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As Preferências e as Perceções de Comunicação do Doente Oncológico na
Primeira Consulta de Oncologia Médica

Rodrigo Santos Vicente

Orientador: Prof. Doutor Miguel Marques da Gama Barbosa

Documento provisório

Dissertação especialmente elaborada para obtenção do grau de mestre em Cuidados
Paliativos

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**A impressão desta dissertação foi aprovada pelo Conselho Científico da Faculdade
de Medicina de Lisboa em reunião de 21 de Novembro de 2023**

Resumo

Introdução: A primeira consulta de oncologia médica é, para o doente, um momento determinante para a compreensão do diagnóstico e prognóstico da sua doença. Este estudo tem como objetivo avaliar as preferências de comunicação do doente oncológico durante a primeira consulta de oncologia médica e avaliar as diferenças entre as preferências e as percepções. **Métodos:** Um total de 169 doentes oncológicos responderam ao *Communication in First Medical Oncology Questionnaire* (C-FAQ), um questionário constituído por duas partes que avalia as preferências e percepções do doente em relação ao conteúdo (qual e quanta informação é fornecida), facilitação (onde e quando a informação é transmitida) e suporte (apoio emocional) durante a sua primeira consulta de oncologia médica. Foi realizada uma análise comparativa para avaliar as diferenças entre preferências e percepções. **Resultados:** O conteúdo foi identificado como a dimensão mais importante da comunicação em comparação com a facilitação e o suporte. O conhecimento do médico, a honestidade e a clareza das informações foram as características mais importantes. Os doentes avaliaram a maioria dos itens da primeira parte do questionário como “muito importante”. Contudo, a percepção dos entrevistados sobre os elementos de comunicação presentes durante a consulta ficou abaixo do esperado em 11 itens, revelando discrepâncias significativas na prática clínica. **Conclusões:** As três dimensões de conteúdo, facilitação e suporte foram altamente valorizadas pelos doentes, embora as preferências se focassem mais no conteúdo. As discrepâncias entre as preferências e percepções de comunicação podem ser interpretadas como uma oportunidade para melhorar o treino das equipas médicas nas competências de comunicação.

Palavras-chave: Comunicação em saúde, Relação médico-doente, Psico-oncologia, Câncer, Oncologia, Preferências

Abstract

Background: The first medical oncology appointment serves as a platform for patients to comprehend their diagnosis and prognostic implications of cancer. This study aimed to determine patients' communication preferences during their first medical oncology appointment and to assess the disparities between patients' preferences and perceptions.

Methods: A total of 169 cancer patients participated by completing the Communication in First Medical Oncology Appointment Questionnaire (C-FAQ), a two-section questionnaire designed to assess patients' preferences and perceptions regarding Content (information provided and its extent), Facilitation (timing and location of information delivery), and Support (emotional support) during their first medical oncology appointment. A comparative analysis was conducted to assess the variations between preferences and perceptions. **Results:** Content emerged as the most significant dimension compared to Facilitation and Support. The physician's knowledge, honesty, and ability to provide clear information were considered the most important attributes. Patients evaluated most of their preferences as "very important". Patients' perception of the communication dimensions present during their appointment was below preferences for 11 items, indicating significant discrepancies in clinical practice. **Conclusions:** Patients highly valued their preferences concerning Content, Facilitation, and Support dimensions of communication. However, patient preferences were more prominently oriented towards the Content dimension. The discrepancies between preferences and perceptions should be viewed as an opportunity for enhancing communication skills through training.

Key-words: Health communication, doctor-patient relationship, psycho-oncology, cancer, oncology; preferences

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Agradecimentos

Aos meus pais e irmã,

Aos meus amigos,

Aos meus colegas de mestrado,

Ao Serviço de Oncologia Médica do Hospital Professor Doutor Fernando Fonseca, em especial à Marina Vitorino, Ana Mendes, Telma Caleça, Rita Freitas, Ricardo Ferreira, Sofia Prada e Telma Martins por todo o suporte operacional e pelo tempo dedicado à concretização do projecto,

À Dr^a Teresa Fiúza, Catarina Santos, Andreia Chaves e Diogo Alpuim pelos conselhos, motivação e revisão do trabalho,

À Equipa Intra-hospitalar de Cuidados Paliativos do Hospital Professor Doutor Fernando Fonseca, nas pessoas da Dr^a Paula Custódio, Iuri Correia, Sílvia Sereno, Catarina Faria, Tânia Afonso, Rita Mascarenhas, Vera Ramos, Mafalda Ramalheira, Rita Santiago e Maria Lima por todos os valores pessoais e profissionais que me transmitiram. Sendo os principais responsáveis por percorrer este caminho, o exemplo dado do humanismo e dedicação aos doentes fará de mim um melhor Oncologista. Obrigado pela aprendizagem e pelo apoio incondicional em todos os momentos,

Ao Prof. Doutor Miguel Barbosa pela tutoria e acompanhamento irrepreensíveis.

