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Associação de Enfermagem Oncológica Portuguesa

BENEFÍCIOS DA TELENFERMAGEM NO SEGUIMENTO DA PESSOA COM DOENÇA HEMATO-ONCOLÓGICA: UMA REVISÃO SISTEMÁTICA

Revisão Sistemática com a finalidade de mapear a evidência científica sobre os benefícios do seguimento da pessoa com doença hemato-oncológica através da telenfermagem.

YOUNG ADULTS WITH CANCER IN PALLIATIVE CARE/END OF LIFE CARE: INTEGRATIVE LITERATURE REVIEW

Uma revisão integrativa da literatura utilizando estudos publicados entre 1 de janeiro de 2017 e 19 de janeiro de 2024.

NURSING BEST PRACTICE RECOMMENDATIONS FOR INTRAVESICAL INSTILLATION IN BLADDER CANCER: ADAPTATION TO THE PORTUGUESE ONCOLOGICAL CARE

O estudo da adaptação das recomendações de boas práticas para a instilação intravesical de terapêutica antineoplásica da Associação Europeia de Enfermeiros de Urologia para o contexto oncológico português.

DISTRESS NA PESSOA COM DOENÇA HEMATONCOLÓGICA SUBMETIDA A TRANSPLANTE: UMA REVISÃO INTEGRATIVA DA LITERATURA

Revisão Integrativa da Literatura com objetivo de Investigar os cuidados de enfermagem, promotores do alívio do distress na pessoa com doença hematoncológica, em isolamento hospitalar.

BENEFITS OF PATIENT AND PUBLIC INVOLVEMENT IN CANCER RESEARCH: LITERATURE REVIEW

Revisão sobre a identificação dos benefícios do envolvimento dos doentes e do público na investigação do cancro.

NURSE-LED GASTROSTOMY CARE: A BUSINESS CASE

Uma análise do modelo de cuidados liderado por enfermeiros especialistas em enfermagem médico-cirúrgica, centrado na pessoa com gastrostomia.

NURSING INTERVENTIONS TO PROMOTE COPING IN PATIENTS WITH CANCER: A SCOPING REVIEW

Realizada uma Scoping Review com o objetivo de mapear as intervenções de enfermagem promotoras do coping nas pessoas com doença oncológica.

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A Associação de Enfermagem Oncológica Portuguesa (AEOP) tem a honra de anunciar a publicação do N.º 51 da Revista Onco.News, a última edição do ano de 2025. Publicamos recentemente o o regulamento relativamente à utilização do IA. Temos tido aumento de submissão de artigos e da qualidade dos mesmos o que atesta a qualidade da nossa revista. Nesta edição, reforçamos o compromisso com a divulgação científica na área da Enfermagem Oncológica. Os artigos em destaque são:

Benefícios da telenfermagem no seguimento da pessoa com doença hemato-oncológica: uma revisão sistemática. Artigo que evidencia a necessidade de programas estratégicos e estruturados de acompanhamento, que permitam responder de forma sistematizada às necessidades das pessoas com doença hemato-oncológica.

Jovens adultos com cancro em cuidados paliativos/fim de vida: revisão integrativa da literatura

Artigo que explora um contexto de elevada vulnerabilidade, salientando a importância da atuação de equipas multidisciplinares para uma abordagem integral e humanizada.

Distress na pessoa com doença hematoncológica submetida a transplante: uma revisão integrativa da literatura. Artigo que reforça o papel crucial dos cuidados de enfermagem no alívio do distress emocional, contribuindo para a melhoria do bem-estar e da adaptação da pessoa submetida a transplante.

Benefícios do envolvimento dos doentes e do público na investigação do cancro: revisão da literatura. Artigo que demonstra como o envolvimento ativo constitui um recurso fundamental para qualificar a investigação, tornando-a mais pertinente e centrada nas reais necessidades.

Cuidados conduzidos por enfermeiros em gastrostomia: Proposta de Valor. Artigo que apresenta um modelo alternativo e inovador de cuidados de enfermagem, para otimizar a prática clínica.

Intervenções de Enfermagem Promotoras do Coping na Pessoa Adulta com Doença Oncológica – Uma Scoping Review. Artigo que destaca as intervenções cognitivo-comportamentais como estratégias centrais para fortalecer o coping.

Esta edição sublinha a importância da investigação como alicerce para práticas inovadoras e humanizadas, assim como a valorização do papel dos enfermeiros na promoção da qualidade de vida e da segurança das pessoas com doença oncológica e suas famílias.

Convidamos todos os profissionais de saúde, investigadores e estudantes a explorar os contributos desta publicação e a partilhar o conhecimento produzido.

Gostaríamos de aproveitar para realçar que este ano a maioridade da AEOP foi conquistada. Foi assumida a nova liderança com motivação rumo a novos desafios e com o compromisso de difundir a Ciência em Enfermagem Oncológica, que merece ser continuamente fortalecida, reconhecida e valorizada!

"Juntos, seremos mais fortes! Juntos, cuidaremos melhor! Juntos, faremos a diferença!"

Sandra Ponte
Presidente da AEOP

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BENEFÍCIOS DA TELENFERMAGEM NO SEGUIMENTO DA PESSOA COM DOENÇA HEMATO-ONCOLÓGICA: UMA REVISÃO SISTEMÁTICA

Benefits of telenursing in the follow-up of people with hematologic-oncological disease: systematic review

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RESUMO

Introdução: A pessoa com doença hemato-oncológica carece de necessidades especiais, pelo impacto psicológico do diagnóstico e pelo percurso até à alta médica. As pessoas, no pós-alta, apresentam sintomatologia relativa à doença e aos tratamentos.

Objetivo: Mapear a evidência científica sobre os benefícios do seguimento da pessoa com doença hemato-oncológica através da telenfermagem.

Metodologia: Revisão Sistemática. As bases de dados CINAHL e MEDLINE foram pesquisadas para incluir estudos entre 2014 e 2023, utilizando os descritores "Telenursing", "Chemotherapy ""Hematology" e "Oncology nursing".

Resultados: Identificamos 33 estudos científicos, mas após aplicar os critérios de inclusão e de exclusão finalizamos com 21 artigos.

Conclusão: Incentivo para futuras pesquisas e um suporte ao desenvolvimento de programas estratégicos para o acompanhamento sistematizado às pessoas com doença hemato-oncológica.

PALAVRAS-CHAVE: Telenfermagem; Hematologia; Neoplasia maligna; Antineoplásicos.

ABSTRACT

Introduction: The person with hematologic-oncologic disease requires special needs, due to the psychological impact of the diagnosis and the journey until medical discharge. People, post-discharge, present symptoms related to the disease and treatments.

Objectives: To map the scientific evidence on the benefits of monitoring people with hematologic-oncologic disease through telenursing.

Methodology: Systematic Review. The CINAHL and MEDLINE databases were searched to include studies between 2014 and 2023, using the descriptors "Telenursing", "Chemotherapy", "Hematology", and "Oncology nursing", addressing the question, "What are the benefits of monitoring people with hematologic-oncologic disease through telenursing?"

Results: We identified 33 scientific studies, but after applying the inclusion and exclusion criteria, we finalized with 21 articles.

Conclusion: Encourages future research and supports the development of strategic programs for the systematic follow-up of people with hematologic-oncologic disease.

KEYWORDS: Telenursing; Hematology; Malignant Neoplasm; Antineoplastic Agents.

Introdução

A incidência de doenças oncológicas em Portugal tem aumentado a uma taxa constante de 3% ao ano, alinhando-se com as tendências europeias. Projeções indicam que o número de casos de cancro excederá os 20 milhões até 2030[1]. As doenças oncológicas são a segunda causa de morte em Portugal, tendo subido significativamente nos últimos anos. As pessoas com doença oncológica enfrentam desafios clínicos, familiares, sociais e laborais, decorrentes das diferentes estratégias terapêuticas. Nomeadamente os tratamentos medicamentosos, como a quimioterapia (QT), utilizada em 70% dos casos, são agressivos e têm efeitos colaterais severos[2]. A assistência ao doente deverá iniciar-se na admissão, continuar durante a hospitalização, a reabilitação e acompanhamento no pós-alta. A pessoa com doença hemato-oncológica maligna, aquando de condições clínicas estáveis tem alta hospitalar, porém não está totalmente recuperada, existindo a necessidade de otimizar a continuidade dos cuidados à pessoa e seu cuidador. A ocorrência de doença hematológica constitui uma transição do âmbito de saúde/doença, de acordo com a Teoria das Transições de Meleis. Assim, o papel do enfermeiro é interagir com as pessoas, estejam elas em situação de saúde ou doença, e melhorar o contexto sociocultural onde se encontram inseridas e verificando se estão sofrendo algum tipo de transição ou estão antecipando a mesma; as interações enfermeiro utente são organizadas em torno de um propósito e o enfermeiro utiliza algumas ações terapêuticas para melhorar, trazer ou facilitar a saúde[3].

As pessoas com doença hemato-oncológica que recebem alta hospitalar podem apresentar sintomas e toxicidades durante o período nadir, necessitando de supervisão e vigilância para minimizar complicações graves[4]. Um estudo de Beck et al.[5] identificou dor (41,5%), febre (18,5%) e náuseas/vómitos (16,9%) como os sintomas mais comuns em unidades de urgência e emergência, seguindo-se outros nomeadamente, dispneia, astenia, tosse, disfagia, sangramento, sincope, entre outros.

Oliveira et al.[6] constataram, numa revisão sistemática que cuidadores enfrentam dificuldades no pós-alta devido à falta de informações, destacando a necessidade de protocolos de alta hospitalar para minimizar o impacto desta transição. A assistência deve começar na admissão e continuar na reabilitação e acompanhamento pós-alta. As pessoas não monitorizadas podem apresentar complicações, resultando em reinternamentos e aumento da morbimortalidade[7,8].

A Ordem dos Enfermeiros (OE) destaca que a teleconsulta de enfermagem – telenfermagem, deve seguir diretrizes da Organização Mundial de Saúde (OMS), da Administração Central do Sistema de Saúde (ACSS) e dos Serviços Partilhados do Ministério da Saúde (SPMS), permitindo avaliações à distância e planeamento de cuidados.[9] Esta consulta melhora a gestão de recursos, o acesso aos cuidados e a capacitação dos cidadãos na gestão de sua saúde.

A OE define a teleconsulta de enfermagem como uma consulta realizada à distância, utilizando comunicações interativas, audiovisuais e de dados, com registo obrigatório.[10,11] Esta intervenção promove a comunicação entre enfermeiros e pacientes, englobando telemonitorização, telereabilitação e telerrastreio. A evidência científica demonstra que a teleconsulta oferece diversas vantagens, incluindo a promoção da saúde sem necessidade de internet, redução de barreiras de acesso e individualização do atendimento, sendo especialmente útil para pessoas com doenças estigmatizantes[12].

Existem vários estudos sobre a utilização da teleconsulta de enfermagem nestas pessoas, e por esse motivo, considera-se fulcral mapear a evidência científica sobre os benefícios do seguimento da pessoa com doença hemato-oncológica através da telenfermagem.

Método de Revisão Sistemática

A presente revisão foi formulada em consonância com a mnemónica PICO (quadro 1) e pretende responder à seguinte questão de pesquisa: Quais os benefícios do seguimento da pessoa com doença hemato-oncológica através da telenfermagem?

Quadro 1. Mnemónica PICO

P - População	Pessoas com doença hemato-oncológica
I - Intervenção	Seguimento da pessoa com doença hemato-oncológica através da telenfermagem
C – Contexto	Domicílio
O – Outcome	Prestação de cuidados segura e com qualidade (benefícios)

Fonte: Adaptado de Joanna Briggs Institute (JBI)[13]

Esta pesquisa alicerçou-se numa revisão sistemática da literatura com resumo narrativo.

Critérios de inclusão: Participantes foram as pessoas adultas com doença hemato-oncológica maligna que regressaram ao domicílio após realizar ciclo de QT. Intervenção: Foram consideradas as intervenções de teleconsulta de enfermagem que transmitissem cuidados e conduzissem à prática clínica. Resultados: Foram incluídos os resultados primários como os benefícios do seguimento da pessoa

com doença hemato-oncológica através da telenfermagem no domínio do autocuidado e controlo sintomático e como resultados secundários o impacto deste seguimento para as pessoas e para os enfermeiros. Foram incluídos os estudos qualitativos, quantitativos e de revisão sistemática com moderada e alta qualidade metodológica publicadas em revistas nacionais e internacionais entre 2014 e 2023 e em Inglês, Francês, Espanhol ou Português.

Foram excluídos estudos teóricos ou de opinião e todos os estudos que não apresentassem os critérios de inclusão anteriormente descritos e os que não tivessem no título ou abstract/resumo teleconsulta de enfermagem e pessoa com doença hemato-oncológica maligna e cujo objetivo não fosse avaliar o seu efeito nas pessoas com doença oncológica maligna.

Estratégica de pesquisa: A revisão sistemática foi conduzida por dois revisores de forma independente. Nos momentos de discordância recorremos à consulta de um terceiro elemento. Executamos a pesquisa de forma trifásica: Primeiramente identificamos os descritores Medical Subject Headings (MeSH): "Telenursing", "Chemotherapy", "Hematology" e "Oncology nursing". Posteriormente, a conjugação dos descritores foi feita com os termos boleanos "AND" e "OR". Na terceira fase foi realizada a pesquisa, exclusivamente em bases de dados online, nomeadamente a CINAHL® Complete e MEDLINE® Complete, disponíveis através da plataforma EBSCOhos.

Apresentação dos Resultados

Após pesquisa nas bases de dados com a frase boleana anteriormente mencionada e após a avaliação metodológica resultaram 33 estudos científicos. Para esta avaliação os revisores utilizarão a lista de verificação da avaliação crítica do JBI para revisões sistemáticas e sínteses de investigação. A inclusão dos estudos baseou-se em pontuação de corte pré-definida, nomeadamente: score de <3/10 – excluído devido a qualidade baixa; de 4-6/10 – qualidade moderada e 7-10/10 – alta qualidade. Depois foram analisados de acordo a checklist Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) (Fig. 1). Sete artigos foram removidos por estarem duplicados. Após, procedeu-se à análise dos textos na íntegra e por dois revisores autónomos, sendo a decisão de exclusão baseada no acordo mútuo ou parecer de terceiro revisor. Após aplicar os critérios de inclusão e de exclusão, excluímos dois destes artigos, por não estarem relacionados com o tema, e três foram excluídos devido a um ser na área pediátrica e não em adultos, perfazendo assim um total de 21 artigos para análise (figura 1).

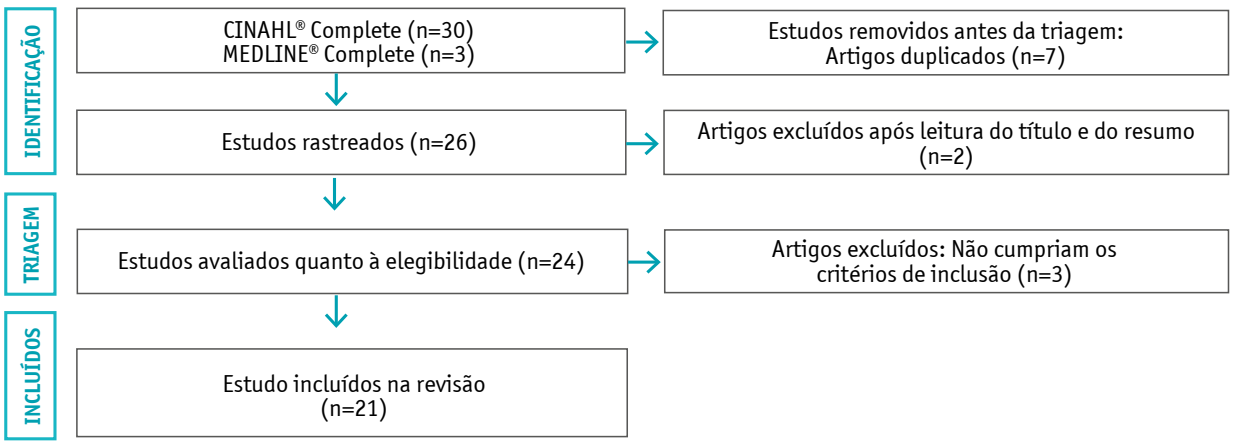

Figura 1. Fluxograma de PRISMA.

Constatou-se que os estudos utilizam a metodologia qualitativa (descritivos), quantitativa (ensaios clínicos randomizados) e revisões de literatura.

Em relação ao ano de publicação, identificou-se a prevalência de estudos publicados em 2017, com 5 artigos, seguindo-se os anos de 2016 e de 2015 com 4 artigos. Depois foram os anos de 2021, 2019 e 2018 com 2 artigos, e por fim o ano de 2020 e 2015, com 1 artigo cada.

A sinopse dos estudos selecionados é descrita no quadro 2, de acordo com o ano de publicação, objetivos de estudo, tipo de estudo e resultados primários e secundários.

Quadro 2. Caracterização geral dos artigos revistos.

AUTOR (ES)	DATA	OBJETIVO DO ESTUDO	TIPO DE ESTUDO	POPULAÇÃO	INTERVENÇÃO	RESULTADOS
Alencar et al.[14]	2019	Conhecer a satisfação dos doentes com cancro acerca dos cuidados de enfermagem	Revisão integrativa da literatura	13 artigos	Atendimento telefónico pela equipa de enfermagem	Satisfação, pela comunicação e ligação com os enfermeiros, confiança e controlo do tratamento; Acompanhamento, continuidade das orientações e da educação, avaliação da adesão ao tratamento, redução das idas à urgência
Barbosa et al.[15]	2016	Identificar e analisar o processo de comunicação na Telenfermagem	Revisão integrativa da literatura	10 artigos	Atendimento telefónico pela equipa de enfermagem	A distância impõe barreiras comunicativas em todos os elementos: remetente, destinatário e mensagem e nas duas formas de transmissão
Barros[16]	2016	Construir e aplicar follow-up de enfermagem via telefone do doente submetido ao transplante de células-tronco hematopoiéticas autogénico	Método descritivo	9 doentes	– Duração média da teleconsulta de 25 minutos – Contato semanal até ao 90º dia pós-alta	Acessível. Esclarece dúvidas, orienta, dá suporte ao enfrentamento. Controla as complicações e reduz os custos. Segurança pela continuidade e acompanhamento, o autocuidado é avaliado. Pode ser encaminhado a outros profissionais. Fortalecimento do vínculo entre doente e equipa multiprofissional
Breen et al.[17]	2015	Avaliar a intervenção de Telessaúde para monitorização/administração remota de efeitos colaterais da quimioterapia em doentes com cancro hematológico	Ensaio clínico randomizado, controlado	222 doentes	Utente introduz parâmetros de possíveis efeitos secundários 2 vezes ao dia na aplicação, se emitir um alerta o enfermeiro contacta a pessoa (30 min)	Maior precisão na monitorização e gestão dos sintomas dos doentes com cancro hematológico, em tratamento de quimioterapia
Breen et al.[18]	2017	Avaliar a aceitabilidade, usabilidade e viabilidade do Aplicativo ASyMS-H	Ensaio clínico randomizado controlado	17 doentes	Utente introduz parâmetros de possíveis efeitos secundários na aplicação e após o enfermeiro realiza a consulta com duração de 30min	Reafirmação; fortalecimento; aumento da consciência de saúde / adesão ao autocuidado; promoção de intervenção e redução dos efeitos colaterais. Comunicação com profissionais. Mais benéfico para quem tem sintomas mal controlados
Cruz, Ferreira & Reis[19]	2014	Conhecer a opinião dos doentes acerca do acompanhamento telefónico semanal oferecido pela equipa de enfermagem	Estudo descritivo e exploratório, longitudinal, prospetivo	22 doentes	7 semanas consecutivas após alta	Esclarece dúvidas e facilita a recuperação no domicílio. Maior segurança para os cuidadores. Satisfação com o acompanhamento telefónico, devido ao contato direto com enfermeiros, construção de confiança e controlo do tratamento

AUTOR (ES)	DATA	OBJETIVO DO ESTUDO	TIPO DE ESTUDO	POPULAÇÃO	INTERVENÇÃO	RESULTADOS
Ferreira et al.[20]	2017	Monitorar os efeitos adversos da quimioterapia antineoplásica em doentes submetidos a tratamento ambulatorial por meio do acompanhamento telefónico enquanto estratégia de provimento de conforto	Estudo longitudinal, prospetivo, com abordagem quanti-qualitativa	21 doentes	Semanalmente, e sete contatos telefónicos foram realizados, com cada participante	Identifica sinais e sintomas e fortalece a relação profissional doente. A teleconsulta semanal possibilita a educação em saúde, enfrentamento e gestão de efeitos adversos. Conforto pelo alívio, tranquilidade ou transcendência. Avalia preocupações os desejos, conhecimento da pessoa, reforça e encoraja mudanças de comportamento e de estilo de vida
França et al.[21]	2019	Verificar a eficácia da telenfermagem no controle de náuseas e vómitos induzidos pela quimioterapia antineoplásica	Ensaio clínico controlado, randomizado	61 doentes	– 5 a 6h após, 24 horas após alta, 3 dias e no 5º dia após alta – duração média de 10 min	Redução de náuseas e vómitos associados à quimioterapia. Melhora o autocontrolo e as complicações da doença, possibilitando a mudança de hábitos
Machado, Santana & Hercules[22]	2020	Relatar o desenvolvimento e aplicabilidade de uma Central de Teleatendimento como intervenção de enfermagem	Estudo descritivo do tipo relato de experiência	48 doentes	– 1º e 4º dia após – contacto diário durante 7 dias – duração média de 25min	O acompanhamento telefónico pelo enfermeiro favorece a continuidade das medidas de atenção domiciliar
Mooney et al.[23]	2017	Testar a eficácia do sistema automatizado de gestão de sintomas para determinar se há redução dos sintomas relacionados à quimioterapia	Ensaio clínico randomizado longitudinal	358 doentes	– contacto diário durante 7 dias – duração média de 25min	Todos os sintomas, exceto diarreia, melhoraram. Monitorização domiciliar e acompanhamento para o atendimento de sintomas mal controlados. Sem um acompanhamento adequado e oportuno, a telessaúde não melhor os resultados dos doentes
Nejad et al.[24]	2016	Determinar e comparar os scores do índice de stress de cuidadores informais de doentes com cancro da mama	Estudo experimental	30 doentes	– 2 teleconsultas com duração entre 30 a 45minutos (24h após alta, 48h) – 2 consultas de 10min semanais após a consulta das 48h	O stress do cuidador diminuiu após a educação do doente-cuidador A educação do doente-cuidador e o programa de acompanhamento foi benéfico no índice do esforço do cuidador
Hinstistan et al.[25]	2017	Determinar os efeitos terapêuticos do acompanhamento telefónico pelo enfermeiro às doentes com cancro de pulmão	Quasi-experimental	60 doentes	1 semana após alta	Ajuste dos sintomas secundários à quimioterapia e da qualidade de vida de funcionamento social. Aceitável e viável de contato com o doente e é uma maneira conveniente e eficiente de oferecer aos doentes apoio e continuidade dos cuidados
Kondo et al.[26]	2015	Investigar o uso do serviço de consulta por telefone que é disponível aos doentes e seus cuidadores para aconselhamento e controle de eventos adversos e complicações decorrentes do tratamento do cancro	Ensaio clínico randomizado	253 doentes	344 consultas	Evita que os sintomas se tornem incontroláveis e evita visitas desnecessárias e caras ao hospital. Além disso, esse serviço telefónico pode ser usado para monitorar os eventos adversos, avaliar a eficácia do tratamento e aumentar a satisfação geral do doente

AUTOR (ES)	DATA	OBJETIVO DO ESTUDO	TIPO DE ESTUDO	POPULAÇÃO	INTERVENÇÃO	RESULTADOS
Louzada et al.[27]	2018	Identificar os sinais e sintomas dos doentes com Linfoma de Hodgkin submetidos ao protocolo quimioterapia	Descritivo, prospetivo, quantitativo		286 teleconsultas, realizado em tratamento em regime de ambulatório	Importante estratégia para o controle eficaz do regime terapêutico, permitindo a identificação precoce e o manejo dos sinais e sintomas, com ação em tempo real a queixa
Sousa, Santo & Pinheiro[28]	2017	Analisar a produção científica acerca do acompanhamento, por telefone, pelo enfermeiro, no pós-alta do doente com doença onco-hematológica, na redução do evento de readmissão hospitalar	Revisão integrativa da literatura	6 artigos	Atendimento telefónico pela equipa de enfermagem	Proximidade do doente, quando geograficamente longe. Segurança, conforto e qualidade de vida. Identificação dos efeitos secundários da quimioterapia no pós-alta, com controlo e imediata intervenção. Evita o agravamento e readmissão. Reduz gastos. Menos satisfeitos com a profundidade do relacionamento, com o tempo despendido e por não serem examinados
Stamm et al.[29]	2015	Avaliar a eficácia da intervenção telefónica realizada por enfermeira na diminuição dos escores de ansiedade de doentes em tratamento radioterapia	Ensaio clínico randomizado	39 doentes	Duas ligações telefônicas, realizadas no 7º e 15º dias pós-tratamento	Amplia a ação de enfermagem, na assistência às necessidades que surgem no decorrer do tratamento, como é o alívio da ansiedade. Intervenção inovadora e de fácil acesso, com vistas a ampliar os resultados em saúde
Ream et al.[30]	2015	Adaptação e avaliação do Beating Fatigue – uma intervenção psicológica aplicada pelo telefone	Exploratório	21 doentes	Aplicado a teleconsulta conforme solicitação do doente	Exceto na depressão, houve melhoria ao longo do tempo. Melhorou a intensidade e o sofrimento associado à fadiga, a ansiedade e a auto-eficácia no controle da fadiga. Monitoriza os efeitos adversos, de forma rápida e eficaz, orientando para intervenções
Vaz, Silva & Silva[31]	2016	Identificar os sintomas mais prevalentes durante a quimioterapia em mulheres com cancro de mama	Estudo descritivo, prospetivo e com abordagem quantitativa	15 doentes	16 teleconsultas. No após a administração dos tratamentos, no oitavo dia, no décimo dia após alta	Acompanha os doentes ao longo de todo o tratamento de quimioterapia. Aumenta o vínculo entre profissional e doente. Identifica e avalia os efeitos adversos do tratamento e o seu controlo. Dificuldades em estabelecer o contato e, por conseguinte, acompanhar as doentes
Teixeira et al.[32]	2021	Descrever experiências de implantação de processos administrativos e assistenciais de instituições prestadoras de atendimento oncológico durante a pandemia	Descritivo, qualitativo	3 doentes	Semanal, de acordo sintomatologia	Favorece a educação em saúde, segurança e bem-estar. Os profissionais avaliaram que a telemedicina é eficiente, sem aumento da carga de trabalho. Os doentes desejavam-na como parte de seus cuidados futuros, citando custos reduzidos e tempo de viagem
Traeger et al.[33]	2021	Avaliar se os cuidados padrões aliados à intervenção levaram a uma menor carga de sintomas relatada pelo doente, maior satisfação com o cuidado e uma menor probabilidade de depressão e sintomas de ansiedade	Ensaio clínico randomizado	120 doentes	– Semanal após os dois primeiros tratamentos – Duração de 15min	Fadiga foi o mais relatado. Segurança, mas não melhorou a carga de sintomas, a satisfação com os cuidados ou a probabilidade de sintomas de ansiedade e depressão durante os primeiros dois ciclos de quimioterapia

Interpretação dos resultados

Com base na revisão da literatura efetuada verificamos que a telenfermagem apresenta vários benefícios, nomeadamente no controlo da sintomatologia, para o utente (custos, ganhos em saúde), para o profissional (educação, relação terapêutica, continuidade dos cuidados, carga de trabalho) e para a família.

No que concerne ao controlo sintomático, a telenfermagem é considerada um instrumento na identificação, monitorização e avaliação dos efeitos secundários do tratamento, bem como um meio de controlo de forma rápida e eficaz, podendo ainda ser pertinente na orientação para as intervenções, reduzindo a intensidade dos sintomas (fadiga, ansiedade e sofrimento) e melhorando a autoeficácia no controlo destes sintomas[31,33]. Segundo Sousa et al.[7] e Louzada et al.[27] esta intervenção visa a identificação precoce dos efeitos adversos à QT no pós-alta, bem como no controlo imediato aquando da sua avaliação, evitando o agravamento do quadro clínico e readmissão por complicações preventivas. Barros[16], Hinstistan et al.[25], Stamm et al.[29] e Ferreira et al.[20] também corroboram que esta é benéfica e de forma significativa no controlo sintomático pós-QT. Mooney et al.[23] reportam que todos os sintomas, exceto a diarreia, foram menores após a telenfermagem, salientando que os sintomas podem ser minimizados por meio de monitorização domiciliar automatizada, e à distância. Breen et al.[18] complementam referindo que esta intervenção permite monitorização e gestão dos sintomas com maior precisão aquando alta pós-QT principalmente nos utentes que vivenciam efeitos colaterais mais numerosos e intensos. Ainda França et al.[21] acrescentam que o autocontrolo, promovido pela telenfermagem, melhora e diminui as possíveis complicações do tratamento.

Relativamente ao benefício desta consulta para o utente Breen et al.[17,18] mencionam a reafirmação, fortalecimento, aumento da consciência de saúde, adesão ao autocuidado, promoção de intervenção clínica oportuna e melhor recordação de efeitos colaterais e comunicação com profissionais / família / amigos. Hinstistan et al.[25] referem que os scores de qualidade de vida em relação à dimensão social aumentaram em relação ao grupo de controlo. No estudo de Teixeira et al.[32] os doentes desejaram que a consulta telefónica fosse inserida nos cuidados do futuro, pois aumentou a satisfação deste no geral. Kondo et al.[26] também mencionam que esta intervenção vem eliminar a exposição desnecessária ao ambiente hospitalar e a um possível risco de contaminação infeciosa. Outra componente importante para os utentes e que esta intervenção prevê é a redução dos custos inerentes às deslocações desnecessárias às urgências, ao hospital/clínicas[7,14,19,26,29,32]. Quando aos cuidadores, Nejad et al.[24] mencionam que o índice de stress do cuidador diminui após a educação executada na consulta, promovendo maior segurança.

Outros benefícios demonstrados na revisão e de grande relevância estão relacionados com os enfermeiros. Após a análise categorizamos estes benefícios na educação, na relação terapêutica, na continuidade dos cuidados e na carga de trabalho. Quanto à educação, Nejad et al.[24] mencionam que o doente cuidador obteve um programa de acompanhamento e que resultou num efeito benéfico no índice de esforço do cuidador em comparação com o tratamento usual. Segundo Barros[16] é possível esclarecer dúvidas remanescentes, orientar o cuidado domiciliar pós-alta, obter suporte ao enfrentamento de uma nova condição de saúde e ter a oportunidade de poder dialogar com um profissional da saúde, o qual está a par das suas condições de saúde através de uma tecnologia viável e acessível. França et al.[21] acrescentam que é possível a mudança de hábitos e comportamentos a partir da intervenção telefónica e que é possível a implementação de estratégias de educação para a saúde, enfrentamento e gestão de efeitos adversos com o objetivo de promover ao doente conforto, acompanhamento, alívio e tranquilidade ou transcendência. Stamm et al.[29] complementam que esta intervenção traz implicações para o processo de ensino, uma vez que contribuiu para a disseminação do conhecimento de enfermagem em oncologia, despertando a reflexão acerca de estratégias inovadoras de cuidado e de assistência a doentes. E como referem Teixeira et al.[32], favorece a educação em saúde de forma contínua. Relativamente à categoria da relação terapêutica, a telenfermagem possibilita proximidade com o doente[7], fortalecendo o vínculo e a relação enfermeiro-utente[16,20,25,31]. Alencar et al.[14] acrescentam mencionando que os doentes referem satisfação neste acompanhamento pois permite um contato direto com o profissional em sua casa, construindo uma relação de confiança. Desta feita, esta intervenção também permite a continuidade dos cuidados[14,22,25], com apoio e acompanhamento nas necessidades que possam surgir ao longo do tratamento[25,29,31] até à avaliação da adesão ao tratamento e ensinos realizados[14]. Barros[16] salienta a continuidade dos cuidados com a oportunidade de identificar complicações e conseguir encaminhar o utente, atempadamente, a outros profissionais.

