time" and 13 patients (21.7%) indicating "Sometimes." No patients reported that their lives were not worthwhile. Additionally, the majority of patients felt good about themselves as individuals (n = 51; 85%), and no patients expressed negative feelings about themselves. When asked about wasted time, most patients responded with "None at all" (n = 50; 83.3%). A minority of patients reported "Up to half a day wasted" (n = 9; 15%) and "More than half a day wasted" (n = 1; 1.7%). Regarding whether any practical matters resulting from their illness, either financial or personal, had been addressed, most patients (n = 41; 68.3%) stated, "Practical problems have been addressed, and my affairs are as up to date as I would wish." Some patients (n = 11; 18.3%) reported that "Practical problems are in the process of being addressed," while others (n = 8; 13.3%) indicated "I have had no practical problems."

As shown in Table 5, the majority of patients (n = 49; 81.7%) completed this questionnaire independently. A few patients received assistance from family members or friends (n = 6; 10%) and from palliative care staff (n = 5; 8.3%).

3.4. ESAS and POS Measures According to the Sociodemographic Characteristics, Type of Cancer and ECOG

In Table 6, the authors present a univariate analysis for the total POS and ESAS score with clinical and social factors.

Table 6. Univariate analysis for the total POS and ESAS overall score.

Variable	ESAS-GDS Total Score *		POS Total Score *	
	Effect (chi)	*p Value*	*Effect (chi)*	*p Value*
Gender	4.849	0.089	2.396	0.302
Marital status	4.541	0.474	2.462	0.782
Education level	6.369	0.383	7.600	0.269
Number of children	6.510	0.164	10.420	0.034 **
Companion	2.626	0.757	3.815	0.576
Residence	0.819	0.845	3.885	0.274
Types of neoplasm	7.262	0.402	5.493	0.6
ECOG	7.602	0.107	1.827	0.768

ESAS—Edmonton Symptom Assessment Scale; ECOG—Eastern Cooperative Oncology Group. * Analyses performed with Kruskal–Wallis; ** $p < 0.05$.

There was no clinical or social factor associated with total ESAS and POS score, except the number of children, which was significantly related with POS score.

The total scores of the ESAS-GDS and POS according to the type of cancer are present in Figure 3.

Patients with head and neck tumors exhibited a median Palliative Outcome Scale (POS) score of 17 [13; 19] and a median Edmonton Symptom Assessment System—Global Distress Scale (ESAS-GDS) score of 43.5 [34.25; 48]. In contrast, patients with digestive cancer reported a median ESAS score of 39 [34.25; 48] and a median POS score of 15 [13; 19].

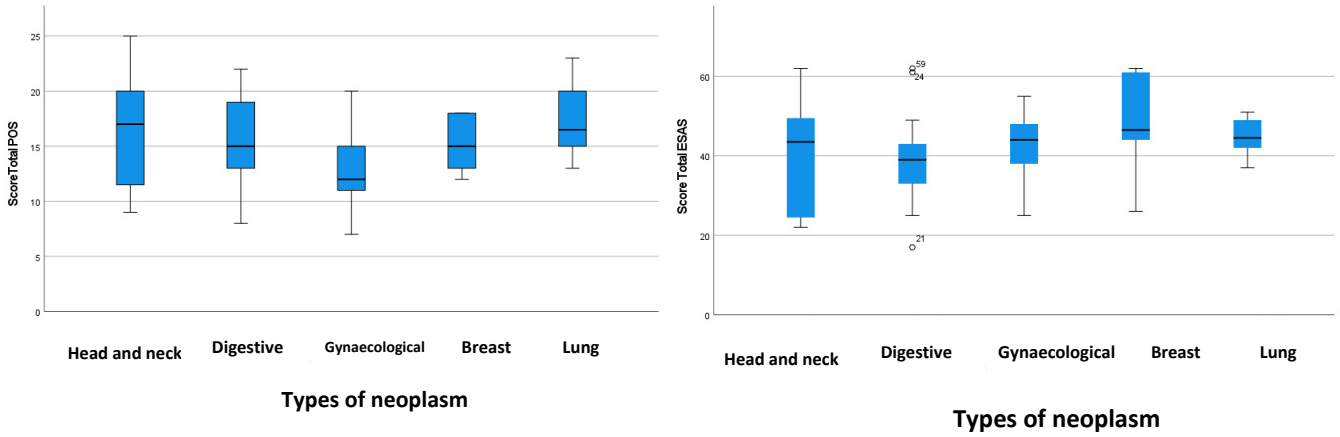


Figure 3. Distribution of ESAS-GDS and POS total score according to the types of neoplasm.

Patients with breast and gynecological tumors demonstrated very similar results regarding median Edmonton Symptom Assessment System—Global Distress Scale (ESAS-GDS) and Palliative Outcome Scale (POS) scores. In breast cancer patients, the median POS score was 15 [13; 18.75], while the median ESAS score was 46.5 [34.25; 48]. For patients with gynecological tumors, the median POS score was 12 [12.5; 19] and the median ESAS score was 44 [36; 48.5].

Patients with lung cancer presented a median POS score of 16.5 [13; 19] and median ESAS score of 44.5 [35.5; 48].

The total scores of the ESAS-GDS and POS according to the ECOG status are present in Figure 4.

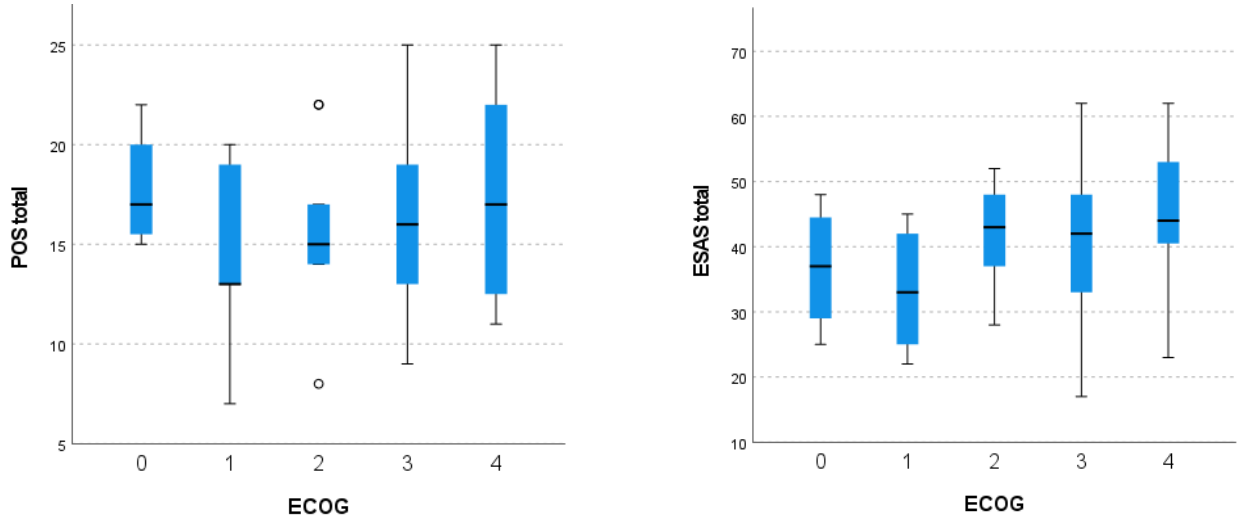


Figure 4. Distribution of ESAS-GDS and POS total score according to the ECOG status.

Patients who were fully active (ECOG 0) exhibited a median POS score of 17.75 [15.25; 21] and a median Edmonton Symptom Assessment System–Global Distress Scale (ESAS-GDS) score of 36.75 [27; 46.25].

On the other hand, patients with some restrictions in physically strenuous activities (ECOG 1) reported a median ESAS score of 33.3 [24.25; 42.75] and a median POS score of 14.17 [11.5; 19.25].

Patients that were capable of all self care but unable to carry out work activities (ECOG 2) presented a median ESAS score of 42.10 [36.5; 48.75] and median POS score of 15.70 [14; 18.25].

Furthermore, patients that were only capable of limited self care and were confined to a bed or chair for more than 50% of their waking hours (ECOG 3) demonstrated a median POS score of 16.16 [13; 19] and ESAS score of 40.68 [33; 48]. Patients completely disabled and totally dependent on others (ECOG 4) presented very similar results regarding ESAS (46.53 [39; 55]) and POS score (16.8 [12; 22]).

In Figure 5, the authors demonstrate the analysis between total POS score and the number of children of the patients observed. This analysis is statistically significant.

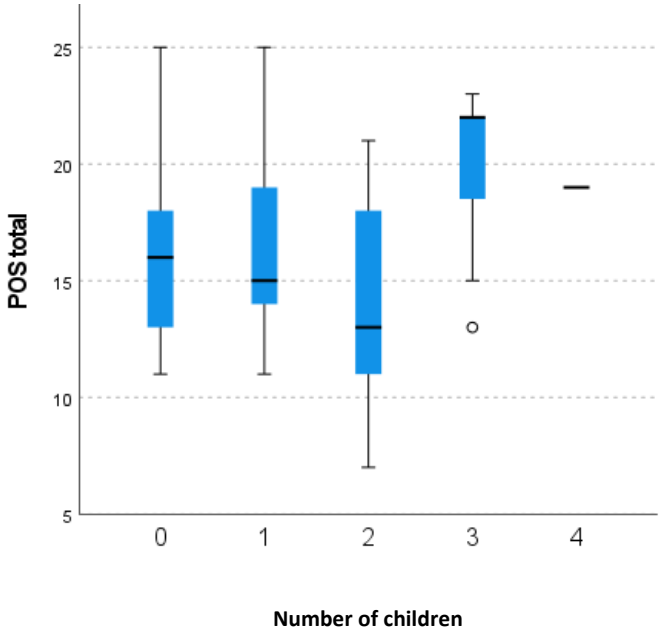


Figure 5. Distribution of POS total score according to the number of children.

Patients without children or with only one child exhibited a median POS score of 16 [11; 18] and 16.71 [13.5; 19.50], respectively. On the other hand, patients with two children presented a median POS score of 14 [11; 18]. Finally, patients with three or more children showed a median POS score of 19.86 [15; 22].

There was no significant correlation between age with ESAS (r = −0.069, p = 0601) and POS (r = 0.099, p = 0.452) score.

3.5. Correlation Between ESAS and POS

An analysis was conducted to evaluate the correlation between symptom severity, as measured by the ESAS-GDS, and quality of life, as assessed by the POS.

The results demonstrated a positive and statistically significant correlation between the total scores of the POS and ESAS-GDS scales ($p < 0.01$). This finding indicates that higher GDS scores, which reflect poorer symptom control, are associated with higher POS scores, signifying a deterioration in quality of life (Table 7).

Table 7. Spearman's correlations between the total POS score and the ESAS (total and each item).

	Total POS Score
Pain	0.356 **
Fatigue	0.270 *
Nausea	0.090
Depression	0.382 **
Anxiety	0.415 **
Drowsiness	0.228

Table 7. *Cont.*

	Total POS Score
Appetite	0.352 **
Dyspnea	0.077
Well-being	0.171
Total ESAS Score	0.448 **

* $p < 0.05$; ** $p < 0.01$.

Furthermore, a significant correlation was identified between pain, depression, anxiety, and loss of appetite, all with $p < 0.01$, and quality of life. A similar positive correlation was observed between fatigue and quality of life, albeit with $p < 0.05$. Thus, the high severity of these symptoms is associated with a decline in quality of life.

4. Discussion

In this specific population of hospitalized cancer patients, there was a predominance of the male gender, with a median age of 72 years (range: 43–94), which differs significantly from other studies. For instance, Karaman et al. conducted a study evaluating the Edmonton Symptom Assessment Scale (ESAS) in a palliative care population, reporting a mean age of 54.04 ± 15.89 years and a predominance of the female gender (51.9%) [30]. Antunes and Ferreira conducted a study to validate the Integrated Palliative Care Outcome Scale (IPOS) in a Portuguese palliative population, which revealed a mean age of 66.8 ± 12.7 years [31]. Kaasa et al. conducted a survey examining patient demographics in European palliative care units, which revealed a mean age of 66 years and a predominance of the female gender (56%) [32].

This difference can be attributed to the types of cancer observed in the study. A notable predominance of digestive cancers (41.7%) and head and neck cancers (20%) was found. Digestive system cancers are among the most lethal for men, who also exhibit a higher susceptibility to head and neck cancers [33,34]. In 2019, data indicated that head and neck cancers were 1.2 times more prevalent in males than in females [33,34].

Modonesi et al. conducted a study in an Italian palliative care unit, which yielded somewhat different results. In their study, the most frequently encountered cancer site was digestive tumors (30.2%), followed by lung tumors (18.5%) and breast tumors (11.1%) [35]. The introduction of immunotherapy for lung cancer treatment, which has significantly improved survival rates, may account for its lower prevalence in our study. Since the approval of immune checkpoint inhibitors, the treatment paradigm for lung cancer and its survival outcomes have been markedly altered [36]. Studies have demonstrated a substantial improvement in survival rates among patients following the implementation of immunotherapy [37].

In this study, when evaluating the total ESAS and POS scores across the various tumor types, there are minimal differences observed. Patients with head and neck tumors exhibit a higher median POS score. Conversely, patients with breast, gynecological, and lung cancers demonstrate a higher median ESAS score.

We also presented an analysis of the total POS and ESAS score with ECOG and social factors. There was no clinical or social factor associated with total ESAS and POS score, except the number of children, which was significantly related with POS score.

The authors did not find data in the literature that would justify these results. However, we know that family caregivers play a key role in palliative care, and understanding the relationship between patient and family caregivers is important [38]. Family involvement, knowledge about disease and treatments, abilities to communicate with the patient and team improve caregiver and patients' quality of life [39].

Families of palliative patients face various stressors, ranging from critical decisions about care to grief [40]. As they are faced with adverse circumstances, the different members of the family can be important resources, particularly for the patient [40]. However, these

same circumstances could induce conflicts [40]. The types of conflicts range from different needs or preferences for communication [40]. Disputes may arise due to the perception of insufficient assistance from a particular family member [41], the difficulty of reaching agreement on the coordination of patient care and reappearance of past tensions [42]. From the authors' perception, these conflicts can be accentuated in larger families, with members with different coping styles. Family conflicts in themselves can be a source of stress for the patient and affect their quality of life.

The Edmonton Symptom Assessment System (ESAS) is a credible and validated instrument for assessing the intensity of symptoms in palliative care, facilitating their identification and monitoring [10]. Over time, the management of pain and nausea has improved significantly through the use of targeted and effective therapies [43]. However, other symptoms, such as anorexia and the overall sense of well-being, have received comparatively less attention in research [43]. Current treatments for these symptoms have demonstrated limited effectiveness, raising important questions about the true impact of palliative care in alleviating such symptoms and the associated suffering [43].

In this study, symptoms such as pain, nausea, drowsiness, and dyspnea were reported with mild to moderate scores, likely reflecting an earlier initiation of palliative care assessments in both internal and external consultations. According to Cochrane reviews, early palliative care interventions can yield more beneficial effects not only in symptom intensity and management but also in overall quality of life [44]. While the authors noted only small effect sizes, these may still be clinically significant in advanced disease contexts where prognosis is limited [44].

Symptoms such as fatigue, depression, anxiety, loss of appetite, and well-being received the highest scores in this sample, indicating that these symptoms were more challenging to manage. Loss of appetite and weight loss are prevalent in advanced cancer cases [45]. However, cachexia cannot be solely attributed to inadequate caloric intake, as it is not reversed by caloric supplementation [45]. Biochemical alterations, including anemia, inflammation, and low albumin levels, play significant roles in this process [45,46].

Anorexia is one of the most common symptoms encountered in palliative care [46]. In a study involving a sample of 3030 patients receiving palliative care, 26% reported experiencing moderate or severe anorexia [47]. The pharmacologic treatments currently available predominantly include appetite stimulants; however, these interventions generally do not reverse cachexia in most patients [48].

Similarly to anorexia, many patients in palliative care experience fatigue [49]. Due to its multifactorial etiology, the assessment and treatment of fatigue can be challenging [49]. It is often necessary to investigate potential reversible causes that may be amenable to treatment [49]. If such causes are not identified, there are limited pharmacological options available for patients in palliative care [49]. Additionally, non-pharmacological approaches have shown limited efficacy [49].

Non-pharmacological therapies constitute complementary treatments in the area of palliative care, which aim to improve patients' quality of life, reducing symptom burden [43]. In the literature, some of the non-pharmacological interventions with an impact on oncological palliative care include physiotherapy, music therapy, massage therapy, cognitive–behavioral strategies and aromatherapy [50]. In particular for fatigue, aerobic exercise has consistent effects on depression and sleep quality [51].

In the case of anorexia, non-pharmacological interventions include dietary advice and assistance in reducing food-related stress, particularly in relation to family members [52]. The promotion of small, energy-rich and appetizing-looking meals constitutes an effective type of non-pharmacological intervention in daily clinical practice in this area, reducing patient and family stress in relation to meals [53]. It should be noted that some studies have shown that patients who lived alone had more loss of appetite upon admission, with improvement during hospitalization [54]. The social aspect of eating is crucial in treating loss of appetite [54]. Assistance with food preparation and initiatives such as shared meals

with other patients, caregivers and/or healthcare professionals can be beneficial during hospitalization [54].

Life-threatening illnesses can be significant triggers for anxiety and depression [45]. In addition to addressing physical needs, it is crucial to consider psychological, social, and spiritual needs as well [45]. Care teams must prioritize all these dimensions when providing care to patients in palliative settings and should be equipped with the multidisciplinary human resources necessary to address them effectively [45].

The Palliative Outcome Scale (POS) is a psychometrically reliable tool designed to assess the quality of life of patients in palliative care [21]. It effectively identifies five key areas: emotional well-being, consequences of the disease on daily life, received information and support, anxiety, and burden of disease [12].

It was observed that symptoms such as nausea, coughing, and constipation, as well as anxiety experienced by both patients and their families, significantly impacted the quality of life in our sample. The healthcare team should prioritize early identification and management of both physical and emotional symptoms. Siemens et al. found that approximately 20% of patients newly diagnosed with advanced oncological disease exhibited considerable levels of anxiety and depression, which were associated with a significant decline in quality of life [45]. Identifying previously unrecognized palliative needs is essential for achieving better outcomes [49]. Without adequate symptom screening, patients may experience diminished well-being, negatively affecting their daily activities, sleep quality, and interpersonal relationships [55].

Finally, the authors would like to highlight that this study was carried out in patients with palliative needs, in the context of oncological disease. However, we know that several non-oncological diseases are also indicated for palliative care. Indeed, symptomatic control in patients in these two contexts may be different, because the symptom burden may differ [56]. Patients with non-oncological diseases had shorter episode durations and were more affected by symptom clusters [56]. On the other hand, oncological patients had an additional communicational/practical cluster [56]. Non-oncological patients had significantly higher odds of fatigue, insomnia and impairment in emotional and physical functioning, but also in quality of life, while cancer patients had higher odds of pain [57].

Limitations

This study has several limitations that warrant mention.

First, the sample size was relatively small, which was influenced by the research being conducted during the COVID-19 pandemic. This period significantly impacted patients' access to palliative care, particularly concerning the assessment of palliative needs, restrictions on visitation, and the increase in telemedicine consultations [58].

Additionally, conducting this investigation within a single hospital further constrained the sample size. Future studies should aim to include more palliative care units and a larger and more diverse patient population in order to reduce bias and give a more insight into demographic and symptomatic trends in Portuguese palliative care.

Another limitation was the exclusion criteria. The authors excluded all patients who did not speak Portuguese, had communication difficulties, were terminally ill or were unable to comprehend the study and/or provide written consent.

Including patients with communication difficulties or cognitive impairment, potentially with caregiver reporting, could capture data from a broader spectrum of palliative populations. On the other hand, addressing linguistic diversity by including Portuguese interpreters or translated material would also increase sample inclusion.

Finally, the cross-sectional design of the study, in which the researchers contacted the study participants just once, allowed us to understand the current status of the patients but did not enable us to evaluate the continuity of care and the impact of care on the control and management of symptoms of people with palliative needs. Therefore, a longitudinal study is recommended for future investigations.

5. Conclusions

This study aims to provide a comprehensive profile of symptomatic intensity and patients' perceptions of quality of life among Portuguese oncological palliative patients at the time of hospital admission.

Our findings indicate a positive correlation between high severity of global symptoms and a perception of reduced quality of life. When analyzing specific symptoms, we observed a positive correlation between poor quality of life and symptoms such as pain, fatigue, depression, anxiety, and anorexia/loss of appetite. Uncontrolled pain and depression have negative consequences on the quality of life of these patients and their caregivers. It is known that optimizing symptomatic control increases the survival of patients in palliative care [59–61].

Conversely, it was found that symptoms, along with self- and family-related anxiety, were the most significant issues impacting the quality of life in this population.

By incorporating both scales in this study, the authors were able to achieve a more comprehensive understanding of the physical and psychological symptoms experienced by patients with advanced cancer. It would be beneficial for future research to also include patients in palliative care for non-oncological conditions. A positive correlation was identified between the Palliative Outcome Scale (POS) and the Edmonton Symptom Assessment System–Global Distress Scale (ESAS-GDS), indicating that inadequate symptom control adversely affects the quality of life of these patients.

Future studies would benefit from a larger and more inclusive sample and also a longitudinal design to capture a broader range of palliative care experiences. Furthermore, the inclusion of additional measurement instruments to further assess symptom burden and quality of life would benefit palliative care investigations in Portugal. It would be effective to conduct the assessments earlier in the course of patients' care to ensure symptom control and optimize quality of life throughout the disease.

Author Contributions: F.G.—data collection, Conceptualization and methodology, F.G.; software, M.G.; validation, F.G., M.G. and I.P.; formal analysis, I.P.; Investigation, F.G.; Resources, F.G.; Data curation, F.G.; Writing—original draft, F.G., M.G. and I.P.; Writing—review and editing, I.P., V.A.S., F.R., R.N.; Visualization, V.A.S., F.R. and R.N.; Supervision, F.R. and R.N. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: Data collection respected the rules of the Helsinki Protocol and the Oviedo Convention, and it was approved by the ethics and management committee of the Portuguese Institute of Oncology Francisco Gentil Coimbra (No. TI 17/2020, 9 November 2020). The data measurement tools were distributed individually, accompanied by a letter explaining the nature and objectives of the study and ensuring the confidentiality of the data.

Informed Consent Statement: Informed consent was obtained from all subjects.

Data Availability Statement: The datasets generated and analyzed during the current study are available from the corresponding author upon reasonable request.

Acknowledgments: The authors would like to acknowledge the support of the Portuguese Institute of Oncology Francisco Gentil Coimbra and the University of Porto.

Conflicts of Interest: The authors declare no conflicts of interest.