Lista de abreviaturas

C	<i>Content</i>
C-FAQ	<i>Communication in first oncology appointment questionnaire</i>
F	<i>Facilitation</i>
HADS	<i>Hospital Anxiety and Depression Scale</i>
HFF	Hospital Professor Doutor Fernando Fonseca
M	<i>Mean</i>
MPP	<i>Patient's Preferences Questionnaire</i>
S	<i>Support</i>
SD	<i>Standard deviation</i>
SSQ6	<i>Social Support Questionnaire Short Form – 6 items</i>
SSQ6N	<i>Index of available support perception in Social Support Questionnaire Short Form – 6 items</i>
SSQ6S	<i>Index of satisfaction with social support in Social Support Questionnaire Short Form – 6 items</i>
UE	União Europeia

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1. Contextualização teórica

1.1. O doente oncológico e os cuidados paliativos

Em concomitância com a evolução tecnológica, a melhoria das ferramentas diagnósticas e disponibilidade de novas terapêuticas, 2.6 milhões de pessoas são anualmente diagnosticadas com cancro nos 27 países da União Europeia (UE).¹ Embora a taxa de mortalidade padronizada por idade nos países da UE esteja a diminuir, espera-se que o número absoluto aumente devido ao envelhecimento da população.¹ Com isto, prevê-se igualmente um aumento da multimorbilidade e uma maior complexidade na abordagem clínica ao doente oncológico idoso.² No ano de 2020, em Portugal, os tumores malignos foram a segunda maior de causa de mortalidade (23%), seguido das doenças cardiovasculares (28%).³ Ainda que com uma mortalidade expressiva, o cancro é considerado cada vez mais uma doença crónica.⁴ Com as novas terapêuticas, há cada vez mais sobrevivências de longa duração e, com isso, um elevado número de indivíduos que enfrenta inúmeras complicações inerentes às terapêuticas realizadas, como a cirurgia, quimioterapia, imunoterapia, terapêuticas dirigidas e radioterapia.⁵

A confirmação de uma doença oncológica constitui um diagnóstico ameaçador de vida e de grande impacto físico, psicológico e social.⁶ Além do sofrimento físico que implicam as múltiplas intervenções e tratamentos geradores de sequelas e toxicidades, o doente é confrontado com a finitude da sua vida e são abaladas as suas expetativas e aspirações futuras.⁶ Esta perceção pode, ainda, variar em função da biologia da doença, do estadiamento atribuído, do intuito curativo ou paliativo do tratamento, mas também de outros fatores individuais.⁶ De um modo geral, a complexidade inerente ao doente oncológico faz com que seja frequente o surgimento de determinadas necessidades de intervenção em saúde que integram o âmbito da Medicina Paliativa.⁷ A Organização Mundial de Saúde define os Cuidados Paliativos como uma abordagem integrada e

centrada no doente que presta cuidados diferenciados promotores de qualidade de vida aos doentes que enfrentam uma doença potencialmente mortal, e respetivas famílias/cuidadores.⁸ Surgidos na década de 1960 no Reino Unido e com um desenvolvimento conceptual e operacional notórios ao longo dos anos em vários países, são cuidados que pressupõem uma identificação e avaliação das necessidades paliativas, assim como prevenção e alívio do sofrimento em todas as dimensões.^{9,10} Além da abordagem à dor como um todo e outros sintomas físicos que se instalem no decorrer da doença, a afirmação da morte como um processo natural, bem como a integração dos princípios psicológicos e espirituais nos cuidados prestados são alguns dos princípios dos Cuidados Paliativos.¹¹ Não surpreende, portanto, que o doente oncológico represente uma percentagem expressiva de doentes com necessidades paliativas.⁷ Um estudo português com 1.273 doentes hospitalizados, levado a cabo em 11 hospitais portugueses, identificou estas necessidades em 51.4% da amostra, na qual 67.2% apresentava doença oncológica.¹² Fruto das diversas barreiras no momento da referenciação, entre as quais a ausência de uma equipa especializada disponível, a ausência de critérios inequívocos e a dificuldade de identificar o momento de referenciação leva a que, globalmente, apenas 14% dos doentes que necessita de cuidados paliativos acaba por recebê-los efetivamente.^{8,12}

Atualmente, é defendido um modelo de intervenção precoce, integrado e planeado, centrado na pessoa com tempos medianos de sobrevivência de 24 meses, adequada identificação dos doentes em todos os níveis de prestação de cuidados, com adequada gestão dos casos e planeamento avançado dos cuidados.¹² Atendendo à natureza deste tipo de cuidados, a comunicação revela-se uma ferramenta fundamental na relação humana, bem como na prestação de cuidados, constituindo um importante recurso na intervenção em Cuidados Paliativos.^{13,14}

1.2. A importância da comunicação em oncologia e cuidados paliativos

A comunicação é a pedra-basilar na relação entre profissionais de saúde, doentes e famílias/cuidadores. É um processo dinâmico, multidirecional, verbal e não verbal, e dependente da informação fornecida pelo entrevistado e pelo profissional de saúde.¹³ Em consonância com competências interpessoais como a empatia, comunicar pressupõe captar informações relevantes que facilitem o diagnóstico, informar sobre prognóstico, efeitos adversos e opções terapêuticas possíveis mas também aconselhar adequadamente à luz do interesse e vontade do doente.¹⁵ Essas são as premissas de uma relação médico-doente de confiança e que permitem ir ao encontro das necessidades dos doentes, facilitar a compressão da informação fornecida e prestar suporte emocional.¹⁴ Uma comunicação bem-sucedida pode ser sinónimo de uma maior adesão ao plano terapêutico e a uma melhoria dos resultados obtidos nas intervenções em saúde.¹⁴

Enfrentar o diagnóstico de uma doença potencialmente mortal é gerador de angústia e uma antevisão de sofrimento. O curso da doença oncológica é habitualmente longo e, mesmo que haja uma perspetiva de cura, todo o processo pressupõe mecanismos de adaptação, por parte do doente, face aos múltiplos procedimentos invasivos e dolorosos, medicações com vários efeitos adversos, atrasos na terapêutica que podem comprometer a sua eficácia, entre outros.¹⁶ Durante este caminho, é frequente a necessidade de transmissão de más notícias, isto é, informação que suscite algum grau de sofrimento e que altere negativamente a perspetiva do doente e dos seus familiares em relação ao futuro.¹⁷

A tarefa de comunicação de más notícias não é considerada, de todo, fácil. Na perspetiva do médico, além do desconforto em facultar determinada informação que irá suscitar reações negativas, podem não ser óbvias quais as preferências ou necessidades de informação dos doentes.¹⁸ Além disso, os clínicos consideram que existe pouca

formação em comunicação em saúde e em transmissão de más notícias, durante o seu percurso formativo.¹⁸ Por outro lado, a disponibilidade do doente para receber informação e a forma como a percebe, poderá depender do estado emocional, dos mecanismos de *coping* de que dispõe ou, ainda, da própria doença e do seu estadiamento.^{14,19} A expectativa, experiências prévias, bagagem cultural e crenças estabelecidas parecem influenciar o que os doentes desejam saber em termos de prognóstico e a forma como lidam com a informação.^{17,20} É, pois, fundamental a identificação das necessidades de informação individuais, bem como compreender o impacto da doença na esfera psicológica.

