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A Mixed-Methods Study of the Unmet Needs and Burdens of Illness of Patients with Bladder Cancer in France

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Abbreviations

BC- bladder cancer

NMIBC- non-muscle-invasive bladder cancer

MIBC- muscle-invasive bladder cancer

BCG- Bacillus Calmette-Guerin

TURBT- Transurethral removal of bladder tumor

PAG- Patient Advisory Group

CVC- Cancer Vessie France

AFU- French Urological Association

EAU- European Association of Urology

ESMO- European Society for Medical Oncology

CHU- French University Hospital

CLCC- French Cancer Center

ASR- Age-standardized Rate

SoC- Standard of Care

GP- General Practitioner

QoL- Quality of Life

Abstract

Introduction: Bladder cancer is one of the top 10 most commonly diagnosed cancers worldwide. It is divided into non-muscle-invasive (NMIBC) and muscle-invasive (MIBC). The mortality rate in France is one of the highest in Western Europe, and patients experience significant burdens due to the high recurrence rates and limited treatment options, especially for NMIBC, for which systemic immunotherapies are being studied. Despite accounting for one of the highest lifetime costs of all cancers, it receives low research funding, and significant gaps in knowledge remain.

Methods: A mixed-methods approach was employed, through a patient survey and interviews with physicians. A total of 81 patients answered the questionnaire and 7 physicians (4 oncologists and 3 urologists) were interviewed. The qualitative data was analyzed using ATLAS.ti, while for the quantitative data, descriptive analysis was performed in Excel and statistical analysis in R.

Results: In practice, NMIBC patients are only seen by urologists, often in private clinics, while MIBC patients are treated by both oncologists and urologists. NMIBC patients thus receive fewer supportive resources, and their needs are under-considered. One of the biggest unmet needs identified was receiving complete and comprehensible information. It was found to be a significant predictor of the satisfaction with the management of the disease (OR=7.88), satisfaction with the resources received (OR=8.15), as well as levels of implication in care decisions (OR=8.07). In terms of how the organization of care should change to better meet these needs, especially in the face of the potential new NMIBC treatments, no consensus could be reached, but oncologists' involvement seems likely necessary, due to urologists' inexperience with such therapies.

Conclusions: Evidence-backed policies need to be implemented to address the current organizational challenges and ensure NMIBC patients have access to supportive care. In addition, an in-depth review of the informative resources patients receive is necessary.

Keywords: Bladder Cancer, Organization of Care, Supportive Care, Patient Perspectives

Introduction

Context

Bladder cancer is among the top 10 most commonly diagnosed cancers worldwide (Sung et al., 2021), constituting around 3% of all cases. The incidence rate is higher among men, situating it at number 6 among the most common cancers, and the male-to-female incidence rate is almost 4:1 (ASR/100000 being 9.5 for men and 2.4 for women) (World Cancer Research Fund International, n.d.). There are more than 13000 diagnoses per year in France, with the number increasing yearly (National Cancer Institute, n.d.). Despite there being a lower incidence than in other countries in the region (ASR=10.1), the mortality rate is one of the highest in Western Europe (ASR=3.4) (Cancer Today, 2024), even though France has the highest expenditure per bladder cancer patient in the EU (Leal et al., 2016). Smoking is one of the main risk factors, estimated to contribute to 50% of all cases (Rink et al., 2015), and the median age of diagnosis is 73 years (Cumberbatch et al., 2018), adding significant challenges to care delivery.

Most bladder cancers are urethral carcinomas, around 75-80% of which are classified as non-muscle-invasive (NMIBC), cases where the tumor is limited to the inner lining of the bladder (Kamat et al., 2016). The rest of the cases are muscle-invasive, and the treatment pathways and specialists involved are different depending on the cancer type.

Treatment Patterns

The French Urological Association sets classification, diagnosis, and treatment guidelines, which closely follow European ones. NMIBC cases are divided into 4 categories based on the risk of progression to muscle-invasive disease- low, intermediate, high, and very high risk (although in practice and research, often only 3 are considered, the high and very high categories being merged). After confirmation of diagnosis with cystoscopy, followed by imaging and staging of the disease, treatment is given accordingly. All patients will undergo TURBT- a minimally invasive surgery to remove the tumor- and then will receive one dose of intravesical chemotherapy (with Mitomycin-C) or BCG. Low-risk patients will then be followed up with cystoscopies, whereas higher-risk patients will receive the BCG treatment (Neuzillet et al., 2022). It is important to note that there are significant discrepancies between the official European/French guidelines and the daily practice, with low-risk patients being more likely to be over-treated and over monitored, and high-risk patients- under-treated and under-monitored (Hendricksen et al., 2019).

BCG was initially developed as a vaccine to prevent tuberculosis, but, in the case of BC, it stimulates the immune system to fight off the cancer. It is delivered under local anesthetic directly to the bladder through a catheter. However, more than 50% of patients treated with BCG will experience tumor recurrence, and some develop BCG-resistant tumors, against which there are currently limited options, and the standard of care is radical cystectomy (removal of the bladder) (Pillippu Hewa et al., 2024). In addition, BCG needs to be followed long-term, up to 3 years for high-risk patients, and it has numerous side effects, such as fatigue, fever, and muscle pain that last up to 72 hours (Lobo et al., 2021).

The treatment consists of an induction period of a dose weekly for 6 weeks, followed by a maintenance period of a weekly dose for 3 weeks at the 3-, 6-, and 12-month marks. However, only 50% of patients complete the recommended minimum 1-year regimen (Serretta et al., 2016). Despite being the most efficient treatment for 30 years, questions remain regarding its mechanism and effective clinical application, and, for high-risk patients, it is a suboptimal option, as it reduces the risk of progression to muscle-invasive cancer in only 26-27% of cases (Brandau & Suttmann, 2007).

Another aspect to consider regarding the BCG treatment is the shortages in the medication that have occurred due to its low cost, which does not incentivize production. This led to quotas being implemented in France in the past, to prioritize it for patients based on need levels (Neuzillet et al., 2023). There are also concerns related to the environmental impact resulting from the BCG bacteria that are released after the treatment, despite strict handling protocols (Wilson, 2023).

Because of the proven clinical, humanistic, and economic burdens, especially for NMIBC patients due to the difficulties associated with the BCG treatment and the lack of alternative options (Grabe-Heyne et al., n.d.), several systemic immunotherapies are currently being studied in phase 3 clinical trials (Lebacle et al., 2021), with one already approved in the US (FDA, 2020), but not yet in France. They only target high-risk patients, and several uncertainties persist, including the risk-benefit profile, adverse effects, as well as which specialists will need to be involved in their administration, since they are systemic treatments and thus very different than the current NMIBC standard of care, which includes only local treatments (Lobo et al., 2022). In addition, a medical device has also received FDA approval for the same patient population, as a local therapy, closer to the SoC (Serani, 2023). The existing guidelines don't specify which specialists should be involved in the management of BC (oncologists, urologists, others) depending on risk stratification and type. Only the ESMO guidelines mention that MIBC cases should receive multidisciplinary care via tumor board discussions or consultations with a medical oncologist, radiation oncologist, and urologist (Powles et al., 2022).

If the disease becomes muscle invasive, patients will receive more traditional cancer treatments, such as systemic chemotherapy and radiation therapy. Most of them will undergo bladder resection (coupled with prostatectomy for men and hysterectomy for women) (Neuzillet et al., 2022), a surgery with a significant negative permanent impact on patients' lives, including their psychological and sexual health (Clements et al., 2022). Treatments and even risk stratification for NMIBC are thus thought of as strategies to avoid progression to MIBC and avoid cystectomy.

There are also ongoing clinical trials with immunotherapies for MIBC, with some already approved in France, which can potentially improve health outcomes (Bamias, 2018).

Patient Experience

In terms of the general awareness of BC risk factors and symptoms, studies have shown poor knowledge levels in the French population (Rouprêt et al., 2020), although current initiatives to improve it exist both at a community level in France (AFU, 2024), as well as at a European level (EAU, 2023). For patients who are at the diagnosis and treatment stages, there are brochures available on the AFU website with information about the disease, treatments, and side effects (AFU, n.d.), although it is not known if doctors offer these resources to patients and if they are accessible enough, considering the advanced age of most patients. There is also an initiative to offer patients a surveillance card with information about the BCG treatment to help with the reporting and management of the side effects (ANSM, 2021), but evaluation of this program is lacking. Despite being a common cancer and accounting for the highest lifetime costs of all cancers (Sievert et al., 2009), BC receives low research funding and significant gaps in knowledge remain (Boormans & Zwarthoff, 2016). This may also have an impact on patients if they feel that their disease is not given enough recognition in the medical community.

A recent global survey from the World Bladder Cancer Patient Coalition of 1198 respondents from 45 countries was implemented to fill some of those gaps, especially related to patient burdens and experiences. The France-specific results included 91 patients and showed that 68% of respondents did not know the symptoms of BC before diagnosis, and 81% did not receive information about clinical trials. In addition, 35% experienced barriers in treatment access, 38% of those who needed it did not receive emotional support, and 78% of those who needed it did not receive practical support (Makaroff et al., 2023). Some of the recommendations from this study were to improve public awareness of BC symptoms and risk factors, ensure access to innovative treatments through clinical trials, improve early detection, and increase access to information and support for patients (World Bladder Cancer, 2023). Studies adapted to the needs and specificities of the French patient and organizational context are lacking.

Objectives

This study aims to find answers to the following questions:

- What factors impact BC patient trajectories and outcomes, is it access to treatments and supportive resources (psychological, nutritional, sexual, financial), location, or type of specialists involved in the care pathway?
- What types of doctors are involved, and in what capacity depending on the BC type?
- How should the organization of care change in the face of the new treatments to facilitate their safe and equitable delivery?
- How satisfied are patients with the care, treatments, support, and information they receive?
- Where in the treatment journey and which patients have the highest unmet needs that would require public health interventions?

With the promise of new treatments in the next years, now is the optimal time to evaluate the unmet needs of BC patients and enact policy and organizational changes, if required, to diminish the burdens currently experienced. The project will aim to understand the clinical practice and how it differs from the guidelines, as that is essential in answering the questions above, but will not focus on evaluating the clinical interventions. The goal is to showcase patient perspectives as that is currently lacking and reach some conclusions which could serve as the basis for future policy and program implementations.

One of the sub-goals of the project is to diminish the knowledge gap regarding the BCG treatment, as the reasons for why it is often interrupted have not been rigorously investigated yet (Serretta et al., 2016).

Methods

To answer the research questions, a mixed-methods approach was employed, through a patient questionnaire and physician interviews, in order to obtain data both on patient satisfaction, impact and treatments through the survey, and information regarding the organization of care, treatment pathways, and resources offered to patients from the physician interviews.

Qualitative Phase

The goal of this part is to gather insights regarding the challenges associated with the current organization of care and resources available, and understand how patients are referred, diagnosed, and treated, and how their needs are perceived and addressed by the medical teams. In addition, outlooks toward future potential changes and improvements will be collected. A total of 65 doctors were contacted independently with an interview request. Their profiles were identified based on research of peer-reviewed publications as well as databases of attendees at relevant congresses such as the European Association of Urology (EAU, 2024). A mixture of urologists and oncologists were contacted to obtain both perspectives. A diverse mix of profiles was aimed to be included (doctors from university hospitals, cancer centers, private clinics, and regional hospitals), however, it was easier to find contact information for physicians with published research, most of whom work for major hospitals. They were also considered optimal participants for this study, as they would have sufficient knowledge about the ongoing clinical trials involving the new therapies and about larger organizational issues, which might not affect smaller health institutions to the same extent.

All participants who agreed to be interviewed followed through with the appointment. In total, 8 interviews were conducted in English including one with a representative of the patient association Cancer Vessie France, as well as 7 with physicians (4 oncologists and 3 urologists) to gather insights from their varied professional experiences (Table 1).

Questions were asked on the following topics:

- → the way patients are initially referred and diagnosed in practice,
- → what treatments they receive according to their cancer type,
- → which type of institutions they are treated in,
- → what kind of information they are offered, and at which stages of their journeys,
- → if and how the organization of care should change,
- → what support is offered to patients outside of the main treatments.

The full interview guide is available in Appendix 2, and some probing and additional questions were asked during the interviews depending on the information received.

