

Barriers to accessing palliative care in advanced liver disease

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Abstract

This study analyzed, from a bioethical perspective and through an integrative review, the barriers to accessing palliative care for patients with advanced liver disease. The guiding research question was: "What are the barriers to accessing palliative care for these patients across different levels of healthcare?" The literature search was conducted in the Medline/PubMed and Scopus databases using descriptors related to palliative care and end-stage liver disease. After screening 410 articles, 27 studies published between 2019 and 2024 were included and qualitatively analyzed. The barriers identified were classified into three categories: patient-related, physician-related, and institutional. Among patients, the main barriers included the association of palliative care with end-of-life care, limited understanding of prognosis, and fear of losing the opportunity for liver transplantation. For physicians, important barriers included prognostic uncertainty, transplant eligibility concerns, and limited availability of palliative care specialists. At the institutional level, the main challenges were the lack of outpatient palliative care clinics, insufficiently trained professionals, and the absence of automated care processes.

Keywords: Bioethics. Palliative care. End-stage liver disease.

Resumo

Barreiras ao acesso a cuidados paliativos na doença hepática avançada

Este estudo analisou, com enfoque bioético e por meio de revisão integrativa, as barreiras ao acesso de pacientes com doença hepática avançada a cuidados paliativos. A questão norteadora foi: "Quais são as barreiras ao acesso a cuidados paliativos para esses pacientes nos diferentes níveis de atenção?". A busca foi realizada nas bases Medline/PubMed e Scopus, com descritores relacionados a cuidados paliativos e doença hepática terminal. Após triagem de 410 artigos, foram incluídos e analisados qualitativamente 27, publicados entre 2019 e 2024. As barreiras foram classificadas em três categorias: pacientes, médicos e institucionais. Entre os pacientes, destacaram-se a associação de cuidados paliativos a fim de vida, o desconhecimento prognóstico e o receio de perder a chance de transplante. Para médicos, pesaram fatores como incerteza prognóstica, elegibilidade para transplante e indisponibilidade de especialistas. Institucionalmente, faltam ambulatorios, profissionais treinados e processos automatizados.

Palavras-chave: Bioética. Cuidados paliativos. Doença hepática terminal.

Resumen

Barreras al acceso a los cuidados paliativos en la enfermedad hepática avanzada

Este estudio analizó, desde una perspectiva bioética y mediante una revisión integradora, las barreras para el acceso de pacientes con enfermedad hepática avanzada a los cuidados paliativos. La pregunta orientadora fue: «¿Cuáles son las barreras para el acceso a los cuidados paliativos de estos pacientes en los diferentes niveles de atención sanitaria?» La búsqueda se realizó en las bases de datos Medline/PubMed y Scopus, utilizando descriptores relacionados con los cuidados paliativos y la enfermedad hepática terminal. Tras el cribado de 410 artículos, se incluyeron y analizaron cualitativamente 27 estudios publicados entre 2019 y 2024. Las barreras se clasificaron en tres categorías: relacionadas con los pacientes, con los médicos y con las instituciones. Entre los pacientes, destacaron la asociación de los cuidados paliativos con el final de la vida, el desconocimiento del pronóstico y el temor a perder la oportunidad de un trasplante hepático. En cuanto a los médicos, influyeron factores como la incertidumbre pronóstica, la elegibilidad para el trasplante y la escasa disponibilidad de especialistas en cuidados paliativos. A nivel institucional, se observaron carencias de consultas ambulatorias de cuidados paliativos, de profesionales capacitados y de procesos asistenciales automatizados.

Palabras clave: Bioética. Cuidados paliativos. Enfermedad hepática en estado terminal.

The authors declare no conflict of interest.

Advanced liver cirrhosis is irreversible and its symptom burden is comparable to cancer, as its complications cause intense suffering to patients and their families¹. Disease progression increases prognostic uncertainty and complicates therapeutic decision-making, with biological complications such as ascites, digestive bleeding, infections, neoplasms, and hepatic encephalopathy, the latter being a frequent complication, which affects more than 40% of patients². Alcohol-related cases can also present psychological disorders such as anxiety, depression, and even suicide attempts, in addition to social isolation^{1,3}.

Despite decompensated cirrhosis patients having an average survival of approximately two years, palliative care (PC) referral is frequently delayed. This leads to therapeutic obstinacy, prolonged hospitalizations, and high hospital costs, thus diminishing the potential benefits of PC⁴. Still, only about 21% of patients receive a referral⁵, due to barriers involving patients, professionals, and institutions⁶. Reflection on such barriers from a bioethical perspective can strengthen supportive and responsible practices in health care⁷.