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2. INTENSITY OF SYMPTOMS AND PERCEPTION OF QUALITY OF LIFE ON ADMISSION TO PALLIATIVE CARE

Gonçalves F, Gaudêncio M, Paiva ICS, Rego F, Nunes R. Intensity of Symptoms and Perception of Quality of Life on Admission to Palliative Care: Reality of a Portuguese Team. Healthcare (Basel). 2024 Aug 1;12(15):1529. doi: 10.3390/healthcare12151529. PMID: 39120232; PMCID: PMC11312417.

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Intensity of Symptoms and Perception of Quality of Life on Admission to Palliative Care: Reality of a Portuguese Team

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Abstract: Background: Palliative care (PC) corresponds to an approach that enhances the quality of life for patients facing life-threatening diseases, such as cancer, as well as for their families. There are various models for providing palliative care. Early referral to PC of patients with advanced cancer has a significant positive impact on their quality of life. However, the criteria for early referral still remain controversial. Objectives: To evaluate patients' symptomatic intensity and perception of quality of life on admission to a PC unit and to analyze these two variables according to different models of approach (outpatient and inpatient care). Methods: A cross-sectional, descriptive, and correlational study was conducted with a sample of 60 patients sequentially admitted to a PC unit from palliative outpatient consultations or other inpatient services in a tertiary hospital dedicated to oncology care. The evaluation protocol included a sociodemographic and medical questionnaire, the Edmonton Symptom Assessment Scale (ESAS), and the Palliative Care Outcome Scale (POS) completed by patients within the first 24 h after admission. Results: The participants were mostly male (61.7%), with a median age of 72 years. The majority of patients (n = 32; 53.3%) were undergoing outpatient treatment, while the remaining individuals (n = 28; 46.7%) were transferred from other hospital services (inpatient care). In the outpatient care group, higher scores for fatigue and dyspnea were observed. Conversely, in the inpatient care group, higher scores were observed for pain, depression, and anxiety. There were significant differences between the two groups regarding the POS dimensions of meaning of life, self-feelings, and lost time. In the inpatient group, there was a longer time between diagnosis and referral to PC; however, it was also in the inpatient group that there was less time between PC referral and first PC evaluation, between PC referral and PC unit admission, and between PC referral and death. There were no significant correlations between referral times and ESAS/POS scores in the inpatient and outpatient groups. Conclusions: The patients admitted to the Palliative Care Unit presented a high symptom burden and changes in the perception of quality of life. However, there are no statistically significant differences between one model of approach in relation to the other. It was found that poorer symptom control and quality of life were associated with a shorter referral time for PC, because this was only initiated after curative care was suspended, particularly in our institutional context. Early referrals to the PC team are essential not only to relieve symptom-related distress but also to improve treatment outcomes and quality of life for people with cancer.

Keywords: medical oncology; palliative care; quality of life; outcome assessment; symptom assessment

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Citation: Gonçalves, F.; Gaudêncio, M.; Paiva, I.C.S.; Rego, F.; Nunes, R. Intensity of Symptoms and Perception of Quality of Life on Admission to Palliative Care: Reality of a Portuguese Team. *Healthcare* **2024**, *12*, 1529. https://doi.org/10.3390/healthcare12151529

Academic Editors: Ana Cláudia Mesquita Garcia, Simone Yuriko Kameo and Namie Okino Sawada

Received: 25 June 2024
Revised: 25 July 2024
Accepted: 29 July 2024
Published: 1 August 2024

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1. Introduction

The World Health Organization (WHO) defines palliative care (PC) as an approach that improves the quality of life of patients and their families who are facing problems

associated with life-threatening illness through the early identification and treatment of pain, alongside other physical, psychosocial, and spiritual problems [1].

In Portugal, access to palliative care is considered to be a universal right regulated in the Basic Health Law approved in 2012 [2]. According to this law, palliative care "must respect the autonomy, will, individuality, the dignity of the person and the inviolability of human life" [2]. It was the law that defined the creation of PC teams at the local level in Portugal, organized into PC units, in-hospital PC support teams, and community PC support teams [2].

Wiencek et al. describe various models for providing palliative based on the reality experienced in the United States of America—Ambulatory Palliative Care Clinic, Home-Based Palliative Care, Inpatient Palliative Care Units, and Inpatient Consultation Services [3].

Although a number of benefits have been attributed to inpatient and outpatient care individually, the relative impact of one in relation to the other is not as well-described [4–8]. The two environments are characterized by marked differences in the process of care [4–8]. A recent study has shown that an outpatient palliative care model reduces hospital admissions, improves quality of life, and prolongs patient survival [4,9].

Traditionally, PC for cancer patients was initiated only after the completion of curative treatment was finished [10]. However, it has been proven that early referral of these patients not only enhances their quality of life but may also potentially improve survival rates simultaneously [4].

Early referral to PC for patients diagnosed with advanced cancer significantly improves their overall quality of life [11]. Although the definition of early referral has not been well-established, some randomized trials described the following criteria for early referral: 2 to 3 months after the diagnosis of advanced disease and Eastern Cooperative Oncology Group (ECOG) performance status of 2 or less [12]. Other authors described referral time to palliative care in relation to death: first PC referrals more than one year before the patient's death are classified as "early" (ER); referrals between 3 and 12 months before death are classified as "intermediate"; and referrals made less than 3 months before the patient's death are classified as "late" (LR) [13].

Referral criteria are still controversial [10]. Severe symptoms, poor performance status, comorbidities, and prognosis are among the most common criteria [10].

The difficulty of early referral of cancer patients to PC is related to the difficulty in establishing a correct prognosis [11]. In fact, oncologists readily admit the difficulty in estimating survival of 3, 6, or 12 months [11]. Other reasons implicated in the delay of referral to PC are the scarcity of time during consultations to discuss PC and failures in the assessment of psychological, spiritual, or social needs [12].

Late referral of patients to PC has an impact on symptomatic control and quality of life [14]. Several studies have shown that early initiation of PC significantly improves the quality of life of patients with advanced cancer if initiated concomitantly with standard oncology care [14]. Humphreys et al. concluded that late referrals may have a negative impact on health outcomes [15]. So, it is important to design and implement hospital policies that encourage early referral to palliative care, particularly for advanced cancer patients [15]. Patients referred to palliative care within the first week of hospital admission experienced significantly shorter lengths of stay and lower in-hospital mortality rates compared to those referred after 1 week following admission [15].

As already mentioned, one of the objectives of PC is to promote quality of life for patients and their families. However, the perception of quality of life is very subjective and presented with different concepts.

According to the WHO, quality of life could be defined as the individual's perception of their position in life, based on values, culture, goals, expectations, and concerns [16].

Several scales are used to measure quality of life in the cancer and PC context, including the Eastern Cooperative Oncology Group Performance Status Scale (ECOG) and the QLQ-C30 designed by the European Organization for Research and Treatment of Cancer (EORTC) [17].

It is recognized that assessment of PC and cancer patients' quality of life requires that the emphasis of the measurement is not only on the relief of pain and other symptoms [17]. It is also important to consider the resolution of emotional, social, psychological, and spiritual problems, as well as information and establishing good contacts and support with family members [17].

The Palliative Care Outcome Scale (POS) seeks to assess these dimensions, having been developed particularly for cancer and palliative patients [17,18].

The general aim of this study is to evaluate patients' symptomatic intensity and perception of quality of life on admission to a Palliative Care Unit.

The specific aims of the study are the following:

- To analyze patients' symptomatic intensity and perception of quality of life upon PC unit admission, according to different models of approach (outpatient and inpatient care);
- To evaluate the referral time to PC in the global sample and according to different models of approach (outpatient and inpatient care);
- To correlate the referral time to PC with patients' symptomatic intensity and perception of quality of life according to different models of approach (outpatient and inpatient care).

2. Materials and Methods

The authors conducted a cross-sectional descriptive and correlational study, carried out at an oncological tertiary hospital, after approval from the Ethics Committee of the institution where the study was conducted (opinion No. TI 17/2020).

2.1. Data Collection

Data collection respected the rules of the Helsinki Protocol [19] and the Oviedo Convention [20].

The data measurement tools were distributed individually, accompanied by information explaining the nature and objectives of the study to each participant. Additionally, an informed consent form was provided, ensuring the confidentiality of the data.

After obtaining authorization through informed consent, the data were collected using an evaluation protocol specifically designed for this purpose. The protocol included a sociodemographic and medical questionnaire (including age, gender, origin service before admission, types of cancer, and stage at diagnosis), an Edmonton Symptom Assessment Scale (ESAS), and a Palliative Care Outcome Scale (POS).

This protocol was applied in the first 24 h following admission to the Palliative Care Unit.

The Edmonton Symptom Assessment Scale (ESAS) is a multi-dimensional assessment tool used for self-reporting the intensity of symptoms in daily assessments of palliative care patients [21]. It is implemented and valid in several countries [22]. The ESAS consists of a numerical scale that evaluates the 10 most common symptoms in cancer patients—pain, fatigue, nausea, depression, anxiety, sleepiness, well-being, dyspnea, appetite, and one other optional symptom, and it uses a score from 0 (no intensity) to 10 (worst intensity) to measure suffering associated with both physical and psychological symptoms [22].

In this study, the authors used a validated subtype of the ESAS, the Global Distress Score (GDS), a sum of the first 9 physical and psychosocial ESAS symptoms [10]. The GDS was calculated and grouped into 3 cohorts based on previous work and clinical experience as follows: high (GDS $\geq$ 35), moderate (16 $\geq$ GDS > 34), and low (GDS < 15) [23]. The Palliative Care Outcome Scale (POS) was developed in the United Kingdom, and it is a multi-dimensional scale that can be used to assess the quality of life of patients in palliative care [24]. In fact, the POS was developed to measure quality of care and well-being in patients in palliative care, but it is also a good measure of quality of life because it addresses aspects related to physical, psychological, and spiritual symptoms, practical and emotional concerns, as well as psychosocial needs of the patient and family. It presents two versions, one "self" for the patient and the other "proxy" for the health professional, with identical

and reliable answers [24]. We used the original version of "self" with 11 questions, which are scored on a 5-point Likert scale [24]. It addresses aspects related to physical, psychological, and spiritual symptoms, practical and emotional concerns, as well psychosocial needs of the patient [24]. The score can vary from 0 to 40 points, with the latter score being the one that represents the worst quality of life [24]. The questions present in this scale and used in the study were the following: "1—Over the past 3 days, have you been affected by pain; 2—Over the past 3 days, have other symptoms e.g., nausea, coughing or constipation seemed to be affecting how you feel; 3—Over the past 3 days, have you been feeling anxious or worried about your illness or treatment; 4—Over the past 3 days, have any of your family or friends been anxious or worried about you; 5—Over the past 3 days, how much information have you and your family or friends been given; 6—Over the past 3 days, have you been able to share how you are feeling with your family or friends; 7—Over the past 3 days, have you felt that life was worthwhile; 8—Over the past 3 days, have you felt good about yourself as person; 9—Over the past 3 days, how much time do you feel has been wasted on appointments relating to your healthcare, e.g., waiting around for transport or repeating tests; 10—Over the past 3 days, have any practical matters resulting from your illness, either financial or personal, been addressed.

Subsequently, the authors collected data from the clinical files of patients included in the study to determine referral/admission times (time between the diagnosis and PC referral; time between PC referral and first PC evaluation; time between PC referral and unit admission; time between diagnosis and PC unit admission; and time between PC referral and death).

2.2. Sample

A consecutive sample of 60 patients admitted to a Palliative Care Unit was included in this study. These patients had already been previously assessed by palliative care (on an outpatient basis or through the in-hospital palliative care team).

The inclusion criteria encompassed adult cancer patients (≥18 years old) admitted to the Palliative Care Unit between January and March 2021. The study encompassed cancer patients who willingly consented to participate and demonstrated an understanding of the study's objectives. Those unwilling to participate, individuals with communication disabilities, or those unable to comprehend and/or provide consent were excluded.

2.3. Statistical Analysis

The variables in the entire sample were characterized using the most appropriate descriptive statistics available.

Categorical and qualitative variables were described using absolute and relative frequencies (N and %). Quantitative variables were characterized by the mean, quartiles, minimum, and maximum.

Quantitative and qualitative variables were compared with the Mann–Whitney test. Correlations between qualitative variables were performed using the Spearman correlation coefficient.

The database was organized using Microsoft Excel® 2016 software. Statistical analysis was performed using the IBM SPSS® Statistics program (version 25.0 for Windows®). The tests were performed at a significance level of 95% ($p < 0.05$).

3. Results

3.1. Sociodemographic and Clinical Characteristics and POS and GDS Scores of the Sample

The sample predominantly comprises males (n = 37; 61.7%), with a median age of 72 years (from 43 to 94 years).

Most of the patients (n = 32; 53.3%) were receiving outpatient treatment (in palliative care ambulatory), while the remaining patients (n = 28; 46.7%) were transferred from other services of the institution, where they were already being assessed by the in-hospital

palliative care team (hospitalized patients). Concerning the type of tumor, most patients had digestive tumors (41.7%), followed by head and neck tumors (20%) (Table 1).

Table 1. Sociodemographic and clinical characteristics and POS score and GDS score of the sample (n = 60).

Variables	Descriptive
Gender, *n* (%)	
Male	37 (61.7)
Female	23 (38.3)
Age (years), median [Q1; Q3], min–max	72 [58.25; 79], 43–94
Origin service before admission, *n* (%)	
Ambulatory/outpatient	32 (53.3)
Hospitalization/inpatient	28 (46.7)
Types of cancer, *n* (%)	
Head and neck	12 (20)
Cutaneous	3 (5)
Digestive	25 (41.7)
Gynecological	5 (8.3)
Hematologic	1 (1.7)
Breast	6 (10)
Prostate	2 (3.3)
Lung	6 (10)
Stages of cancer, *n* (%)	
Stage I	3 (5)
Stage II	8 (13.3)
Stage III	6 (10)
Stage IV	43 (71.6)
POS score *, median [Q1; Q3], min–max	15 [13; 19], 7–25
ESAS score (GDS) *, median [Q1; Q3], min–max	43 [35; 48], 17–62
ESAS score (GDS) cohorts based on the total sum of the answers, *n* (%)	
Low (0–15)	0
Moderate (16–34)	13 (21.7)
High (≥35)	42 (70)

Q1—first quartile; Q3—third quartile; * total score was obtained by adding the items. ESAS—Edmonton Symptom Assessment Scale; POS—Palliative Outcome Scale; GDS—Global Distress Score.

Most of the patients were at stage 4 of cancer at diagnosis (71.6%). However, it was observed that three patients were at stage I and eight at stage II. These patients had other advanced diseases rather than cancer, and the objective of treatment was not curative.

The POS score exhibits a median of 15 (from 7 to 25) (Table 1). On the other hand, the median Global Distress Score (GDS) is 43, with extreme values from 17 to 62 (Table 1). Most participants (n = 42; 70%) scored a GDS $\geq$ 35, which corresponds to a high symptom burden (Table 1).

3.2. Relationship of Different Palliative Care Approaches in Symptom Control and Perception of Quality of Life upon Admission to the PC Unit

The scores of the ESAS scale of the groups in outpatient and inpatient care are presented in Table 2. In this sample, the results of the ESAS scale were compared for each symptom of the groups in outpatient and inpatient care.

Table 2. Frequencies of the patients' answers to the ESAS scale—inpatient vs. outpatient care (median ([Q1; Q3]).

	Outpatient Care (*n* = 34)	**Inpatient Care (*n* = 26)**	**Mann–Whitney's *p*-Values**
Pain	2.5 [0; 7]	4.5 [0; 6.75]	0.875
Fatigue	7 [5; 7.25]	6.5 [5; 7]	0.835
Nausea *	0 [0; 6]	0 [0; 4.75]	0.789
Depression	5 [3.75; 6]	6 [4; 6.75]	0.219
Anxiety *	5 [5; 6]	6 [5.25; 7]	0.066
Drowsiness **	5 [1.75; 5]	5 [3.5; 6]	0.196
Appetite	6 [5; 7]	6 [5; 8]	0.866
Dyspnea	3 [0; 5.25]	0 [0; 5]	0.451
Well-being	6 [5; 7]	6 [5; 7]	0.076
Total score ***	42.5 [33; 49]	42.5 [36; 47]	0.850

* 1 missing; ** 3 missing; *** Global Distress Score (GDS).

In the outpatient care group, a higher median ESAS score was noted for fatigue and dyspnea. On the other hand, in the inpatient care group, a higher median ESAS score was observed for pain, depression, and anxiety. For the remaining symptoms, the median ESAS scores are the same in both groups. However, in none of the cases were there any statistically significant differences.

Regarding the GDS, there is a median score of 42.5 in both groups, which corresponds to a high symptom burden. However, there were no statistical differences, either (Table 2).

The POS scale scores for both the outpatient and inpatient care groups can be found in Table 3. The item "*If any, what have been your main problems in the last 3 days?*" was not considered in this study. The scores' distribution was statistically significant for the following items: meaning of life, self-feelings, and lost time ($p < 0.05$) (Table 3). The inpatient group exhibited higher median scores concerning meaning of life and self-feelings ($p = 0.031$ and 0.047, respectively). However, concerning the "lost time" item, the outpatient group displayed a higher median score ($p = 0.033$) (Table 3).

Table 3. Frequencies of the patients' answers to the first 10 questions of the POS scale—inpatient vs. outpatient care (median ([Q1; Q3]).

Items\Score	**Outpatient Care (*n* = 34)**	**Inpatient Care (*n* = 26)**	**Mann–Whitney's *p*-Values**
1. Pain	2 [0; 3]	2 [0; 3]	0.876
2. Other symptoms	2 [1.75; 3]	3 [2; 3]	0.110
3. Anxiety about disease	3 [2; 3]	3 [2; 3]	0.145
4. Family's anxiety *	3 [2; 3]	3 [3; 3]	0.456
5. Information *	1 [1; 2]	2 [1; 2]	0.396
6. Sharing Information *	1 [1; 2]	2 [1; 2]	0.330

Table 3. *Cont.*

Items\Score	Outpatient Care (n = 34)	Inpatient Care (n = 26)	Mann–Whitney's p-Values
7. Meaning of life	1 [1; 1]	1 [1; 2]	0.031 **
8. Self-feelings	1 [1; 1]	1 [1; 2]	0.047 **
9. Lost time	0 [0; 0.5]	0 [0; 0]	0.033 **
10. Practical problems	0 [0; 2]	0 [0; 1.5]	0.628
Total Score	15 [12; 18]	17 [14; 20]	0.041

* 1 missing; ** $p < 0.05$.

3.3. Relationship between PC Referral/Admission Times, Symptom Intensity, and Perception of Quality of Life

The sample showed a median time between diagnosis and referral to palliative care of 516.53 days (minimum 12 and maximum 2938 days), a median time between PC referral and first palliative evaluation of 10.6 days (ranging from a minimum of 0 to a maximum of 42 days), a median referral time between diagnosis and PC unit admission of 564.59 days (ranging from a minimum of 24 to a maximum of 2954 days), a median referral time between PC referral and unit admission of 50.68 days (ranging from a minimum of 0 to a maximum of 632 days), and a median referral time between PC referral and death of 36 days (ranging from a minimum of 3 to a maximum of 893 days) (Table 4).

Table 4. Times related to palliative care (admission, evaluation, referral, and death) of the sample (n = 60).

Variables	Descriptive
Time between the diagnosis and PC referral, median [Q1; Q3], min–max (days) *	323 [196.5; 651], 12–2938
Time between PC referral and first PC evaluation, median [Q1; Q3], min–max (days) **	3 [1; 22.75], 0–42
Time between diagnosis and PC unit admission, median [Q1; Q3], min–max (days) ***	439 [221.75; 682.75], 24–2954
Time between PC referral and unit admission, median [Q1; Q3], min–max (days) ****	8 [2; 47], 0–632
Time between the PC referral and death, median [Q1; Q3], min–max (days) *****	36 [11; 104], 3–893

Q1—first quartile; Q3—third quartile; PC—palliative care; *—3 missing; **—4 missing; ***—4 missing; ****—4 missing; *****—7 missing.

In the inpatient group, there was a longer time between diagnosis and referral to palliative care (600 days) (Table 5). On the other hand, it was also in the inpatient group that there was less time between PC referral and first PC evaluation (2 days), between PC referral and PC unit admission (3 days), and between PC referral and death (31 days) (Table 5). All of these results were statistically significant ($p < 0.05$) (Table 5).

Table 5. Times related to palliative care (admission, evaluation, referral, and death)—inpatient vs. outpatient care (median).

	Outpatient Care (n = 32)	Inpatient Care (n = 28)	Mann–Whitney's p-Values
Time between the diagnosis and PC referral (days)	446	600	0.044 *
Time between PC referral and first PC evaluation (days)	18	2	<0.001 **
Time between PC referral and unit admission (days)	88	3	<0.001 **
Time between diagnosis and PC unit admission (days)	535	602	0.288
Time between the PC referral and death (days)	133	31	<0.001 **

* $p < 0.05$; ** $p < 0.01$.

There were no statistically significant differences between the two groups in terms of time between diagnosis and the PC unit admission (p = 0.288) (Table 5).

Finally, the authors intend to evaluate the correlation between referral times in PC, the severity of symptoms, and perception of quality of life.

It was found that the total score of ESAS was negatively correlated with referral times in the sample and outpatient group (Table 6). In general, higher scores on ESAS (worse symptom control) were related to shorter referral time for palliative care, particularly in the sample and outpatient group.

Table 6. Spearman's correlations (r, p-value) between referral times and the ESAS total score in the sample and in the groups—inpatient vs. outpatient care.

	All Patients (n = 60)	Outpatient Group (n = 32)	Inpatient Group (n = 28)
Time between the diagnosis and PC referral	−0.168 (0.235)	−0.175 (0.373)	−0.233 (0.273)
Time between PC referral and first PC evaluation	−0.141 (0.323)	−0.198 (0.313)	0.043 (0.846)
Time between PC referral and unit admission	−0.093 (0.517)	−0.251 0.198	0.322 (0.134)
Time between diagnosis and PC unit admission	−0.277 (0.049) *	−0.271 (0.162)	−0.322 (0.134)
Time between the PC referral and death	−0.214 (0.139)	−0.359 (0.071)	0.053 (0.811)

* $p < 0.05$.

On the other hand, in the inpatient group, some referral times presented a positive correlation with ESAS score, although without statistical significance (Table 6). Some of these times were the time between PC referral and first PC evaluation, the time between PC referral and unit admission, and the time between PC referral and death. In these correlations, it was observed that the longer time was related to severe symptom burden.

As we can see in Table 6, there was only a statistically significant correlation between the total ESAS score and time between diagnosis and PC unit admission in the sample (−0.277; p = 0.049). This correlation was negative, which means that the longer time between diagnosis and PC admission was related to less severe symptoms.

