

The profile of the onco-hematology patient in the palliative care: 4 years of experience

Maria Eduarda Couto, MD^{a,*}, Isabel Oliveira, MD^a, Mário Mariz, MD^a, José Ferraz Gonçalves, MD, MSs, PhD^b

Abstract

Objectives: Most of the palliative care (PC) patients have oncologic diseases, being hematologic tumors a small part of them. According to the literature, onco-hematologic (OH) patients should be individualized from those with solid tumors for the specialized care required along their disease course. This study aims to review the casuistry of OH patients referred to PC in a specialized oncologic hospital and help to understand better how hematologists can improve the care of these patients.

Methods: We analyzed all OH patients referred to the PC service in 1 oncologic hospital along 42 months, through consultation of their clinical files.

Results: A total of 179 patients were reviewed (52.% males, median age of 71 years): 48.6% had non-Hodgkin lymphoma, 26.3% had multiple myeloma, 10.6% had acute leukemia, 14.5% had other OH diseases; 88.2% were treated for their OH disease (96.2% with chemotherapy, 28.5% radiotherapy, and 21.5% hematopoietic stem cell transplant). The referral was heterogeneous among physicians (27.4% by 1 physician). Most patients were firstly observed as inpatients (55.3%) and 17.9% in the outpatient consult. At the end of the study, 98.9% of the patients died (88.7% in the hospital, 10.2% at home). The median time between the end of treatment and referral to PC was 46 days and between referral and death was 16 days. We also reviewed medical prescription in the last month of life and we noticed that most invasive orders were requested by hematologists (as antibiotic prescription, imaging, and biopsy studies).

Significance of results: This study demonstrated that OH patients should be referred earlier to PC and that a more intensive team work needs to be practiced between PC and hematologists. More educational programs for healthcare workers on this issue are needed in order to guarantee a more effective assistance in the appropriate time.

Keywords: care, end-of-life, haematology, onco-hematologic patients, oncology, palliative care

Introduction

According to the literature, onco-hematologic (OH) patients have substantial illness burden (including physical and psychological, being less likely to report symptoms in any disease phase, poor quality of life, undergo more aggressive therapies at the end-of-life), have low palliative care (PC) service use in consultation and hospice, high rates of hospitalization and are more likely to die in the hospital than patients with solid tumors.¹⁻⁹ It has already been proved that PC can help patients along their disease course in symptomatic control and negative feelings dealing (as anxiety and depression), improving quality of life, overall survival, and caregiver outcomes. These good results were shown to be sustained after 3 months, including in the OH settings.^{10,11}

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article

^a Onco-Hematology Service, ^b Palliative Care Service, Instituto Português de Oncologia do Porto FG, EPE, Porto, Portugal.

* Corresponding author. Instituto Português de Oncologia do Porto FG, EPE (IPO-Porto), Rua Dr António Bernardino de Almeida, 4200-072 Porto, Portugal. E-mail address: eduarda.scouto@gmail.com (Maria Eduarda Couto).

Copyright © 2019 The Authors. Published by Wolters Kluwer Health, Inc. on behalf of PBJ-Associação Porto Biomedical/Porto Biomedical Society. All rights reserved.

This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal.

Porto Biomed. J. (2019) 4:6(e39)

Received: 18 March 2019 / Accepted: 18 June 2019

<http://dx.doi.org/10.1097/j.pbj.0000000000000039>

Therefore, an earlier integration of PC in the disease course seems to be a relevant aim (since the diagnosis is an idea defended by some PC specialists).^{1,3,12,13}

The main obstacles identified for an earlier integration of PC services in OH patients are the repeated patient's requirement for a more aggressive treatment (having unrealistic expectations about the benefits of chemotherapy), the unclear illness trajectory (diseases are often still theoretically curable, even in statistically poor-prognosis settings), the erroneous perspective of PC for most OH physicians (they focus in treatment goals and responsiveness to chemotherapy, viewing PC mainly as end-of-life care), the lack of cooperation between medical professionals in most hospitals (OH physicians tend to be the lone physicians caring for their patients, not being team-oriented as in PC), the lack of PC physicians dedicated solely to OH patients, and the absence of places available in PC units (most of them occupied by solid tumor patients).^{9,12,14,15}

A proper allocation of medical resources at the end-of-life care needs to be set, which requires a definition of the OH patient profile in the PC, becoming easier to understand what is being done (and how) and clarifying what can be improved.¹² This study aims to define the profile of the OH patient referred to PC and review the last month of life of these patients (medical interventions demanded by PC and OH physicians, comparing both) and also understand better how hematologists can improve the care of these patients.