Existem algumas recomendações estabelecidas na literatura sobre como devem os médicos preparar uma comunicação de más notícias, qual o ambiente de suporte ideal e de que forma as informações devem ser transmitidas. O SPIKES (*Setting up interview, Perception, Invitation, Knowledge, Emotion, Strategy/Summary*) é um protocolo disseminado pela comunidade científica, que estruturou o processo de transmissão de más notícias ao doente em vários momentos: (i) preparação da entrevista, (ii) avaliação a percepção do doente, (iii) convite para o diálogo, (iv) facultar informações ao doente, (v) abordar as emoções com respostas empáticas e (vi) estratégia e resumo.²¹ Outros dois exemplos de protocolos disponíveis na literatura constam adicionalmente na tabela 1.

Tabela 1 - Exemplos de recomendações e orientações na comunicação de más notícias

Autor e país de origem	Resumo
Baile et al. ²¹	<i>SPIKES</i> : Preparação da entrevista, avaliação a percepção do doente, convite para o diálogo, facultar informações ao doente, abordar as emoções com respostas empáticas, e estratégia e resumo.
Girgis and Sanson-Fisher ²²	Garantir a privacidade e o tempo adequado, avaliar a compreensão, fornecer informações de forma simples, incentivar à expressão sentimentos, discutir opções de tratamento, oferecer suporte para a partilha de informações a outros, e facultar informações sobre serviços de apoio.
Rabow and McPhee ²³ 04/04/2024 16:24:00	Preparar, construir uma relação terapêutica, comunicar bem, enfrentar as reações dos pacientes e familiares, incentivar e validar emoções.

No entanto, a redação destas recomendações decorre de artigos de opinião, revisões de literatura, estudos de caso e outros estudos descritivos com amostras reduzidas, sem integrar uma dimensão prática e robusta da real preferência dos doentes.¹⁷ Além de refletir a visão dos profissionais de saúde, é importante que a base empírica das *guidelines* seja validada junto dos doentes e corresponda às suas necessidades. Neste sentido, um estudo Australiano procurou avaliar, junto de 131 doentes recém diagnosticados com melanoma, as preferências de comunicação no momento do seu diagnóstico, e identificar as discrepâncias existentes entre as *guidelines* orientadoras e a opinião dos próprios.²⁴ Neste estudo, observa-se que a maioria das directrizes estabelecidas são correspondidas pelas preferências dos doentes.²⁴ Contudo foram identificadas algumas discrepâncias que culminam na formulação, por parte dos autores, de três orientações propostas: promover o aumento da confiança do doente sobre o melhor tratamento proposto, considerar como secundário o auxílio na partilha do seu diagnóstico com terceiros e retirar a recomendação de presença de um segundo profissional de saúde no momento da transmissão da notícia.²⁴

Procurando aprofundar o conhecimento e avaliar, também na perspectiva do doente, quais as suas preferências na comunicação do diagnóstico quanto ao conteúdo (qual e quanta informação é fornecida), facilitação (onde e quando a informação é transmitida) e suporte (apoio emocional), foi criado e aplicado a 351 doentes o questionário *Measure of Patients' Preferences questionnaire*.¹⁷ Neste estudo, os inquiridos consideraram a experiência do médico, e a informação prestada sobre a sua doença e tratamentos como as áreas de maior importância. Ao invés, aspectos relacionados com o suporte foram considerados os menos importantes.¹⁷ Considerando as mesmas dimensões da comunicação, resultados semelhantes foram encontrados num estudo que envolveu doentes canadianos com neoplasia da próstata, bem como noutro estudo levado a cabo em Inglaterra.^{25,26} Neste último, foram destacadas a importância da confiança nas competências do médico e nas discussões promovidas sobre o tratamento e prognóstico.²⁶

Mais recentemente, com o duplo objetivo de avaliar as preferências de comunicação dos doentes e a experiência vivida no momento do diagnóstico, um estudo alemão desenvolveu o questionário *Marburg Breaking Bad News Scale* no qual um conjunto de questões categorizadas de acordo com as dimensões do protocolo SPIKES foram colocadas a uma amostra de 350 doentes após receberem o diagnóstico.¹⁹ No que diz respeito às preferências na comunicação, entre os 37 itens do inquérito, foi considerada como mais importante a clareza transmitida sobre a progressão da doença e o possível sofrimento.¹⁹ Dos 10 itens que receberam maior importância, 5 abordaram tópicos relacionados com a informação facultada sobre a doença, 3 foram projetados para medir aspectos relacionados com a “estratégia e resumo” e 2 versaram sobre aspetos do ambiente envolvente.¹⁹ Contrastando com os estudos prévios, apenas 46.2% dos doentes oncológicos se mostraram completamente satisfeitos quando inquiridos sobre o processo

de comunicação observado aquando do diagnóstico.¹⁹ Verificou-se, assim, que o protocolo SPIKES não cobriu totalmente todas as necessidades da população do estudo e houve uma discrepância importante entre a percepção e as preferências do doente.¹⁹ A maior diferença entre o que os doentes pretendiam e o que obtiveram foi verificada no tópico sobre a “explicação definitiva do curso da doença”.¹⁹