The interviews were conducted online through Microsoft Teams or Zoom between April 11, 2024, and June 10, 2024. They were recorded with the participants' consent and were subsequently transcribed verbatim. Data was then analyzed using the latest version of ATLAS.ti (version 24) to uncover overarching themes. The first interview was with the representative of the patient association, which was semi-structured, and informed the questions asked to the physicians. After the first interviews with an oncologist and a urologist, their answers guided the questions that were asked to the doctors of the same specialty in the following interviews. Two separate code groups were created for the two types of specialists to distinguish the themes between them.

The interview with the PAG representative was done early and had a larger focus on NMIBC patients. Thus, the insights were used for the development of the patient questionnaire and the doctor interviews, but due to space and content limitations, they will not be included at length in the final report.

The qualitative data was analyzed first to utilize the conclusions reached in the quantitative data analysis.

Table 1. Profiles of respondents in order of interview dates.

Code Assigned	*Type of Hospital*	*Area of Specialization*	*Date of Interview*
PAG	N/A	Representative of Cancer Vessie France	11.04.2024
ONC1	CLCC	Medical oncology, research	21.05.2024
URO1	CHU	Urothelial cancers	22.05.2024
URO2	CHU	Clinical trials, research	27.05.2024
ONC2	CLCC	Bladder, prostate cancers	27.05.2024
ONC3	CHU	Genito-urinary cancers, clinical research	29.05.2024
URO3	CLCC	Urological cancers	30.05.2024
ONC4	CLCC	GU cancers, Phase 1 clinical trials	10.06.2024

Quantitative Phase

The quantitative part was designed to obtain patient perspectives regarding their needs and burdens, satisfaction with the care, information, and resources received, the types of specialists they saw, and what improvements in care they feel are needed. Initially, data from the National Healthcare Database (SNDS) was planned to be utilized through a platform that has an existing contract with Pfizer. However, that was proven to be unfeasible due to time and resource constraints, and also because it does not contain enough information to meet the study objectives. Instead, a patient questionnaire was designed, based on the literature review, to obtain information from patients regarding the following topics:

- → their treatment journeys,
- → burdens encountered,
- → ease of access to treatments, specialists, and resources,
- → supportive resources received,
- → impact of the disease on different aspects of their lives,
- → information obtained,
- → knowledge of the disease before diagnosis,
- → satisfaction with the management of their disease.

The survey was validated by 10 medical, patient advocacy, and health and value colleagues from Pfizer, before being sent to the patient association Cancer Vessie France, the only bladder cancer association in the country, which increases the representativeness of the data. After their verification of the survey, a pilot phase was initiated, where 6 patients completed it and assessed it by writing any comments they had regarding what should be changed or added to the existing questions. Subsequently, the survey was finalized with the integration of the feedback from the pilot phase and sent by the patient association to all their member patients by email on May 27th and resent on June 5th. The survey is solely in a digital form (Microsoft Form) and has 55 questions but is designed so that only the pertinent questions to a respondent's journey appear, and most questions are multiple-choice or scale based. The majority of questions were set as required, in order to avoid having missing and incomplete data. The total number of patients who were contacted was not revealed by the PAG. Some of the physicians interviewed also agreed to send it to their patients, although it is not clear which of them ultimately sent it. The survey is presented in complete and original form (in French) in Appendix 1.

The inclusion criteria were being aged 18 and older and having bladder cancer currently or in the past, without other restrictions.

Table 2. Participant characteristics

Category	**Subcategory**	**Total sample (N=81)**	
		N	**%**
Age	35-44	6	7%
	45-54	7	9%
	55-64	33	41%
	65-74	26	32%
	75-84	9	11%
Gender	Male	52	64%
	Female	29	36%
Professional Status	Full-time	18	22%
	Part-time	5	6%
	Unemployed	9	11%
	Retired	43	53%
	Self-employed	5	6%
	Not reported	1	1%
BC Type	NMIBC	67	83%
	MIBC	8	10%
	Metastatic (MIBC)	5	6%
	Not known by the patient	1	1%
NMIBC Risk Category	Low	6	7%
	Intermediate	13	16%
	High	34	42%
	Not known by the patient	13	16%
	Other	1	1%
Location Type	Urban (>100 000 inhabitants)	25	31%
	Suburban (10 000-100 000 inhabitants)	25	31%
	Rural (<10 000 inhabitants)	31	38%

There were a total of 81 answers at the time of the analysis (52 males, 29 females) (Table 2). Data was analyzed using Excel for the descriptive analysis and R for the statistical tests. According to the literature, results from the qualitative data, and the descriptive analysis, some variables of interest were selected and recoded (Appendix 3), and the associations between them were tested with Fisher's tests in R. The variables for which p-values <=0.20 were found were included in 6 final multivariate logistic regressions. Due to space limitations, most of the tables containing the results of the logistic regressions are attached in Appendix 5.

This is an **individual and independent project** for the MPH thesis, not sponsored by Pfizer. However, throughout the project duration, advice from multiple Pfizer departments were integrated:

- *Health and Value (Health Economics and Outcomes Research, Market Access)*- for support throughout the project.
- *Patient Advocacy*- to establish contact with the patient association and validate the survey to ensure that patients' interests and rights are respected.
- *Medical*- to verify the survey and ensure the medical accuracy of the questions included.

Ethical Approval

Because the questionnaire was designated to patients, an independent ethical approval was strongly considered, but was determined to not be feasible with the timeline and resources available. However, efforts were made to respect ethical and privacy guidelines. In addition to the verification of the survey by multiple experts in patient advocacy and the patient association, no identifying or personal questions were included, and neither the patient association nor the physicians who distributed it have access to the data. There is also no possibility to match any answer to a specific patient since the data is anonymous. In the context of this thesis, not intended to be published in a journal, these steps should be considered enough to comply with ethical standards.

Additional External Data (optional inclusion)

Additional data was considered to be included, especially if the current methods would not have yielded sufficient results. There were 8 interviews conducted with French patients as part of a recent Pfizer global study on the topic of "Patient experience and unmet needs in high-risk non-muscle-invasive bladder cancer" (Kopenhafer et al., 2024). In that study, those 8 interviews were analyzed in combination with 24 others from patients from the US, the UK, and Germany and combined with quantitative data. Additional insights could have potentially been extracted for this project if focusing only on the French patients. The transcripts were thus reviewed but will not be included in the results since they do not present new insights and focus only on high-risk NMIBC, so they are not representative for the current study.

Results

Qualitative Phase

Clear differences emerged between the oncologists and urologists interviewed regarding the main topics discussed, but views were largely similar within each specialization. For that reason and the fact that it became clear that they treat different patient subgroups (only overlapping in MIBC care), oncologists' views will be presented first on all the 5 main topics assessed, which have been found to be strongly interconnected (organization of care, patient access to supportive care, physician perceptions of patient needs, information offered to patients, and the impact of the disease on patients' lives), followed by urologists' views, in addition to those of the PAG representative. With this presentation, a better general conclusion of the views of each type of specialist can be achieved than if presented side-by-side.

Insights from Oncologists

Organization of care

All respondents reported that NMIBC patients do not see oncologists during their treatment pathways and are mainly treated by urologists, who receive BC patients from GPs or other urologists.

MIBC patients are treated by oncologists with systemic treatments such as chemotherapy and radiation therapy, and by urologists for the TURBT and cystectomy. In their care, there is greater collaboration between the different types of specialists.

Across the board, oncologists expressed uncertainty about how the current organization of care will/should change in the face of the potential new NMIBC therapies, and about whether they will ultimately be integrated into the SoC. No steps were mentioned having been taken to assess how that change should occur, even though the results of the clinical trials are expected in a few months. They all agreed, however, that oncologists will need to be involved in NMIBC patient care if the new immunotherapies get approved:

> *"But for the moment I'm not sure we will have systemic immunotherapy as part of the treatment of the non-muscle invasive [bladder cancer]. But if they do, if they are approved, then oncologists will have to administer them because they have more experience with systemic [treatments]." (ONC2)*

In the view of ONC1, oncologists spend more time with their patients than urologists and have a more systemic (medical rather than surgical) approach, which is important for MIBC patients, due to the nature of the treatments they receive:

> *"We use more time to discuss with our patients. So, I think it's important to see all the patients who are metastatic, and obviously, we see the patients who need chemotherapy because the patient needs to have a medical, a real medical, you know, doctor? Not a surgeon, but a medical doctor."*

In her view, which was in agreement with those of the other 3 oncologists, this approach would be beneficial for NMIBC patients if systemic immunotherapies are approved, even if these drugs could be handled by urologists alone if they show minimal side effects in the clinical trials:

> *"So, I think it's not a good idea that urologists keep these patients even if the drug is easy and there are few adverse events, as you can see the bottom [line] is to have a medical oncologist to have a global point of view on the patients." (ONC1)*

A main unmet need mentioned stems from the fractured organization of care, with a lot of NMIBC patients being treated in private practices, where urologists do not have the habit of building a collaborative approach with oncologists and other specialists, who practice in hospitals.

> *"A lot of private urologists do the surgery and then after give the patients like a ball to the medical oncologist without some real information and steps that make it fluent for the patient and for the medical oncologist. So, this may be a big gap and unfortunately, it's the vast majority of the patients who are followed by this type of activity in private… around two-thirds of patients are referred to private [clinics]." (ONC3)*

Finally, another aspect mentioned was the additional time that would be required if the new medications are integrated into the NMIBC SoC, but one of the oncologists presented a solution that might be able to be utilized in the future. ONC4 postulated that, taking into account urologists' expertise lies in surgery and not systemic therapy, they might not feel comfortable or inclined to focus on immunotherapies, thus in-home care with trained nurses after the first 1-3 cycles of the treatment received in a hospital setting might be a feasible solution. However, this option is currently only in a pilot phase in ONC4's hospital, with chemotherapy as the treatment tested, and having enough trained nurses was mentioned as a potential barrier.

Access to supportive care

Oncologists reported offering their patients (MIBC) access to different support specialists- psychologists, nutritionists, sexual specialists, stoma management specialists, social workers, aestheticians, specialized nurses, pain specialists- resources associated with the medical oncology departments, based on the needs of individual patients, or based on direct patients' requests. They mentioned scarcity and prioritization of these resources as the main reasons why NMIBC patients do not typically receive access to them. Two out of the four oncologists, however, recognized the need for higher access to such resources for this patient group.

In a particular case, ONC3 mentioned being an investigator in a clinical trial of NMIBC immunotherapies, but that she was still not able to offer access to those patients to the resources available in her department:

> *"Probably all the TVNIM [NMIBC] patients should benefit from these helps [resources], but the fact is that due to the small number of participants [in the clinical trial], we cannot afford to propose it to everybody. So, we prefer to select the patients for whom it's very important to have this support."*

Better prognosis and fewer needs are other reasons in the views of an oncologist (ONC2) for the lack of resources for NMIBC patients:

> *"Yes, you keep your bladder, you don't have radiation. You will have only resection, transurethral resection. After, you will have a second look and you do BCG therapy or not, sometimes you do some Mitomycin-C, but it's really rare. It's like BCG therapy for one or two years… It's because it's really a better prognostic."*

Perception of patient needs

In the view of the same oncologist and after assessing NMIBC patient needs as lower than those of MIBC patients, the main need in terms of supportive care for NMIBC patients stems from his view that not enough patients see their disease as serious, and thus, in his opinion, there is a need for more intentional information and education:

> *"So, the patient minimizes their disease and sometimes they are not doing the follow-up as they should. They are not quitting smoking as they should, so I think more than supportive care, it should be like information to say it's bad, what you have, it's serious. Because most of the patients say- I have a polyp, and it's like polyp in the colon [which] is benign. But in the bladder, it's not a polyp, it's a real cancer. So yes, a lot of, most of the time the patient minimizes the disease in the non-muscle-invasive [bladder*

> *cancer]. And so, I think we have to work on this to say that it's an important disease and it's 80% of the patients."*

These perceptions are inadvertently thought of by the physicians in the context of the other patients with other cancers that they see or that are treated in their respective hospitals, as they often offered comparative examples, like the one above and the following one from ONC3, which ties the themes of needs and information and showcases a similar view to that of ONC2:

