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Cancer care continuity: a qualitative study on the experiences of French healthcare professionals, patients and family caregivers

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| Abstract: | <p>Introduction: Continuity of care has many positive outcomes. Yet, in oncology, it may rapidly be disrupted. It is therefore essential to investigate the perceptions of users. Our aim was thus to describe and compare the perceptions of cancer care continuity of patients, family caregivers and various healthcare professionals involved in cancer care in France, one of the countries most affected by cancer.</p> <p>Methods: The urology and senology cancer departments of two hospitals, as well as community physicians, were involved: 54 hospital healthcare professionals including mainly physicians, nurses and medical secretaries; 12 city physicians; 41 patients and their family caregivers. We carried out a qualitative study using N-Vivo® and a deductive approach to code the interviews into the following dimensions of continuity: informational, organisational and relational.</p> <p>Results: Three different perspectives were highlighted: hospital healthcare professionals primarily focused on organisational aspects (71% of their discourse), city physicians on their need for information from hospitals (40% of their discourse), and patients/caregivers on relational aspects with professionals (51% of their discourse). However, the three dimensions of continuity were intertwined as the major focus of each type of participant impacted their perspective of the other spheres of coordination.</p> |

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| | <p>Discussion: Working on the main perspective of each category of person involved in cancer care could improve, in turn, the other spheres of continuity for these people. For example, dealing with organisational issues with hospital physicians could be an indirect and original way to enhance their relationships with patients, which are so important to the latter.</p> |
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Introduction: Continuity of care has many positive outcomes. Yet, in oncology, it may rapidly be disrupted. It is therefore essential to investigate the perceptions of users. Our aim was thus to describe and compare the perceptions of cancer care continuity of patients, family caregivers and various healthcare professionals involved in cancer care in France, one of the countries most affected by cancer.

Methods: The urology and senology cancer departments of two hospitals, as well as community physicians, were involved: 54 hospital healthcare professionals including mainly physicians, nurses and medical secretaries; 12 city physicians; 41 patients and their family caregivers. We carried out a qualitative study using N-Vivo® and a deductive approach to code the interviews into the following dimensions of continuity: informational, organisational and relational.

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Discussion: Working on the main perspective of each category of person involved in cancer care could improve, in turn, the other spheres of continuity for these people. For example, dealing with organisational issues with hospital physicians could be an indirect and original way to enhance their relationships with patients, which are so important to the latter.

Key words: neoplasms; case management; qualitative research; health personnel; caregivers; physicians;

INTRODUCTION

Continuity of care is the patient's experience of care over time as being coherent and linked¹. To achieve continuity, care coordination between healthcare professionals (HCPs) is required: all the people involved in care, who depend on one another to do their jobs, need to know the role of the others and to exchange information with them². More precisely, care coordination can be defined as 'the deliberate organization of patient care activities between two or more participants... involved in a patient's care to facilitate the appropriate delivery of health care services... often managed by the exchange of information among participants responsible for different aspects of care'². Continuity of care is the result for patients of a good coordination of care by involved HCPs. This is why, although different, the two concepts are interrelated.

The increasing complexity of treatments and the number of participants in cancer care, along with more personalised diagnostic and treatment approaches, make disjointed care more likely^{3,4}. However, coordinated care is of utmost importance. It has many positive outcomes such as better pain management, fewer and shorter hospital visits^{5,6}, more patient satisfaction⁷ and quality of life⁸, and less mortality⁵. This is why continuous and coordinated care is now a major goal of many governmental health plans, including the French Cancer Plan 2014-2019, goal 7⁹. In fact, France is among those countries with the highest incidence of cancer worldwide¹⁰, and Northern France is the region most affected¹¹.

In the major cities of France, the clinical pathway of cancer patients frequently involves two types of organisation: a Regional University Hospital and a Comprehensive Cancer Centre. In Northern France, these two organisations are present on a single site and are coordinated by the Regional Reference Cancer Centre of Northern France. In total, 20,000 cancer patients, coming from all over this region (4 million inhabitants), are treated each year on this site. The cancer pathway in France also involves primary care physicians and community health resources, sometimes including small community hospitals for remote populations. In this complex context, continuity of care may be rapidly compromised, especially in Northern France, one of the most disadvantaged regions from a socio-economic point of view¹². Indeed, in such an underprivileged area, patients often have poor health literacy, a risk factor of inadequately coordinated care¹³.