1.3. A primeira consulta de oncologia médica

Muito além do diagnóstico, e no curso da doença oncológica previamente descrita, situações como um resultado analítico desfavorável, a progressão da doença e a suspensão definitiva de tratamentos onco-dirigidos, exigem do profissional de saúde uma abordagem cuidada e empática.²⁷⁻²⁹ Entre os diversos momentos no trajeto da doença oncológica, a primeira consulta é considerada crucial no acolhimento de um doente no serviço de oncologia: além da comunicação ou validação do diagnóstico, é a ocasião onde é dado sentido ao mesmo e onde há lugar para uma avaliação clínica, discussão do prognóstico e do plano terapêutico. É também o momento propício para a partilha de receios, preocupações e angústias face à doença.³⁰ O momento do diagnóstico da doença oncológica tem sido amplamente discutido enquanto momento-chave na comunicação de más notícias. Contudo, nenhum outro avaliou, até hoje, as preferências quanto à comunicação com o médico assistente no cenário específico de uma primeira consulta de oncologia médica. É, pois, relevante a utilização de competências em comunicação que correspondam às necessidades dos doentes, que promovam cuidados centrados na pessoa e uma melhoria dos *outcomes* clínicos neste contexto.

Neste pressuposto, foi conduzido o estudo “As Preferências e as Percepções de Comunicação do Doente Oncológico na Primeira Consulta de Oncologia Médica” que teve como objetivo avaliar as preferências de comunicação do doente oncológico durante

a primeira consulta de oncologia médica e avaliar as diferenças entre as preferências e as percepções.

Do ponto de vista clínico, compreender as preferências de comunicação dos doentes permite que os médicos estejam mais atentos e receptivos às necessidades dos doentes durante um período vulnerável de suas vidas. Por outro lado, a reflexão sobre os resultados obtidos permite a discussão de estratégias de comunicação e elaboração de directrizes adaptadas à circunstância. A diferença entre as preferências e percepções possibilita, ainda, apontar oportunidades de melhoria nos aspectos da comunicação que possam ser discrepantes e, assim, promover programas de formação em competências de comunicação para as equipas de saúde.

Com base no estudo realizado, a seção seguinte aborda os conteúdos do artigo científico elaborado. Este encontra-se atualmente submetido e aceite para publicação na revista *Psycho-Oncology*, e, por isso, redigido em língua inglesa.

2. Artigo Científico

2.1.Introduction

Effective communication involving the physician, patient, and family is crucial for meeting patient needs and providing safe, high-quality, and patient-centred care.¹⁵ Communication plays a role in regulating patients' emotions, facilitating comprehension of information, and identifying patients' perceptions and expectations.¹³

In the oncological setting, patients are thrust into a whirlwind of diagnostic tests, invasive procedures and complex treatments, leaving them with little opportunity to process their circumstances.¹⁶ Physical, emotional, social, and financial concerns are expected to impact individuals and their families. Indeed, discussions about patients'

losses and suffering can be particularly challenging, given the number of potentially unfavourable events over time.¹⁷ Physicians often struggle to determine how much information to disclose to the patient and acknowledge a lack of expertise in delivering bad news.¹⁸

Beyond the diagnosis, numerous situations throughout the cancer journey present challenges, encompassing relapses, disease progression, subsequent lines of therapy, toxicities, treatment delays, and the definitive suspension of antineoplastic therapies.^{27–29} The bad news perception correlates with patients' stress and anxiety levels, their ability to manage adverse information, their satisfaction with care, and their adjustment to health outcomes.^{14,19} Inadequate doctor-patient communication skills can lead to psychological distress, including heightened anxiety and depression, and hinder effective psychological adaptation to cancer.³¹

Several protocols outline how physicians should prepare for delivering bad news, the manner in which they should provide the information and the appropriate physical environment for discussions.^{21–23} For the disclosure of negative information to cancer patients about their condition, the SPIKES protocol was outlined by Baile et al.²¹ This acronym denotes (i) Setting up the interview, (ii) assessing the patient's Perception, (iii) obtaining the patient's Invitation, (iv) providing Knowledge and information to the patient, (v) addressing the patient's Emotions, and (vi) Strategy and Summary.²¹ Limited evidence exists regarding adherence to these tools and the impact of their use on patients' satisfaction. Furthermore, evidence suggests differences between doctors' and patients' preferences regarding delivering bad news.¹⁹

Several studies have aimed to deepen our understanding and evaluate, from the patient's perspective, the communication process required when receiving bad news. The Measure of Patients' Preferences questionnaire (MPP) was developed to assess patient

preferences regarding Content, Facilitation, and Support.¹⁷ The Marburg questionnaire applied the Breaking Bad News Scale, incorporating questions aligned with the six dimensions of the SPIKES protocol.¹⁹ In this study, only a minority of the interviewed cancer patients expressed satisfaction with the communication process. The SPIKES protocol did not fully address all the needs of the study population, resulting in a disparity between the information delivered and how it was conveyed, as well as patient preferences.¹⁹

Beyond the delivery of the diagnosis, the first medical oncology appointment represents a pivotal moment in the trajectory of the oncological disease. Typically, it is a stressful occasion during which the diagnosis and prognosis are discussed or confirmed. Many patients already possess their diagnosis but lack further information regarding the implications of cancer on their lives. Therapeutic strategies, potential side effects, and short- and long-term complications can also be addressed. Furber et al. examined how patients perceived their initial oncology consultation and how the emotional context could impact their informational requirements.³⁰ Their findings revealed that patients' emotions and anxieties might curtail their inclination to seek more information to obviate distress. Additionally, age, sex, education, and cultural background have influenced communication preferences and truth-telling practices.^{17,19,32}

Social support is important in addressing psychological challenges like anxiety and depression, both prevalent among cancer patients.³³ It could be pertinent to identify patients at heightened risk due to psychosocial vulnerability stemming from inadequate social support. Additionally, comprehending how social factors can impact communication is crucial.³⁴

It is essential to develop strategies to gather information and meet patients' needs according to their perspective on the first medical oncology appointment. This approach

not only aids in mitigating the challenges of the appointment itself but also contributes to enhanced medical care outcomes and knowledge generation.³⁰

This study aimed to evaluate patients' communication preferences during their first medical oncology appointment. It also assessed patients' perceptions regarding the communication elements present in their first encounter with an oncology appointment. Additionally, it identified disparities between patients' reported perceptions and preferences in this context.