> *"So, let's say compared with other cancer types like prostate cancer, like kidney cancer, it's not exactly the same population in terms of patients, they are probably more expecting to receive rather than to go through and search some data and some information. So, I think that just giving the book will not be helpful, it's necessary to have somebody explaining, motivating, and things like that…It's [because of] the age, it's also the fact that it's probably a different socio-demographic population. Not everybody, of course, I'm making some generalizations, let's say that more frequently, we have some patients with both alcohol and tobacco use and so that makes that they are more frail also in terms of physical abilities with some cardiovascular disease, comorbidities, and so it's not exactly the same population, so it's probably more difficult to make them change their behavior."* (ONC3)

Information offered

Oncologists mentioned spending time to talk about the treatment plan with each patient, without offering them additional materials, in an effort to not overwhelm them and help them process and understand their diagnosis and treatments:

> *"Because I tell them a lot. I just give them one paper that I do with the plan of treatment, is the only paper I give them because otherwise, I think they have too many papers, you know."* (ONC2)

The close collaboration of oncologists with other healthcare professionals, within a multidisciplinary treatment team, is also showcased here, as nurses are involved in helping patients understand their diagnosis and treatments:

> *"We also have a nurse that will take time to explain a second time everything I explained in my consultation so like this, the patient has the second information with different words."* (ONC2)

Impact of the disease on patients

The duration of the treatment of 6 months or more, with surgeries, chemotherapy, and radiation therapy was identified by the oncologists as having the biggest impact on various aspects of patients' lives, such as professional, personal, and financial. According to them, the cystectomy is the element of the treatment that represents the biggest burden on patients, and brings a lot of adjustments that are difficult to accept:

> *"I think the biggest difficulty is to accept the surgery, you know, the ablation of the bladder. Yes, I think it's very, very difficult for the patient to have this surgery, and yes, [it is a] modification of their body." (ONC1)*

ONC3 shared an example of how a patient was severely impacted financially because of not being able to work due to the treatments, despite the apparent access to social workers ("*we have a social assistant for everything to do with the money [aspect]*"):

> *"She was quite poor because she was working at the hospital, but as a, not a nurse, but assistant of the nurse and she stopped eating to feed her child. Because she didn't have as much money as she needed to live because of the stop in work, so she had to stop eating and so I think it's a [financial] burden."*

Insights from Urologists

Organization of care

Firstly, urologists also expressed reservations about the potential new treatments since the results are not available yet but pointed out the preliminary data and the insights from the US where one immunotherapy (pembrolizumab) is already approved for NMIBC as being less positive than expected. These views are similar to those of ONC3, who participated in a clinical trial.

> *"So, it might change, and maybe in the next years it will appear in the non-muscle-invasive bladder cancer. But I think right now the results are not that impressive. So, it's not going to happen soon." (URO3)*

They added that these medications have the potential of diminishing some of the clinical unmet needs such as the low response rate to the BCG treatment, and, largely agreeing with oncologists, mentioned that an increased collaboration with them will be required, if the medications are approved, because of the lack of experience of most urologists with systemic immunotherapies:

> *"They could change the management of BCG naïve patients, meaning that we may associate BCG and systemic immunotherapy, in order to increase the response rate of BCG, because the response rate of BCG alone is almost 60% only... So, we [have] a need in this point, but the solutions which are coming are systemic treatments with immune checkpoint inhibitors. Most of the urologists don't have any experience with them... and most of the urologists in France [will] have to work with medical oncologists if we need to prescribe immune checkpoint inhibitors in association with BCG." (URO2)*

An important point re-emphasized was that because of the current organization of care, with a lot of urologists working in private clinics, there is a lack of collaboration with oncologists, but also no availability of other specialists, which would be required to help manage the systemic side effects of the new treatments. A drastic change in the way urologists operate would also be needed- from only localized treatments (BCG, intravesical chemotherapy) and surgeries (TURBT, cystectomy) to a more systemic, multi-organ care.

> *"But if you want to do immunotherapy, intravenous immunotherapy, you need to be trained to deal with the side effects and you need to have the resources around you. So, you need to have dermatologists for toxicity or cardiologists for cardiac toxicity, you need to have endocrinologists for endocrine disease. You need to have all this set up because [if] the patient experiences side effects of immunotherapy, those need to be taken care of quite fast to avoid dramatic side effects that sometimes can be lethal." (URO1)*

This is also the only urologist who believes, with some reservations regarding the timeline of the implementation of that change, that urologists will need to manage NMIBC patient care alone even after the potential introduction of systemic immunotherapies, because of the high number of patients, which would make it unfeasible for oncologists to be involved. Scarcity of time and resources were also voiced as uncertainties on this topic by oncologists, but from the 7 doctors interviewed, all but one agreed that oncologists will need to be involved in some capacity, yet to be determined. In his argument, URO1 brought up the example of Germany, where urologists are already administering these immunotherapies:

> *"I do believe that urologists will have to do so. It's already the case in Germany, for example, that urologists are taking care of the systemic therapy, even in the non-*

> *muscle-invasive space, so I do think that oncologists will have way too many patients to deal with and the urologists should be involved. But that's going to be a case-by-case approach, and I'm not sure everybody will jump."*

In a different interview, URO3 referenced the centralized nature of cystectomies in England when talking about the differences in the organization of care, showing that physicians take notice of the changes occurring in the field in neighboring countries. The mentions of the US from an oncologist, particularly regarding the earlier approval of pembrolizumab, however, had a more distant nature, due to the larger differences between the two countries:

> *"Let's say that in the United States, [NMIBC] immunotherapy has already been approved and is given to some patients. It seems that it's not so, so many patients, meaning that it's probably less than what was expected at the beginning, according to the epidemiology." (ONC3)*

Perception of patient needs

In a somewhat surprising result, urologists, similar to oncologists, viewed NMIBC needs as not serious because of the nature of the disease and treatments received.

> *"To have a non-muscle invasive bladder tumor is very [burdensome], but they are not really considered like a cancer patient, because it's not a muscle-invasive bladder tumor. So, there is no chemotherapy, there is no heavy treatment, there is no heavy surgery, there is no radiation therapy." (URO2)*

Access to supportive care

Even though urologists recognize some patient needs, they stressed that they are not able to routinely address them to the necessary specialists because there are not enough professionals, and MIBC patients are prioritized. NMIBC patients are thus not able to be systematically offered and referred to supportive specialists, with the biggest needs being smoking cessation specialists and physical therapists:

> *"So, we need specialists to address patients for smoking cessation, but these kinds of specialists are not very frequent and it's not so easy for urologists to address patients to this kind of specialists... Because there are not enough doctors... So, for patients, we don't have the same helps [support] as for the muscle-invasive patients. So, we can't refer patients to a psychologist because psychologists do not have enough time to receive these kinds of patients which are very, very numerous. So, in the best world,*

> *yes, we want to address the patient to a psychologist, but in fact, it's an unmet need." (URO2)*

Another major barrier mentioned in access to supportive care was that it is not reimbursed for this patient population (NMIBC), with the same constraint being the reason why some patients don't have access to novel medications that are already available in the US.
URO1 stressed the importance of implementing high-level policy changes to ensure NMIBC patients have access to the resources they need, although he conceded that these reforms will be difficult to be achieved considering the perception that the medical community has about NMIBC patients, with their needs being under-considered:

> *"We do need the help of patient coalitions and patient associations to get this forward because obviously what is needed is not found right now-there are no phones [assistance lines] in supportive care. If you want to do supportive care in non-muscle-invasive, it's hard to justify to the authorities, although it's needed. So, we have to show to the authorities that it is needed, get that reimbursed in the pathway so that patients can have psychological support, and make sure that they have appropriate and adequate symptoms treatment and then they have a way to report the symptoms, thus all the supportive care that is needed in that space is lacking right now." (URO1)*

Information offered to patients

A barrier that was mentioned by a urologist regarding patients' access to information was that *"the median age of diagnosis of those patients [means they] have really limited access to the internet."* (URO1).

Two out of the three urologists said that before each treatment they offer their patients brochures that are also available on the AFU website, and include the following information:

> *"So, most of the patients in France will have this kind of information, so it's a seven-page information. So you have, let's say for BCG, you have anatomical considerations that the patient needs to know before, then what about the disease, what about the other option, what is the preparation, how we do it, what is expected after the instillation, what are the risks and complications, what the patient should be aware of, what are the signs that [there is a need] to have an urgent consultation to a clinic? There are also the numbers of the service that is the counsel for smoking cessation, and then there is also the consent for patients [to declare] which person is of trust to take medical decisions if they cannot make them themselves. So basically, they have*

> *these documents that are available, you have one for BCG, Mitomycin-C, TURBT, cystectomy, and chemo." (URO1)*

Only two urologists mentioned offering the card designated to help report side effects, in line with the existing policy, while highlighting its importance:

> *"The patient has a specific card to explain that they receive BCG and in case of symptoms, there is a phone number to call in order to have a specialist who knows the side effects of BCG. Because if we treat what would look like cystitis, but it's not a cystitis, because it is due to BCG with the same antibiotics then you make some mistakes, so we have to know that the patient receives BCG to treat them correctly." (URO2)*

The only need for change identified regarding information was from a urologist who doesn't usually offer the AFU brochures in his daily practice but said *"I don't think it's really relevant, but maybe we should inform them more about patient associations." (URO3)*

Impact of the disease on patients

All the urologists agreed that one of the largest negative impacts for all NMIBC patients regardless of risk categories comes from the frequent cystoscopies, which are invasive and painful tests that have to be done every few months to a few years to check the progression of the disease, and cause a lot of anxieties for patients:

> *"After the first month, we see them very, very regularly with the three-month cystoscopies or six-month cystoscopies. So, it's quite demanding for them, it's quite an invasive follow-up because it's not just a blood test or an ultrasound, it's endoscopic. When they come to the hospital for the cystoscopy, they very often have the anxiety of a relapse. So maybe for them it's a burden of psychological [nature], an issue about the anxiety of the relapse each time they come, I think it's the main issue for them." (URO3)*

The BCG treatment was also reported to be very burdensome for patients, because of the many side effects, for which no clear treatments or preventive methods were mentioned, as well as due to the long duration of each instillation and the treatment overall, which can be recommended for up to 3 years, but only a small fraction of patients finish the full duration. A new piece of information, not reported in the literature, is that side effects can be heavier after 18-24 months of BCG, increasing the treatment burdens:

> *"You have to know that almost 20% of patients only have three years maintenance treatment due to BCG side effects. The side effects of BCG are very heavy and*

> *[burdensome] for patients, mainly for the last induction treatments after the 18 months or 24 months. So, patients have to stop not because doctors want to stop, but because the patient can't support more instillations." (URO2)*

Urologists confirmed that they surveil patients for 2 hours before urination after which patients can leave. In terms of the shortages, one of them mentioned that this risk is no longer pertinent because BCG production capacity has been increased, but said that during the last shortage, a significant number of patients had to have cystectomies, which otherwise could have been avoided, and that a score was implemented to determine priority levels, confirming what was reported in the literature.

Insights from the Patient Association

The representative of the patient association highlighted the unmet needs and significant burdens felt by low-grade NMIBC patients, who have limited treatment options and may also feel like their needs are not prioritized in the medical and research settings:

> *"We see unmet needs for patients particularly in the low-grade NMIBC profile, where some patients have multiple, frequent, low-grade recurrences that don't respond to BCG. These patients endure a lot of suffering and reduced quality of life due to repeat TURBT and cystoscopies. There is a lack of treatment options for them after BCG or Mitomycin-C failure, and long-term impact on their urinary comfort, social aspects, sleep patterns, etc. These patients may feel that there is a lack of recognition and treatment options for their side effects as well, and there is hardly any research that focuses on low-grade NMIBC."*

They also mentioned the difficulty patients feel in reporting side effects, as not every patient receives a surveillance card, and there is no dedicated helpline. Thus, the patient association frequently receives questions regarding this aspect from patients. In addition, the limited pain and side effects management options linked to the BCG treatment were also reported as barriers:

> *"Another important aspect in the NMIBC patient experience is pain management during instillations and routine cystoscopy, some patients may receive pain management for bladder instillations, some don't, such as local anesthesia gel, or virtual reality devices such as HypnoVR)."*

Quantitative Phase

First, assessing the representativeness of the data was prioritized.