Methods

This study was planned and executed in an oncology center that receives more than 10,000 new patients' referrals per year,

including with OH diseases. This center includes a 40-bed PC service, with 3 rooms for consultation dedicated to the outpatients. The clinical data required for this study were obtained from the clinical files of all OH patients referred to this PC unit along the 42 months in analysis (from July 2014 to December 2017).

Nowadays, the main criteria used in our institution for admission of these patients in the PC unit are that: progressive incurable disease or if the patient has refused treatment if competent to do so, patients with complex symptom control or psychosocial issues important to the patient that cannot be readily managed by the OH team, patients needing end-of-life care planning and if the patient agrees to the referral to the PC team if competent to choose. All patients admitted in this PC unit must have been previously referred by their OH assistant physician.

The data selected included information about demography and disease characterization (diagnostic date, treatments prescribed and survival data). Additionally, the last month of life was analyzed in the following parameters: intensive care unit (ICU) admission, antimicrobial therapies prescribed, blood transfusion administered, invasive procedures ordered, and imaging studies done; this evaluation was analyzed individually by the specialty who demanded these orders (becoming possible to compare orders from OH physicians with orders from PC physicians). The information obtained was analyzed using descriptive statistics methods. These data were last reviewed in February 2019. There was no need to have patient consent to obtain data for this study in patients who were already dead and there is no personal identification of the patients at any point. The study was allowed and guided by the Clinical Department where it was developed. There was no funding used in this study.

Results

One hundred seventy-nine OH patients were identified and analyzed (all the referrals received in the PC along the 42-month analysis), being characterized in Table 1. Most patients were referred from the OH service and only 4 were referred from the Bone Marrow Transplant Service. The majority of the OH patients analyzed were diagnosed with non-Hodgkin lymphoma (NHL) firstly and multiple myeloma (MM) secondly followed by acute leukemia, chronic leukemia, myelodysplastic syndrome, Hodgkin lymphoma, lymphoproliferative disease unspecified, and Sézary syndrome. A total of 158 patients (88.3%) were treated for their OH disease, with a median of 2 lines before referral. Most of them were treated with chemotherapy (85.5%) and were not exposed to radiotherapy (71.5%) or transplantation (only 21.5% were transplanted, being 80% submitted to autologous hematopoietic stem cell or bone marrow transplantation).

The median proportion of OH patients' referrals in the total number of referrals received in the PC unit between 2014 and 2017 was 2.6%, as expressed in Table 2. Table 3 clarifies the circumstances of referral and their orientation: all the referrals were requested for symptomatic control in patients with refractory disease. Most of the patients were referred in their last hospital admission before death. The median time between the last treatment date and referral to PC was 46 days and between the referral date and death was 16 days. They were observed by the PC for the first time mainly as inpatients (58.1%), some in the outpatient consult (22.3%) and 23.5% were not observed before death. There were also 3 patients whose admission in the PC unit was refused (1 by the patient's demand

Table 1

Characterization of the patients analyzed.

Characterization of OH patients analyzed	n	%
Number of patients analyzed	179	100
Median age, years [min-max]	71 [19-99]	
Male gender	94	52.5
Main referral specialty		
Onco-hematology service	175	97.8
Bone marrow transplant service	4	2.2
Main diagnosis of OH patients		
NHL	87	48.6
MM	47	26.3
Acute leukemia	19	10.6
Chronic leukemia	12	6.7
MDS	6	3.4
HL	5	2.8
Lymphoproliferative disease, unspecified	2	1.1
Sézary syndrome	1	0.6
Number of patients treated	158	88.3
Median number of treatment lines before referral to PC, n [min-max]	2 [1-8]	
HSCT	34	21.5
Auto-transplantation, n	27	
Allo-transplantation, n	10	
Chemotherapy treatment	152	96.2
Radiotherapy treatment	45	28.5