2.2.Methods

2.2.1. Participants

A comprehensive survey was conducted on 169 outpatients from the Medical Oncology Department of *Hospital Professor Doutor Fernando Fonseca* (HFF), Portugal. All patients were 18 years or older and had received a cancer diagnosis (whether newly diagnosed, facing relapse, or experiencing disease progression). Moreover, all participants were proficient in the Portuguese language and capable of providing written informed consent. Exclusion criteria included patients with dementia or cognitive impairment.

2.2.2. Instruments

Demographical variables such as age, sex, marital status, country of origin, qualifications and occupation were collected. Furthermore, the study encompassed the following clinical variables: tumour location, disease status, intended treatment approach, and the duration from diagnosis to the first appointment.

The C-FAQ (Communication in first oncology appointment questionnaire) was developed within this study to assess patients' communication preferences and

perceptions during the first medical oncology appointment. The questionnaire comprises two sections. The first section includes 49 items to assess patients' preferences concerning a range of doctor-patient communication elements, which are derived from the MPP and Marburg Breaking Bad News Scale. The subsequent section includes 40 items, identical to those in the first part, designed to assess patients' perception of the communication elements present during their initial appointment. Participants rated items in both sections using a Likert scale ranging from 0 ('not at all') to 4 ('entirely'). The items in both sections were categorised according to Parker et al. (2001) into Content (the information provided and its extent; $\alpha = .93$), Facilitation (contextual variables and setting; $\alpha = .92$), and Support (emotional support during the interaction; $\alpha = .85$).

The Hospital Anxiety and Depression Scale (HADS) was used to assess psychological morbidity and as a screening tool for anxiety and depression. It includes two subscales that individually measure depression and anxiety, each comprising 7 items rated on a 4-point severity scale.³⁵

The Social Support Questionnaire–Short Form (SSQ6) is a 6-item measure of social support. Each item poses a question that elicits a two-part response: Part 1 asks participants to indicate the number of individuals (ranging from 0 to 9) available for support in specific circumstances, and Part 2 asks participants to rate their satisfaction (ranging from 0 “not satisfied” to 9 “fully satisfied”) with these individuals. The SSQ6N indicates the perceived support index available, while the SS6QS represents the satisfaction index concerning that support.³⁶

2.2.3. Procedure

A cross-sectional study was designed. Starting from 20th January to 20th November 2022, the research team documented all incoming requests for new medical

oncology appointments. After the first appointment, the research team engaged with patients and assessed their eligibility. During this process, the researchers maintained no involvement in the patients' care. The questionnaire was delivered to the patients for completion in their homes, with a stipulated return timeframe of three weeks.

The Research Ethics Committee of HFF approved this study (002/2022).

2.2.4. Statistical analysis

A descriptive analysis was conducted to describe the demographic and medical characteristics of the sample. A repeated measure t-test was conducted to compare the dimensions of Content, Facilitation, and Support. To compare patients' communication preferences with their perceptions during the first appointment, a paired sample t-test was carried out on the subset of items that garnered the highest ratings of "very important" above the median. An ANOVA test was used to assess differences in preferences according to sex, marital status, tumour location, disease status, treatment approach, country of origin, qualifications, occupation, and HADS scale. Pearson's correlation assessed potential associations among the three dimensions (Content, Facilitation, and Support) and variables such as age, duration from diagnosis to the first appointment, and SSQ6N and SSQ6S. All the statistical analyses were performed using the SPSS software version 27.

2.3.Results

A total of 191 questionnaires were distributed, and 169 (88.5%) were returned. Among these, 163 (96.4%) were either fully completed or had less than 10% missing answers. The remaining questionnaires had over 50% of the answers missing, rendering

them unsuitable for analysis. The primary reason for non-return was the lack of psychological or emotional capacity required to complete the questionnaire.

Table 2 presents the demographic and medical characteristics of the participants. Participants' ages ranged from 22 to 88 years, averaging 64.5 years (SD = 12.10). The most prevalent diagnoses included gastrointestinal cancer, breast cancer, lung cancer, or other thoracic tumours. Among all patients, 89.6% received a recent cancer diagnosis. The average duration since diagnosis was 7.3 months (SD = 23.10), with 70.6% of diagnoses occurring within 3 months before their first appointment.

Depression and anxiety scores (assessed through HADS) and social support levels (assess through SSQ6) were measured through patient-reported outcomes. The findings show that 80.4% of the sampled individuals reported a depression score of eight or higher. Over 50% of patients reported an anxiety score of eleven or higher, signifying the presence of severe anxiety symptoms. The averages of the two subscales SSQ6N and SSQ6S showed no statistically significant differences ($p = .140$).

