1 REVIEW ORIGINAL RESEARCH

2 Julie Devictor et al

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4 **Title:** Nurse coordinator roles in the management of patients with hepatocellular carcinoma: a French
5 national survey

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Abstract:

Hepatocellular carcinoma (HCC) mostly occurs in patients with chronic liver disease (CLD). HCC treatment may have a direct impact on CLD prognosis. HCC management can therefore become complex, involving multiple health care providers, such as oncologists, hepatologists, radiologists, and surgeons. In France, dedicated nurses have been involved in patient care pathways. Their impact is poorly documented.

Purpose:

To determine the country-wide distribution of HCC nurse coordinators in French health care settings and to describe their roles and responsibilities.

Patients and methods:

A survey using a multi-item questionnaire (including center characteristics, nurse coordinator characteristics, and quality indicators such as patient care pathway initiation timeline, scheduled length of hospital stay, diagnostic disclosure process) was conducted. All French liver cancer centers planning to participate in a prospective national cohort study (CHIEF) were invited to participate. Bivariate analysis compared centers with a nurse coordinator to those without.

Results:

Among the 42 of 72 (58%) centers that replied, 14 (33%) treated fewer than 75 HCC patients; treatment mostly took place in hepatology units (34/42 (89%). Sixteen nurse coordinators were part of the health care team in 13 of the 42 centers. Among these 13 centers, 11 were university hospitals and 11 followed more than 75 patients per year. The median number of patients followed in these centers was 300 (min-max 44- 600) in 2017. All nurse coordinators were involved in providing patient information and counseling. Other roles included treatment monitoring (13/16), care coordination (12/16), psychological support (12/16) and treatment planning (11/16). Sixteen nurse coordinators conducted diagnostic disclosure nurse consultations; seven initial patient contact consultations; and six held outpatient nurse consultations were performed respectively, with wide heterogeneity between centers. The presence of a nurse coordinator was associated with completion of the full diagnostic disclosure process ($p=0.045$).

Conclusion:

In France, nurse coordinators for HCC patient pathway management are present mainly in university hepatology units with a caseload of more than 75 patients per year. All provide patient information and counseling but their roles in care coordination, patient support and holistic assessment were heterogeneous and not standardized.

Keywords: case management, liver cancer, nurse roles, nurse navigator, patient care pathway

Introduction

Hepatocellular carcinoma (HCC) represents about 90% of primary liver cancers worldwide and is a major global health problem [1] with high associated mortality rates [2]. HCC occurs in more than 90% of patients who have underlying chronic liver disease, and is usually diagnosed at the cirrhosis stage [3]. The prevalence of HCC has been rising with hepatitis C infections and lifestyle-related risk factors. In France, 10,580 new cases were diagnosed in 2018 with a median age at diagnosis of 69 years [4].

Due to the frequent presence of at least two diseases (cirrhosis and cancer), the management of HCC can be complex, requiring the involvement of multiple health care providers, ideally within a coordinated care pathway. It is widely accepted that a multidisciplinary team is beneficial in the management of patients with complex diseases such as HCC [5]. Moreover, recent data suggest that overall median survival is improved when treatment is initiated in centers with an annual caseload of more than 75 patients [6].

Since 2009, to improve the quality of care for cancer patients, all health care institutions in France with cancer treatment activities, whether public or private, must have a specific authorization from the national Public Health authority. Regulatory obligations include three pillars: cross-cutting quality criteria; accreditation from the National Cancer Institute for the most common treatment options; and, for some treatments such as surgical tumor removal, radiotherapy and chemotherapy,

a minimum annual caseload threshold. The cross-cutting quality measures are based on the objective of attaining comprehensive patient care beginning at diagnosis. They include implementation of the full diagnostic disclosure process, implementation of multidisciplinary tumor boards, providing personalized care, monitoring clinical practice standards, and offering access to ancillary care, innovative therapies, and clinical trials.