A intervenção telenfermagem, e segundo a evidência científica, amplia resultados em saúde com o auxílio no controle das complicações e reduz dos custos para o sis-

tema de saúde[16,29,30] com a diminuição das deslocações às consultas de ambulatório para o controlo sintomático[7] e às urgências[14]. Teixeira et al.[32] complementam que a nível de carga de trabalho a consulta telefónica é menor em comparação às consultas presenciais.

Conclusão

A pessoa com doença hemato-oncológica apresenta necessidades muito especiais, quer pelo peso psicológico do diagnóstico, quer pelo percurso que terá de percorrer até à alta médica. É comum os doentes em fase de tratamentos ativos, numa fase pós alta apresentarem sintomatologia relativa à própria doença, mas também, com grande relevo, efeitos secundários inerentes aos tratamentos de QT, com impacto negativo para o doente e cuidador a todos os níveis, sendo os mais frequentes encontrado na bibliografia pesquisada e na nossa realidade da prática, náuseas/vómitos, diarreia, dor, neutropenia febril, anorexia, fadiga, infeções oportunistas bacterianas e fúngicas, mucosite, dispneia, hemorragias, entre outros.

Através da pesquisa e análise crítica da bibliografia pesquisada, foi fundamentada a importância do acompanhamento pelo enfermeiro no pós alta da pessoa submetida a tratamentos de QT e a importância das novas tecnologias (neste caso a teleconsulta de enfermagem), associadas como instrumentos fundamentais de um contacto mais próximo, à medida das necessidades de cada doente, auscultando, monitorizando eventuais complicações que possam agravar a sua situação clínica e/ou provocar dano ao doente, comprometendo o continuo dos tratamentos essenciais ao controlo da sua doença assim como o impacto que tem ao nível económico no que concerne à ida aos serviços de urgência, importantes em qualquer organização de saúde.

Como limitações à realização deste estudo destacamos a escassez de estudos em telenfermagem aplicada a pessoas com doença hemato-oncológica.

Por fim, acreditamos que a contribuição e divulgação deste estudo pode ser um fator importante em políticas de saúde, podendo impulsionar e motivar a implementação desta intervenção nas diferentes áreas de cuidados, a nível hospitalar e comunitário, contribuindo para uma prática de excelência baseada na evidência.

Referências Bibliográficas

1. Bray F. The evolving scale and profile of cancer worldwide: much ado about everything. Cancer Epidemiol Biomarkers Prev. 2016;25(1):3-5.
2. Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, et al. Cancer treatment and survivorship statistics, 2019. CA Cancer J Clin. 2019;69(5):363-85.
3. Silva R, Carvalho A, Rebelo L, Pinho N, Barbosa L, Araújo T, et al. Contributos do referencial teórico de Afaf Meleis para enfermagem de reabilitação. Rev Investig Enferm. 2019;26(2):35-44.
4. Sousa R, Santo F, Pinheiro F. Telemonitoramento como tecnologia aliada ao cuidado de enfermagem ao paciente com doença onco-hematológica. Res Soc Dev. 2018;9(9):1-17.
5. Beck JL, Cogo SB, Eberhardt TD, Eberhardt AP, Gomes TF, Perlini NMO, et al. Caracterização das pessoas com doença hemato-oncológica atendidas em uma unidade de urgência e emergência. Esc Anna Nery. 2019;23(3):1-8.
6. Oliveira E, Ferreira W, Oliveira E, Dutra D. Cuidados pós-alta em pacientes idosos com sequelas de acidente vascular cerebral: Planejamento de alta hospitalar. Rev Saude Desenvolv. 2017;11(9):172-97.
7. Sousa RM, Santo FH, Pinheiro FM. Estudo de caso sobre as demandas de cuidados de enfermagem dos pacientes onco-hematológicos hospitalizados. Rev Enferm UFPE Online. 2017;11(10):3796-806.
8. Sousa R, Santo F, Pinheiro F. Acompanhamento por telefone no pós-alta dos doentes onco-hematológicos: revisão integrativa da literatura. Rev Enferm Cent Oeste Min. 2017;7(1824):1-11.
9. SPMS. Plano Estratégico Nacional para a telessaúde 2019-2022. PENTS: Centro Nacional de TeleSaúde. 2019. Available from: https://www.spms.min-saude.pt/wp-content/uploads/2019/11/PENTS_portugu%C3%AAs.pdf
10. Ordem dos Enfermeiros. Consultas de Enfermagem à distância TELENFERMAGEM. Lisboa: Ordem dos Enfermeiros Centro; 2021.
11. Parecer do Conselho de Enfermagem 53/2021. Consulta de enfermagem e teleconsulta de enfermagem. Ordem dos Enfermeiros. 2021. Available from: https://www.ordemenfermeiros.pt/media/21536/parecer-n%C2%BA-53_ce_13012021_consulta-enfermagem-e-teleconsulta-de-enfermagem.pdf
12. Pedrosa SC. Efetividade do acompanhamento telefónico no estilo de vida de pessoas vivendo com HIV. Fortaleza: Pós-graduação em Enfermagem, Universidade Federal do Ceará; 2018.
13. Instituto Joanna Briggs. Instituto Joanna Briggs Níveis de Evidência. 2014. Available from: https://jbi.global/sites/default/files/2019-05/JBI-Levels-of-evidence_2014_0.pdf
14. Alencar L, Sardinha A, Nogueira A, Pascoal L, Rolim I. Satisfação dos doentes oncológicos acerca dos cuidados de enfermagem. Ver Enferm UFPE Online. 2019;13(3):752-62.
15. Barbosa I, Dias KA, Paes M. The communication process in Telenursing: integrative review. Rev Bras Enferm. 2016;69(4):718-25.
16. Barros M. Follow-up de enfermagem ao doente pós-transplante de células tronco hematopoiéticas autogénico. Florianópolis: Universidade Federal de Santa Catarina; 2016.
17. Breen S, Ritchie D, Schofield P, Hsueh YS, Gough K, Santamaria N, et al. O Sistema de Intervenção Remota do Doente e Gerenciamento de Sintomas (PRISMS) - uma intervenção mediada por telessaúde que permite o monitoramento em tempo real dos efeitos colaterais da quimioterapia em doentes com neoplasias hematológicas: protocol. Trials. 2015;472.
18. Breen S, Kofoed S, Ritchie D, Dryden T, Maguire R, Kearney N. Remote real-time monitoring for chemotherapy side-effects in patients with blood cancers. Collegian. 2017;24(6):541-9.
19. Cruz F, Ferreira E, Reis P. Consulta de enfermagem via telefone: relatos dos doentes submetidos à quimioterapia antineoplásica. R Enferm Cent O Minho. 2014;4(2):20.
20. Ferreira E, Cruz F, Jesus C, Pinho D, Kamada I, Reis P. Telephone contact as a strategy for the promotion of comfort to the patient submitted to chemotherapy. J Nurs UFPE Online. 2017;11(5):1936-42.
21. França A, Rodrigues A, Aguiar M, Silva R, Freitas F, Melo G. Telenfermagem para Controle de Náuseas e Vómitos Induzidos Por Quimioterapia: Ensaio Clínico Randomizado. Texto Contexto Enferm. 2019;28(1):e20180404.
22. Machado T, Santana M, Hercules A. Central de telecuidado: Perspectiva de intervenção de enfermagem. Cogitare Enferm. 2020;25:e66666.
23. Mooney KH, Beck SL, Wong B, Dunson W, Wujcik D, Whisenant M, et al. Automated home monitoring and management of patient-reported symptoms during chemotherapy: results of the symptom care at home RCT. Cancer Med. 2017;6(3):537-46.

24. Nejad Z, Aghdam A, Hassankhani H, Sanaat Z. The effects of a patient care giver education and follow-up program on the breast cancer caregiver strain index. Iran Red Crescent Med J. 2016;18(3):e21627.
25. Hinstistan S, Nural N, Cilingir D, Gursoy A. Therapeutic effects of nurse telephone follow-up for lung cancer patients in Turkey. Cancer Nurs. 2017;40(6):508-16.
26. Kondo S, Shiba S, Udagawa R, Ryushima Y, Yano M, Uehara T. Assessment of adverse events via a telephone consultation service for cancer patients receiving ambulatory chemotherapy. BMC Res Notes. 2015;8:315.
27. Louzada K, Brevidelli M, Baiocchi O, Domenico E. Aconselhamento telefônico: identificação de sintomas em doentes com linfoma em quimioterapia antineoplásica. Acta Paul Enferm. 2018;31(6):616-26.
28. Sousa R, Santo F, Pinheiro F. Acompanhamento por telefone no pós-alta dos doentes onco-hematológicos: revisão integrativa da literatura. Rev Enferm Cent Oeste Min. 2017;7(1824):1-11.
29. Stamm B, Girardon-Perlini N, Pasqualoto S, Beutee M, Magnago T. Intervenção telefónica para manejo da ansiedade de pacientes oncológicos: ensaio clínico randomizado. Acta Paul Enferm. 2018;31(2):137
30. Ream E, Gargaro G, Barsevick A, Richardson A. Management of cancer-related fatigue during chemotherapy through telephone motivational interviewing: modeling and randomized exploratory trial. Patient Educ Couns. 2015;98(2):199-206.
31. Vaz D, Silva C, Silva R. Acompanhamento presencial e telefónico dos sintomas em mulheres com câncer de mama submetidas à quimioterapia. Rev Enferm UERJ. 2016;24(5):e15577.
32. Teixeira T, Moura V, Santos P, Carneiro A, Domenico L. Pandemia de Covid-19 e atendimento especializado em oncologia: relato de experiência. Rev Cuidarte. 2021;12(2):e1377.
33. Traeger L, McDonnell TM, McCarty CE, Greer JA, El-Jawahri A, Temel JS. Nursing intervention to enhance outpatient chemotherapy symptom management: Patient-reported outcomes of a randomized controlled trial. Cancer. 2015;121(21):3905-3913.

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Conflito de interesses

Os autores declaram que não há conflitos de interesses relacionados a este trabalho.

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YOUNG ADULTS WITH CANCER IN PALLIATIVE CARE/END OF LIFE CARE: INTEGRATIVE LITERATURE REVIEW

Jovens adultos com cancro em cuidados paliativos/fim de vida: Revisão integrativa da literatura

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ABSTRACT

Introduction: Young adults with cancer in palliative care and/or end of life care are a particularly vulnerable population, about which very little has been studied. The main goal of this review is to summarize their experience.

Methods: An integrative literature review was conducted in the databases PUBMED®, CINAHL Complete®, MEDLINE Complete® and Scielo® (studies published between January 1st 2017 and January 19th 2024). The review was done following the Joanna Briggs Institute guidelines and PRISMA flowchart.

Results: Five articles of various methodologies were included. Among them, a few key themes come to light such: care preferences; negative aspects of the experience; their needs; the familial and social context; and the nurse's intervention.

Results: Five articles of various methodologies were included. Among them, a few key themes come to light such: care preferences; negative aspects of the experience; their needs; the familial and social context; and the nurse's intervention.

Conclusion: This is a context of extreme vulnerability, that requires the intervention of a multidisciplinary team. Therefore, it is necessary to support and enable health care professionals to adopt better practices. This remains a subject that requires deeper research.

KEYWORDS: Young adult; Cancer; Palliative care; End of life care.

RESUMO

Introdução: Jovens adultos com cancro em cuidados paliativos e/ou de fim de vida são uma população particularmente vulnerável, sobre a qual muito pouco tem sido estudado. O principal objetivo desta revisão é sumarizar a sua experiência.

Métodos: Uma revisão integrativa da literatura foi realizada nas bases de dados PUBMED®, CINAHL Complete®, MEDLINE Complete® e Scielo® (estudos publicados entre 1 de janeiro de 2017 e 19 de janeiro de 2024). Seguiram-se as guidelines do Joanna Briggs Institute e o fluxograma PRISMA.

Resultados: Foram incluídos cinco artigos de variadas metodologias. Desses, alguns temas principais ressaltam, tais como: preferências de cuidados; aspetos negativos da experiência; necessidades; contexto familiar e social; e a intervenção do enfermeiro.

Conclusão: Este é um contexto de extrema vulnerabilidade, que requer a intervenção de uma equipa multidisciplinar. É, portanto, necessário apoiar e capacitar profissionais de saúde para uma melhor prática. Este permanece um tema que requer mais investigação.

PALAVRAS-CHAVE: Jovem adulto; Cancro; Cuidados paliativos; Cuidados de fim de vida.

Introduction

Young adults with cancer are a particularly vulnerable population, about which there hasn't been much research. Even though the importance of adequate care to this age group is internationally recognized, there is still a lack of evidence on the best care practices and communication methods with young people.

Despite there not being a universal definition, young adults in oncology can be defined as individuals between the ages of 18 and 39 years[7]. This is a life stage in which various changes and big life transitions occur, both on personal, relational and professional levels. This is the stage when it's expected that young adults start having jobs, leave their parents' houses and earn their independence and autonomy, establishing relationships and forming their own families.

However, when it comes to young adults with cancer, a rupture in the normal experience of this life stage happens, with a complete disturbance of normal development (emerging independence, self-image, social relationships, transitions between school and work, career establishment, and families)[1]. Thus, we may safely state that this is a distinct population within the oncology community, for the unique challenges in their disease trajectory: related with diagnosis, treatment, advanced care planning and survivorship[4]. This becomes even more notorious when we address young adults with cancer receiving palliative care and/or end of life care, since they face a particularly vulnerable situation, because of the threat that advanced cancer represents.[1]

In the above-mentioned population, perspectives of a "normal" life are affected, and individuals feel forcefully removed from the stream of life[2]. Facing cancer, the expected conquests of this life stage such as establishing autonomy, social relationships, education or career goals and forming a family are suspended. Consequently, these individuals may feel a lack of control over their own lives. and there might come up existentialist questions about the meaning of life and the time they have left.

In the face of disease progression or the inability to effectively manage their symptoms, the concept of palliative care is often introduced. Yet, this can be a conflicting experience due to the impact that the term "palliative" has on young adults, who associate it with death and dying[3]. Therefore, it's important to distinguish palliative and end of life care, since the two can coexist but their purposes are fundamentally different.

Palliative care can be defined as care that improves the young adult's quality of life facing a life-threatening illness.[8] This type of care is not only necessary at the end of life but also at any stage of the disease in which needs related to symptom management where identified (such as pain, dyspnea, tiredness, among others), giving support on physical, psychological, social or spiritual level. The identification of this need and the anticipatory introduction of palliative care has been proven as a useful tool in lowering the number of unnecessary hospitalizations and health services use. There is an approach by a multidisciplinary team, alongside the young adult and its family, to focus on the specific needs and preferences of each individual[5], that can go from daily living activities to bereavement support. However, being a recipient of this type of care doesn't mean the cessation of curative treatments[4].

On the other hand, end of life care focuses on helping those suffering from advanced, progressive and incurable illness to live as well as possible, until their death[5]. It covers physical, emotional, social and spiritual strands, supporting all during the period (days, weeks or months) the young adult has left to live. It might mean ceasing ongoing treatments and shifting the care focus to an exclusively palliative approach, in which the main objective is to help the individual reach their goals. Deep down, it's centered around the dignification of death, considering the wishes and preferences of the one being cared for.

Following that, the objectives for this integrative review are summarize the experience of young adults with cancer in palliative and/or end of life care, realizing what their needs are, their care preferences and the unpleasant aspects of the experience, keeping in mind the context in which they're inserted (mostly, familial); it's also an objective to understand in which way nurses can intervene in this population. This way, this study's relevancy is to center around the fact that this is an understudied population so far, and only by knowing more about it we'll be able to know how nurses can best intervene in supporting it.

Methodological Procedures of an Integrative Review

To answer the previously formulated objectives, we opted to conduct an integrative literature review. This review was conducted following the model detailed by Dhollande et al. (2021)[12].

The starting point to this investigation emerged from a reflection on the daily practice and the observation that there's no studies or guidelines regarding this specific population. Therefore, the following starting question emerged: "What is the experience of young adults with cancer in palliative care and/or end of life care?" As

secondary questions, we have: "What are their needs and care preferences?"; "What are the aspects of the experience?"; and, at last, "How to better intervene as a nurse?"

To structure this question, the "PICo" strategy was invoked, as seen on Table 1.

Table 1. PICo strategy

POPULATION (P)	INTEREST PHENOMENON (I)	CONTEXT (Co)
Young adults with cancer	Experience	Palliative care End of life care

Thereby, having formulated the research question, we established the inclusion and exclusion criteria (Table 2) for the selection of studies being included in the investigation. This was done in a way to guide both the research and the selection of scientific literature.

Table 2. Inclusion and exclusion criteria

	INCLUSION CRITERIA	EXCLUSION CRITERIA
Population	Young adults with cancer	Paediatric population Old people
Context	Palliative care End of life care	Other care contexts
Publishing date	Between 2017-2024	Previous to 2017
Text availability	Full text/PDF	Full text unavailable
Language	Portuguese, English or Spanish	–
Type of studies	All designs of studies	–

At this point, the descriptors to be used on the research were determined. We used both MeSH descriptors and natural language terms, to gather the most compatible results with the research question. This was followed by combining the corresponding boolean operators, coming up with the following boolean phrase: ((Young adult) AND (Cancer)) AND (Palliative care)). This was the starting point to the evidence research, that was initiated on December 15th 2023, and finished in January 19th 2024.

Research was conducted electronically, through the databases: PUBMED®, CINAHL® Complete and MEDLINE® Complete (via EBSCOhost®) and Scielo®. The article identification and inclusion process went accordingly to Figure 1, through PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses).

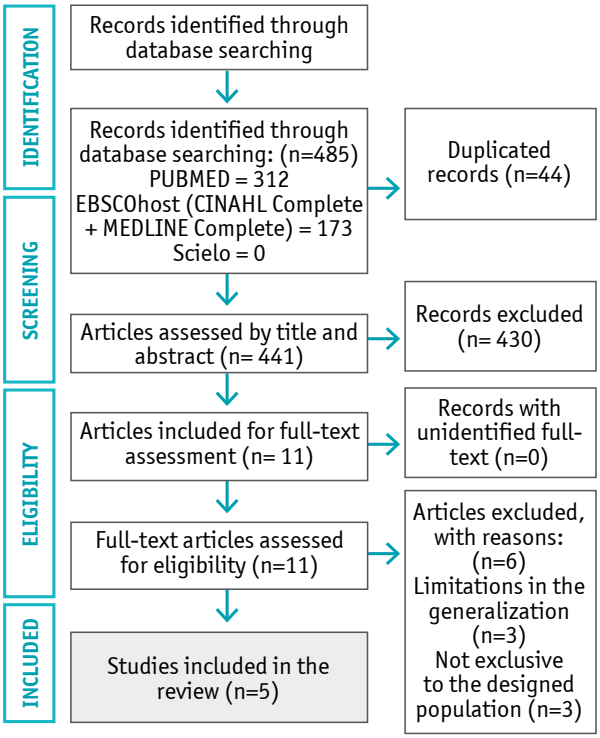

Figure 1. PRISMA flow diagram

Once finished the critical appraisal of research results, we read the scientific articles and selected the most relevant information in each, according to the methods of an integrative review, therefore, not distinguishing quantitative, qualitative or another kind of study. Then, we proceeded to extract the data and reduce it, analyzing it, and drawing conclusions and implications for clinical practice in nursing.

To better evaluate the methodological quality of the selected studies, we resorted to the Joanna Briggs Institute's Critical Appraisal Tools (2020), classifying the items in its checklist, as seen in Table 3. Studies classifying under 25% were considered as being of low quality, between 26% and 50% were considered as being satisfactory, between 51% and 75% were considered as good quality and studies classifying above 76% were considered as being very good quality.

The research, selection and scientific literature analysis process was conducted by both authors that, in the absence of a consensus, reunited to obtain unanimity in their evaluation, trying to keep as little bias as possible.

Table 3. JBI Critical Appraisal Tools evaluation of the selected studies

STUDY	STUDY DESIGN	STUDY EVALUATION AND CLASSIFICATION TOOL	EVIDENCE LEVEL ACCORDING TO JBI
Sansom-Daly et al., 2020[6]	Narrative synthesis	Checklist for Systematic Reviews and Research Syntheses (JBI, 2020) With a total of 11 items from which 8 were affirmative – Classification = 73%, good methodological quality.	5a
Burgers et al., 2022[9]	Qualitative study	Checklist for Systematic Reviews and Research Syntheses (JBI, 2020) With a total of 10 items from which 9 were affirmative – Classification = 90%, very good methodological quality	3e
Avery et al., 2020[8]	Qualitative study	Checklist for Systematic Reviews and Research Syntheses (JBI, 2020) With a total of 10 items from which 10 were affirmative – Classification = 100%, very good methodological quality	3e
Ngwenya et al., 2017[10]	Narrative synthesis	Checklist for Systematic Reviews and Research Syntheses (JBI, 2020) With a total of 11 items from which 9 were affirmative – Classification = 81%, very good methodological quality	5a
Emerson et al., 2022[6]	Descriptive article	Checklist for Textual Evidence: Expert Opinion (JBI, 2020) With a total of 6 items from which 6 were affirmative – Classification = 100%, very good methodological quality	5b

Results

After the analysis, following the criteria established and as illustrated in Figure 1, five articles were included in this integrative review, all of which have been published between 2017 and 2024. All articles are in English, encompassing various research methods (narrative synthesis, qualitative studies and a descriptive article). We excluded studies whose limitations (limited to a country, per example) didn't allow a generalization of their results or studies that didn't center exclusively on our selected population. It is worth to mention that, within this selection, we have studies from journals published by organizations such as the European Society for Medical Oncology or the American Society of Clinical Oncology, as well as scientific journals within the subjects of oncology, palliative medicine and adolescent and young adult oncology.

The results of our research were organized and separated into different themes, those being: care preferences, negative aspects of the experience, needs, familial and social context, and the nurses' experience.

Care preferences

Regarding the preferences of young adults with cancer in palliative care and/or end of life care, these pass by promoting normalcy, which might translate into receiving the same treatment as their "healthy" peers, normalizing the situation they are living in a way to decrease the discrimination felt and, therefore, enhance their coping. It might also mean the maintenance of routines and habits, pursuing activities they led before the diagnosis and remaining in contact with others, thus allowing an improved sense of self and identity[10].

Another key aspect is opening the dialogue about end of life – here, it is preferred that the healthcare professional takes the lead, since their experience can lead the conversation in an open, honest and culturally sensitive way[11], helping ease feelings of impotence on the young adult[10].

Lastly, another main theme regarding this population's preferences is the advanced directive of will. Advanced care planning is a critical step to accepting and preparing the death of a young person and covers both ethic and legal matters and simple tasks such as making a wish list that can be checked out short-term[11]. This same study points out the contribution that advanced directives of will give to better decision making by both healthcare professionals and family, decreasing emotional burden and regret, and improving the patient's quality of life by aligning their medical decisions and their values and preferences.

Negative aspects of the experience

Considering that the experience of young adults with cancer is never positive we can, still, highlight some of the negative aspects that stand out according to the literature. Henceforth, as previously mentioned, there's a rupture in the stage of life, completely upsetting what a typical development should be[8], that is now contemplating a situation that poses an imminent risk to their life, instead of focusing on building a future.

Another aspect that is particularly referred to in a study[8] is the conflicting experience of being categorized as young and palliative, simultaneously. This occurs because of the perception of young adults as being strong and healthy and the expectation that they'll be able to overcome a cancer diagnosis, which causes some resistance and distress, who then feel obligated to delay or limit conversations around end of life, pain or depression. These social expectations not only apply to those around the young adult, as they themselves feel it's hard to accept the transition, initially associating the word palliative with death, dying and disease progression. These conceptions have been kept, even after healthcare professionals informed them that palliative care is not a synonym of end of life, representing a challenge to their will to get better and survive cancer. Consequently, this is an emotionally difficult experience that most participants feel too young to face, believing they have not yet lived enough to comprehend or accept the possibility of dying.

Still on a psychological level, this situation primarily represents a loss of "self", that leads to a sense of loss of control and feelings of helplessness, as their autonomy decreases and their dependency on others increases[10]. These feelings were more prevalent in the age group between 25 and 40 years, whose individuals often go back to depending on their own parents' care – this represents a change of roles that isn't always well accepted. The lack of control over symptoms and daily tasks leads to feelings of insecurity.

When it comes to physical symptoms, young adults feel these as a bigger burden – such as higher levels of complex pain once compared to other age groups, with a consequent increase in suffering and lower quality of life[8]. Medication and treatments such as palliative chemotherapy or radiotherapy can help manage symptoms, reducing incidence and intensity of symptoms such as pain, breathlessness, cough, swelling, ulceration, bleeding, neurological deficits, and decreased mobility[11].

Needs

The needs of young adults with cancer in palliative care and/or end of life care can be divided into the following categories: clarification of how they'd like to live the end of their life, psychosocial needs, existential needs, developmental needs and needs for health care.

One of the main needs of young adults with cancer in palliative care and/or end of life care is the clarification of how they would like to live the end of their lives. In this sense, it is highlighted the importance and potential benefits of an early introduction of palliative care within the course of the illness, as to better symptom management and the incorporation of a patient-centered communication[11]. This is relevant to ease communication around end-of-life situations, both in early stages and when it's needed to support a patient with an incurable disease. However, the ideal timing for this approach and the factors that influence young adult's preferences regarding palliative care remain unknown, there being little research on the individual or familial aspects that influence the wish for or preparation of this kind of dialogue, and the existing biases that might have conditioned the results.

Relatively to who might introduce this communication, it's considered that it should be a multidisciplinary team that's vast, confident and capable of conducting conversations about end of life[11]. These should be professionals that have established a good relationship with the young adult and their family, and that are able to understand their psychosocial needs, values and priorities. They should be comfortable in exploring tough and sensitive subjects. The nurse's role on these teams stands out, but also the one with elements such as priests or other religious leaders.

Dialogue should be individualized, approaching key aspects identified as important, such as physical, psychological and existential ones. It should allow the expression of the young adult's preferences from an early stage, while they are susceptible to change. It's not possible to develop guidelines on what should be addressed in these conversations and how, once each young adult has their livingness, and should be approached as such. Yet, we can resort to advanced care planning tools to explore this dialogue, and to make communication between young adults, their family and members of the multidisciplinary team clearer.

Still on this population's psychosocial needs we find out the need for psychological support and specialized monitoring (that, ideally, should be available for all people near the end of life), addressing in this way negative feelings associated with their clinical situation, such as fear and uncertainty. Besides, it's also important to promote relationships between peers – allowing them to belong to a group of people that can identify with their experience – and building a legacy. Legacy building consists in a set of activities that allow patients to review their life and its meaning while creating a lasting memento that can be appreciated by family and friends and has been shown effective in improving communication between parents and children at the end of life[11].

When it comes to existential needs, we have the conceptualization of disease and suffering, the spiritual beliefs and the existence of a faith community[11]. In this regard, psychotherapy (and meaning centered psychotherapy, particularly) has a relevant role by allowing the young adult to process personal issues and feelings related to their illness, easing into a better understanding of what brings meaning to their lives and assisting them in maintaining that meaning, facing disease progression[11]. It's also important to promote the presence of religious leaders, according to the person's wish.

Developmental needs are essentially centered in maintaining independence and autonomy, as much as possible, and promoting activities suitable for the age group[11]. A cancer diagnosis interrupts the normal living of this age bracket, so crucial as it's a phase in which young adults start new journeys on occupational, educational and interpersonal levels[11], interrupting the normal trajectory of their lives and the achievement of developmental milestones such as establishing autonomy, social relationships, educational or career goals and building a family. Especially in patients between the ages of 18 and 24 years old, the role of independence and social support should be emphasized, as they are critical in this period.

Relatively to need for health care, we have the care preferences (hospital setting versus home setting, per example) and symptom management. As for the last one, it's pointed out a prevalence of the following physical symptoms: fatigue (57-96%), lowered mobility (76%), pain (73%), anorexia (71%) and dyspnea (6-21%)[6]. However, in the last week of life pain and dyspnea are the most common symptoms[6]. As for psychological symptoms in the last month of life, it's sadness or grief, anxiety, fear (of being alone, death, and/or pain), and guilt that stand out[11].

In conclusion, care initiatives that are centered on the person should be developed aiming for the medical, psychological and support needs that are unique to each patient, granting them a meaningful end of life[9].

Familial and social context

Familial and social context is of the utmost importance when we talk about young adults with cancer in palliative care and/or end of life care, since it's not rare that the informal carers are parents or partners, there being a dependency relationship. And in the cases in which this doesn't check they are, still, the support network of the one going through this tough situation.

So, it's necessary to include these people in the care provided. On one hand, it's needed to understand how willing they are in establishing dialogue around end of life, acknowledging their concerns and empowering them regarding the rhythm and shape of each given conversation[11]. On the other hand, it's essential to align expectations regarding to prognosis, outcomes and decision making on the care that is to be provided, given that, per example, young adults tend to prefer a death at home instead of the hospital, yet their parents fear that it might create traumatic memories associated with the physical space, the impact that this experience might have on the siblings and doubt their ability to effectively manage the symptoms at home[11].

A different aspect about which the multidisciplinary approach to the family is essential is the grief associated with end of life, since this coping process happens distinctly in each family member and it's frequent that it begins simultaneously with the transition to exclusive palliative care, when there aren't more curative treatments to offer[11]. Bereaved parents that didn't have the chance to talk about end of life with their child regretted it and expressed the ways it could've helped them to prepare for child's death and the bereavement process[10]. This way, palliative care represents an opportunity for the family to look for support, be included in care and pose questions privately (without the young adult's presence)[8]. Families have a central role in this phase of the young adult's life, but for that need to be supported, wishing to be involved in the decision-making process[10].

Generally, it's apparent the young adult's concern over not burdening their families, that being one of their main priorities[8]. To safeguard their health, a few young adults in one of the studies[8] went so far as to avoid talking about certain parts of their illness with their parents/romantic partners which ultimately led to rifts in their relationships.

The nurse's intervention

The nurse's involvement with the cancer-stricken young adult in palliative care and/or end of life care involves a variety of factors. Yet, it seems to be consensual in literature that optimal care combines the best evidence to culturally sensitive care, using for that language that is also sensitive to the subject. It's necessary to recognize each person as a unique individual, with preferences that can change throughout the delivery of care, being important to contradict the concept of "one size fits all", since care should be individualized to each patient.

The nurse's main tasks consist in giving voice to the young adult, helping them achieve short-term goals, assisting the building of a legacy and guaranteeing physiological comfort. Therefore, it's relevant to achieve the management of physical symptoms, which should comprise not only behavioral and environmental interventions but also managing the medication (using, per example, WHO's pain ladder) and the establishment of treatments such as palliative chemotherapy or radiotherapy[11].

However, not only physical symptoms are deserving of attention. The nurse should also intervene in promoting coping for the "lost" life – both the one not being fully lived through the illness, and the one that might not be lived given the prospect of bad prognosis –for example. facilitating adaptive coping strategies. Therefore, it is necessary to prepare for grief and bereavement, promoting family support and finding purpose in life. Additionally, it's necessary to enhance the young adult's quality of life by encouraging them to be active and spend time in comforting environments surrounded by their loved ones, exploring and identifying preferences in relation to the place of death.

Just so happens that health care professionals too face challenges while taking care of this population, and nurses are included in this. A study[9] catalogues these challenges, grouping them in four categories: emotional confrontation, questioning professional attitude and skills, navigating uncertainty and obstacles in the healthcare organization to provide age- and disease-appropriate care.

Emotional confrontation consists mainly of transference and countertransference phenomena, and the impact on the healthcare professional (especially when the patient and the professional are emotionally close due to both being around the same age, or when the professional has children the patient's age). It leads to feelings of helplessness and sadness related to a bigger sense of empathy and compassion for this population compared to older age groups. Ultimately, it can lead to a bigger emotional burden[9].

Questioning professional attitude and skills can be defined by the thin balance between caring versus meddling; it can as well be defined as the uncertainty felt when the recipient of care isn't very communicative or the professional doesn't know them that well, or in the presence of the triad healthcare professional-young adult-parents (that represents an added challenge, mainly when there's a disagreement between the young adult and their family)[9].

Navigating uncertainty refers to subjects such as communication around prognosis (in which healthcare professionals have reported feeling doubt and difficult emotional management), or communication around end of life (in which aspects such as uncertainty about the right moment to approach or fear of causing hopelessness by doing it were highlighted)[9].

Discussion

During this study, it was possible to answer the research question, as it was possible to deepen the particularities of the experience of young adults with cancer in palliative care and/or end of life care.