Early integration of PC can mitigate vulnerabilities, avoid futile treatments, and improve quality of life and survival. The *Supportive and Palliative Care Indicators Tool – Brazilian version* (SPIC-Br)⁸ is a tool that helps identify people with indications for PC and make ethical decisions in these situations. It cites the following potentially serious clinical complications of cirrhosis in the last year as criteria for indicating PC: diuretic-refractory ascites, hepatic encephalopathy, hepatorenal syndrome, bacterial peritonitis, recurrent variceal bleeding due to portal hypertension, and when liver transplantation is no longer possible. In Brazil, Ministry of Health Ordinance 3,681/2024⁹ consolidates the National Palliative Care Policy, which aims to expand access to PC throughout the health care network.

The objective of this study was to analyze the barriers to accessing palliative care for patients with advanced liver disease, considering bioethical dimensions and different levels of health care.

Method

This integrative review adopted the following steps: problem identification (variables of interest,

such as concepts, target population, and health problem); database search; data review and analysis; and, finally, review presentation¹⁰. The research question was formulated using the PCC (population, concept, and context) strategy, where P is patients with advanced liver disease, C is barriers to accessing palliative care, and the second C is all levels and modes of health care in different countries. We defined the following guiding question: “What are the barriers to accessing palliative care for patients with advanced liver disease across different levels of health care?”

The literature search used the MEDLINE/PubMed and Scopus databases and adopted descriptors selected according to the terms of the Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH), with the following strategies:

- a. (“Palliative care”[All Fields] AND “Advanced Liver Disease”[All Fields]) AND (y_5[Filter]);
- b. (“Palliative care”[All Fields] AND “End-Stage Liver Disease”[All Fields]) AND (y_5[Filter]);
- c. (“Palliative care”[All Fields] AND “Liver failure”[All Fields]) AND (y_5[Filter]);
- d. (“Palliative care”[All Fields] AND “Decompensated cirrhosis”[All Fields]) AND (y_5[Filter]); and
- e. (“Supportive palliative care”[All Fields] AND “End-Stage Liver Disease”[All Fields]) AND (y_5[Filter]).

We also conducted a search in the grey literature, with consultation of the *webpage* of the American Association for the Study of Liver Diseases.

It included randomized controlled trials, controlled clinical trials without randomization, case-control or cohort studies, qualitative or descriptive studies, and expert opinions or consensus, involving participants aged 18 years or older, published between January 2019 and April 2024. The time frame of the five years prior to the research (2019–2024) was chosen to ensure the inclusion of recent studies and avoid the incorporation of outdated evidence, given that the field of palliative care has shown significant advances in terms of research and practice. Duplicate articles, review articles, and articles that did not answer the guiding question were excluded.

The level of evidence of the included studies was classified according to the hierarchy proposed by Melnyk and collaborators¹¹, considering the methodological design of each

study. This classification organizes studies into seven hierarchical levels, with Level I being considered the strongest evidence and Level VII being considered the weakest evidence. The classification comprises: level I, systematic reviews or meta-analyses of randomized clinical trials; level II, randomized clinical trials; level III, controlled clinical trials without randomization; level IV, case-control or cohort studies; level V, systematic reviews of qualitative or descriptive studies; level VI, qualitative or descriptive studies; and level VII, expert opinion or consensus.

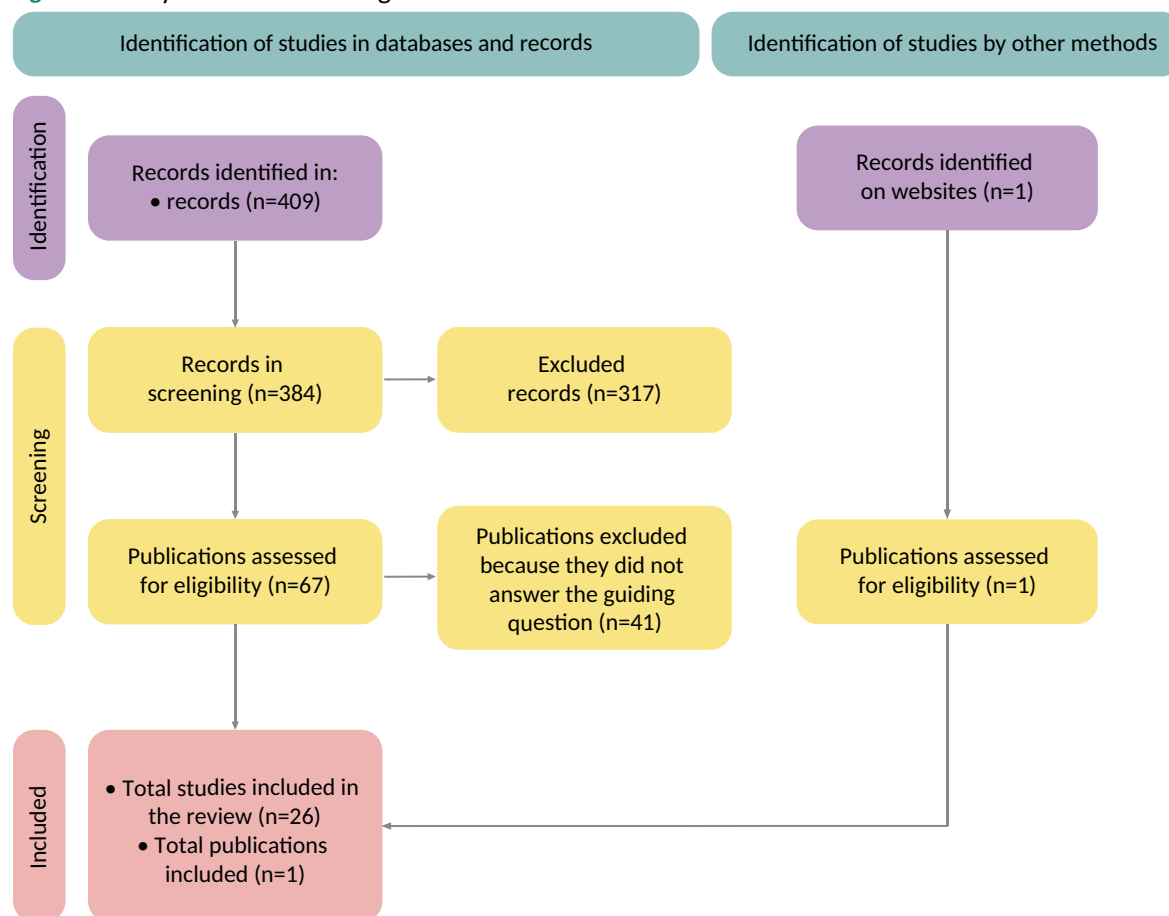
Phillips and Kedarisetty⁶ was adopted as the basis for the three categories relative to the origin of barriers to PC in patients with advanced liver disease: barriers from physician perspective, barriers from patient perspective, and institutional barriers.

