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Nurse coordinator roles in the management of patients with hepatocellular carcinoma: A French national survey

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1 REVIEW ORIGINAL RESEARCH

2 Julie Devictor et al

3

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

6

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32 **Abstract:**

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

38 **Purpose:**

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

41 **Patients and methods:**

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

47 **Results:**

48 Among the 42 of 72 (58%) centers that replied, 14 (33%) treated fewer than 75 HCC patients;
49 treatment mostly took place in hepatology units (34/42 (89%). Sixteen nurse coordinators were part
50 of the health care team in 13 of the 42 centers. Among these 13 centers, 11 were university hospitals
51 and 11 followed more than 75 patients per year. The median number of patients followed in these
52 centers was 300 (min-max 44- 600) in 2017. All nurse coordinators were involved in providing patient
53 information and counseling. Other roles included treatment monitoring (13/16), care coordination
54 (12/16), psychological support (12/16) and treatment planning (11/16). Sixteen nurse coordinators
55 conducted diagnostic disclosure nurse consultations; seven initial patient contact consultations; and
56 six held outpatient nurse consultations were performed respectively, with wide heterogeneity between
57 centers. The presence of a nurse coordinator was associated with completion of the full diagnostic
58 disclosure process ($p=0.045$).

59 **Conclusion:**

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

64

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

66

67 **Introduction**

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

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

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

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

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

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

104 **Material and methods**

105 **Survey design**

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

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

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

117

118 **Survey and data collection**

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

130

131 **Data analysis**

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

138 using Pearson's Chi2 test and Fisher's exact test for binary variables and Student's t-test (normally
139 distributed variables) or Wilcoxon's test (non-normal distributions) for continuous variables. A p-value
140 ≤ 0.05 was considered statistically significant.

141 **Results**

142 **Center characteristics**

143 Forty-two of 72 centers (58%) participated. The cumulative number of patients with HCC
144 followed in those centers in France in 2017 was 9,079, including 4,331 newly diagnosed cases. All
145 questionnaires were completed by physicians, except in one center where the nurse coordinator
146 responded. The geographical distribution of the centers and their declared annual caseload are
147 presented in Figure 1. The median number of HCC cases per center was 200, ranging from seven to
148 800 (Table 1). Fourteen centers (33%) followed fewer than 75 patients per year; 12 (29%) had an
149 annual caseload of 75 to 249 patients, eight centers (19%) followed 250 to 399 patients and another
150 eight followed more than 400 patients per year. Twenty-seven centers (64%) were part of university
151 hospitals and 32 (76%) regularly participated in clinical trials (Table 1).

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

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

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

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

171

172 **Nurse coordinator characteristics**

173 The 13 centers that had a nurse coordinator on staff followed a median of 300 patients in
174 2017 (min-max 44-600), eleven of them were university hospitals (Table 1). The presence of a nurse
175 coordinator was more frequent in centers following at least 200 patients per year ($p = 0.036$) (Data
176 not shown). The nurse coordinators had been practicing in a coordinator role for a median of three
177 years (0.5-20 years) and had a median professional experience of seven years (min-max 0-23 years)
178 prior to being hired in the position (Table 3). In the open question section, four centers mentioned that
179 the nurse coordinator's activities were not dedicated only to the management of patients with HCC
180 but also involved the management of patients with other gastro-intestinal cancers (n=3) and liver
181 transplant recipients (n=1) (Data not shown).

182

183 **Nurse coordinator roles and responsibilities (Table 3)**

184 All nurse coordinators were involved in providing patient information and counseling. Most of
185 them had a direct telephone line that patients or health care providers could contact if they had
186 questions or concerns (14/16). Most monitored treatment side effects and disease progression
187 (13/16), provided psychological support (12/16), coordinated patient care within and out of the
188 hospital (12/16), including treatment scheduling. Seven nurse coordinators were the first contact
189 patients had with the center. Less than half provided outpatient consultations (6/16) whereas a
190 majority of them conducted diagnosis disclosure nurse consultations (13/16). Half of the nurse

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

194 Nurse coordinators were involved in roles and activities identified in this survey with wide
195 heterogeneity between centers (Figure 2). Nurse coordinators took on all these roles and activities in
196 only one center (No 2) whereas the nurse coordinator of another center (No 12) was involved only in
197 information / counseling, diagnostic disclosure nurse consultation and psychological support (Table
198 3 and Figure 2).