Certain recurring themes were identified, intertwining amongst each other. That is the case of the difficulties felt facing the concept of "palliative"[8], or those related to the autonomy loss that the disease progression often implies[8,9,10]. We can then understand the importance of the life stage and the individual life cycle in how this population experiences this situation, and the singularity of their needs in comparison to the pediatric population or the general adult population. There's a need for holistic care that includes not only symptom management but also emotional support[9], psychological counseling, and opportunities for young adults to express their wishes and concerns about the end of life[6,11].

Regarding care preferences, in one study[8] the participants mentioned appreciation on having time and space to express their feelings and concerns about having cancer at a young age, which was facilitated by palliative care. This was especially crucial due to the existential challenges of being categorized as palliative[8], and the connotation that the term holds.

In another study[6], participants felt that their loved ones didn't always understand what they were going through, and that the opportunity to talk to experienced professionals or people in the same situation was beneficial. Groups on social media or direct contact with other young adults with cancer in palliative care and/or end of life care were solutions found by those who felt more isolated, to find comfort.

For some of the participants in the first study[8], being associated with palliative care has positively affected their will to live, leading them to focus on what they have yet to live, to challenge their prognosis. However, it wasn't like this for all, since there were participants who considered not starting new life projects due to the possibility that this might be interrupted. It acted as a reminder to every one of the seriousness of their disease and its mortality.

Regarding the negative aspects of the experience, participants in a study felt that hospitalization represents

a deterioration in their disease progression, seeing this space as a place to die[10]. Participants in end-of-life reported feeling that other needs such as existential concerns weren't addressed in the current health system, and that there was little referral to specialized support[10]. It was also mentioned by informal caregivers of young adults who were dying, the inadequacy of health services, neither pediatric nor adult services being appropriate to end of life care, not existing, therefore, a health system available for them[10].

Their needs were also identified and set as the following categories: clarification of how they'd like to live the end of their life, psychosocial needs, existential needs, developmental needs and needs for health care.

The role of family and support network is highlighted[8,10,11]. It's also highlighted the importance of communication (towards the young adult/family and among the interdisciplinary team) as a care tool[6,9,11]. This should be open and initiated by the healthcare professional[10], promoting better outcomes for the young adult (less anxiety, bigger sense of control, among others); it's important that the young adult feels they have time and space to go through this health-disease transition[8]. Family involvement and decision making alongside the patient, family and multidisciplinary team (in formal or informal moments) are other aspects of major importance. It becomes, then, obvious the need for an early introduction of palliative care in the illness trajectory, and the benefits of it[6,8].

Lastly, as elements of a multidisciplinary team, this study underlines the crucial role of nurses in providing holistic palliative and end of life care, suitable for this age gap. This can be done through the nurse's intervention, in aspects such as assisting in the achievement of short-term goals, building a legacy, guaranteeing physiological comfort through the management of physical symptoms (through behavioral and environmental interventions, medication and palliative treatments), managing psychological symptoms (such as the "loss" of their lives as they were/could be, grief/bereavement and the lack of purpose in life), supporting the family, and some others.

Only through these interventions will the care be truly holistic and suitable for this age category. However, nurses also face many challenges when caring for young adults in palliative care and/or end of life care, that can be categorized in the following way: emotional confrontation, questioning professional attitude and skills, navigating uncertainty and obstacles in the healthcare organization to provide age- and disease-appropriate care.

As limitations of this study, it can be considered that the circumstantial age/particular life cycle of each individual cannot be studied, due to its specificity. Gaining a greater understanding of the specific care needs of this population is necessary, however, the lack of studies around this subject didn't allow us to reach this goal in full. The research in full text can also be considered a limitation.

As recommendations for clinical practice, we highlight the early introduction of palliative care in the illness trajectory, allowing better control over the disease and better outcomes. The individualization of care is another aspect of paramount importance.

Regarding recommendations for future investigation, we propose the future realization of studies with broader populations, which methods include both qualitative and quantitative data. We also suggest the establishment of nursing interventions that are specific to this population, according to the ICNP taxonomy, and the development of studies on their effectiveness.

The knowledge of the experience of young adults in these circumstances opens the doors to the development of specifically adapted models of care that allow the provision of more individualized and, therefore, more approachable healthcare (and, specifically, nursing care). However, it's necessary to consider that there is still a lack of knowledge about the differences in the experience of young adults upon different diagnosis, prognosis and sociocultural backgrounds.

Conclusion

In this integrative review we investigated the experience of young adults with cancer in palliative care and/or end of life care, exploring in detail their needs and care preferences, the negative aspects of their experience, the importance of familial and social context and, lastly, the nurse's intervention.

Through this research, it was possible to clarify that this is, indeed, an extremely vulnerable situation which requires the intervention of a multidisciplinary team that is competent and capable of discussing topics around advanced illness and end of life and intervene on those. These young adults present very distinct care needs, with unique preferences, valuing above all the promotion of normalcy and autonomy even in illness and requiring time and space to process what they're going through. Many felt that they were too young to face such a threat to their lives, evoking negative feelings associated with the experience.

Family and social networks represent a pilar in supporting young adults with cancer in palliative care and/or end of life care. It's essential that an intervention with this population takes into consideration the particularities of the stage of life they're at, given that it's a critical moment in development in which reaching personal, professional and familial goals is suspended by cancer. The nurse is a central figure throughout the process, intervening over maintaining the quality of life, familial support, promoting coping and bereavement and legacy building. However, healthcare professionals also face challenges while practicing along with this population, that should be tackled through more training and support.

This study meets the premises of existing literature, bringing contributions to a theme that has been, so far, briefly explored.

Therefore, it becomes necessary to support healthcare professionals and enable them for a practice that is more reflexive and based on evidence. This can be done by providing practical tools and inserting them in the health system – some guidelines have already been published, and specific training has started to be developed worldwide.

References

1. Avery J, Geist A, D'Agostino NM, Kawaguchi SK, Mahtani R, Mazzotta P, et al. "It's More Difficult…": Clinicians' Experience Providing Palliative Care to Adolescents and Young Adults Diagnosed With Advanced Cancer. JCO Oncol. Pract. 2019 Nov 25;16(1):100–8.
2. Knox MK, Hales S, Nissim R, Jung J, Lo C, Zimmermann C, et al. Lost and stranded: the experience of younger adults with advanced cancer. Support Care Cancer. 2016 Sep 27;25(2):399–407.
3. Batzler YN, Schallenburger M, Schwartz J, Marazia C, Neukirchen M. The General Public and Young Adults' Knowledge and Perception of Palliative Care: A Systematic Review. Healthcare. 2024 May 7;12(10):957–7.
4. Gaertner J, Knies A, Nauck F, Voltz R, Becker G, Alt-Epping B. "Curative" treatments and palliative care: the lack of consensus. Curr Opin Oncol. 2014 Jul 1;26(4):380–4.
5. NHS. What end of life care involves. NHS. 2022. Available from: https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/
6. Sansom-Daly UM, Wakefield CE, Patterson P, Cohn RJ, Rosenberg AR, Wiener L, et al. End-of-Life Communication Needs for Adolescents and Young Adults with Cancer: Recommendations for Research and Practice. J Adolesc Young Adult Oncol. 2020 Apr 1;9(2):157–65.
7. JAYAO. What Should the Age Range Be for AYA Oncology? J Adolesc Young Adult Oncol. 2011 Mar;1(1):3–10.
8. Avery J, Mosher PJ, Kassam A, Srikanthan A, Zimmermann C, Castaldo Y, et al. Young Adult Experience in an Outpatient Interdisciplinary Palliative. Care Cancer Clinic. 2020.
9. Burgers VWG, van den Bent MJ, Darlington ASE, Gualthérie van Weezel AE, Compter A, Tromp JM, et al. A qualitative study on the challenges health care professionals face when caring for adolescents and young adults with an uncertain and/or poor cancer prognosis. ESMO Open. 2022 Jun 1;7(3).
10. Ngwenya N, Kenten C, Jones L, Gibson F, Pearce S, Flatley M, Hough R, Stirling LC, Taylor RM, Wong G, Whelan J. Experiences and Preferences for End-of-Life Care for Young Adults with Cancer and Their Informal Carers: A Narrative Synthesis. J Adolesc Young Adult Oncol. 2017 Jun;6(2):200-212.
11. Emerson ND, Tabuenca K, Bursch B. End-of-Life Care in Patients with Cancer 16-24 Years of Age. Curr Oncol Rep. 2022 Feb;24(2):195-202.
12. Dhollande S, Taylor A, Meyer S, Scott M. Conducting integrative reviews: a guide for novice nursing researchers. J. Res. Nurs. 2021 Aug 1;26(5):427–38.

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NURSING BEST PRACTICE RECOMMENDATIONS FOR INTRAVESICAL INSTILLATION IN BLADDER CANCER: ADAPTATION TO THE PORTUGUESE ONCOLOGICAL CARE

Recomendações de boas práticas de enfermagem para instilação intravesical no cancro da bexiga: Adaptação para o cuidado oncológico português

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ABSTRACT

The study aimed to translate and adapt best practice recommendations for intravesical instillation of antineoplastic therapy by the European Association of Urology Nurses to the Portuguese oncological context. The work followed the ADAPTE methodology, involving three phases (preparation, adaptation, and finalisation), including external review using the Delphi method.

The translation and adaptation resulted in terminological standardisation and the exclusion of elements misaligned with the national context. Recommendations that did not reach consensus within the working group (n=16) were externally evaluated by expert nurses in intravesical antineoplastic therapy from various oncological contexts identified by intentional and snowball sampling (N=19 Round I, N=16 Round II). Four initial recommendations did not reach consensus; two were eliminated, and the remaining were evaluated in a second round.

This study successfully adapted the recommendations to the Portuguese context, promoting evidence-based practices. Validation by an expert panel confirms their relevance and applicability, strengthening oncological care in Portugal.

KEYWORDS: Administration, Intravesical; Bacillus Calmette–Guérin; Evidence-Based Practice; Mitomycin; Oncology Nursing.

RESUMO

O estudo teve como objetivo traduzir e adaptar as recomendações de boas práticas para a instilação intravesical de terapêutica antineoplásica da Associação Europeia de Enfermeiros de Urologia para o contexto oncológico português. Foi utilizada metodologia ADAPTE (preparação, adaptação e finalização) incluindo revisão externa pelo método Delphi.

A tradução e adaptação cultural resultaram na padronização terminológica e exclusão de elementos não alinhados com o contexto nacional. As recomendações que não alcançaram consenso dentro do grupo de trabalho (n=16) foram avaliadas externamente por enfermeiros peritos em terapia antineoplásica intravesical de vários contextos oncológicos identificados por amostragem intencional e em bola de neve (n=19 Fase I, n=16 Fase

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II). Quatro recomendações iniciais não alcançaram consenso; duas foram eliminados e os demais foram avaliados em segunda fase.

Este estudo adaptou as recomendações ao contexto português, promovendo práticas baseadas em evidências. A sua validação confirma a relevância e aplicabilidade, fortalecendo os cuidados oncológicos em Portugal.

PALAVRAS-CHAVE: Administração Intravesical; Bacillus Calmette–Guérin; Prática Baseada na Evidência; Mitomicina; Enfermagem Oncológica.

Introduction

In oncology, where therapies evolve rapidly, evidence-based practice is essential. Intravesical instillation, a key treatment for non-muscle invasive bladder cancer, is subject to significant variability in clinical practice, impacting its safety and effectiveness. A national round table of experts identified discrepancies across clinical settings, prompting the formation of a working group to review and standardise best practice recommendations for intravesical instillation.

Background

Bladder cancer is the 10th most common cancer worldwide, with approximately 573,000 new cases and 213,000 deaths annually. It is more prevalent in men, with an incidence rate of 9.5 per 100,000, nearly four times higher than in women[1].

In Portugal, bladder cancer is a significant health concern, particularly among males. According to the Global Cancer Observatory's 2022 data, bladder cancer ranks as the fourth most common cancer in Portuguese men, following prostate, colorectal, and lung cancers. Specifically, there were 2,660 new cases reported among males, accounting for 7.0% of all male cancer diagnoses. In contrast, bladder cancer is less prevalent among females, not appearing in the top five cancers for women in Portugal. When examining mortality, bladder cancer does not rank among the top three causes of cancer-related deaths in Portugal for either sex. However, its incidence remains notable, underscoring the importance of targeted prevention and treatment strategies[2].

Intravesical instillation is a key treatment for non-muscle invasive bladder cancer (NMIBC), which accounts for 70-80% of bladder cancer cases. Administering therapeutic agents directly into the bladder via a catheter ensures high local drug concentration with minimal systemic absorption, significantly reducing tumour recurrence and progression. This localized treatment minimizes side effects and maximizes efficacy, improving patient outcomes and quality of life[3, 4].

The primary agents used in intravesical instillation are Bacillus Calmette-Guérin (BCG) and Mitomycin-C. BCG, an immunotherapy, activates the immune system to attack bladder cancer cells, reducing recurrence and delaying progression, and is the gold standard for high-risk NMIBC[5]. Mitomycin-C, a chemotherapeutic, inhibits DNA synthesis, effectively reducing recurrence in intermediate-risk NMIBC, especially when BCG is unsuitable[6]. Together, these agents provide a comprehensive approach to treating bladder cancer.

Variability in practice directly affects outcomes, with studies showing that deviations from standard protocols increase tumour recurrence, progression, and complications such as infections and bladder irritation[3, 7]. Inconsistent use of personal protective equipment (PPE) and preparation areas also exposes healthcare workers to hazardous drugs, posing occupational health risks[8]. Standardizing practices is essential to ensure high-quality care and protect both patients and providers.

Standardized guidelines for intravesical instillation are essential to address the variability in clinical practice.

Evidence-based guidelines, like those from the European Association of Urology Nurses (EAUN), offer comprehensive recommendations for preparation, administration, and monitoring of intravesical therapy[9]. These guidelines aim to harmonize practices across healthcare settings, ensuring consistent, high-quality care for all patients. They also facilitate provider training, improving competency and confidence in administering treatments[4]. Adherence to these guidelines enhances treatment efficacy, reduces adverse events, and protects both patients and staff.

Research Question

This study aims to adapt the Nursing Best Practice Recommendations for Intravesical Instillation of Antineoplastic Therapy, developed by the EAUN[9], for use in Portuguese oncological care. The objectives are I) to translate and culturally adapt the recommendations for the Portuguese context, and II) to evaluate them through expert review in Portuguese urological oncological care. The goal is to preserve the integrity of the original guidelines while ensuring their relevance and applicability for nurses and oncology patients in Portugal, addressing the research question: how can the EAUN Best Practice Recommendations be adapted and evaluated for effective use in Portuguese oncological care?

Methodology

This methodological multi-method study follows the adapted ADAPTE approach (Amer et al., 2015), consisting of 12 steps to ensure the recommendations' integrity and applicability in Portuguese oncological care. A working group of expert nurses in intravesical antineoplastic therapy (with 3 to 20 years of experience) from five clinical contexts across mainland Portugal conducted the study.

Translation and Adaptation Process

Preparation Phase

A search for best practices in intravesical instillation of antineoplastic agents yielded no national results, but the European Association of Urology Nurses (EAUN) Best Practice Recommendations were identified internationally[9]. Developed by a multidisciplinary team, these guidelines followed a rigorous process involving specialist nurses, urologists, and safety representatives. The recommendations, based on the Oxford Centre for Evidence-based Medicine's grading system, integrate scientific knowledge, nursing experience, patient perspectives, and available resources into evidence-based practice.

Before this study began, permission was obtained from the original authors to adapt the recommendations for Portuguese oncological care. An update of the document is planned for 2025.

Adaptation Phase

This phase involved translating the document from English to European Portuguese while ensuring semantic and conceptual equivalence and occurred February to September 2024. Two working group members both fluent in English and native Portuguese speakers, shared the translation task. To ensure accuracy, all group members individually reviewed the translated version in a shared document, assessing its congruence with the original version and the relevance and applicability of the recommendations within the Portuguese context. They identified ambiguities and inconsistencies, which were systematically analysed in multiple joint meetings. Through these discussions, cultural, structural, and health policy barriers and facilitators were identified, and consensus was reached. An external review of the recommendations that did not reach consensus among working group members was conducted using the Delphi method in March and April 2024.

Finalisation and Documentation

The modified recommendations were reviewed for relevance and accuracy, ensuring alignment with the originals, and then integrated into the final document. A plan for implementation, evaluation, and monitoring was developed. The finalisation and documentation occurred from October to December 2024.

Delphi Methodology

The external review followed the Delphi method for its structured and iterative approach to gathering expert perspectives[10].

Expert nurses in intravesical antineoplastic therapy were invited to participate in the review panel through intentional snowball sampling. Each working group member reached out to their professional network to identify potential participants with relevant expertise, ensuring a diverse representation of professionals actively engaged in this field. The selection of experts was guided by established principles. Benner[11] defines expertise as the ability to intuitively grasp complex problems, distinguishing essential elements without being distracted by irrelevant details. Complementarily, the Portuguese Nursing[12] emphasizes that expert knowledge is fundamentally derived

from clinical experience, reinforcing the practical competencies essential for high-quality care in intravesical instillation.

Participants were selected based on their direct involvement in intravesical instillation and their ability to to provide meaningful contributions to the adaptation process, ensuring both representativeness and competence for valid results. Professional or academic degrees were not criteria for inclusion or exclusion. As recommended, we aimed to include 10 to 15 experts from diverse clinical contexts across Portugal, ensuring a breadth of professional experience and institutional representation.

Nurses who accepted the invitation received a confidential and anonymous link to the questionnaire, which compiled the recommendations that lacked consensus. No incentives were provided. Participants answered demographic questions and rated their agreement (0-10) and each recommendation's relevance/applicability (1-5). An open field allowed suggestions, ensuring both quantitative and qualitative feedback. The threshold for expert consensus was set at 75% agreement (votes ≥8) for acceptance, acknowledging the iterative nature of Delphi rounds in refining and validating the adapted recommendations[10, 13].

Responses were analysed using descriptive statistics to identify consensus and divergence. Based on the first round's feedback, recommendations were revised for a second round. To quantify expert consensus on relevance and applicability, the mean (M) and standard deviation (SD) for each recommendation's scores were calculated in both rounds. To assess the reliability of expert ratings, an Intraclass Correlation Coefficient (ICC: Two-Way Mixed Model, Consistency) was computed in Round I, where multiple recommendations were rated. This model was selected as it is appropriate when a fixed group of raters evaluates multiple items, aligning with established methodologies for inter-rater reliability assessment[14]. ICC values were interpreted following established thresholds[15], where ICC < 0.50 indicates poor reliability, 0.50–0.75 represents moderate reliability, 0.75–0.90 indicates good reliability, and values ≥ 0.90 represent excellent reliability. These categories provide a standardized approach for evaluating the consistency of expert ratings.

The final Delphi phase provided panel members with a summary of the collective opinions, including justifications for decisions. This allowed participants to review their responses considering the group consensus, resulting in the final, adapted recommendations.

Results

Translation and Cultural Adaptation

The two working group members fluent in English and native Portuguese speakers, who shared the translation task, had 38 years old and 40 years old, and 12 and 4 years of experience in oncology nursing. After reviewing the entire document, the Working Group integrated comments into the final version, ensuring linguistic and content coherence. Terminology was standardized (e.g., *paciente* to *utente*), and elements misaligned with the Portuguese context were excluded.

Bladder cancer incidence and NMIBC risk categorization were updated[1], along with procedure norms following EU-OSHA guidelines[16]. Discussions also addressed administration times, therapeutic regimens, and drug preparation methods.

Sections specific to the USA and other European contexts were removed to create a document tailored to the needs and clinical practice of nurses in Portugal, promoting its effective implementation.

The recommendations were adapted for the Portuguese oncological context, addressing medication preparation, protective equipment, treatment schemes for Mitomycin C and BCG, patient positioning, and professional training. Among these, sixteen recommendations did not reach consensus among working group members and were subsequently evaluated using the Delphi methodology (**Table 1** – supplementary file).

eDelphi

In the first Delphi round, 19 experts participated: 63% were nurses, 21% were specialist nurses, and 16% were nurse managers (Table 2). Regarding academic qualifications, 74% held a bachelor's degree and 26% a master's degree (Table 3). Nurses had a mean professional experience of 22.26 years (SD = 6.95), with a median of 20 years and a mode of 19 years. Their experience in the current clinical context had a mean of 14.05 years (SD = 6.53), with a median of 13 years and a mode of 19 years. The range of professional experience spanned 13 to 42 years, while experience in the current clinical context ranged from 4 to 30 years (Table 4).

Table 2. Professional title of the experts participating in Rounds 1 and 2

PROFESSIONAL TITLE	ROUND 1, N=19 N (%)	ROUND 2, N=16 N (%)
Nurse	12 (63)	7 (44)
Specialist Nurse	4 (21)	5 (31)
Nurse manager	3 (16)	4 (25)
Total	19	16

Table 3. Academic degree of the experts participating in Rounds 1 and 2

ACADEMIC DEGREE	ROUND 1, N=19 N (%)	ROUND 2, N=16 N (%)
Bachelor's Degree	14 (74)	13 (81)
Master's Degree	5 (26)	3 (19)
Total	19	16

Table 4. Professional experience of the experts participating in Rounds 1 and 2

STATISTIC	ROUND I		ROUND II	
	OVERALL	CURRENT CONTEXT	OVERALL	CURRENT CONTEXT
Mean (SD)	22.26 (6.95)	14.05 (6.53)	25.94 (9.93)	16.69 (12.65)
Median	20	13	24	12
Mode	19	19	19	40
Range (Min-Max)	13-42	4-30	14-42	2-20

In the second round, 16 nurses participated: 44% were nurses, 31% specialist nurses, and 25% nurse managers (Table 2). Academically, 81% held a bachelor's degree and 19% a master's degree (Table 3). Nurses had a mean professional experience of 25.94 years (SD = 9.93), with a median of 24 years and a mode of 19 years. Their experience in the current clinical context had a mean of 16.69 years (SD = 12.65), with a median of 12 years and a mode of 40 years. The range of professional experience spanned 14 to 42 years, while experience in the current clinical context ranged from 2 to 40 years (Table 4).

In the first round, significant contributions led to consensus on 12 recommendations, with discrepancies in four (Table 5, see supplementary file). Except for recommendations 4 and 5, all received applicability and relevance ratings above 3.5, with a minimum agreement of 63% for recommendation 9. Recommendations 4 and 5 were eliminated due to a lack of consensus above 75%. The reliability analysis yielded ICC = 0.898, 95% CI [0.189 – 0.559], $p < 0.001$, indicating good to excellent reliability in expert evaluations. One item was removed from the analysis due to zero variance in ratings.

Recommendation 4 (21%), suggesting that BCG and Mitomycin-C be prepared by two nurses, did not reach a consensus due to varied opinions. Discussions raised concerns about efficiency, safety, and resource limitations. Some experts argued that two nurses were unnecessary, as Mitomycin-C is prepared by pharmacy technicians and BCG often arrives pre-prepared. The emphasis shifted toward the importance of double-checking patient data rather than requiring two nurses.

Recommendation 5 (37%) on the administration of BCG and Mitomycin-C by two nurses also generated divided opinions, like Recommendation 4. While two nurses could enhance safety by reducing errors, experts acknowledged the practical limits of human resources. With proper protective equipment and a closed system, one nurse could safely manage administration, though dose validation and patient verification might still require two nurses. A well-trained nurse following proper procedures could perform the administration alone.

Based on open-response comments, recommendations 8 and 9 were merged and reformulated for the second round of expert scrutiny (Table 6, see supplementary file). Experts agreed with the statements but noted their interconnection, prompting the consolidation. As only one recommendation was rated in Round II, it was not possible to compute the ICC, as this measure requires multiple items to assess reliability.

Recommendation 1 (79%), stating that intravesical medication does not require preparation in a laminar flow chamber when using a closed system, generated productive comments. While BCG practices were accepted, Mitomycin-C was noted as requiring a laminar flow chamber due to handling needs.

Experts agreed that antineoplastic agents should be prepared in a laminar flow chamber, with differentiation between medications based on safety requirements. They emphasized strict protection during cytostatic handling and recognized closed systems for improving safety and reducing aerosol exposure. Additionally, process simplification was noted to save time and enhance treatment efficiency. This recommendation received a mean relevance score of 4.32 (SD = 0.58) and a mean applicability score of 4.17 (SD = 0.62).

Regarding **Recommendation 2** (95%), the experts agreed on the need for dedicated BCG preparation ar-

eas. Preventing contamination was deemed crucial, with unanimous support for separating BCG from other medications. Experts emphasized protocols for safe use, including inactivity periods and decontamination, to prevent cross-contamination. This recommendation received a mean relevance score of 4.84 (SD = 0.37) and a mean applicability score of 4.53 (SD = 0.84).

Recommendation 3 (100%) emphasized minimizing exposure risk during intravesical medication preparation and administration using personal protective equipment. Experts reinforced the importance of strict adherence to protective measures to ensure healthcare professionals' safety. This recommendation received a mean relevance score of 4.95 (SD = 0.23) and a mean applicability score of 4.95 (SD = 0.23).

Recommendation 6 (79%), advocated using the smallest possible intermittent urinary catheter for intravesical instillations, reaching clear consensus. Experts agreed that catheter size should be personalized based on patient conditions, with smaller sizes preferred to minimize trauma. Larger catheters may be necessary for patients with a history of leaks. It was also agreed that keeping the catheter clamped during treatment preserves a closed system, reducing contamination and injury risks. This recommendation received a mean relevance score of 4.11 (SD = 1.33) and a mean applicability score of 4.16 (SD = 1.30), indicating moderate to strong expert agreement on its importance and feasibility.

Regarding **Recommendation 7** (89%), advocating for luer lock catheters to minimize exposure risk during intravesical instillations, was widely accepted. Experts supported making it a standard, recognizing that the luer lock system reduces therapeutic leakage and enhances safety by providing a secure connection, minimizing accidental disconnections and exposure to hazardous substances. This recommendation received a mean relevance score of 4.47 (SD = 0.70) and a mean applicability score of 4.26 (SD = 1.10), reflecting strong expert agreement on its importance and feasibility.

Experts had differing views on **Recommendations 8 and 9**, particularly concerning bladder fullness and premature urination. Some felt positional changes were unnecessary unless discomfort required the patient to lie down. The consensus emphasized patient comfort, access to appropriate sanitary facilities, and continuous monitoring to manage potential complications. Proper waste management was also highlighted. The final reformulated recommendation received a mean relevance score of 3.75 (SD = 1.29) and a mean applicability score of 3.81 (SD = 1.17), indicating moderate consensus among experts. With over 50% agreement and supporting scientific evidence, the working group included both recommendations in the final document.

Recommendation 10 (84%) on bladder medication retention, specifying one hour for Mitomycin-C and two hours for BCG, was accepted. This aligns with clinical best practices and patient-specific conditions, with retention duration determined by the physician based on the patient's tolerance. This recommendation received a mean relevance score of 4.47 (SD = 1.02) and a mean applicability score of 4.32 (SD = 1.16)

Recommendations 11 (84%) and 12 (79%) on Mitomycin-C treatment regimens were widely accepted without major suggestions for modification. Experts emphasized that administration and treatment regimens should follow medical guidance and the usual practices of healthcare services and professionals. Recommendation 11 received a mean relevance score of 4.47 (SD = 0.77) and a mean applicability score of 4.53 (SD = 0.77), while Recommendation 12 received 4.37 (SD = 0.83) for relevance and 4.42 (SD = 0.84) for applicability, reflecting strong expert consensus on their importance and feasibility.

Recommendation 13 (84%), suggesting the first urination after intravesical instillation occur in the clinic before discharge, was considered with practical and safety concerns. Experts emphasized following hospital norms for urine elimination, including catheter drainage and closed-system waste disposal, to control drug-containing urine and ensure proper waste treatment.

While some experts suggested that home care guidelines could make in-clinic urination unnecessary, most agreed it reduces splashing and contamination, providing a safer environment for patients and cohabitants. This recommendation received a mean relevance score of 4.47 (SD = 1.07) and a mean applicability score of 4.32 (SD = 1.20).

Recommendation 14 (84%) suggesting the first spontaneous urination be performed sitting and followed by a double flush, was widely accepted. Experts highlighted this practice as crucial for minimizing splashing and contamination from the drug present in the urine after intravesical instillation. This recommendation received a mean relevance score of 4.42 (SD = 1.07) and a mean applicability score of 4.32 (SD = 1.29).

Recommendation 15 (95%), on marking the toilet used for the first urination after intravesical instillation for cleaning per institutional norms received consensus. It was recognized as important for reducing contamination risk.

However, some professionals raised concerns about the feasibility of dedicating a specific toilet due to high patient volume, making control and monitoring challenging. This recommendation received a mean relevance score of 4.68 (SD = 0.91) and a mean applicability score of 4.05 (SD = 1.65).

For **recommendation 16** (100%), comments unanimously highlighted the importance of specialized training for nurses administering intravesical medication. Training was considered essential as part of the nurse's professional integration and a necessary practice for any new procedure. This recommendation received a mean relevance score of 4.84 (SD = 0.37) and a mean applicability score of 4.84 (SD = 0.37).

Discussion

The adaptation of the EAUN Best Practice Recommendations to the Portuguese context yielded key findings aligned with best practices in oncology nursing. Standardised procedures, as noted in prior studies, are essential for reducing variability in clinical practices, directly impacting the safety and efficacy of treatments[17].

The process of terminological standardisation was critical for ensuring clarity and relevance to Portuguese healthcare professionals, facilitating easier implementation and adherence to best practices. High levels of consensus among the expert panel indicate that the adapted guidelines are well-suited to the specific needs of Portuguese oncological care.

For instance, recommendations on the use of closed systems for BCG preparation and the mandatory use of individual protective equipment highlight a strong emphasis on safety and infection control[18,19].

The use of closed systems for medication preparation and administration, as recommended in the current guidelines, is supported by studies highlighting their effectiveness in reducing contamination risks and improving safety outcomes[20]. Additionally, the focus on individual protective equipment and specific preparation areas for intravesical medications is consistent with best practices identified in prior studies. Research has shown that stringent infection control measures, including the use of personal protective equipment and dedicated preparation areas, are essential for preventing healthcare-associated infections and protecting healthcare workers from hazardous exposures[21,22].

Moreover, the adaptation process highlighted the importance of tailoring guidelines to accommodate local practices and resources. This includes recognising the distinct handling requirements for different antineoplastic agents and adjusting practices accordingly. For example, while closed systems were recommended for BCG to reduce exposure risk, Mitomycin-C was noted to require preparation under a laminar flow chamber, acknowledging its specific safety demands. Such distinctions are crucial for maintaining high standards of care and ensuring the safety of both patients and healthcare providers[23-25]

The recommendations that did not initially achieve consensus provided valuable insights into the practical challenges faced by healthcare providers. For example, the proposal that the preparation of Mitomycin-C and BCG should be conducted by two nurses was met with concerns regarding resource availability and efficiency. These discussions highlighted the need for evidence-based and practically feasible guidelines within the constraints of local healthcare settings[24].

These practical challenges identified in the current study, such as the resource constraints for having two nurses prepare or administer medications, mirror findings from other settings. Studies have reported similar issues, where the availability of trained personnel and the allocation of sufficient resources are critical factors influencing the implementation of clinical guidelines[23]. The adapted recommendations' flexibility in allowing for single-nurse administration under certain conditions is a pragmatic solution that balances safety with practical feasibility, ensuring that the final recommendations are both effective and implementable[25,26].

The study has some constraints that might limit the interpretation and generalization of the results. The translation process was conducted by two working group members rather than independent translators. However, all group members individually reviewed the translated version, identifying inconsistencies and discussing them in multiple meetings until consensus was reached. This approach was considered a viable alternative to enhance conceptual equivalence and maintain methodological rigor. Additionally, the Delphi process was conducted asynchronously, limiting real-time dialogue and the richness of feedback, though this approach was necessary to accommodate nurses' varying schedules. Additionally, the relatively small expert panel may not fully reflect the diversity of perspectives across Portuguese healthcare settings, and the reliance on subjective judgments introduces potential bias. Lastly, the recommendations were adapted to current Portuguese practices and resources, which may limit their applicability in different settings. Ongoing review and updates will be necessary to keep the guidelines relevant as medical knowledge evolves.

Conclusion

The adapted guidelines strengthen established oncology nursing practices, adding to the evidence supporting standardised care to improve patient outcomes and healthcare safety. By aligning with previous studies, these recommendations offer a solid framework for optimising intravesical instillation practices in Portugal.