The barriers extracted from the results and discussions of the studies were entered into an Excel spreadsheet with the pieces of information that characterize the studies. Subsequently, they were grouped/organized by similarity and categorized by the inductive content analysis method described by Elo and Kyngäs¹², which involves the preparation, organization, and report steps. In the preparation step, the selected data were carefully read, with definition of the unit of analysis. In the organization step, the data were submitted to open coding, followed by code grouping by similarity and category formation,

allowing the categories to emerge inductively from the analyzed material. In the report stage, the analysis procedures and results were described and presented, with synthesis of the identified categories and main barriers related to the phenomenon under study.

The review report was based on the (PRISMA) checklist for systematic reviews¹³, which provides essential items to ensure the transparency and completeness of systematic review reporting, including the description of the search strategy, study selection, data extraction, and data synthesis. We also considered the recommendations of Toronto and Remington¹⁰ for conducting and reporting integrative reviews, encompassing steps such as problem identification, literature search and selection, evidence review and synthesis, and results presentation.

In total, 409 publications were identified in the consulted databases, of which 25 were excluded for being duplicates, resulting in 384 articles. After reading titles and abstracts, 317 articles were excluded, leaving 67 articles, of which 40 articles did not meet the guiding question. Thus, 27 articles were included in the review, with 26 original articles and 1 expert consensus obtained from the grey literature, which addressed barriers to accessing palliative care for patients with advanced liver disease at different levels of health care (Figure 1).

Figure 1. Study selection flow diagram

For the descriptive analysis, the percentages referring to the general characteristics of the studies were calculated based on the 27 included studies. For the analysis of barriers, the percentages were calculated separately for each category, with calculation bases of 13 studies for patient-related barriers, 21 studies for physician-related barriers, and 12 studies for institutional issue-related barriers. As a same study could present barriers belonging to more than one category, the calculation bases were considered independently for each group.

Results

Of the 27 studies included, most were conducted in North America, mainly in the United States (78%), followed by Europe (11%), Oceania (7.5%), and Asia (3.5%). No studies conducted in Latin America or Africa were identified.

The barriers to accessing palliative care in advanced liver disease were organized into three groups, presented in Charts 1, 2, and 3: patient-related barriers, physician-related barriers, and institutional issue-related barriers, respectively. Of the 27 studies included, 19 were presented in more than one table, as they reported barriers belonging to two or all three groups analyzed.

From the perspective of patients, frequently reported by physicians and caregivers, notable barriers include confusion between PC and end-of-life care¹⁴⁻¹⁶ and lack of knowledge about prognosis¹⁷⁻¹⁹ (23% of studies). Concerns about the possibility of PC interfering with transplant eligibility^{15,16} (15%) and the lack of health insurance^{20,21} (15%) were also cited. In addition, other barriers involved sociodemographic factors, such as age, sex, knowledge level, income, habits, minority groups, and emotional condition^{17,20-26} (Chart 1).