The diagnostic disclosure process, which initiates the patient care pathway following a positive diagnostic test, was an emblematic measure of the first *Plan Cancer* in France [7]. It includes four steps: 1) a physician consultation during which the provider discusses the diagnosis and available treatment options; 2) a specialist nurse consultation to reiterate the medical information and verify the patient's understanding, to provide support and an opportunity for reformulation, and to offer information on patient rights and support groups; 3) a social worker and ancillary care specialist consultation (e.g. physiotherapist, psychologist, pain management team); and 4) The initiation of coordinated care management between the hospital and the patient's general practitioner.

Coordination programs, also known as "navigation", have been implemented in oncology departments internationally to optimize patient care pathways [8]. In France, some liver cancer treatment centers have dedicated one of their nurses to care coordination and case management for patients with primary liver cancers. However, they have never been evaluated for HCC management. The aims of this exploratory survey were therefore to determine the country-wide distribution of HCC nurse coordinators in French health care settings and to describe their roles and responsibilities.

Material and methods

Survey design

A survey with a focus on practice analysis was conducted using a questionnaire. All French liver cancer treatment centers managing patients with HCC (with or without a dedicated nurse coordinator on staff) that planned to participate in a prospective national cohort study (CHIEF) (n=72) were invited to participate. The questionnaire, which was designed specifically for this study by one nurse coordinator (J.D) and two hepatologists (N.G, M.B), was piloted and validated in two centers,

then sent to the referral physician of each of the 72 centers. The questionnaire could be completed either by a physician or by a nurse coordinator. Two reminders were sent 4 and 8 weeks later to the centers that did not initially respond. All data was collected from the questionnaires, on a declarative basis, for 2017. Centers were invited to respond using their databases.

For clarity purposes, throughout the text, the term “nurse coordinator” will refer to a nurse with at least 50% of their working hours dedicated to the management of HCC.

Survey and data collection

The questionnaire was divided in three sections. The first part described treatment center characteristics, including setting (public university or non-university hospital, private clinic) therapeutic options available (surgery, liver transplantation, interventional radiology, oral antiangiogenic treatment, and/or supportive care), frequency of multidisciplinary liver tumor boards, number of therapeutic procedures performed, and number of nurse coordinators on staff. The second part described nurse coordinators characteristics, including professional experience and main responsibilities, as well as an open question on the nurse coordinator’s roles in patient care. The third part dealt with quality indicators, including scheduled length of hospital stay for interventional radiology treatments, steps of diagnostic disclosure process, and time interval between initial patient contact and multidisciplinary tumor board. The questionnaire also included a, open question on nurse coordinator responsibilities.

Data analysis

Data are presented as numbers (%) for binary variables and as median (min – max) for continuous variables. Centers were categorized into those with a nurse coordinator and those without. The associations between the presence of a nurse coordinator on staff and centers’ characteristics then selected quality indicators (patient care pathway initiation timeline, scheduled length of hospital stay, diagnostic disclosure process) were evaluated using bivariate analysis. The same indicators were compared between centers based on their characteristics. The strength of association was evaluated

using Pearson's Chi2 test and Fisher's exact test for binary variables and Student's t-test (normally distributed variables) or Wilcoxon's test (non-normal distributions) for continuous variables. A p-value ≤ 0.05 was considered statistically significant.

Results

Center characteristics

Forty-two of 72 centers (58%) participated. The cumulative number of patients with HCC followed in those centers in France in 2017 was 9,079, including 4,331 newly diagnosed cases. All questionnaires were completed by physicians, except in one center where the nurse coordinator responded. The geographical distribution of the centers and their declared annual caseload are presented in Figure 1. The median number of HCC cases per center was 200, ranging from seven to 800 (Table 1). Fourteen centers (33%) followed fewer than 75 patients per year; 12 (29%) had an annual caseload of 75 to 249 patients, eight centers (19%) followed 250 to 399 patients and another eight followed more than 400 patients per year. Twenty-seven centers (64%) were part of university hospitals and 32 (76%) regularly participated in clinical trials (Table 1).