Table 2 - Demographical and medical characteristics of participants (n=163)

Age, mean in years (SD)		64.5(12.1)
Sex, n(%)		
	Male	83(50.9%)
	Female	80 (49.1%)
Marital status, n(%)		
	Married or living with partner	112(68.7%)
	Widowed	18(11%)
	Single	18(11%)
	Divorced	15(9.2%)
Country of origin, n(%)		
	Portuguese	
	Portuguese-speaking African	

2.3.1. Patients' preferences concerning Content, Facilitation and Support elements of communication

The C-FAQ items were predominantly assessed as “very important” [Mdn 65.85% (11.525)]. The most highly ranked statements exceeding the median are presented in Table 3 according to the three dimensions of Content, Facilitation, and Support, along with the frequency of “very important” responses. Of these, 50% pertained to Content items; 30% related to Facilitation; and 20% associated to Support. All percentages obtained regarding communication preferences are available in Appendix 1.

Upon analysing the three dimensions of patient-reported preferences, significant differences were found between Content, Facilitation, and Support. Content ($M=3.69$, $SD=0.35$) emerged as the most important component when compared with Facilitation ($M=3.56$, $SD=0.39$), ($t(30.13) = 17.38$, $p < .001$), and Support ($M=3.46$, $SD=0.44$), ($t(24.14) = 7.12$, $p < .001$). Facilitation was considered more important than Support ($t(24.14) = 16.42$, $p < .001$).

Table 3 - Percentage of responses regarding communication preferences relating to Content, Facilitation and Support

	Very important (%)
Content	
The doctor is up-to-date on research on my type of cancer	79.1
The doctor is honest about the severity of my condition	78.5
I am given information in simple, clear language	77.9
The doctor tells me the best treatment option	77.2
I feel confident about my doctor's skill	75.9
The doctor gives me as much information as possible about my cancer	74.8
I am given detailed information about the results of medical tests	74.6
The doctor explains the impact of treatment options on my daily life	73.5
The doctor talks clearly about the course of my oncological disease, according to the information he or she has	72.8

The doctor lets me know all the different treatment options	70.6
Facilitation	
The doctor asks me what I want to know about my cancer	72.8
The doctor makes sure I understand everything that is said	70.2
The space where the consultation takes place is suitable for my needs	68.1
The doctor lets me know how I can contact them to ask questions or to express my concerns before the next appointment	67.5
The doctor asks what I want to know about treatment options	66.7
The doctor gives me all the information in a logical order	66.3
Support	
The doctor truly listens to me	69.9
The doctor tries to understand my concerns	69.6
The doctor expresses concern for me	69.6
I can have a companion at the consultation	66.3

Note: This table only included the items ranked as "very important" above the median in terms of preferences

Regarding Content, patients often rated as “very important” physicians’ knowledge and honesty, along with receiving clear and comprehensible information about their condition and detailed insights into treatment options.

Within the Facilitation dimension, patients attributed the highest level of importance to the doctor’s concern about the clarity and amount of information regarding cancer and treatments. Moreover, patients valued their involvement in treatment decisions and appreciated facilities such as a physical space tailored to their needs, as well as the convenience of posing questions before their next appointment.

In terms of Support, being understood and actively listened to, as well as having the doctor express concerns, were also regarded as highly important. However, fewer patients considered it “very important” to have other healthcare professionals present or to receive assistance in discussing cancer with others.

2.3.2. Comparison of patients' communication preferences with perceptions

The findings in Table 4 show patients' preferences with the highest ratings alongside their perceptions during the initial medical oncology appointment. A paired-sample t-test was used to compare patients' communication preferences and perceptions. Eleven items showed significantly higher 'entirely' ratings on the preferences side. Most of these items were related to the Content dimension (54.5%).

Table 4 - Comparison of highest-rated patients' communication preferences with perceptions in the first medical oncology appointment

	Preferences M(SD)	Perception M(SD)	t(160)	p	Cohens' d
The doctor is up-to-date on research on my type of cancer(C)	3.79(0.41)	3.53(0.68)	4.70	<.001	0.73
The doctor is honest about the severity of my condition(C)	3.77(0.46)	3.66(0.51)	2.49	.014	0.57
I am given information in simple, clear language(C)	3.78(0.42)	3.81(0.39)	-1	.319	0.47
I feel confident about my doctor's skill(C)	3.76(0.43)	3.63(0.53)	2.7	.008	0.61
The doctor gives me as much information as possible about my cancer(C)	3.74(0.45)	3.61(0.71)	2.13	.035	0.74
I am given detailed information about the results of medical tests(C)	3.76(0.44)	3.62(0.67)	2.43	.016	0.66
The doctor talks clearly about the course of my oncological disease, according to the information he or she has(C)	3.72(0.46)	3.65(0.54)	1.41	.160	0.62
The doctor asks me what I want to know about my cancer(F)	3.73(0.45)	3.61(0.71)	2.146	.033	0.68
The doctor tells me how my cancer could affect my daily routine(C)	3.69(0.50)	3.41(0.79)	3.9	<.001	0.91
The doctor makes sure I understand everything that is said(F)	3.70(0.48)	3.58(0.62)	2.09	.039	0.67
The doctor truly listens to me(S)	3.70(0.46)	3.64(0.5)	1.42	.158	0.56
The doctor tries to understand my concerns(S)	3.68(0.49)	3.56(0.65)	2.64	.009	0.73
The doctor expresses concern for me(S)	3.69(0.48)	3.59(0.58)	1.85	.067	0.65

The doctor describes my treatment options in detail(C)	3.66(0.53)	3.57(0.64)	1.4	.164	0.76
The reason for the appointment is explained(C)	3.66(0.56)	3.75(0.44)	-1.82	.071	0.61
The space where the consultation takes place is suitable for my needs(F)	3.52(0.59)	3.70(0.46)	-3.74	<.001	0.61
The doctor lets me know how I can contact them to ask questions or to express my concerns before the next appointment(F)	3.66(0.53)	3.51(0.78)	2.46	.015	0.82
The doctor asks what I want to know about treatment options(F)	3.64(0.58)	3.39(0.86)	3	.003	0.90
The appointment takes place in a private place(F)	3.56(0.59)	3.70(0.53)	-3.01	.003	0.58
I can have a companion at the consultation(S)	3.53(0.82)	3.66(0.65)	-0.74	.46	0.56