Chart 1. Barriers to accessing palliative care for patients with advanced liver disease in studies related to patients

Authors	Year	Country	Sample	Patient type	Study method	Barrier code	Level of evidence
Ufere and collaborators ¹⁴	2019	USA	396 physicians	Inpatients	Cross-sectional research	1	VI
Donlan and collaborators ¹⁵	2021	USA	15 patients 14 caregivers	Outpatients	Qualitative research	1, 2	VI
Esteban and collaborators ¹⁶	2019	USA	311 physicians	Inpatients	Qualitative research	1, 2	VI
Barnes and collaborators ¹⁷	2020	Australia	74 patients	Inpatients	Retrospective cohort study	5	IV
Brown, Aksan, Muir ¹⁸	2023	USA	19,308 patients	Inpatients and outpatients	Retrospective study	5	VI
Vieira da Silva and collaborators ¹⁹	2023	Portugal	54 patients	Inpatients	Prospective study	5	VI
Alterio and collaborators ²⁰	2021	USA	27,263 patients with cancer (HCC)	Inpatients and outpatients	Retrospective study	9, 10, 11	VI
Rogal and collaborators ²¹	2022	USA	Patients	Inpatients and outpatients	Systematic reviews and meta-analyses	11, 17	I
Kabaria and collaborators ²²	2021	USA	585,859 patients	Inpatients	Retrospective cohort study	14, 15, 16	IV
Woodland and collaborators ²³	2023	United Kingdom	29,514 patients	Inpatients (cirrhosis/cancer)	Retrospective cohort study	12, 13	IV
Ufere and collaborators ²⁴	2019	USA	396 physicians	Inpatients	Cross-sectional research	3, 4	VI
Jordan and collaborators ²⁵	2022	United Kingdom	1,528 patients	Inpatients, outpatients, home, hospice	Retrospective study	6, 7	VI
Dunn and collaborators ²⁶	2019	USA	174 physicians	Outpatients	Qualitative research	8	VI

1: confuses palliative care with end-of-life care; 2: imagines it negatively affects the possibility of transplant; 3: cultural factors affecting the perception of palliative care; 4: unrealistic patient expectations about their prognosis; 5: lack of knowledge about one's own prognosis; 6: not being cancer; 7: caregiver lack of knowledge about patient prognosis; 8: patient refusal; 9: Hispanic ethnicity; 10: lower education level; 11: lack of health insurance; 12: being male; 13: alcohol use; 14: young age; 15: minority groups, such as African Americans and Hispanics; 16: low income; 17: family feeling overburdened at the time of hospitalization; HCC: hepatocellular carcinoma

From the perspective of physicians, the main barrier was the disease not being cancer (43%)^{4,23,27-33}, followed by the perception that PC represents only end-of-life care^{14,16,28,30,34} and young age^{16,23,27,28,35} (both cited in 24%). Alcohol use^{4,16,17,35} and prognostic uncertainty^{17,18,21,34} were indicated in 19% of the articles, and

transplant eligibility was indicated in 14%^{16,21,33}. Other factors included unavailability of specialists^{16,21} and competing demands on time^{21,24} (9%), in addition to sociodemographic variables, professional training, lack of training, and lack of clear evidence for referral, among others^{4,16,17,19,21,24,26,27,30,34-37} (Chart 2).

Notable institutional barriers included the lack of process automation^{16,38}, non-uniformity of outpatient PC services^{29,34}, shortage of trained professionals^{34,36}, and deficiency of resources^{17,29}, which appeared in about 17% of the articles. Other barriers included hospital size, lack of access, time availability, and lack of knowledge^{16,20,22,26,28,29,36,39} (Chart 3).

Chart 2. Barriers to accessing palliative care for patients with advanced liver disease in studies related to physicians

Authors	Year	Country	Sample	Patient type	Study method	Barrier code	Level of evidence
Chen and collaborators ⁴	2021	Australia	116 patients	Inpatients	Retrospective study	25, 26, 27	IV
Ufere and collaborators ¹⁴	2019	USA	396 physicians	Inpatients	Cross-sectional research	22, 54	VI
Esteban and collaborators ¹⁶	2019	USA	311 physicians	Inpatients	Qualitative research	18, 19, 20, 21, 22, 23, 24, 25	VI
Barnes and collaborators ¹⁷	2020	Australia	74 patients	Inpatients	Retrospective cohort study	25, 34, 45	IV
Brown, Aksan, Muir ¹⁸	2023	USA	19,308 patients	Inpatients and outpatients	Retrospective study	34	VI
Vieira and collaborators ¹⁹	2023	Portugal	54 patients	Inpatients	Prospective study	33	VI
Alterio and collaborators ²⁰	2022	USA	Patients	Inpatients and outpatients	Systematic reviews and meta-analyses	19, 20, 22, 28, 34, 50, 51, 52	I
Woodland and collaborators ²³	2023	United Kingdom	29,514 patients	Inpatients (cirrhosis/cancer)	Retrospective cohort study	24, 27	IV
Ufere and collaborators ²⁴	2019	USA	396 physicians	Inpatients	Cross-sectional research	28, 29, 30	VI
Dunn and collaborators ²⁶	2019	USA	174 physicians	Outpatients	Qualitative research	44	VI
Gupta and collaborators ²⁷	2022	USA	1,421,849 patients	Inpatients	Retrospective study	24, 27, 39, 40, 41, 42, 43	VI
Mohy-Ud-Din and collaborators ²⁸	2023	USA	316,970 patients	Inpatients and outpatients	Retrospective cohort study	22, 24, 27	VI
Najafian and collaborators ²⁹	2019	USA	58 patients	Outpatients – TS discharge	Retrospective study	27	VI
Patel and collaborators ³⁰	2024	USA	21,987 patients	Inpatients	Retrospective cohort study	22, 27, 31, 32	IV
Peng and collaborators ³¹	2020	Taiwan	14,247 patients	Inpatients (cirrhosis/cancer)	Retrospective cohort study	27	IV
Ufere and collaborators ³²	2019	USA	44,933 patients	Inpatients	Prospective cohort study	27	IV