Most patients that were treated with interventional radiology (95%) were followed in centers that had an annual caseload of more than 75 patients (Data not shown). Among the centers that performed interventional radiology, seven admitted patients to oncology units (18%) and 34 to hepatology units (89%) (Table 1). Patient hospitalization began on the day prior to treatment administration for 81.6% of patients receiving chemoembolization and radioembolization, and for 59% of patients in whom percutaneous ablations were performed (Data not shown). For scheduled interventional radiology, 47.5 % of patients were hospitalized in a short-stay unit (≤ 5 days), 25 % in a conventional hospitalization unit and 27.5% in both units (Data not shown). Fourteen percent of the centers surveyed declared conducting care coordination between the hospital and the patient's general practitioner (Table 2).

Practitioners attending the multidisciplinary tumor board included mostly physicians: hepatologists (100%), surgeons (97%), radiologists (89%), oncologists (89%), interventional

radiologists (86%), and residents (84%). Non-medical staff such as social workers, research staff, and nurses rarely attended the boards. Nurses regularly attended the meeting in 24% of centers (Data not shown).

Thirteen centers (31%) had a dedicated nurse coordinator on staff (table 1), and six others planned to open a nurse coordinator position. Three of these 13 centers, whose annual caseloads ranged from 280 to 450 and provided liver transplant care, had two nurse coordinators (Data not shown).

Nurse coordinator characteristics

The 13 centers that had a nurse coordinator on staff followed a median of 300 patients in 2017 (min-max 44-600), eleven of them were university hospitals (Table 1). The presence of a nurse coordinator was more frequent in centers following at least 200 patients per year ($p = 0.036$) (Data not shown). The nurse coordinators had been practicing in a coordinator role for a median of three years (0.5-20 years) and had a median professional experience of seven years (min-max 0-23 years) prior to being hired in the position (Table 3). In the open question section, four centers mentioned that the nurse coordinator's activities were not dedicated only to the management of patients with HCC but also involved the management of patients with other gastro-intestinal cancers ($n=3$) and liver transplant recipients ($n=1$) (Data not shown).

Nurse coordinator roles and responsibilities (Table 3)

All nurse coordinators were involved in providing patient information and counseling. Most of them had a direct telephone line that patients or health care providers could contact if they had questions or concerns (14/16). Most monitored treatment side effects and disease progression (13/16), provided psychological support (12/16), coordinated patient care within and out of the hospital (12/16), including treatment scheduling. Seven nurse coordinators were the first contact patients had with the center. Less than half provided outpatient consultations (6/16) whereas a majority of them conducted diagnosis disclosure nurse consultations (13/16). Half of the nurse

coordinators worked on patient care pathway harmonization (8/16). Few of them participated in multidisciplinary tumor boards (5/16) or attended the medical consultation (3/16). Few were involved in clinical research (3/16) or multidisciplinary tumor board organization (2/16).

Nurse coordinators were involved in roles and activities identified in this survey with wide heterogeneity between centers (Figure 2). Nurse coordinators took on all these roles and activities in only one center (No 2) whereas the nurse coordinator of another center (No 12) was involved only in information / counseling, diagnostic disclosure nurse consultation and psychological support (Table 3 and Figure 2).

Quality indicators

Having a nurse coordinator on staff was associated with completion of the full diagnostic disclosure process ($p=0.045$) and with offering a nurse consultation in the diagnostic disclosure process ($p=0.016$) (Table 2).

There was no difference between centers with and without nurse coordinators in terms of scheduled length of hospital stay for chemoembolization ($p=0.76$) or percutaneous ablation ($p=0.92$), delay in access to patient care ($p=1$), and coordination with community-level practitioners ($p=0.27$) (Table 2).

Discussion

To our knowledge, this is the first survey to have explored the roles and responsibilities of nurse coordinators in French HCC treatment centers. Several studies have described and evaluated the missions of nurse coordinators in oncology [9] [10] [11] [12] [13] [14]. However, apart from managing the toxicity of oral therapies [16], the roles and activities of nurse coordinators in the management of HCC in France has been poorly documented [15].

Our survey shows that most French patients with HCC were treated in hepatology units, in centers with a caseload of more than 75 patients per year. In contrast to other cancers, the prognosis and treatment options for HCC depend not only on the tumor's stage but also on the severity of liver

dysfunction. Therefore, the management of HCC requires expertise in both hepatology and in the HCC management of treatment side effects. Recent data suggest overall median survival time is improved when curative treatment is performed as first line therapy, and when treatment is initiated in large centers (patient caseload >75 patients per year) [6].