The adapted guidelines have significant implications for clinical practice in Portuguese oncological care. Standardising intravesical instillation is expected to improve the consistency and quality of care for non-muscle invasive bladder cancer patients. Following evidence-based recommendations reduces treatment variability and enhances patient safety. Additionally, the successful adaptation of these guidelines can serve as a model for other countries, allowing Portugal to contribute to global efforts to standardise and improve oncological care by sharing lessons and best practices. Future research should focus on longitudinal studies to assess the implementation and long-term impact of the guidelines on patient outcomes, worker safety, and treatment efficacy. These studies would provide valuable data on real-world effectiveness and areas for improvement.

References

1. Bray F, Laversanne M, Sung H, Ferlay J, Siegel RL, Soerjomataram I, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer Journal for Clinicians. 2024;74(3):229-63.
2. Ferlay J, Ervik M, Lam F, Laversanne M, Colombet M, Mery L, et al. Global cancer observatory: cancer today (version 1.1). Lyon, France: International Agency for Research on Cancer. 2024.
3. Liu G, Li B, Xu Z, Wang J, Ma S, Kan Y, et al. Bacillus calmette-guerin for the treatment of non-muscle invasive bladder cancer: history and current status. Discovery Medicine. 2022;33(169):85-92.
4. Witjes JA, Bruins HM, Cathomas R, Compérat EM, Cowan NC, Gakis G, et al. European Association of Urology guidelines on muscle-invasive and metastatic bladder cancer: summary of the 2020 guidelines. European Urology. 2021;79(1):82-104.
5. Lobo N, Brooks NA, Zlotta AR, Cirillo JD, Boorjian S, Black PC, et al. 100 years of Bacillus Calmette–Guérin immunotherapy: from cattle to COVID-19. Nature Reviews Urology. 2021;18(10):611-22.
6. Duan H, Deng Z, Zou J, Zhang G, Zou X, Xie T. The Efficacy and Safety of Hyperthermia Intravesical Chemotherapy in the Treatment of Non-Muscle-Invasive Bladder Cancer: A Meta-Analysis. Urologia Internationalis. 2024;108(4):322-33.
7. Li R, Li Y, Song J, Gao K, Chen K, Yang X, et al. Intravesical gemcitabine versus mitomycin for non-muscle invasive bladder cancer: a systematic review and meta-analysis of randomized controlled trial. BMC Urology. 2020;20:1-8.
8. Burroughs GE, Connor TH, Mead KR, Reed LD. Preventing occupational exposure to antineoplastic and other hazardous drugs in health care settings. CA Cancer Journal for Clinicians. 2006;56(6):354-65.
9. Lauridsen SV, De Blok W, Retinger NL, Jensen BT, Turner B, Villa G, et al. Intravesical instillation with mitomycin C or bacillus Calmette-Guérin in non-muscle invasive bladder cancer: European Association of Urology Nursing; 2015.
10. Keeney S, Hasson F, McKenna H. Consulting the oracle: ten lessons from using the Delphi technique in nursing research. Journal of Advanced Nursing. 2006;53(2):205-12.
11. Benner P. From novice to expert: Excellence and power in clinical nursing practice. Commemorative edition: Prentice-Hall International London; 2001.
12. Portuguese Nursing Order Parecer n.º 10/2017: Diferenciação das intervenções de enfermagem do enfermeiro especialista em enfermagem médico-cirúrgica em relação ao enfermeiro generalista, num serviço de urgência. 2017.
13. Kennedy HP. Enhancing Delphi research: methods and results. Journal of Advanced Nursing. 2004;45(5):504-11.
14. Gisev N, Bell JS, Chen TF. Interrater agreement and interrater reliability: key concepts, approaches, and applications. Research in Social and Administrative Pharmacy. 2013;9(3):330-8.
15. Koo TK, Li MY. A guideline of selecting and reporting intraclass correlation coefficients for reliability research. Journal of Chiropractic Medicine. 2016;15(2):155-63.
16. European Commission. Guidance for the Safe Management of Hazardous Medicinal Products at Work. 2023.
17. Peyton CC, Chipollini J, Azizi M, Kamat AM, Gilbert SM, Spiess PE. Updates on the use of intravesical therapies for non-muscle invasive bladder cancer: how, when and what. World Journal of Urology. 2019;37:2017-29.
18. Szewczyk Jr MT, Soefje SA. Development of an innovative delivery system for bacillus Calmette-Guérin bladder administration. American Journal of Health-System Pharmacy. 2021;78(1):60-4.
19. Marx AH, Nowicki DN, Carlson RB, Schultz KM, Sickbert-Bennett E, Weber DJ. Bacille Calmette-Guérin preparation and intravesical administration to patients with bladder cancer: risks to healthcare personnel and patients, and mitigation strategies. Infection Control & Hospital Epidemiology. 2024;45(4):520-5.
20. Liu S, Zhang C, Peng L, Lu Y, Luo D. Comparative effectiveness and safety of intravesical instillation treatment of interstitial cystitis/bladder pain syndrome: a systematic review and network meta-analysis of randomized controlled trials. International Urogynecology Journal. 2021;32:1061-71.
21. Simons A, Toland S. Protecting nurses against the risks of occupational exposure to systemic anticancer therapy agents. Cancer Nursing Practice. 2024;23(4).
22. Connor TH, McDiarmid MA. Preventing occupational exposures to antineoplastic drugs in health care settings. CA Cancer Journal for Clinicians. 2006;56(6):354-65.
23. Wang T, Tan J-YB, Liu X-L, Zhao I. Barriers and enablers to implementing clinical practice guidelines in primary care: an overview of systematic reviews. BMJ open. 2023;13(1):e062158.
24. Wang Z, Norris SL, Bero L. The advantages and limitations of guideline adaptation frameworks. Implementation Science. 2018;13:1-13.
25. Klaic M, Kapp S, Hudson P, Chapman W, Denehy L, Story D, et al. Implementability of healthcare interventions: an overview of reviews and development of a conceptual framework. Implementation Science. 2022;17(1):10.
26. Bora A-M, Piechotta V, Kreuzberger N, Monsef I, Wender A, Follmann M, et al. The effectiveness of clinical guideline implementation strategies in oncology—a systematic review. BMC Health Services Research. 2023;23(1):347.

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Declaration of conflicting interests

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Supplementary File

Table 1, results from translation and cultural adaptation. Tables 5 and 6, results from Delphi rounds 1 and 2, respectively.

Table 1. Recommendations lacking consensus among the working group (original, forward-and back-translation versions).

RECOMMENDATIONS	ORIGINAL LANGUAGE	PORTUGUESE TRANSLATION	BACK-TRANSLATION
2	BCC should not be prepared in areas where intravenous drugs are prepared	O BCG não deve ser preparado em áreas onde são preparados outros medicamentos.	BCG should not be prepared in areas where other medications are prepared.
3	To reduce risk of exposure during drug preparation and administration personal protective clothing should be worn in accordance with local and hospital safety procedures. When performing intravesical instillations, healthcare workers should use protective equipment that protects them against contamination with medication	Para reduzir o risco de exposição durante a preparação e administração da medicação intravesical, deve ser usado equipamento de proteção individual de acordo com os procedimentos de segurança locais e hospitalares, nomeadamente luvas de proteção tipo B, bata impermeável, máscara FFP2, e óculos de proteção.	To reduce the risk of exposure during the preparation and administration of intravesical medication, personal protection equipment should be used in accordance with local and hospital safety procedures, namely type B protective gloves, a waterproof gown, an FFP2 mask, and protective goggles.
6	In intravesical instillations an intermittent catheter with the smallest size possible should be used	Nas instilações intravesicais deve ser utilizado um cateter de drenagem urinária intermitente com o menor calibre possível.	For intravesical instillations, an intermittent urinary drainage catheter with the smallest possible caliber should be used.
7	In intravesical instillations a luer lock catheter is recommended to reduce risk of exposure.	Nas instilações intravesicais recomenda-se um cateter luer lock para reduzir o risco de exposição.	In intravesical instillations, a luer lock catheter is recommended to reduce the risk of exposure.
8	The anatomy of the empty bladder allows the wall of the bladder to make contact with the intravesical medication, and the patient should be encouraged to mobilise as usual. In some hospitals and clinics, after the drugs are instilled, the patient is rotated side-to-side every 15 min. to enhance contact of the drug with the entire bladder mucosa. In the product description (SPC) of BCG Tice, patients are advised to rotate after instillation, whereas staying mobile is advised in SPC of BCG Medac. However, there is no evidence to support these practices	Atualmente nas instilações intravesicais não existe evidência que apoie a prática de alternância de decúbitos. A pessoa deve por isso ser encorajada a deambular, pois a anatomia da bexiga vazia permite que toda a superfície entre em contato com a medicação intravesical.	Currently, there is no evidence to support the practice of alternating positions during intravesical instillations. Therefore, the patient should be encouraged to ambulate, as the anatomy of the empty bladder allows the entire surface to come into contact with the intravesical medication.
10	The dwell time that is commonly practised is 1–2 h	O tempo de permanência dos medicamentos na bexiga é de 1 a 2 horas.	The retention time of the medication in the bladder is 1 to 2 hours.
11	Chemotherapy (MMC): one single immediate postoperative instillation; or immediate postoperative instillation followed by 6 weekly instillations and then, if cystoscopy is negative, monthly instillations for a period of 1 year	O tratamento com Mitomicina C pode contemplar: a) a administração em dose única no pós-operatório imediato; b) uma instilação no pós-operatório imediato seguido de 6 instilações semanais de indução e, se a cistoscopia for negativa, instilações mensais por um período de 1 ano.	The Treatment with Mitomycin-C may include: a) a single dose administration immediately postoperatively; b) one instillation immediately postoperatively followed by 6 weekly induction instillations, and if the cystoscopy is negative, monthly instillations for a period of 1 year.
12	BCG: there is no immediate postoperative instillation of BCG. Administration should not start sooner than 2 weeks after TUR-BT and consists of 6 weekly instillations: induction course followed by 3 weekly instillations (maintenance) at 3, 6, 12, 18, 24, 30 and 36 months, provided that cystoscopy and cytology are negative	No tratamento com o BCG não há instilação deste fármaco no pós-operatório imediato. A administração não deve começar antes de 2 semanas após a RTU-TV e consiste em 6 instilações semanais (indução) seguida de 3 instilações semanais (manutenção) aos 3, 6, 12, 18, 24, 30 e 36 meses, desde que a cistoscopia e a citologia sejam negativas.	In the treatment with BCG, there is no instillation of this drug immediately postoperatively. Administration should not begin before 2 weeks after TURBT and consists of 6 weekly instillations (induction) followed by 3 weekly instillations (maintenance) at 3, 6, 12, 18, 24, 30, and 36 months, provided that cystoscopy and cytology are negative.

RECOMMENDATIONS	ORIGINAL LANGUAGE	PORTUGUESE TRANSLATION	BACK-TRANSLATION
14	In some countries, it is advised to flush the toilet twice with the lid closed	A primeira micção espontânea deve ser realizada sentada na sanita, efetuando descarga dupla.	The first spontaneous urination should be performed while sitting on the toilet, with a double flush.
15	When the toilet is used by more persons, cleaning with normal detergent and water is advised	O WC utilizado para a primeira micção espontânea deverá ser sinalizado para limpeza posterior de acordo com a norma institucional.	The toilet used for the first spontaneous urination should be marked for subsequent cleaning according to institutional guidelines.
16	Nurse specialist administering intravesical therapies needs to be trained and assessed by a competent practitioner	O enfermeiro que administra medicação intravesical deve ser previamente formado, treinado e avaliado por um profissional com competência teórico-prática neste tipo de procedimento.	The nurse administering intravesical medication must be previously trained, educated, and evaluated by a professional with theoretical and practical competence in this type of procedure.

Table 5. Results of the first Delphi round.

RECOMMENDATIONS	RELEVANCE (1–5)	APPLICABILITY (1–5)	AGREEMENT (1–10)	
	MEAN (SD)	MEAN (SD)	MEAN (SD)	% ≥ 8
1. When a closed system is used, the medication for intravesical instillation does not need to be prepared in a laminar flow chamber	4,32 (0,58)	4,17 (0,62)	7,95 (3,06)	79
2. BCG should not be prepared in areas where other medications are prepared	4,84 (0,37)	4,53 (0,84)	9,58 (0,90)	95
3. To reduce the risk of exposure during the preparation and administration of intravesical medication, personal protection equipment should be used in accordance with local and hospital safety procedures, namely type B protective gloves, a waterproof gown, an FFP2 mask, and protective goggles	4,95 (0,23)	4,95 (0,23)	10,00 (0)	100
4. The preparation of BCG and Mitomycin-C should be carried out by two nurses	2,95 (1,47)	2,37 (1,61)	4,05 (3,75)	21
5. The administration of BCG and Mitomycin-C should be carried out by two nurses.	3,16 (1,46)	2,58 (1,68)	5,26 (4,15)	37
6. For intravesical instillations, an intermittent urinary drainage catheter with the smallest possible caliber should be used	4,11 (1,33)	4,16 (1,30)	8,47 (2,97)	79
7. In intravesical instillations, a luer lock catheter is recommended to reduce the risk of exposure	4,47 (0,70)	4,26 (1,10)	8,68 (3,13)	89
8. Currently, there is no evidence to support the practice of alternating positions during intravesical instillations. Therefore, the patient should be encouraged to ambulate, as the anatomy of the empty bladder allows the entire surface to come into contact with the intravesical medication	4,26 (1,15)	3,84 (1,50)	7,53 (3,31)	68
9. In special situations, the patient may remain catheterized and stay in bed during the time the medication is retained in the bladder (e.g., individuals with cognitive impairment, urinary incontinence). In these circumstances, due to bed immobility, positions should be alternated every 15 minutes	3,58 (1,68)	3,63 (1,71)	6,95 (4,13)	63
10. The retention time of the medication in the bladder is 1 to 2 hours	4,47 (1,02)	4,32 (1,16)	8,84 (2,52)	84

RECOMMENDATIONS	RELEVANCE (1–5)	APPLICABILITY (1–5)	AGREEMENT (1–10)	
	MEAN (SD)	MEAN (SD)	MEAN (SD)	% ≥ 8
11. The treatment with Mitomycin-C may include: (a) a single dose administration immediately postoperatively; (b) one instillation immediately postoperatively followed by 6 weekly induction instillations, and if the cystoscopy is negative, monthly instillations for a period of 1 year	4,47 (0,77)	4,53 (0,77)	9,11 (1,76)	84
12. In treatment with BCG, there is no indication of a single dose administration (immediately postoperative). Administration should begin not before 2 weeks after TURBT and consist of 6 weekly instillations (induction) followed by 3 weekly instillations (maintenance) at 3, 6, 12, 18, 24, 30, and 36 months, provided that cystoscopy and cytology are negative	4,37 (0,83)	4,42 (0,84)	8,95 (1,90)	79
13. The first spontaneous urination after intravesical instillation should be performed in the healthcare facility	4,47 (1,07)	4,32 (1,20)	8,89 (2,75)	84
14. The first spontaneous urination should be performed while sitting on the toilet, with a double flush	4,42 (1,07)	4,32 (1,29)	8,74 (2,66)	84
15. The toilet used for the first spontaneous urination should be marked for subsequent cleaning according to institutional guidelines	4,68 (0,91)	4,05 (1,65)	9,37 (2,31)	95
16. The nurse administering intravesical medication must be previously trained, educated, and evaluated by a professional with theoretical and practical competence in this type of procedure	4,84 (0,37)	4,84 (0,37)	9,89 (0,46)	100

Table 6. Results of the second Delphi round.

RECOMMENDATIONS	RELEVANCE (1–5)	APPLICABILITY (1–5)	AGREEMENT (1–10)	
	MEAN (SD)	MEAN (SD)	MEAN (SD)	% ≥ 8
Currently, there is no evidence to support the practice of alternating positions during intravesical instillations. Therefore, the patient should be encouraged to ambulate, as the anatomy of the empty bladder allows the entire surface to come into contact with the intravesical medication. Exceptions are made for special situations where the patient may remain catheterized in bed during the medication retention time in the bladder (e.g., individuals with cognitive impairment, urinary incontinence). In these bedridden circumstances, positions should be alternated every 15 minutes	3,75 (1,29)	3,81 (1,17)	6,31 (4,38)	56

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DISTRESS NA PESSOA COM DOENÇA HEMATONCOLÓGICA SUBMETIDA A TRANSPLANTE: UMA REVISÃO INTEGRATIVA DA LITERATURA

Distress in people with hematological disease undergoing transplantation: An integrative literature review

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RESUMO

Introdução: No transplante de células hematopoiéticas a pessoa apresenta risco elevado de adquirir uma infeção, pelo que se encontra em isolamento protetor, sendo este um fator potenciador do distress.

Objetivo: Investigar os cuidados de enfermagem, promotores do alívio do distress na pessoa com doença hematoncológica, em isolamento hospitalar.

Metodologia: Revisão Integrativa da Literatura, segundo Whittemore & Knafl com base em pesquisas nas bases de dados MEDLINE, CINAHL e Google Académico. Foram aplicados critérios de inclusão e exclusão, resultando em 10 estudos relevantes para análise.

Resultados: Os cuidados de enfermagem incluíram a promoção da literacia em saúde, musicoterapia, meditação, terapia de resolução de problemas, novas tecnologias e a da partilha de experiências. Essas estratégias demonstraram validade no alívio do distress em pessoas com doença hematoncológica.

Conclusão: Os cuidados de enfermagem são essenciais para o alívio do distress emocional, tanto por meio de intervenções farmacológicas quanto não farmacológicas.

PALAVRAS-CHAVE: Distress Emocional; Cuidados de Enfermagem; Isolamento Hospitalar; Paciente Oncológico.

ABSTRACT

Introduction: In hematopoietic cell transplantation, the person is at high risk of acquiring an infection and is therefore in protective isolation, which is a factor that increases distress.

Objective: To investigate nursing care that promotes the relief of distress in people with cancer in hospital isolation.

Methodology: This is an Integrative Literature Review based on bibliographic research carried out in the MEDLINE, CINAHL Complete databases and a free search on the Google Scholar platform.

Results: Nursing care based on the promotion of literacy, music therapy, meditation and problem-solving therapy, as well as new technologies and the promotion of shared experiences, demonstrate validity in relieving distress.

Conclusion: It is important to provide nursing care to relieve distress, both through pharmacological and non-pharmacological interventions.

KEYWORDS: Emotional Distress; Nursing Care; Hospitals Isolation; Cancer Patient.

Introdução

O cancro, cada vez mais prevalente, revela-se a segunda causa de morte a nível mundial, com cerca de 10 milhões de mortes em 2022[1]. Na Europa, o cancro é também a segunda principal causa de mortalidade nos países da União Europeia, após as doenças cardiovasculares, em que todos os anos mais de 1,2 milhões de pessoas morrem devido à doença[1]. Portugal não é exceção, sendo que em 2022 registaram-se sensivelmente 33 mil mortes por cancro, no nosso país[2].

No que concerne às neoplasias hematológicas, estas provocam alterações nas células sanguíneas ou nos tecidos de origem dessas células, o que resulta em desequilíbrio entre a produção e a eliminação das mesmas[3]. As neoplasias hematológicas, designadamente a leucemia, o mieloma múltiplo, o linfoma de linfoma de Hodgkin e o Linfoma Não-linfoma de Hodgkin, somaram um total de mais de 1,3 milhões de casos, com uma mortalidade respetiva de aproximadamente 700 mil pessoas em todo o mundo[2].

O tratamento para este tipo de neoplasia inclui quimioterapia, imunoterapia, cirurgia, radioterapia e o Transplante de Células Hematopoiéticas (TCTH)[4]. Relativamente ao TCTH, este consiste na infusão de células progenitoras hematopoiéticas, com origem na medula óssea, no sangue periférico ou no sangue do cordão umbilical, em que a recolha das células estaminais é feita por aspiração, diretamente da medula óssea ou por leucaférese, com o intuito de tratar e/ou prolongar a vida da pessoa com doença hematológica[4]. Previamente à infusão das células tronco hematopoiéticas, a pessoa é submetida ao condicionamento, um protocolo de quimioterapia de alta dose, composto pela mielodepressão, que se direciona às células-tronco e a linfodepleção, que atua no sistema linfático do hospedeiro[4].

O TCTH potencia o aparecimento de infeções, alterações gastrointestinais e pulmonares, disfunção renal, hepática ou cardíaca e após o transplante, existe risco de falência do enxerto, de recaída e do surgimento de nova neoplasia[5-6]. A pessoa submetida a transplante de células hematopoiéticas, apresenta risco elevado de adquirir uma infeção em ambiente hospitalar devido a uma imunodeficiência grave, pelo que se encontra em isolamento protetor[7]. Neste sentido, deverá permanecer num quarto individual, com sistema de ventilação com diferencial de pressão positiva e sem contacto com visitas, visto que as infeções podem significar morbilidade e mortalidade significativas[4]. Para a prevenção de infeções endógenas, a higiene oral, os cuidados com a pele e a utilização de antibióticos, como medida profilática, são essenciais. Além destas, o controlo da qualidade do ar, da água, da higiene alimentar e do ambiente são também imprescindíveis[4].

Paralelamente, diversos estudos apontam para o impacto negativo que o isolamento tem na saúde mental e emocional, sendo um fator potenciador de distress, depressão e alterações de humor[7,8]. A pessoa com doença oncológica experimenta diversas mudanças na sua vida, face ao diagnóstico e no decorrer do tratamento, tanto emocional como fisicamente e também ao nível do funcionamento social e familiar[9,10]. O distress foi reconhecido como o sexto sinal vital e deve ser valorizado em todos os estadios da doença, pela importância e impacto significativo que tem no decorrer do percurso da pessoa com doença oncológica[9,10].

Neste contexto, o enfermeiro desempenha um papel fundamental na identificação do fenómeno do distress, na prestação de apoio e no encaminhamento psicossocial, quando necessário[11]. A identificação e gestão do distress, desde cedo, proporciona uma melhor adesão ao tratamento, uma comunicação mais eficaz e ajudam a atenuar sentimentos como raiva, tristeza e medo, o que previne o desenvolvimento de ansiedade e depressão[9], promovendo uma abordagem holística para o bem-estar emocional e social da pessoa com doença oncológica[11].

Considerando a pertinência de rever a evidência acerca do cuidado de enfermagem promotor do alívio do distress da pessoa com doença hematoncológica, realizámos esta Revisão Integrativa da Literatura (RIL), com a finalidade de sintetizar a evidência disponível sobre este fenómeno.

Procedimentos metodológicos

Para a realização do presente trabalho, cumprindo o rigor metodológico, seguimos as cinco etapas definidas por Whittemore & Knafl[13], designadamente: identificação objetiva e clara do problema; pesquisa da literatura em bases de dados, através dos descritores definidos; avaliação dos dados através da organização dos resultados obtidos; análise dos dados, assim como interpretação e discussão dos resultados e, finalmente, apresentação dos dados de forma sintética e objetiva. Em relação à primeira etapa da RIL, o desenvolvimento metodológico, de acordo com este referencial, pressupõe a definição da problemática em estudo e a definição da questão de pesquisa clara e objetiva que deve ser formulada através da união de quatro elementos referentes à mnemónica PICO: população (P), intervenções alvo de estudo (I), comparação (C) e os resultados obtidos[13]. Após identificar o problema e com

base na estratégia de pesquisa PICO, desenvolvemos a seguinte questão de investigação: "Quais são os cuidados de enfermagem, promotores do alívio do distress na pessoa com doença hematoncológica?".

Table 1. Estratégia PICO

P (POPULAÇÃO)	Pessoa adulta hospitalizada com doença hematoncológica, submetida a transplante
I (INTERVENÇÃO ALVO DE ESTUDO)	Cuidado de enfermagem, promotor do alívio do distress
C (COMPARAÇÃO)	Comparação com o cuidado de enfermagem que não tem esse objetivo
O (RESULTADOS OBTIDOS)	Cuidados de enfermagem promotores do alívio do distress

Seguidamente, identificámos, de acordo com os descritores MeSh e Decs, as palavras-chave, designadamente: "nursing care", "emotional distress" e "cancer patient".

Em relação à segunda etapa da RIL, para a pesquisa recorreu-se às bases de dados MEDLINE e CINAHL, através do motor de busca *EBSCOhost* Web e ainda o Google Académico. Esta foi realizada, utilizando descritores "MeSH" e outros termos para expansão da pesquisa. Para a obtenção de resultados, foi utilizado o operador booleano "*OR*" entre termos similares e "*AND*" para a consolidação entre os termos da pesquisa, dando origem à equação booleana final (Tabela 2). Definimos como critérios de inclusão dos artigos: publicações realizadas nos últimos 5 anos, de forma a ter acesso à evidência mais recente, artigos escritos em português e inglês, população adulta e idosa, artigos que se relacionem com a temática e com metodologia adequada. Por outro lado, como critérios de exclusão de artigos, definimos: artigos duplicados; artigos escritos noutra língua que não sejam português e inglês; população pediátrica; grávidas e animais; artigos cujo título e resumo não correspondam à questão de pesquisa e artigos com metodologia não adequada (comentários a artigos, atas de congressos e artigos de opinião).

No que concerne à 3.ª etapa da RIL, um total de 1605 artigos foram considerados das bases de dados MEDLINE e CINAHL e 3 publicações identificadas no Google Académico. Os artigos foram selecionados por dois revisores, de acordo com os critérios de inclusão e exclusão definidos anteriormente, através da plataforma *Rayyan*. Foram excluídos 20 artigos duplicados e 1003 com data anterior a 2019. Sendo elegíveis para leitura do título, 582 artigos. Mediante uma observação mais detalhada do Título e do Resumo, 551 foram excluídos e 31 considerados elegíveis, dos quais 7 foram selecionados para análise. Das publicações identificadas, foram apuradas para leitura 3. Totalizando 10 artigos que foram incluídos (Figura 1) e alvo de discussão e sistematização neste artigo, conforme ilustra a Tabela 3.

A quarta e última etapa da RIL, referente à apresentação dos dados obtidos, será apresentada no capítulo dos resultados e discussão.

Tabela 2. Estratégia de pesquisa *MEDLINE (EBSCOhost) and CINAHL (EBSCOhost)* conduzida entre 5 de abril e 17 de maio de 2024. Lisboa, Portugal.

PESQUISA	DESCRITORES
#1	MH ("Hematopoietic Stem Cells+") OR (MH "Hematologic Neoplasms+") OR (MH "Hematopoietic Stem Cell Transplantation") OR (MH "Cancer Patients") OR (MH "Oncology+") OR "Cancer Patients"
#2	(MH "Psychological Distress+") OR "distress" OR (MH "Psychosocial Intervention")
#3	(MH "Nursing Care+") OR (MH "Nursing Interventions") OR (MH "Oncology Nursing+")
#4	[MH ("Hematopoietic Stem Cells+") OR (MH "Hematologic Neoplasms+") OR (MH "Hematopoietic Stem Cell Transplantation") OR (MH "Cancer Patients") OR (MH "Oncology+") OR "Cancer Patients" AND (MH "Psychological Distress+") OR "distress" OR (MH "Psychosocial Intervention") AND (MH "Nursing Care+") OR (MH "Nursing Interventions") OR (MH "Oncology Nursing+")]

Resultados

Numa fase posterior à identificação e seleção dos artigos, procedeu-se à leitura completa destes e organizou-se os resultados obtidos, de forma sintética e objetiva numa tabela-síntese (Tabela 3), a fim de dar resposta à questão de investigação, designadamente: autor (es)/ano; tipo de estudo; objetivo; população; cuidados de enfermagem promotores do alívio do distress e implicações para a prática.

O processo de pesquisa resultou num total de 7 artigos selecionados nas bases de dados referidas anteriormente e 3 artigos selecionados no *Google Scholar*.

Os artigos incluídos na RIL, foram realizados em 6 países diferentes, nomeadamente Itália (n=1), Estados Unidos da América (n=5), Austrália (n=1), Alemanha (n=1), Turquia (n=1), Brasil (n=1). Quanto às metodologias, predominam os estudos randomizados controlados (n=3) e os estudos quasi-experimentais (n=3), seguindo-se os estudos prospetivos (n=2) e com menor expressividade as revisões da literatura (n=1). Em relação aos contextos de cuidados observados, estes são na sua maioria unidades de internamento e centros de oncologia.