continues...

Chart 2. Continuation

Authors	Year	Country	Sample	Patient type	Study method	Barrier code	Level of evidence
Ufere and collaborators ³³	2020	USA	230 patients	Outpatients	Retrospective cohort study	19, 27	IV
Woodrell and collaborators ³⁴	2023	USA	16 physicians	Inpatients and outpatients	Cross-sectional qualitative study	22, 34, 35, 36, 37, 38	VI
Holden and collaborators ³⁵	2020	USA	397 patients	Inpatients	Retrospective cohort study	24, 25, 53	IV
Shinall Jr and collaborators ³⁶	2022	USA and Canada	24 physicians	Not cited	Qualitative research	46, 47, 48	VI
Verma and collaborators ³⁷	2024	USA	18 caregivers	Patients under evaluation for LT	Cross-sectional study	49	VI

18: mild disease; 19: transplant eligibility; 20: unavailability of palliative care specialist; 21: lack of solvable palliative issues; 22: perceptions that palliative care is end-of-life care; 23: concerns about opioid-based palliative care; 24: young age; 25: alcohol use; 26: clinicians referred less to palliative care than gastroenterologists; 27: not being cancer; 28: competing demands on physician time; 29: insufficient communication between physician and family about the objectives of care; 30: insufficient training in cultural competence on end-of-life care; 31: compensated liver disease; 32: differences as to race and ethnicity (compared to whites: Hispanics received more consultations and black patients received fewer consultations); 33: insufficient communication between physician and patient about prognosis; 34: prognostic uncertainty; 35: lack of information or understanding about the services provided by palliative care; 36: lack of symptoms warranting referral; 37: idea that palliative care is inconsistent with curative therapies; 38: concerns that patients perceive loss of hope from the treatment team; 39: being male; 40: not being white; 41: lack of health insurance; 42: low income; 43: hospitalization for less than five days; 44: uncertainty about when to refer to palliative care; 45: physician difficulties in engaging with patients in prognosis discussions; 46: difficulties in interaction between hepatology and palliative care teams; 47: cultural differences between hepatology and palliative care teams; 48: competing objectives and priorities; 49: non-observation of caregiver needs: lack of attention and information; 50: lack of evidence-based referral criteria; 51: lack of role clarity among specialists; 52: lack of provider training; 53: married; 54: feeling of ownership of these patients; TS: transplant service; LT: liver transplant

Chart 3. Barriers to accessing palliative care for patients with advanced liver disease in studies related to institutional issues

Authors	Year	Country	Sample	Patient type	Study method	Barrier code	Level of evidence
Esteban and collaborators ¹⁶	2019	USA	311 physicians	Inpatients	Qualitative research	55, 56	VI
Barnes and collaborators ¹⁷	2020	Australia	74 patients	Inpatients	Retrospective cohort study	59	IV
Alterio and collaborators ²⁰	2021	USA	27,263 patients	Inpatients and outpatients	Retrospective study	63, 65	VI
Kabaria and collaborators ²²	2021	USA	585,859 patients	Inpatients	Retrospective cohort study	64	IV
Ufere and collaborators ²⁴	2019	USA	396 physicians	Inpatients	Cross-sectional research	67, 68	VI
Dunn and collaborators ²⁶	2019	USA	174 physicians	Outpatients	Qualitative research	62	VI
Mohy-Ud-Din and collaborators ²⁸	2023	USA	316,970 patients	Inpatients and outpatients	Retrospective cohort study	63	IV
Najafian and collaborators ²⁹	2019	USA	58 patients	Outpatients – TS discharge	Retrospective study	57, 59, 60	VI

continues...