It was found that the total score of POS was negatively correlated with referral times in the sample and the outpatient group (Table 7). In general, higher scores on POS (worse perception of life) were related to shorter time between PC referral and first PC evaluation.

Table 7. Spearman's correlations (r, p-value) between referral times and the POS total score in the sample and in the groups—inpatient vs. outpatient care.

	All Patients (n = 60)	Outpatient Group (n = 32)	Inpatient Group (n = 28)
Time between the diagnosis and PC referral	0.083 (0.548)	−0.078 (0.686)	0.108 (0.601)
Time between PC referral and first PC evaluation	−0.348 (0.01) **	−0.322 (0.089)	−0.034 (0.873)
Time between PC referral and unit admission	−0.240 (0.081)	−0.225 (0.240)	0.164 (0.434)
Time between diagnosis and PC unit admission	−0.005 (0.971)	−0.124 (0.523)	0.096 (0.650)
Time between the PC referral and death	−0.263 (0.062)	−0.169 (0.410)	−0.049 (0.817)

** $p < 0.01$.

On the other hand, in the inpatient group, some referral times presented a positive correlation with the POS score. Some of these times were the time between the diagnosis and PC referral, the time between PC referral and unit admission, and the time between the PC referral and death. In these correlations, it was observed that the longer time was related to worse perception of life.

As we can see in Table 7, there was only a statistically significant correlation between total POS score and time between PC referral and first PC evaluation in the sample (−0.348, $p = 0.01$). This correlation was negative, which means that the longer time between PC referral and first evaluation was related to less severe perception of life. At last, there was no significant correlation with POS score and referral times in the inpatient and outpatient groups.

4. Discussion

In this sample, there was a predominance of males, with a median age of 72 years. The predominance of males in our sample can be attributed to two factors: the small number of patients with breast cancer (10%) and digestive (41.7%) and head/neck (20%) tumors as the most common in this population. Colorectal and gastric tumors are the main causes of death related to cancer, and they have a higher mortality rate in men [25]. On the other hand, males are more susceptible to head and neck cancers than females, which had an impact on the incidence [26].

The most prevalent types of tumors in this study were digestive cancer (41.7%) and head/neck cancer (20%). Only 10% of the patients referred to PC had lung cancer. Fairchild et al. described that 29.9% of palliative patients had lung and digestive cancer, while only 3.2% had head/neck cancer [27]. In the sample, it was found that the majority of patients were in stage IV at diagnosis, which means that they presented an advanced disease.

This study was performed in a Portuguese PC unit dedicated to oncological PC. The PC team cares for around 400–500 patients per year and offers several types of support: an inpatient consultation team, a PC unit, and outpatient consultation.

Patients admitted to the PC unit may either come from outpatient consultation or other medical wards of the hospital after an evaluation of the in-hospital PC team. On the date of admission to the PC unit, 32 patients (53.3%) were admitted from the outpatient clinic. The remaining patients ($n = 28$; 46.7%) were hospitalized in other wards of the hospital with the support of the in-hospital palliative care support team (inpatient care). Hochman et al. performed a study that compared the characteristics of inpatients and outpatients [28]. In their sample, the majority of patients were outpatient ($n = 417$; 66%) [28], which was similar to the current study.

One of the authors' objectives was to analyze patients' symptomatic intensity and perception of quality of life at PC unit admission in general and according to different models of approach (outpatient and inpatient care).

In the sample, the Global Distress Score (GDS) presented a median score of 43, with a minimum of 17 and a maximum of 62. Most participants scored a GDS $\geq$ 35 (n = 42; 70%), which corresponds to a high symptom burden. The ESAS scale is a pragmatic, patient-centered symptom assessment tool that is easy to administer, interpret, and report [29]. It can identify responsiveness, minimal clinically important differences, and clusters of symptoms [26]. The ESAS scale is a unidimensional score that assesses only symptom intensity [29].

On the other hand, the sample presented a POS median score of 15, with a minimum of 7 and a maximum of 25. The POS is an outcome scale that inherently encompasses the multidimensionality of quality of life [30]. So, in the sample, the patients seem to have a relatively satisfactory quality of life despite the high symptomatic lack of control, but individualized care is essential. These results could be attributed to the comprehensive nature of POS, which evaluates dimensions beyond the common symptoms in advanced disease [24]. The POS measures a range of aspects, including physical symptoms, psycho-

logical well-being, and emotional and spiritual needs, but also information and support requirements [24].

In the outpatient care group, a higher median ESAS score was noted for fatigue and dyspnea. On the other hand, in the inpatient care group, a higher median ESAS score was observed for pain, depression, and anxiety. For the remaining symptoms, the median ESAS scores are the same in both groups. However, in none of the cases were there any statistically significant differences. Hochman et al. developed a study regarding symptom burden in palliative care, focusing on both outpatient and inpatient settings [28]. Outpatients reported more severe fatigue, pain, and nausea [28]. The inpatient group reported more intensity in symptoms, such as anorexia and dysphagia [28]. The differences between the two studies could be justified by the sample used. Our study focused specifically on oncological palliative patients, while Hochman et al.'s study encompassed both oncological and non-oncological patients. The intensity of symptoms in most cancer patients varies based on the type of cancer, its stage, and the treatments received [31,32]. In metastatic cancer, 35% to 96% of patients experience pain, 32% to 90% experience fatigue, and 10% to 70% experience shortness of breath [33].

Statistically significant differences were observed between the outpatient and inpatient care groups in terms of POS dimensions, such as meaning of life, self-feelings, and lost time. In this study, the distribution of values was statistically significant for meaning of life ($p = 0.031$) and self-feelings ($p = 0.047$), with a higher median score in the inpatient group, while lost time ($p = 0.033$) had a higher median score in the outpatient group. Hence, patients in the inpatient care group reported feeling that life was worthwhile and had a more positive self-perception compared to those in the outpatient group. Conversely, patients in the outpatient group expressed feelings of wasting time during healthcare appointments, such as waiting for transport or repeating tests.

Santos et al. carried out a study with the aim of identifying the factors that influence patients' quality of life (QoL) in home-based palliative care [34]. In the study, 22.2% of patients felt good about themselves "all the time" and 55.5% of patients spent up to half of the day on health-related commitments, including self-care activities as well as others related to therapeutic prescriptions [34]. The observed differences can be attributed to the care settings—our patients were under the care of both outpatient and inpatient services, rather than receiving specialized home care teams. The inpatient group presented higher values of quality of life and care, which can be justified by the intensive psychological intervention performed by the in-hospital palliative care team. As expected, patients from outpatient care demonstrated higher scores in lost time due to consultations and their associated logistics.

Another objective of the study was to evaluate the referral time to PC in the sample and according to different models of approach (outpatient and inpatient care) in order to understand if the PC referral was early or late in our context. The sample exhibited a median time between diagnosis and referral to palliative care of 323 days, a median time between PC referral and the first PC evaluation of 3 days, a median referral time between diagnosis and PC unit admission of 439 days, a median referral time between PC referral and unit admission of 8 days, and a median referral time between PC referral and death of 36 days. All measured times had statistically significant differences between outpatient and inpatient care groups, except for the time between diagnosis and PC unit admission.

In this study, the median time between diagnosis and referral to palliative care was 51,653 days, which corresponds to more than 1 year. Taking into account that 71.6% of patients under study presented stage IV tumors at diagnosis, this time does not seem at all appropriate. Ferrell et al. described that all patients with advanced cancer should be followed up simultaneously by a multidisciplinary team with oncologist and palliative professionals in the first 8 weeks after diagnosis [35]. In our hospital context, institutional policy determined that referral for palliative care should preferably be carried out when curative care is suspended. The lack of health professionals dedicated to PC is one of the reasons for this option.

Furthermore, the time between diagnosis and PC referral was higher in the inpatient care group (600 days). These patients were often receiving systemic treatment with unrealistic expectations about the curative potential of chemotherapy and were referred to palliative care towards the end of their lives.

The median time between PC referral and first PC evaluation was 3 days in the sample, suggesting a quick PC response. This time was longer in the outpatient group (18 days) than the inpatient care group (2 days). Outpatient care is often the result of early referral during the course of the disease, allowing a longitudinal relationship to be built with the patient and family [36]. On the other hand, inpatient palliative care teams are often involved later in the course of the disease, usually providing management of acute symptoms and decision making in the context of hospitalization [36]. Capelas et al. presented a Delphi study that tried to define some quality indicators for palliative care teams [37]. One of the indicators defined was the initial assessment taking place within the first 48 h after referral to the PC team [37].

The median time between PC referral and unit admission was 8 days. This time was longer in the outpatient care group (88 vs. 3 days). The same is observed when we analyze the time between the PC referral and death.

The PRISMA study showed that, in Portugal, more than half of people would prefer to die at home, but, in reality, more than 60% of deaths occur in hospitals and only 20% at home [38]. Sousa et al. performed a study in a specialized Palliative Cancer Care Unit in Portugal that revealed that patients were admitted to the hospital from the emergency department (56.1%), followed by in-hospital transfer from oncology units (22%) [39].

Most of the patients followed by the in-patient PC team were in oncology wards. These patients were often already in supportive care, with high-burden symptoms, when they were referred to the PC team. This abrupt transition from curative treatments to palliative care can be traumatic for the patient and family, and it can cause hopelessness and fear of abandonment [40].

Tagami et al. conducted a study investigating the timing of palliative care referral for patients with advanced cancer [41]. It was reported that 20.9% (n = 102) of patients were referred at diagnosis, 11.4% (n = 56) during anti-cancer treatment, and 36.2% (n = 177) when there were no further treatment options [41]. An additional 5.1% reported that they had never been referred to specialized palliative care (SPC) during their lifetime [41]. The lack of symptomatic control and the suffering caused by the disease are best understood by a PC team that can accompany the patient both during standard oncology treatments and at the end of life [42].

So, the intervals between referral to palliative care, admission to the unit, and the terminal event are quicker in the inpatient group compared with the outpatient care group. In our sample, the PC team was effectively managing patients in an outpatient context for almost three months (88 days) before they needed hospitalization (either for clinical or psychosocial reasons like caregiver exhaustion), considering the late transition to palliative care [43].

The time between PC referral and death was about 36 days. The referral time to PC can range from the last 6 months to a year of life or just a few weeks. Definitions of early integration in PC may be different and controversial. The literature suggests that it takes at least 3 to 4 months to fully benefit from palliative care provided by a multidisciplinary team [44]. In 2018, the Lancet Commission on Palliative Care and Pain Relief concluded that there was a global shortage of palliative care and pain relief [45].

At last, the authors intend to correlate the referral times to PC with patients' symptomatic intensity and perception of quality of life, according to different models of approach (outpatient and inpatient care).

It was found that the total score of ESAS was negatively correlated with referral times in the sample and outpatient group. In general, higher scores on ESAS (worse symptom control) were related to shorter referral time for palliative care. In the sample, there was a statistically significant correlation between the time of diagnosis and admission to the

PC unit. A negative correlation was observed, which means that the shorter the time, the greater the intensity of symptoms upon admission. These findings are in line with the literature, in which poor symptom control is one of the main reasons for hospitalization in palliative care [46]. As the disease progresses, it is natural for physical symptoms to worsen.

On the other hand, in the inpatient group, some referral times presented a positive correlation with the ESAS score, although without statistical significance. In these correlations, it was observed that the longer time was related to severe symptom burden.

The same results were found in relation to the POS score. It was found that the total score of POS was negatively correlated with referral times in the sample and outpatient group. In general, higher scores on POS (worse perception of life) were related to shorter time between PC referral and first PC evaluation. There was only a statistically significant correlation between total POS score and time between PC referral and first PC evaluation in the sample (-0.348, $p = 0.01$). This correlation was negative, which means that the longer time between PC referral and first evaluation was related to less severe perception of life.

Early referrals to PC teams are essential not only to relieve symptom distress but also to improve treatment outcomes and quality of life for people with cancer [47]. Referrals to palliative care often come too late to significantly improve the quality of life of patients with cancer. Patients are typically referred to the palliative care team late in the course of their illness, with an average of 30–60 days before death [48]. Physicians face several barriers to early referral of patients to palliative care [49]. Among these barriers are the uncertainty regarding the evolution of the disease process and prognosis, the existence of periods of remission, the difficulty in transmitting bad news, the lack of knowledge about palliative care, the lack of time in consultations, and the difficulty of accessing this care [49].

Poorer symptom control and lower quality of life were observed in association with a shorter time between diagnosis and referral to palliative care, which can be explained by the late diagnosis of these patients, who in most cases were stage IV at presentation. Based on these results, an early referral of patients to palliative care is recommended. Most studies have found that better management of symptoms in patients with metastatic cancer is associated with increased survival [50,51]. PC could play a fundamental role in early interventions regarding symptom control as well as offering psychosocial support, contributing to improved survival rates and enhancing the quality of life of cancer patients [40]. An earlier referral to the PC team is associated with a reduced need for intensive medical care and improved quality outcomes for cancer patients [50,51].

Many authors have acknowledged the absence of consensus in the literature regarding patients who should be referred in the ambulatory setting [52]. Criteria, such as cancer diagnosis, prognosis, physical symptoms, performance status, psychosocial distress, and end-of-life care planning, are suggested as potential reasons for PC referral [52].

With this study, the authors have tried to understand the reality of PC in their institution, with a view to improving practices related to patient referral. The result of this study led to an institutional change seeking to refer hospitalized patients earlier in order to allow better PC intervention with patients and families.

Limitations

The authors acknowledge certain limitations in the current research.

One of the limitations identified in this study is the relatively small sample size. On the other hand, the fact that this study took place only in one institution limited the sample size. The authors recognize this sample size limitation. However, our objective is not to extrapolate the results to other centers nationwide. In the near future, it would be interesting to extend this study to other national units. One of the objectives of this work is to draw attention, despite being a local study, to a reality that is observed in the PC area, even with existing knowledge and training on the topic.

In addition to the sample size, the authors recognize that the study covers a three-month period in 2021, which may seem like a short period of time.

Another limitation of the study is that the evaluation of these instruments was carried out only upon admission, with no other time to see the more specific effect of the palliative care intervention. The majority of patients admitted to the Unit have uncontrolled symptoms, which in itself constitutes a reason for hospitalization.

5. Conclusions

This study evaluated the symptomatic intensity and perception of quality of life of patients admitted to a Palliative Care Unit in a hospital dedicated to cancer care, but also referral times and the effect of different PC models of approach.

It was found that poorer symptom control and quality of life were associated with a shorter referral time for palliative care, because palliative care was initiated only after curative care was suspended, particularly in our institutional context.

In general, the authors observed that patients admitted to the Palliative Care Unit have a high symptom burden and changes in the perception of quality of life. However, there are no statistically significant differences between one model of approach in relation to the other.

The optimization of symptomatic intensity in PC is associated with improved quality of life, greater compliance, and even longer survival without prejudice to quality of life [34]. Symptoms may be due to cancer (direct or indirect consequences of cancer), treatment-related adverse effects, and/or comorbidities [53]. The symptom and quality of life measurement tools routinely used in clinical practice are, respectively, the Edmonton Symptom Assessment Scale (ESAS) and the Palliative Care Outcomes Scale (POS) [54–56].

Expanding this study to include the population of non-oncological palliative patients would be beneficial in future research. In addition, the use of alternative instruments to assess symptoms and quality of life, along with the exploration of additional reference criteria, could enrich future studies. More work is needed to define the most appropriate assessment tools for routine screening and referral to inpatient and outpatient palliative care. This approach would allow us to more comprehensively measure the impact of our work on patient referral and quality of life in palliative care, both in oncological and non-oncological contexts.

Author Contributions: F.G.—data collection, writing, and review; M.G.—writing and review; I.C.S.P.—statistical analysis and review; F.R. and R.N.—review. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: Data collection respected the rules of the Helsinki Protocol and the Oviedo Convention, and it was approved by the ethics and management committee of the Portuguese Institute of Oncology Francisco Gentil Coimbra (No. TI 17/2020, 9 November 2020). The data measurement tools were distributed individually, accompanied by a letter explaining the nature and objectives of the study and ensuring the confidentiality of the data.

Informed Consent Statement: Informed consent was obtained from all subjects.

Data Availability Statement: The datasets generated and analyzed during the current study are available from the corresponding author upon reasonable request.

Acknowledgments: The authors would like to acknowledge the support of the Portuguese Institute of Oncology Francisco Gentil Coimbra and the University of Porto.

Conflicts of Interest: The authors declare no conflicts of interest.

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3. EVALUATION OF EMOTIONAL DISTRESS IN ONCOLOGY PALLIATIVE PATIENTS: EDMONTON SYMPTOM ASSESSMENT SYSTEM (ESAS) AND PALLIATIVE OUTCOME SCALE (POS)

Gonçalves F, Gaudêncio M, Paiva I, Rego F, Nunes R. Evaluation of Emotional Distress in Oncology Palliative Patients: Edmonton Symptom Assessment System (ESAS) and Palliative Outcome Scale (POS)-A Portuguese Cross-Sectional Study. Cancers (Basel). 2024 Dec 19;16(24):4232. doi: 10.3390/cancers16244232. PMID: 39766131; PMCID: PMC11674550."

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Evaluation of Emotional Distress in Oncology Palliative Patients: Edmonton Symptom Assessment System (ESAS) and Palliative Outcome Scale (POS)—A Portuguese Cross-Sectional Study

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Simple Summary: Patients with advanced cancer often have high levels of emotional suffering, so it is necessary to identify their palliative needs and address them effectively. Although distress is highly prevalent among patients receiving palliative care, research in this area indicates that it remains significantly underdiagnosed and undertreated. The aim of our cross-sectional and correlational study was to analyze the psychometric properties of the Edmonton Symptom Assessment System (ESAS) and the Palliative Outcome Scale (POS) among inpatient cancer patients receiving palliative care in a Portuguese palliative care unit. We confirmed that self-reported anxiety and depression (reported through the ESAS scale) are correlated to emotional questions (reported through the POS), namely, anxiety related to disease, the meaning of life, and sharing feelings. This study showed us that the ESAS and POS complement each other as practical and easy-to-use tools for evaluating emotional distress in the context of palliative care.

Abstract: Introduction: Cancer patients in palliative care frequently experience psychological distress, encompassing cognitive, behavioral, and emotional dimensions. This distress can significantly affect their capacity to accept the inevitability of death. Commonly, such distress manifests as sadness, depression, anxiety, and fear, which may culminate in an existential crisis. Objectives: The purpose of this study was to analyze the psychometric properties of the Edmonton Symptom Assessment System (ESAS) and the Palliative Outcome Scale (POS) among hospitalized cancer patients receiving palliative care in a Portuguese palliative care unit. Methods: Data were collected from psychological screening instruments (ESAS and POS) used in oncology patients admitted to an oncology palliative service. The study period spanned from January 2021 to March 2021. Results: The study included a convenience sample of 60 patients diagnosed with advanced cancer who were sequentially admitted to a palliative care unit. The most frequently reported primary oncological diagnoses were gastrointestinal (41.7%) and head/neck (20%) tumors. The majority of the patients were male (n = 37; 61.7%), with a median age of 72 years (range: 43–94 years). Key findings from the analysis indicated the following associations: anxiety and self-reported symptoms (higher levels of patient anxiety related to illness or treatment were strongly correlated with increased self-reported anxiety ($p < 0.01$)); emotional sharing and perceived meaning of life (patients who shared their feelings less frequently with family and friends were significantly less likely to find meaning in life ($p < 0.01$) and were more likely to report a poorer self-perception ($p < 0.05$)); understanding the importance of life and self-perception (a diminished understanding of the importance of life was associated with worsened self-perception ($p < 0.01$)); anxiety and depressive symptoms (greater anxiety related to the disease or its treatment correlated with an increased severity of depressive symptoms ($p < 0.01$)). Discussion and conclusion: There are numerous validated instruments available for measuring emotional distress. Among these, the ESAS and POS complement each other as practical and easy-to-use tools for evaluating emotional distress in patients admitted to palliative care settings. Findings revealed that anxiety and concerns

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Citation: Gonçalves, F.; Gaudêncio, M.; Paiva, I.; Rego, F.; Nunes, R. Evaluation of Emotional Distress in Oncology Palliative Patients: Edmonton Symptom Assessment System (ESAS) and Palliative Outcome Scale (POS)—A Portuguese Cross-Sectional Study. *Cancers* **2024**, *16*, 4232. https://doi.org/10.3390/cancers16244232

Academic Editor: Albert Tuca-Rodríguez

Received: 1 December 2024
Revised: 15 December 2024
Accepted: 17 December 2024
Published: 19 December 2024

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related to the disease and its treatment, as measured by the POS, served as predictors of the risk for self-reported anxiety and depression identified by the ESAS. Furthermore, the items within the POS that evaluate the emotional component demonstrated strong internal correlation, supporting their combined use for a comprehensive assessment of this dimension.

Keywords: anxiety; cancer; depression; emotional exhaustion; palliative care; palliative medicine; psychological distress

1. Introduction

Cancer and its trajectory from diagnosis to death are associated with significant distress. According to the National Comprehensive Cancer Network (NCCN), distress is defined as "an unpleasant, multifactorial experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with a person's ability to cope effectively with cancer, their physical symptoms and their treatment; extending along a continuum from normal feelings of vulnerability, sadness, and fear of problems that can become disabling, such as depression, anxiety, panic, social isolation and existential and spiritual crisis" [1].

Patients with advanced cancer often have high levels of suffering, so it is necessary to identify their palliative needs and address them effectively. The symptoms that most affect the quality of life of patients in palliative care, often reducing survival, are pain, asthenia, and emotional symptoms such as anxiety and depression [2–4].

According to the World Health Organization (WHO), "Palliative care aims to prevent and relieve health related suffering of adults, children and their families facing problems associated with life-threatening illness. It is based on a comprehensive and person-centred approach, addressing physical, psychological, social and spiritual suffering" [5].

Although emotional suffering is highly prevalent among patients receiving palliative care, research in this area indicates that it remains significantly underdiagnosed and undertreated [6,7].

The early identification of psycho-emotional symptoms in patients receiving palliative care is crucial for ensuring timely referral to psychological or psychiatric consultations [8,9].

Numerous validated instruments are described in the literature to measure emotional distress; however, there is no consensus on which one best evaluates it. Examples include the Distress Thermometer (DT) [10], the Hospital Anxiety and Depression Scale (HADS) [11], and the Brief Symptom Inventory (BSI) [12], among others.

These instruments are used to identify and measure the primary symptoms associated with suffering, as well as the presence of depression, anxiety, existential concerns, spirituality, hope, and demoralization [13].