HL = Hodgkin lymphoma, HSCT = hematopoietic stem cell or bone marrow transplanted patients, MDS = myelodysplastic syndrome, MM = multiple myeloma, NHL = non-Hodgkin lymphoma, OH = onco-hematologic, PC = palliative care.

and other 2 for the lack of admission criteria). Two patients were admitted in another PC unit closer from their residency (according to their choice) and another 1 was followed solely in domiciliary consultations. From the 98.9% of the patients who died, 89.2% had that event in the hospital, 10.2% at home, and 0.6% in an unknown place.

The analysis of the number of referrals to PC by OH physician demonstrated a relevant heterogeneity among health professionals, being one of them responsible for 27.4% of all referrals (72.6% of the referrals were divided between 12 physicians). Table 4 clarifies this issue. In this institution, there is no division of professionals by pathology group or severity of disease.

The last month of life of all OH patients referred to the PC unit (n = 177) was reviewed, so it could be possible to understand the aggressiveness of the treatment prescribed in this period (an

Table 2

Number of onco-hematologic referrals to PC according to the year analyzed (from 2014 until the end of 2017) and the proportion of onco-hematologic patients' referred to PC in the total number of referrals to PC (solid and liquid tumors).

Distribution of the referrals of OH patients along the study period (n, %)		
2014	65	36.3
2015	35	19.6
2016	52	29.1
2017	27	15.1
Proportion of OH referrals between all referrals to PC (%)		
2014		16.8
2015		2.2
2016		3.2
2017		1.5

OH = onco-hematologic, PC = palliative care.

Table 3
Circumstances of referral, follow-up, and survival analysis (time to the event and circumstances of death).

Circumstances of referral	n	%
Main aim for referral: symptom control	179	100
Median number of hospital admissions after referral	0	
Median number of emergency admissions after referral	0	
Median time between the end of the last treatment and referral to PC, d [min–max]	[(-14)–3056]	
Median time between the referral to PC and death, d [min–max]	16 [0–870]	
Place of first clinical observation of the OH patients referred to PC		
Inpatient settings	99	55.3
Deaths before observation	42	23.5
Out-patient consult	32	17.9
Refuses	3	1.7
Transference to another PC unit	2	1.1
Domiciliary consultation	1	0.6
Mortality at the end of the study	177	98.9
Death in the hospital	157	88.7
Death at home	18	10.2
Unknown place of death	2	1.1

OH = onco-hematologic, PC = palliative care.

indirect measure of the quality of end-of-life care of these patients). Only 1 patient was excluded from this last month of life analysis as there was no information available. This topic is clarified in Table 5, comparing the prescription made under OH care and under PC demand. The majority of the invasive procedures and investigation studies were demanded by OH physicians (all ICU admissions, bone marrow biopsies and myelograms, positron emission tomography, magnetic resonance imaging studies, transthoracic echocardiograms, lumbar punctures, biopsies or cytology, and bronchofibroscopy), diminishing that frequency as the patients were mainly cared by the PC team (responsible for all percutaneous endoscopic gastrostomy placements and cystostomy). There were 2 central venous catheterizations, only demanded by OH physicians, and 4 surgeries in the operation room (3 of them demanded by OH physicians). Some invasive procedures were made in the first 6 months after the

Table 4
The heterogeneity of referrals among onco-hematologic physicians (all of them are able to diagnose, treat, and follow any onco-hematologic disease, with no selection by disease severity).

Physicians who referred the patients analyzed	n	%
Physician 1	49	27.4
Physician 2	23	12.8
Physician 3	19	10.6
Physician 4	17	9.5
Physician 5	16	8.9
Physician 6	14	7.8
Physician 7	12	6.7
Physician 8	10	5.6
Physician 9	7	3.9
Physician 10	4	2.2
Physician 11	4	2.2
Physician 12	3	1.7
Physician 13	1	0.6

diagnosis: 2 ICU admissions, 2 myelograms, 2 bone marrow biopsies, 1 parenteral nutrition, 1 nasogastric tube placement, 9 patients did blood transfusion, 6 imaging studies, 8 antibiotic prescriptions and 4 other procedures (pulmonary and cerebral biopsy, 1 cytology, 1 central venous catheterization placement, and 1 hepatic abscess drainage).