Notes: A paired sample t-test was used to compare patients' communication preferences with perceptions. This analysis only included the items ranked as "very important" above the median regarding preferences.
C=Content; F=Facilitation; S=Support

2.3.3. Correlations between patients' preferences and demographic and medical variables

A significant and negative correlation was found between the 'time from diagnosis to first appointment' and the Support dimension ($r = -.19$, $p < .050$), suggesting that the more time elapsed since diagnosis, the less support is needed during the first appointment. No significant correlations were observed between age or either of the two subscales SSQ6N and SSQ6S, and patients' communication preferences.

Similarly, no significant differences were observed in means among Content, Facilitation, or Support dimensions concerning the patient's age, sex, marital status, tumour location, disease status, country of origin, qualifications, occupation, treatment approach, or HADS subscales outcomes.

2.4. Discussion

This study assessed patients' perceptions of the communication elements related to Content, Facilitation, and Support dimensions that were present during their first

medical oncology appointment. Additionally, it aimed to investigate the differences between patients' perceptions and their preferences in this context. The findings indicated that the Content dimension was deemed the most important. Although both the Facilitation and Support dimensions were ranked lower, patients still considered them important, warranting thorough consideration.

2.4.1. Patient's preferences regarding the Content dimension

The physician's knowledge, honesty, and the provision of clear information about cancer and treatment were the most significant areas. Before the first consultation, patients lack a comprehensive understanding of their diagnosis, which explains their eagerness for information. Acquiring appropriate initial information also facilitates better adjustment of expectations throughout the trajectory of the disease.³⁰ In a 60-item questionnaire assessing the importance and satisfaction with care, the quality of medical care and the technical competence of clinicians were reported as the greatest importance to cancer patients.³⁷ Our findings are consistent with other studies where physicians' knowledge, clarity, and willingness to discuss treatment were deemed highly important by patients.^{17,25,38}

2.4.2. Patient's preferences regarding the Facilitation dimension

Significant results were observed for C-FAQ items related to the patient's preference to be asked by a doctor about what they wish to know about cancer and to have the assurance that they comprehend the information. Patients value the opportunity to influence the amount of information shared, which supports their sense of empowerment.³⁹ Emotional status and subsequent fear of receiving negative news can influence the perception of medical terminology. Hence, the validation of comprehension

is crucial, as indicated by our results. The preference for a consultation environment tailored to the patient's needs emphasises the necessity of specific conditions for effective information assimilation. The absence of these facilitation elements in other studies resulted in a less favourable communication experience.^{17,25,38}

2.4.3. Patient's preferences regarding the Support dimension

Patients valued the empathy demonstrated by doctors when they displayed concern for patients' emotions and attentively listened to them. Conversely, items concerning interactions with individuals beyond the doctor-patient relationship were rated as "very important" by fewer than 30% of participants. It is likely that if patients feel satisfied with the support provided by their doctor, they may not attribute as much importance to the presence of other professionals. Additionally, patients might prefer to initially receive and understand all information privately, rather than share it immediately.

Patients with a longer duration between diagnosis and their first consultation expressed less preference for Support. This finding could be explained by the establishment of their support network, assimilation and adjustment to the information, clarifications provided by other healthcare practitioners, and the emotional regulation developed during this period.^{40,41}

2.4.4. Patients' preferences vs. perceptions

When comparing the 20 highest-rated preferences with the perceptions of their first oncology appointment, there were 11 items where perceptions were rated lower than the preferences, revealing significant discrepancies. This suggests that certain patient preferences are not being fulfilled in clinical practice, highlighting an opportunity to improve communication during the first appointment.

All aspects of communication were highly valued, irrespective of patient age, sex, marital status, tumour location, disease status, country of origin, qualifications, occupation or treatment approach. The results concerning anxiety and depression suggest that patients are distressed due to the diagnosis they are facing. More than 50% of participants reported severe anxiety symptoms, and 80.4% reported a depression score of eight or higher. Although no significant differences were found between the HADS subscales outcomes and the three communication dimensions, empathetic patient-centred care might influence patients' psychological well-being, potentially reducing their anxiety and fostering greater trust in their oncologist.⁴²

Having social support networks in oncology is vital for managing crises and aiding patient's physical and psychological adjustment.³⁴ However, no significant correlations were observed between social support and communication preferences. To validate these findings, it would be important to conduct this study across various centres.

2.4.5. Study limitations

This study included patients with diverse types of cancers, disease stages, treatment settings, and backgrounds. Our findings may capture the preferences of a wide spectrum of patients. Conducting a multicentric study could enhance the robustness of the results and validate their applicability across different contexts. The elevated presence of anxiety and depression might be linked to participant's reduced emotional capacity for completing the questionnaire, potentially explaining why 11.5% of participants did not return the questionnaires.

An extension of the current study could involve investigating potential variations in individual patient preferences over time. Recording the consultation could enable a supplementary analysis and introduce insights from physicians. Future studies might also

explore the possibility of separately assessing perceptions and preferences and determine whether such an approach influences the outcomes.

2.4.6. Clinical implications

Understanding patients' communication preferences allows physicians to be more aware and responsive to patients' needs during a vulnerable period of their lives. There should be ongoing discussions about communication strategies, leading to the development of guidelines tailored to this context. Topics such as informing patients about the practical impact of cancer on daily life and determining their informational needs regarding treatment options could be integrated, as these expectations often go unaddressed. The promotion of communication skills training programs for healthcare teams is essential.