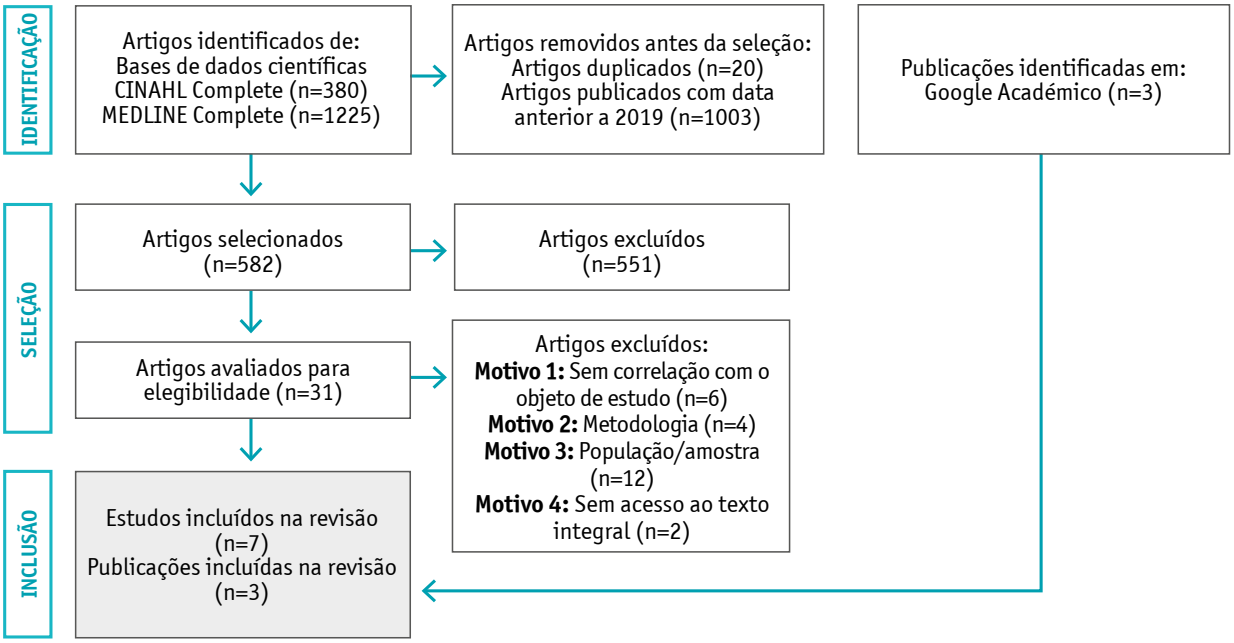

Figura 1. Fluxograma PRISMA do processo de seleção dos artigos

Tabela 3. Tabela-síntese dos artigos obtidos na pesquisa

ESTUDO	AUTORES/ANO	TIPO DE ESTUDO	OBJETIVO	POPULAÇÃO	CUIDADOS DE ENFERMAGEM PROMOTORES DO ALÍVIO DO DISTRESS	IMPLICAÇÕES PARA A PRÁTICA
Estudo 1[13]	Mariana Santos, Filipe Thomaz, Rafael Jomar, Angela Abreu, Gunnar Taets, 2021	Estudo quasi experimental	Avaliar o impacto imediato da música sobre o stress e distress na pessoa com doença oncológica durante o tratamento em ambiente hospitalar	Composta por 26 participantes, com idade igual ou superior a 18 anos	A intervenção consiste na audição de três músicas escolhidas pelo próprio, durante 15 min. A intervenção foi realizada individualmente e apenas uma vez, de forma a avaliar o impacto imediato da mesma. Antes e após a intervenção foi realizada a análise do stress fisiológico, pela avaliação dos níveis de cortisol, e do distress, através do termómetro de distress	A utilização da música permitiu diminuir o stress e o distress na pessoa com doença oncológica
Estudo 2[14]	Barbara J. Henry, 2022	Revisão da Literatura	Descrever estratégias de alívio dos sintomas de depressão e ansiedade e consequentemente do distress emocional	Pessoa com doença oncológica e ansiedade e/ou depressão associada	Descritas estratégias farmacológicas e não farmacológicas para o alívio da sintomatologia da ansiedade e depressão associadas à doença oncológica	É necessário e importante avaliar a sintomatologia e consequentemente o encaminhamento para recursos adequados e profissionais especializados quando necessário. O enfermeiro deve ser capaz de gerenciar suas próprias emoções e evitar o esgotamento, utilizando técnicas de autocuidado como psicoterapia, terapia de pares e métodos de apoio e relaxamento

ESTUDO	AUTORES/ANO	TIPO DE ESTUDO	OBJETIVO	POPULAÇÃO	CUIDADOS DE ENFERMAGEM PROMOTORES DO ALÍVIO DO DISTRESS	IMPLICAÇÕES PARA A PRÁTICA
Estudo 3[15]	Gizem İlayda Geyik, Sibel Doğan, Hanefi Ozbek, Ali Timucin Atayoglu, 2021	Estudo quasi experimental	Explorar os efeitos da musicoterapia nos parâmetros físicos e mentais da pessoa com doença oncológica durante o TCTH	Composto por 30 pessoas internadas numa unidade de TCTH no mínimo há 7 dias	Musicoterapia durante 30 min, selecionada por especialistas em musicoterapia e composta por peças instrumentais que concordavam com o "Shahnaz Maqam", durante o transplante de medula óssea	A musicoterapia pode ter efeitos positivos como a diminuição do distress e dos níveis de ansiedade das pessoas com cancro durante o TCTH, de uma forma fácil, económica e segura e pode ser integrada no processo de tratamento da pessoa
Estudo 4[16]	Marco Cioce, Franziska Michaela Lohmeyer, Rossana Moroni, Marinella Magini,Alessandra Giraldi,Paola Garau, Maria Carola Gifuni, Vezio Savoia, Danilo Celli, Stefano Botti, Gianpaolo Gargiulo,Francesca Bonifazi, Fabio Ciceri, Ivana Serra, Maurizio Zega, Simona Sica,Andrea Bacigalupo,Valerio De Stefano and Umberto Moscato, 2020	Estudo controlado randomizado	Comparar a educação padrão com a educação terapêutica, na qualidade de vida, no distress e no conhecimento da pessoa submetida a TCTH	36 pessoas, com idade igual ou superior a 18 anos, submetidas a TCTH num hospital em Itália	Realização de uma entrevista educativa de 60 min, na semana anterior à admissão em que são abordados efeitos secundários, riscos, complicações e comportamentos preventivos. São também explanados os problemas psicológicos mais frequentes na área onco-hematológica e dadas instruções a nível nutricional	A educação terapêutica permite à pessoa uma compreensão abrangente e adequada do processo vivenciado ao longo do TCTH fazendo com que o estado de ansiedade e depressão não necessitem de intervenções psicoterapêuticas e psiquiátricas especializadas
Estudo 5[17]	Wonsun Sunny Kim, Shelby Langer, Michael Todd, Linda Larkey, Soojung Jo, Lauren R Bangerter, Nandita Khera, 2022	Estudo quasi-experimental	Investigar o êxito de utilizar a narração de histórias digitais como intervenção para combater o distress e aumentar o apoio social na pessoa submetida a TCTH	40 pessoas submetida a TCTH, com idade média de 59.2 anos	**Grupo de intervenção:** Assistir a narrativas digitais, contadas na primeira pessoa por alguém que tenha vivenciado uma situação semelhante, cada uma com 3-4 minutos durante 15 minutos **Grupo de controlo:** Visualizar vídeos informativos de 3/4 minutos durante 15 minutos, que abordam sintomas, gestão da dor, controlo de infeções e o plano de exercício físico e de nutrição	A visualização de histórias digitais sobre vivências e desafios emocionais contados na primeira pessoa, pode combater o distress e melhorar a perceção de apoio social na pessoa submetida a TCTH
Estudo 6[18]	Richard J. Lawrence, Stuart J. Lee, Lynda J. Katona, Sue De Bono, Peter J. Norton, Sharon Avery, 2022	Estudo controlado randomizado	Verificar a utilidade de uma intervenção do manual de autoajuda durante a fase aguda do TCTH	40 candidatos a TCTH designados aleatoriamente para uma intervenção do manual de autoajuda ou para tratamento habitual	O manual foi integrado numa sessão de introdução de 60 minutos para familiarizar a pessoa com o conteúdo. Efetuada uma sessão de reforço de 30 minutos, 2-3 semanas após o transplante, para incentivar o envolvimento com o material	Fornece evidências preliminares dos benefícios de um manual de autoajuda durante a hospitalização para um TCTH

ESTUDO	AUTORES/ANO	TIPO DE ESTUDO	OBJETIVO	POPULAÇÃO	CUIDADOS DE ENFERMAGEM PROMOTORES DO ALÍVIO DO DISTRESS	IMPLICAÇÕES PARA A PRÁTICA
Estudo 7[19]	Friedrich Balck, Anja Zschieschan, Anja Zimmermann, Rainer Ordemann, 2019	Estudo controlado randomizado	Investigar o efeito do treino de resolução de problemas, no distress psicológico, no coping, na dor, no distress global e no comportamento de resolução de problemas em pessoas submetidas a TCTH	Composta por 45 pessoas no grupo de intervenção e 46 no grupo de controlo	A intervenção foi realizada durante a fase de aplasia medular e incluiu cinco sessões individuais de 1 hora. A primeira sessão teve início 2 dias antes do transplante	A ansiedade, o distress psicológico, a dor e o stress geral foram reduzidos após o treino de resolução de problemas no grupo de intervenção em comparação com os do grupo de controlo. O coping ativo foi reforçado, a resolução de problemas e a capacidade de lidar com os problemas das pessoas demonstrou melhoria, não se registaram alterações na depressão e no apoio social
Estudo 8[20]	Maggie C. Compernolle, Jennifer A. Sledge, 2020	Estudo prospetivo	Analisar os efeitos de uma intervenção mente-corpo no distress psicológico das pessoas hospitalizadas com doenças malignas hematológicas e dos seus cuidadores	Composto por 34 participantes, 29 pessoas com doença hematológica maligna e 5 cuidadores internados na unidade de transplante de medula óssea	A intervenção é realizada pela enfermeira oncológica e pela professora da ioga, com duração de 20min. Inicialmente os participantes procuram uma posição confortável e são solicitados a fecharem os olhos. Posteriormente, concentram-se numa respiração abdominal profunda, proporcionando um momento direcionado para a consciencialização das sensações presentes, sem julgamentos	Os enfermeiros podem ajudar a aliviar os sintomas de distress em pessoas com neoplasias hematológicas, integrando no plano de cuidados a educação sobre como realizar atividades simples e curtas de mindfulness
Estudo 9[21]	Gabriel Lopez, Alejandro Chaoul, Carla L Warneke, Aimee J Christie, Catherine Powers-James, Wenli Liu, Santhosshi Narayanan, Marvin Delgado-Guay, Yisheng Li, Eduardo Bruera, Lorenzo Cohen, 2023	Estudo piloto	Determinar a viabilidade de intervir através da meditação em sintomas como ansiedade e depressão e examinar a associação entre a frequência e a duração da prática e os resultados auto-relatados pelas pessoas	Composta por 35 participantes, 17 no grupo de meditação e 18 no grupo de controlo, a sua maioria do sexo feminino (94%) com neoplasia da mama (60%) pertencentes ao MD Anderson's Integrative Medicine Center clinical services	Sessões de meditação de 5, 10 ou 15 minutos através de um aplicativo móvel, pelo menos uma vez por dia, durante duas semanas	A utilização de um aplicativo móvel de meditação permite melhorias em vários sintomas de distress
Estudo 10[22]	Colleen Vega, Robin L Whitney, Josef Hannah, Grant Smith, 2022	Estudo quasi experimental	Avaliar a utilidade da realidade virtual (RV) nos sintomas de distress experienciados pela pessoa submetida a transplante alogénico de células tronco hematopoiéticas	20 participantes com idade entre os 19 e os 70 anos, hospitalizados num centro académico	Realizar sessão de RV sobre temas como viagens, meditação, jogos, entretenimento e desporto, durante 20 minutos, duas vezes por semana, ao longo de duas semanas, com recurso a óculos destinados para tal	A RV pode proporcionar uma intervenção de baixo custo para melhorar os sintomas de distress

Discussão

Após a revisão da literatura, emergiram distintamente dois tipos distintos de cuidados, designadamente os cuidados farmacológicos e não farmacológicos promotores do alívio do distress. Relativamente aos cuidados não farmacológicos, emergiram cinco dimensões, nomeadamente a musicoterapia, a promoção da literacia, as novas tecnologias, as terapias complementares e a partilha de experiências.

Cuidados farmacológicos no alívio do distress

No que concerne aos cuidados farmacológicos para o alívio do distress, segundo Henry[14], a maioria dos sintomas listados para avaliar o distress, nas ferramentas *Distress Thermometer* e *Problem List*, correspondem a sintomas de depressão e ansiedade, tais como medo, nervosismo, tristeza, preocupação e perda de interesse pelas atividades habituais. Desta forma, a terapêutica de recurso no alívio dos distress coincide com a terapêutica utilizada no tratamento da ansiedade e depressão. O início da terapêutica é justificado quando a sintomatologia depressiva ou ansiosa está presente diariamente por duas semanas ou mais, sendo iniciada numa dose reduzida e progredindo consoante necessidade. Frequentemente os fármacos são prescritos por 6 meses ou mais, ou até melhoria dos sintomas, no entanto podem ser administrados durante a vida toda[14].

Cuidados não farmacológicos no alívio do distress

Musicoterapia

A evidência postula a importância de olhar além dos sintomas de distress físico, dando a devida importância ao distress emocional, que deve ser identificado e colmatado. A musicoterapia, uma forma leve de cuidado, é um método não invasivo que constitui uma estratégia não farmacológica no alívio do distress da pessoa com doença oncológica, na medida em que surge como uma alternativa capaz, do ponto de vista psicológico, de gerar emoções positivas e diminuir emoções negativas[13,15].

A música permite à pessoa transportar-se para um outro universo, fora do ambiente hospitalar, em que se imagina sem dor, saudável e livre do ambiente hostil, de sofrimento e de privação em que se encontra[13]. A música utiliza atributos próprios da relação humana, essenciais para a construção de vínculo no espaço do cuidado hospitalar[13], de especial importância na pessoa em situação de isolamento protetor. Com base na evidência, emerge uma relação positiva entre a ansiedade e o distress após sessões de musicoterapia, postulando a viabilidade da mesma como parte integrante do processo de tratamento[13,15].

Do ponto de vista fisiológico, é responsável pela redução significativa de cortisol salivar, um biomarcador dos níveis de stress[13], é eficaz na redução da frequência cardíaca, da frequência respiratória e dos valores de tensão arterial diastólica. Observa-se também o aumento dos níveis de saturação de oxigénio e a libertação de endorfinas, potenciadas pela música[15].

Promoção da literacia

A intervenção de promoção da literacia, previamente ao transplante, deve incidir em temas como os efeitos adversos, os riscos, as complicações, os comportamentos preventivos e o controlo de infeção[16,17]. A existência de informação proporciona uma sensação de controlo, aumenta a auto-eficácia para a recuperação[17] e reduz a incerteza, impactando, de forma positiva, na condição psicológica da pessoa submetida a TCTH. Desta forma, o processo é vivenciado com menor nível de medo, preocupação e desmoralização[16]. Além disso, de acordo com a evidência, a literacia proporciona uma redução significativa nos domínios ansiedade e depressão e melhora os níveis de distress e qualidade de vida[14,16-18]. No estudo de Lawrence et al.[18] observa-se, pela verbalização dos participantes, que o acréscimo de conhecimento tornou possível aumentar a confiança para lidar com o TCTH, permitiu depreender o impacto que o transplante poderá ter sobre si próprio e ajudar a sentir-se melhor emocionalmente.

Terapias complementares

A pessoa que experiencia emoções e sintomas negativos durante o TCTH tem, com base na evidência, na Meditação e na Terapia de Resolução de Problemas, meios para compreender a natureza dos problemas e direcionar os seus esforços para alterar, não só a natureza, como a sua reação aos mesmos. As terapias enunciadas potenciam o reconhecimento e a atenção propositada às sensações ou sintomas, permitindo compreender de forma mais abrangente a sua experiência[14,19-21]. Assim, o enfermeiro é capaz de prestar cuidados mais individualizados para reverter os sintomas e efeitos secundários do tratamento[20].

A evidência demonstra que as pessoas com menor capacidade de resolução de problemas e falta de controlo apresentam níveis mais elevados de sintomas depressivos e ansiedade, desta forma o treino da mente pode influenciar a perceção dos sintomas de distress, a forma de lidar com os mesmos e alterar indiretamente o estado mental[19].

A meditação e o treino de resolução de problemas, conduzem a uma melhoria clinicamente significativa na diminuição do distress[20]. Também o coping ativo é reforçado, a pessoa é capaz de reduzir a orientação negativa para o problema e melhorar a resolução do mesmo[19-21].

Novas tecnologias

A realidade virtual (RV) foi identificada pela evidência como uma distração cognitiva, que visa múltiplas modalidades sensoriais com recurso a cenários gerados com os quais a pessoa pode interagir. Os efeitos lúdicos e imersivos da RV oferecem uma distração agradável que permite orientar a atenção da pessoa e bloquear estímulos, como a dor ou ansiedade, o que permite melhorar os sintomas de distress na pessoa hospitalizada[22]. Segundo a literatura analisada, a RV é responsável por melhorias significativas em sintomas associados ao distress como a dor, depressão, fadiga, ansiedade, apetite, qualidade de vida, bem estar e sonolência[22].

Conforme enunciado por Kim et al.[17], a situação de isolamento hospitalar e a instabilidade somática dos doentes submetidos a TCTH, constituem um desafio pela dificuldade de coordenação com intervenções que envolvam a presença física de profissionais. O formato digital utilizado demonstra ser uma alternativa viável, uma intervenção baseada na tecnologia é um veículo de apoio psicossocial fácil de fornecer, flexível, de baixo custo e não invasivo[22].

Partilha de experiências

Segundo Kim et al.[17], a partilha de experiências permite melhorar a compreensão e o envolvimento no processo de saúde-doença, na medida em que facilita à pessoa compreender a sua experiência e definir estratégias de coping.

O isolamento exigido pelo TCTH implica que a pessoa receba pouco apoio social para além do prestado pelos profissionais de saúde. A grande vantagem da visualização de histórias digitais pela voz de pessoas que passaram por processos similares é proporcionar um efeito semelhante ao proporcionado pelas relações sociais reais e aumentar a perceção de apoio social, visto que a pessoa se identifica com o narrador, com o contexto e se envolve na história[17].

Assistir à partilha da experiência de uma pessoa com um percurso semelhante, pode estimular a melhoria da saúde emocional e psicológica, traduzindo-se na diminuição da depressão e ansiedade, com eficácia na redução do distress[17].

Conclusão

Os achados da atual revisão da literatura corroboram a importante contribuição do enfermeiro no alívio do distress da pessoa com doença oncológica em isolamento protetor. As intervenções não farmacológicas, como a musicoterapia, o uso de novas tecnologias e a partilha de experiências, mostraram-se promotoras no alívio do distress, complementando as abordagens tradicionais. Além disso, o estudo evidencia a importância de desenvolver estratégias de cuidados centrados na pessoa, integrando abordagens tecnológicas e terapias complementares para melhorar a qualidade de vida da pessoa com doença hematoncológica.

Seria importante investigar mais aprofundadamente o impacto de novas tecnologias no alívio do distress da pessoa com doença hematoncológica em isolamento protetor. Estudos longitudinais poderiam avaliar a efetividade dessas intervenções ao longo do tratamento, oferecendo insights sobre seu impacto na recuperação emocional e social das pessoas com doença hematoncológica.

Este estudo apresenta algumas limitações que devem ser consideradas. A inclusão de artigos foi restrita a publicações em português e inglês, o que pode ter excluído evidências relevantes em outros idiomas. A heterogeneidade metodológica dos estudos selecionados também pode influenciar a comparação dos achados. Por fim, a maioria dos estudos analisados avaliou apenas efeitos de curto prazo, sendo necessário aprofundar investigações sobre o impacto a longo prazo das intervenções de enfermagem no alívio do distress.

Referências Bibliográficas

1. World Health Organization. Cancer [Internet]. 2022 [cited 2024 Nov 6]. Available from: https://www.who.int/news-room/fact-sheets/detail/cancer
2. Ferlay J, Ervik M, Lam F, Laversanne M, Colombet M, Mery L, et al. Global Cancer Observatory: Cancer Today [Internet]. 2024 [cited 2024 Nov 6]. Available from: https://gco.iarc.who.int/today
3. Fernandes A. Mestrado em Enfermagem na Área de Especialização em Enfermagem Médico-Cirúrgica, na Área de Intervenção em Enfermagem Oncológica Relatório de Estágio - O conforto da pessoa com doença hemato-oncológica: Intervenções de Enfermagem. 2020.
4. Carreras E, Dufour C, Mohty M, Kröger N. Hematopoietic Stem Cell Transplantation and Cellular Therapies: The EBMT Handbook. 2020.
5. Instituto Português de Oncologia de Lisboa. ALOTRANSPLANTE. 2021.
6. Instituto Português de Oncologia de Lisboa. AUTOTRANSPLANTE. 2021.
7. Letrecher S. The impact of protective isolation in a hematology unit on staff, patients, and their families. Int J Appl Psychoanal Stud. 2023;21(1). doi:10.1002/aps.1812.
8. Basilio L, Miguel I, López H, Pacheco Z, Susana A-R. Distrés psicológico, ansiedad y depresión en pacientes ingresados en aislamiento hospitalario [Internet]. 2022 [cited 2024 Nov 6]. doi:10.35667/Metas.
9. Perdigão MM de M, Rodrigues AB, Carvalho REFL de, Oliveira SKP de, Anjos SJ dos, Almeida PC de. Distress em Pacientes Oncológicos no

Brasil: Revisão Integrativa da Literatura. Rev Bras Cancerol. 2022;68(3). doi:10.32635/2176-9745.rbc.2022v68n3.2402.

10. Okuma GY, Manhães MFM, Pedras RN, Azevedo IM, De Domenico EBL, Bergerot CD. Espiritualidade, Religiosidade, Distress e Qualidade de Vida em Pacientes Oncológicos. Rev Psicol Saúde. 2021;13(2):3–17. doi:10.20435/pssa.v13i2.1097.
11. Granek L, Nakash O, Ariad S, Shapira S, Ben-David M. Mental health distress: Oncology nurses' strategies and barriers in identifying distress in patients with cancer. Clin J Oncol Nurs. 2019;23(1):43–51. doi:10.1188/19.CJON.43-51.
12. Whittemore R, Knafl K. The integrative review: Updated methodology. J Adv Nurs. 2005;52(5):546–53. doi:10.1111/j.1365-2648.2005.03621.x.
13. Santos MS, Thomaz FM de, Jomar RT, Abreu AMM, Taets GG de CC. Music in the relief of stress and distress in cancer patients. Rev Bras Enferm. 2021;74(2). doi:10.1590/0034-7167-2019-0838.
14. Henry BJ. Symptom Management in Oncology: Depression and Anxiety. Semin Oncol Nurs. 2022;38(1). doi:10.1016/j.soncn.2022.151251.
15. Geyik Gİ, Doğan S, Ozbek H, Atayoglu AT. The effect of music therapy on the physical and mental parameters of cancer patients during hematopoietic stem cell transplantation. Perspect Psychiatr Care. 2021;57(2):558–64. doi:10.1111/ppc.12578.
16. Cioce M, Lohmeyer FM, Moroni R, Magini M, Giraldi A, Garau P, et al. Impact of educational interventions on psychological distress during allogeneic hematopoietic stem cell transplantation: A randomised study. Mediterr J Hematol Infect Dis. 2020;12(1). doi:10.4084/MJHID.2020.067.
17. Kim W, Langer S, Todd M, Larkey L, Jo S, Bangerter LR, et al. Feasibility of a Digital Storytelling Intervention for Hematopoietic Cell Transplant Patients. J Cancer Educ. 2022;37(5):1275–85. doi:10.1007/s13187-020-01948-2.
18. Lawrence RJ, Lee SJ, Katona LJ, De Bono S, Norton PJ, Avery S. A Self-Help Manual for Psychological Distress and Quality of Life During a Haemopoietic Stem-Cell Transplant: An Effectiveness and Acceptability Pilot. J Clin Psychol Med Settings. 2023;30(4):846–55. doi:10.1007/s10880-022-09923-3.
19. Balck F, Zschieschang A, Zimmermann A, Ordemann R. A randomized controlled trial of problem-solving training (PST) for hematopoietic stem cell transplant (HSCT) patients: Effects on anxiety, depression, distress, coping and pain. J Psychosoc Oncol. 2019;37(5):541–56. doi:10.1080/07347332.2019.1624673.
20. Compernolle MC, Sledge JA. Effects of a Mindfulness Intervention on Hospitalized Patients With Hematologic Malignancies and Their Caregivers. Oncol Nurs Forum. 2020;47(1):70–8. doi:10.1188/20.ONF.70-78.
21. Lopez G, Chaoul A, Warneke CL, Christie AJ, Powers-James C, Liu W, et al. Self-administered Meditation Application Intervention for Cancer Patients With Psychosocial Distress: A Pilot Study. Integr Cancer Ther. 2023;22. doi:10.1177/15347354221148710.
22. Vega C, Whitney RL, Hannah J, Smith GM. Virtual Reality for Symptom Management in Patients Undergoing Hematopoietic Stem Cell Transplantation: A Quality Improvement Initiative. Oncol Nurs Forum. 2022;49(3):233–41. doi:10.1188/22.onf.233-241.

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Conflito de Interesses

Os autores declaram não haver conflitos de interesse.

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BENEFITS OF PATIENT AND PUBLIC INVOLVEMENT IN CANCER RESEARCH: LITERATURE REVIEW

Benefícios do envolvimento dos doentes e do público na investigação do cancro: Revisão da literatura

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ABSTRACT

Currently, cancer research allows for earlier diagnosis and more effective treatments. The complexity and socio-economic impact of the disease require innovative approaches such as patient and public involvement in research.

The aim of this review is to identify the benefits of patients and public involvement in cancer research.

The scale for non-systematic reviews, Scale for the Assessment of Narrative Review Articles (SANRA), was followed.

There are individual, ongoing research, ethical and social benefits from this holistic approach that meets the expectations and demands of people and those involved in providing healthcare to people with cancer. Ensuring that the needs, perspectives and concerns of these people are taken into account leads results that promote transparency and trust for the scientific community and clinical practice.

In conclusion, patient and public involvement in cancer research contributes to improving the quality of research.

KEYWORDS: Cancer; Narrative review; Patient and public involvement; Research.

RESUMO

Atualmente a investigação no cancro permite diagnósticos mais precoces e tratamentos mais eficazes. A complexidade e impacto socioeconómico da doença exigem abordagens inovadoras como a participação dos doentes e do público na investigação.

O objetivo desta revisão é identificar os benefícios do envolvimento dos doentes e do público na investigação do cancro.

Foi utilizada a escala para revisões não sistemáticas, Scale for the Assessment of Narrative Review Articles (SANRA).

Destacam-se benefícios individuais, no contínuo da investigação, éticos e sociais decorrentes desta abordagem holística que atende às expectativas e exigências das pessoas e dos envolvidos na prestação de cuidados de saúde à pessoa com doença oncológica. Garantir que as necessidades, perspetivas e preocupações destas pessoas sejam consideradas permite resultados promotores de transparência e confiança para a comunidade científica e na prática clínica.

Em suma, o envolvimento dos doentes e público na investigação do cancro contribui para melhorar a qualidade da investigação.

PALAVRAS-CHAVE: Cancro; Revisão narrativa; Envolvimento dos doentes e do público; Investigação.

Introduction

According to the latest World Cancer Report, an estimated 20 million new cases of cancer and 9.7 million deaths from cancer are projected for 2022. Approximately one in five men or women will develop cancer in their lifetime, while one in nine men and one in twelve women are expected to die from the disease[1].

Cancer is a problem with a major social, public health and economic impact, accounting for approximately one in six deaths (16.8%) worldwide, causing three in ten premature deaths among adults aged 30-69 years and ranks as one of the three leading causes of death in this age group in 177 of the 183 countries surveyed[1].

In Portugal, as in Europe, oncological diseases are the main cause of premature death and years of healthy life lost. These diseases hinder increases in life expectancy and are associated with significant social and macroeconomic costs[1,2].

Open science is a comprehensive approach to scientific research that promotes transparency, accessibility, and collaboration across all disciplines. It aims to make scientific knowledge and the production process available to everyone, benefiting both the scientific community and society at large. This approach emphasises not only the accessibility of scientific findings but, also, ensures the creation of knowledge is inclusive, equitable, and sustainable[3].

In recent decades, the open science movement has been a significant driver of the utilisation of patients and public involvement (PPI) in health research[4]. The success of this involvement is contingent upon the processes of involvement in service users, researchers, and the communities involved in health research. It is thus imperative to optimise this involvement and the context in which it is developed in order to derive the greatest benefit from this resource in the context of research[5].

Since the 1950s, health care users in the United Kingdom (UK) have actively campaigned for their perspectives to be included in health care decisions. These efforts challenged conventional assumptions and provided the ways for advocacy, political lobbying, the provision of alternative forms of services and care, and user-led research and training. This movement was catalysed by the high-profile medical scandals of the time[6].

In the 1970s and 1980s, emancipatory approaches to user-led research emerged, countering to the traditional medical model of knowledge. However, there was an inherent resistance to recognising lay knowledge in biomedical research[6,7].

By the 1990s, the acceptance of patients and public involvement in research began to increase. In 1996, the UK established the INVOLVE[6,7] group, which emphasised flexibility, funding, shared values, and the political philosophy in advancing this area. Legislation on PPI in health research has, subsequently, been consolidated and integrated into research funding streams, requiring researchers to demonstrate how such involvement has influenced proposals and will continue throughout the study [6,7].

The United States, through the National Cancer Institute, has also actively promoted PPI in cancer research through countless initiatives such as the Cancer Moonshot, which aims to catalyse scientific discovery about cancer, increase collaboration and improve data sharing[8]. Portugal has also joined to the 'Europe: United Against Cancer' initiative 2020[9], aiming to improve cancer research and implement PPI. A recent study concluded that the majority of national organisations show strong interest in involving across all phases of oncology research to ensure that results meet the patient's real needs. However, this involvement should be greater and more meaningful in practice[9]. To address economic and social inequalities in European cancer care, innovative research themes are crucial. These included person-centred care, big data, mobile digital technology and molecular and genetic profiling, which facilitate collaboration between patients and research centres throughout the oncological care pathway, from prevention to diagnosis, treatment and care[10]. The European Cancer Patients' Coalition emphasises placing patients' needs at the core of cancer policy, care and research. Collaborating with European Commission and other collaborators, the coalition promotes cancer health policies, emphasising the significance of patients' involvement in innovation and education[11]. In 2020, the European Standard EN 17398:202 was published as reference framework for the implementation and development of patient involvement in healthcare[10]. Close collaboration among researchers, healthcare professionals, patients and the public can bring significant benefits for all stakeholders involved. In this sense, it is essential to encourage and value the active participation of the public and patients at all stages of oncology research[12,13].

PPI in research is typically divided into four phases: 1) setting research priorities; 2) research design and planning; 3) research conduct and operation; 4) dissemination, communication and post approval activities. There are 16 opportunities for involvement associated

with these phases: communication of results, regulatory aspects, health technology assessment, study report, information to participants, information and safety committee, study steering committee, meeting with researchers, ethical review, informed consent, patient information documents, funding, practical considerations, research protocol design, research protocol synopsis, identification of patient needs[14]. In turn, Roquette et al.[9] organised opportunities to get involved according to the stages of cancer research, as shown in Table 1.

Given the growing recognition of the importance of incorporating patient perspectives into healthcare, as also has emerged as a vital component of cancer research, a robust level of evidence of this involvement supporting this involvement is therefore required. Therefore, this narrative review aims to identify the benefits of PPI in cancer research.

Methodology

In developing this article, the SANRA[15] scale was used to contribute to improving the standard of this non-systematic review. A narrative review was employed to identify the benefits of involving the patients and public in cancer research. These benefits include improvements in health outcomes for users, from prevention and diagnosis to treatment of cancer, as well as improvements in the methodological quality and dissemination of cancer research results.

Narrative literature reviews are a common feature of health research, accounting for the largest share of text types in medicine[15]. Despite the absence of the rigour characteristic of randomised studies, literature reviews in their development or assessment of methodological quality, their impact on clinical practice and research is notable. Recent studies indicate that these reviews are employed to address research questions that encompass broader or more comprehensive themes[15–17].

This narrative literature review was conducted with the objective of providing an answer to the research question: 'What are the benefits of patients and public involvement in cancer research?'

In order to guarantee a comprehensive search, primary and secondary studies, encompassing both qualitative and quantitative research, were included as criteria for inclusion, as well as other types of literature, without restriction as to time or language.

A literature search was conducted on MEDLINE (via PubMed) between April and June 2024 with the objective of identifying published studies that address the aforementioned research question.

The text words contained in the titles and abstracts of relevant articles and the index terms used to describe the articles were employed in the development of the search strategy for MEDLINE (Table 2). Manual retrieve of all the studies selected for critical appraisal were subjected to further analysis to identify any addi-

Table 1. Phases of research & opportunities for patients and public involvement in cancer research

PHASES OF RESEARCH	OPPORTUNITIES FOR PATIENT AND PUBLIC INVOLVEMENT IN CANCER RESEARCH
Research priorities	Identification of patients' needs
Research design and planning	Study's synopsis design Protocol design Practical considerations Fundraising Patient information leaflet about the project Informed consent Ethical review
Conducting research and operations	Project monitoring investigator meetings Trial Steering Committee Data and Safety Monitoring Committee Information to participants Study reporting
Dissemination, communication and post-approval	Health Technology Assessment Regulatory affairs Post-study communication

Adapted from Roquette et al., 2024

tional studies. The review included studies published in all languages from the date of publication to the present, and which included participants of all ages.

Table 2. Search strategy developed in MEDLINE (via Pubmed).

PESQUISA	ESTRATÉGIA DE PESQUISA	RESULTADOS
#1	((((((((((("patient engagement"[Title/Abstract]) OR ("patient involvement"[Title/Abstract])) OR ("patient participation"[Title/Abstract])) OR ("public and patient involvement"[Title/Abstract])) OR ("public engagement"[Title/Abstract])) OR ("citizen participation"[Title/Abstract])) OR ("citizen science"[Title/Abstract])) OR ("patient public involvement"[Title/Abstract])) OR ("public involvement"[Title/Abstract])) OR ("co-research"[Title/Abstract])) OR ("research participation"[Title/Abstract])) OR ("Patient Participation"[MeSH Terms])) OR ("Citizen Science"[MeSH Terms])	46,909
#2	((("Cancer research"[Title/Abstract]) OR ("Oncology research"[Title/Abstract])) OR ("Cancer investigation"[Title/Abstract])) OR ("Oncology investigation"[Title/Abstract])	23,005
#3	#1 AND #2	250

Following the completion of the search, all identified citations were collated and uploaded to Mendeley Reference Manager v.2.117.0. Duplicate articles were excluded, and all others were screened based on their title and abstract to determine their suitability for inclusion in this analysis.

The titles and abstracts were screened by an independent reviewer for compliance with the established inclusion criteria. The pertinent studies were retrieved in their entirety, and the complete screen selection was subjected to a thorough examination by the independent reviewer to ascertain their compliance with the established inclusion criteria. The SANRA-Scale for the Assessment of Narrative Review Articles[15] was attended to contribute to improve the standard of this non-systematic review article.

The theoretical and practical relevance of this research lies in its potential contribution to the development of person-centred care and participatory research.

The methodology employed is appropriate for addressing the research question developed, as it permits comprehensive exploration of the subject matter and facilitates the organisation of existing evidence on this topic, which remains relatively unexplored.

Results

In accordance with the established inclusion criteria, a total of 16 studies published between 2012 e 2024, were included. Most of the included articles were primary[9,18–20] and secondary[5,12,13,21–24] studies. However, other type of literature[7,14,25–27] were also included. The majority of these studies were conducted in European countries[5,7,9,12,14,18–23,25,26], specifically Denmark[12], Portugal[9], and the United Kingdom[5,7,18,19,22,23,25,26]. However, studies were also conducted in Australia[13], Canada[24], and the United Arab Emirates[27].

Development

When linked to cancer research, close collaboration between researchers, patient organisations, healthcare professionals, patients and the general public has the potential to yield substantial benefits for all parties involved. It is therefore vital to foster, recognise and facilitate the active involvement of the public and patients at all stages of oncology research[12,19,27].