The male-to-female ratio is similar to what is found in the literature, as 52/81 (64%) of respondents to the survey are male, and official data from 2018 (National Cancer Institute, n.d.) (the last year for which data is available) showed that 81% of cases diagnosed that year were male. 67/81 (82%) of patients reported having NMIBC, versus 75% from the literature (Burger et al., 2013). In addition, 49 patients (60%) documented being or having been a smoker, which is the main risk factor, seen in 50% of cases, according to research (Rink et al., 2015). Finally, 51% of NMIBC patients reported being in the high-risk category, closely matching the 50% rate found in publications (Porten & Cooperberg, 2012). Patient locations are also diverse, representing different parts of the country, including all 13 regions of metropolitan France (Fig.1).

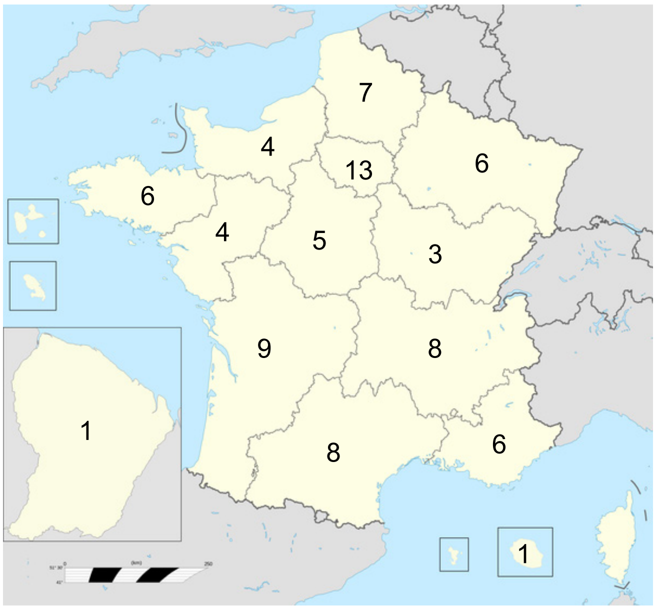


Figure 1. Map of respondents according to geographic region.

Treatment Pathways

63/67 NMIBC patients reported seeing only a urologist during their treatment pathway, and only 4 saw an oncologist and urologist.

Taking into consideration that these results are from patient accounts and not medical records, the information obtained largely matches that seen in the literature and coming from the physician interviews. Smoking was found to be the main risk factor, with 60% of patients being or having been a smoker. The main comorbidities were cardiovascular-related (hypertension, heart disease, COPD). In terms of the treatment pathways, the results largely match the guidelines and the information relayed by the doctors. NMIBC patients undergo a TURBT first, followed by BCG, and some have a second TURBT after BCG and rarely- Mytomycin-C. This aspect is in line with what was explained by physicians- that Mytomycin-C is not often used in

France for NMIBC patients. Almost all MIBC patients reported undergoing cystectomy. Their treatment pathway also includes systemic chemotherapy (and, in some cases, radiation therapy) as mentioned by oncologists, but these treatments were not part of the questions addressed to patients (Fig.2).

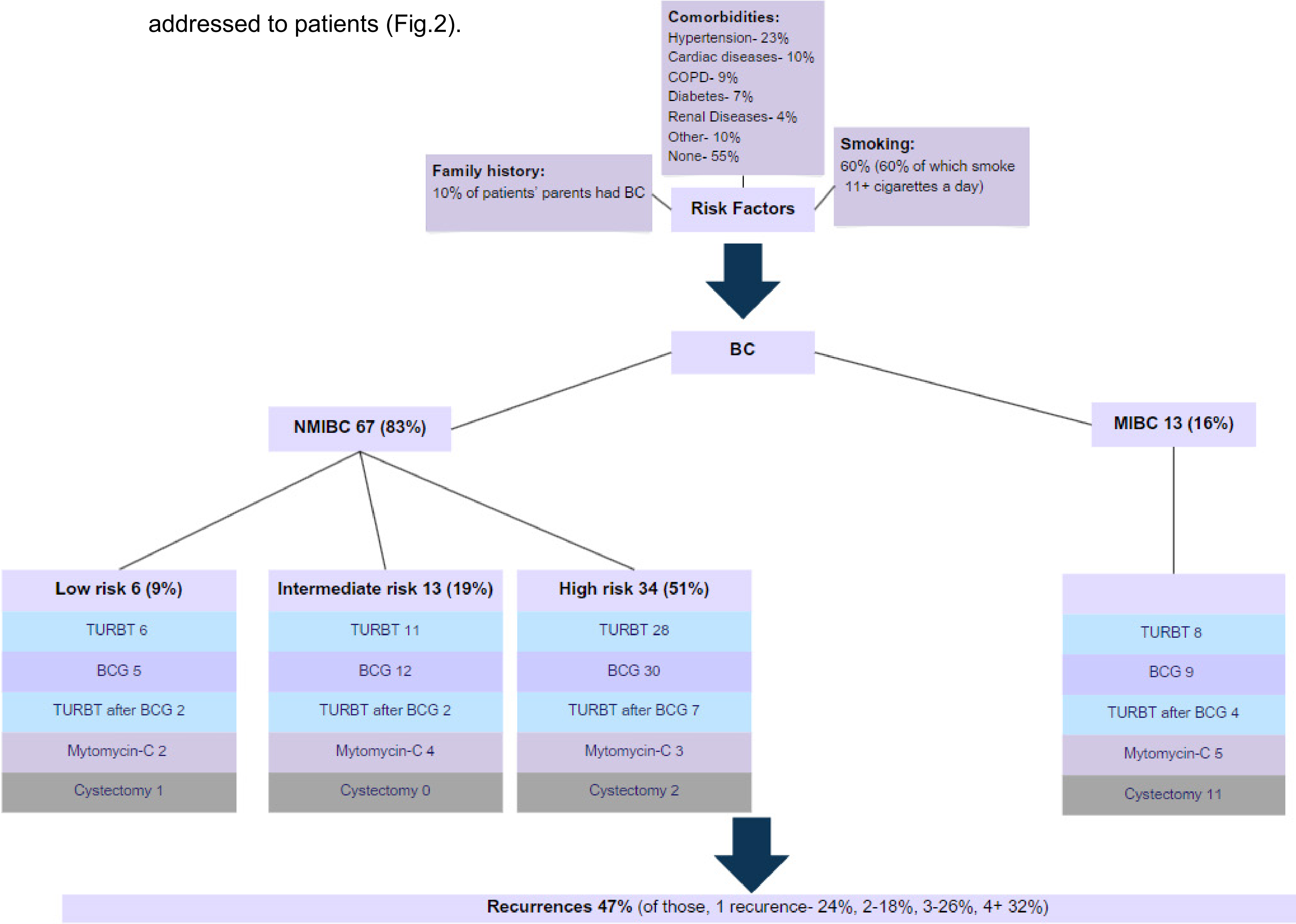


Figure 2. Patient-reported treatment journeys with the frequency of specific treatments, risk factors and recurrences.

BCG Treatment

Of the 73 patients who received the treatment, 54 (74%) reported having side effects, the most common ones being:

- fatigue (52%),
- fever (27%),
- nausea (12%),
- painful and frequent urination (62%),
- muscular pain (19%),
- loss of appetite (11%),
- pain during instillation (15%)

4 patients detailed that they had BCGite, a serious, tuberculosis-like complication.

A large part of the BCG patients (52%) felt the effects in the first 48 hours after the instillation, with the rest experiencing them later than 48 hours.

In terms of what was prescribed to treat the side effects, a large proportion of answers (27%) revealed no prescription, 70%- anti-inflammatory medications, and 15%- antibiotics, or a combination of treatments, as this was a multiple-choice question.

However, patients were overall satisfied with the management of the side effects by the medical team, with an average score of 3.53 on a 1-5 scale (1= “very unsatisfied”, 5= “very satisfied”).

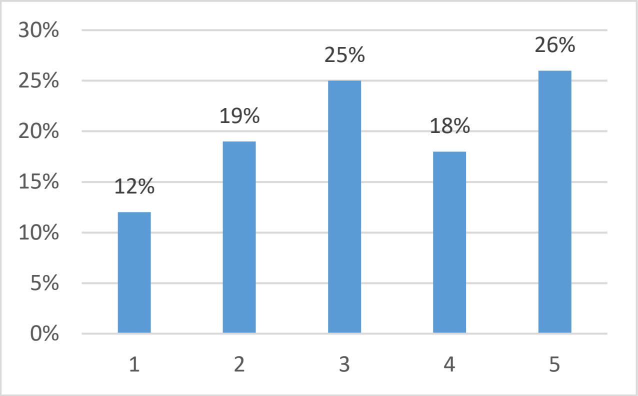


Figure 3. Pain and discomfort levels during BCG instillations (1= “None/very little”, 5= “a lot”)

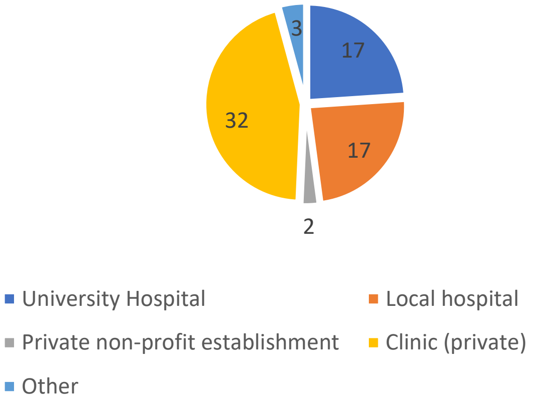


Figure 4. Location of the BCG treatments

Regarding the instillation period, the overall pain level felt was 3.26, on a scale of 1-5, with 44% of patients registering high levels of 4 or 5 (Fig. 3). Only 29 (40%) patients said they were surveilled after the instillations.

27% of patients reported ending the treatment sooner than recommended, with the main reason being the side effects (55% of answers), followed by inefficacy (20% of answers).

In terms of the location of the treatment, most patients outlined receiving BCG in private clinics, followed by an equal number of patients receiving it in local or university hospitals (Fig. 4). A large number of patients -25/74 (34%) only received the induction doses (up to 6), and 23 (31%) others had a treatment of up to 1 year, thus the vast majority did not reach the recommended duration of 3 years.

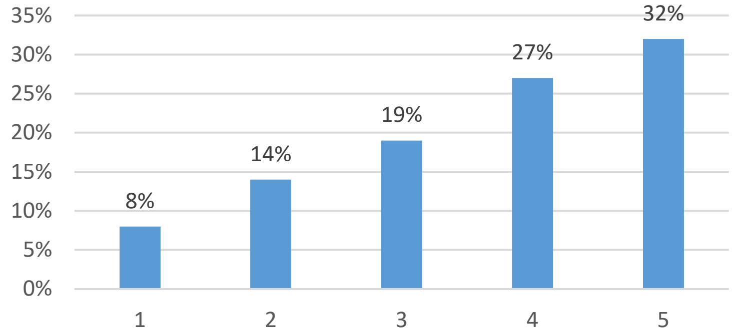


Figure 5. Overall satisfaction with the BCG treatment (1= “very unsatisfied”, 5= “very satisfied”)

Despite the high pain levels and side effects mentioned, the average overall satisfaction with the BCG treatment was 3.6 (Fig.5).

Knowledge

Regarding the knowledge levels of the disease before diagnosis, a large number of respondents assessed it as being very low, with the average score being 2.51 (Fig.6).

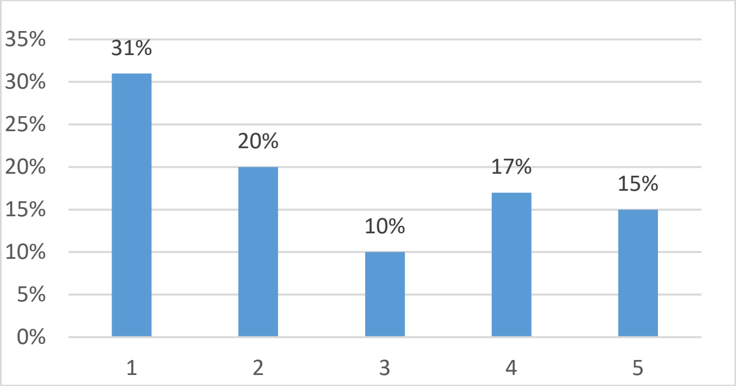


Figure 6. Prior to diagnosis knowledge levels of bladder cancer risk factors and symptoms (1= "very low", 5= "complete")

The majority of patients assessed the information they received regarding diagnosis and treatment options as complete or fully complete (86% for diagnosis, and 75% for treatment), whereas concerning secondary effects and their management, the answers were almost equally split between complete and incomplete. The area in which patients felt they received the most incomplete details was psychological support, with 70% of the answers being in the incomplete/somewhat complete categories (Fig.7).