Given the substantial number of patients experiencing symptoms of anxiety and depression, identifying signs of pathological distress or depression becomes crucial. This recognition would enable early referrals for psychological assessment and appropriate follow-up care.

2.5. Conclusions

Patients' preferences concerning Content, Facilitation, and Support dimensions of communication were highly valued, with a greater emphasis on Content in patient preferences. Discrepancies between communication preferences and perceptions should be viewed as opportunities to enhance training in communication skills for healthcare teams, enabling them to address patient needs. Further research is needed to explore the complexities of the doctor-patient relationship and how patients' communication needs can be effectively satisfied.

2.6.Appendix

Table 5 - Percentage of responses regarding communication preferences relating to Content

Item	0.Not important at all (%)	1.Slightly important (%)	2.Moderatly important (%)	3.Importan (%)	4.Very important (%)
The doctor is up-to-date on research on my type of cancer	0.0	0.0	0.0	20.9	79.1
The doctor is honest about the severity of my condition	0.0	0.6	0.0	20.9	78.5
I am given information in simple, clear language	0.0	0.0	0.0	22.1	77.9
The doctor tells me the best treatment option	0.0	0.0	0.6	22.2	77.2
I feel confident about my doctor's skill	0.0	0.0	0.0	24.1	75.9
The doctor gives me as much information as possible about my cancer	0.0	0.0	0.6	24.5	74.8
I am given detailed information about the results of medical tests	0.0	0.0	0.6	23.0	74.6
The doctor explains the impact of treatment options on my daily life	0.0	0.0	0.6	25.9	73.5
The doctor talks clearly about the course of my oncological disease, according to the information he or she has	0.0	0.0	0.6	26.5	72.8
The doctor lets me know all the different treatment options	0.0	0.0	1.2	28.2	70.6
The doctor tells me how my cancer could affect my daily routine	0.0	0.0	1.9	27.8	70.4
The doctor describes my treatment options in detail	0.0	0.6	1.2	29.4	68.7
The reason for the appointment is explained	0.6	0.0	0.6	30.2	68.5
I am given enough time to ask all my questions	0.0	0.0	1.8	35.0	63.2
I am given information about new experimental therapies	0.6	0.6	7.4	32.7	58.6
The doctor takes time to give full answers to all my questions	0.0	0.0	1.8	41.1	57.1

Table 6 - Percentage of responses regarding communication preferences relating to Facilitation

Item	0.Not important at all (%)	1.Slightly important (%)	2.Moderately important (%)	3.Important (%)	4.Very important (%)
The doctor asks me what I want to know about my cancer	0.0	0.0	0.0	27.2	72.8
The doctor makes sure I understand everything that is said	0.0	0.0	0.6	29.2	70.2
The space where the consultation takes place is suitable for my needs	0.0	0.6	2.5	28.8	68.1
The doctor lets me know how I can contact them to ask questions or to express my concerns before the next appointment	0.0	0.6	0.6	31.3	67.5
The doctor asks what I want to know about treatment options	0.6	0.0	1.2	31.5	66.7
The doctor gives me all the information in a logical order	0.0	1.2	0.6	31.9	66.3
The appointment takes place in a private place	1.8	1.8	4.3	25.8	66.3
The doctor involves me in the treatment decision	0.6	1.2	2.5	30.2	65.4
The doctor tells me the news in person	0.6	0.6	3.8	32.5	62.5
The doctor makes it clear that I can ask any questions	0.0	0.0	0.6	36.8	62.6
The doctor gives me enough time to think about the information given during the consultation	0.0	0.6	0.6	38.0	60.7
The doctor looks me in the eye	1.2	0.0	3.1	35.8	59.9
The doctor has enough time for the consultation	0.0	0.6	1.2	38.7	59.5
The doctor checks if I have any doubts about what he or she is telling me	0.0	0.6	0.6	40.1	58.6
I can make another appointment within days to discuss treatment options	0.6	1.2	3.1	37.9	57.1
The doctor summarises the consultation at the end	0.0	1.2	4.9	37.4	56.4
The doctor only informs me about my clinical situation after he or she has received all the clinical information	2.5	1.8	5.5	36.2	54.0
The doctor warns me there will be unfavourable news	2.5	2.5	6.2	35.8	53.1
The doctor ensures that the appointment is not interrupted	0.0	1.9	8.8	37.5	51.9

Table 7 - Percentage of responses regarding communication preferences relating to Support

Item	0.Not important at all (%)	1.Slightly important (%)	2.Moderately important (%)	3.Important (%)	4.Very important (%)
The doctor truly listens to me	0.0	0.0	0.0	30.1	69.9
The doctor tries to understand my concerns	0.0	0.0	1.2	29.4	69.6
The doctor expresses concern for me	0.0	0.0	0.6	29.8	69.6
I can have a companion at the consultation	1.8	1.8	4.3	25.8	66.3
The doctor gives me hope	0.6	0.0	5.6	28.4	65.4
The doctor tells me about resources in the community	0.0	0.0	2.5	32.7	64.8
The doctor shares his or her doubts and concerns about my illness	0.6	1.2	3.1	33.1	62.0
The doctor informs me about all the resources of the medical oncology service	0.0	0.0	3.7	36.2	60.1
I am encouraged to talk about my feelings	0.0	1.2	4.9	34.4	59.5
The doctor demonstrates he or she is able to understand what I am feeling	0.0	0.6	6.8	34	58.6
The doctor informs my family members about my diagnosis	0.6	1.2	6.2	37	54.9
The doctor helps me figure out how to tell other people about my cancer	2.5	8.7	12.4	41.6	34.8
Another healthcare provider is present to offer information or support	5.0	14.4	15.6	41.3	23.8

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