There is thus a need to identify the factors responsible for poor cancer care continuity from the perspectives of the users. This need is particularly strong in Europe where data on cancer care continuity are lacking in spite of the highest incidences of cancer worldwide. A recent review contains only three European studies out of the 30 considered, and no French study⁷. Furthermore, the majority of studies refer to the views of patients and families only¹⁴. It is true that patients and their family caregivers are the first affected with continuity problems. In particular, the role of family caregivers, which will be referred to as 'caregivers' in the rest of the article for greater readability, is of utmost importance. Indeed, the caregiver is the one assisting with care and health-related assistance to a family member during cancer illness and treatment¹⁵, and provides 70% to 80% of care for those with cancer¹⁵. Care refers to as many

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3 activities including, among many others, medication acquisition, symptom management, supervision of
4 treatments, decision making and coordination of care¹⁵. However, care coordination needs to be examined
5 from different perspectives than only the one of patients or caregivers^{14,16}. For example, as the
6 involvement of general practitioners (GPs) in cancer care improves the physical and social well-being of
7 patients¹⁷, their perspectives of cancer care coordination warrant investigation. Yet, in a recent meta-
8 analysis, only one out of the 45 studies reviewed considered the different perspectives (e.g. of patients
9 and professionals) of cancer care coordination¹⁴ and did not include GPs.

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13 Our aim was therefore to describe and compare the perceptions of cancer care continuity, and
14 underlying coordination, of French patients, their caregivers and a variety of HCPs including both hospital
15 and community physicians. To the best of our knowledge, this study is the first to take such an overarching
16 view of the perceptions of cancer care continuity in one of the regions most affected by cancer worldwide.
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20 **METHODS**

21 ***Design***

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23 This study is a cross-sectional qualitative study. We have chosen a qualitative study to allow the
24 emergence of new potential content on continuity of care. Indeed, since no French study has yet been
25 carried out on the topic and since most research did not include HCPs, we did not know in advance the
26 perceptions of people involved in cancer care nor the specific problems encountered by them, hence the
27 need for a qualitative approach.
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31 Then, interviews were chosen for three reasons: 1) because it is the appropriate method to explore
32 perceptions and experiences, which fits our question research, 2) as the experience of continuity of care
33 can be a sensitive issue for patients with regard to HCPs but also for HCPs in questioning the system or
34 even their colleagues, and 3) for convenient reasons as it would have been difficult to gather at the same
35 time different HCPs.
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40 ***Procedure***

41 Data collection was carried out in the north of France during January 2015 and April 2016.

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43 Hospital HCPs. Urology and senology were chosen because of their high number of patients and
44 as the clinical pathway for these patients involve the two hospitals and community practitioners. A
45 convenience sample was constituted with the help of the Regional Reference Cancer Centre, who gave us
46 an initial list of HCPs' to contact they thought would be willing to participate, also ensuring a variety of
47 HCPs to obtain a diversity of experiences, and then these HCPs gave us the names of other HCPs and so
48 on. Only six people refused due to lack of time. Willing professionals were contacted by our research
49 assistant for a face-to-face interview.
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53 City physicians were chosen at random from a list of 20 who had followed up cancer patients
54 treated at the University Hospital or at the Regional Cancer Centre in 2014. Although city physicians were
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3 paid for their participation in the research (to compensate the not given consultations during the
4 interview), nine refused to take part.

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6 Patients and caregivers were approached both during hospitalisation and in early survivorship, so
7 as to record points of view during treatment as well as later on, with the benefit of hindsight.

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9 During hospitalisation, patients were approached by the nurse manager who explained the
10 research to them. At random she selected patients undergoing a variety of treatments. No patient refused.
11 They signed an informed consent and were then contacted by the research assistant for a face-to-face
12 interview at the hospital. Their relative, designated by the patient, was also invited to participate in the
13 study. No relative refused; they all signed an informed consent and were interviewed at the hospital,
14 independently of the patient.

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16 Patients after treatment were chosen at random from a list of those who had ended treatment
17 between 3 months and one year ago. They were contacted by the research assistant who explained the
18 study to them. Upon acceptance, they were posted a written informed consent form to sign and return to
19 us. A convenient time for face-to-face or telephone interviews was then arranged. One relative refused to
20 participate.

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22 All interviews were recorded and transcribed verbatim. Confidentiality was guaranteed.
23 Interviews were 45 minutes long on average with shorter interviews from city physicians.

24 25 **Research ethics**

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27 The study complied with the Declaration of Helsinki and was approved by the ethics committee of the
28 Regional Reference Cancer Centre and of both participating centres.

29 30 **Data collection**

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32 Semi-directive interviews were carried out with the following overarching themes for all groups in order
33 to explore (Table 1):

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- 36 - their own spontaneous understanding of the “continuity and coordination of care”. What do these
 - 37 terms refer to for each person?
 - 38 - how they personally experience the continuity of care and why;
 - 39 - the elements they think hinder the continuity and coordination of care.