This review identified four main benefits of public and patient involvement in cancer research: individual benefits, benefits to the research continuum, ethical benefits and societal benefits.

Individual benefits for participants

A number of individual advantages are listed for the involvement of the PPI in research such as improvements in self-confidence and self-esteem, greater health literacy, particularly with regard to one's own illness and to research, development of personal skills, intellectual stimulation, feelings of hope, appreciation, validation, altruism, and personal satisfaction resulting from the experience, integration into support networks, and rewards of various kinds, such as comfort or economic rewards[18,22].

The motivation and determination of the researchers, who were inspired by the resilience, innovation and tenacity of the volunteer research participants[22].

Collaborative work offers advantages for the public, patients and researchers alike[19]. These include increased knowledge about the conditions of participation, interventions to be developed and the amplification of research perspectives; reduction of atria or imbalances between participants and researchers; establishment of reciprocal relationships of respect between research participants and the obtaining of more meaningful perceptions due to the proximity between research participants[19,22].

Benefits for the research continuum

Involving the patients and public at various stages of cancer research offers distinct advantages.

Defining and setting priorities

The necessity of defining and prioritising at the outset of research is now well established. Involvement facilitates the identification of pertinent research areas by incorporating the perspectives of patients and researchers in the topic selection process, enabling the identification of relevant knowledge gaps, assisting in the resolution of practical issues, and delineating emerging research trends[13,20,22].

Research design and planning

In the research design and planning phase, the benefit of this collaboration is evident in the optimisation of the study design; in the definition of research questions that are pertinent to patients and focused on their needs, which would otherwise not have been foreseen; in the design of the research objectives; in the development of different interventions throughout the study and in the advancement of the discourse about the most appropriate methodology, thereby promoting a more comprehensive and inclusive approach[9,12,13,22,23].

Conducting the investigation and operations

In terms of the methodology employed and the procedures undertaken, there were clear benefits to be gained from the assessment of the suitability and development of data collection instruments; the amendment of the wording of these instruments through the identification of poorly worded questions in preliminary questionnaires; the adaptation and enhancement of the sensitivity of research language in information leaflets developed for patients to plan language; the invitation extended to people to participate in the study; the selection of an optimal time to deploy the data collection instruments in the community; the increase in the level of recruitment to the studies; and the improvement of retention rates[12,14,20,23]. The involvement of the patients and public in the analysis and writing up of research results has a beneficial impact on the quality of research reports, ensuring that they are based on user experiences and reach their full potential[5,20,22]. Ellis et al.[24] review revealed a plethora of terms used to describe the involvement of patient and public authors in research. However, only 11%[24] of studies identified them as members of a panel or advisory board. Additionally, just 27%[24] of reviews provided detailed descriptions of the roles of co-author partners, and there was often a paucity of information regarding the specific contributions of co-authors to the review process[24]. Furthermore, the authors indicate that only 14% of the articles in question made any mention of the involvement of the public and patients as authors in the abstract. This was typically only indicated in the affiliation of authors, the methodology, or the contributions section.

Dissemination, communication and post-approval

Finally, in the dissemination and outreach phase of cancer research, this approach facilitates the interpretation, sharing and appropriateness of results through the important relationships and influence of participants in the community. Promoting researchers' access to participants helps to improve recruitment, response and retention rates, improves the quality of the data obtained, allows for the inclusion of groups rarely included in research, and optimises the dissemination of study results by ensuring relevant education and information that can help to reduce health inequalities[7,12,14,23,26].

The positive contributions of PPI are cross-cutting and can be seen throughout the cancer research process, namely in improving study design, better prioritisation of research, the quality of materials provided to patients, the development of research questions that are relevant and meaningful to patients, the appropriateness of methodology, the development of data collection tools, the analysis of data and research results. Other positive aspects include securing and improving the recruitment strategy and increasing response rates, disseminating research results more widely and, finally, making studies more robust by ensuring that research and its results meet the real needs of patients rather than the perceptions of professionals[12–14,18].

Ethical benefits

The evidence outlines the ethical advantages of public and patient involvement in enhancing the relevance, utility, and benefit of clinical research for patients. This is achieved by ensuring that research and its outcomes align with patients' unmet needs, by assisting in defining what is deemed acceptable to participants, particularly on sensitive or contentious issues, and by facilitating improvements. The informed consent document provides clarification regarding the nature of the study and the potential risks involved. It also optimises the experience of participating in research by adapting amenities and

respecting participants' time and needs. Finally, it improves the dissemination and sharing of research developments and results between researchers and the public and patients[20,25].

Social benefits

The social benefits of this collaboration can be enumerated as follows: the development of research designs that include aspects that, without the consultation and participation of volunteers, would not be considered by researchers; improved policies and access to research funding; positive social influence in reducing the stigma of minority communities; inclusion of populations that are still underrepresented in research; development of people-centred healthcare and more meaningful treatments for patients[14,18,20,22].

Nevertheless, the advancements that have been achieved thus far, the strategy in question has yet to be fully integrated into the broader landscape of cancer research[9,12].

There is a conspicuous absence of PPI throughout the research process[13,21]. While there was some involvement in the initial design of the study, it was minimal in the subsequent phases.

In summary, it is recommended that efforts be made to encourage and disseminate the implementation of this precursor resource at the national and international levels. This will facilitate the active integration of public and patient perspectives, ensuring that research and clinical practices are aligned with their needs and priorities. This approach is patient-centred and integrates perspectives in cancer research and treatment, which can significantly contribute to improving the quality and relevance of the studies developed. It also guarantees applicable results in clinical practice and promotes transparency in research and trust in the scientific community[7,9,14].

In developing this review, limitations were identified in relation to the complexity of the concept of PPI. This made the database search process challenging due to the complexity of the search strategies employed and the selection of studies to be included in the review. Another limitation is the selection of articles only be done by two researchers as also the no involvement of a librarian expert in reviewing the searches. In an effort to address any potential selection bias, we have taken several steps to ensure a fair and objective process: the clarification of eligibility criteria, the pilot testing of the selection process, and the attainment of a consensus resolution.

However, by compiling and disseminating the benefits identified, we aim to promote the implementation of public and patient involvement in cancer research and contribute to improving healthcare for people with cancer.

Future research would benefit from exploring the benefits of community and patient involvement in cancer research from the perspectives of researchers, policy makers, funders, patients and the public, as well as identifying potential barriers to its implementation and strategies to overcome them.

In clinical practice, investing in participant literacy, increasing community and patient support group involvement, publicising initiatives and introducing rewards for participants can significantly improve the quality of care for people with cancer and reveal previously unrecognised benefits of public and patient involvement in cancer research.

Conclusion

The detrimental impact of cancer on global health and the urgent need to eradicate this disease, together with the open science movement, have led to a growing interest in involving the patients and public in this area of research.

This approach has proven to be crucial in promoting more significant scientific advances in cancer prevention, diagnosis and treatment. It does this by ensuring the relevance of research, including the needs and priorities identified by the public and patients; improving the methodological quality of research; increasing recruitment and response rates; and contributing to a better public understanding of the disease. In essence, PPI is central to promoting transparency, collaboration and relevance in oncology research. It enables a person-centred approach that takes into account a diversity of perspectives and produces better results. Collaboration between researchers and the community can facilitate innovative discoveries, more effective clinical practice and greater community involvement in research.

References

1. Bray F, Laversanne | Mathieu, Sung H, Ferlay J, Siegel RL, Soerjomataram I, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin [Internet]. 2024 Apr 4 [cited 2024 Apr 15];1–35. Available from: https://onlinelibrary.wiley.com/doi/full/10.3322/caac.21834
2. Despacho n.o 13227/2023 do Gabinete da Secretária de Estado da Promoção da Saúde: Estratégia Nacional de Luta contra o Cancro, Horizonte 2030 [Internet]. Diário da República n.o 248/2023, Série II de 2023-12-27 2023. Available from: https://diariodarepublica.pt/dr/detalhe/despacho/13227-2023-835712442

3. UNESCO. UNESCO Recommendation on Open Science [Internet]. 2023 [cited 2024 Oct 14]. Available from: https://www.unesco.org/en/open-science/about
4. Rius C, Liu Y, Sixto-Costoya A, Valderrama-Zurián JC, Lucas-Dominguez R. State of open science in cancer research. Clin Transl Oncol. 2024;
5. Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, et al. Mapping the impact of patient and public involvement on health and social care research: A systematic review. Health Expect. 2012;17(5):637–50.
6. Wilson P, Mathie E, Keenan J. ReseArch with Patient and Public invOlvement: a RealisT evaluation– the RAPPORT study. In: ReseArch with Patient and Public invOlvement: a RealisT evaluation– the RAPPORT study. 3rd ed. Health Serv Deliv Res ; 2015.
7. Collins K, Boote J, Ardron D, Gath J, Green T, Ahmedzai SH. Making patient and public involvement in cancer and palliative research a reality: Academic support is vital for success. BMJ Support Palliat Care. 2015;5(2):203–6.
8. Sharpless NE, Singer DS. Progress and potential: The Cancer Moonshot. Cancer Cell. 2021 Jul 12;39(7):889–94.
9. Roquette C, Crisóstomo S, Milagre T, Ribeiro RS, Pedro AR, Valente A. Patient organisations' views, motivations and experiences on patient involvement in cancer research: a pilot study in Portugal. BMJ Open. 2024 Jan 24;14(1).
10. Stjernswärd S, Glasdam S. The European Standard EN 17398:2020 on Patient Involvement in Health Care – a Fairclough-Inspired Critical Discourse Analysis. Policy Polit Nurs Pract. 2022 May 1;23(2):130–41.
11. Lorenzo F de, Apostolidis K. The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer. Mol Oncol. 2019 Mar 1;13(3):653–66.
12. Pii KH, Schou LH, Piil K, Jarden M. Current trends in patient and public involvement in cancer research: A systematic review. Health Expect. 2019 Feb;22(1):3-20.
13. Bergin RJ, Short CE, Davis N, Marker J, Dawson MT, Milton S, et al. The nature and impact of patient and public involvement in cancer prevention, screening and early detection research: A systematic review. Prev Med (Baltim). 2023 Feb 1;167:107412.
14. Geissler J, Ryll B, di Priolo SL, Uhlenhopp M. Improving Patient Involvement in Medicines Research and Development: A Practical Roadmap. Ther Innov Regul Sci. 2017 Sep 1;51(5):612–9.
15. Baethge C, Goldbeck-Wood S, Mertens S. SANRA—a scale for the quality assessment of narrative review articles. Res Integr Peer Rev. 2019 Dec;4(1).
16. Sukhera J. Narrative Reviews: Flexible, Rigorous, and Practical. J Grad Med Educ. 2022 Aug 1;14(4):414–7.
17. Nazareth C, Kalil M, Kalil M. Revisão de literatura e revisão sistemática: uma análise objetiva. International Journal of Science Dentistry [Internet]. 2021;Janeiro/Julho(55):39–47. Available from: http://www.periodicos.uff.br/index
18. Gordon L, Dickinson A, Offredy M, Smiddy J. A research note on the benefit of patient and public involvement in research: The experience of prostate cancer patients regarding information in radiotherapy. Radiography. 2017 May 1;23(2):167–70.
19. Thompson J, Bissell P, Cooper C, Armitage CJ, Barber R. Credibility and the "professionalized" lay expert: reflections on the dilemmas and opportunities of public involvement in health research. Health (London). 2012 Nov;16(6):602–18.
20. Mosconi P, Colombo C, Paletta P, Gangeri L, Pellegrini C, Garralda E, et al. Public and patient involvement: a survey on knowledge, experience and opinions among researchers within a precision oncology European project. BMC Cancer. 2023 Dec 1;23(840):1–10.
21. Colomer-Lahiguera S, Corbière T, Reeb-Landry F, Ninane F, Addeo A, Eicher M. [Patient involvement in oncology research - Development of a reference framework in French-speaking Switzerland]. Rev Med Suisse. 2022 Mar;18(775):621–5.
22. Price A, Albarqouni L, Kirkpatrick J, Clarke M, Liew SM, Roberts N, Burls A. Patient and public involvement in the design of clinical trials: An overview of systematic reviews. J Eval Clin Pract. 2018 Feb;24(1):240-253.
23. Wilkinson C, Gibson A, Biddle M, Hobbs L. Public involvement and public engagement: An example of convergent evolution? Findings from a conceptual qualitative review of patient and public involvement, and public engagement, in health and scientific research. PEC Innov. 2024 Apr 7;4:100281.
24. Ellis U, Kitchin V, Vis-Dunbar M. Identification and Reporting of Patient and Public Partner Authorship on Knowledge Syntheses: Rapid Review. J Particip Med. 2021 Jun 10;13(2):e27141.
25. INVOLVE. Impact of public involvement on the ethical aspects of research [Internet]. 2016 [cited 2024 Jul 1]. Available from: www.invo.org.uk/posttypepublication/public-involvement-in-researchimpact-on-ethical-aspects-of-research
26. Pattison N, Lee M. Two tribes coming together: Patient and public involvement in cancer research. Eur J Cancer Care (Engl). 2014 Jan;23(1):1–2.
27. Arumugam A, Phillips LR, Moore A, Kumaran SD, Sampath KK, Migliorini F, Maffulli N, Ranganadhababu BN, Hegazy F, Botto-van Bemden A. Patient and public involvement in research: a review of practical resources for young investigators. BMC Rheumatol. 2023 Mar 9;7(1):2.

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Ethics Committee Approval

Not applicable.

Conflict of Interest

The authors declare that there is no conflict of interest.

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NURSE-LED GASTROSTOMY CARE: A BUSINESS CASE

Cuidados conduzidos por enfermeiros em gastrostomia: Proposta de Valor

Atención de gastrostomía dirigida por enfermeras: Una Propuesta de Valor

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ABSTRACT

Percutaneous gastrostomy tube placement is a crucial method for providing long-term enteric nutrition in patients with cancer. The process involves four stages: decision-making consultation, hospital admission, device implantation in a hybrid operating room, and discharge to the community. Post-discharge care is typically physician-led, aligning with Portuguese health policies. However, expanding nurse-led interventions could alleviate physician burden, enhance care integration, and improve outcomes such as quality of life, patient engagement, and satisfaction. Nurses' involvement, guided by clinical expertise and person-centered care principles, ensures effective follow-up tailored to individual needs. While nurse-led care shows promise, its economic impact remains underexplored, raising concerns about cost-efficiency in community-based gastrostomy management. This article advocates for a nurse-led model to optimize care for gastrostomy patients, addressing gaps in current practices while maintaining quality and potentially achieving greater cost-effectiveness.

KEYWORDS: Gastrostomy; Nurse specialists; Business case; Nurse-led; Person-centred; Nursing consultation.

RESUMO

A sonda de gastrostomia percutânea radiológica é crucial para fornecer nutrição entérica em doentes com cancro. Envolve quatro etapas: consulta para tomada de decisão, admissão hospitalar, implantação do dispositivo numa sala híbrida e alta para a comunidade. Os cuidados são liderados por médicos. No entanto, a expansão das intervenções lideradas por enfermeiros pode aliviar a carga sobre o radiologista de intervenção, melhorar a integração dos cuidados e potenciar resultados como a qualidade de vida, o envolvimento do doente e a sua satisfação. O envolvimento do enfermeiro especialista em enfermagem médico-cirúrgica, guiado por expertise clínica e princípios de cuidados centrados na pessoa, assegura acompanhamento eficaz e individualizado. Embora os cuidados liderados por enfermeiros mostrem potencial, o seu impacto económico permanece pouco explorado, levantando preocupações sobre a eficiência de custos na gestão da gastrostomia. Este artigo defende um modelo alternativo para otimizar os cuidados, abordando lacunas enquanto mantém a qualidade e, potencialmente, alcança maior custo-efetividade.

PALAVRAS-CHAVE: Gastrostomia; Enfermeiro especialista; Proposta de valor; Cuidado centrado na pessoa; Consulta de enfermagem; Cuidados conduzidos por enfermeiro.

RESUMO TRADUZIDO

La sonda de gastrostomía percutánea radiológica es esencial para proporcionar nutrición enteral en pacientes con cáncer. Incluye cuatro etapas: consulta para toma de decisiones, ingreso hospitalario, implantación del dispositivo en sala híbrida y

alta a la comunidad, con atención habitualmente dirigida por médicos. Ampliar las intervenciones lideradas por enfermeras podría aliviar la carga médica, mejorar la integración de los cuidados y potenciar resultados como calidad de vida, participación y satisfacción del paciente. La intervención de enfermeras especializadas, basada en experiencia clínica y principios de atención centrada en la persona, asegura un seguimiento efectivo y personalizado. Aunque estas intervenciones muestran gran potencial, su impacto económico no ha sido explorado a fondo, lo que plantea dudas sobre la eficiencia del manejo comunitario de la gastrostomía. Este artículo aboga por un modelo liderado por enfermeras para optimizar la atención, abordar deficiencias actuales y mejorar la relación costo-beneficio.

PALABRAS CLAVE: Gastrostomía; Enfermera especialista; Atención dirigida por enfermeras; Propuesta de valor; Atención centrada en la persona; Consulta de enfermería

Background/Introduction

Percutaneous gastrostomy tube placement is a widely accepted method for providing long-term enteric nutrition and serves important health outcomes in adult and pediatric populations with cancer or neurologic diseases.[1–3] The implementation procedure, and its continuous care originate important health transitions, usually managed in medical appointments led by physicians. Generically, creating a radiologic percutaneous gastrostomy involves four sequential stages according to the availability of professionals and hospital resources: (1) hospital medical consultation for decision-making; (2) medical consultation for admission to hospitalization; (3) device implantation in a hybrid operating room (mixed team); (4) medical discharge to the community. After discharge, follow-up is determined by Portuguese health policies and most transitions are carried out by a physician, who also performs functions in the hybrid intervention room.[4–6], therefore, the expansion of autonomous nursing interventions can help reduce the burden and optimize and integrate care. After implantation, the patient is under the care of the hospital team, with the frequency of care defined according to the nurse's clinical guidance and person-centred care principles.[2,3,7] Nurse-led activities can improve outcomes, particularly quality of life, patient engagement, and patient satisfaction.[8,9] However, the economic impact of these activities is not well studied, although it does not appear to be detrimental.[9,10] This fact raises doubts as to whether, in fact, care management for gastrostomy patients in the community is being carried out as efficiently and cost-effectively as possible. This article aims to present a business case pitch privileging nurse-led interventions regarding the care of the person with gastrostomy.

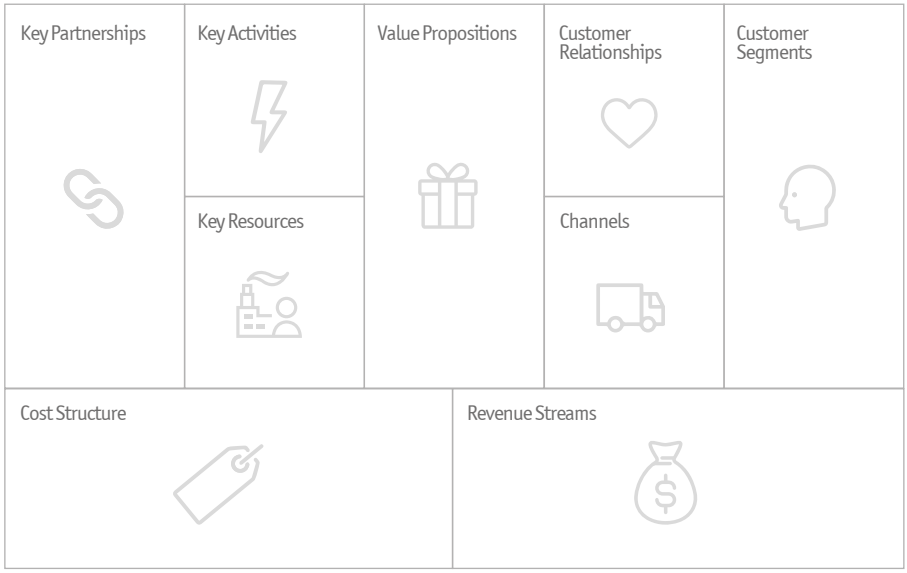
Development

The business case

A business case plan should provide stakeholders a structured proposal or framework for decision-making. Although not born in healthcare[11,12] , in this context this approach to care planning might be a perfect way to approach the complexity of nursing transforming into quantifiable, evidence-based projects or objective proposals from a cost-benefit and quality point of view.[13–15] Not necessarily aiming to constitute a project in itself, the business case should overview objectives, costs and potential benefits or risks. It might be linked, if accepted, to a continuous improvement cycle such as "before", "during" and "after implementation".[16,17]

The current business case thus intends to propose care exclusively led by nurses, supported by the nursing consultation methodology[18,19] and primary nurse work method.[20] The med-surge specialist nurse will autonomously assume the interdependent dimensions of admission to hospitalization, discharge to the community and follow-up. Nurse-led methodology has already shown to be beneficial, in the pediatric community, and proximity and tailored care in gastrostomy patients has already been shown to be beneficial[21,22] The methodology is the visual presentation proposed by Osterwald e Pigneur – "*Business Model Canvas*".[23]

Figure 1. Business Model Canvas



1. The customer segments

The customer segment represents the heart of any business case as it comprises the stakeholders that benefit from the model itself, preferably generating revenue. In this case, two important segments will benefit from implementing the proposed changes: people submitted to radiologically inserted gastrostomy as well as its' caretakers when applicable. This model might also apply to endoscopic gastrostomy since the clinical pathway is similar. As referred before, this patient segment represents an important share of the total patients who use enteral feeding as their primary nutritional support and is a widely spread condition.[24–27] Special needs regarding this population are distributed through a series of incursions in the healthcare system each with different focus and goals. The prominent navigation landmarks include:

- Medical or multidisciplinary decision-making consultation;
- Medical admission to infirmary;
- Medical device implantation in hybrid room;
- Discharge to the community;
- Community follow-up.

2. Value proposition

Value proposition encompasses the advantages if a particular model from the stakeholders' perspective. As stated before, this model is directed to a unique population, prone to deficient continuity of care due to multiple contacts with the health system. In this nurse-led model, these contacts will be enriched with directed interventions towards patient and caretaker-centered needs. We believe an evolution away from a physician-centred care, will create value by improving the quality of care through:

- Assuring patient advocacy towards informed decision-making[28];
- Ensuring correct beforehand patient preparation (regarding technical, health quality and security issues);
- Securing handoff and handout and reducing missed care[29] (ensuring continuity of care);
- Encouraging self-care, self-management shown to be beneficial[30], and with potential improvement in quality of life[31] ;
- Promoting self-monitoring, management of complications when requested and beyond the scope of self-care[2,3,32];
- Conducting basic nutritional assessment[33];
- Evaluating the need for differentiated referral (nutrition, psychological, social worker, medical);

3. The channels

Channels constitute the means of communication used to provide a service. The channels planned to cover the needs of people with an ostomy are already found in

any health institution. They are provided for in the legislation and statutes of regulatory bodies and do not require further financial investment. These include a nursing consultation in person, over the phone or via communication platforms[18,19,34]. Additional support will be provided via email and short-messaging support groups, following telehealth, principals.[35] Additionally, creating a monthly digital "*open-hour*" for all professionals who wish to be enlightened about gastrostomy care is advised.

4. Customer relationships

In a given business, the relationship with the customer can take different forms, depending on the characteristics of the customer service and goals to be achieved. In the particular case of ostomized patients and the management of their care, this relationship can become complex and expensive for the healthcare system. Therefore, the central methodology adopted for the relationship will be that of primary nursing. This nurse will serve all patients in this group and will be the entry hub into the healthcare system, creating objective and explicit reference interdisciplinary communication channels. The primary nursing methodology has proven to be beneficial not only to the patient[36] and caretaker but also the nurse.[30]

5. Revenue streams (the financial case[37]):

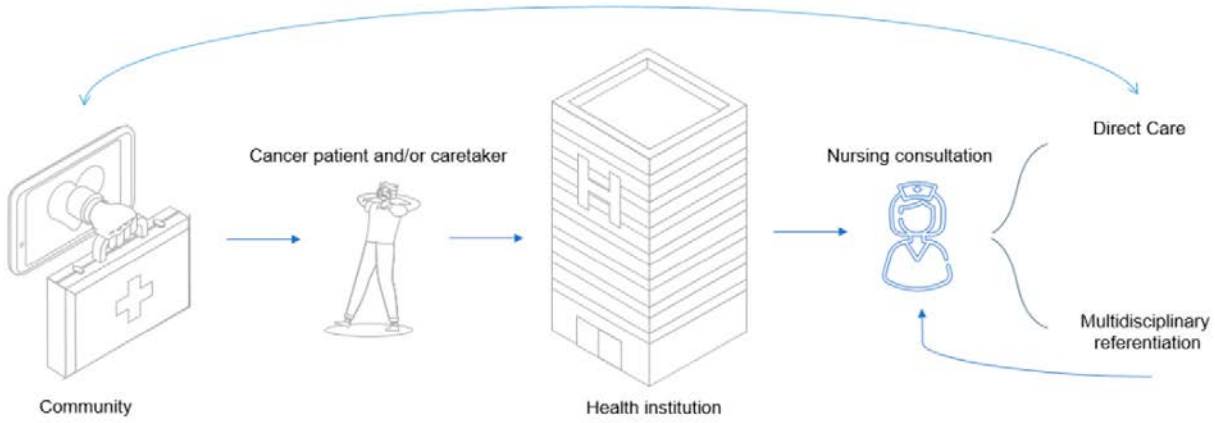
In a business, revenue streams encompass the profit from the sale of a product. In health systems, particularly the portuguese, providing care is not always associated with direct payment. In Portugal, the health financing model used is based on the Beveridge model, making healthcare services available to all citizens on a payment basis taxes[38] and moderating fees, which aim to prevent excess use and have a role in moderating healthcare consumption.[39] Thus, in the business case now exposed, although sustained by proximity care, we are not in a position to outline forms of direct financial profit, but rather a potential for cost reduction, related (in a non-exhaustive way) with:

- Lowering rates:
  - Nurse-led consultation is cheaper by 40% than physician-led consultation, especially in the emergency room[18];
  - Nurse-led tube replacement in consultation room is approximately 80% cheaper when compared to the traditional hybrid room replacement;
- Reducing delayed or cancelled events related to factors like deficient or uncertain preparation[40];
- Reducing patient and health system, transportation fees, using the documented benefits of telemedicine[41];
- Reducing hospital readmission and emergency services usage, due to inadequate patient empowerment and complications, such as local infection and leaking [22,35].
- Out-of-pocket and intangible costs.

6. Key resources

Key resources represent the assets and consequential value needed to achieve the proposed goals. The resources that are needed depend largely on the nature of the proposal. In healthcare, namely cancer care, the most expensive resource are cancer drugs.[42] Although this business

Figure 2. Nurse as entry hub into the healthcare system



case is exclusive to cancer patients, further investment is not related to drugs but mostly on human resources. Therefore, the only resource indispensable to respond to this new approach to care is a nurse specialized in medical-surgical nursing, preferably with increased competence in oncological nursing and/or advanced training in ostomy. All other necessary resources are expected to be pre-existing in a health institution equipped to implant a gastrostomy. Among these, the following stand out: a consultation office equipped as referred to in the supplementary material section, a mobile phone with an internet connection and clinical consumables related to specific management of the medical device.

7. Key activities

Key activities refer to the main actions or interventions stakeholders take to attain success. When dealing with patients, success is translated by positive outcomes (either patient-reported or professional-reported). Examples of positive outcomes in the gastrostomized patient are: undelayed and complication-free tube placement and management, patient and caretaker mastery regarding knowledge, ability and attitude (or volition) to manage the device, adherence to good practice and unfragmented continuity of care. Indeed, given the nature of care, the intention is to center key activities in the scope of practice of reference nurse. These will include nursing care aiding to facilitate the implementation of transition processes, as stated below:

- Enabling the person and significant caregiver to experience the minimally invasive procedure through teaching, instructing and training;
- Developing a care design plan according to the needs identified along the continuum:
  - Conducting first consultation with cancer patient (anamnesis, physical examination, informed consent, first contact with medical device)[33];
  - Using telephonic pre-procedure consultation to review preparation (as stated in the supplementary material section)[35];
  - Providing evidence-based care activities during the periprocedural period, and securing correct and documented handoff to inpatient infirmary and community[43];
  - Ensuring first consultation 15 days after tube implantation and follow-up consultations according to patient needs and device characteristics during office hours[2,3];
  - Guarantee minimal support during out-of-office hours using digital communication channels[35];
- Providing direct care in the presence of tube-related complications[7];
- Creating and measuring nursing care-sensitive indicators, namely satisfaction with care, engagement level, capacitation, self-efficacy and quality of life.

8. Key partnerships

Care coordination and continuity ensure that all providers and organizations involved in health care provide the proper care at the right time, involving a people-centric approach. Although autonomous nurse-led follow-up has proven to be valuable[44], multiple partnerships must be created to avoid gaps in care. The most important partnership will be created with the patient itself, based on the benefits of relationship continuity.[45] Implementation and maintenance of the current nurse-led care will be reinforced by:

- Creating and publishing normative roles and responsibilities of all people involved in care, including the patient's role in self-care;
- Presenting the new model of care beforehand to institutional stakeholders, including interventional radiology clinicians, nursing administration and representatives of the various interdisciplinary departments, including nutrition and surgical and medical wards;
- Promoting regular workshops among community and external institution nurses, empowering them to collaborate with care;
- Establish relationships with research groups to study and continuously improve care supported in evidence-based practice.

9. Cost structure

Costs must be reduced for all incursions into the health system since resources are finite. Although the nature of this business case focuses on an apparent reduction in funds spent, this is a reductive view of its overall value. Besides the initial investment in a specialized nurse, as referred to in "*key resources*", there is no prediction of any costs increase. Consequently, it is important to note that, as in any other "healthcare business", the preferred outcomes will not necessarily focus on profit but rather on value-based care, a mixed approach that will not only seek to reduce as much as possible the expense associated with care but simultaneously provide the best possible outcomes for the person treated.[46]

Table 1. Business Case Canvas (gastrostomy patient)

<table>
<tr><th colspan="5">BUSINESS MODEL CANVAS (SUMMARIZED)</th></tr>
<tr><th>KEY PARTNERS</th><th>KEY ACTIVITIES</th><th>VALUE PROPOSITIONS</th><th>CUSTOMER RELATIONSHIPS</th><th>CUSTOMER SEGMENTS</th></tr>
<tr>
<td rowspan="3">• Patient
• Caretaker
• Multidisciplinary team
• Community nurse
• Research group</td>
<td>• Teaching, instructing and training
• Developing an individualized care plan
• First consultation (anamnesis, physical examination, informed consent, first contact with medical device)
• Using telephonic pre-procedure consultation
• Providing periprocedural care and handoff
• Providing regular follow-up
• Guarantee support during out-of-office hours
• Providing direct care in the presence of complications
• Creating and measuring nursing care-sensitive indicators</td>
<td rowspan="3">• Patient advocacy towards informed decision-making
• Efficient patient preparation
• Continuity of care
• Patient and caretaker empowerment
• Effective interdisciplinary and multidisciplinary collaboration</td>
<td>• Primary nursing</td>
<td rowspan="3">• The person proposed to radiologically inserted gastrostomy
• Caretakers</td>
</tr>
<tr><th>KEY RESOURCES</th><th>CHANNELS</th></tr>
<tr>
<td>• Nurse specialized in medical-surgical nursing, preferably with increased competence in oncological nursing and/or advanced training in ostomy</td>
<td>Nursing consultation:
• In person
• Telehealth
• “Open-hour”</td>
</tr>
<tr><th colspan="2">COST STRUCTURE</th><th colspan="3">REVENUE STREAMS</th></tr>
<tr><td colspan="2">Value-Based Healthcare</td><td colspan="3">Lowering personnel rates:
• Reducing delayed or cancelled procedures
• Reducing transportation fees
• Reducing hospital readmission and emergency services usage
• Limiting out-of-pocket and intangible costs</td></tr>
</table>

Conclusion

Expanding specialized intervention nursing represents a strategic opportunity to improve clinical and financial indicators. The use of team elements with lower rate/per hour worked, can provide sustainability to this model. However, the initial investment does not fit entirely into the current portuguese economic and legislative conjuncture. The main risks associated with this remolding might be related to resistance to change by stakeholders (perception of activity, confusion of roles), resistance by funders to the allocation of differentiated human resources (perceived value) and the absence or inadequacy of “nurse-led acts” in the current health regulations.