Discussion

The publication of this casuistry about the OH patients admitted in the PC is a contributing step to understand better the profile of these patients and the level of care given nowadays. The review of 179 cases from the same PC service in a study as this one strengthens the results and conclusions obtained, for the representative number of cases described when compared with other studies from the literature.^{2,4,5,7} For comparison reasons, we found that in the same institution and period (between 2015 and 2017) 198 OH patients died, not being referred previously to PC (for the lack of criteria according to OH physicians).

It was found a slightly high prevalence of the male gender and advanced ages in this study, as it happens with most OH diseases irrespective their PC referral. The OH service was the main service of referral, as expected (patients in the bone marrow transplant service are those with higher clinical investment). The most common diagnosis was NHL, followed by MM which are the most frequently diagnoses found in OH patients. Acute leukemia is the third most frequent diagnosis, being a worse prognosis disease compared to NHL and MM. Among the 179 patients studied, 88.3% received treatment for their disease (others had no performance status to initiate treatment or died before its beginning). Chemotherapy was the most common treatment, followed by radiotherapy and hematopoietic stem cell or bone marrow transplant. Most patients had done 2 lines of treatment at the time of referral (for most, the first treatment was a tentative for remission, usually followed by an unsuccessful second treatment).

The median annual percentage of OH referrals to PC in this oncologic institution is 2.6%, lower than described in the literature (which suggest that OH patients are around 7% of all the patients admitted in PC units, according to Le Blanc et al).⁶ Besides being few patients, the availability of the PC team to admit and care for all the OH patients referred is lower than desirable in space and human resources (the number of physicians, nurses, and other professionals, as in many PC units nowadays), being the reason why 23.5% of the patients died before being observed in this study.

There was a short period of time between the end of the last OH treatment and referral to PC (median of 46 days) and between referral and death (median of 16 days), evidencing that most patients are referred to PC lately in their disease course, shortening the opportunity to improve their end-of-life care. Many OH physicians also rather follow their patients until their death, controlling their symptoms, as described in the literature. There were 2 cases whose admission in the PC was refused for the lack of criteria. An investment at this level of care is emergent, moving PC observation upstream in order to guarantee assistance for these cases in an adequate period of time.^{15–17} The majority of the OH patients studied died shortly after being referred to PC (98.3%), 89.2% of them in the hospital (only 10.2% died at home), which is a bad criteria in the end-of-life care that should also be improved. According to the literature, when asked most patients choose to die in their own home and not in health facilities.¹⁸ In this population, most patients preferred the

Table 5**Invasive techniques and prescriptions ordered in the last month of the onco-hematologic patients referred to PC between 2014 and 2017.**

The last month of life (n = 176)	n	OH responsibility		PC responsibility	
		n	%	n	%
ICU stay	5	5	100	0	0
Myelogram	6	6	100	0	0
Bone marrow biopsy	6	6	100	0	0
Hemodialysis	3	2	66.7	1	33.3
Parenteral nutrition	5	4	80	1	20
Nasogastric tube	6	5	83.3	1	16.7
Percutaneous endoscopic gastrostomy	1	0	0	1	100
Blood transfusion	238	199	83.6	39	16.4
Imaging studies			39 patients		
PET	1	1	100	0	0
Echography	3	2	66.7	1	33.3
CT	38	35	92.1	3	7.9
MRI	4	4	100	0	0
Transthoracic echocardiogram	6	6	100	0	0
Other procedures			33 patients		
Lumbar puncture	12	12	100	0	0
Toracocentesis	13	11	84.6	2	15.4
Palliative radiotherapy	8	6	75	2	25
Paracentesis	4	3	75	1	25
Central venous catheterization	2	0	0	2	100
Pulmonary biopsy	2	2	100	0	0
Cutaneous biopsy	1	1	100	0	0
Mediastinic mass biopsy	1	1	100	0	0
Retroperitoneal cytology	1	1	100	0	0
Cerebral biopsy	1	1	100	0	0
Hepatic biopsy	2	2	100	0	0
Liver abscess drainage	1	1	100	0	0
Adenopathy biopsy	1	1	100	0	0
Leg mass cytology	1	1	100	0	0
Ommaya reservoir placement	1	1	100	0	0
Pacemaker removal	1	1	100	0	0
Cystostomy and catheter positioning	1	0	0	1	100
Bronchofibroscopy	1	1	100	0	0
Cataract surgery	1	1	100	0	0
Twisted bowel obstruction surgery	1	0	0	1	0
Orthopedic surgery	2	2	100	0	0
Antimicrobial prescription			93 patients		
Antibiotics	94	87	92.6	7	7.4
Antifungals	30	27	90.0	3	10.0