Chart 3. Continuation

Authors	Year	Country	Sample	Patient type	Study method	Barrier code	Level of evidence
Woodrell and collaborators ³⁴	2023	USA	16 physicians	Inpatients and outpatients	Cross-sectional qualitative study	57, 58	VI
Shinall Jr and collaborators ³⁶	2022	USA and Canada	24 physicians	Not cited	Qualitative study	58, 66	VI
Johnson and collaborators ³⁸	2023	USA	273 patients	Inpatients	Retrospective cohort study	55	IV
Whitsett and collaborators ³⁹	2022	USA	45 hepatology fellows	Not cited	Qualitative research	61	VI

55: lack of higher process automation; 56: unavailability of palliative care specialists; 57: outpatient palliative care not uniformly available; 58: shortage of trained palliative care professionals; 59: lack of resources; 60: palliative care available only to inpatients with non-malignant liver disease; 61: gaps in training/insufficient training in palliative care; 62: health care team with insufficient knowledge about services provided by palliative care; 63: inadequate training of providers/caregivers; 64: hospitalization in a non-university hospital or small hospital; 65: lack of nearby palliative care services in racial/ethnic minority communities (accredited services are located further away from these communities, making access difficult); 66: limited time and personnel for addressing palliative care issues; 67: low reimbursement for time spent providing palliative care; 68: insufficient peer recognition of the importance of palliative care; TS: transplant service

Discussion

Regardless of the origin of the barriers to palliative care, we found three challenging interconnected core areas: the lack of knowledge core, the access core, and the ethical-moral core.

Lack of knowledge core

A common barrier to PC (related to patients, physicians, and institutions) was patients not having oncological disease^{4,23,25,27-33,39}. Of the total articles, 40% cite this barrier, which prevents or at least delays timely referral for PC and its benefits.

According to the *Global Atlas of Palliative Care 2020*⁴⁰, worldwide, patients with non-malignant conditions would have more needs for PC, followed by cancer patients. Approximately 45% of deaths in 2017 were of people who needed PC. Among these, approximately 70% were related to non-oncological diseases, which include liver diseases. These corresponded to about 2.4% of deaths from non-oncological diseases among people who needed PC.

Practical moral attitudes that provide positive benefit should be taken. The virtue of physicians who perceive suffering caused by non-oncological diseases will make it possible to provide the best for patients⁴¹. The obstacle, persistent among professionals, of quantifying human suffering based on a cancer diagnosis needs to be overcome to offer PC. Authors have reported that advanced

liver disease presents symptoms that are similar to advanced cancer, such as lung cancer¹. The conceptual and cultural barrier of cancer seems to be present in all areas of care and involves moral patients and moral agents. Patient perception can improve if they are informed during consultations, in health care centers, hospitals, and through social media campaigns, for example.

Another common barrier among physicians and patients is the risk of conveying lack of hope by referral to PC, given the idea that it is end-of-life care (15% of articles)^{14,16,28,30,34}. This idea is present among patients¹⁵⁻¹⁷, as reported by Philips and Kedarisetty⁸, according to whom patients associate PC with situations related to death. Patients believe that by accepting referral they may lose opportunities to receive curative treatments, such as liver transplant^{16,17}. This shows that they lack knowledge that cure goals can be proposed regardless of whether or not the patient is under the care of the PC team.

A simple approach clarifying that PC is provided concurrently with cure proposals addressed this misconception and facilitated the acceptance of this care by patients¹⁶. Physicians also do not consider referring to PC patients still eligible for transplant (14%)^{15,21,33}, which leads to this benefit not being offered in conjunction in transplant services, possibly due to the “barrier of concerns” that PC is inconsistent with curative therapies³⁴. Contradicting this barrier, a study showed that

referrals to liver transplant services were higher for patients served by PC in a 12-month period²⁶. Since not all initially eligible candidates will undergo liver transplant, if they are referred late, there may not be enough time for them to benefit from PC.

To mitigate the aforementioned barriers, the option of PC can be offered to patients on the transplant waiting list, with clear information about the functions of PC, respecting the patient's decision to accept or not accept this care. Thus, their autonomy is respected while exercising the ethical and human obligation to help and offer the best possible benefit to generally weakened patients⁴¹.

Lack of knowledge and uncertainties about the prognosis demonstrated by physicians (19%)^{17,18,21,34} and patients (23%)¹⁷⁻¹⁹ denote how complex this disease is. There is much misinformation and perhaps a lack of clearer evidence-based criteria on the function of PC and when to refer patients²¹. This is inferred from the lower referral by clinicians in relation to gastroenterologists⁸. Doubts can increase the risk of therapeutic obstinacy in the end stage of the disease. If there is no clarity, the team needs to have moral sensitivity to make the best decisions, combining adequate technical training and communication.

Other barriers include physician difficulty in engaging with patients and families in discussions and the difficulty in communication with the PC team (14%)^{21,24,37}, which can be overcome by seeking to make decisions jointly with patients, once they are duly informed about the disease, so that their reason can assist them at this time⁹. Valuing the time with patients and providing them with space to talk with the medical team, also involving families and caregivers (when applicable), may be one of the ways to reduce their suffering.