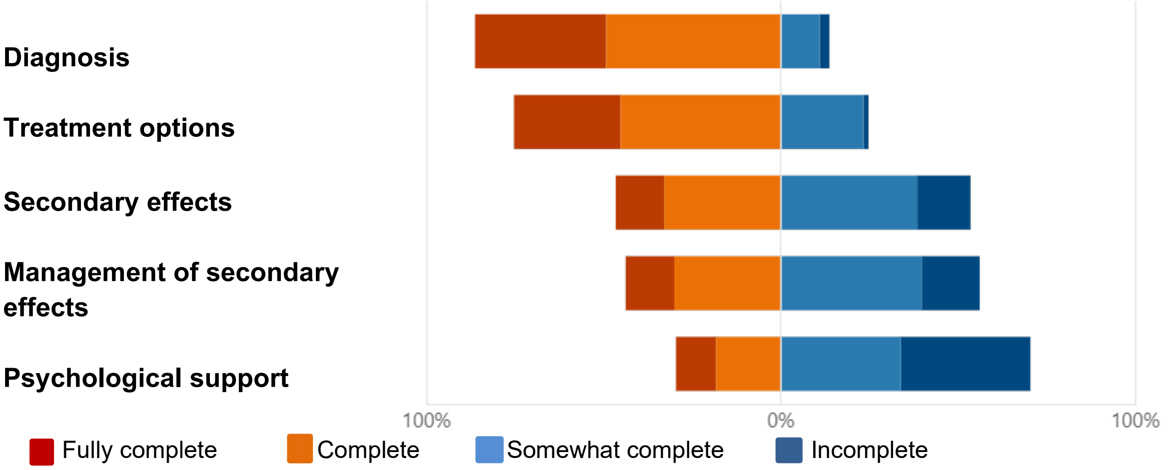


Figure 7. Assessment of the levels of information received according to the subject.

Patients expressed a need for more information in the following areas, ranked by the number of answers:

- Treatments (45)
- Secondary effects (36)
- Psychological support (24)
- Diagnosis (21)
- Patient associations (17)
- Support for caregivers (14)
- Financial support (11)

Only 14 patients were informed about available clinical trials, 2 participated, and only 8 were given the card with information on how to report side effects.

Satisfaction

When asked how implicated they were in the treatment decision-making process, patients overall reported medium and high levels of involvement. The overall score was 3.56, with the average slightly higher for MIBC patients (Fig. 8).

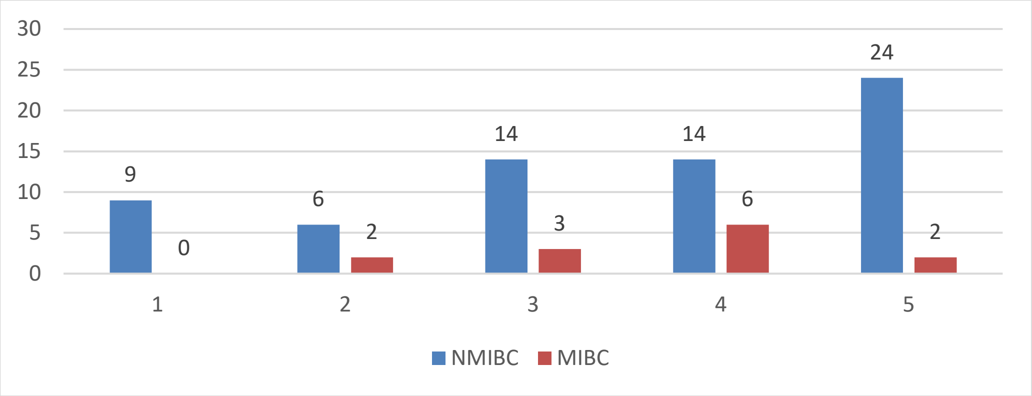
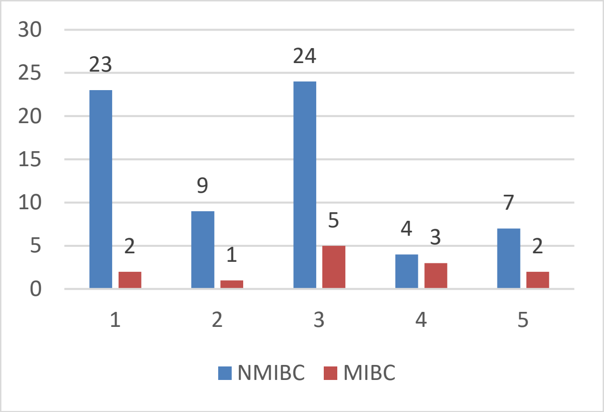


Figure 8. Patient implication in the treatment decision process (1= "not at all implicated", 5= "fully implicated") by BC type.

Patients were also largely satisfied with the ease of getting an appointment with a urologist, with the average score on the same scale being 3.75. Patients receiving the BCG treatment reported that it was generally easy to access the treatment, with an overall score of 2.43, and 47% of patients choosing option 1= "very easy".

Regarding the resources offered outside of the treatments, satisfaction levels were lower, with an average of 2.56. MIBC patients were overall more satisfied (average- 3.15) versus NMIBC patients (average- 2.45). Only 13/67 (19%) of NMIBC patients and 5/13 (38%) of MIBC patients outlined positive satisfaction levels with the resources they received (Fig.9).

The aspect that received the highest score for patient satisfaction was the management of the disease by the medical team, with an overall score of 4.01. 52/67 (78%) NMIBC patients and 6/13 (46%) MIBC patients were satisfied or very satisfied (Fig.10).



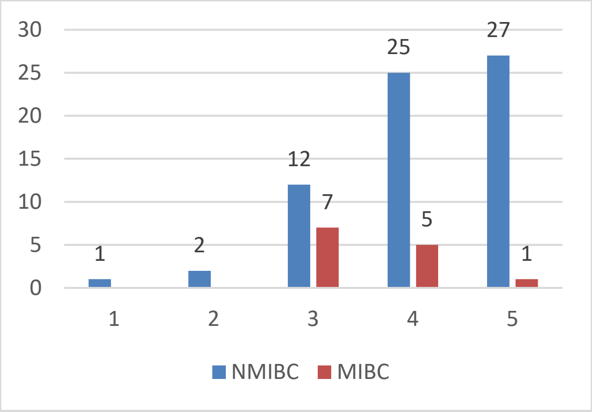


Figure 10. Patient satisfaction with the resources received outside of the treatment (ex. psychologist, smoking cessation specialist) (1= "very unsatisfied", 5= "very satisfied") by BC type.

Figure 9. Patient satisfaction with the management of their disease by the medical team (1= "very unsatisfied", 5= "very satisfied") by BC type.

Impact

The biggest impact felt by patients was on their personal life, with an overall score of 3.73 if taking into account all patients, followed by sexual life with 3.49, and sleep with 3.28. MIBC patients felt a larger impact on their lives in all categories except for sleep, and especially on their sexual lives, which is likely tied to the cystectomies that most of them undergo (Fig 11).

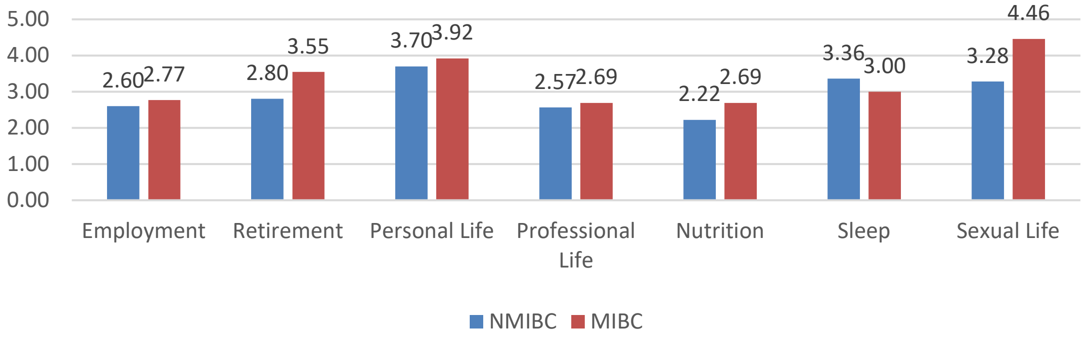


Figure 11. Average scores for the impact of the disease on the following aspects of patient lives: employment, retirement (if applicable), personal life, professional life, nutrition, sleep, sexual life (1= "No/little impact", 5= "A lot of impact")

With regards to employment, the answer with the most responses for both patient categories was 1 ("No/little impact"), followed by 5 ("A lot of impact"), whereas for retirement a large part of the NMIBC patients (17) also felt little or no impact, and an increasing trendline was observed for the other options. For personal life, a large proportion of patients reported having a high impact, 38/67 NMIBC patients and 10/13 MIBC patients choosing one of the 2 highest scores. Nutrition was less severely affected, with most answers being in the lowest impact categories, 61% of NMIBC patients and 46% of MIBC patients choosing options 1 or 2. In the sleep category, the trendline was more linear, with slightly more answers for the high-impact category, especially for NMIBC patients. Finally, all MIBC patients chose one of the 3 highest options when assessing the impact on their sexual life. The detailed graphs for each individual category are available in Appendix 4.

Statistical Analysis

Based on the literature review and insights gathered from the qualitative part and the surveys, 71 Fisher's Tests were performed in R (the detailed codes are presented in Appendix 3) to determine if there are statistically-significant associations with the variables of interest (dependent variables- type of specialists, information received, total impact on patients' lives, satisfaction with the management of their disease by the medical team, satisfaction with resources received, and implication in the decision-making process).

Table 3. Representation of the P-values resulting from the Fisher's Tests performed.

Y X	**Type of Specialist**	**Information received (cumulative)**	**Total Impact**	**Satisfaction with management of thei disease by doctors**	**Satisfaction with resources**	**Decision Implication**
Type of specialist		P= 0.892	P= 0.3841	P= 0.06407	P= 0.1789	P= 0.1021
Info received	NA		P= 0.4105	P= 0.09826	P= 0.017*	P= 0.01713*
Total impact	NA	P= 0.4105		P= 0.2472	P=0.7833	NA
Satisfaction with management	NA	NA	P= 0.2472		P= 0.06825	P= 0.2082
Satisfaction with resources	P=0.1789	P= 0.017*	P=0.7833	P=0.06825		NA
Decision Implication	NA	P=0.01713*	P= 0.06275	P= 0.2082	P= 0.6662	
BC Type	P= 1.525e-05 ***	P= 0.3664	P= 0.5148	P= 0.09238	P= 0.02466*	P= 0.2377
Location	P= 0.8101	P=0.5962	P= 0.0417*	P= 0.7365	P= 0.3413	P= 0.1904
Knowledge	P= 0.8326	P=0.1727	P= 0.2375	P= 0.3138	P= 0.1383	P= 0.1652
Age	P= 0.7504	P=0.5167	P= 0.8882	P= 0.07138	P= 0.2134	P= 0.736
Gender	P= 0.3582	P= 0.688	P= 0.3602	P= 0.7952	P= 0.009201**	P= 1
Professional status	P= 0.3833	P=0.3537	P= 0.2931	P= 0.7442	P= 0.9388	P= 0.8057
Smoking status	P= 1	P=0.4904	P= 0.5977	P= 0.9094	P= 0.4603	P= 1
Family history	P= 1	P=0.3083	P= 0.7077	P= 0.8044	P=1	P= 0.1289

Legend: P*<0.05, P**<0.01, P***<0.001 P<0.20

Several tests yielded significant P-values outright, with the variable for cancer type forming a significant association with the type of specialist seen (P<0.001), and satisfaction with resources (P<0.05). Further significant relationships were found between satisfaction with resources and information received (P<0.05), gender and satisfaction with resources (P<0.01). The variable for Information was found to have a significant association with implications in decisions (P<0.05), while location was significantly associated with total impact (P<0.05) (Table 3).