In our survey, only 31% of the participating centers declared having a nurse coordinator on staff, the majority saw more than 75 patients per year. The implementation of nurse coordination in the oncology field is strongly recommended by many countries [17] [18] [19]. Their role in improving the collaboration between the hospital and community-level care is one of the priorities of the third French *Plan Cancer* (2014-2019) [20]. Despite such recommendations, the distribution of nurse coordinators in oncology is highly heterogeneous both in France and in other countries. However, the government of Queensland, Australia implemented nurse navigator positions (equivalent to nurse coordinator) in every hospital and health care service [21].

The median professional experience of nurse coordinators was seven years (0-23 years). In practice, wide variations in the professional certifications, job titles, and scope of work of oncology nurse navigators have been observed [22]. Nevertheless, in the oncology field, holistic assessment, education, patient and family support and care coordination are the main responsibilities of nurse coordinators described in the literature [23][11]. The roles and activities described for HCC care in our study were similar to those described in the literature in the oncology field.

The presence of a nurse coordinator on staff was associated with the full completion of the diagnosis disclosure process, thanks to the fulfillment of the nurse consultation, which enabled those centers to meet care quality guidelines and national recommendations. Nevertheless, our survey shows that timely access to care and coordination with community level practitioners were not improved in centers with nurse coordinators. This could be partly explained by the heterogeneity of nurse coordinator roles between centers. Though our sample was too small and heterogeneous to generalize our findings, the standardization of clinical practice and patient care pathways associated with nurse coordinator roles and activities could improve patient outcomes [22]. Moreover, coordination with the patient's general practitioner was seldom performed. These findings confirm the

results of a study conducted in 2015 among 1,193 French General Practitioners (GP), which showed that only 31% of them had complete information on their patients' cancer treatment plan, despite national guidelines recommending care coordination between the specialists and GPs involved in the patient's care [24].

Furthermore, assessing the impact of HCC nurse coordinators in improving patient care is challenging due to the lack of standardization of their roles and responsibilities and due to the differences in the organizational structure of the centers. In addition, our survey confirmed that clinical practice was not homogenous across centers and the organization of care may differ from region to region [6]. A qualitative study exploring HCC patient care management and pathways, and the role of nurse coordinators, using in depth interviews of both patients and health care professionals, could provide valuable information.

Many centers showed interest in this survey and more than half of those that were contacted agreed to participate. Their cumulative caseload represented 40,5% of the annual incidence of HCC in France [25]. Our survey explored center-level indicators on the quality of care pathways, based on declarative data. Other indicators, particularly at the patient level, could have been assessed. Further research is warranted, including patient-level analysis using data from medical records. Other quality indicators that may be associated with the presence of a nurse coordinator might include the delay from initial patient contact to treatment initiation and quality of life for patients and family members. The retrospective design of the survey, which used declarative data could not assess these parameters but a study is currently underway in order to do so.

Conclusion

This survey is a first overview of the nurse coordinator's roles and responsibilities in the management of patients with HCC in France. HCC patient pathway management by a nurse coordinator occurred mainly in hepatology units affiliated with a university hospital that generally had a high annual patient case load. Though all provided patient information and counseling, their roles in care coordination, patient support and holistic assessment were heterogeneous and their activities

were not standardized. Standardizing practices could help to improve quality of care, patient quality of life and measure patient-reported outcomes.

Disclosure

The author reports no conflicts of interest in this work.

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350 **Table 1:** Center characteristics, data presented as n (%) unless otherwise specified