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41 The probes varied for each category of people as follows. If necessary, hospital HCPs were invited to
42 explore continuity within their department, between departments within the hospital and with other
43 institutions or professionals outside their institution. Patients and caregivers were invited to think about
44 continuity between their first symptoms, tests and diagnosis, then during treatments in hospital, and in
45 the aftermath of treatments. City physicians were asked to describe continuity when referring their
46 patients to hospitals, then when their patients were treated in hospitals and after treatments.

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48 At the time of the study, the research assistant who carried out the interviews had a position of
49 researcher and was not a clinician nor familiar with the topic of coordination of care.

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Initially, we planned to interview 20 participants of each category of people to reach saturation (i.e. when there is no new information), but this cut-off was revised for hospital HCPs and city physicians. Indeed, the former had various experiences so that more interviews were required while the latter had homogenous views thus requiring less interviews.

Data analysis

Data analysis was performed by three of us: two researchers in health psychology and one public health physician.

Because our goal was to describe and compare the perspectives of continuity from the different categories of interviewees, we first used a deductive approach with a predetermined coding system. Based on Haggerty's model¹⁸, we coded the data into the three following categories (see Table 2 for an accurate description of each category): informational continuity, organisational continuity, and relational continuity. This conceptual framework was chosen for its heuristic features: with only three categories, the model is parsimonious but enables the emergence of sub-content within each category. That is why it suited our need for comparison, thanks to parsimony, while allowing an inductive approach, which was needed here.

The first three interviews of each category of people (i.e. patients/caregivers, hospital professionals, city physicians) were independently analysed and coded by three of us to ensure the reliability of the coding. When one of us was not sure about the coding, a discussion was undertaken and our coding system was adjusted accordingly. After these adjustments, the analysis of the remaining interviews was shared between us.

Our meaning units were sentences or parts of sentences. If one meaning unit was related to one of the three predetermined categories, it was assigned to the corresponding category. Otherwise, it was not coded. The coding was performed using N-Vivo 10[®], which enabled a quantitative coding of the discourse, thus a weighting of the three predetermined types of continuity for each category of people (see Table 3). It should be noted that our interviews did not broach continuity in terms of the predetermined categories. Therefore, respondents' answers and coding were not dependent on the interview-related questions. Within each predetermined category, a content analysis was performed ensuring that quality criteria were met¹⁹. Quotes were chosen to illustrate recurrent ideas among many participants.

At the end of the analytic process, the HCPs who participated in the study were invited to a debriefing meeting on the results and interpretations. This enabled us to ensure that no personal or biased interpretation had been done. Chosen quotes were also presented and submitted to discussion on their generalization and interest with regards to the topic.

RESULTS

In total, 107 people were interviewed (Table 3):

- 54 hospital HCPs, mostly physicians, nurses and secretaries;
- 12 city physicians, mostly GPs.
- 21 patients and 20 caregivers: 22 (11 patients and 11 caregivers) interviewed in hospital during treatment and 19 (10 patients and 9 caregivers) interviewed between 3 months and one year after the end of treatment. With one exception (i.e. a daughter), all caregivers were spouses of patients. The participants in remission were different from those in hospital.

HOSPITAL HCPs

Seventy-one percent of the corpus of all HCPs was coded into the predefined category “organisational difficulties” (Table 4).

Organisational issues (71%)

Lack of time (29%). HCPs were very frustrated by not being able to spend enough time with patients because of their heavy caseload, including paperwork burden:

‘We are inundated with forms to fill in during consultations and have a limited time due to increasing numbers of patients. So we try to act quickly, not to botch it, to keep a dialogue with patients and not act like secretaries but we often fill in these forms too briefly and this has poor consequences for our colleagues’ (Surgeon, University Hospital, 4).

Lack of resources (23%). HCPs highlighted a lack of qualified personnel, especially secretaries, telephone operators, and case managers:

‘Everybody agrees that there’s a need for case managers to ensure coordination between city physicians and hospitals, but who is going to pay for this?’ (Female surgeon, Cancer Centre, 40).

Moreover, a high turnover of HCPs, especially nurses and resident physicians, was reported as a problem. Insufficient training was also mentioned for residents, requiring staff to spend considerable time explaining the pathology and treatments to them. The residents then moved on after six months, just as they were beginning to feel comfortable and useful in the ward.