The Emotional Thermometer is considered the instrument of choice for assessing psychological distress; however, it is not always routinely used by palliative care teams. In practice, the Edmonton Symptom Assessment System (ESAS) and the Palliative Outcome Scale (POS) are the most commonly utilized tools for assessing symptoms in these patients [14].

The Edmonton Symptom Assessment Scale (ESAS) [15] is one of the most widely used instruments for identifying and evaluating the intensity of the most common symptoms in patients receiving palliative care [16]. However, it is known that the psychological symptoms assessed by the ESAS—namely, anxiety and depression—are often overestimated by patients, as this scale refers to symptoms experienced over the last week [17,18].

Hearn and Higginson were pioneers in the development of the POS, a scale initially designed to measure outcomes in palliative care [19]. The scale includes 10 items that assess the physical, psychological, social, and spiritual aspects of these patients' well-being [19]. Items 3, 6, 7, and 8 of the POS are closely related and should be evaluated together, as they pertain specifically to the patient's psychological well-being [20]. When scores on these

items are elevated, it is important to consider the presence of depressive pathology, anxiety disorders, or non-existential spiritual suffering [20].

Given the relevant role that instruments such as the ESAS and POS can play in daily practice in palliative care, documenting their validity is equally important. Therefore, the main objective of this study was to analyze the psychometric properties of the Edmonton Symptom Assessment System (ESAS) and the Palliative Outcome Scale (POS).

2. Material and Methods

2.1. Sample and Design

The authors conducted a cross-sectional, descriptive, and correlational study to assess emotional distress in cancer patients admitted to a Portuguese palliative care unit.

The sample comprised 60 patients who were consecutively admitted between January and March 2021.

The inclusion criteria were defined as adult patients with oncological pathology, receiving palliative care at the hospital, and capable of providing informed, voluntary consent to participate in the study. Exclusion criteria included minors, patients not fluent in Portuguese, those with cognitive deficits, and individuals in the terminal phase of illness.

2.2. Ethical Consideration

Participation in the study was voluntary. Confidentiality and anonymity of participants were assured throughout all stages of the study, with data identified by exclusive code numbers and stored on password-protected laptops, accessible only to the researchers.

2.3. Patient and Public Involvement

Participants were not directly or indirectly involved in the design, implementation, reporting, or dissemination of the study.

2.4. Instruments

The authors developed a sociodemographic and clinical questionnaire that included variables such as age, gender, education level, marital status, residence, companions (caregivers), cancer type, and Eastern Cooperative Oncology Group (ECOG) performance status. The ECOG scale is used to assess the functional level of patients, with scores ranging from 0 (fully active) to 4 (completely unable to perform self-care activities) [21].

The ESAS was developed by Bruera in 1991 and is a validated instrument for identifying and measuring the severity of the most common symptoms in patients with advanced cancer. The scale includes several visual and numerical assessments, scored from 0 to 10 (where 0 reflects the absence of the symptom and 10 represents the worst possible intensity), measuring symptoms such as pain, fatigue, nausea, drowsiness, dyspnea, appetite, depression, anxiety, and well-being [15,22]. It is an easy-to-use tool for both patients and healthcare professionals, having been translated and validated in over 20 languages. The scale takes an average of 1 to 2 min to complete, even for cancer patients in palliative care or those with low health literacy [23].

The literature suggests that while the Edmonton Symptom Assessment Scale (ESAS) is not ideal for diagnosing anxiety and depression, it can serve as an effective screening tool in patients with advanced cancer, who often experience multiple symptoms. The use of various instruments to assess each symptom individually can be logistically challenging, making the ESAS a practical and legitimate option for screening. Studies indicate that scores above 2 on the ESAS are sufficiently sensitive to identify the presence of depression and anxiety [24].

The Palliative Outcome Scale (POS) was developed in 1999, originally designed to measure outcomes in palliative care, particularly psychological well-being and quality of care. It is widely used across several European countries and has been translated and validated in multiple languages. The questions focus on the last three days, and the estimated time for completion is approximately 10 min [20].

The Palliative Outcome Scale (POS) includes two versions: one for the patient and one for the clinical staff. It consists of 10 items, each scored from 0 to 4 on a Likert scale, and these items can be considered individually or summed as a total score. The total score ranges from 0 to 40, with 0 indicating the best quality of life and 40 representing the worst. Additionally, the POS includes two open-ended questions related to the patient's primary concerns [20,25].

The Palliative Outcome Scale (POS) is a multidimensional scale with strong psychometric properties, particularly evident in items 3, 6, 7, and 8. Item 3 also captures family anxiety and should be considered separately. Item 7 ("felt that life was worthwhile") reflects the spiritual component of the scale [20]. Items 5, 9, and 10 assess the quality of care received, while items 1 and 2 evaluate physical symptoms, including pain and other symptoms such as nausea, cough, and constipation [20].

2.5. Statistics

Microsoft® Excel 2016® was used to design the database, and SPSS version 25® was employed for statistical analysis.

For the statistical analysis, frequencies and percentages were calculated for categorical variables, while medians with interquartile ranges were used for quantitative variables. Spearman's rank correlation coefficient was applied to evaluate correlations between the various variables, with p values less than 0.05 considered statistically significant.

3. Results

3.1. Sample's Characteristics

During the study period, 60 patients were included. None of the patients declined participation or were excluded.

The sample's participants had a median age of 72 years (interquartile range: [58.25; 79]), with the majority being male (61.7%). Most patients were married (81.7%) and were living at home (83.3%). Regarding tumor type, most participants had digestive cancer (41.7%), followed by head and neck cancer (20%), breast cancer (10%), and lung cancer (10%) (Table 1).

Table 1. Demographic and clinical characteristics of the sample, POS and ESAS scores, and ECOG performance status (N = 60).

Variables		Sample
Gender, *n* (%)	Male	37 (61.7)
	Female	23 (38.3)
Age (years)	Median [Q1; Q3]	72 [58.25; 79]
	Minimum	43
	Maximum	94
Education level, *n* (%)	Elementary school	49 (81.7)
	High school	5 (8.3)
	Graduation	4 (6.7)
	Absent	2 (3.3)
Marital status, *n* (%)	Married	49 (81.7)
	Single	9 (15)
	Divorced	4 (6.6)
	Widow	16 (26.7)
Residence, *n* (%)	Home	50 (83.3)
	Nursing home	10 (16.7)

Table 1. *Cont.*

Variables		Sample
Companions, *n* (%)	Spouse	30 (50)
	Son/daughter	7 (11.7)
	Siblings	1 (1.6)
	Father/mother/parents	3 (5)
	Without companion	12 (20)
	Other caregivers	7 (11.7)
Types of cancer, *n* (%)	Head and neck	12 (20)
	Cutaneous	3 (5)
	Digestive	25 (41.7)
	Gynecological	5 (8.3)
	Hematologic	1 (1.7)
	Breast	6 (10)
	Prostate	2 (3.3)
	Lung	6 (10)
Total POS Score *	Median [Q1; Q3]	15 [13; 19]
	Minimum	7
	Maximum	25
Total ESAS (GDS) Score *	Median [Q1; Q3]	42.5 [34.25;48]
	Minimum	15
	Maximum	62
ECOG performance status at admission	0	4 (6.6)
	1	6 (10)
	2	10 (16.6)
	3	25 (41.6)
	4	15 (25)

Q1—First quartile; Q3—Third quartile; * Total score was obtained by adding the items.

To assess the functional status of the sample, the authors used the Eastern Cooperative Oncology Group (ECOG) performance status scale. This scale evaluates a patient's level of functioning based on their ability to perform self-care, engage in daily activities, and maintain physical ability [26].

At admission to the palliative care (PC) unit, 6.6% of participants had an ECOG score of 0, indicating they were fully active and able to perform all activities. Moreover, 10% of patients had an ECOG score of 1, meaning they were restricted in physically strenuous activities but able to perform light work. The majority of participants had ECOG scores of 3 and 4, indicating they were capable of only limited self-care or were completely disabled, with severely restricted functionality.

Regarding the global Palliative Outcome Scale (POS) data, participants had a median POS score of 15 (interquartile range: [13; 19]). The Global Distress Score (GDS), a validated subtype of the Edmonton Symptom Assessment Scale (ESAS), is calculated and categorized into three cohorts: high (GDS $\geq$ 35), moderate (16 $\leq$ GDS < 35), and low (GDS < 15) [27]. In this sample, the median GDS score was 43 (range: 17 to 62). The majority of participants (70%) had a GDS $\geq$ 35, indicating a high symptom burden.

3.2. Edmonton Symptom Assessment Scale (ESAS) and Palliative Outcome Scale (POS)—Emotional and Psychological Dimensions

Regarding the ESAS scale, Table 2 presents the descriptive analysis of the psychological dimensions of the scale in the sample.

Table 2. Descriptive analysis of the ESAS Emotional and psychological dimensions by severity (*N* (%)).

	0	Mild (1–3)	Moderate (4–6)	Severe (7–10)
Depression	3 (5)	7 (11.7)	39 (65)	11 (18.3)
Anxiety *	1 (1.7)	6 (10.2)	36 (61)	16 (27.1)

* 1 missing.

In terms of depression, the majority of participants reported moderate to severe levels at palliative care (PC) admission (n = 50; 83.3%). Specifically, 39 patients (65%) exhibited moderate levels, corresponding to a score between 4 and 6 on the ESAS scale. On the other hand, 11 patients presented severe levels of distress, with scores ranging from 7 to 10. Only 10 patients did not report depression or had mild levels of distress.

For anxiety, the sample exhibited high levels of this symptom, with 61% of participants reporting moderate anxiety and 27.1% experiencing severe anxiety. These findings are consistent with those observed in the depression dimension.

Table 3, on the other hand, presents the descriptive analysis of the psychological dimensions of the POS scale.

Table 3. Descriptive analysis of participants' responses to the psychological items of the POS scale (*N* (%)).

Items\Score	0	1	2	3	4
3. Have you been feeling ANXIETY ABOUT DISEASE or treatment?	1 (1.7)	6 (10)	13 (21.7)	36 (60)	4 (6.7)
6. Have you been able to SHARE how you are feeling? *	5 (8.5)	29 (49.2)	21 (35.6)	4 (6.8)	0 (0)
7. Have you felt that life was worthwhile (MEANING OF LIFE)?	7 (11.7)	38 (63.3)	13 (21.7)	2 (3.3)	0 (0)
8. Have you felt good about yourself as a person (SELF-FEELINGS)?	7 (11.7)	35 (58.3)	16 (26.7)	2 (3.3)	0 (0)

* 1 missing. Question 3: 0—no; 1—Occasionally; 2—Sometimes; 3—Most of the time; 4—Always. Question 6, 7, 8: 0—Always; 1—Most of the time; 2—Sometimes; 3—Occasionally; 4—Never.

Regarding anxiety related to the disease process and treatment, the majority of participants reported feeling worried about this (n = 40; 66.7%). Some patients indicated "Sometimes affects my concentration now and then" (n = 13; 21.7%), while others responded "Most of the time often affects my concentration" (n = 36; 60%).

The majority of patients felt that their life was worthwhile (n = 38; 63.3% – responded "Most of the time") and some indicated "Sometimes" (n = 13; 21.7%). No patients considered their life to be not worthwhile. Furthermore, most patients felt good about themselves as individuals (n = 51; 85%), with no patients reporting negative feelings about themselves.

Finally, the authors would like to note that the majority of patients (n = 49; 81.7%) completed the POS questionnaire independently. The remaining patients were assisted by a family member or friend (n = 6; 10%) or by palliative care staff (n = 5; 8.3%).

3.3. Relationship Between ESAS and POS Emotional Dimensions

An analysis was conducted to assess the correlation between the emotional dimensions of the ESAS and POS (Table 4).

A significant correlation was found between self-reported anxiety and anxiety related to the disease (as measured by the POS scale) ($p < 0.01$) (cells in blue). Specifically, higher levels of anxiety related to the disease or treatment were associated with increased self-reported anxiety (ESAS).

It was also found that the less patients shared their feelings, the less they perceived life as meaningful ($p < 0.01$) (cells in orange) and the worse they felt about themselves ($p < 0.01$) (cells in brown).

On the other hand, the less the patient understands the importance of life, the worse they feel about themselves ($p < 0.01$) (cells in purple).

Table 4. Spearman's correlations between the emotional dimensions of ESAS and POS (r).

		ESAS		POS			
		Depression	**Anxiety**	**Anxiety About Disease** [1]	**Sharing Feelings** [2]	**Meaning of Life** [3]	**Self-Feelings** [4]
ESAS	Depression	-	0.792 **	0.386 **	0.245	0.079	0.083
	Anxiety	0.792 **	-	0.473 **	0.164	0.095	0.140
POS	Anxiety about disease [1]	0.386**	0.473 **	-	−0.006	0.143	0.042
	Sharing feelings [2]	0.245	0.164	−0.006	-	0.529 **	0.342 **
	Meaning of life [3]	0.079	0.095	0.143	0.529 **	-	0.635 **
	Self-feelings [4]	0.083	0.140	0.042	0.342 **	0.635 **	-

* $p < 0.05$; ** $p < 0.01$. 1—Have you been feeling ANXIETY ABOUT DISEASE or treatment? (Question 3). 2—Have you been able to SHARE how you are feeling? (Question 6). 3—Have you felt that life was worthwhile (MEANING OF LIFE)? (Question 7); 4—Have you felt good about yourself as a person (SELF-FEELINGS)? (Question 8). Cells in blue—correlation between self-reported anxiety and anxiety related to the disease (measured by the POS scale). Cells in orange—correlation between sharing feelings and meaning of life questions (POS). Cells in brown—correlation between sharing feelings and self-feelings questions (POS). Cells in purple—correlation between self-feelings and meaning of life questions (POS). Cells in pink—correlation between self-reported depression (ESAS) and anxiety related to the disease (POS). Cells in yellow—correlation between self-reported depression and anxiety (ESAS).

Finally, the greater the depressive state reported by the patients, the higher their anxiety related to the disease ($p < 0.01$) (cells in pink) and self-reported anxiety ($p < 0.01$) (cells in yellow).

4. Discussion

Psychological suffering in patients with advanced diseases and those receiving palliative care is often overlooked, creating a significant gap in the holistic management of these patients. Many individuals experience fear, sadness, and grief throughout the course of their disease [13,28]. Literature indicates that psychopathological conditions such as anxiety and depression in cancer patients have prevalence rates ranging from 35% to 50% [13,29,30]. These prevalence rates can be attributed to several factors, including gender, cancer's primary site, measurement instrument used, and the timing/setting of the evaluation [29,30].

Given the recognized impact of emotional suffering on patient well-being, its identification is essential. In the final weeks of life, patients often experience profound sadness and hopelessness, which can diminish their sense of life's meaning and impair their ability to engage in meaningful relationships [31,32].

In our sample, the majority of participants were male, with a median age of 72 years. These findings are consistent with the existing literature. Pitzer et al. indicated that patient's gender did not significantly affect access to palliative care, although some studies have reported worse outcomes for men [33]. Similarly, Christ et al. found that, among 337 patients admitted to a palliative care unit (inpatient care) in Switzerland during 2019, the average age was 71 years, with 56% of patients being male [34]. On the other hand, Sousa et al. examined the sociodemographic characteristics of patients admitted to a palliative care unit (inpatient care) in a Portuguese oncology hospital, finding an average age of 64 years, but, unlike our study, it was observed that 63.4% of patients were female [35].

In our sample, the most frequently observed neoplasm was digestive cancers (41.7%), followed by head and neck neoplasms (20%). These findings are consistent with some data available in the literature. For example, a study carried out in a Brazilian public hospital (inpatient care) found that the most common neoplasms were digestive (colon/rectum—22%; pancreas—16.9%; and stomach—13.6%), followed by head and neck cancers (8.5%) [36]. However, other studies have reported breast cancer as the most prevalent type of cancer in palliative care. A 2015 study found that 34% of patients had breast cancer (outpatient and inpatient care) [37].

Regarding the global Palliative Outcome Scale (POS) data, the participants exhibited a median POS score of 15 (interquartile range: 13;19) and a median Global Distress Score (GDS) of 43 (range: 17-62). A majority of the participants (70%) had a GDS $\geq$ 35, reflecting a

high symptom burden. Furthermore, 66.6% of the participants had an Eastern Cooperative Oncology Group (ECOG) performance status of 3 or 4, indicating a significant degree of functional impairment. These results are consistent with expectations, as the primary reasons for admission to a palliative care unit are typically inadequate symptom control and significant functional limitations.

Symptom management is a fundamental pillar of palliative care. High-quality care necessitates the use of validated and effective measurement instruments to document and assess symptoms accurately.

The Edmonton Symptom Assessment System (ESAS) is a multidimensional instrument that is easy to use and demonstrates good reliability in identifying and assessing the intensity of the 10 most common symptoms in palliative care, including those in patients nearing the end of life [38]. The scale consists of ten self-report items, assessing two emotional symptoms, seven physical symptoms, and an overall sense of well-being. However, it is important to note that the emotional component of the ESAS, which includes anxiety and depression, has not been formally validated within this instrument [24,38]. According to Vignaroli et al., a score greater than 2 out of 10 on the ESAS's anxiety and depression items in palliative care patients is considered the ideal cutoff point for screening these symptoms [24].

Gontijo et al. also found high prevalence rates of anxiety and depression in palliative care patients (outpatient clinic); this was associated with perceived quality of life, functional status, and the presence of other uncontrolled physical symptoms, such as fatigue, nausea, vomiting, and loss of appetite [39]. Similar to our findings, these patients had high symptom intensity (with a median GDS score of 43, ranging from 17 to 62) and low functionality (66.6% had an ECOG score of 3 or 4) [39]. Furthermore, Traldi Macedo et al. presented a cross-sectional study, involving 59 patients with advanced cancer (inpatient care), 52.5% of whom had depression and 76.3% had anxiety [36]. These data were obtained through the assessments with the ESAS tool [36]. In our study sample, the majority of patients exhibited high levels of depression and anxiety at admission to the palliative unit, with 83.3% experiencing depression and 61% experiencing anxiety.

The ESAS is a multidimensional scale that assesses symptomatic intensity, including physical and emotional symptoms. However, for a more complete assessment, it may be necessary to evaluate all dimensions of palliative care, including physical, psychological, spiritual, and social aspects.

The Palliative Outcome Scale (POS), developed by Irene Higginson at the Department of Palliative Care and Policy at King's College London, is a 10-item multidimensional scale [40]. The scores range from 0 to 4 and assess various aspects such as pain and other physical symptoms, patient and family anxiety, emotional well-being, quality of information provided, and social support over the previous three days [40]. The POS is available in two versions: the self-version for the patient and the proxy version for healthcare staff. In this study, we utilized the self-version, as we believe that the patients' own responses provide the most reliable information [40].

The psychological well-being component of the POS is represented by items 3, 6, 7, and 8, with the total score for these items ranging from 0 to 16 [20].

In the study, 66.7% of patients reported feeling worried and anxious about the disease process and its treatment. Only 6.7% were able to share how they were feeling, 3.4% felt that life was worthwhile, and 3.4% felt good about themselves as a person.

Traldi Macedo et al. reported that, approximately 39% of patients (admitted to a palliative care unit—inpatient care) gave severe scores (3 or 4) on the following question: "Have you been feeling anxious or worried about your illness or treatment?" [36]. Additionally, 18.6% of patients responded similarly to the question "Have you been able to share how you are feeling with your family or friends?" [36]. Around 32% reported severe scores for the question "Have you felt that life was worthwhile?", and 13.5% gave severe scores for the question "Have you felt good about yourself as a person?" [36].

Bausewein et al. conducted a study with 118 patients to validate the Palliative Outcome Scale (POS) in Germany [41]. The scale was administered on days 1 to 3 after admission (inpatient care), and then again after 3 or 4 days [41]. The study included all patients referred to palliative care over a 3-month period in 2002 [41]. In the initial assessment, severe scores (3/4) were reported by 41% of patients regarding anxiety about their disease or treatment [41]. Only 10% of patients reported being able to share how they felt; 36% felt that life was worthwhile; and 29% felt good about themselves as a person [41].

Antunes et al. conducted a multi-center study involving 1,703 cancer and non-cancer patients (inpatient and outpatient care) to explore the psychometric properties of the Integrated Palliative Outcome Scale (IPOS) [42]. They found that 13.3% of the participants felt anxious or worried about their disease, while 9.6% reported feeling depressed [42]. The study concluded that the IPOS is an effective tool for screening these two psychological symptoms in patients with advanced disease [42].

The discrepancies between our study and the existing literature may be attributed to several factors. The institution's policy at the time of the study stipulated that patients would only be referred to the palliative care team once curative treatments were no longer pursued, meaning that referrals were often made at a late stage, with patients nearing the end of life. Furthermore, the study was conducted during the COVID-19 pandemic, a period marked by social isolation due to restrictions on interpersonal contact and visits from family and friends in hospitals. These factors likely contributed to a heightened sense of distress among patients. In line with this, Obispo-Portero et al. conducted a multicenter study with 401 patients with advanced cancer during the pandemic (outpatient care) and found that the incidence of anxiety and depression was 36% and 35%, respectively [43].

Lastly, the authors decided to correlate the ESAS psychological dimensions (anxiety and depression) with POS psychological questions.

This analysis revealed several significant correlations: greater anxiety regarding the illness or treatment was associated with higher levels of self-reported anxiety ($p < 0.01$); the less the patient shares their feelings with family and friends, the less they perceive life as meaningful ($p < 0.01$), and the worse they feel about themselves ($p < 0.05$); a lower understanding of the importance of life was linked to a worse self-perception ($p < 0.01$); and higher levels of anxiety related to the disease or treatment were associated with increased depressive symptoms ($p < 0.01$).

Anxiety and concern regarding the disease and treatments measured by the POS appears to be predictive of the patient's self-reported anxiety and depression in the ESAS. The items that assess the emotional component in the POS are self-correlated with each other, so they must be observed together.

The study demonstrates the importance of a holistic assessment and management of anxiety in palliative care. At the time this study was carried out, patients had a psychological assessment when the physician, nurse, and/or social worker identified this need and requested psychological support. This approach was adapted to the presence of only two psychologists included in the multidisciplinary team (but also with the role of supporting the entire oncology unit). This study demonstrated the importance of earlier evaluation and support of psychological symptoms, and, at the moment, the team is made up of four members, which allows for the assessment of practically all patients, especially upon admission to the unit (inpatient care).

5. Limitations

The sample size is relatively small, which was influenced by the conduct of the research during the COVID-19 pandemic.

Conducting this research in a single hospital further constrained the sample characteristics and size. Future studies should aim to expand the sample by involving multiple palliative care teams, in order to reduce bias and include a larger and more diverse patient population, including, for example, non-oncological patients.

The cross-sectional design of the study allowed knowing the current status of the patients but did not evaluate the palliative intervention on the management of emotional symptoms. Further studies of longitudinal use of the ESAS and POS in management of distress are recommended.