Center characteristics	Total N=42	Centers with a nurse coordinator N=13	Centers without a nurse coordinator N=29	<i>P value</i>
Setting				
Public University hospital	27 (64%)	11 (85%)	16 (55%)	0.44
Public non-university hospital	9 (21%)	1 (7.5%)	8 (28%)	0.22
Private clinic	6 (14%)	1 (7.5%)	5 (17%)	0.47
Number of patients treated / year Median [IQR]	9079 200 [45.5;330]	3481 300 [80;400]	5598 150 [30;250]	0.1
Center size: > 75 patients / year	28 (67%)	11 (85%)	17 (59%)	0.47
Treatment options				
Liver transplantation	12 (29%)	4 (31%)	8 (28%)	1
Liver resection	37 (88%)	11 (85%)	26 (90%)	1
Percutaneous ablation	38 (90%)	13 (100%)	25 (86%)	0.59
Intra-arterial chemoembolization	37 (88%)	13 (100%)	24 (83%)	0.6
Intra-arterial radioembolization	21 (50%)	7 (54%)	14 (48%)	0.74
Oral systemic treatment	41 (98%)	13 (100%)	28 (97%)	1
Participation in clinical trials	32 (76%)	12 (92%)	20 (69%)	0.27

Frequency of multidisciplinary liver tumor board				
Weekly	33	13 (100%)	20 (74%)	0.15
Bi-Monthly	7	0	7 (26%)	-
None (patients referred to an off-site tumor board)	2	0	2 (5%)	-
Hospital Unit for treatment administration*				
Hepatology	34	13 (100%)	21 (72%)	0.085
Oncology	7	3 (23%)	4 (14%)	1
Liver surgery	9	1 (8 %)	8 (28%)	0.46

351 * Multiple responses accepted

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353 **Table 2:** Patient care pathway quality indicators

	Centers with a Nurse Coordinator n=13	Centers without a Nurse Coordinator n=29	<i>P value</i>
Scheduled length of hospital stay for interventional radiology treatments , days, mean (min-max)			
Chemoembolization (n=37)	3,31 (2–5)	3,32 (2–5)	0.76
Percutaneous ablation (n=38)	2,24 (1–3)	2,26 (2–3)	0.92
Radioembolization (n=21)	1,86 (1–2)	3,30 (2–7)	0.00

Time between initial patient contact and multidisciplinary liver tumor board			
≤ 1 week	4 (31%)	7 (27%) ¹	1
> 1 week	9 (69%)	19 (73%) ¹	-
Steps diagnostic disclosure, n (%)			
1 – Physician diagnostic disclosure consultation	13 (100%)	29 (100%)	1
2 – Nurse consultation	11 (85%)	13 (45%)	0.016
3 – Social worker consultation	9 (69%)	19 (66%)	0.81
4 – Care coordination between hospital and community level practitioners	3 (23%)	3 (10%)	0.27
Complete diagnostic disclosure process, n (%)	3 (23%)	1 (3%)	0.045

¹ Data missing for 3 of 29 centers

Table 3: Nurse coordinator characteristics

Number of nurse coordinators	
Practice setting	
University Hospital	14

Non-University Hospital	1
Private Clinic	1
Professional title	
Nurse coordinator	7
Consultation nurse	4
Care pathway nurse	3
Education nurse	2
Number of years of nursing experience prior to nurse coordinator job	
≤ 1 year	6
2-10 years	3
≥ 10 years	7
Roles and responsibilities	
Providing information / counseling	16
Monitoring treatment side effects and disease progression	13
Psychological support	12
Coordination with providers within the hospital	12
Coordination with out of hospital providers	12
Treatment planning and monitoring	11

Patient care pathway harmonization	8
Initial patient contact	7
Clinical research	3
Multidisciplinary tumor board organization	2
Main activities	
Telephone hotline	14
Diagnostic disclosure nurse consultation	13
Outpatient nurse consultation	6
Participation in multidisciplinary tumor board	5
Participation in medical consultation	3

** Multiple responses accepted

Figure 1: Country-wide distribution of liver cancer treatment centers following hepatocellular carcinoma patients in 2017

Figure 2: HCC nurse coordinator centers: main roles and activities

Care coordination, patient support, education, and holistic assessment are the four main nurse coordinator responsibilities described in the literature in the oncology field. Regarding these missions, eight main roles and three main activities were identified in this survey. A number was attributed to each center (C: No). Centers 1-2-3 had two nurse coordinators. The others had one nurse coordinator. Roles are represented by a rectangle and activities by a dotted rectangle. The size of the rectangle is proportional to the number of centers that reported the role or activity in question. These roles and activities were not standardized and were center dependent.