Bibliography

1. Karthikumar B, Keshava SN, Moses V, Chiramel GK, Ahmed M, Mammen S. Percutaneous gastrostomy placement by intervention radiology: Techniques and outcome. Indian J Radiol Imaging [Internet]. 2018 Apr 1 [cited 2024 Jul 17];28(2):225. Available from: /pmc/articles/PMC6038225/
2. Miguel Madaleno Cardoso P, Sofia Abreu Miguel S, Ferreira Santos S, Francisco F, Marques L, Rosa Varela Silveira M, et al. Consensus Paper: Ostomias de alimentação. 2023.
3. DGS. Indicações Clínicas e Intervenção nas Ostomias de Alimentação em Idade Pediátrica e no Adulto. 2016.
4. Morgan R, Haslam P, McCafferty I, Bryant T, Clarke C, McPherson S, et al. Provision of Interventional Radiology Services 2023. Cardiovasc Intervent Radiol. 2024 Jan 1;47(1):3–25.
5. Amour E, Hays D, Gandhi R. Outpatient Interventional Oncology: Primum Non Nocere. Endovasc. Today. 2019;18(10):94–7.
6. Mahnken AH, Boullosa Seoane E, Cannavale A, de Haan MW, Dezman R, Kloeckner R, et al. CIRSE Clinical Practice Manual. Cardiovasc Intervent Radiol. 2021 Sep 1;44(9):1323–53.
7. Roveron G, Antonini M, Barbierato M, Calandrino V, Canese G, Chiurazzi LF, Coniglio G, Gentini G, Marchetti M, Minucci A, Nembrini L, Neri V, Trovato P, Ferrara F. Clinical Practice Guidelines for the Nursing Management of Percutaneous Endoscopic Gastrostomy and

Jejunostomy (PEG/PEJ) in Adult Patients: An Executive Summary. J Wound Ostomy Continence Nurs. 2018 Jul/Aug;45(4):326-334.

8. Bonetti L, Tolotti A, Anderson G, Nania T, Vignaduzzo C, Sari D, et al. Nursing interventions to promote patient engagement in cancer care: A systematic review. Int J Nurs Stud. 2022 Sep 1;133:104289.
9. Laurant M, van der Biezen M, Wijers N, Watananirun K, Kontopantelis E, van Vught AJ. Nurses as substitutes for doctors in primary care. Cochrane Database Syst Rev. 2018 Jul 16;7(7):CD001271.
10. Bryant-Lukosius D, Carter N, Reid K, Donald F, Martin-Misener R, Kilpatrick K, et al. The clinical effectiveness and cost-effectiveness of clinical nurse specialist-led hospital to home transitional care: a systematic review. J Eval Clin Pract [Internet]. 2015 Oct 1 [cited 2024 Apr 18];21(5):763–81. Available from: https://onlinelibrary.wiley.com/doi/full/10.1111/jep.12401
11. Post B. A Business Case Framework for Group Support Technology. J Manag Inf Syst. [Internet]. 1992 [cited 2024 Aug 15];9(3):7–26. Available from: https://www.jstor.org/stable/40398040
12. Maes K, Grembergen W Van, De Haes S. Identifying Multiple Dimensions of a Business Case: A Systematic Literature Review. Electron J Inf Syst Eval.. 2014;17(1):047-059.
13. Welch TD, Smith TB, Niklinski E. Creating a Business Case for Success. Nurs Adm Q [Internet]. 2023 Apr 1 [cited 2024 Aug 15];47(2):182–94. Available from: https://journals.lww.com/naqjournal/fulltext/2023/04000/creating_a_business_case_for_success.10.aspx
14. Sanford K. Making the Business Case for Quality and Nursing. Nurse Lead. 2011 Jan;9(1):28–31.
15. Welch TD, Smith TB. Anatomy of a business case. Nurs Adm Q [Internet]. 2022 Jan 1 [cited 2024 Aug 14];46(1):88–95. Available from: https://journals.lww.com/naqjournal/fulltext/2022/01000/anatomy_of_a_business_case.12.aspx
16. Hitt LM, Wu DJ, Zhou X. Investment in enterprise resource planning: Business impact and productivity measures. J Manag Inf Syst. 2002;19(1):71–98.
17. Hsiao R. Knowledge Sharing in a Global Professional Service Firm. MIS Quarterly Executive [Internet]. 2008;7(2):1–14. Available from: https://www.researchgate.net/publication/220500601
18. Portaria 207/2017. Diário da República. 2017. p. 3550–708.
19. SRC - OE. Guia De Recomendações Para As Consultas De Enfermagem À Distância/Telenfermagem. 2021;1–26. Available from: https://www.ordemenfermeiros.pt/media/21380/guia-telenfermagem_final.pdf
20. Parreira P, Santos-Costa P, Neri M, Marques A, Queirós P, Salgueiro-Oliveira A. Work methods for nursing care delivery. Int J Environ Res Public Health. 2021 Feb 2;18(4):1–17.
21. Patel R, Mutalib M, Pradhan A, Wright H, Upadhyaya M. Nurse-led service for children with gastrostomies: a 2-year review. Br J Nurs [Internet]. 2021 Apr 22 [cited 2024 Oct 31];30(8):462–6. Available from: https://pubmed.ncbi.nlm.nih.gov/33876678/
22. White S, Kurien M, Simpson G, Grant J, Sanders DS, McAlindon M. Supporting patients with percutaneous endoscopic gastrostomy (PEG) in the community: developing a home enteral feed programme to avoid hospital readmissions. Gut [Internet]. 2011 Apr 1 [cited 2024 Dec 18];60(Suppl 1):A96–A96. Available from: https://gut.bmj.com/content/60/Suppl_1/A96.2
23. Osterwalder A, Pigneur Y. Business Model Generation. Wiley & Sons; 2010.
24. Meine MC, Tusato IH, Hoffmeister N, Meine GC. Percutaneous radiologic gastrostomy versus percutaneous endoscopic gastrostomy for enteral feeding: A systematic review and meta-analysis. JPEN J Parenter Enteral Nutr [Internet]. 2024 Aug 1 [cited 2024 Oct 31];48(6):667–77. Available from: https://pubmed.ncbi.nlm.nih.gov/38806284/
25. Ahmed Z, Iqbal U, Aziz M, Arif SF, Badal J, Farooq U, et al. Outcomes and Complications of Radiological Gastrostomy vs. Percutaneous Endoscopic Gastrostomy for Enteral Feeding: An Updated Systematic Review and Meta-Analysis. Gastroenterology Res [Internet]. 2023 Apr [cited 2024 Oct 31];16(2):79–91. Available from: http://www.ncbi.nlm.nih.gov/pubmed/37187550
26. Fontes F, Fernandes D, Almeida A, Sá I, Dinis-Ribeiro M. Patient-Reported Outcomes after Surgical, Endoscopic, or Radiological Techniques for Nutritional Support in Esophageal Cancer Patients: A Systematic Review. Curr Oncol.[Internet]. 2024 Oct 14;31(10):6171–90. Available from: https://www.mdpi.com/1718-7729/31/10/460
27. Palmer SJ. An update on enteral feeding in the community. Br J Community Nurs [Internet]. 2023 Apr 2 [cited 2024 Oct 31];28(4):194–6. Available from: https://pubmed.ncbi.nlm.nih.gov/36989198/
28. Stavroulakis T, Baird WO, Baxter SK, Walsh T, Shaw PJ, McDermott CJ. Factors influencing decision-making in relation to timing of gastrostomy insertion in patients with motor neurone disease. BMJ Support Palliat Care. 2014;4(1):57–63.
29. Moura ECC, Lima MB, Peres AM, Lopez V, Batista MEM, Braga F das CSAG. Relationship between the implementation of primary nursing model and the reduction of missed nursing care. J Nurs Manag [Internet]. 2020 Nov 1 [cited 2024 Dec 17];28(8):2103–12. Available from: https://pubmed.ncbi.nlm.nih.gov/31433878/
30. Ferrua R, Nelson JW, Gatta C, Croso A, Gilot CB, Molin AD. The Impact of the Primary Nursing Model on Cultural Improvement: A Mixed-Method Study. Creat Nurs [Internet]. 2016 Nov 1;22(4):259–67. Available from: https://doi.org/10.1891/1078-4535.22.4.259
31. Huang Y, Li S, Lu X, Chen W, Zhang Y. The Effect of Self-Management on Patients with Chronic Diseases: A Systematic Review and Meta-Analysis. Healthcare (Switzerland) [Internet]. 2024 Nov 1 [cited 2024 Dec 18];12(21):2151. Available from: https://www.mdpi.com/2227-9032/12/21/2151/htm
32. DeLegge M. Gastrostomy tubes: Placement and routine care [Internet]. 2020. Available from: www.uptodate.com
33. Liu Y, Bennell J. Evaluation of a new nurse-led gastrostomy assessment service. Clin Nutr ESPEN. 2019 Feb 1;29:267.
34. Ordem dos Enfermeiros. Consultas de Enfermagem à distância: Guia de Recomendações. Coimbra; 2021.
35. Chen BL, Lien HC, Yang SS, Wu SC, Chiang HH, Lin LC. Impact of Mobile Apps in Conjunction With Percutaneous Endoscopic Gastrostomy on Patients' Complications, Quality of Life, and Health-Related Self-Care Behaviors: Randomized Clinical Trial. JMIR Mhealth Uhealth. 2023;11.
36. Gonçalves I, Mendes DA, Caldeira S, Jesus É, Nunes E. The Primary Nursing Care Model and Inpatients' Nursing-Sensitive Outcomes: A Systematic Review and Narrative Synthesis of Quantitative Studies. Int J Environ Res Public Health [Internet]. 2023 Feb 1 [cited 2024 Dec 17];20(3):2391. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC9915435/
37. Overview | Five Case Model [Internet]. [cited 2024 Dec 17]. Available from: https://fivecasemodel.co.uk/overview/
38. Wallace LS. A view of health care around the world. Ann Fam Med. 2013 Jan-Feb;11(1):84.
39. Entidade Reguladora da Saúde. Direitos e deveres dos utentes dos serviços de saúde [Internet]. 2021. Available from: www.ers.pt
40. Kilgour J, McLean G, Paul E, Knight R. Identifying delays in the outpatient interventional radiology department: a quality improvement study. J Med Radiat Sci [Internet]. 2023 Mar 1 [cited 2024 Dec 17];71(1):72. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC10920948/
41. Despacho 3571/2013 | Diário da República [Internet]. [cited 2024 Dec 17]. Available from: https://diariodarepublica.pt/dr/detalhe/despacho/3571-2013-1759945
42. Hofmarcher T, Lindgren P, Wilking N, Jönsson B. The cost of cancer in Europe 2018. Eur J Cancer [Internet]. 2020 Apr 1 [cited 2024 Dec 18];129:41–9. Available from: http://www.ejcancer.com/article/S0959804920300265/fulltext
43. Fernandes DM da S. Interventional Radiology Nursing: an Evolving competence. OncoNews. 2025 Jan 1;2025-January-June(50).

44. Halai V, Maclean D, Smith V, Beverley S, Maher B, Stedman B, Bryant T, Breen D, Modi S. The Evolving Role of the Clinical Nurse Specialist in Interventional Oncology. Cardiovasc Intervent Radiol. 2023 Aug;46(8):1097-1098.
45. Starfield B. Is Patient-Centered Care the Same As Person-Focused Care? Perm J [Internet]. 2011 Jun [cited 2024 Dec 19];15(2):63. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC3140752/
46. Teisberg E, Wallace S, O'Hara S. Defining and Implementing Value-Based Health Care: A Strategic Framework. Academic Medicine [Internet]. 2019 May 1 [cited 2024 Dec 19];95(5):682. Available from: https://pmc.ncbi.nlm.nih.gov/articles/PMC7185050/

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SUPPLEMENTARY MATERIAL

Simplified framework: nursing telephone consultation

Conducted 48 hours prior to the procedure to ensure the safe completion of the procedure on the scheduled date and time:

1. Reinforce or provide information about the purpose of the procedure, the need for a 6-hour fasting period, a minimum hospitalization of 24 hours, bringing home medications and a caregiver, suspension of antiplatelet medication (if applicable), known allergies, or other contraindications;
2. Address any questions or concerns;
3. Request a bed reservation for hospitalization;
4. Document the entire decision-making process in the information system (nursing diagnoses and interventions), using the available terminology and establishing continuity with the scheduled procedure.

Simplified framework: nursing follow-up consultation and resources

GOAL: The development of this procedure aims to provide a set of clinical guidelines that standardize and implement autonomous nursing consultation for people with feeding stomas, in accordance with nursing care quality standards. This procedure only provides monitoring and follow-up for the person after the placement of the medical device and can be complemented with a telephone nursing consultation.

Technical operating guidelines (continuity of care and resource management)

- The gastrostomy nursing office aims to respond to the monitoring and follow-up of the person undergoing gastrostomy by the medical specialty of interventional radiology;
- The expected service is nine patients per 7-hour shift with a 30-minute interval for each patient;
- The allocated human resources consist of a nurse and an operational assistant exclusively assigned for this purpose;
- The office ensures continuity of care in accordance with possible and pre-existing procedures:
  - During the period of operation, all people whose need for face-to-face assistance is foreseen within its scope of intervention may be referred. These include complications originating exclusively from the device or associated with its maintenance; referral is made by direct contact with the office and care requires authorization from the assigned nurse; this may have an internal origin and, in this case, responsibility for additional guidance and care is the sole responsibility of the originating department;
  - Whenever possible, appointments of this nature should be made at this office and at the assigned time;
  - Telephone assistance to gastrostomy patients follows principles of telehealth;
  - In case of an undesirable outcome that requires the support of imaging techniques for its resolution, patient should be referred directly to the interventional physician present for decision-making;
- Scheduling is carried out by the clinical secretary of the interventional radiology service in accordance with the clinical guidance of the nurse and principles of person-centered care;
  - First consultation 2: 15 days after placement (written indication in the request associated with the MCDT) in the angiography room;
  - Next 2: 2 to 6 months, according to the manufacturer's instructions and needs detected (written indication in the information system in the associated episode);
  - Non-regular appointments may be made in case of complications;
  - Medical referral must be made in the case of serious complications or a probe placed less than 4 weeks ago 2;

NOTE: The main decision-making criterion for scheduling is the need to change the probe. Two dimensions contribute to this decision:

1. When it is safe to change the tube for the first time (traditionally, the stoma is well-formed after 4 weeks, and before this period, the referral should be medical);
2. The maximum period the tube can maintain function without deteriorating and causing dysfunction (depends on manufacturer instruction).

- The nurse checks the workroom for environmental hygiene and comfort;
  - Meets the recommendations of the local infection control workgroup and waste management resources;
  - Guarantees privacy (closed door, use of sanitizable screen);
  - Confirms or asks the operational assistant to check the functioning of the air conditioning (around 21ºC);
- The nurse checks the workroom for necessary material resources:
  - Stretcher, sink, mirror and support chair for family caregiver and/or person with gastrostomy;
  - Operation of oxygen ramp and suction system;
  - Generic supplies (disposable cups, small protectors, stretcher, paper roll);
  - Non-specific clinical material (support cart with sanitizable top, 10cc, 20cc and feeding syringes, spike, size 11 scalpel with handle, 10*10cm compresses, small drainage compresses, dressing material, clean gloves);
  - Specific material for gastrostomy (probes 18, 20, 22 and 24FR);
  - Drugs (double distilled water, **anaesthetic** lubricating gel, skin protection spray, 250ml saline irrigation solution, non-alcoholic antiseptic, other wound treatment agents, according to specific needs)

- The nurse consults the current information system for the daily schedule for the resource;
  - For each person, the nurse checks the pre-existing care design plan and the last consultation regarding the feeding ostomy;
  - The nurse uses the call system and summons the person to the consultation room.

Technical implementation guidelines (admission to consultation)

- Nurse welcomes the person into the room and identifies them by institutional identification standards;
- Nurse identifies the companion, their relationship with the person with a stoma and the degree of involvement in managing the stoma;
- Nurse asks the patient about the purpose of the scheduled appointment;
- Nurse assesses the general condition of the person with a stoma and asks when they last ate (water: 2 hours; enteral formula or food: 4 hours);
- With the collaboration of the operational assistant and according to the objective of the consultation, the nurse positions the person appropriately:
  - To replace the probe or treat the local condition, the patient must be placed in a supine position, promoting rectilinearity of the abdominal wall and a favorable position for the stoma;
  - For self-management training consultation, the person and caregiver can remain seated;

Technical guidelines for execution (changing a gastrostomy tube in a formed stoma)

- Nurse obtains verbal consent to begin the procedure;
- Nurse assesses the following parameters in the pre-existing probe:
  - Type, positioning and calibre of the device (attachment to skin, tube depth, ring position, clamp position, if applicable);
  - Device integrity (integrity of all device components, namely ring, clamps and closure systems);
  - Patency (if the person mentions that there is difficulty, the patency should be tested using an injection of 50cc of water at room temperature);
- Nurse assesses the presence of a closed dressing, the stoma and the peri-stoma skin;
- Nurse prepares the work table for tube replacement:
  - Non-sterile table protection;
  - Two pairs of clean gloves;
  - Antiseptic solution (if signs of infection) or saline;
  - Anesthetic lubricating gel;
  - Scalpel no. 11 with handle;
  - Feeding syringe;
  - 1 10cc syringe without luer lock to deflate the balloon
  - 1 syringe without luer lock, with the volume of distilled water appropriate for the balloon to be filled;

- Compresses 10*10;
- Gastrostomy tube;
- Dressing material, if applicable.

• Nurse replaces the device:
  - Clean the peristomal skin with saline solute on or antiseptic, if necessary (visibly dirty area);
  - Applies anesthetic gel to the stoma;
  - Completely deflate the fixation balloon and cut the corresponding access route;
  - Remove the probe by placing one hand on the abdominal wall and pulling the probe in a single firm movement;
  - Assess the appearance of the removed probe for signs of damage;
  - Introduces the new probe at the planned depth;
  - Fill the balloon with the amount of distilled water indicated on the probe;
  - Position the ring 1 cm from the skin or adapt an extension if using a low-profile probe;
  - Checks the correct positioning of the probe in the gastric cavity (flush with 50cc of water without resistance, peri-stoma losses or pain and/or comparison with the previous depth);
  - Cleans the peristomal skin with saline solution (performs dressing care if there is a complication or the ostomized person so requires);
  - Assists in the uprising, if applicable.

Technical guidelines for implementation (training)

The nurse must collect data that allows for the diagnosis of potential gaps in the competence of the person or family caregiver and use strategies such as teaching, instructing, training, supervising and supporting the development of skills to:

- Early recognition of skin complications by daily assessment of the peristomal skin and mucosa, namely "leakage", hypergranulation, erythema, infection and oral cavity conditions;
- Recognize and manage other complications early, by regularly assessing device characteristics, namely partial or total externalization of the device, balloon packing and deflation;
- Comply with good practice in the use of the medical device (discuss instrumental aspects):
  a. Daily skin and probe care;
  b. Basic infection control precautions (includes oral hygiene and hand hygiene);
  c. Food administration;
  d. Administration of medication;
- Use mechanisms to instrumentalize other dimensions of the therapeutic regime that may interfere with the implanted device, namely:
  a. Oral medication regimen;
  b. Established diet;
  c. Use coping mechanisms that favor psychosocial adaptation and reconstruction of autonomy.

NOTE: Insufficient training for self-management related to the device constitutes a criterion for referral to the consultation, and the potential to care for the gastrostomy must be reassessed at every consultation. The nurse should not end the consultation without asking the person and caregiver if there are any additional health needs.

Technical execution guidelines (records in information system)

The nurse documents the entire associated decision-making process (nursing diagnoses and associated interventions) in the current information system, using the available language and establishing a relationship of continuity with the previous consultation and the next appointment. It also documents:

- Reason for consultation;
- General condition of the person with a stoma;
- Level of training of the person and/or family caregiver regarding the medical device;
- Characteristics and condition of the probe to be replaced, if applicable:
  a. Type and gauge;
  b. Integrity and patency;
     - Skin condition and treatments performed, if applicable;
     - Characteristics of the introduced probe:
       a. Type and gauge;
       b. Volume introduced into the balloon;
       c. Additional fixing mechanisms;
       d. Lot.
- Scheduling of the next nursing appointment and reason.

Whenever there is a need for continuity of care in the community, an institutional nursing discharge note must be prepared, including unequivocal indications about the nature and frequency of the care (skin, stoma, probe, training). Whenever possible, direct telephone contact should be made with the respective community health unit.

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NURSING INTERVENTIONS TO PROMOTE COPING IN PATIENTS WITH CANCER: A SCOPING REVIEW

Intervenções de enfermagem promotoras do coping na pessoa adulta com doença oncológica: Uma scoping review

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ABSTRACT

Introduction: A cancer diagnosis is a life-changing event that often causes distress, adversely affecting quality of life and survival. Interest in interventions aimed at supporting emotional, social, and behavioural adaptation has grown, establishing them as a key quality indicator in oncology care. **Objective:** To map nursing interventions that promote coping in cancer patients. **Methodology:** A scoping review was conducted following the Joanna Briggs Institute methodology (JBI) and PRISMA-ScR guidelines. Searches were carried out in databases such as CINAHL, MEDLINE, and the Cochrane Library® covering the period from 2019 to 2024. The study protocol was registered on OSF with registration number 10.17605/OSF.IO/TUCMA. **Results:** Of 1,547 records identified, 18 were included in the final analysis. Cognitive-behavioural interventions were the most prevalent, with most programmes comprising 6 to 12 sessions, each lasting between 45 and 90 minutes. **Conclusion:** Mapping nursing interventions that promote coping in cancer patients provides valuable insights for clinical decision-making and the dissemination of scientific evidence.

KEYWORDS: Psychological adaptation; Coping Skills; Nursing Intervention; Oncology Nurse.

RESUMO

Introdução: A doença oncológica configura-se como um evento adverso que frequentemente provoca distress, impactando negativamente a qualidade de vida e a sobrevivência. O interesse nas intervenções focadas na adaptação emocional, social e comportamental tem aumentado, tornando-se um indicador de qualidade nos cuidados oncológicos. **Objetivo:** Mapear as intervenções de enfermagem promotoras do coping nas pessoas com doença oncológica. **Metodologia:** Realizada uma Scoping Review, segundo a metodologia proposta pelo Joanna Briggs Institute (JBI) e as diretrizes PRISMA-ScR. Consultaram-se bases de dados como: CINAHL, MEDLINE e Cochrane Library® entre 2019 e 2024. O protocolo do estudo foi registado na OSF com o número de registo 10.17605/OSF.IO/TUCMA. **Resultados:** Dos 1547 registos, foram extraídos para análise 18. As intervenções cognitivo-comportamentais destacaram-se com programas compostos por 6 a 12 sessões de 45 a 90 minutos. **Conclusão:** Este mapeamento constitui-se uma ferramenta importante na tomada de decisões clínicas e na disseminação da evidência científica.

PALAVRAS-CHAVE: Adaptação Psicológica; Habilidades de decisão; Interveção Enfermagem; Enfermagem Oncológica.

Introduction

The incidence of oncological diseases has progressively increased, with an estimated 19.9 million new cancer cases diagnosed worldwide in 2022, of which 69.6 thousand were diagnosed in Portugal.[1] According to GLOBOCAN Statistics, 2022, it is projected that over 35 million new cancer cases will occur by 2050, an increase of 77% compared to the 20 million cases estimated in 2022.[2] Survival rates have also seen significant improvements, with approximately 12 million survivors in Europe, due to advances in early detection, effective therapies, and supportive care.[3] Cancer diagnosis continues to be regarded as an adverse life event that requires emotional adjustment, which often negatively impacts the quality of life of individuals with cancer and may potentially affect their survival.[4] Recent studies indicate that, despite significant scientific progress, the prevalence of clinically significant distress in individuals with oncological disease remains at approximately 50%.[5–6] Emotional issues, particularly anxiety and depression, are the most frequently reported problems, followed by family-related issues and the exacerbation of physical symptoms.[5] Scientific evidence suggests that about one-third of this population presents with symptoms of psychiatric disorders, with anxiety and depression being the most common, regardless of the type, stage, or phase of the disease.[7–9] However, the emotional response to stressors related to this condition is represented on a spectrum that can range from normative symptoms, such as distress, worry, uncertainty, sadness, and even hopelessness, to severe emotional symptoms that may eventually meet the diagnostic thresholds for psychiatric disorders.[10–12] Therefore, it is the responsibility of healthcare professionals to understand the difference between non-pathological fluctuations resulting from short-term emotional responses to life challenges and more specific and impactful psychopathological conditions, such as anxiety disorders and depressive disorders.[13] According to some authors, early recognition and intervention optimise patients' emotional regulation, decision-making capacity, and treatment adherence.[14] Additionally, the emotional support of individuals with cancer is considered an integral part of quality care delivery.[15] International guidelines indicate that monitoring and intervening in the emotional distress of these patients is a minimum standard of practice in oncological care and is considered an indicator of the quality of care provided by healthcare professionals, particularly nurses.[16–18] Despite growing recognition of the nurse's role in delivering holistic, patient-centred care that includes emotional and psychological support[19] there remains a lack of standardised, well-documented interventions tailored to help cancer patients cope with the emotional impact of their diagnosis and treatment.[16] A preliminary exploratory search across major databases revealed no existing scoping reviews on this topic, highlighting a knowledge gap. Therefore, this study aims to map the available evidence on nursing interventions that promote coping in adults with cancer, providing a foundation for evidence-based practice, enhancing the quality of psychosocial care in oncology nursing, and supporting the optimisation of coping strategies implemented in clinical settings.

Methodology

This scoping review was conducted following the methodology recommended by the Joanna Briggs Institute (JBI) and aligned with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR)[20]. The primary objective was to map nursing interventions and programmes aimed at promoting coping in adults with cancer. The research question guiding this review is: "What nursing interventions and programmes promote coping in adults with cancer?". The research question and the eligibility criteria were defined using the PCC mnemonic (Population, Concept, and Context) in accordance with the methodology proposed by the JBI.[19] Regarding the context (C), all intervention contexts were considered without restriction. The review included primary studies, specifically quantitative studies, qualitative studies, and studies employing a mixed-methods approach, including those using methodological triangulation. Exclusion criteria applied were records that did not involve nursing interventions; those focused solely on family members, partners, or caregivers; and records with therapeutic interventions aimed at children and adolescents, due to the specific nature of interventions required for these groups. To ensure both the relevance and recency of the data, a temporal filter was applied, covering the period from 1 February 2019 to 1 February 2024. The search was conducted via EBSCOhost Web® using the following databases: Cumulative Index to Nursing and Allied Health (CINAHL Ultimate®), MedicLatina®, Medical Literature Analysis and Retrieval System Online (MEDLINE®), Library, Information Science & Technology Abstracts, and Nursing & Allied Health Collection Comprehensive. The Boolean equation used was: (((Neoplasms) OR (Cancer) OR ("Cancer Patient"))

NOT (Child))) AND ((Adaptation) OR (Psychological) OR (Coping)) AND ((Nursing) OR ("Nursing care")). For the Cochrane Library® database, a Boolean equation tailored to its specific cataloguing and indexing structure was employed to maximise search sensitivity and precision (Lefebvre et al., 2019):

(Neoplasms OR Cancer OR "Cancer Patient" NOT Child) AND (Adaptation, Psychological OR Coping) AND (Nursing OR "Nursing care"). The search results were exported to Rayyan software, where duplicate records were removed. The review involved two independent reviewers who analysed the selected records according to the predefined inclusion and exclusion criteria. Discrepancies were resolved through consensus or consultation with a third reviewer. Record selection occurred in three stages: first, titles and abstracts were screened against the inclusion criteria. Second, reference lists of included studies were checked to identify additional relevant studies. In the third stage, full texts were reviewed to confirm eligibility. To map the data, the reviewers developed collection instruments, and the extracted information was presented in a narrative format, discussing the results in relation to the research objectives. The analysis was conducted in two phases: the first involved a descriptive analysis of the methodological characteristics of the records, including the year, origin, study design, cancer type and stage, and sample size. The second phase categorised the evidence into four groups of nursing interventions: typology, format, frequency, and assessment tools. The study protocol was registered on OSF with the registration number 10.17605/OSF.IO/TUCMA on October 2024.

Results

Search and Selection Process

The initial search yielded 1,547 records, comprising 262 from CINAHL Ultimate®, 980 from MEDLINE®, 3 from the Library, Information Science & Technology Abstracts, 6 from MedicLatina®, 96 from the Nursing & Allied Health Collection Comprehensive, and 200 from the Cochrane Library®. Among these, 261 duplicates were identified and removed. Following this process, 1,286 records were retained for screening and analysis, ultimately leading to the inclusion of 18 records. No additional relevant records were identified through checking the reference lists of included studies. Figure 1 depicts the PRISMA-ScR flowchart, illustrating the process of record selection and inclusion.

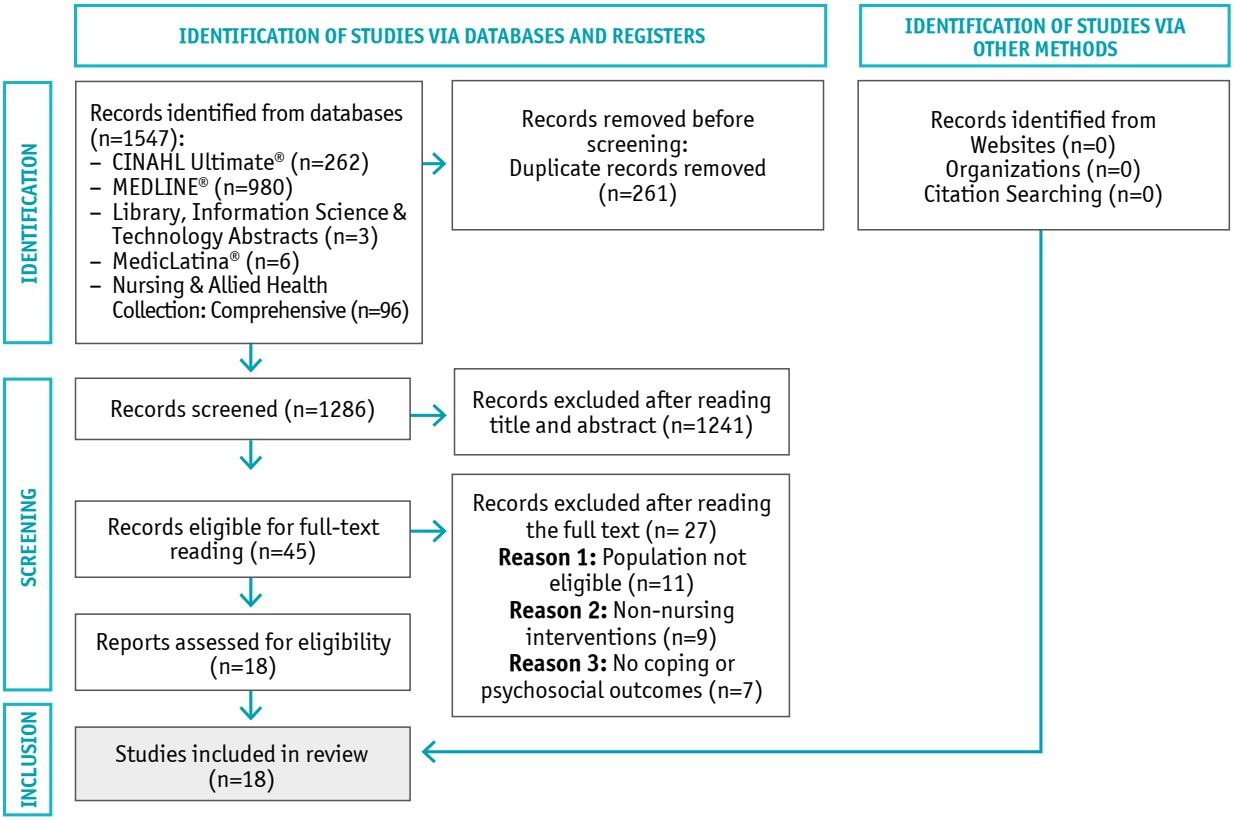

Figure 1. Flowchart PRISMA extension for scoping reviews

Overview of Included Studies

The analysis of the 18 included records facilitated an evaluation of the operationalisation of intervention programmes designed to promote coping in individuals with cancer. This analysis outlines the methodologies, structures, nursing interventions, and characteristics of the target population, including the type and stage of the disease. Table 1 provides a summary of the key records, emphasising their main objectives and the outcomes achieved.