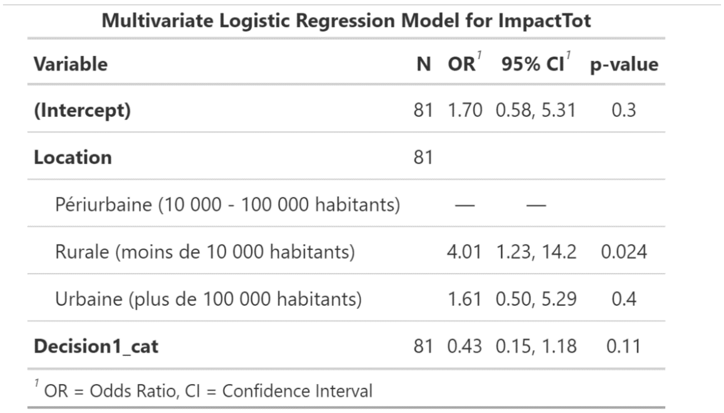
Afterward, multivariate logistic regressions were built to further examine the cumulative significance of the associations with P<0.2 resulting from the individual Fisher's tests.

In the first model, with the type of specialist as the dependent variable, NMIBC patients were found to have 95% lower odds (OR=0.05, 95% CI: 0.01-0.39) of seeing an oncologist, with the p-value being significant (0.004) (Appendix 5-Table 5).

In the second model, a significant relationship (P=0.016) was detected between the variable for implication in care decisions and the levels of information received, with patients who felt they were highly implicated being 4.93 (95% CI: 1.44-20.3) times more likely to assess as sufficient the cumulative information received (Appendix 5-Table 6).

In the regression with total impact as the dependent variable, the only subcategory with significant results was that of "Rural" (p=0.024<0.05), thus respondents from rural areas are 4.01 (95% CI: 1.23-14.2) times more likely than those in suburban areas to have a high cumulative impact of the disease (Table 4).

Table 4. Results of the multivariate logistic regression for Total Impact (dependent variable) versus Location and Implication in the treatment decision-making process (independent variables), with the associated Odds Ratios, Confidence Intervals, and p-values.



Multivariate Logistic Regression Model for ImpactTot

Variable	N	OR[1]	95% CI[1]	p-value
(Intercept)	81	1.70	0.58, 5.31	0.3
Location	81			
Périurbaine (10 000 - 100 000 habitants)		—	—	
Rurale (moins de 10 000 habitants)		4.01	1.23, 14.2	0.024
Urbaine (plus de 100 000 habitants)		1.61	0.50, 5.29	0.4
Decision1_cat	81	0.43	0.15, 1.18	0.11

[1] OR = Odds Ratio, CI = Confidence Interval

In the fourth model, the information variable was found to be a statistically significant predictor of satisfaction with the management of the disease (P=0.004), thus patients who received high levels of information were 7.88 (95% CI: 2.24-38.4) times more likely to be satisfied with the management of their disease by the medical team (Appendix 5-Table 7).

In the next model, multiple variables were found to have a significant impact on the variable for resource satisfaction: having NMIBC (P=0.016), receiving enough information

(OR=8.15, CI: 2.11-46.3, P=0.007), and being a male (OR=0.07, CI: 0.01-0.33, P=0.002) Importantly, NMIBC patients had 97% lower odds (OR=0.03, CI: 0.00-0.46) versus metastatic MIBC patients of being satisfied with the resources received (Appendix 5-Table 8).

The final model, with implication in decision-making as the dependent variable, yielded a significant association from the variables for information received (P<0.001), and knowledge of the disease (P=0.032), patients knowledgeable of the disease before diagnoses being 4.58 (95% CI: 1.22-20.5) times more likely to be highly implicated in the decisions of their care (Appendix 5-Table 9).

Discussion

The main unmet needs identified include access to appropriate information and supportive care, especially for NMIBC patients. In terms of the burdens of illness, the biggest ones for NMIBC patients are the frequent cystoscopies which bring anxiety and the side effects of the BCG treatment, for which there are no effective solutions, as well as the long duration of the treatment. For MIBC patients, the largest burdens stem from the bladder removal and the associated difficulties that follow. These aspects need to be considered in the context of the complicated organization of care, where NMIBC patients only see urologists for their treatments, in large part in private clinics, and their needs are also largely under-perceived. The potential introduction of systemic immunotherapies will require changes to this organization, although no consensus could be reached as to what those changes should be and how they can be effectively implemented.

The findings related to the unmet needs are in line with what was identified in other studies, with a systematic review of NMIBC supportive care needs showing the biggest ones as being psychological and physical, followed by information and physician-patient communication (Schubach et al., 2024).

With regard to the impact felt by patients, other studies have also found that MIBC patients are more negatively impacted, as for example, one study showed a 10-point difference on the BUSS QoL scale in favor of NMIBC patients (Chung et al., 2019). This can be explained by the treatments they receive, as MIBC treatments include systemic chemotherapy and radiation therapy, as well as cystectomies, in most cases. The same study also evaluated information needs, with the results showing the highest needs on the topics of side effects and treatments, whereas the data of the present study showcases the biggest information need as being on the topic of psychological support (Fig. 7). The discrepancies can be explained by the differences in health systems and geographic locations (North America for the other study).

Concerning the BCG treatment, despite the frequent side effects for which there are few solutions, and the long duration of the treatment with low response rates, the associated relatively high satisfaction scores from patients, reported in other studies as well (Kopenhafer et al., 2024), may be due to the lack of alternative treatments with fewer burdens, and also the fact that one of the main goals of the BCG, as explained by physicians, is to avoid progression to MIBC and cystectomy, so patients may feel that the benefits outweigh the burdens felt.

There were also large discrepancies between the guideline recommendations for BCG treatment duration of 1-3 years (Gontero et al., 2024) and the practice reported by both physicians and patients. These findings are also corroborated by other studies, such as a European survey of physicians which showed that only 11% of intermediate and 35% of high-risk NMIBC patients receive 3 years of BCG treatment (Hendricksen et al., 2019). Another study has shown that the maintenance treatment, if given at all, follows a sub-optimal schedule (Grabe-Heyne et al., 2022). Since the new immunotherapies will not replace the BCG and may even be administered at the same time, more clinical studies are needed to understand what the best treatment schedule is, how treatment adherence can be increased, and perhaps how to better limit and address the side effects experienced by patients. Further research has suggested that in order to improve outcomes of NMIBC patients and the management of their disease, other aspects in the treatment pathways should be targeted, such as potential therapies for the large number of BCG-unresponsive patients, the use of biomarkers to avoid the burdensome cystoscopies, as well as screening and prevention strategies, since the risk factors are well documented (Campi et al., 2018).

The underperceived unmet needs of NMIBC patients by the medical and research communities is another important aspect since they are the stakeholders who can serve as the primary drivers of change.

It is worth noting that multiple systematic literature reviews have identified major evidence gaps on this topic (Paterson et al., 2018), and even less research exists in the European and French contexts, making reaching certain conclusions difficult. However, a major French cohort - COBLAnCE- was implemented in 2012 and a total of 1800 BC patients were recruited until 2018 and followed up for 6 years. Different studies can thus be put in place to fill the existing knowledge gaps regarding treatment patterns, health outcomes, and current epidemiology of the disease, as the cohort is linked with the French National Health Data system (Lebret et al., 2023).

Comparing the current results with those of the recent World Bladder Cancer study (Makaroff et al., 2023), the present study has also shown similarly low levels of knowledge of BC risk factors and symptoms before the diagnosis, and similar levels of involvement in the treatment decision-making process. A comparably high impact in all areas of life was demonstrated, especially personal and sexual life, however, the results regarding resources available were more positive in the global study, but cannot be directly compared due to the differences in questions asked. Regarding the global conclusions and recommendations of the report, most of them were proven to be pertinent, especially improving public awareness of BC symptoms and risk factors, increasing access to innovative treatments through clinical trials, and improving access to information and emotional support (Makaroff et al., 2023). Despite the study's global nature, patient experiences and burdens identified seem to have a universal nature to some degree.

Finally, and perhaps the most vital aspect, that directly impacts and is related to the other elements, is the organization of care. There are virtually no published studies regarding what should and can be changed on a system and policy level to improve health outcomes and limit the burdens patients face. The results show that access to supportive care is unequal and directly linked to the cancer subtype and thus the specialist patients see (only urologists for NMIBC and oncologists + urologists for MIBC). That is due, in large part, to the way care is structured in France for these patients, with oncologists working in dedicated cancer centers or large hospitals and being connected to a multitude of support specialists, such as psychologists, smoking cessation specialists, nutritionists, sexual specialists, and others that they can directly refer their patients to. In comparison, urologists work in large part (2/3) in private clinics with no direct link to support specialists, but they are also restrained from referring their patients by the lack of reimbursement of these resources for NMIBC patients, according to the information received from the interviews. This is a major inequity, especially in the context of the social health insurance system in France (Or et al., 2023), and can also be tied back to the lack of robust evidence on the unmet needs of patients, which would support reimbursement being introduced for supportive care.

Another pertinent inequity found was tied to location, with patients in rural areas reporting a higher impact of the disease on their lives. This result is corroborated in other studies, such as one of multiple French cancer registries that showed that prognosis was negatively impacted by being further away from a referral center (Gardy et al., 2023).

Our data also showed that NMIBC patient needs are under-considered and somewhat under-evaluated by doctors, as their needs are more subtle, but not less valid than those of most cancer patients (including MIBC) who receive chemotherapy and radiation therapy.

In the regression models, the independent variable associated with the highest number of statistically-significant relationships was that of levels of information received, since it was found to be a predictor for satisfaction with the management of the disease, and resources received, as well as levels of implication in care decisions. Thus, this aspect seems to be a pertinent target for a potential public health intervention.

In terms of how the organization of care should change if systemic immunotherapies are approved for NMIBC patients, no consensus was able to be reached among physicians, however, almost all of them agreed that oncologists will need to be involved in some capacity, due to urologists not being familiar with these treatments and not having access to other specialists such as endocrinologists and dermatologists to help manage the potentially significant side effects.

Limitations

The main limitation of the study is not having an independent ethical approval, which would allow for a potential journal publication and thus higher visibility of the results. In addition, it might have been helpful to interview additional KOLs such as policymakers to gather insights regarding the organization of care from different perspectives. The patient sample size is another limitation, making it difficult to find significant and representative correlations in the data. In terms of biases, recall bias could have been a factor for patients, in addition to sampling bias, since most of the patients who answered are members of a patient association, and thus might be more informed and involved than the average patient.

Conclusions and Recommendations

More France-specific research is necessary to prove the unmet needs of BC patients, especially outside the main treatments. With the new therapies, additional studies will be put in place by pharmaceutical companies to prove the unmet needs and drive the reimbursement of their products. However, while these treatments may improve health outcomes and diminish burdens for some patient groups, policies and organizational changes are needed to ensure the safe and optimal administration of these therapies as well as more equitable access to supportive resources for all BC patients, not just those concerned by these medications.

A Delphi panel or another type of study conducted independently by the AFU or another physician organization could be put in place to reach a consensus on what organizational changes are needed. That would potentially increase the chances of efficient policies being adopted. Cancer Vessie France and other stakeholders should also be involved to ensure patient perspectives are considered in the policy-making process. Finally, a review should be initiated to assess and adapt the information patients receive in the form of brochures and surveillance cards to ensure they meet their needs and are comprehensive and accessible.

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List of Appendices

Appendix 1. Patient survey in French (original)

Identification des difficultés pour les patients atteints du cancer de la vessie en France

Bonjour,

Je suis Octavian, étudiant en Master de Santé Publique à l'École des hautes études en santé publique (EHESP) à Paris.

Dans le cadre de mon mémoire je mène une enquête visant à comprendre les difficultes associées au cancer de la vessie ainsi que les défis auxquels sont confrontés les patients tout au long de leur traitement et de leur suivi médical.

Vos réponses seront essentielles pour identifier les domaines où des améliorations pourront être apportées afin d'optimiser la qualité de vie et diminuer les difficultés de votre parcours medical.
Elles resteront entièrement confidentielles. Aucune information d'identification ne sera demandée.

Cela prendra environ 10 à 15 minutes.
Je vous remercie sincèrement pour votre participation et votre contribution précieuse à cette enquête.