Equipment issues (18%). The biggest hurdle was the impossibility of communicating medical information (e.g. transfer of images) between the Cancer Centre, the University Hospital and city physicians because of computer systems locked for security reasons. The current system of communication by mails was also

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3 deemed no longer appropriate. HCPs wanted direct communication by emails with colleagues and patients
4 because of its instantaneity.
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8 **Unclear task allocation (9%).** Oncologists wished that community GPs were more involved in cancer
9 patient follow-up. However, they reported that the division of each party's tasks was not clear. HCPs also
10 reported handling tasks that should be done by other professionals. For example, oncologists were
11 sometimes requested to see a patient whereas, from their point of view, the patient's problem was minor
12 and should have been handled by residents and nurses, or by city GPs. Nurses reported that at the day
13 hospital, because it was not defined who was in charge of booking the return ambulance for patients, this
14 was sometimes not done. As summed up by an oncologist:
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17 *'There's a technical aspect. Organisational charts should be drawn up with the tasks and*
18 *responsibilities of each person and at each step. Groups of people like that is not a good thing*
19 *because in the end nobody is responsible for anything.'* (Oncologist, University Hospital, 3).
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23 **Lack of structure for communication between and within institutions (6%).** Little was organised to ensure
24 both institutions communicated with each other. For example, there were no special phone lines between
25 the physicians of the two institutions. As one oncologist of the Cancer Centre (5) stated angrily:
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27 *'It's intolerable that we, as a privileged partner of the University Hospital, cannot have easy*
28 *access to them!'* (Surgeon, Cancer Centre, 40).
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33 **Informational issues (19%)**

34 Overall, each professional reported suffering from insufficient information from other professionals.
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37 **Between hospitals and the community (30%).** Oncologists wished they had more information from GPs
38 about the medical history of patients whom they had referred to them.
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40 *'I receive letters from GPs saying 'Mr XXX has prostate cancer, thank you for what you will do for*
41 *him'. Come on! I need to know his treatments, comorbidities, medical and familial history, and*
42 *life situation'* (Oncologist, Cancer Centre, 2).
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46 **Between the University Hospital and the Cancer Centre (20%).** Some HCPs of the Cancer Centre reported
47 difficulties in identifying their cancer colleagues at the University Hospital. Consequently, they sometimes
48 did not know whom to call when they needed information.
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50 Furthermore, because of a lack of information exchange between institutions, HCPs did not know
51 what had been said to patients by HCPs from the other institution, which made them feel uncomfortable
52 in front of patients.
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4 **Within an institution (17%).** Each profession complained that colleagues of other professions did not
5 provide them with enough information. For example, nurses complained that oncologists did not give
6 them enough information, especially when they had to give atypical care that required more indications.
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9 **With patients (10%).** HCPs reported that patients' need for information was difficult to handle. When
10 patients lacked information, they became anxious and called the department to speak to someone, which
11 disrupted the HCPs' activity while they handled the phone calls.
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14 15 16 **Relational issues (10%)**

17 **Expressed by physicians (66%).** Physicians reported that the coordination of care was also dependent on
18 good relationships between HCPs.
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20 *'We're lucky that our medical secretary worked at the cancer centre for many years, she knows*
21 *very well how it functions, she knows a lot of people over there, and clearly I think that it works*
22 *due to a good and mutual understanding between people'* (Rheumatologist, University Hospital
23 and Cancer Centre, 13).
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27 Physicians spoke little about their relationships with patients, but when they did, it was to report cases in
28 which bad news was delivered abruptly to patients causing distrust in medical professions and thus
29 sometimes a lack of patient adherence to medical decisions and treatments.
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32 33 **Expressed by other HCPs (34%).**

34 Just like physicians, other HCPs did not pay much attention to HCP-patient relationships as an important
35 aspect of care coordination. They nevertheless acknowledged that the high number of HCPs in cancer care
36 gave patients a feeling of cold and impersonal care with negative consequences:
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39 *'Patients sometimes see other HCPs, like homeopaths, who are important to them, but very often,*
40 *because of impersonal hospital care, they don't talk to physicians about all of this and then we*
41 *don't understand why the patient refuses the treatment; sometimes they listen more to outside*
42 *opinions than our medical ones'* (Psychologist, University Hospital, 39)
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47 Interviews with patients and caregivers as well as with GPs (results below) were rather
48 homogeneous and focused on a few key points, thus the three predetermined categories were not split
49 further into subcategories
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52 53 **PATIENTS AND CAREGIVERS**

54 Their responses were much less developed than those of HCPs but their spontaneous answers referred to
55 relational issues.
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Relational issues (51%)

Relational issues pertained to the lack of empathy of some HCPs, especially resident physicians, which explained the disruptions or difficulties in continuity. Mr. P. (Patient in remission, 2) explained that seven years before having cancer, he had a very difficult appointment with an urologist to have some tests regarding a suspected cancer:

'He treated me like a dog... it was shameful'.