One patient did not have information available about his last month of life.

CT=computerized tomography, ICU=intensive care unit, MRI=magnetic resonance imaging, OH = onco-hematologic, PC = palliative care, PET = positron emission tomography.

hospital/hospice to die due family issues, mainly obstacles in education of the families in the care of end-of-life patients and socioeconomic issues (most families do not have the resources needed to prepare their houses in order to receive and care for their families).

The referral to PC was very heterogeneous among physicians (all of them can be responsible for any OH diagnosis and follow-up, nor being organized by disease groups, in any disease severity), which evidences a different knowledge about the importance of PC in the OH patient (the main referral physician is the only one whose main specialty is oncology, which might justify the number of referrals). It is required an improvement in the promotion of educational programs for health professionals nonspecialized (and specialized) in PC, in order to improve their knowledge on what PC services can offer in the care of these patients, and the right time of referral. A weekly group discussion about patients who might needed the care of both specialties should be promoted in each hospital who cares for

OH patients, promoting the share of clinical cases and knowledge.^{15,16}

The National Quality Forum suggested metrics indicative of poor quality at the end-of-life care and hospice use in the oncologic patient (that can also be applied to OH): prescription of chemotherapy in the last 14 days of life, more than 1 emergency department visit in the last days of life, admission in the ICU in the last month of life, and suboptimal use of hospice services (defined as use of hospice care services for <3 days or not at all).¹⁹ According to the literature, these metrics do not seem to be followed in OH patients.²⁰ This study evidenced that in the last month of life of the 176 patients reviewed the majority of them went through a diversity of invasive techniques that may be considered aggressive (including ICU admission, biopsies, hemodialysis, imaging studies, blood transfusions, antimicrobial prescription), mainly prescribed under OH physicians demand. When PC assumed these patients, the volume of medical interventions and prescriptions reduced substantially. This

information also supports the existence of a relevant gap between the end-of-life care provided by OH and PC, including in the last month of life, as described in the literature.⁹ More studies about the profile of the OH should be done in other centers, in order to allow a comparison of these findings and to become easier to define indications about the specific care needed in this group of patients and to define metrics adequate for evaluation of the end-of-life in this context, apart from those already selected for solid tumors.

Conclusion

According to the literature, there are many obstacles to an earlier integration of PC in OH patient's care: there is always uncertain of the OH disease course, an inadequate perspective of many OH physicians about PC and the lack of shared care between professionals of many hospitals, the patients' demand for more aggressive treatments, among others.

This study included a relevant number of OH patients in the PC settings, which is a population not commonly found characterized in the literature. The number of OH patients referred to this PC unit was lower than what is described in other countries (2% vs 7%, evidencing a smaller utilization of PC services in this institution).

It is relevant the short period of time between the end of treatments and referral to PC and between referral to PC and death in this population. Most patients were observed for their first time as inpatients, frequently in their last admission before death and most of these events occurred in the hospital (mainly for educational and socioeconomic family issues). Only 17.9% of the patients were followed as out-patients, a practice that must be improved in order to increase the quality of life in end-of-life care for those who still are autonomous or have specialized care at home.

The amount of referrals to PC was heterogeneous among the 13 physicians analyzed dedicated to the OH patient (one of them was responsible for 27.4% of them) evidencing different knowledge about the ability and utility of PC in the symptomatic control of OH patients in any disease stage.

In the last month of life of these patients, OH physicians were more invasive than PC physicians, being responsible for all ICU admissions and biopsies demanded in this period of time. Compared to PC physicians, OH physicians demanded more invasive procedures, imaging studies and prescribed more antimicrobials, without positive impact in the outcome of these patients.