Insufficient training in cultural competences was more related to physicians with more than ten years of practice, while those with less professional experience showed to be more prepared²⁴. Possibly, this is a result of the increased teaching of PC in medical training or in specialization courses, which has increased the knowledge and mastery of this practice.

Improvements in communication skills are needed, as evidenced by the lack of adequate

training for hepatology fellows in situations such as breaking bad news and addressing prognostic and psychological issues²⁰. A simple, responsible, and ethical approach, which takes into consideration the patient's best interests, promotes understanding and trust that the best will be provided to them⁹.

Several cited barriers relate to a lack of knowledge about PC, ranging from a lack of information to a lack of academic training. These barriers can be reduced with annual information campaigns about the function of PC, geared toward those who work in this area and patients, at all levels of health care.

Access core

The lack of health insurance is considered a barrier by physicians (5%)²⁷ and patients (15%)^{20,21}. Low income also presented as a barrier for physicians (5%)²⁷ and patients (8%)²², shedding light on the social difficulty of accessing the resource. Other patient-related barrier refers to linguistic and communication difficulties, which can limit the understanding of information about PC and complicate the identification of and access to specialized services²⁰. However, it is necessary to seek strategies that make it possible to offer the most dignified and humanized care possible, considering the conditions and resources available in each context⁴². Accordingly, the perspective of distributive justice reinforces the need to promote equitable access to palliative care, so that its provision does not depend on acts of charity or benevolence, but is guaranteed as part of health care⁴¹.

Even in developed countries, where greater availability of investments would be expected, the unavailability of PC resources and services and the unequal distribution of these services across the territory are observed as institutional barriers. The greater distance between services accredited in PC and certain populations, including racial and ethnic minorities, can hinder access and increase inequalities in the supply of this care and of trained teams (42%)^{16,17,20,29,34}. PC is mainly made available in larger hospitals, with more than 300 beds, according to Alterio and collaborators²⁰, but this would not be entirely justifiable, as PC do not essentially depend on large structures, but rather on training and availability of professionals.

The limited reimbursement for time spent providing palliative care and the insufficient recognition of the importance of PC by other professionals were also identified as institutional barriers for those working in PC. It is observed that discussions about PC occur more at the hospital level than at the outpatient level²⁴. It is necessary to improve the remuneration of these PC specialists. Given the barriers related to the availability and distribution of services, it is noted the need to expand the supply of PC at different levels of health care, especially in primary health care and outpatient services. Higher availability of these services can favor the longitudinal follow-up of patients with advanced liver disease, reduce exclusive dependence on hospital care, and facilitate timely access to PC, according to the clinical needs and preferences of patients.

Still considering institutional barriers, the insufficiency of process automation was found in the United States, a developed country³⁸. The availability and integration of clinical information through automated systems are particularly relevant in urgency and emergency situations, in which patients with advanced liver disease may require quick decision-making and immediate procedures. In these contexts, timely access to relevant medical record information can support clinical decision-making and continuity of care. Properly recording the clinical severity, preferences, and advance directives of patients can also favor decisions aligned with their previously expressed values and wishes, contributing toward avoiding disproportionate procedures and therapeutic obstinacy⁹.

Also cited as institutional barriers are gaps in physician training³⁹ and lack of provider training (17%)^{20,28}. Standardizing PC training within medical training curricula is a means to improve the communication with all involved parties and resolve doubts and misunderstandings about PC.

As a consequence of the delay caused by barriers to PC, there may occur situations of therapeutic obstinacy, with disrespect for the principle of non-maleficence, so dear to bioethics⁴¹. For example, attempts to resuscitate patients in serious clinical condition and known to be beyond recovery, disrespecting their dignity and, possibly, their wishes.

Institutional barriers can be even more pronounced in countries with lower availability of resources, such as Latin American countries, where difficulties in accessing PC may also be related to the lack of these services in the health care network. Intersectoral initiatives can help identify and reach populations in situations of greater vulnerability and favor their access to PC⁴³. Adequate allocation of resources for implementation and provision of these services is fundamental for ensuring dignified and equitable care⁴¹, in addition to having the potential to reduce hospitalizations and hospital costs⁷. Thus, the expansion and organization of PC supply should be considered in the planning and allocation of resources for health care, especially in Latin American countries.

Vulnerable patients are primarily those with low income or without health insurance, conditions that can restrict their possibilities for access and choice in health care. This group demands public actions guided by social justice⁴⁴. The State is responsible for promoting conditions that guarantee access to a social protection infrastructure, including PC⁴⁵. The bioethics of protection, initially discussed in the Latin American context, offers a relevant perspective for this discussion, and can also be applied to the analysis of access barriers identified in developed countries, where social and economic vulnerability conditions can equally compromise the access to PC.