Table 1. Records included in the Scoping Review

	AUTHORS	METHODOLOGY	OBJECTIVES	RESULTS/CONCLUSIONS
1	**Pourfallahi et al. (2020)**[21]	Quasi-experimental study with pre-post test	To analyse the impact of an informational and emotional support program, implemented by nurses, on the perceptions of the disease and on the emotional management of people with cancer.	A 10-week information and emotional support program implemented by nurses can lead to changes in perceptions of the disease without altering the effectiveness of emotional management.
2	**Sowada (2019)**[22]	Systematic Literature Review	To carry out an integrative literature review that reinforces the scientific evidence inherent in the practice and health gains of qigong in people with cancer, with an emphasis on the management of fatigue secondary to the disease process.	The analysis of the 22 studies indicated that the use of tai chi and qigong significantly improves fatigue, depression, sleep disturbances, and overall quality of life in people with cancer.
3	**Samami et al. (2021)**[23]	Randomized controlled clinical trial	Investigate the effect of a program promoting coping strategies and stress management for women with breast cancer.	The program showed a significant increase in problem-focused coping, but a decrease in emotion-focused coping scores. This can be explained by the stage of the pathological process, limited number of sessions, short interval between sessions and smaller sample size.
4	**Chow et al. (2020)**[24]	Randomized clinical trial	To evaluate the effects of a psychoeducational intervention program focused on disease uncertainty, anxiety and sexual functioning in a cohort of Chinese patients with gynecological cancer.	Users who received psychoeducational intervention reported significantly greater reductions in illness ambiguity, inconsistency and general uncertainty, as well as greater likelihood of being sexually active, increased libido for partners and greater intimacy between the couple.
5	**Chen et al. (2021)**[25]	Pre/post-intervention pilot study	To evaluate the feasibility and preliminary efficacy of the FOCUS psychoeducational program implemented by nurses in an oncology day hospital for patients and their families.	The results indicated an increase in self-efficacy in both users and caregivers, greater emotional well-being in users and a higher quality of life in caregivers, as well as a decrease in substance use by caregivers.
6	**Pace et al. (2019)**[26]	Randomized clinical trial	To compare the acceptability and effectiveness of Cognition-Based Compassion Training with Cancer Health Education in improving depressive symptoms and other domains of quality of life in cancer survivors and informal caregivers. As well as to determine the relationship between the results of the health care received with biomarkers of inflammation and diurnal cortisol rhythm.	This study aims to determine whether Cognition-Based Compassion Training is more effective than Cancer Health Education in improving depressive symptoms and quality of life, as well as optimizing the results of biomarkers of inflammation and the diurnal cortisol rhythm.
7	**Hamidian et al. (2019)**[27]	Quasi-experimental study	To determine the effect of cognitive-behavioural training on post-traumatic growth in women with breast cancer referred for chemotherapy treatment.	Cognitive-behavioural intervention has shown a positive and significant effect on post-traumatic growth in women with breast cancer.

	AUTHORS	METHODOLOGY	OBJECTIVES	RESULTS/CONCLUSIONS
8	**Fergus et al. (2022)[28]**	Randomized clinical trial	This study aims to examine participants' perceptions regarding three key aspects: the structure and content of the online intervention, the value of including a professional facilitator, and the benefits and drawbacks of the CoupleLinks program.	The study explores the benefits of using the Couplelinks platform for couples, highlighting its role in promoting open communication channels, creating shared quality moments, evoking feelings of togetherness and stimulating new insights into the relationship. These benefits position online interventions as a viable and flexible alternative to traditional couples counselling, offering an approach that is accessible and adaptable to contemporary needs.
9	**Chen et al. (2022)[29]**	Pilot Study	To evaluate the feasibility and acceptability of the Caring for Couples Coping with Colorectal Cancer (4Cs: CRC) program.	It aims to demonstrate that the Caring for Couples Coping with Colorectal Cancer (4Cs: CRC) program can effectively support couples dealing with colorectal cancer in mainland China.
10	**Lai et al. (2021)[30]**	Experimental Study	To determine the effectiveness of cognitive behavioural techniques (CBT) in improving the quality of sleep, anxiety, depression and health of individuals with breast cancer.	The results suggest that CBT increases sleep quality, reduces anxiety and depressive symptoms, optimizes users' coping skills and consequently improves their quality of life.
11	**Nasution et al. (2020)[31]**	Quasi-experimental quantitative study with pre- and post-tests	This study aims to determine the effectiveness of spiritual intervention on the coping and spiritual well-being of gynecological cancer patients.	This study showed that coping and spiritual well-being in the intervention group increased significantly after receiving the spiritual intervention. The first and third sessions promote emotion-focused coping, while the second and fourth sessions promote problem-focused coping.
12	**Matthys et al. (2021)[32]**	International multicenter randomized three-arm clinical trial	To evaluate the DIAdIC study, which will determine the effectiveness of two psychosocial and educational interventions aimed at improving the emotional functioning and self-efficacy of the family caregiver-user dyad.	This study aims to determine which type of intervention promotes the best results in terms of the emotional functioning and self-efficacy of the user-caregiver/family member dyad.
13	**Johns et al. (2020a)[33]**	Non-randomized, single-arm pilot study	To evaluate the feasibility, acceptability and preliminary effects of a mindfulness-based intervention to facilitate advance care planning (ACP) for adults with advanced cancer and their families/caregivers.	The mindfulness intervention showed feasibility and acceptability, promoting improvements in advance care planning (ACP) and associated results for users and caregivers/family members.
14	**Lambert et al. (2021)[34]**	Multicenter, stratified, parallel, pilot randomized clinical trial with two groups.	To test the acceptability and reliability of the TEMPO (Tailored, Web-based, Psychosocial, and Physical Activity Self-Management) program for men with prostate cancer and their caregivers.	The TEMPO program aims to assess whether it improves psychosocial self-management and physical activity in men with prostate cancer, as well as in their caregivers and family members.
15	**Kim & Yoo (2022)[35]**	Quasi-experimental study with pre-and post-test	To investigate the effects of a nurse-led advanced practice psychoeducational program on distress, anxiety, depression, cancer coping, health-promoting behaviour and quality of life in colorectal cancer survivors.	The psychoeducation program showed positive effects in reducing suffering and anxiety among cervical cancer survivors, enhancing their coping abilities, and improving their overall quality of life.
16	**Reb et al. (2020)[36]**	Mixed single-group studies	To assess the feasibility, acceptability and preliminary effects of a nurse-led intervention to manage fear of cancer progression in patients with advanced cancer.	The analysis showed improvements over time in fear of disease progression. Skills training helped control anxiety and fear, and participants reported feeling calmer and more focused.

	AUTHORS	METHODOLOGY	OBJECTIVES	RESULTS/CONCLUSIONS
17	Johns et al. (2020b)[37]	Three-arm Randomized Clinical Trial	To evaluate the feasibility and preliminary effectiveness of group-based Acceptance and Commitment Therapy (ACT) for Fear of Cancer Recurrence (FCR) in women with breast cancer.	The study found that group Acceptance and Commitment Therapy (ACT) is a promising intervention for women who have undergone breast-conserving surgery. It was effective in reducing fear of cancer recurrence and other psychological difficulties, as measured by the Perceived Stress Scale (PSS) and the Memorial Symptom Assessment Scale (MSAS).
18	Peixoto et al. (2023)[38]	Pilot Study Protocol	To present the protocol for a pilot study aimed at assessing the acceptability and feasibility of a psychoeducational nursing intervention designed to promote the adaptation of cancer survivors, with a focus on coping and anxiety.	The study aims to demonstrate the effectiveness of the proposed psychoeducational intervention program in enhancing adaptation among cancer survivors, optimizing coping strategies, and reducing anxiety symptoms.

Characteristics of Interventions

These records highlighted the integration of interventions and programmes developed by nurses, with their characterisation (encompassing their name, target population, methodology, interventions, structure, and operationalisation) presented in Table 2.

Table 2. Characterization of the programs and interventions developed by nurses - Part I

AUTHOR / YEAR/ COUNTRY	PROGRAM NAME	TARGET POPULATION	PROGRAM STRUCTURE		INTERVENTIONS
			TYPE OF SESSIONS	SESSION FEATURES	
Pourfallahi et al. (2020)[21] -Iran -	Support Care Cancer	Cancer patients on chemotherapy treatment (n: 80)	Individual Intervention	10 sessions weekly - 5 face-to-face sessions (45' a 90') + 5 follow-up telephone sessions (7' a 10')	Cognitive behavioural intervention a) Emotional support program
Sowada (2019)[22] - USA -	Qigong	Fatigue management in cancer survivors	Prevalence of group-based interventions	Predominance of records with 12 weekly sessions	Predominance of records in the field of cognitive behavioural intervention
Samami et al. (2021)[23] - Iran -	Supportive program on coping strategies and stress in women diagnosed with breast cancer	Women with breast cancer, up to one year after diagnosis, undergoing chemotherapy. (n =60)	Group Intervention	6 sessions weekly (90') + 1 follow up assessment at the end of the 1st month + homework	Cognitive behavioural intervention a) Diaphragmatic breathing b) Progressive muscle relaxation training, c) Coping strategies training d) Stress management e) Emotional regulation
Chow et al. (2020)[24] - China -	EIP	Women with newly diagnosed gynecological cancer ((n = 202)	Individual intervention	4 sessions - 1st, 2nd and 4th: face-to-face sessions (45' to 60') 3rd: telephone session (20 to 35')	Psychoeducational intervention

AUTHOR / YEAR/ COUNTRY	PROGRAM NAME	TARGET POPULATION	PROGRAM STRUCTURE		INTERVENTIONS
			TYPE OF SESSIONS	SESSION FEATURES	
Chen et al. (2021)[25] - USA-	FOCUS	Adult Cancer patients and their caregivers /family members (n=60)	Dyadic intervention	6 to 9 weeks of intervention 3 sessions: 2 home visits (6 weeks apart) + 1 telephone session of 30' + educational material	Cognitive behavioural intervention a) Psychosocial intervention b) Motivational interviewing c) Aid relationship d) Psychoeducational intervention
Pace et al. (2019)[26] - USA -	CBCT (Cognition-Based Compassion Training) + CHE (Cancer Health Education)	Solid Tumor Survivors who have completed treatments other than hormone therapy and their caregivers/family (n=40 dyads)	Dyadic intervention	CBCT: 8 sessions weekly + 2 follow up sessions CHE: 8 face-to-face sessions (120'/ weekly) + 10' homework + telephone contacts	Cognitive behavioural intervention a) Compassion training based on cognition and psychoeducation
Hamidian et al. (2019)[27] - Iran -	Cognitive Emotional Training on Post-traumatic Growth	Patients with Breast Cancer (n=85)	Group intervention	3 weeks 5 sessions (2x/week, 60' a 90')	Cognitive behavioural intervention a) Cognitive-emotional training in post-traumatic growth
Fergus et al. (2022)[28] - Canada -	Couplelinks	Young couples dealing with breast cancer on a chemotherapy treatment (n=86)	Dyadic intervention	8 weeks: 6 asynchronous online sessions + weekly homework + telephone follow-up	Psychoeducational intervention a).Assertive communication training
Chen et al. (2022)[29] - China -	Caring for Couples Coping with Colorectal Cancer "4Cs: CRC" Program	Couples dealing with colorectal cancer (n= 20 dyads)	Dyadic intervention	6 weeks: 5 online sessions weekly + 3 face-to-face sessions, twice a week (60' to 90')	Cognitive behavioural intervention
Lai et al. (2021)[30] - Taiwan -	Cognitive Behavioural Therapy plus Coping Manage-ment for Depression and Anxiety (CBTM)	Breast cancer patients during the recovery period. Experimental group (n= 36), Control group (n= 34)	Group intervention	12 sessions /2h / weekly	Cognitive behavioural intervention focused on identity a)Problem-solving training, b)Restructuring dysfunctional beliefs, c)Promoting coping, d)Relaxation and rehabilitation techniques. e)Symptom management
Nasution et al. (2020)[31] - Indonesia -	Spiritual Intervention towards Coping and Spiritual Well-being	Patient with gynecological cancer (n=108)	Group intervention	2 weeks: 4 sessions (60' a 90')	Psychotherapeutic intervention with a focus on spirituality: a)Relaxation techniques, b)Assertive communication training c) Promoting coping

AUTHOR / YEAR/ COUNTRY	PROGRAM NAME	TARGET POPULATION	PROGRAM STRUCTURE		INTERVENTIONS
			TYPE OF SESSIONS	SESSION FEATURES	
Matthys et al. (2021)[32] - Belgium, Denmark, Ireland, Italy, the Netherlands and the United Kingdom	DIAdIC Study: FOCUS + iFOCUS	Patient with advanced cancer and their direct caregiver / family member	Dyadic intervention	12 weeks: iFOCUS: 4 online sessions (30') + FOCUS: 2 home visits (90') + video session 30'	Cognitive behavioural intervention a)Promoting the family process, b)Cognitive restructuring, c)Promoting coping, d)Emotional regulation e)Symptom management, f)Problem-solving training
Johns et al. (2020a)[33] - USA -	MODEL Care - Mindfully Optimizing Delivery of End-of-Life Care	Adults with metastatic cancer and their caregivers (n=26)	Dyadic intervention	6 sessions weekly (120') + 20'/daily mindfulness sessions	Psychotherapeutic intervention: a) Mindfulness training, b)Interpersonal effectiveness training c)Assertive communication training
Lambert et al. (2021)[34] - Canada -	TIME	Prostate cancer patients and their caregivers	Dyadic intervention	10 Weeks: 5 asynchronous online modules + digital library suggested interval of 2 weeks between modules;	Cognitive behavioural intervention a)Management of physical symptoms, b) Stress management, d)Assertive communication training, e)Problem-solving training, e)Support in the decision-making process
Kim & Yoo (2022)[35] - Correia do Sul -	Advanced practice psycho-educational program led by nurses	Colon Rectal Cancer Survivors (n=39)	Mixed intervention	6 sessions weekly (120') 5 group sessions + 1 individual session	Psychotherapeutic intervention: a) Coping skills training b)Problem-solving training, c)Stress management and emotional regulation
Reb et al. (2020)[36] - USA -	Day By Day (DBD)	Patients with stage III or IV gynecological or lung cancer (n = 31) exhibiting dysfunctional levels of fear of progression or emotional distress	Individual Intervention	8 weeks: 7 videocall/ telephone sessions (1st face-to-face assessment followed by 6 non-face-to-face sessions)	Psychotherapeutic intervention: a)Cognitive restructuring b)Behavior modification c) Relaxation therapy / mindfulness training d)Decision-making support
Johns et al. (2020b)[37] - USA -	Group intervention program based on Acceptance and Commitment Therapy (ACT)	Patient after breast-conserving surgery with fear of cancer recurrence.	Group intervention	6 sessions: 120' weekly + education sessions	Psychotherapeutic intervention: Acceptance and Commitment Therapy (ACT)
Peixoto et al. (2023)[38] - Portugal -	Educational nursing intervention to promote adaptation in survivors	Cancer survivors	Mixed intervention	8 sessions weekly: 60' group sessions (1,3,5, 7) + 30' individual or dyadic intervention (2,4,6 e 8)	Psychoeducational Intervention

Summary of Outcomes

Most of the records included in this review were published in 2020 (n=6);[21,24,31,33,36,37] five in 2021;[23,25,30,32,34] three in 2022;[28,29,35] three in 2019[22,26,27] and one in 2023[38]. The USA has the highest prevalence of scientific evidence on this topic (n=6);[22,25,26,33,36,37] Iran followed with three records (n=3);[21,23,27] Canada[28,34] and China[24,29] with two records each; Taiwan[30], Indonesia[31], South Korea[35] and Portugal[38] with one record each. In addition to a record involving several countries, Belgium, Denmark, Ireland, Italy, the Netherlands and the United Kingdom.[32] In terms of the most commonly employed methodology, randomised clinical trials ranked as the most prevalent (n=7),[23,24,26,28,32,34,37] followed by quasi-experimental studies (n=4),[21,27,31,35] pilot studies (n=3),[25,29,33] experimental studies (n=1),[30] systematic literature reviews (n=1),[22] mixed studies (n=1)[36] and pilot study protocols (n=1).[38] A significant number of records included more than one type of cancer (n=8),[21,22,25,26,32,33,36,38] followed by breast cancer records (n=5),[23,27,28,30,37] rectal cancer (n=2),[29,35] gynaecological cancer (n=2)[24,31] and prostate cancer (n=1).[34] Most of the records considered intervention in the phase of the disease between initial diagnosis and treatments (n=7),[21,23–25,28,29,34] six focused on the survival phase (n=6)[22,26,30,35,37,38] and three in the palliative phase (n=3).[32,33,36] One of the records considered intervention in both the treatment and survival phases[27] and another considered the intervention regardless of the stage of the cancer disease.[31] The analysed records included population samples of more than 20 participants, with the largest being Chow et al.[24], which comprised 202 participants. Regarding interventions and approaches to facilitate coping in adults with cancer, those within the cognitive-behavioural field were particularly emphasised (n=10)[21–23,25–27,29,30,32,34]. This was followed by programs with exclusive interventions in the psychotherapeutic domain (n=5)[31,33,35–37] and in the psychoeducational domain (n=3).[24,28,38] Of the coping-promoting psychotherapeutic interventions mentioned, relaxation and mindfulness techniques (n=7)[22,23,30,31,33,36,37], promotion of the family processes (n=7)[25,26,28,29,32–34], stress management skills training (n=5)[22,23,34,35,37], communication skills training (n=5)[24,28,31,33,34] and the problem-solving technique (n=4)[30,32,34,35] were the most emphasised by the scientific community. It was also found that dyadic intervention (user/family member or caregiver) was mentioned in seven records (n=7)[25,26,28,29,32–34], group interventions in six records (n=6)[22,23,27,30,31,37], individual intervention in three (n=3)[21,24,36] and the mixed intervention in two (n=2),[35,38] The strategies adopted to implement the nursing interventions were predominantly face-to-face (n=14).[21–26,29–31,33,35–38] Although four records (n=4) combined face-to-face sessions with follow-up telephone consultations.[21,24–26] However, two records (n=2) indicated the exclusive use of online sessions as an intervention strategy[28,34] and two records (n=2) considered both modalities (face-to-face and non-face-to-face).[29,32] The sharing of educational material and the sending of homework was identified in five records (n=5).[25,26,27,33,37]

The most used inclusion criteria across the studies were age (18 years or older), a recent cancer diagnosis or undergoing cancer treatment, the ability to understand the local language, and availability to participate in the proposed sessions. In contrast, the exclusion criteria varied across the studies but generally involved medical conditions that could impede active participation in the programme.

Discussion

The variety of methodologies used reflects the complexity of the subject and the need for multidisciplinary approaches.

Cognitive-behavioural interventions appear to be widely supported in the scientific community. According to Hamidian et al.,[27] group interventions enhance cognitive and emotional adaptation by fostering discussion, sharing experiences, and restructuring beliefs. Pourfallahi et al.,[21] argue that individual interventions provide personalized attention and are effective for addressing specific needs and emotional challenges, but they limit peer support, which is crucial for coping. Dyadic interventions, on the other hand, strengthen support and communication within the family context.[34] Mixed interventions combine the benefits of the approaches, although they are more complex in terms of operationalisation.

Regarding the setting of interventions, the inclusion of digital methodologies has been noted, offering increased convenience, accessibility, and, when asynchronous, flexibility.[28,29,32,34] However, face-to-face interventions allow for more direct interaction, which can facilitate a deeper understanding of individual needs and foster trust and security.

Individual, dyadic, and group interventions, delivered through both face-to-face and online formats, play a crucial role in supporting adults with cancer. Each approach offers distinct advantages and presents unique challenges. The choice of the most suitable strategy should be based on the individual's specific needs and preferences, in conjunction with available resources and logistical support from healthcare professionals.

The literature widely agrees that the phase of the disease between initial diagnosis and treatment is crucial, with homework assignments recognized as an effective strategy for consolidating knowledge and skills during this stage.[25,33,34,26]

The recommended number of sessions for a programme that addresses the emotional and psychosocial needs of individuals with cancer generally ranges from 6 to 12 sessions (n = 11).[23,26,28–30,32,33,35–38]

Regarding session duration, there was greater consensus on durations between 45 and 90 minutes (n = 9)[21,23–25,27,29,31,36,38] depending on the intervention methodology, depth of content, and planned activities.

In terms of session frequency, the analysed records indicated that weekly interventions were predominant (n = 9).[21–23,26,30,33,35,37,38]

Despite the valuable findings, several limitations should be noted. The diversity of methodologies, the cancer types studied, and the lack of long-term follow-up limit the generalisability of results. Therefore, future research should focus on standardising interventions, assessing long-term effects, and comparing digital with face-to-face approaches on coping.

Conclusions and Implications for Clinical Practice

The results indicate that the scientific community has increasingly developed programmes aimed at facilitating the adaptation and emotional adjustment of patients and their families to cancer. This is largely due to the recognition of the importance of such interventions in optimising the management of emotional and psychosocial challenges associated with the disease, which have both direct and indirect effects on the well-being and quality of life of this population.

A holistic and personalised approach, tailored to individual and contextual needs, remains essential for fostering healthy adaptation to the disease process and improving the quality of life for cancer patients.

Although the results suggest the potential effectiveness of these interventions, it is important to acknowledge the limitations of this review, including the possible exclusion of relevant studies due to the limited selection of databases and the lack of an evaluation of the methodological quality of the included studies.

These findings underscore the ongoing need for further research in this field, with the goal of enhancing nursing interventions and providing more effective support to cancer patients and their caregivers.

Mapping the therapeutic interventions implemented by nurses to promote coping in individuals with cancer could serve as a valuable tool to support nursing decision-making and clinical practice. It could also contribute to the development of nursing programmes aimed at promoting coping in adults with cancer, as well as facilitate the dissemination of existing evidence on this subject.

References

1. Ferlay J, Ervik M, Lam F, Laversanne M, Colombet M, Mery L, et al. Global Cancer Observatory: Cancer Today. Lyon, France: International Agency for Research on Cancer. Available from: https://gco.iarc.who.int/today [Internet]. Lyon, France: International Agency for Research on Cancer.; 2024 [citado 14 de julho de 2024]. Disponível em: https://gco.iarc.who.int/today
2. Bray F, Laversanne M, Sung H, Ferlay J, Siegel RL, Soerjomataram I, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2024;74(3):229–63.
3. European Comission. Advancing the Right To Be Forgotten - Stocktaking of Progress and Challenges [Internet]. Conference apresentado na: Cancer Survivorship; 2024 mai; Brussels, Belgium. Disponível em: https://health.ec.europa.eu/events/cancer-survivorship-advancing-right-be-forgotten-2024-05-14_en
4. Kissane D. Beyond the psychotherapy and survival debate: the challenge of social disparity, depression and treatment adherence in psychosocial cancer care. Psychooncology. 2009 Jan;18(1):1–5.
5. Alsughayer LY, Altamimi LA, Alsaleh FS, Alsaghan L, Alfurayh I, Abdel-Aziz NM, et al. Prevalence and determinants of distress among oncology patients at a tertiary care medical city in Riyadh, Saudi Arabia. Saudi Med J. 2021 Jul;42(7):761–8.
6. Peters L, Brederecke J, Franzke A, de Zwaan M, Zimmermann T. Psychological Distress in a Sample of Inpatients With Mixed Cancer-A Cross-Sectional Study of Routine Clinical Data. Front Psychol. 2020;11:591771.
7. Harami RV, Ghorbani A, Ghaffariyan S, Asgari N, Akbari M, Ranjbaran F, et al. Psychological and psychiatric issues in patients diagnosed with cancer: A review study. J Prev 2023 Dec 29;9(1):e35238–e35238.
8. Niedzwiedz CL, Knifton L, Robb KA, Katikireddi SV, Smith DJ. Depression and anxiety among people living with and beyond cancer: a growing clinical and research priority. BMC Cancer. 2019 Dec; (1):1–8.
9. Nikbakhsh N, Moudi S, Abbasian S, Khafri S. Prevalence of depression and anxiety among cancer patients. Casp J Intern Med. 2014 Summer:5(3):167.
10. Caruso R, Nanni MG, Riba MB, Sabato S, Grassi L. The burden of psychosocial morbidity related to cancer: patient and family issues. Int Rev Psychiatry Abingdon Engl. 2017 Oct;29(5):389–402.
11. Van Beek FE, Jansen F, Mak L, Lissenberg-Witte BI, Buter J, Vergeer MR, et al. The course of symptoms of anxiety and depression from time of diagnosis up to 2 years follow-up in head and neck cancer patients treated with primary (chemo)radiation. Oral Oncol. 2020 Mar;102:104576.
12. Wang X, Wang N, Zhong L, Wang S, Zheng Y, Yang B, et al. Prognostic value of depression and anxiety on breast cancer recurrence and mortality: a systematic review and meta-analysis of 282,203 patients. Mol Psychiatry. 2020 Dec;25(12):3186–97.
13. Grassi L, Caruso R, Riba MB, Lloyd-Williams M, Kissane D, Rodin G, et al. Anxiety and depression in adult cancer patients: ESMO Clinical Practice Guideline†. ESMO Open [Internet]. 2023 Apr 1; [citado 30 de julho de 2024];8(2). Disponível em: https://www.esmoopen.com/article/S2059-7029(23)00375-7/abstract

14. Riba MB, Donovan KA, Ahmed K, Andersen B, Braun Ii, Breitbart WS, et al. NCCN Guidelines® Insights: Distress Management, Version 2.2023: Featured Updates to the NCCN Guidelines. J Natl Compr Canc Netw. 2023 May 1; 21(5):450–7.
15. Holland JC, Alici Y. Management of distress in cancer patients. J Support Oncol. 2010;8(1):4–12.
16. Greally H, Love D, Mullen L. HSE.ie. 2020 [citado 18 de maio de 2024]. Hospital and Community-based Psychosocial Care for Patients with Cancer and their Families: A Model of Care for Psycho-Oncology. Disponível em: https://www.hse.ie/eng/services/list/5/cancer/profinfo/psycho-oncology-programme/model%20of%20care.pdf
17. Holland JC, Lazenby M, Loscalzo MJ. Was There a Patient in Your Clinic Today Who Was Distressed? J Natl Compr Cancer Netw JNCCN. 2015 Sept;13(9):1054–6.
18. Jacobsen PB, Jim HS. Psychosocial interventions for anxiety and depression in adult cancer patients: achievements and challenges. CA Cancer J Clin. 2008;58(4):214–30.
19. Karam M, Chouinard MC, Poitras ME, Couturier Y, Vedel I, Grgurevic N, Hudon C. Nursing care coordination for patients with complex needs in primary healthcare: a scoping review. Int J Integr Care. 2021 Mar 19;21(1):16. doi: 10.5334/ijic.5518. PMID: 33776605; PMCID: PMC7977020.
20. Pourfallahi M, Gholami M, Tarrahi MJ, Toulabi T, Kordestani Moghadam P. The effect of informational-emotional support program on illness perceptions and emotional coping of cancer patients undergoing chemotherapy. Support Care Cancer Off J Multinatl Assoc Support Care Cancer. 2020;28(2):485–95.
21. Sowada KM. Qigong: Benefits for Survivors Coping With Cancer-Related Fatigue. Clin J Oncol Nurs. 2019;23(5):465–9.
22. Samami E, Elyasi F, Mousavinasab SN, Shojaee L, Zaboli E, Shahhosseini Z. The effect of a supportive program on coping strategies and stress in women diagnosed with breast cancer: A randomized controlled clinical trial. Nurs Open. 2021;8(3):1157–67.
23. Chow KM, Chan CWH, Choi KC, Siu KY, Fung HKS, Sum WM. A theory-driven psycho-educational intervention programme for gynaecological cancer patients during treatment trajectory: A randomised controlled trial. Psychooncology. 2020;29(2):437–43.
24. Chen HL, Annie Kao TS, Reuille KM, Northouse L. FOCUS Program: Treating Patients With Cancer and Family Caregivers as a Unit of Care. Clin J Oncol Nurs. 2021;25(3):E17–25.
25. Pace TWW, Dodds SE, Sikorskii A, Badger TA, Segrin C, Negi LT, et al. Cognitively-Based Compassion Training versus cancer health education to improve health-related quality of life in survivors of solid tumor cancers and their informal caregivers: study protocol for a randomized controlled pilot trial. Trials. 2019;20(1):247.
26. Hamidian P, Rezaee N, Shakiba M, Navidian A. The Effect of Cognitive-Emotional Training on Post-traumatic Growth in Women with Breast Cancer in Middle East. J Clin Psychol Med Settings. 2019;26(1):25–32.
27. Fergus K, Tanen A, Ahmad S, Gardner S, Warner E, McLeod D, et al. Treatment Satisfaction With Couplelinks Online Intervention to Promote Dyadic Coping in Young Couples Affected by Breast Cancer. Front Psychol. 2022;13:862555.
28. Chen M, Gong J, Cao Q, Li Q. The development and evaluation of a web-based complex intervention: The caring for couples coping with colorectal cancer «4Cs: CRC» program. Asia-Pac J Oncol Nurs. 2022;9(5):100050.
29. Lai HL, Chen CI, Lu CY, Huang CY. Cognitive Behavioural Therapy plus Coping Management for Depression and Anxiety on Improving Sleep Quality and Health for Patients with Breast Cancer. Brain Sci [Internet]. 2021;11(12). Disponível em: https://search.ebscohost.com/login.aspx?direct=true&db=mdc&AN=34942916&lang=pt-pt&site=ehost-live
30. Nasution LA, Afiyanti Y, Kurniawati W. Effectiveness of Spiritual Intervention toward Coping and Spiritual Well-being on Patients with Gynecological Cancer. Asia-Pac J Oncol Nurs. 2020;7(3):273–9.
31. Matthys O, De Vleminck A, Dierickx S, Deliens L, Van Goethem V, Lapeire L, et al. Effectiveness of a nurse-delivered (FOCUS+) and a web-based (iFOCUS) psychoeducational intervention for people with advanced cancer and their family caregivers (DIAdIC): study protocol for an international randomized controlled trial. BMC Palliat Care. 2021;20(1):193.
32. Johns SA, Beck-Coon K, Stutz PV, Talib TL, Chinh K, Cottingham AH, et al. Mindfulness Training Supports Quality of Life and Advance Care Planning in Adults With Metastatic Cancer and Their Caregivers: Results of a Pilot Study. Am J Hosp Palliat Care. 2020;37(2):88–99.
33. Lambert SD, Duncan LR, Ellis J, Robinson JW, Sears C, Culos-Reed N, et al. A study protocol for a multicenter randomized pilot trial of a dyadic, tailored, web-based, psychosocial, and physical activity self-management program (TEMPO) for men with prostate cancer and their caregivers. Pilot Feasibility Stud. 2021;7(1):78.
34. Kim HK, Yoo YS. [Effects of the Advanced Practice Nurse-Led Psychoeducational Program for Colorectal Cancer Survivors]. J Korean Acad Nurs. 2022;52(3):245–60.
35. Reb AM, Borneman T, Economou D, Cangin MA, Cope DG, Ma H, et al. A nurse-led intervention for fear of cancer progression in advanced cancer: A pilot feasibility study. Eur J Oncol Nurs Off J Eur Oncol Nurs Soc. 2020;49:101855.
36. Johns, Stutz, Talib, Cohee, Beck-Coon, Brown LF, et al. Acceptance and commitment therapy for breast cancer survivors with fear of cancer recurrence: A 3-arm pilot randomized controlled trial. Cancer. 2020;126(1):211–8.
37. Peixoto TADSM, dos Santos Martins Peixoto NM, Santos Pinto CA, Vilaça de Brito Santos CS. Intervenção Educacional Em Enfermagem Para Promover a Adaptação Nos Sobreviventes De Câncer: Protocolo Para Estudo-Piloto: Cogitare Enfermagem. Cogitare Enferm. janeiro de 2023;28:1–15.
38. Reb, Borneman, Economou, Cangin, Patel, Sharpe, et al. Fear of Cancer Progression: Findings From Case Studies and a Nurse-Led Intervention. Clin J Oncol Nurs. 2020;24(4):400–8.
39. Peters M, Godfrey C, Mcinerney P, Munn Z, Trico A, Khalil H. Scoping Reviews. Em: JBI Manual for Evidence Synthesis [Internet]. 2024.a ed. JBI; 2024. Disponível em: https://synthesismanual.jbi.global.

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