Considering all these findings described above, the authors think that there is a need of more debate on the referral issue of OH patients to PC, with educational programs on this issue (for health professionals and families) and a more shared care of these patients since the diagnosis, in order to improve the knowledge in this area and the care of this special group of oncologic patients, individualized from solid tumors.

Acknowledgment

None.

Conflicts of interest

The authors declare no conflicts of interest.

Presentation: "A 4-year experience in Palliative Care of the Onco-hematology patient," Abstract PB2392, 23rd European Hematology Congress. June 14 to 17, 2018. Stockholm, Sweden.

References

- [1] LeBlanc TW, El-Jawahri A. When and why should patients with hematologic malignancies see a palliative care specialist? *Hematology Am Soc Hematol Educ Prog.* 2015;2015:471–478.
- [2] Freeman AT, Wood WA, Fox A, et al. Access to palliative care consultation and advance care planning for adults with high-risk leukemia. *J Palliat Med.* 2017;21:225–228.
- [3] Howell DA, Shellens R, Roman E, et al. Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data. *Palliat Med.* 2011;25:630–641.
- [4] Hui D, Didwaniya N, Vidal M, et al. Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. *Cancer.* 2014;120:1572–1578.
- [5] Alt-Epping B, Wulf G, Nauck F. Palliative care for patients with hematological malignancies—a case series. *Ann Hematol.* 2011;90:613–615.
- [6] LeBlanc TW, Abernethy AP, Casarett DJ. What is different about patients with hematologic malignancies? A retrospective cohort study of cancer patients referred to a hospice research network. *J Pain Symptom Manage.* 2015;49:505–512.
- [7] LeBlanc T, Abernathy A, Casarett D. Palliative care for patients with hematologic malignancies: a profile of patients with blood cancers referred to the CHOICE Hospice Network. *J Pain Symptom Manage.* 2014;47:490.
- [8] McCaughan D, Roman E, Smith AG, et al. Determinants of hospital death in haematological cancers: findings from a qualitative study. *BMJ Support Palliat Care.* 2018;8:78–86.
- [9] Earle CC, Landrum MB, Souza JM, et al. Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J Clin Oncol.* 2008;26:3860–3866.
- [10] Hematology ASO Supporting palliative care. *Ash Clin News.* 2016.
- [11] Hematology ASO Palliative care: time for hematology to step up. *Ash Clin News.* 2015.
- [12] Niscola P, Tendas A, Scaramucci L, et al. End of life care in hematology: still a challenging concern. *Ann Palliat Med.* 2014;3:7–11.
- [13] Hui D, Park M, Liu D, et al. Attitudes and beliefs toward supportive and palliative care referral among hematologic and solid tumor oncology specialists. *Oncologist.* 2015;20:1326–1332.
- [14] LeBlanc TW, O'Donnell JD, Crowley-Matoka M, et al. Perceptions of palliative care among hematologic malignancy specialists: a mixed-methods study. *J Oncol Pract.* 2015;11:E230–E238.
- [15] Hennessy JE, Lown BA, Landzaat L, et al. Practical issues in palliative and quality-of-life care. *J Oncol Pract.* 2013;9:78–80.
- [16] Manitta VJ, Philip JA, Cole-Sinclair MF. Palliative care and the hematological patient: can we live together? A review of the literature. *J Palliat Med.* 2010;13:1021–1025.
- [17] Kain DA, Eisenhauer EA. Early integration of palliative care into standard oncology care: evidence and overcoming barriers to implementation. *Curr Oncol.* 2016;23:374–377.
- [18] Vidal M. Exploring the preferences for place of death among cancer patients and their family caregivers. *J Clin Oncol.* 2015;33 (suppl):40–140.
- [19] LeBlanc TW, Roeland EJ, El-Jawahri A. Early palliative care for patients with hematologic malignancies: is it really so difficult to achieve? *Curr Hematol Malig Rep.* 2017;12:300–308.
- [20] LeBlanc TW. Palliative care and hematologic malignancies: old dog, new tricks? *J Oncol Pract.* 2014;10:e404–e407.