Finally, the authors would like to add that there is a long delay between the data collection and their publication, which is related to excessive work in professional terms, partly related to the COVID-19 pandemic. However, the results found make sense in the context of palliative care, as we can see in the discussion section.

6. Conclusions

Emotional distress is common in patients with advanced cancer [44,45].

There are several tools to identify and evaluate patient with psychological symptoms and in need of more specialized assessment [46,47]. However, there is a lack of consensus regarding the best instrument to assess suffering and emotional distress in palliative care [46,47].

This study evaluated the psychometric properties of the ESAS and POS. It was found that the anxiety and concern related to the disease and treatment, as measured by the POS, served as a predictor for self-reported anxiety and depression in the ESAS. The items assessing the emotional component of the POS were strongly correlated with one another and should be used together when evaluating this dimension.

These instruments are widely used in clinical practice within palliative care due to their ease of use, which facilitates better integration into the routine operations of care teams.

Although neither of these scales is specifically designed to assess the psychological profile of patients in palliative care, they are among the most commonly utilized measurement tools by palliative care teams. Elevated scores on the psychometric items of each scale may serve as an indication for the implementation of more specific instruments, such as the Emotional Thermometer or the Anxiety and Depression Scale, and underscore the need for intervention by the team's psychologist or psychiatrist.

Author Contributions: Conceptualization, F.G.; methodology, F.G.; validation, F.G.; formal analysis, F.G., M.G. and I.P; investigation, F.G.; resources, M.G.; data curation, F.G.; writing—original draft preparation, F.G. and M.G.; writing—review and editing, I.P., F.R. and R.N.; visualization, M.G. and I.P.; supervision, F.R. and R.N. All authors have read and agreed to the published version of the manuscript.

Funding: This research received no external funding.

Institutional Review Board Statement: Data collection respected the rules of the Helsinki Protocol and the Oviedo Convention, and it was approved by the ethics and management committee of the Portuguese Institute of Oncology Francisco Gentil Coimbra (No. TI 17/2020, 9 November 2020). The data measurement tools were distributed individually, accompanied by a letter explaining the nature and objectives of the study and ensuring the confidentiality of the data.

Informed Consent Statement: Informed consent was obtained from all subjects.

Data Availability Statement: The datasets generated and analyzed during the current study are available from the corresponding author upon reasonable request. Some of the results are similar to those presented in another article, as they are the result of the same research project (Gonçalves, F., Gaudêncio, M., Paiva, I., Semedo, V. A., Rego, F., & Nunes, R. (2024). Impact of Symptom Distress on the Quality of Life of Oncology Palliative Care Patients: A Portuguese Cross-Sectional Study. *Healthcare*, *12*(23), 2487. https://doi.org/10.3390/healthcare12232487).

Acknowledgments: The authors would like to acknowledge the support of the Portuguese Institute of Oncology Francisco Gentil Coimbra and the University of Porto.

Conflicts of Interest: The authors declare no conflicts of interest.

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CAPÍTULO

6

DISCUSSÃO

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Este estudo foi realizado numa população específica de doentes portadores de patologia oncológica com seguimento em cuidados paliativos no dia em que foram admitidos na Unidade de Cuidados Paliativos.

Verificou-se um predomínio dos indivíduos do género masculino (n=37; 61,7%) e a mediana de idades foi de 72 anos (intervalo 43-94). Estes resultados não diferem muito do que se encontra na literatura. Segundo os autores Pitzer et al., o tipo de género não afeta significativamente o acesso aos cuidados paliativos, embora alguns estudos indiquem piores resultados para os homens (Pitzer et al., 2023). Da mesma opinião são os autores Christ et al, ao verificarem que nos 337 doentes admitidos numa Unidade de Cuidados Paliativos da Suíça em regime de internamento durante o ano de 2019, a média de idades foi de 71 anos e 56% eram homens (Christ et al., 2023). Por outro lado, Sousa et al. avaliaram as caraterísticas sociodemográficas dos doentes internados numa Unidade de Cuidados Paliativos portuguesa e verificaram que 63,4% eram mulheres e a media de idades era de 64 anos (Sousa, Moreira, & Pires, 2023). Karaman et al. realizaram um estudo em que utilizaram a Escala de Avaliação de Sintomas de Edmonton (ESAS) numa população de doentes em cuidados paliativos e encontraram um predomínio de indivíduos do género feminino (51,9%) e uma média de idades de 54,04 +- 15,89 anos (Karaman et al., 2022). Antunes e Ferreira conduziram um estudo de validação da Integrated Palliative Care Out come Scale (IPOS) numa população portuguesa de doentes em cuidados paliativos e verificaram que os participantes apresentavam uma média de idades de 66,8+-12,7 anos (Antunes & Ferreira, 2020). Kaasa et al. estudaram as caraterísticas sociodemográficas de doentes admitidos em Unidades de cuidados paliativos europeias e constataram um predomínio das mulheres (56%) e uma média de idades de 66 anos (Kaasa et al., 2007).

O predomínio dos homens nesta amostra pode ser atribuído a dois fatores: o pequeno número de cancros da mama presente (10%) e serem os tumores do foro digestivo (41,7%) e de cabeça e pescoço (20%) os mais prevalentes. Sabe-se que os cancros gastrointestinais (nomeadamente colo-retais e gástricos) e os cancros de cabeça e pescoço são os que apresentam maior taxa de mortalidade no homem (Kaasa et al., 2007). Num estudo realizado num hospital público do Brasil em doentes internados verificou-se que o tipo de neoplasias mais comuns foram as do foro digestivo (colo-retal em 22%, pâncreas em 16,9% e gástrico em 13,6%), seguido pelas neoplasias de cabeça e pescoço (8,5%) (Macedo et al., 2022).

Em 2019, afirmou-se que os cancros de cabeça e pescoço eram cerca de 1,2 vezes mais prevalentes nos homens do que nas mulheres (Semprini et al., 2024; Park et al., 2022; Kim et al., 2018). Modonesi et al. realizaram um estudo numa Unidade de Cuidados Paliativos italiana, em que os resultados foram um pouco diferentes. Neste estudo, o tipo de cancro mais prevalente foi o digestivo (30.2%), segudo pelo cancro do pulmão (18.5%) e pelo cancro da mama (11.1%) (Modonesi et al., 2005). Outros estudos indicam que o tipo de cancro mais comum em cuidados paliativos é o cancro da mama. Em 2015, um estudo realizado em cuidados paliativos quer em regime de internamento, quer em regime de ambulatório, encontrou taxas de 34% de doentes com cancro de mama (Paiva et al., 2015). Fairchild et al. nos seus estudos encontraram uma prevalência de 29,9% de doentes em cuidados paliativos com cancro do pulmão e do trato gastro-intestinal e somente de 3,2% de cancros de cabeça e pescoço (Sharon et al., 2020).

A introdução da imunoterapia para o tratamento do cancro do pulmão melhorou significativamente a sobrevivência dos doentes com esta neoplasia (Mamdani et al., 2022), o que pode justificar a sua baixa prevalência na amostra deste estudo. A litertura mostra-nos que houve uma melhoria substancial taxa de sobrevida dos doentes com cancro desde que a imunoterapia começou a ser implementada (Mouritzen et al., 2021).

A equipa de cuidados paliativos do hospital onde o estudo foi realizado cuida em média de cerca de 400-500 doentes por ano e tem diversos tipos de tipologias: internamento, consulta externa e equipa intra-hospitalar de suporte em cuidados paliativos.

Os doentes admitidos na Unidade de internamento provieram ou da Consulta Externa de Cuidados Paliativos ou de outros serviços do hospital após avaliação pela Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos. À data de internamento na Unidade de Cuidados Paliativos, 32 doentes (53,3%) foram admitidos a partir da Consulta Externa. Os restantes doentes (n=28; 46,7%) encontravam-se noutras enfermarias do hospital com o apoio da Equipa Intra-Hospitalar de Suporte em Cuidados paliativos. Hochman et al. realizaram um estudo em que compararam as caraterísticas dos doentes em regime de ambulatório com os que se encontravam internados (Hochman et al., 2016). Naquela amostra, a maioria dos doentes também se encontravam em regime de ambulatório (n= 417; 66%) (Hochman et al., 2016), similar ao estudo desta dissertação.

Nesta amostra, verificou-se que a maioria dos doentes se apresentava em estadio IV à data do diagnóstico, logo numa fase muito avançada da doença. Além disso, 66,6% dos participantes apresentavam um ECOG 3 ou 4, ou seja, apresentavam

um baixo nível de funcionalidade. Estes resultados estão de acordo com o esperado, uma vez que os principais motivos de internamento de doentes em cuidados paliativos são o inadequado controlo sintomático e a limitação funcional.

Um dos objetivos do estudo foi avaliar a intensidade dos sintomas e a percepção da qualidade de vida nas primeiras 24 horas de admissão na UCP tanto na amostra em geral como nos dois subgrupos em particular (ambulatório vs internados). Neste estudo, quando avaliado o score total da ESAS e da POS para cada tipo de neoplasia, as diferenças observadas foram mínimas. Doentes com tumores de cabeça e pescoço apresentaram uma mediana mais alta na POS. Os tumores da mama, ginecológicos e do pulmão foram os que apresentaram medianas mais altas na ESAS.

Nesta amostra, o GDS apresentou como mediana um score de 43, sendo o valor mínimo 17 e o máximo 62. A maioria dos participantes obtiveram um GDS superior ou igual a 35 (n= 42; 70%), o que significa que o descontrolo sintomático era elevado. A escala ESAS é um instrumento que apenas permite avaliar a presença e a intensidade dos sintomas em causa.

A avaliação realizada através da escala POS permitiu obter uma mediana de 15, sendo o mínimo de 7 e o máximo de 25. A escala POS é uma escala de resultados que engloba a multidimensionalidade da qualidade de vida nos doentes em cuidados paliativos (Rugno & De Carlo, 2016). Assim, na amostra os doentes apresentam uma qualidade de vida relativamente satisfatória, apesar do elevado descontrolo sintomático. Estes resultados podem ser atribuídos à natureza holística da POS, que avalia outras dimensões, para além dos sintomas na doença avançada (Bausewein et al., 2011). A POS avalia uma série de aspetos em cuidados paliativos, incluindo sintomas físicos, bem-estar psicológico, necessidades emocionais e espirituais e as informações e suporte dados à família.

De acordo com a Declaração Universal dos Direitos Humanos e a Declaração de Bioética da UNESCO, a bioética é um campo global, plural e transdisciplinar, centrado nos princípios dos direitos humanos, nomeadamente o respeito pela dignidade e autonomia de todos. Assim, o controlo sintomático em cuidados paliativos com base nos princípios fundamentais da bioética é fundamental, sendo igualmente um imperativo ético maximizar todos os esforços para que a melhor qualidade de vida possível seja atingida. (Nunes & Rego, 2018; Leão, Gallo & Nunes, 2022).

No grupo dos doentes admitidos na UCP que eram seguidos na Consulta externa de cuidados paliativos, verificou-se uma mediana mais alta da ESAS para os ítems fadiga e dispneia. No grupo dos doentes internados noutras enfermarias do IPO verificou-se que a ESAS apresentou uma mediana mais elevada para a dor, depressão

e ansiedade. Para os restantes sintomas, a mediana foi igual em ambos os grupos. No entanto, em nenhum dos casos houve diferenças estatisticamente significativas.

Hochman et al. desenvolveram um estudo em que avaliaram a carga sintomática dos doentes em cuidados paliativos, tanto em regime de ambulatório como em regime de internamento e verificaram que os doentes que permaneciam no domicílio apresentavam mais fadiga, dor e náuseas (Hochman et al., 2016). Os doentes que haviam sido internados apresentavam mais anorexia e disfagia (Hochman et al., 2016). A diferença encontrada entre os dois estudos pode ser justificada pelo tipo de amostra. No estudo desta dissertação apenas foram incluídos doentes oncológicos, enquanto o estudo de Hochman et al. englobou tanto doentes oncológicos como não oncológicos.

A intensidade dos sintomas na maioria dos doentes com cancro varia de acordo com o tipo de neoplasia, o seu estadio e o tratamento recebido (Solano et al., 2006; AlQadire & Al Khalaileh, 2016). No cancro metastático, 35% a 96% dos doentes sentem dor, 32% a 90% fadiga, e 10% a 70% dispneia (Henson et al., 2020).

Diferenças estatisticamente significativas foram observadas entre os dois grupos em vários itens da POS, tais como no significado da vida, sentimentos com o próprio e tempo perdido. Neste estudo, a distribuição dos valores com significado estatístico verificou-se no significado da vida ($p = 0,0031$) e sentimentos com o próprio ($p= 0,0047$), com uma mediana superior no grupo dos doentes previamente internados à admissão na UCP. Quanto ao tempo perdido ($p = 0,033$), a mediana foi superior no grupo dos doentes seguidos na consulta externa de cuidados paliativos. Assim, o grupo dos doentes internados apresentaram uma perceção menos positiva de que a vida valia a pena e de auto-perceção em comparação como os doentes que permaneciam no domicílio. Os doentes em ambulatório tiveram a noção de maior tempo perdido, nomeadamente no que diz respeito a trasnportes e realização de exames complementares de diagnóstico.

Santos et al. realizaram um estudo cujo objetivo foi identificar os fatores que influenciavam a qualidade de vida dos doentes em cuidados paliativos domiciliários (dos Santos, Soeiro, & Maués, 2020). Neste estudo, 22,2% dos doentes referiram sentir-se bem com eles próprios e 55,5% consideraram que os cuidados relacionados à sua saúde ocupavam mais de metade dos seus dias (dos Santos, Soeiro, & Maués, 2020). As diferenças observadas em relação ao estudo que deu origem a esta dissertação podem ser atribuídas ao local de cuidados – os doentes desta investigação eram seguidos por equipas de cuidados paliativos hospitalares (Consulta externa vs Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos) enquanto os doentes do

estudo de Santos et al. eram seguidos por equipas de cuidados paliativos domiciliários.

O grupo dos doentes internados apresentou valores menos satisfatórios de qualidade de vida, o que se pode explicar pelo internamento em si, fora do seu ambiente familiar. Tal como esperado, os doentes provenientes da consulta externa queixaram-se mais do tempo gasto em consultas e logística associada.

A Escala de Avaliação de Sintomas de Edmonton (ESAS) é um instrumento credível na avaliação de sintomas em cuidados paliativos, possibilitando a sua monitorização ao longo do tempo (Bruera et al., 1991).

Ao longo dos anos, a abordagem da dor e das náuseas tem melhorado significativamente através da descoberta de terapêuticas alvo eficazes (Henson et al., 2020). No entanto, outros sintomas como a anorexia e o bem-estar em geral, têm recebido comparativamente menos atenção nos estudos de investigação (Henson et al., 2020). Os tratamentos atuais desses sintomas têm demonstrado eficácia limitada, levantando importantes questões sobre o verdadeiro impato dos cuidados paliativos no alívio sintomático e no sofrimento associado (Henson et al., 2020).

Neste estudo, sintomas tais como a dor, as náuseas, a sonolência e a dispneia apresentaram níveis ligeiros a moderados, refletindo o início rápido e eficaz dos cuidados paliativos nos doentes tanto em regime de ambulatório como de internamento assim que referenciados. De acordo com uma revisão de Cochrane, a intervenção precoce dos cuidados paliativos pode trazer não só efeitos benéficos na intensidade dos sintomas como na melhoria global da qualidade de vida (Haun et al., 2017). A fadiga, a depressão, a ansiedade, a perda de apetite e o bem-estar obtiveram a pontuação mais alta nesta amostra, significando que estes sintomas são mais difíceis de controlar.

A perda de apetite e a caquexia são muito comuns nas fases avançadas da doença oncológica (Siemens et al., 2020). Contudo, a caquexia não pode ser atribuída apenas à baixa ingesta calórica, dado que na maioria das vezes não é revertida com a sua suplementação (Siemens et al., 2020). Alterações analíticas, como a anemia, alterações dos parâmetros inflamatórios e baixos níveis de albumina têm um papel significativo neste processo (Siemens et al., 2020; Strasser & Bruera, 2002). A anorexia é um dos sintomas mais comum nos cuidados paliativos (Strasser & Bruera, 2002). Num estudo que envolveu uma amostra de 3030 doentes em cuidados paliativos, 26% apresentavam anorexia em níveis moderados a severos (Agar & Razmovski-Naumovski, 2024). O tratamento farmacológico incluiu essencialmente estimulantes do apetite; contudo, estas intervenções não reverteram a maioria dos doentes com caquexia (Turcott et al., 2021). À semelhança da anorexia, muitos

doentes queixam-se também de fadiga (Klasson et al., 2021). Dada a sua etiologia multifactorial, a abordagem e o tratamento da astenia é também um desafio (Klasson et al., 2021). Torna-se necessário investigar potenciais causas reversíveis passíveis de tratamento (Klasson et al., 2021). Se essas causas não forem identificadas, são poucas as opções terapêuticas farmacológicas nos doentes em cuidados paliativos (Klasson et al., 2021).

As terapêuticas não farmacológicas também têm mostrado uma eficácia limitada (Klasson et al., 2021). Consistem em terapêuticas complementares que têm como alvo a melhoria da qualidade de vida dos doentes em cuidados paliativos, ao tentar reduzir a carga sintomática (Henson et al., 2020). Na literatura, algumas das intervenções não farmacológicas com impacto na área dos cuidados paliativos são a fisioterapia, a musicoterapia, a massagem terapêutica, as estratégias cognitivo-comportamentais e a aromaterapia (Hosokawa et al., 2022). No caso particular da fadiga, o exercício aeróbico, tem resultados positivos consistentes na depressão e na qualidade do sono (Tomlinson et al., 2014). No caso da anorexia, as intervenções não farmacológicas incluem aconselhamento alimentar e redução do stress do doente e familia à hora das refeições (Childs e Jatoi, 2019). Refeições pequenas e atrativas e enriquecidas constituem um tipo de intervenção não farmacológica eficaz na rotina dos cuidados paliativos (Ehret & Jatoi, 2021).

É importante realçar que os doentes que vivem sozinhos apresentam uma maior redução do apetite à admissão, melhorando ao longo do internamento (Helgesen et al., 2024). A atenção à dimensão social é fundamental no tratamento da falta de apetite em cuidados paliativos (Helgesen et al., 2024). Iniciativas como a partilha de refeições com outros doentes, cuidadores ou profissionais de saúde podem ser uma grande ajuda durante o internamento (Helgesen et al., 2024).

A gestão adequada dos sintomas, mais especificamente da anorexia, em cuidados paliativos deve respeitar os princípios da bioética, nomeadamente da autonomia, da beneficência e da não-maleficiência, evitando a futilidade terapêutica como é o caso da alimentação e hidratação artificiais nos doentes em fim de vida (Block, 2007).

As doenças ameaçadoras de vida podem desencadear o aparecimento de psicopatologia como seja a ansiedade e a depressão (Siemens et al., 2020). Além das necessidades físicas, é importante estar igualmente atento às necessidades psicológicas, sociais e espirituais (Siemens et al., 2020). A equipas de cuidados paliativos devem priorizar todas as dimensões quando prestam estes cuidados e serem dotadas dos recursos humanos multidisciplinares necessários para tal. (Siemens et al., 2020).

A Palliative Outcome Scale (POS) é uma medida psicométrica válida para avaliar a qualidade de vida dos doentes em cuidados paliativos (Stevens et al., 2005). Identifica cinco áreas chave: o bem-estar emocional, as consequências da doença na vida diária, o suporte e informação recebida, a ansiedade e o impacto negativo da doença (Ferreira et al., 2008). Sintomas como as náuseas, a tosse, a obstipação e a ansiedade sentida tanto por doentes como por familiares tiveram um forte impacto na qualidade de vida dos doentes da amostra em estudo.

A equipa deve priorizar a identificação e a abordagem precoces tanto dos sintomas físicos como emocionais. Siemens et al. descobriram que cerca de 20% dos doentes recentemente diagnosticados com doença oncológica avançada exibiam níveis consideráveis de ansiedade e depressão, os quais condicionavam declínio da qualidade de vida (Siemens et al., 2020). A identificação precoce de necessidades paliativas não reconhecidas induz a que se obtenham melhores resultados (Klasson et al., 2021). Sem a triagem adequada dos sintomas, os doentes podem sentir diminuição do seu bem-estar, afetando negativamente as suas atividades da vida diárias, a qualidade do sono e as relações inter-pessoais (Chapman et al., 2022).

Também foi analizado o comportamento da pontuação total da POS e da ESAS com o ECOG e com os fatores sociais. Não se verificou nenhuma correlação entre o score total da ESAS ou da POS com nenhuma caraterística social ou clínica, exceto no número de filhos, os quais apresentaram uma associação estatisticamente significativa com a POS. Não há na literatura estudos que justifiquem estes achados. Contudo, não se pode esquecer o importante papel da família como cuidadora de doentes em cuidados paliativos, pelo que perceber a relação exsitente entre o doente e os filhos cuidadores é importante (Krug et al., 2016). O envolvimento da família, o conhecimento que têm acerca da doença e dos tratamentos, as habilidades comunicacionais com o familiar doente e com a equipa melhoram a qualidade de vida do doente e dos cuidadores (Pop, Puia, & Mosoiu, 2022). Os familiares dos doentes em cuidados paliativos enfrentam vários eventos stressores, desde a tomada de decisões difíceis até ao luto (Lichtenthal & Kissane, 2008).

Os diversos membros da família são importantes para enfrentarem circunstâncias adversas e ajudarem o familiar enfermo (Lichtenthal & Kissane, 2008). No entanto, estas mesmas circunstâncias também podem ser fonte de conflito (Lichtenthal & Kissane, 2008).

Os conflitos podem emergir quando há a percepção de que um determinado familiar presta assistência insuficiente (Strawbridge & Wallhagen, 1991), quando há dificuldade na coordenação de cuidados ou pensamentos ruminativos sobre climas de tensão anteriores (Kramer, Boelk, & Auer, 2006). Estes conflitos tendem a acentuar-

se quanto mais numerosas são as famílias, com membros com diferentes estilos de coping. Os conflitos familiares podem ser eles próprios uma fonte de stress para o doente, afetando a sua qualidade de vida.

Outro objetivo deste estudo foi avaliar o tempo de referenciação a cuidados paliativos na amostra total e de acordo com os diferentes modelos de abordagem (ambulatório vs internamento) no sentido de perceber se esta referenciação foi precoce ou tardia. Na amostra total, verificou-se que a mediana entre o diagnóstico e a referenciação a cuidados paliativos foi de 323 dias, entre o tempo de referenciação e a primeira avaliação por cuidados paliativos de 3 dias, entre o diagnóstico e e a admissão na UCP de 439 dias, entre o tempo de referenciação e a admissão na UCP de 8 dias e entre a referenciação a cuidados paliativos e a morte de 36 dias. Todos os períodos de tempo apresentaram diferenças estatisticamente significativas entre os dois grupos da amostra, exceto no tempo que decorreu entre o diagnóstico e a admissão na Unidade de Cuidados Paliativos.