Ethical-moral core

The common barriers among physicians and patients include alcohol abuse. Physicians tend to refer less frequently to PC (12%)^{4,16,17,35} patients with dependence, possibly due to stigmatization, resulting in unequal approaches to patients with liver disease of other etiologies. In theory, the former would have a greater indication, as they have a higher chance of not receiving a transplant due to the need for abstinence.

Although patients with liver disease of alcohol-related etiology have shown less willingness to accept referral to PC²³, it is important to ensure they have the possibility of choice and the exercise of autonomy. The discussion about PC should not be postponed, as patients with cirrhosis of alcoholic etiology may present episodes of hepatic

encephalopathy, which could possibly compromise consciousness and the ability to participate in decision-making about their own care⁴¹. Therefore, the planning of care goals and the drafting of advance directives should preferably be carried out in advance and during periods when decision-making capacity is preserved⁸.

For physicians, a patient being young constitutes a barrier to accessing PC (24%)^{16,23,27,28,35}. Among young patients, this barrier may be related to the expectation of longer survival and the hope for benefit from more aggressive treatments, as well as the reluctance of patients and their families to accept or discuss the PC approach²². However, in patients with liver cancer, the chance of referral for PC was inverted: that is, younger patients were referred more frequently than people aged over 65 years. It is observed that the importance given to suffering is greater when the cancer patient is young. However, older patients or older adults with cancer should not be stigmatized; their right to accessing PC should be equal to that of younger people⁴².

Among physicians, especially gastroenterologists and hepatologists, it was identified a perception that the responsibility for the care of patients with advanced liver disease remains under their management, which may constitute a barrier to the integration of PC¹⁴. Although most physicians participating in the study did not consider hepatologists to be the most adequate professionals to conduct palliative care for patients with advanced liver disease, they recognized having responsibilities related to aspects of PC, including the management of physical and psychological symptoms and the discussion of advance directives¹⁴. This dynamics can favor a paternalistic approach, in which decision-making about care remain predominantly centered on the professional, limiting patient participation in choices related to their own treatment⁹.

This type of barrier subjects patients to situations of moral vulnerability, especially those who are part of groups that are discriminated against and even excluded on the basis of cultural standards and who are not supported by the organizations that should protect human life⁴⁴. Beneficence is the basis of moral values and guides initiatives in favor of patient interests at the difficult time when their autonomy and medical paternalism clash⁹. Moral and cultural values should be balanced in ethical conduct so as to

prevent attitudes that diminish the importance of certain patient groups, so they can have their rights guaranteed.

The moral values of medicine are expressed in decisions that are beneficial for patients with a view to cure⁹. However, organ cure medicine needs to be expanded with the help of PC so that patients are cared for in all dimensions (beyond the biological, psychological, spiritual, and social dimensions) and have their dignity preserved.

In Brazil, hospital bioethics committees, when present, can contribute to the multidisciplinary discussion of bioethical conflicts, as well as to the development of educational initiatives and institutional recommendations. In the context of advanced liver disease, these initiatives can contribute toward preventing therapeutic obstinacy, promoting respect for patient preferences and advance directives, and fostering the preservation of patient dignity, reducing potential conflicts between health care teams and family members. The committees can also develop educational initiatives geared toward health care teams, reinforcing the importance of integrating PC and care for the needs of patients in situations of greater moral and social vulnerability.

A limitation of the research is that personal perceptions of experiences were captured during a time of psychological stress, which may affect their observations about forms of care, complex structures, and human attitudes. Another limitation is that most studies present evidence levels IV and VI, due to being qualitative studies. Furthermore, almost all studies originate from developed countries, and their findings may not correspond to the reality found in developing countries.

Final considerations

This review presented the main barriers to palliative care in advanced liver disease, especially in patients with liver cirrhosis. These barriers encompass lack of knowledge, access difficulties, and ethical-moral issues related to patients, physicians, and institutions. The analysis of the bioethical aspects of these barriers showed that it is necessary to evolve in this care. By showing the difficulties so that such patients are served by

PC, the objective is to contribute to the search for solutions that improve their quality of life.

It is essential to implement public policies geared toward addressing or improving deficiencies in palliative care, especially for people with non-oncological diseases, such as liver cirrhosis. It is also recommended that gastroenterology and hepatology medical societies provide more information about PC to improve its understanding and applicability.

We found no studies conducted in African and Latin American countries; however, it is imagined, given their characteristic context of social inequality, that they have a predominance of institutional barriers, especially those related to inequities in access to health care and in the care for patients with advanced liver disease. It is necessary to conduct studies to further assess such barriers within the reality of each country or continent with the aim of improving the access of these patients to palliative care.

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Data availability: All data used or generated in this study are described and presented in full in the body of the article.

Editor-in-charge: Dilza Teresinha Ambrós Ribeiro

Received: 7.20.2025

Revised: 4.12.2026

Approved: 4.17.2026