As a result, Mr. P. waited for several years before making the decision to see an urologist again:

'I gave up for 4 or 5 years, that's it'.

Another participant (the wife of a patient) confided:

'If you feel ignorant, and it's true that you are, a bit looked down on, you can't ask what you want to ask, because you think, well, it's going to be stupid what I'm going to say, and then problems occur and you think I should have dared to ask!' (Wife of patient in remission, 2).

Organisational issues (29%)

Waiting times between diagnosis and surgery and between surgery and the start of chemotherapy were deemed too long and caused anxiety and a feeling of disrupted care. Hasty discharges were also perceived as a disruption of care by caregivers who had to organise the return home in a hurry and reported a lack of follow-up after the end of treatment. Patients and caregivers also complained about the high number of professionals they met due to specialisations and turnovers, along with the difficulty of identifying the role of each one and whom to contact according to their questions or worries.

'You establish a relationship of trust with the oncologist, she knows you well, you feel safe and then she leaves! You have to start all over again with someone else, it's unpleasant' (Hospitalised patient, 7).

Informational issues (19%)

Patients and caregivers were undermined by divergent information from various HCPs, notably between senior physicians and resident physicians. These discrepancies were stressful, making them lose their sense of control. They also wanted more intelligible information, whether oral or written, and more information about treatment side-effects and possible risks.

'I asked a nurse if my current treatment was chemotherapy, she said no, then I asked my oncologist, he said yes. It's very irritating, this feeling that they can't be trusted.' (Hospitalised patient, 4).

COMMUNITY PHYSICIANS

The content of GP interviews was rather evenly distributed across the three dimensions of continuity.

Informational issues (40%)

City physicians unanimously reported a lack of information from their hospital peers, particularly about patient treatments. Sometimes they had to organise home care without any information from hospitals. Mails sent to them at patient discharge were reported as very incomplete and sometimes arriving too late, after their consultations with patients. As a GP described (56), it is a very uncomfortable situation:

'We're less well-informed than the patients themselves! So I have to wait for the patient to explain to me his/her treatment before I can say something, but in fact, I can't answer their questions, so I cloud the issue a little bit... if I said 'Oh sorry, I don't know', our trust relationship would be damaged'.

Organisational issues (34%)

City physicians mainly reported difficulty in contacting the hospital. As there was no dedicated phone line for them in the hospitals, they had to go through the general switchboard, and were then not always directly referred to the relevant person.

'The problem is the switchboard, you can't reach anyone, it's terrible. I don't understand why there's no phone line for physicians, it's so time-consuming, and that's a deterrent' (GP, 61).

Relational issues (26%)

City physicians wished they could communicate more with their hospital colleagues, whom they do not know at all. They were also annoyed when hospital physicians asked for tests to be done again in Lille whereas they had already been carried out outside the city.

'What I'm criticising is that in Lille, they want Lille-based professionals for the examinations. One gets the impression that, in their eyes, the tests done outside Lille are less valuable. And then our patients tell us, 'You do realise, Doctor, I have to go back to Lille again'' (GP, 66).

Furthermore, city gynaecologists complained that their patients were "stolen" by hospitals and monitored there after treatment, which created strained relationships between both parties.

DISCUSSION

To sum up the results, three different perspectives were highlighted: hospital HCPs, whose reports were thoroughly developed, primarily focused on organisational aspects (71% of their discourse), city physicians on their need for information from hospitals (40% of their discourse), and patients/caregivers on relational aspects with professionals (51% of their discourse).

The organisational issues raised by HCPs pertained to lack of time and resources, high turnover in HCPs compromising continuity, equipment issues, unclear task allocation and a lack of formal structures for communication between and within institutions. City physicians focused on a need for information