Neste estudo, a mediana temporal entre o diagnóstico e a referenciação a cuidados paliativos foi de 323 dias, correspondendo quase a um ano. Tendo em conta que cerca de 71% dos doentes se encontrava em estadio IV ao diagnóstico, este hiato de tempo não é, de todo, apropriado. Ferrel et al. são da opinião que todos os doentes com cancro avançado devem ser seguidos simultaneamente por uma equipa multidisciplinar que inclua o oncologista e o paliativista nas primeiras oito semanas após o diagnóstico (Ferrell et al., 2017).

No contexto hospitalar onde o estudo foi realizado, as políticas institucionais da altura determinavam que a referenciação a cuidados paliativos apenas deveria ter lugar após esgotadas todas as terapêuticas curativas. A escassez de recursos humanos dedicados aos cuidados paliativos era uma das principais razões para que tal acontecesse.

O tempo que decorreu entre o diagnóstico e a referenciação a cuidados paliativos foi mais elevada no grupo dos doentes internados (600 dias). Estes doentes encontravam-se a receber tratamentos de quimioterapia e foram apenas referenciados a cuidados paliativos no fim de vida.

O tempo que decorreu entre a referenciação a CP e a primeira avaliação pela equipa de cuidados paliativos teve uma mediana de cerca de 3 dias, o que sugere prontidão na resposta desta equipa. No entanto, esta mediana foi superior no grupo dos doentes em ambulatório, cerca de 18 dias comparativamente aos 2 dias no grupo dos doentes internados. Os doentes provenientes da Consulta externa de cuidados paliativos são geralmente referenciados mais cedo no decurso da trajetória da doença, permitindo que seja criada uma relação de auto-confiança com o doente e família

(Hoerger et al., 2018). Por outro lado, as equipas intra-hospitalares de suporte em cuidados paliativos são habitualmente envolvidas mais tarde no curso da doença, levando a que, muitas vezes, apenas possam intervir no controlo das agudizações de sintomas e tomada de decisões em contexto de hospitalização (Hoerger et al., 2018).

Capelas et al. realizaram um estudo Delphi em que tentaram definir indicadores de qualidade para as equipas de cuidados paliativos (Capelas et al., 2018). Um desses indicadores foi que as avaliações de cuidados paliativos fossem realizadas nas primeiras 48 horas após a referenciação para a equipa (Capelas et al., 2018). Neste estudo, o tempo que decorreu entre a referenciação e a admissão na UCP teve uma mediana de 8 dias. Este hiato temporal foi maior no grupo dos doentes em ambulatório (88 vs 3 dias). Resultados idênticos foram observados no tempo que decorreu entre a referenciação a cuidados paliativos e a morte. Um estudo PRISMA mostrou que, em Portugal, mais de metade dos doentes preferiam que o seu local de morte fosse em casa, mas, na realidade, a verdade é que mais de 60% das mortes ocorrem nos hospitais e somente 20% em casa (Gomes et al., 2012).

Sousa et al. conduziram um estudo numa equipa de cuidados paliativos portuguesa dediacada a doentes com cancro em que foi avaliada a proveniência dos doentes; verificaram que 56,1% eram admitidos a partir dos serviços de urgência e 22% através da transferência do serviço de oncologia (Sousa, Moreira, & Pires, 2023).

A maioria dos doentes seguidos pela Equipa Intra-Hospitalar de Suporte em Cuidados Paliativos encontravam-se internada em enfermarias de Oncologia. Muitos destes doentes já se encontravam em tratamento de suporte, apresentando uma elevada carga sintomática, quando foi pedido o apoio da equipa de cuidados paliativos. A transição abrupta dos tratamentos curativos para os tratamentos paliativos pode ser muito traumática para o doente e família, causando desesperança e medo de abandono (Burge et al., 2005).

Tagami et al. investigaram o tempo de referenciação para cuidados paliativos em doentes com cancro (Tagami et al., 2022). Verificaram que 20,9% (n = 102) dos doentes foram referenciados à data do diagnóstico, 11,4% (n = 56) durante os tratamentos anti-neoplásicos e 36,2% (n = 177) quando já não havia mais opções terapêuticas curativas (Tagami et al., 2022). Cerca de 5,1% dos doentes referiram que nunca foram referenciados para equipas especializadas de cuidados paliativos (Tagami et al., 2022).

O descontrolo sintomático e o sofrimento causado pela doença podem ser melhor compreendidos por uma equipa de cuidados paliativos que acompanhe o doente tanto durante os tratamentos oncológicos standard como no fim de vida (Devi, 2011).

O tempo que decorreu entre a avaliação por cuidados paliativos, a admissão na UCP e a morte foram menores no grupo dos doentes internados comparativamente ao grupo de doentes seguidos na Consulta externa de cuidados paliativos. Neste estudo, a equipa de cuidados paliativos acompanhou em média os doentes em regime de ambulatório durante cerca de três meses (88 dias) previamente à necessidade de admissão na UCP (frequentemente por motivos clínicos ou psicossociais, tal como a exaustão do cuidador), o que reflete uma referenciação tardia a cuidados paliativos (Hirvonen et al., 2020).

O tempo que decorreu entre a referenciação a cuidados paliativos e a morte teve uma mediana de 36 dias. Sabe-se que a referenciação a cuidados paliativos é feita entre 6 meses a um ano antes da morte até a apenas alguns dias ou semanas antes da mesma. A definição de integração precoce dos cuidados paliativos é controversa. A literatura mostra-nos que são necessários no mínimo 3 a 4 meses para que os doentes possam beneficiar em pleno de uma equipa de cuidados paliativos (Davis et al., 2015). Em 2018, a Lancet's Committee on Palliative Care and Pain Relief concluiu que os cuidados paliativos e o alívio da dor era insuficiente a nível global (Knaul et al., 2018).

Na correlação do tempo de referenciação a cuidados paliativos com a intensidade dos sintomas (medido pela ESAS) e a perceção de qualidade de vida (aferida pela POS) na amostra total e de acordo com os diferentes tipos de abordagem (consulta externa vs internamento), verificou-se que o score total da ESAS apresentou uma correlação negativa com o tempo de referenciação a cuidados paliativos na amostra total e no grupo de doentes seguidos na consulta externa. Verificou-se também uma correlação estatisticamente significativa entre a data do diagnóstico e a admissão na UCP. A correlação observada foi negativa, significando que quanto menor foi esse tempo, maior foi a intensidade dos sintomas à admissão.

Estes resultados estão de acordo com o que é descrito na literatura, em que o descontrolo sintomático é um dos principais motivos de internamento em cuidados paliativos. À medida que a doença progride, é natural que a sintomatologia agrave (McMillan, 1996).

No grupo dos doentes internados noutras enfermarias do Hospital onde o estudo foi realizado, alguns dos tempos calculados apresentaram uma correlação positiva com o score obtido na ESAS, no entanto, sem significado estatístico. Observou-se que quanto maior o tempo decorrido, maior era o descontrolo sintomático. A mesma tendência se pode verificar com a escala POS, cujo score total se correlacionou negativamente com o tempo de referenciação na amostra total e no grupo de doentes seguidos na Consulta externa de cuidados paliativos.

Elevados scores da POS (pior perceção de qualidade de vida) associaram-se a um hiato temporal mais curto entre a referenciação a cuidados paliativos e a primeira avaliação pela equipa em causa. Apenas se verificou uma correlação estatisticamente significativa entre o score total da POS e o tempo que decorreu entre a referenciação a cuidados paliativos e a primeira avaliação pela equipa multidisciplinar de cuidados paliativos na amostra total (−0.348, p «0.01). Esta correlação foi negativa, significando que quanto maior foi o tempo que decorreu entre a referenciação a cuidados paliativos e a primeira avaliação pela equipa de cuidados paliativos menos severa foi a perceção de qualidade de vida.

As referenciações precoces às equipas de cuidados paliativos são essenciais não apenas para aliviar sintomas, mas também para melhorar os resultados e a qualidade de vida das pessoas com cancro (Morita et al., 2009). A referenciação a cuidados paliativos é habitualmente demasiado tardia para melhorar significativamente a qualidade de vida de doentes com cancro. Os doentes são tipicamente referenciados a cuidados paliativos no fim de vida, em média entre 30 a 60 dias antes da morte (Bruera & Hui, 2010).

Os médicos enfrentam várias barreiras à referenciação precoce dos doentes a cuidados paliativos (Hawley, 2017), destacando-se a incerteza quanto à evolução da doença e ao prognóstico, a existência de períodos de remissão, a dificuldade sentida na transmissão de más notícias, a falta de conhecimentos sobre cuidados paliativos, a escassez de tempo para as consultas e a dificuldade no acesso a estes cuidados (Hawley, 2017).

O parco controlo sintomático e a baixa qualidade de vida foram associados a menor tempo que decorreu entre o diagnóstico e a referenciação a cuidados paliativos, o que se pode explicar pelo diagnóstico tardio destes doentes, que maioritariamente se apresentavam em estadio IV à apresentação da doença.

Estes resultados mostram o quanto é importante a referenciação precoce a cuidados paliativos. A maioria dos estudos mostra que uma abordagem otimizada dos sintomas nos doentes com cancro metastático está associada a uma maior sobrevida (National Guideline Centre (UK), 2019; Ghabashi et al., 2021). Os cuidados paliativos têm um papel fundamental no controlo de sintomas, assim como oferecem suporte psicossocial, contribuindo para a melhoria da sobrevida e da qualidade de vida dos doentes com cancro (Burge et al., 2005). Uma referenciação atempada a cuidados paliativos está associada a uma menor necessidade de cuidados intensivos e a uma melhoria dos resultados nos doentes oncológicos (National Guideline Centre (UK), 2019; Ghabashi et al., 2021).

Muitos autores reconhecem a falta de consenso sobre os doentes que devem ser encaminhados para cuidados paliativos (Hui et al., 2016). Critérios como o diagnóstico de cancro, prognóstico, sintomas físicos, status funcional, sofrimento psicológico e plano de cuidados de fim de vida surgem como potenciais razões para esta referenciação (Hui et al., 2016).

A referenciação tardia a cuidados paliativos é um dilema ético e que deve ser tido em conta, uma vez que acresce sofrimento a doentes que se encontram em estado de vulnerabilidade decorrente da sua doença avançada (Hausner, 2021).

Outro objetivo do estudo foi analisar as propriedades psicométricas da escala de avaliação de sintomas de (ESAS) e da Palliative Outcome Scale (POS). O sofrimento psicológico nos doentes com cancro avançado e que recebem cuidados paliativos é, muitas vezes, sub-diagnosticado, representando uma lacuna importante no tratamento destes doentes. Muitos doentes sentem medo, tristeza e luto antecipatório na trajetória da sua doença (Kelly et al., 2006; Antunes et al., 2014).

A literatura mostra-nos que a prevalência da ansiedade e da depressão nos doentes com cancro vai dos 35% aos 50% (Kelly et al., 2006; Zabora et al., 2001; Gruneir et al., 2005). Estas taxas de prevalência podem ser atribuídas a vários fatores, tais como o género, a neoplasia primária, o instrumento de medida utilizado e a própria definição dos conceitos psicopatológicos (Zabora et al., 2001; Gruneir et al., 2005).

Dado o impato do sofrimento emocional no bem-estar do doente, a sua identificação é fundamental. Nas últimas semanas de vida, os doentes frequentemente apresentam sentimentos de tristeza e desesperança, os quais podem colocar em causa qual o significado da sua vida e levar ao isolamento social (Pessin et al., 2002; Breitbart et al., 1995).

A ESAS é uma escala fundamental na avaliação de sintomas em cuidados paliativos, permitindo identificar e medir 6 sintomas físicos, 2 sintomas emocionais e um sintoma mais geral, o bem-estar. Apresenta boa fiabilidade mesmo nos doentes que se encontram em fim de vida (Modonesi et al., 2005). Contudo, é importante realçar que a componente emocional da ESAS, que inclui a ansiedade e a depressão, não foi formalmente validada para este instrumento (Modonesi et al., 2005). De acordo com Vignaroli et al., uma pontuação superior a 2 em 10 nos ítems ansiedade e depressão aferidos pela ESAS nos doentes em cuidados paliativos é considerado o ponto de coorte para a triagem destes sintomas (Vignaroli et al., 2006).

Gontijo et al. foi outro autor que também encontrou elevadas taxas de ansiedade e depressão nos doentes em cuidados paliativos seguidos no ambulatório, aos quais se associava baixa perceção de qualidade de vida, diminuição do status

funcional e a presença de sintomas físicos não controlados, tais como fadiga, náuseas, vómitos e falta de apetite (Garcia et al., 2023). Traldi Macedo et al. realizaram um estudo transversal, que envolveu 59 doentes com cancro avançado e em que 52,5% dos quais a depressão estava presente e em 76,3% a ansiedade, dados estes obtidos através da escala ESAS (Macedo et al., 2022).

No estudo desta dissertação, a maioria dos doentes exibiu elevados níveis de depressão e ansiedade à admissão na UCP, com 83,3% apresentando depressão e 61% ansiedade.

A ESAS é uma escala que avalia a presença e a intensidade dos sintomas físicos e emocionais. Contudo, para uma avaliação mais completa, pode ser necessário avaliar as outras dimensões dos cuidados paliativos, incluindo a física, a psicológica, a espiritual e a social. A escala POS ajuda a avaliar todas estas dimensões. A componente do bem-estar psicológico da POS é representada pelos ítens 3, 6, 7 e 8, com a pontuação total destes ítens variando entre 0 e 16 (Siegert et al., 2010).

Neste estudo, 66,7% dos doentes referiram sentir-se preocupados e ansiosos com a sua doença e respetivos tratamentos. Apenas 8,5% se sentiram capazes de partilhar sempre como se sentiam, nenhum doente sentiu que a sua vida não valia a pena e nenhum pontuou 4 em relação ao item "se sentiam bem consigo próprios". No estudo realizado porTraldi Macedo et al., aproximadamente 39% dos doentes apresentava pontuações severas (3 ou 4) na seguinte questão: "Sente-se ansioso ou preocupado com a sua doença ou tratamento?" (Macedo et al., 2022). Adicionalmente, 18,6% dos doentes responderam de modo similar à questão: "Tem conseguido partilhar o que sente com a sua família e amigos?" (Macedo et al., 2022). Cerca de 32% dos doentes apresentou níveis severos na questão: "Sente que a vida vale a pena?" e 13,5% níveis severos na questão "Tem-se sentido bem consigo próprio?" (Macedo et al., 2022).

Bausewein et al. realizaram um estudo com 118 doentes com o objetivo de validar a POS na Alemanha (Bausewein et al., 2005). A escala foi administrada nos dias 1 e 3 após a admissão na UCP e posteriormente novamente nos dias 3 e 4. O estudo incluiu doentes referenciados a cuidados paliativos durante um período de 3 meses do ano 2002. Na abordagem inicial, scores severos de 3 ou 4 foram reportados em 41% dos doentes no que diz respeito à ansiedade acerca da sua doença e tratamento. Somente 10% dos doentes referiram sentir-se capazes de partilhar como se sentiam; 36% sentiam que a vida valia a pena e 29% sentiam-se bem consigo próprios.

Antunes et al. conduziram um estudo multicêntrico e envolveram 1703 doentes com e sem cancro, internados ou seguidos em ambulatório com o objetivo de

explorar as propriedades psicométricas da Integrated Palliative Outcome Scale (IPOS) (Antunes et al., 2020). Verificaram que 13,3% dos participantes se sentiam ansiosos ou preocupados com a sua doença e 9,6% se sentiam deprimidos. O estudo foi conclusivo de que a IPOS era um instrumento eficaz na triagem destes dois sintomas psicológicos nos doentes com doença avançada.

As discrepâncias entre o presente estudo e os existentes na literatura podem ser atribuídas a vários fatores. A política da Instituição na altura em que a investigação foi realizada estipula que os doentes apenas fossem referenciados a cuidados paliativos quando os tratamentos curativos não fizessem mais sentido, significando que as referenciações apenas eram realizadas num estado tardio, muitas vezes terminal da doença oncológica.

Além disso, o estudo foi conduzido durante a pandemia COVID-19, um período marcado pelo isolamento social devido às restrições impostas de contato interpessoal e visitas de familiares e amigos nos hospitais. Estes fatores contribuíram para os sentimentos de angústia sentidos pelos doentes. Nesse sentido, Obispo-Portero et al. realizaram um estudo com 401 doentes com cancro avançado durante a pandemia COVID-19 e encontraram incidências de ansiedade e depressão de 36% e 35% respetivamente (Obispo-Portero et al., 2022).

A análise de correlação das dimensões psicológicas da ESAS (ansiedade e depressão) com os itens que avaliam o bem-estar emocional da POS revelaram várias correlações significativas: elevada ansiedade relacionada à doença ou tratamento estava associada com elevados níveis de ansiedade auto-referida ($p < 0.01$); quanto menos o doente partilhava o que sentia com familiares e amigos, menos sentia que a vida tinha sentido ($p < 0.01$) e pior se sentia consigo próprio ($p < 0.05$); uma baixa perceção de quanto a vida era importante associou-se com uma baixa perceção de si próprio ($p < 0.01$); elevados níveis de ansiedade em relação à doença ou tratamento associaram-se a um aumento dos sintomas depressivos ($p < 0.01$). A ansiedade e a preocupação com a doença e tratamentos medidos pela POS parecem assim ser preditivas da ansiedade e depressão auto-referidos na avaliação pela ESAS. Os ítens que avaliam a componente emocional da POS correlacionam-se uns com os outros, pelo que devem ser avaliados em conjunto.

A ansiedade e a depressão, embora apresentem elevada prevalência no cancro avançado, permanecem negligenciadas e sub-tratadas em cuidados paliativos causando um negativo impato ético de tal omissão (El Nawawi, Balboni e Balboni, 2012)

O estudo demonstra a importância de uma abordagem holística da ansiedade em cuidados paliativos. À data em que o estudo foi realizado, os doentes só eram

avaliados do ponto de vista emocional quando o médico, o enfermeiro ou o assistente social identificava essa necessidade e requeria suporte psicológico. O estudo demonstrou a importância de uma avaliação precoce e suporte dos sintomas psicológicos dos doentes com cancro avançado, pelo que no momento, houve reforço dos recursos humanos nesta área com a presença de três psicólogos na equipa de cuidados paliativos, permitindo que todos os doentes tenham acesso a estes cuidados, especialmente quando internados e assim o desejam.

Limitações

Este estudo apresentou algumas limitações que devem ser tidas em conta na interpretação dos resultados tais como:

1. o fato de se tratar de um estudo transversal impedir estabelecer relações de causalidade;
2. a pequena dimensão da amostra;
3. a investigação ter decorrido num único centro limita a generalização dos resultados;
4. o curto hiato temporal e o contexto epidemiológico da altura de pandemia COVID-19 poder induzir viés nos resultados obtidos;
5. a não inclusão de instrumentos de medida adicionais para melhor avaliar a carga sintomática e a qualidade de vida destes doentes.

Apesar destas limitações, os dados obtidos fornecem contributos relevantes para a compreensão do controlo sintomático e da qualidade de vida em cuidados paliativos.

Sugestões de melhorias

Os resultados deste estudo destacam a importância da monitorização sistemática dos sintomas como promotor da qualidade de vida dos doentes em cuidados paliativos.

Uma das principais melhorias a considerar é a integração precoce dos cuidados paliativos na trajetória da doença oncológica, uma vez que os sintomas tendem a agravar-se nas fases mais avançadas da doença.

A adoção de uma abordagem multidisciplinar e o desenvolvimento de protocolos e guidelines na gestão dos sintomas podem ajudar a otimizar os resultados obtidos.

Futuramente, são necessários estudos longitudinais e qualitativos para compreender melhor a evolução dos sintomas e o impacto das intervenções ao longo do tempo, nomeadamente na qualidade de vida.

CAPÍTULO

7

CONCLUSÕES

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Em relação ao objetivo principal que era valiar o impato da intensidade dos sintomas na qualidade de vida dos doentes oncológicos em cuidados paliativos à admissão na Unidade de cuidados paliativos (UCP) verificou-se haver uma correlação positiva entre a severidade dos sintomas no seu todo e uma perceção de reduzida qualidade de vida.

Ao analisar as caraterísticas sociodemográficas e clínicas dos participantes da amostra verificou-se uma predominância do género masculino (n=37; 61,7%) e uma mediana de idades de 72 anos (intervalo 43-94). A maioria dos participantes era casada e tinha um ou dois filhos. Mais de 80% viviam no seu domicílio e os cuidadores principais eram maioritariamente o conjugue ou os filhos. 81,7% dos casos possuía o ensino básico. Os tumores do foro digestivo (41,7%) e de cabeça e pescoço (20%) foram os mais prevalentes, à data de admissão na UCP 32 doentes (53,3%) foram admitidos a partir da consulta externa e os restantes doentes (n=28; 46,7%) encontravam-se noutras enfermarias do hospital com o apoio da EIHSCP. Verificou-se também que a maioria dos doentes se apresentava em estadio IV à data do diagnóstico e 66,6% apresentavam um ECOG 3 ou 4, ou seja, apresentavam um baixo nível de funcionalidade.

Em relação aos objetivos de analisar a intensidade dos sintomas dos doentes e a percepção de qualidade de vida na admissão à UCP de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares) e de acordo com os diferentes tipos de neoplasias verificou-se ausência de diferenças estatisticamente significativas.

Outro objetivo do estudo foi avaliar o tempo de referenciação dos doentes para CP na amostra global e de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares). Constatou-se que na amostra total, a mediana entre o diagnóstico e a referenciação a cuidados paliativos foi de 323 dias, correspondendo quase a um ano. O tempo que decorreu entre o diagnóstico e a referenciação a cuidados paliativos foi mais elevada no grupo dos doentes internados (600 dias).

Quando se correlacionou o tempo de referenciação para CP com a intensidade sintomática e qualidade de vida dos doentes de acordo com os diferentes modelos de abordagem (cuidados ambulatórios vs hospitalares) verificou-se que um pior controlo sintomático e uma pior perceção de qualidade de vida estavam asociados a um tempo de referenciação mais curto e não houve diferenças com significado estatístico consoante as diferentes abordagens.

Ao analisar as propriedades psicométricas do Edmonton Symptom Assessment System (ESAS) e da Palliative Outcome Scale (POS) verificou-se que a ansiedade em relação à doença e aos tratamentos medidas pela POS parecem ser preditivas da ansiedade e da depressão medidas pela ESAS.