199

200 **Quality indicators**

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

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

208 **Discussion**

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

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

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

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

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

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

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

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

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

264 **Conclusion**

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

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

272 Disclosure

273 The author reports no conflicts of interest in this work.

274

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- 348

349

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

352

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

354 1 Data missing for 3 of 29 centers

355

356 **Table 3:** Nurse coordinator characteristics

Number of nurse coordinators	
Practice setting	
University Hospital	14

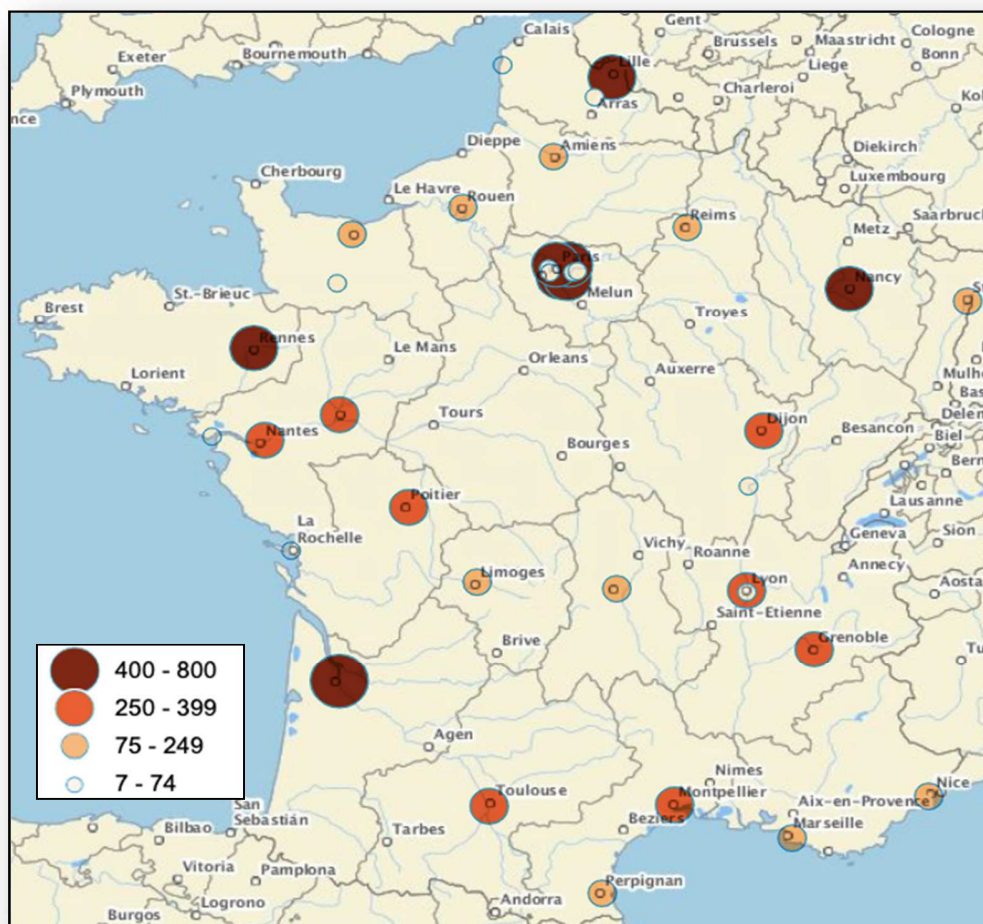
Non-University Hospital	1
Private Clinic	1
Professional title	
Nurse coordinator	7
Consultation nurse	4
Care pathway nurse	3
Education nurse	2
Number of years of nursing experience prior to nurse coordinator job	
≤ 1 year	6
2-10 years	3
≥ 10 years	7
Roles and responsibilities	
Providing information / 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