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3 from hospital HCPs, but the organisational and relational issues they raised were also related to the
4 problem of information transfer. Finally, patients and caregivers mainly addressed the topic through the
5 lens of relationships with HCPs. From their vantage, it seems that HCPs' empathy and information given
6 to them could blunt the bad consequences of organisational flaws.
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9 Our three categories of continuity were therefore interrelated as in previous studies²⁰. Strikingly
10 however, each category of interviewees tackled the continuity of care from a different perspective (Figure
11 1). In line with Canadian and English data²¹, for patients and caregivers, continuity was primarily a matter
12 of relationships and information quality, which further determined their perception of organisation. In
13 contrast, HCPs focused on organisational and informational dimensions, which were the basis of good
14 relationships with patients from their perspective.
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17 These differing concepts of continuity have practical implications. If one wishes to enhance HCP
18 relationships with patients, one might consider targeting organisational and informational issues first,
19 instead of only the resulting relationship issues. This might be the reason why relationship training for
20 cancer HCPs does not give good results in the field²². Without the basic conditions for good HCP-patient
21 relationships, such as enough time to spend with patients²³, an ongoing relationship with the same HCP²⁴
22 and enough information from other colleagues, it becomes difficult for HCPs to be empathetic with
23 patients even though relational and information dimensions are crucial for the latter. The same problem
24 occurs between HCPs. As there are no healthcare coordinators in France, healthcare professionals
25 themselves must think about the information that the next professional will need to manage the patient.
26 This requires a cognitive task to imagine the needs of colleagues and prepare the necessary information
27 accordingly, but cognitive load and mental fatigue can affect these cognitive tasks²⁵. Moreover, the HCP
28 cognitive load is huge: a heavy workload, medical issues, red-tape burden, empathy with patients, and a
29 cognitive task for the coordination of care. This situation is all the more distressing for young residents for
30 whom the medical aspects are not yet fully achieved, and who were logically therefore the HCPs most
31 criticised by patients. In these conditions, it would be beneficial if case managers took over cancer care
32 coordination and continuity.
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40 Patients could also play an important role. Since they are very sensitive to relationships with HCPs'
41 and received information from them, they could be prepared for the consultations by thinking in advance
42 about the questions they want to ask using a question prompt list. Such procedures have proven good
43 results to streamline consultations²⁶, and arguably coordination of care. Furthermore, patients'
44 participation in consultations favours a patient-centred approach from HCPs²⁷, which was the critical
45 dimension of continuity for patients in our sample.
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49 Finally, city physicians focused mainly on poor and delayed information from hospitals. Although
50 not cancer specialists, community primary care providers are often visited by cancer patients for their
51 frequent comorbidities²⁸ and are endorsed by patients as their shared preferred cancer manager with the
52 surgeon²⁹. In spite of this preference, our study confirms that the full integration of GPs in cancer care is
53 still problematic; in particular, the respective roles of GPs and oncologists need to be clearly defined.
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4 **Some limitations are important to report.** First, these results might not be generalised to
5 wealthier regions. Indeed, although France is a rich country, northern France, historically mining and highly
6 industrial, is a much poorer area than other French regions and with a high rate of unemployment.
7 Therefore, contrary to other data²⁰, in our sample, patients and caregivers hardly mentioned their self-
8 responsibility in care coordination. In another region, they could have had a much more organizational-
9 oriented approach. Second, these results are specific to the French cancer care system, which does not
10 provide professional navigators or cancer care coordinators, nor other facilities that have been proven to
11 enhance coordination¹⁴. In this context, care coordination is no one's official responsibility, which
12 significantly worsens organisational and informational continuity. Third, sociodemographic details of the
13 interviewees were lacking. Even if the region is well-known for its socioeconomic deprivation, we do not
14 have any confirmation of such characteristic of patients and relatives. Finally, although great care was
15 taken in the objective analysis of the data with a triangulation with a public health physician and hospitals
16 HCPs to whom results were submitted, the influence of two psychological researchers in the interpretation
17 of the data cannot be excluded.

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23 **In conclusion**, this study highlights three different perspectives of cancer care continuity: hospital
24 HCPs focus primarily on organisational aspects, city physicians on the need for information from hospitals,
25 and patients/caregivers on relational aspects. Accordingly, working on the main concerns for each
26 category could improve, in turn, the other spheres of continuity. In particular, dealing with organisational
27 issues with physicians could be an indirect and original way to enhance their relationships with patients,
28 which are so important to the latter.

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38 39 **AUTHOR CONTRIBUTIONS**

40 Sophie Lelorain has contributed to conception/design, data analysis and writing of the manuscript.
41 Clémence Moreaux has contributed to data collection, analysis and writing. Véronique Christophe and
42 Françoise Weingertner has contributed to funding acquisition, resources providing and project
43 administration. Hélène Bricout has contributed to data analysis, and project administration and writing.
44 All authors have reviewed and edited the drafting.
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48 49 **ETHIC APPROVAL**