Esta investigação representa um contributo substancial ao avanço do conhecimento científico em cuidados paliativos, ao demonstrar claramente que os doentes com cancro avançado apresentam uma elevada carga sintomática, inclusivamente sofrimento emocional intolerável quando são internados em Unidades de Cuidados Paliativos. A integração da ESAS e da POS como instrumentos complementares de avaliação dos sintomas e da qualidade de vida revela ser uma abordagem eficaz, prática e sensível às necessidades paliativas, devendo a sua aplicação ser uma rotina na prática clínica das equipas de cuidados paliativos. Além disso, a identificação da referenciação tardia como fator limitante à qualidade dos cuidados constitui um alerta ético e clínico com implicações diretas na organização dos serviços de saúde. Os resultados obtidos podem, assim, contribuir para que sejam desenvolvidas estratégias de integração precoce dos cuidados paliativos na doença oncológica avançada precoce, melhorar a avaliação multidimensional dos sintomas e consequentemente a qualidade de vida.

Necessidades futuras

Será essencial realizar estudos de investigação longitudinais e de natureza qualitativa que permitam aprofundar o conhecimento sobre o comportamento evolutivo dos sintomas e da qualidade de vida dos doentes internados.

A nível clínico, a implementação de protocolos padrão de abordagem dos sintomas e a integração precoce dos cuidados paliativos na trajetória da doença oncológica devem ser prioritários.

A nível educativo, é fundamental investir na formação específica em cuidados paliativos dos profissionais de saúde.

O desenvolvimento de guidelines a nível nacional e internacional sobre controlo sintomático e indicadores de qualidade de vida dos doentes em cuidados paliativos assim como o desenvolvimento de políticas que permitam a equidade no acesso aos cuidados paliativos e a referenciação precoce permitirá diminuir o sofrimento destes doentes e uma abordagem humanizada centrada na pessoa.

CAPÍTULO

8

PERSPECTIVAS FUTURAS

PERSPETIVAS FUTURAS

Parafraseando Cicely Saunders, 1963 "*O sofrimento mental talvez seja a dor mais intratável de todas.*"

Investigações futuras deverão incluir estudos longitudinais e multicêntricos, com amostras com maior número de participantes, que avaliem o impato das intervenções no comportamento dos sintomas e da qualidade de vida ao longo do tempo.

Associadamente, será importante incluir as visões dos cuidadores e dos profissionais de saúde, bem como explorar intervenções específicas e individualizadas de modo a identificar e melhorar as dimensões mais comprometidos da qualidade de vida.

Sendo a otimização da qualidade de vida o alvo principal dos cuidados paliativos, são necessários mais estudos que tenham como alvo a medida deste item e que permitam avaliar o real alcance das esquipas especializadas na melhoria do bem-estar e qualidade de vida nos doentes em fim de vida.

A aluna gostaria de destacar que este estudo foi realizado em doentes com necessidades paliativas no contexto de doença oncológica. Contudo, é sabido que várias doenças não oncológicas como a demência e as insuficiências terminais de órgãos beneficiam de cuidados paliativos. Na realidade, o controlo de sintomas nos dois contextos pode diferir, dependendo da doença em causa (Gesell et al., 2023).

As doenças não oncológicas caraterizam-se por períodos de agudização em que a melhor abordagem é a avaliação de sintomas por clusteres. Caraterizam-se por apresentarem elevados níveis de fadiga, insónia e distúrbios emocionais e de funcionalidade, enquanto nos doentes com cancro avançado sobressai a dor (Hansen et al., 2024). Futuramente, este tipo de estudos deve incluir também população portadora de doenças não oncológicas.

A utilização de outras escalas que não somente a escala de avaliação de sintomas de Edmonton (ESAS) e a POS para avaliação dos sintomas e da qualidade de vida nesta subpopulação de doentes irá permitir a medida de resultados em cuidados paliativos.

Numa perspetiva futura, é de todo o interesse que a escala de avaliação de sintomas de Edmonton (ESAS) seja de facto validada para a língua portuguesa, e não fique apenas pela sua tradução e adaptação. Se por um lado é verdade que a sua utilização clínica disseminada pelas equipas de cuidados paliativos assim como na

investigação assegura a sua essência, a sua validação criaria bases sólidas para o seu uso e excluiria qualquer dúvida que possa surgir.

CAPÍTULO

9

ARTIGO PUBLICADO APÓS PROVAS PÚBLICAS

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Review

Impact of Artificial Intelligence on the Care of Terminally Ill Patients

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Highlights

What are the main findings?

- Artificial Intelligence (AI) is a technological tool that is increasingly being used, particularly in the context of healthcare. Its use in palliative and end-of-life care presents huge potential.
- The use of AI in palliative care could help professionals with symptom control and development of communication skills, as well as assist in the construction of an advanced care plan and in shared decision-making processes.

What are the implications of the main findings?

- The application of AI in daily practice in palliative care is challenging, and is not without risks and ethical dilemmas.
- Even though it is becoming an increasingly valuable tool, it is important to recognize that it cannot replace human collaboration. Emotional empathy, physical comfort and compassion are qualities that AI is unable to provide.

Abstract

Introduction: In recent decades, demographic aging has led to an inversion of the population pyramid, with a marked increase in the proportion of older adults. This shift has been accompanied by a higher prevalence of chronic and life-limiting diseases, while there have also been significant technical and scientific advances. However, these developments have not been matched by a proportional expansion of healthcare human resources, including in palliative care (PC). Consequently, healthcare systems face increasing pressure, particularly in the provision of end-of-life care. Artificial intelligence (AI) has emerged as a promising tool to support and improve healthcare delivery. **Objective**: This study aims to review the literature on the impact of AI on palliative care, with particular emphasis on its clinical applications and ethical implications in end-of-life care. **Methods**: A narrative review was conducted using a structured search of PUBMED, CINAHL and Web of Science databases, covering publications from the last ten years (2015–2025). Search terms included combinations of "artificial intelligence", "machine learning", "palliative care", "end-of-life care", and "ethics". Articles were included if they addressed clinical applications, implementation challenges or ethical aspects of AI in PC. Reference lists of selected articles were screened to identify additional relevant studies. The findings were analyzed and synthesized thematically into key domains of application and ethical concern. **Results**: The literature suggests that AI is currently a promising tool in PC, particularly in prognostication, symptom assessment, clinical decision support, and communication. These applications may

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Academic Editor: César Leal-Costa

Received: 17 January 2026
Revised: 22 February 2026
Accepted: 25 February 2026
Published: 27 February 2026

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represent a paradigm shift compared to conventional approaches. However, it is important not to forget that patients in PC need much more than algorithmic decision trees. Thus, current evidence is largely exploratory, with limited real-world validation. Empathetic emotional support, physical comfort and compassion are things that artificial intelligence cannot provide. AI does not replace humans in interpersonal relationships and dignity; it only complements them. **Conclusions**: AI-based technologies hold significant potential to address contemporary challenges in PC, including inequitable access, workforce strain, and the need for more efficient service delivery. Nevertheless, their implementation raises substantial ethical concerns related to autonomy, transparency, data governance, and the preservation of human dignity. AI should therefore be understood as a complementary tool that supports—but does not replace—the human dimension of PC.

Keywords: artificial intelligence; digital health; ethical dilemmas; ethics; palliative care; palliative medicine; symptom assessment

1. Introduction

Healthcare professionals play a fundamental role in the health system of any country. The demand for these professionals has increased significantly in recent years in many countries, including Portugal [1].

According to Health at a Glance—Europe 2024, a joint report of the Organization for Economic Co-operation and Development (OECD) and the European Commission, it was estimated that, in 2022, there was a shortage of approximately 1.2 million healthcare professionals in the countries of the European Union [2].

Artificial intelligence (AI) is a growing reality that is transforming our lives on a global scale across social, economic, educational and healthcare domains [3]. Similar changes can also be observed in scientific research and technological development [3].

The speed at which artificial intelligence has been implemented in various areas of human life is not entirely without risks [4]. Thus, while it is true that many AI tools can perform functions more effectively than humans themselves, they lack the humanistic and empathetic aspect. The implementation of AI brings discussions at the ethical and legal levels, examples of which include the lack of clarity and ambiguity of roles, the possible violation of data protection, doubts about liability for errors or biases, and concerns about free and informed consent [4,5].

Ensuring that AI is properly governed requires the establishment of a legal framework, along with continuous monitoring and regular audits, so that its ethical applicability is not called into question [5].

In the specific context of medicine, in addition to the issues above, there is an additional concern regarding the impact that AI may have on clinical practice and the delivery of care [6]. Some studies have already demonstrated that its application has limitations, particularly due to biases in the development and implementation of AI, which can distort results and reproduce or exacerbate existing social inequalities [7].

Several international organizations, such as the World Health Organization (WHO), the European Commission, the European Parliament, the Office of Science and Technology Policy (United States), and the Nuffield Council on Bioethics, have already recommended that its use be subject to oversight [7–11].

AI is becoming an increasingly prominent part of our lives [12]. AI involves the use of machines to perform human cognitive functions, and in many cases, these systems can surpass human capabilities [12]. AI has emerged as a highly promising tool, and its

exponential growth has positively influenced organizational performance by improving efficiency and competitiveness [12].

In the healthcare field, AI is increasingly applied in diagnostic formulation, therapeutic decision-making, medical imaging analysis and the automation of administrative tasks [13]. Although AI can perform certain technical tasks at a level comparable to—or even exceeding—that of healthcare professionals, ethical considerations continue to limit its widespread implementation [13].

In the field of palliative care (PC), the progress is remarkable, creating opportunities to enhance comprehensive patient care, promote well-being and improve quality of life during advanced stages of disease [14,15].

According to the WHO, "Palliative care is an approach that improves the quality of life of patients—adults and children—and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, physical, psychosocial or spiritual." [16].

According to the World Atlas of Palliative Care (developed by WHO), around 60 million people require PC each year, yet only 12% of them have access to this type of care [17]. It is estimated that around 40 million people need PC annually worldwide due to population aging [18]. In 60% of deaths that occur globally, there is a need for PC, with deaths from cancer accounting for 34% of cases [18]. Although the relevance of early initiation of PC in the course of the disease is recognized, referral continues to be late, and in many cases death occurs without patients receiving this care. These types of situations are particularly notable in low-resource countries [19]. PC is essential to end-of-life care for cancer patients and for many individuals with non-cancer terminal illnesses [20–22]. Thus, in the face of the shortage of specialized human resources in PC, AI can become a valuable asset for patients in palliative care [23,24]. However, the urgent ethical dilemmas within such a noble field of medicine—and their implications at the end of life, where care should be guided by holistic and humanistic principles—raise questions about the true value of AI, despite its potential contributions pressing ethical dilemmas in such a noble area of medicine and their implications [23,24].

The aim of this article is to explore the potential applications of AI in PC, examining its benefits, implementation challenges, and key ethical considerations. In particular, it evaluates the main risks, limitations, and ethical challenges associated with integrating AI technologies into such a sensitive clinical context. This raises the following research question: "How can AI be effectively and ethically integrated into PC while mitigating its risks and limitations?"

2. Method

This article is a narrative literature review designed to synthesize and discuss recent studies and research concerning the application of AI in PC, particularly its impact on the care of terminally ill patients, with special attention to ethical considerations and quality of life.

The review is intended for specialists in PC and other healthcare professionals interested in the intersection of AI and end-of-life care.

A comprehensive literature search was conducted in the electronic databases PUBMED, CINAHL and Web of Science, focusing primarily on publications from the last ten years.

The search strategy included the following MESH terms and Boolean operators: ("Artificial Intelligence" OR "Digital Health") AND ("Ethical Dilemmas" OR "Ethics") AND ("Palliative Care" OR "Palliative Medicine") AND "SYMPTOM ASSESSMENT".

The search strategy was adapted according to the specific requirements of each database. To ensure comprehensive coverage of the topic, the search was complemented by relevant books, specialized publications from recognized authors, and selected authoritative websites in the field. Additionally, some essential articles were included regardless of publication date due to their foundational relevance to the subject.

After completing the database searches, all identified records were exported to Rayyan® (Qatar Computing Research Institute, Doha, Qatar; https://rayyan.ai), a web-based tool designed to support the screening process in literature reviews. Duplicate records were removed within the platform. The remaining studies were screened by reviewing titles and abstracts to assess their relevance to the objectives of the review.

Articles considered potentially eligible were retrieved and analyzed in full text to ensure alignment with the proposed themes and research focus.

The inclusion criteria comprised (1) studies published primarily within the last ten years; (2) articles addressing the application of artificial intelligence in palliative care; (3) research discussing ethical aspects, quality of life, symptom management, dignity, or end-of-life care; and (4) publications written in English, Portuguese and Spanish. Foundational or seminal articles were included regardless of publication date when considered essential to the conceptual framework of the review.

Exclusion criteria included (1) studies not directly related to palliative care; (2) articles focusing exclusively on technical AI development without clinical or ethical relevance; (3) conference abstracts without full-text availability; and (4) publications in languages other than English, Portuguese and Spanish.

Data were extracted and organized according to thematic categories identified during the reading process. The findings were analyzed qualitatively, aiming to summarize, compare and critically discuss the existing evidence.

As a narrative review, this study does not follow a systematic review protocol but aims to provide a comprehensive, descriptive, and critical synthesis of the existing literature.

Since this research is based exclusively on the analysis of previously published studies and does not involve human participants, patient data, or primary data collection, ethical approval from an institutional review board or ethics committee was not required.

3. History and Development of Artificial Intelligence

Artificial intelligence and machine learning (ML) are emerging technologies that are transforming society and the way we perceive the world [25].

The goal of AI is to generate machines capable of mimicking the human mind [25]. AI systems have a wide range of applications, with the creation of algorithms capable of performing functions similar to those of humans at the cognitive and autonomy level [25]. ML is a subtype of artificial intelligence in which algorithms are created based on a database that enables decision-making. All these technologies allow for rapid and complex computational development, complementing human reasoning in the performance of tasks with surprising efficiency [25].

The various areas of daily application of AI and ML focus on health, education and the economy, with a significant increase in the accuracy of decisions [26]. In healthcare, for example, AI-based diagnostic and treatment tools are transforming the quality and effectiveness of patient care [26].

The availability of multidimensional data (demographic, clinical, genetic and phenotypic), combined with new technologies accessible through versatile internet-connected devices, reflects the integration of technology in healthcare and improves the delivery of care [27].

Cloud computing allows for faster and more cost-effective analysis of large amounts of data compared to traditional medical approaches [27].

Although AI is considered a recent concept, the truth is that it has existed for years. Knowing its history allows us to understand the concept and its importance today [28,29]. The idea of building machines that mimic human intelligence has existed since ancient times. However, it was only in the 20th century that the first studies on the real potential of AI began [28,29].

Alan Turing, a pioneer in computer science, published the concept of the Turing Machine, a theoretical model capable of performing any calculation by executing a program [30].

In 1943, McCulloch and Pitts presented a model of artificial neurons that attempted to mimic the biological neural network. Although the main goal was to try to understand the workings of the human mind, their work was fundamental in laying the foundations of AI [31,32]. More recently, the company OpenAI created the famous ChatGPT (OpenAI, San Francisco, CA, USA; https://chat.openai.com), a chatbot application with AI trained to hold conversations and answer questions [33].

With this historical review, it becomes clear that the idea that intelligence results from a computational process and can therefore be automated has existed for centuries [34]. There have been several objections to the notion that machines can be intelligent. In response to these criticisms, increasingly sophisticated learning techniques have been developed [34].

Despite these controversies, the beneficial and innovative role of AI in our lives is undeniable [35].

4. Artificial Intelligence in Healthcare

AI is a transformative field of modern computer science with the potential to reshape medical practice and healthcare [36].

Healthcare systems around the world face four major challenges: improving population healthcare, increasing patient satisfaction with health services, enhancing clinical care, and reducing health costs [37–39].

The application of technology in the health field is called eHealth ("electronic health"), which offers a series of tools that allow for improved performance of health systems and the quality of services provided [40]. In addition, it is considered a facilitating tool for communication, progressively expanding services in view of the rapid and continuous evolution of technology [40].

Population aging, along with the exponential growth of chronic diseases and the increase in health costs, represents a significant challenge for government systems to innovate and transform the delivery of care [41,42].

Despite more than a decade of experience using AI in healthcare, its practical applicability remains limited, with many tools still under development or discussion [43].

The exponential growth of AI applications in the 21st century, throughout society in general, has also been reflected in healthcare [44]. This phenomenon became particularly evident with the onset of the COVID-19 pandemic, during which the number of scientific publications in the main OECD countries increased from 35 in 1980 to more than 3400 in 2019 [44].

AI applications are vast, ranging from biomedical research to the management of healthcare organizations. Many hospitals already employ AI technologies to increase efficiency and performance [45,46].

These applications are being developed for virtually all areas of healthcare delivery [47]. Some algorithms are being integrated to support research, clinical decision-making, medical image analysis, and assistance in diagnostics and treatment [47].

In the field of research, its usefulness is increasingly undeniable, as AI allows for the encoding of large amounts of data and the recognition of complex patterns [48,49]. One example of AI application in this area is drug discovery. Researchers at the Massachusetts Institute of Technology (MIT) used AI techniques that enabled the discovery of molecules with antimicrobial activity. The algorithms used made it possible to identify an innovative antibiotic that allowed the cure of patients infected with multidrug-resistant microorganisms [48,49]. The advantages of AI in research are also felt at the level of clinical trials and in the selection of their participants as well as in the area of genetics, allowing for a better understanding of rare diseases and their biomarkers [48,49].

The integration of AI in the clinic is already more controversial. However, there are several medical areas in which it is beginning to prove itself a fundamental tool [48,49]. This is the case in radiology, where the algorithms developed allow for a fairly reliable interpretation of various imaging techniques, such as radiography, CT scan and MRI [50,51]. Technology develops image patterns that allow for the early detection of various diseases, such as cancer, issuing alerts and saving healthcare professionals time in viewing and interpreting images [50,51].

AI algorithms also allow for indicating the best treatment for the individual in question, taking into account their comorbidities and individual characteristics [52].

Another area of AI that has been intensively explored is robotic surgery [53,54]. With the creation of specific algorithms and the precision of the machines, it has become possible to perform surgical procedures that were previously unthinkable. This type of surgery, high-precision robotics, has become the preferred option for many surgeons given the lower risk of complications and postoperative hospitalization [53,54].

In terms of managing hospital organizations, AI has shown outstanding utility, allowing for greater accessibility and equity in patient care [55,56].

Telemedicine is promising in this context [55,56]. It allows patients who live far from healthcare facilities or who are too frail to travel to access consultations (teleconsultations) and medical prescriptions for drugs and complementary diagnostic tests (electronic prescriptions) [55,56].

However, it should be borne in mind that the recent and rapidly increasing introduction of intelligent software is not always ethically acceptable [57–59]. Bioethical principles such as autonomy, equity, and distributive justice can be easily questioned if their monitoring and auditing are not regulated [57–59].

Some population minorities such as LGBTQIA+ individuals, those facing economic hardship, the elderly, and women may be discriminated against in terms of unequal access to healthcare systems [57–59]. Individual variability such as gender, ethnicity, socioeconomic class, sexual orientation, and religion are characteristics that allow for a multifactorial assessment of people's lives. Intersectionality addresses how these characteristics interact with the social, familial, and economic norms implemented in society [60]. Intersectional justice recognizes that discrimination against minorities does not act in isolation, but rather within power groups that mutually reinforce each other [61].

Cyber fraud can expose confidential patient data or circumvent informed consent. It is an ethical imperative to maintain security and trust in healthcare systems and to have a commitment to respecting patient autonomy.

In practice, AI does not replace human intelligence; instead, it augments it [62]. Human interaction in the field of medicine is irreplaceable. Therefore, AI methods should serve only as supportive tools, helping to refine clinical decision-making while maintaining a strong focus on patient-centered care [62].

5. Artificial Intelligence in PC and End-of-Life Care

Artificial Intelligence (AI) is increasingly becoming a part of our lives [63,64]. Although it does not have an established definition, AI can be understood as the attempt to use machines to mimic human cognitive functions that can sometimes even perform better than humans [63,64].

According to the WHO, palliative care is part of a multidisciplinary approach aimed at improving the quality of life of patients, their families, and caregivers through prevention, early identification, and reduction of suffering associated with pain or other physical, psychosocial, or spiritual conditions related to a chronic and incurable disease, which has a significant impact on the life of the patient and those around them [65,66].

In this way, palliative care addresses various pathologies, ranging from cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), acquired immunodeficiency syndrome (5.7%), and diabetes (4.6%), among others [16,67]. However, access to palliative care is far from ideal, especially in low- and middle-income countries, with one possible explanation being the still common misconception that this care is reserved for those at the end of life [68].

One of the pillars of palliative care is symptom control in order to relieve the suffering of patients facing life-threatening illnesses [69]. The main goal is to improve quality of life, not to cure the disease, so effective symptom management becomes a priority [69].

One of the main reasons that lead to patients in palliative care being hospitalized is uncontrolled symptoms [69]. Hence the importance of early integration of these specialized care measures into the disease trajectory, preferably at the time of diagnosis of a life-threatening illness. This approach enables the timely identification of palliative needs that can be addressed through comprehensive early intervention. In recent decades, there has been a strong recommendation from the scientific community for palliative care to be initiated early in cancer patients, more specifically within the first 8 weeks after diagnosis [69].

It is also advocated that palliative care and curative care, such as chemotherapy, be inseparable [69]. This type of approach helps reduce symptom burden, improve quality of life, increase patient and family satisfaction, and even extend survival [69].

However, in healthcare institutions without access to PC, it is essential to identify these needs to ensure early referral [70].

There are currently several lines of research seeking to study how AI can help fill some gaps in access to palliative care [71]. AI has been seen as a valuable tool in relieving symptom burden, in decision-making, in reducing the workload of healthcare professionals, and in improving care [71].

These new technologies allow healthcare professionals to help patients in palliative care manage pain and other symptoms, potentially leading to drastic changes in the way they practice [72,73].

The potential use of AI in decision-making is also equally important in selecting the most effective and safe therapeutic options and ensuring better management of cancer patients in need of palliative care [74,75]. The integration of AI into palliative care can help improve the quality of life of terminally ill patients, as well as alleviate the suffering of the patient and family through humanistic and compassionate approaches centered on the patient [74,75].

AI is equally useful in enhancing skills in patient management in palliative care by professionals trained in the field. The practical application of insights generated by AI in end-of-life care is of utmost importance for the well-being of the patient and family [76,77].

AI allows for the identification and monitoring of symptoms. Mallick et al. designed a remote monitoring tool for symptoms in palliative care patients through the use of

wearable sensors and Raspberry Pi, which allowed the measurement of vital signs such as respiratory rate and heart rate, thereby anticipating the onset of dyspnea crises in patients with advanced metastatic cancer [78].