Informations générales

1

Quel est votre sexe ? *

○ Homme

○ Femme

○ Autre

2

Quel âge avez-vous ? *

○ 18-24

○ 25-34

○ 35-44

○ 45-54

○ 55-64

○ 65-74

○ 75-84

○ 85+

3

Dans quelle région habitez-vous ? *

○ Auvergne-Rhône-Alpes

○ Bourgogne-Franche-Comté

○ Bretagne

○ Centre-Val de Loire

○ Corse

○ Grand Est

○ Hauts-de-France

○ Île-de-France

○ Normandie

○ Nouvelle-Aquitaine

○ Occitanie

○ Pays de la Loire

○ Provence Alpes Côte d'Azur

○ Guadeloupe

○ Martinique

○ Guyane

○ La Réunion

○ Mayotte

4

Quel est votre situation professionnelle actuelle ? *

○ Emploi à temps plein

○ Emploi à temps partiel

○ Sans profession

○ Indépendant

○ Étudiant

○ Retraité

○ Je préfère ne pas le dire

5

Comment décririez-vous la zone géographique dans laquelle vous vivez ? *

○ Urbaine (plus de 100 000 habitants)

○ Périurbaine (10 000 - 100 000 habitants)

○ Rurale (moins de 10 000 habitants)

Contexte de la maladie

6

Avez-vous l'une des maladies suivantes ? *

☐ Hypertension artérielle

☐ Diabète

☐ Maladie cardiovasculaire

☐ Bronchopneumopathie chronique obstructive (BPCO)

☐ Maladie rénale

☐ Non

☐ Autre

7

Fumez-vous ou avez-vous été un fumeur ? *

○ Oui

○ Non

○ Je ne souhaite pas répondre à cette question

8

Combien de cigarettes fumez-vous par jour environ? *

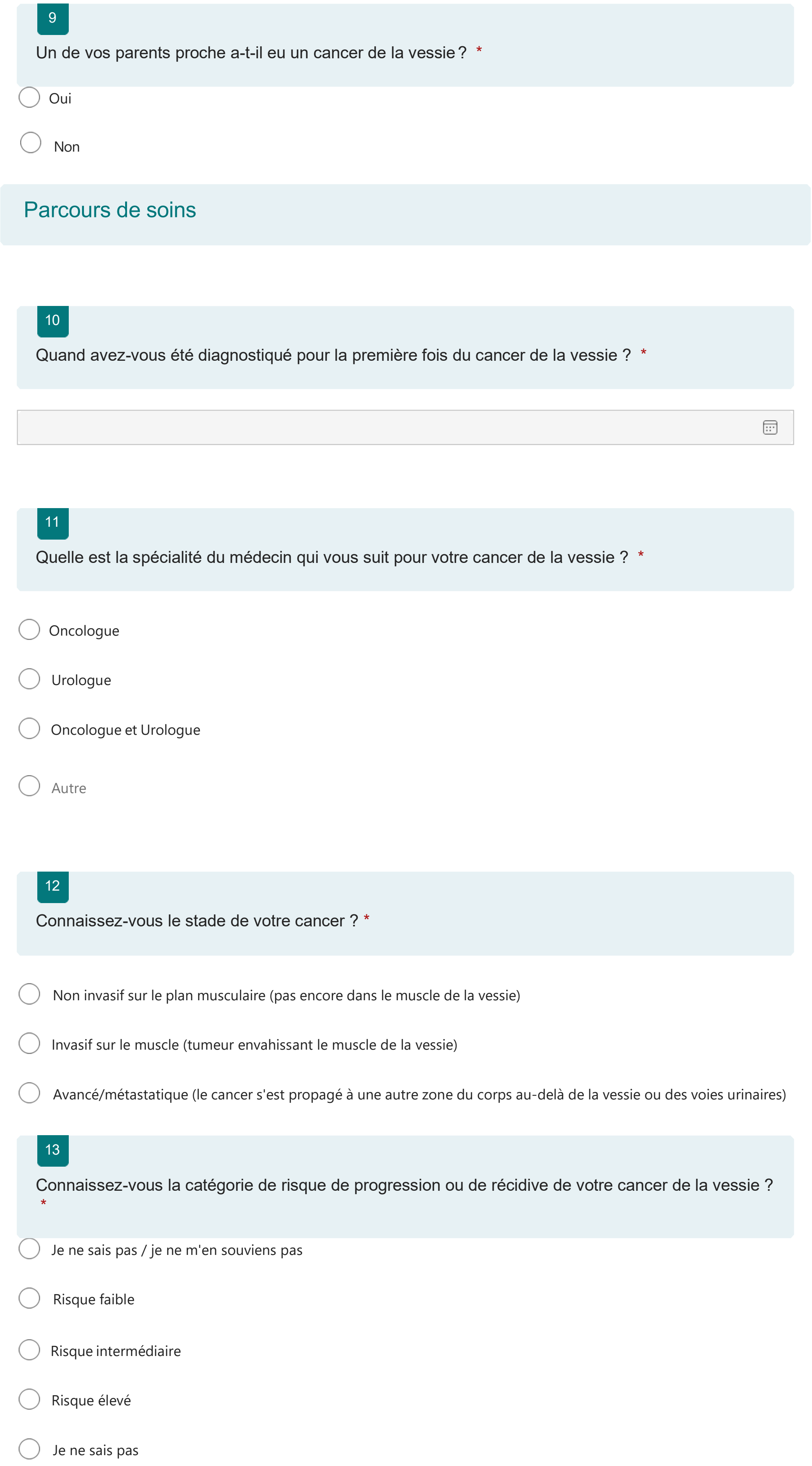
○ 0-1

○ 2-5

○ 6-10

○ 11-20

○ 20+



9

Un de vos parents proche a-t-il eu un cancer de la vessie ? *

○ Oui

○ Non

Parcours de soins

10

Quand avez-vous été diagnostiqué pour la première fois du cancer de la vessie ? *

11

Quelle est la spécialité du médecin qui vous suit pour votre cancer de la vessie ? *

○ Oncologue

○ Urologue

○ Oncologue et Urologue

○ Autre

12

Connaissez-vous le stade de votre cancer ? *

○ Non invasif sur le plan musculaire (pas encore dans le muscle de la vessie)

○ Invasif sur le muscle (tumeur envahissant le muscle de la vessie)

○ Avancé/métastatique (le cancer s'est propagé à une autre zone du corps au-delà de la vessie ou des voies urinaires)

13

Connaissez-vous la catégorie de risque de progression ou de récidive de votre cancer de la vessie ? *

○ Je ne sais pas / je ne m'en souviens pas

○ Risque faible

○ Risque intermédiaire

○ Risque élevé

○ Je ne sais pas

14

Avez-vous eu une rechute ? *

○ Oui

○ Non

15

Combien de rechutes ont été diagnostiquées ? *

○ 1

○ 2

○ 3

○ 4+

16

Avez-vous eu les traitements suivants ? *

☐ Chirurgie pour enlever la tumeur de la vessie (RTUV)

☐ Immunothérapie (BCG)

☐ Chimiothérapie (Mitomycine C)

☐ Chirurgie pour enlever la tumeur de la vessie (RTUV) après BCG

☐ Cystectomie (ablation de la vessie)

☐ Je n'ai pas reçu ces traitements

Traitement BCG

17

Confirmez-vous avoir reçu un traitement de BCG ? *

○ Oui

○ Non

○ Je ne sais pas

18

Quel praticien instille votre traitement par BCG ? *

○ Urologue

○ IDE (Infirmier Diplômé d'État)

○ Autre

19

Dans quel type d'établissement médical avez-vous reçu les traitements de BCG ? *

☐ Centre hospitalier universitaire

☐ Centre hospitalier (anciens hôpitaux locaux)

☐ Etablissement privé à but non lucratif

☐ Clinique

☐ Médecin en ville

☐ Autre

20

Avez-vous ressenti des effets secondaires après le traitement de BCG ? *

○ Oui

○ Non

○ Je ne sais pas

21

Lesquels ? *

☐ Fatigue

☐ Fièvre

☐ Nausée

☐ Urines fréquentes avec inconfort et douleur

☐ Brûlures lors de la miction

☐ Douleur lors de l'instillation

☐ Douleur musculaire

☐ Perte d’appétit

☐ BCGite (réactivation d'une infection systémique latente au BCG)

☐ Autre

22

Quand avez-vous ressenti les effets secondaires les plus forts ? *

○ pendant l'instillation

○ pendant 48h après l'instillation

○ plus de 48h après l'instillation

23

Que vous a prescrit votre médecin pour gérer vos effets secondaires ? *

☐ Rien

☐ Médicaments anti-inflammatoires

☐ Antibiotiques

☐ Soins oncologiques de support : activité physique adaptée, nutrition

☐ Soutien psychologique

☐ Autre

24

Etes-vous satisfait de la prise en charge de vos effets secondaires par l'équipe médicale ? *

Très insatisfait ✓ ✓ ✓ ✓ ✓ Très satisfait

25

Avez-vous ressenti des douleurs ou de l'inconfort pendant le traitement BCG ? *

Très peu/aucun ✓ ✓ ✓ ✓ ✓ Beaucoup

26

Souhaitez-vous nous faire part d'autres informations sur votre effets secondaires du traitement BCG et leur prise en charge ?

27

Avez-vous bénéficié d'une surveillance médicale après l'instillation de BCG ? *

○ Oui

○ Non

28

Combien de doses de BCG vous ont été prescrites ?
*

○ 0-6

○ 7-9

○ 10-12

○ 13-15

○ 16-18

○ 19-30

○ 31-42

○ 43+

29

Combien de doses de BCG avez-vous reçues ? *

○ 0-6

○ 7-9

○ 10-12

○ 13-15

○ 16-18

○ 19-30

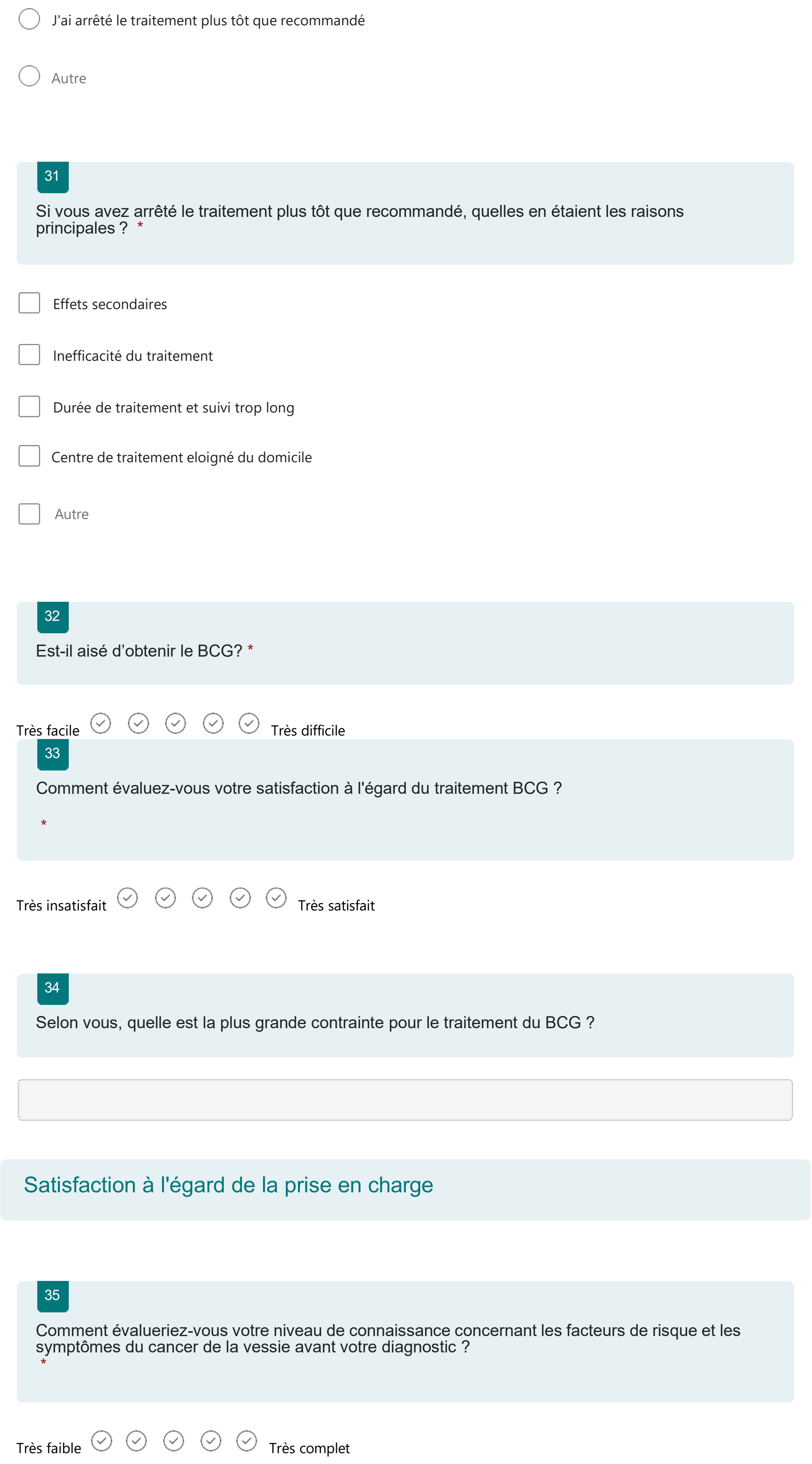
○ 31-42

30

A quelle étape de votre traitement de BCG êtes-vous ?
*

○ J'ai fait toutes les instillations prescrites

○ Mon traitement est actuellement en cours



○ J'ai arrêté le traitement plus tôt que recommandé

○ Autre

31

Si vous avez arrêté le traitement plus tôt que recommandé, quelles en étaient les raisons principales ? *

☐ Effets secondaires

☐ Inefficacité du traitement

☐ Durée de traitement et suivi trop long

☐ Centre de traitement eloigné du domicile

☐ Autre

32

Est-il aisé d'obtenir le BCG? *

Très facile ✓ ✓ ✓ ✓ ✓ Très difficile

33

Comment évaluez-vous votre satisfaction à l'égard du traitement BCG ?