50 The study complied with the Declaration of Helsinki and was approved by the ethics committee of the
51 Regional Reference Cancer Centre.
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Table 1. Questions and scheme of interviews

| Themes | Patients | Family caregivers | Healthcare professionals | City Physicians |
|--|---|-------------------|--|--|
| 1. Spontaneous understanding of "continuity and coordination of care" | What is your spontaneous understanding of the expression "continuity and coordination of care"? What do you think these words refer to? | | | |
| 2. Personal experience | How do you, personally, experience the continuity and coordination of care? Can you tell me why? | | | |
| 3. Barriers | In your opinion, what is hindering or preventing the continuity of care? | | | |
| 4. Probes if necessary, i.e. if not addressed spontaneously by the participant | Tell me how you experienced continuity and coordination of care: <ul style="list-style-type: none"> - during the first symptoms, tests and diagnosis - during treatment in hospital, - in the aftermath of treatment (if relevant as some participants are still under treatment). | | Can you tell me about continuity: <ul style="list-style-type: none"> - within your department, - between departments within the hospital, - with other institutions or professionals outside the institution. | Tell me how you experience continuity and coordination of care: <ul style="list-style-type: none"> - when referring patients to hospitals, - when patients are in hospitals - after treatments. |

Table 2. The coding categories

| | Informational continuity | Organisational continuity | Relational continuity |
|--------------------|---|---|---|
| Definitions | Data are coded when they are about information transfer from a healthcare professional to other people: healthcare professional or patient or institution. The content should relate to the time (appropriate or not) of the transfer and/or to the quality (clear, personalised, congruent with other information given to the patient, etc.) and quantity of the information. | Data are coded here when they refer to finances, resources (all resources including financial and human resources), the allocation of resources, the allocation of roles and responsibilities, and structural issues, i.e. how care is organised, whether care is coherent and timely with complementary services that must not be lacking or redundant. A lack or inappropriate use of resources can be coded here. | All data related to human factors: good or poor relationships, mistrust, empathy, communication, increased demands on patients or healthcare professionals. Relational continuity can be between healthcare professionals or between patients and healthcare professionals. |
| Examples | “When the doctor explained the disease to me, it was Chinese at first for me; he didn’t explain things clearly” (Patient) | “When I call the Regional University Hospital, it takes me 15 minutes to reach my colleague because there is no direct line for GPs to reach oncologists directly so that I have to go through the telephone switchboard first and then wait and wait. This is really upsetting”. (City GP) | “As we know the radiologists very well, we have an excellent relationship with them, it is easy for us to work with them, we call them quite often” (Oncologist) |

Note. The original three categories of Haggerty et al. (2003) were informational, relational and management continuity. However, as the ‘management category’ did not explicitly encompassed organisational issues, we decided to define a larger category ‘organisational continuity’ to fit our purpose.

Table 3. Participants Characteristics

| Characteristics | Number |
|---|---------------|
| Hospital healthcare professionals | 54 |
| Institution | |
| Regional University Hospital | 26 |
| Comprehensive Cancer Centre | 29 |
| Female* | 36 |
| Medical field | |
| Urology | 20 |
| Senology | 19 |
| Both Urology and Senology | 14 |
| Profession | |
| Nurse | 10 |
| Oncologist | 8 |
| Medical secretary | 6 |
| Surgeon | 4 |
| Psychologist | 4 |
| Nursing assistant | 4 |
| Radiotherapist | 3 |
| Radiologist | 3 |
| Others (neurologist, rheumatologist, gynaecologist, anatomo-pathologist, psychiatrist, social worker) | 12 |
| City doctors | 12 |
| General Practitioner | 10 |
| Gynaecologist | 2 |
| Male | 8 |
| Patients and relatives* | 41 |
| During hospitalisation | 22 |
| Medical field | |
| Urology | 8 |
| Senology | 14 |
| Between 3 months and one year after the end of treatment | 19 |
| Medical field | |
| Urology | 8 |
| Senology | 11 |

*no other demographic details were recorded

Table 4. Percentages of the three predetermined categories of continuity issues mentioned in discourses according to the type of interviewee, and of emergent categories for hospital healthcare professionals (HCPs)

| | HCP* | City physicians | Patients and relatives |
|------------------------------------|-----------|-----------------|------------------------|
| Organisational continuity | 71 | 34 | 29 |
| Lack of time | 29 | | |
| Human resources difficulties | 23 | | |
| Equipment issues | 18 | | |
| Unclear task allocation | 9 | | |
| Structural issues | 6 | | |
| Miscellaneous | 15 | | |
| Informational continuity | 19 | 40 | 19 |
| Between institutions and community | 30 | | |
| Between institutions | 20 | | |
| Within institutions | 18 | | |
| With patients | 10 | | |
| Miscellaneous | 22 | | |
| Relational continuity | 10 | 26 | 51 |
| Expressed by physicians | 66 | | |
| Expressed by other HCPs | 34 | | |