DiMartino et al. used natural language processing (NLP) to detect uncontrolled symptoms in the digital medical records of hospitalized and end-of-life patients [79]. Shimada and Tsuneto, using RapidMiner®, were able to predict various symptoms such as pain, dyspnea, fatigue, anxiety, and existential distress, with accuracy ranging from 55% to 88% [80].

On the other hand, Sandham et al., through the Integrated Palliative Care Outcome Scale (IPOS) and various AI techniques (including decision trees), identified several symptoms, such as asthenia and anorexia [81].

The CLARK system used by DiMartino et al. allowed for the identification of symptomatic control issues in 61% of pain cases, 68% of nausea and vomiting cases, and 80% of dyspnea cases [82].

Kim et al. used XGBoost, Random Forest, and others as predictive models for delirium, achieving an accuracy of 69.84% [83].

AI also supports clinical decision-making [19,84]. Wilson et al. replaced common screening methods with a clinical predictive model, which was applied in a home hospitalization context, allowing earlier access to palliative care and reducing the need for patient admission [19,84].

Soltani et al. used LSTM models that allowed for the streamlining of home care services with a long waiting list [85]. Limsomwong et al., through a rule-based system with LexTo, identified patients with palliative care needs with high accuracy [86].

Terminally ill patients need a specialized palliative care team with skills in empathetic communication and compassion [87].

Van Bussel et al. studied the factors that influenced the potential acceptance of a virtual assistant and found that performance, effort, and trust were key in the acceptance decision of the server [88]. Srivastava et al. analyzed ChatGPT in palliative care communication and found it to be very similar to human communication, except regarding topics related to spirituality and death [89].

Yücel et al. compared ChatGPT with Bard and other platforms, finding that the former had a higher predictive value (96%), while Google Bard had the lowest (86%) [90].

Effective symptom management and the improvement of quality of life are the main goals of palliative care, which artificial intelligence is not unaware of [91]. AI allows pain and other symptom control to be carried out in an individualized manner in patients with advanced cancer [91].

In non-oncological contexts, Ott et al. used smart sensors for real-time monitoring of symptoms present in neurodegenerative diseases [92]. However, Deutsch et al. showed that there is a potential bias in these assessments when dealing with specific and less common non-oncological pathologies, which limits the generalization of symptom-based approaches by AI [93].

Emotional support is an essential component of palliative care, and AI could contribute through chatbots and conversational robots [94]. There are already some specific developments, such as Mabu, a robot designed to interact with patients with chronic illnesses. Mabu uses AI to maintain personalized conversations and monitor patients' health status [94].

There has been an increase in the number of individuals with palliative care needs, which are not always adequately met due to a lack of healthcare professionals with specialized training in this area [95]. AI can assist healthcare professionals by improving prognostic accuracy, allowing for the early identification of patients at higher risk of mor-

tality and greater symptom burden [95]. This can help avoid the use of potentially futile and disproportionate treatments in the final days of life, facilitating shared and timely decision-making with patients and their families [95].

AI uses ML techniques to assist in referring patients for PC [96,97]. ML is a subtype of AI, and its construction of predictive algorithms allows for a robust prediction of the probability of death in the context of palliative care within a time frame of between one month and five years. ML is also useful in identifying patients with palliative needs, using digital medical records as a basis [96,97].

While the usefulness of AI is undeniable (Figure 1), it cannot compromise the doctor–patient relationship or empathetic and sensitive communication when delivering bad news [98–100].



Figure 1. A conceptual diagram of AI's applications in palliative care. Note: Image generated using ChatGPT® on 12 January 2026.

In palliative medicine, the goal is to provide holistic and compassionate care to patients at the end of life, ensuring their comfort and preserving their dignity [101].

6. Ethical Issues on the Use of AI in Palliative Care

The integration of artificial intelligence in the context of palliative care is a growing reality, allowing for the extension of life while also improving quality of life and purpose by focusing on individualized care for those in their final stages [98]. This integration must be done carefully, with zeal, to prevent the emergence of important ethical dilemmas such as the lack of privacy of individual and sensitive data, the absence of equity, and the lack of humanism in decision-making in conflicting situations [98].

With AI, traditional palliative care has transformed into a model based on evidence-based medicine [102]. Its use should always be understood as complementary and not a substitute in areas such as the anticipation of uncontrolled symptoms, the appearance of new symptoms, crises of existential suffering, individualized and patient-centered treatment, and improving care [102].

The application of predictive algorithmic models in AI allows for the early identification of palliative needs [103]. Other areas of AI application in end-of-life care include real-time symptom monitoring and the use of virtual assistants that facilitate communication between patients, family members, and healthcare professionals when face-to-face interaction is not possible [103]. These new generations of tools are very promising in improving health outcomes and access to personalized care for patients who would otherwise not have the opportunity to benefit from such a noble area of medicine as PC [103]. Despite all these virtues, we cannot forget the ethical dilemmas that can also arise when dealing with extremely vulnerable patients [103]. Thus, there are ethical imperatives that cannot be overlooked, since we are dealing with people and not merely statistical data [103]. This risk would negate the dignity and respect of patients, negatively affecting the meaning and philosophy of palliative care, which prides itself on being individualized and compassionate care offered to frail patients facing illnesses that threaten their integrity as persons [103].

The ethical issues surrounding AI in palliative care are present in several dimensions and exhibit high complexity. Ferrario et al. reinforced the idea that AI algorithmic models should be used responsibly and showed that algorithmic prediction needs to be conducted in an ethical and clean manner in healthcare in general, as well as in palliative care [104].

Ranard et al. expressed concern about the potential risk of bias in the data used by artificial intelligence algorithms, particularly in cases involving minorities, which could lead to unfounded decisions [105]. The automation of decision-making algorithms leads to biases that are not always visible when using artificial intelligence, making it difficult to explain these decisions and identify responsibilities. Algorithmic equity is essential to ensure fair and non-discriminatory decisions. The different characteristics of people can lead to different decisions, but if biases exist, the decisions will not always be the most correct.

Kay See attempted to study whether AI could serve as a consultant in bioethics, but without clear conclusions [106].

Ethicists legitimately argue that the application of AI in palliative care is consistent with the philosophy of end-of-life care and that technological advancement should not prevent the preservation of human dignity [107]. AI helps palliative care professionals make more accurate decisions in both symptom control and prognosis estimation, but its hasty integration may jeopardize patient autonomy and data privacy [107]. Without the patient's informed consent for the use of their personal information, the use of algorithms based on this information is prohibitive [107].

The final decision always rests with the patient, family, and healthcare professionals together, and can be complemented by AI applications [23]. It is essential that healthcare professionals receive training on the ethical dilemmas of using artificial intelligence and its potential risks so that these new technologies are managed safely and effectively [23].

The application of AI in areas where human contact is essential is not at all easy. Palliative care implies communication imbued with empathy and humanism, as well as holistic patient care, so ethically it may be difficult to conceive that data privacy is not fully ensured, as is informed consent. These assumptions represent ethical imperatives in the integration of AI into palliative care.

The future of AI in PC depends on reconciling digital algorithms with complex ethical dilemmas.

It is recommended that these projects involve PC patients and their families from the outset, ensuring that their values and the cultural contexts in which they are embedded are respected and preserved.

The future use of AI in end-of-life care also depends on the critical training of professionals in digital and ethical fields, investment in research that fully combines clinical, technological, and humanistic knowledge, and the promotion of policies that ensure technological literacy and equitable access to PC. It is therefore necessary to develop responsible and impartial policies so that there is a judicious use of artificial intelligence at a global level while protecting fundamental human rights. Important policies include addressing ethical dilemmas, responsibly protecting data privacy, and encouraging public–private partnerships so that decisions are shared. To achieve this, there must be international standards that guarantee the maximization of AI benefits and the proactive regulation of its risks.

7. Limitations and Future Directions

According to the findings and discussions reported in the literature, AI applications in PC face several significant challenges. Data limitations are a major issue because patient records in PC are often inconsistent or limited. Privacy concerns further restrict the sharing of sensitive data.

Another key challenge is the complexity of human experience. PC addresses not only physical symptoms but also social, emotional and spiritual needs. Ethical and legal challenges are also important. End-of-life care decisions are deeply sensitive, and reliance on AI can raise questions about informed consent.

Integration and acceptance remain barriers. Healthcare professionals may hesitate to trust AI recommendations in charged situations, and incorporating AI into daily workflow can be challenging.

Despite these challenges, AI holds promise for the future of PC. Personalized symptom management could enable prediction of symptom trajectories and support tailored interventions, especially when combined with wearable devices and remote monitoring. Telemedicine and virtual care could provide 24/7 support and monitor emotional well-being, reducing the burden on healthcare providers in resource-limited settings. On the other hand, decision support tools may help clinicians in treatment planning, PC referral timing or medication adjustments while keeping final decisions human-centered. Future AI development should prioritize ethical systems, ensuring quality, equity and inclusivity.

8. Conclusions

Artificial intelligence has the potential to become a powerful complement to healthcare, but not a substitute for clinicians. While AI demonstrates remarkable capacity in data processing, pattern recognition, and language-based tasks, it does not possess the human

attributes that are foundational to high-quality care—namely empathy, compassion, and the ability to form meaningful therapeutic relationships.

Palliative care, by definition, is holistic. It addresses the patient as a whole person across biological, psychological, social, and spiritual dimensions. This approach requires nuanced interpretation of emotional states, sensitivity to silence and nonverbal communication, and the ability to respond to suffering in ways that are deeply relational. Such human presence remains irreplaceable.

Within these boundaries, AI can play a valuable and transformative role. It can streamline administrative processes (e.g., scheduling, prescription reminders), support symptom assessment and severity classification, assist in triaging urgent cases, contribute to prognostic modeling, enhance clinical decision support, and facilitate research. In oncology-focused palliative care in particular, AI-driven prognostication and communication support tools may represent a meaningful shift from conventional approaches, offering data-informed insights that can strengthen—but not supplant—clinical reasoning.

However, important limitations and structural barriers must be acknowledged. Data fragmentation, poor interoperability between systems, incomplete integration of sociodemographic and clinical data, and challenges in secure information exchange hinder effective implementation. Moreover, as highlighted by Miralles et al. (2023), although several clinical contexts appear conducive to AI application, real-world effectiveness remains limited in many settings [102]. Technological promise does not automatically translate into practical benefit.

Ultimately, patients with advanced cancer in palliative care require far more than algorithmic decision trees. They require presence, dignity, compassion, and human connection—elements that no artificial system can authentically reproduce. The responsible integration of AI in palliative care therefore demands a balanced approach: embracing its analytical strengths while safeguarding the centrality of the human relationship. AI should enhance clinicians' capacity to care, not distance them from the very humanity that defines palliative practice.

Author Contributions: Conceptualization—F.G. and M.G.; Methodology—F.G. and M.G.; Resources—M.G.; Data curation—F.G.; Writing—original draft preparation—F.G. and M.G.; Writing—review and editing—S.B.N., F.R. and R.N.; Visualization—M.G.; Supervision—S.B.N., F.R. and R.N. All authors have read and agreed to the published version of the manuscript.

Funding: This article received no external funding.

Institutional Review Board Statement: Not applicable.

Informed Consent Statement: Not applicable.

Data Availability Statement: The authors used AI tools to assist with language editing and to generate a diagram (ChatGPT®). The authors disclose the use of AI during the preparation of this manuscript, and they are fully responsible for the accuracy, integrity and originality of the data review.

Acknowledgments: The authors would like to acknowledge the support of the Portuguese Institute of Oncology Francisco Gentil Coimbra and the University of Porto.

Conflicts of Interest: The authors declare no conflicts of interest.

Abbreviations

AI—Artificial Intelligence; CT—Computed Tomography; IPOS—Integrated Palliative Care Outcome Scale; LGBTQIA+—Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual, plus; LSTM—Long Short-Term Memory; MIT—Massachusetts Institute of Technology; ML—Machine Learning; MRI—Magnetic Resonance Imaging; NLP—Natural Language Processing;

OECD—Organization for Economic Co-operation and Development; PC—Palliative Care; WHO—World Health Organization.

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CAPÍTULO

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CAPÍTULO

11

ANEXOS

ANEXOS

Anexo I - Autorização de reprodução de figura

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Royal Australian College *of* General Practitioners

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Healthy Australia.

6 May 2025

RE: PERMISSION REQUEST

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Kind regards
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Anexo II - Comprovativo de aceitação para publicação do artigo

CONSELHO FEDERAL DE MEDICINA

DECLARAÇÃO

Brasília, 15 de dezembro de 2025

Declaro, para os devidos fins de comprovação acadêmica e profissional, que o artigo intitulado "*Desafios éticos do controle sintomático em cuidados paliativos: reflexão crítica*", de autoria de Florbela Gonçalves, Margarida Gaudêncio, Ana Rocha, Ivo Paiva, Maria Francisca Rego, Rui Nunes foi devidamente aprovado para publicação na *Revista Bioética*, encontrando-se em trâmite editorial final e aguardando para publicação em edição futura.

Documento assinado eletronicamente por **Vanessa de Santana Sertão**, **Assessora II**, em 15/12/2025, às 13:46, com fundamento no art. 5º da RESOLUÇÃO CFM nº2.308/2022, de 28 de março de 2022.

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Anexo III - Autorização da Comissão de Ética

Parecer Final da Comissão de Ética

Trabalho de Investigação nº: TI 17/2020

Data: 09/10/2020

Apreciado na reunião da Comissão de Ética de 09/11/2020 o projeto "Controlo sintomático e Qualidade de Vida em Cuidados Paliativos", foi aprovado por unanimidade dos presentes.....

PEL'A COMISSÃO DE ÉTICA

António José Fragoso Lopes

(*) Indicar o resultado da votação de **aprovação** ou **rejeição** e se por unanimidade ou maioria, assinalando e juntando as declarações de voto que houver.

De: Cristina Pascoal < cristinap@ipocoimbra.min-saude.pt >
Enviado: 17 de dezembro de 2020 16h10
Para: FLORBELA SANTOS GONÇALVES < 3545@ipocoimbra.min-saude.pt >
Cc: RUI ALBERTO LEONARDO SOUSA SILVA < 3231@ipocoimbra.min-saude.pt >; Elio Jorge Alves Rodrigues < 3910@ipocoimbra.min-saude.pt >
Assunto: Pedido de autorização para realização de projeto de investigação

Exma. Senhora
Dra. Florbela Gonçalves

Em resposta ao pedido de autorização para realização do Projeto de Investigação intitulado "Controlo sintomático e qualidade de vida em cuidados paliativos", carregue-me o Conselho de Administração de informar V. Exa. que o mesmo foi autorizado.

Mais se informa que qualquer publicação ou divulgação deverá fazer referência à colaboração do IPO de Coimbra.

Após a sua conclusão, os resultados do estudo deverão ser comunicados ao Gabinete Coordenador da Investigação.

Com os melhores cumprimentos,

Cristina Pascoal
Assistente Técnico/Secretariado do Conselho de Administração

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Anexo IV - Carta de apresentação do estudo

Ex.mo Sr. (a)

A qualidade de vida é um dos principais objetivos a atingir nos doentes em Cuidados Paliativos. Sabe-se que o descontrolo sintomático contribui em muito para que este obejetivo não seja alcançado.

No âmbito do projecto de Doutoramento com o título **"CONTROLO SINTOMÁTICO E QUALIDADE DE VIDA EM CUIDADOS PALIATIVOS"** procurarei contribuir para uma melhor compreensão deste processo.

Venho pedir a sua preciosa colaboração para este estudo, pedindo-lhe que responda a um conjunto de questionários, certificando-se por favor, que não fique nenhuma resposta em branco.

Serão assegurados todos os requisitos éticos, no que se refere ao anonimato e confidencialidade dos dados.

Antecipadamente, grata pela sua colaboração

Florbela Gonçalves

Anexo V - Consentimento informado

DECLARAÇÃO DE CONSENTIMENTO

Designação do Estudo
CONTROLO SINTOMÁTICO E QUALIDADE DE VIDA EM CUIDADOS PALIATIVOS

Eu, abaixo-assinado,
(nome completo do participante)
_____
_____, compreendi a explicação que me foi fornecida acerca da investigação que se pretende realizar, nomeadamente objetivos, finalidades, metodologia e utilidade que a mesma terá para a compreensão do fenómeno em estudo. Foi-me dada oportunidade para fazer as perguntas que julguei necessárias, e de todas obtive resposta satisfatória.
Fui informado do direito de recusar em qualquer momento a minha participação no estudo, sem daí resultar qualquer prejuízo.
Foi-me assegurado o anonimato e a confidencialidade dos dados individuais.
Fui informado de que posso aceder aos resultados do estudo, se o solicitar.
Face ao exposto participo voluntariamente no estudo, através do preenchimento dos instrumentos de recolha de dados, apresentados pelo investigador.

Data: ____ / _____ / 20___
Assinatura do participante: _____

O Investigador responsável:
Nome:
Assinatura: _____

Anexo VI - Questionário sócio-demográfico

QUESTIONÁRIO SOCIO-DEMOGRÁFICO E CLÍNICO

Paciente nº -

Idade -

Género –

Estado civil –

Número de filhos –

Local de residência –

Cuidadores -

Habilitações literárias –

Tipo de neoplasia –

Estadio da neoplasia ao Diagnóstico –

Data de diagnóstico –

Data de morte –

Data de referenciação a cuidados paliativos –

Data da primeira avaliação por cuidados paliativos –

Data de admissão na UCP -

ECOG à admissão na UCP –

Proveniência do doente -

Anexo VII - Palliative Outcome Scale (POS)

Pedro L. Ferreira PL, Ana Barros Pinto A. Medir qualidade de vida em cuidados paliativos: a validação da Palliative Care Outcome Scale em Portugal. Acta Médica Portuguesa. 2011;24(5)

Escala de Resultados de Cuidados Paliativos
QUESTIONÁRIO AO DOENTE (versão 1)

www.pos-pal.org

Nome do/a doente: …….. Data da avaliação: .....

Data de nascimento: ..……..…… Avaliação nº: ……..

Local dos cuidados: ……

Por favor, responda às seguintes perguntas, escolhendo o quadrado ao lado da resposta que é mais verdadeira para si. As suas respostas ajudar-nos-ão a continuar a melhorar os cuidados prestados a si e a outros. Obrigado.

1 NOS ÚLTIMOS 3 DIAS, as dores afectaram-no/na? Assinale apenas um quadrado.

- ❑ 0 Não tive dores ou não me afectaram nada
- ❑ 1 Ligeiramente – mas não o suficiente para as esquecer
- ❑ 2 Moderadamente – as dores limitaram alguma da minha actividade
- ❑ 3 Bastante – a minha actividade ou a concentração foram muito afectadas
- ❑ 4 Horrivelmente – incapaz de pensar em qualquer outra coisa

2 NOS ÚLTIMOS 3 DIAS, sentiu-se afectado/a por outros sintomas ou queixas, por exemplo, enjoos, tosse Ou prisão de ventre? Assinale apenas um quadrado.

- ❑ 0 Não, não tive ou me afectaram nada
- ❑ 1 Ligeiramente
- ❑ 2 Moderadamente
- ❑ 3 Bastante
- ❑ 4 Horrivelmente

3 NOS ÚLTIMOS 3 DIAS, sentiu-se ansioso/a ou preocupado/a com a sua doença ou com o tratamento? Assinale apenas um quadrado.

- ❑ 0 Não, nada
- ❑ 1 De vez em quando
- ❑ 2 Às vezes – afecta a minha concentração de vez em quando
- ❑ 3 A maior parte das vezes – afecta frequentemente a minha concentração
- ❑ 4 Não consigo pensar em mais nada - constantemente preocupado/a e ansioso/a

4 NOS ÚLTIMOS 3 DIAS, algum dos seus familiares ou amigos andou ansioso/a ou preocupado/a consigo? Assinale apenas um quadrado.

- ❑ 0 Não, nada
- ❑ 1 De vez em quando
- ❑ 2 Às vezes – parece afectar a concentração deles
- ❑ 3 A maior parte das vezes
- ❑ 4 Sim, sempre preocupados comigo

5 NOS ÚLTIMOS 3 DIAS, que quantidade de informação foi dada a si e à sua família ou aos seus amigos? Assinale apenas um quadrado.

- ❑ 0 Muita informação – estive sempre à vontade para perguntar o que quis
- ❑ 1 Deram informações mas de difícil compreensão
- ❑ 2 Deram-me informações quando eu pedia mas gostaria de ter tido mais
- ❑ 3 Deram poucas informações e fugiram a algumas perguntas
- ❑ 4 Nenhuma

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6 NOS ÚLTIMOS 3 DIAS, conseguiu partilhar com a sua família ou amigos o modo como se sentia? Assinale apenas um quadrado.

- ❑ 0 Sim, tanto quanto quis
- ❑ 1 A maior parte das vezes
- ❑ 2 Às vezes
- ❑ 3 De vez em quando
- ❑ 4 Não, nada com ninguém

7 NOS ÚLTIMOS 3 DIAS sentiu que a vida era importante? Assinale apenas um quadrado.

- ❑ 0 Sim, sempre
- ❑ 1 A maior parte das vezes
- ❑ 2 Às vezes
- ❑ 3 De vez em quando
- ❑ 4 Não, nada

8 NOS ÚLTIMOS 3 DIAS, sentiu-se bem consigo como pessoa? Assinale apenas um quadrado.

- ❑ 0 Sim, sempre
- ❑ 1 A maior parte das vezes
- ❑ 2 Às vezes
- ❑ 3 De vez em quando
- ❑ 4 Não, nada

9 NOS ÚLTIMOS 3 DIAS, quanto tempo acha que perdeu com as consultas relacionadas com os seus cuidados de saúde, por exemplo, à espera de transporte ou a repetir testes? Assinale apenas um quadrado.

- ❑ 0 Nenhum
- ❑ 2 Quase meio dia gasto
- ❑ 4 Mais de meio dia gasto

10 NOS ÚLTIMOS 3 DIAS, teve alguns problemas práticos, financeiros ou pessoais, resultantes da sua doença? Assinale apenas um quadrado.

- ❑ 0 Os meus problemas práticos foram resolvidos e os meus assuntos estão em dia como eu desejaria
- ❑ 2 Tive alguns problemas práticos que estão a ser resolvidos
- ❑ 4 Tive alguns problemas práticos que não foram resolvidos
- ❑ 0 Não tive problemas práticos

11 Se teve problemas NOS ÚLTIMOS 3 DIAS, indique os mais importantes.

1. .....

2. .....

12 Como respondeu a este questionário? Assinale apenas um quadrado.

- ❑ 0 Sozinho/a
- ❑ 1 Com a ajuda de um amigo ou familiar
- ❑ 2 Com a ajuda de um membro do pessoal

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