357 ** Multiple responses accepted

358

359 **Figure 1:** Country-wide distribution of liver cancer treatment centers following hepatocellular
360 carcinoma patients in 2017
361



363

362

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

365 Care coordination, patient support, education, and holistic assessment are the four main nurse

366 coordinator responsibilities described in the literature in the oncology field. Regarding these missions,

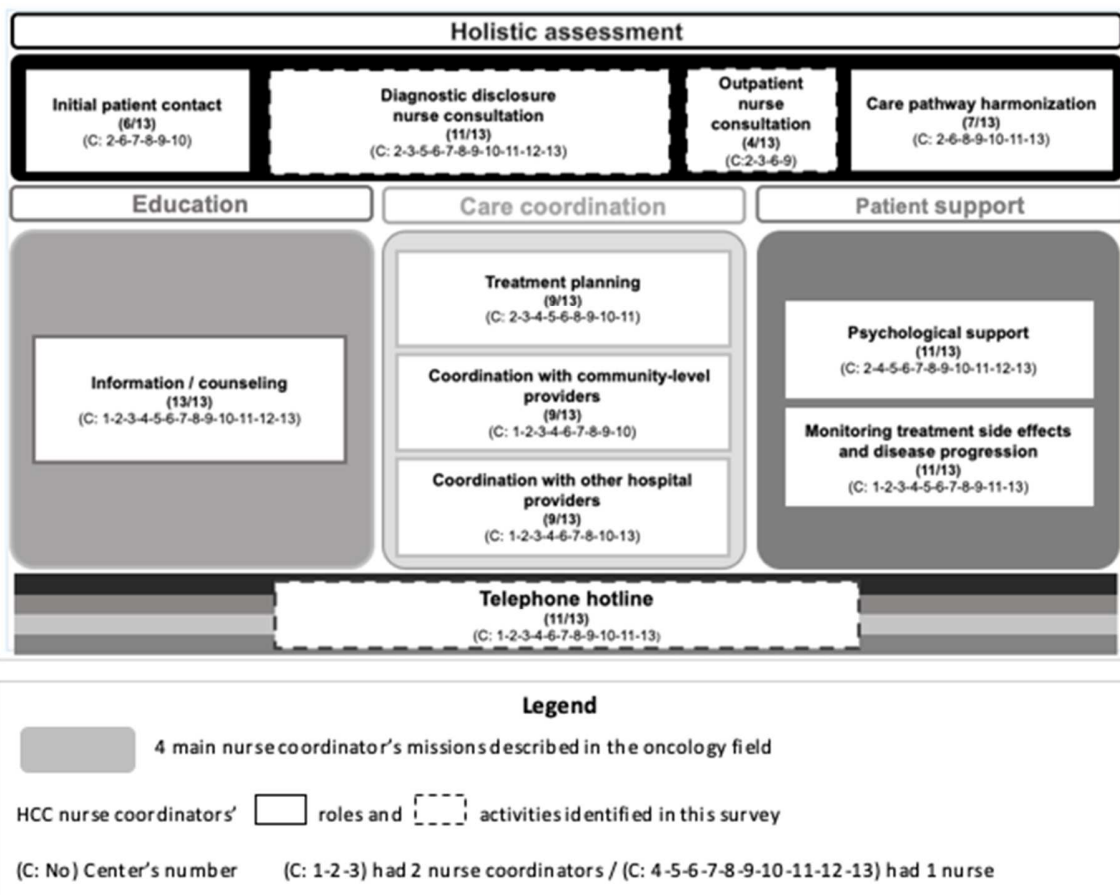
367 eight main roles and three main activities were identified in this survey. A number was attributed to

368 each center (C: No). Centers 1-2-3 had two nurse coordinators. The others had one nurse

369 coordinator. Roles are represented by a rectangle and activities by a dotted rectangle. The size of

370 the rectangle is proportional to the number of centers that reported the role or activity in question.

371 These roles and activities were not standardized and were center dependent.



372