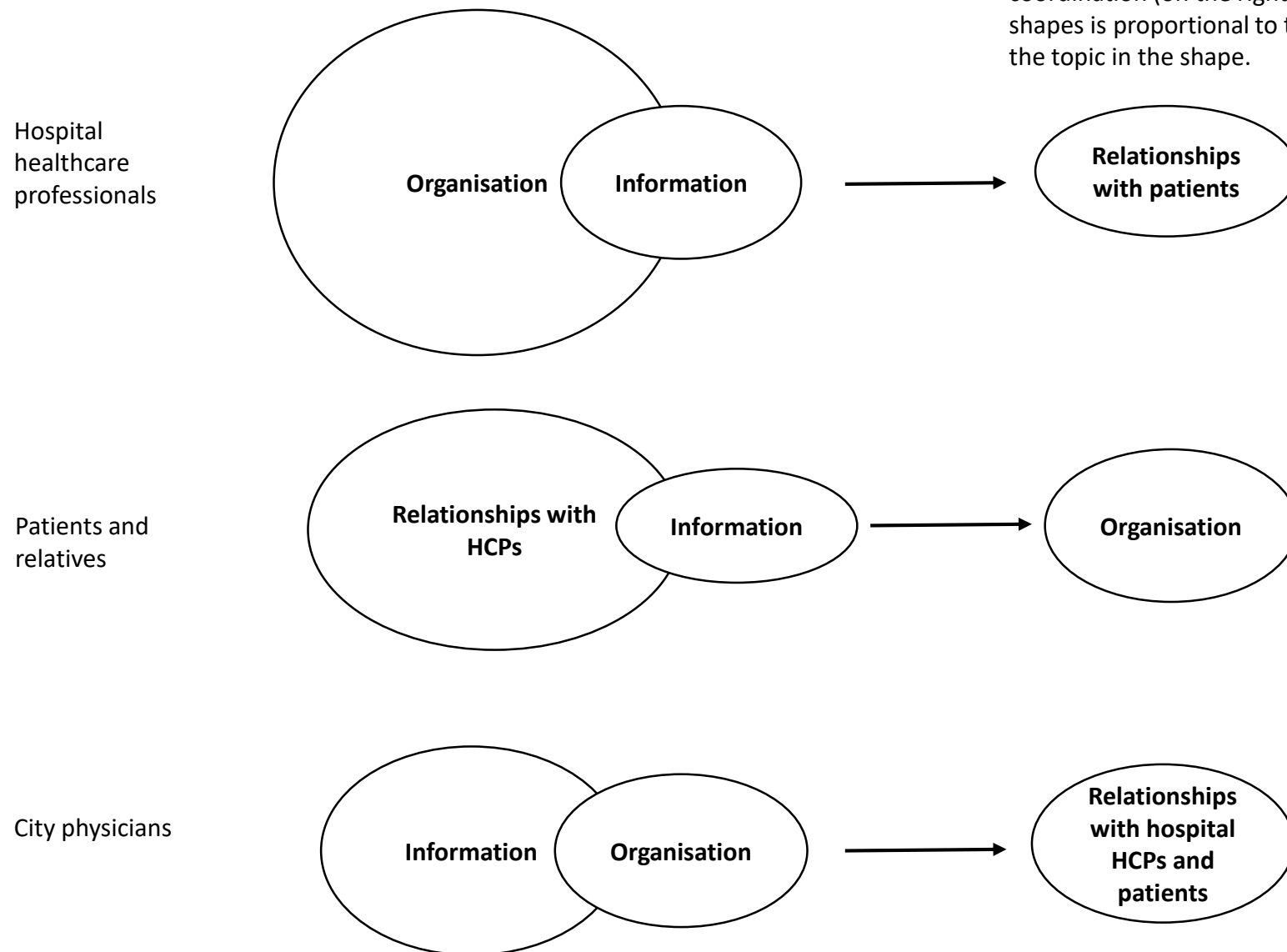
The total of each column is 100%, which represents the total of coded meaning units for each type of interviewee. For example, 71% of the coded meaning units of all hospital healthcare professionals pertained to organisational continuity, and within the 71%, 29% pertained to the lack of time. There were no subcategories for city physicians and patients and relatives as their speech was not developed enough to provide them.

In bold: the highest value of the predetermined category for each type of interviewee

*from the Regional University Hospital and the Comprehensive Cancer Centre

Figure 1. Coordination of care experiences from each category of interviewees

Note. Each category of participants focused mainly on spheres of coordination (on the left of the arrays), which affect their perception of the remaining sphere of coordination (on the right of the arrays). The size of the shapes is proportional to the amount of discourse related to the topic in the shape.



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