*

Très insatisfait ✓ ✓ ✓ ✓ ✓ Très satisfait

34

Selon vous, quelle est la plus grande contrainte pour le traitement du BCG ?

Satisfaction à l'égard de la prise en charge

35

Comment évalueriez-vous votre niveau de connaissance concernant les facteurs de risque et les symptômes du cancer de la vessie avant votre diagnostic ?
*

Très faible ✓ ✓ ✓ ✓ ✓ Très complet

36

Quelle est votre principale source de soutien dans votre parcours de traitement ?
*

○ Conjoint(e)

○ Famille

○ Amis

○ Equipe medicale

○ Pas de soutien

○ Association de patients/caritative

○ Autre

37

Êtes-vous satisfait de la facilité avec laquelle vous pouvez obtenir un rendez-vous avec un urologue?
*

très insatisfait ✓ ✓ ✓ ✓ ✓ très satisfait

38

Dans quelle mesure avez-vous été impliqué dans les décisions concernant votre traitement ?
*

Pas du tout impliqué ✓ ✓ ✓ ✓ ✓ Pleinement impliqué

39

Est-ce que votre médecin vous a remis la carte de surveillance ? *

Données patient(e)

Nom

Prénom

Téléphone

du ___/___/___ au ___/___/___

Traitement par BCG

Coordonnées en cas d'urgence

Nom

Prénom

Téléphone

Coordonnées du médecin

Nom du médecin

Téléphone

Adresse

Carte de surveillance patient pour

BCG-medac

(BCG - bacille de Calmette et Guérin)

medac

INFORMATIONS IMPORTANTES DESTINÉES AUX PROFESSIONNELS DE SANTÉ

Ce/cette patient(e) est/a été traité(e) par BCG-medac pour un cancer de la vessie. BCG-medac peut provoquer des **infections systémiques** pouvant être fatales si elles ne sont pas traitées de façon appropriée.

Le traitement BCG-medac contient une suspension lyophilisée de bactéries BCG (bacille de Calmette et Guérin) vivantes à faible potentiel infectieux provenant de *Mycobacterium bovis*. Cette souche n'est pas virulente. Il n'est donc pas nécessaire que le patient soit isolé.

Des infections systémiques par le BCG peuvent survenir, **même des années après l'administration de la dernière dose en instillation intravésicale**. Ces infections peuvent concerner différents organes, et se manifester par une fièvre, des sueurs nocturnes, une perte de poids, un granulome pulmonaire ou hépatique, une conjonctivite ou un syndrome de Reiter, des abcès, des anévrismes infectés ou une infection d'un implant ou d'un greffon, ainsi que des tissus environnants. Un diagnostic précoce et une prise en charge appropriée sont essentiels pour limiter les éventuelles conséquences de l'infection.

Veuillez noter qu'un test de dépistage d'infections mycobactériennes négatif ne permet pas d'exclure une infection systémique par le BCG, quel que soit le type d'échantillon utilisé (sang, urine, sérum). Plusieurs cas d'hémocultures ou d'analyses d'urine négatives ont été rapportés alors que le patient présentait une infection systémique par le BCG.

La consultation d'un médecin spécialiste des maladies infectieuses est recommandée. Le traitement d'une infection susceptible d'être due au BCG dépend de la nature et de la sévérité des symptômes cliniques, mais pourra consister soit en un traitement symptomatique, soit par des quinolones, soit par un/des antituberculeux associé à des corticoïdes.

Déclarez immédiatement tout effet indésirable suspecté d'être dû à un médicament (Coordonnées nationales au dos de cette carte).

Pour plus d'informations, veuillez consulter le Résumé des Caractéristiques du Produit RCP en vigueur sur la base de données publique des médicaments : http://base-donnees-publique.medicaments.gouv.fr.

○ Oui

○ Non

○ Je ne sais pas

40

Comment jugez-vous le niveau d'informations reçues concernant les sujets suivants ?
*

	Très Complet	Complet	Peu Complet	Incomplet
Votre diagnostic	○	○	○	○
Options de traitement	○	○	○	○

Effets secondaires	○	○	○	○
Gestion des effets secondaires	○	○	○	○
Soutien psychologique	○	○	○	○

41

Quels sont les sujets sur lesquels vous voudriez en savoir plus ? *

☐ Diagnostic

☐ Traitements

☐ Effets secondaires

☐ Soutien psychologique

☐ Soutien financier

☐ Associations de patients

☐ Soutien pour mon entourage

☐ Autre

42

En general, êtes-vous informés des essais cliniques disponibles ? *

○ Oui

○ Non

○ Je ne sais pas

43

Participez-vous actuellement à un essai clinique ? *

○ Oui

○ Non

44

Quelles ressources vous ont été proposées en dehors des traitements ?

(*par exemple:* psychologue, spécialiste du sevrage tabagique, activités complémentaires pour le bien-être mental)

45

Etes-vous satisfait des ces ressources ?
*

Très insatisfait ○ ○ ○ ○ ○ Très satisfait

46

Etes-vous satisfait de la prise en charge de votre maladie par l'équipe médicale qui vous accompagne ? *

Très insatisfait ○ ○ ○ ○ ○ Très satisfait

47

Quels outils ou offres de service pourraient être mis en place pour améliorer votre prise en charge actuelle ?

Impact de la maladie

48

Quel impact le cancer de la vessie a eu sur les aspects suivants de votre vie ?

Emploi
*

pas/peu d'impact ○ ○ ○ ○ ○ beaucoup d'impact

49

Retraite

pas/peu d'impact ○ ○ ○ ○ ○ beaucoup d'impact

50

Vie personnelle *

pas/peu d'impact ○ ○ ○ ○ ○ beaucoup d'impact

51

Vie profesionnelle *

pas/peu d'impact ○ ○ ○ ○ ○ beaucoup d'impact

52

Régime alimentaire *

pas/peu d'impact ○ ○ ○ ○ ○ beaucoup d'impact

53

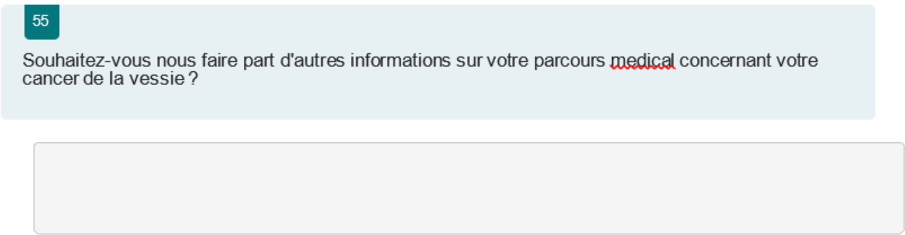
Sommeil *

pas/peu d'impact ○ ○ ○ ○ ○ beaucoup d'impact

54

Vie sexuelle
*

pas/peu d'impact ○ ○ ○ ○ ○ beacoup d'impact



55

Souhaitez-vous nous faire part d'autres informations sur votre parcours medical concernant votre cancer de la vessie ?

Merci d'avoir pris le temps de compléter ce questionaire.

Appendix 2. Physician interview guide

Hello Dr., thank you for taking the time to speak with me today. My name is Octavian, I am doing a Master of Public Health at EHESP and conducting this study as part of my thesis. The goal is to understand patient burdens and unmet needs throughout their patient journeys and what we can do from a public health and management perspective to improve their outcomes.

I have already designed a questionnaire for patients, which I have distributed through Cancer Vessie France, the patient association.

I have some questions to get your expertise on the topic. I am hoping to include these insights in the thesis, in order to get a full picture along with the patient data.

What type of hospital do you practice at? (CHU, CLCC, private, if more than 1)

How many years of experience do you have? +background

To start, can I ask how patients are usually diagnosed- by a GP, who then refers them to you?

What type of specialists are involved?

What assessment is carried out to determine if it is bladder cancer, and what type, stage?

Generally, at what stage are most patients diagnosed and addressed to you?

Along with the diagnosis and treatment options, what other information do patients receive in the beginning?

What is the treatment according to the cancer type?

Do patients receive information regarding clinical trials?

BCG

How many dosages of BCG do you normally recommend by cancer stage?

Who administers the BCG?

Where do most patients receive the treatment, in the hospital, in private clinics?

What percentage of patients, would you say, typically follow the full treatment?

What are the main difficulties of administering the treatment? (shortage, time, number of patients)

What are the main reasons for stopping the treatment earlier?

What side effects do patients have?

When do the strongest side effects occur, during the installation, immediately after, later?

How are the side effects managed by the medical team?

Are patients surveilled after the installation?
Do patients receive a carte de surveillance or information on how to report side effects?

Do patients have access to resources such as psychological support smoking secession specialists?
What are the biggest burdens that patients experience in their treatment journeys?
What aspects of their lives are impacted the most?
What do you think should change on a policy/organizational level to improve patient outcomes, and diminish their difficulties?
How do you think the medications that are currently in clinical trials will impact treatments and outcomes?
Is there anything else you can share about the topic from your experience?
Would you be able to distribute the questionnaire I designed to your patients?

Thank you so much for your time in sharing your insights.

Appendix 3. Main R code utilized and recoding legend

The following recordings were implemented, where needed, to transform variables into binary ones for regressions.

ImpactTot=Sum of individual impact scores; 0=ImpactTot<=18; 1=ImpactTot>18, because if the answers to all 6 mandatory impact questions is 3(neutral) then the score would be 18 and would show no elevated impact

Specialist: 0=Urologue; 1=Urologue et Oncologue, Oncologue

Gender: Male=1, female=0
5-step scales: 1,2,3 (negative up to neutral scores) =0; 4,5 (positive scores)=1)

Info= Incomplete=0, A bit incomplete= 1, Complete=2, Very Complete=3
Average of individual categories; 0=Info<=2; 1=Info>2

No=0; Yes=1

Codes

```
test <- fisher.test(Thesis$Location,Thesis$>ImpactTot)
test

library(epiDisplay)
l1 <- glm(ImpactTot ~ Location, family=binomial(),
```

```
        data=Thesis)
summary(l1)
logistic.display(l1)

library(gtsummary)
library(dplyr)
tbl <- tbl_regression(glm(ImpactTot ~ Location, family=binomial(),
                          data=Thesis),exponentiate = T, conf.level = 0.95, intercept = T)
tbl <- tbl %>%
  modify_header(label = "**Variable**") %>%
  modify_caption("**Univariate Logistic Regression Model for ImpactTot vs Location**") %>%
  add_n() %>%  # Add the number of observations
  bold_labels() # Bold the variable names
tbl
```

Appendix 4. Detailed results for the impact of the disease on patients' lives

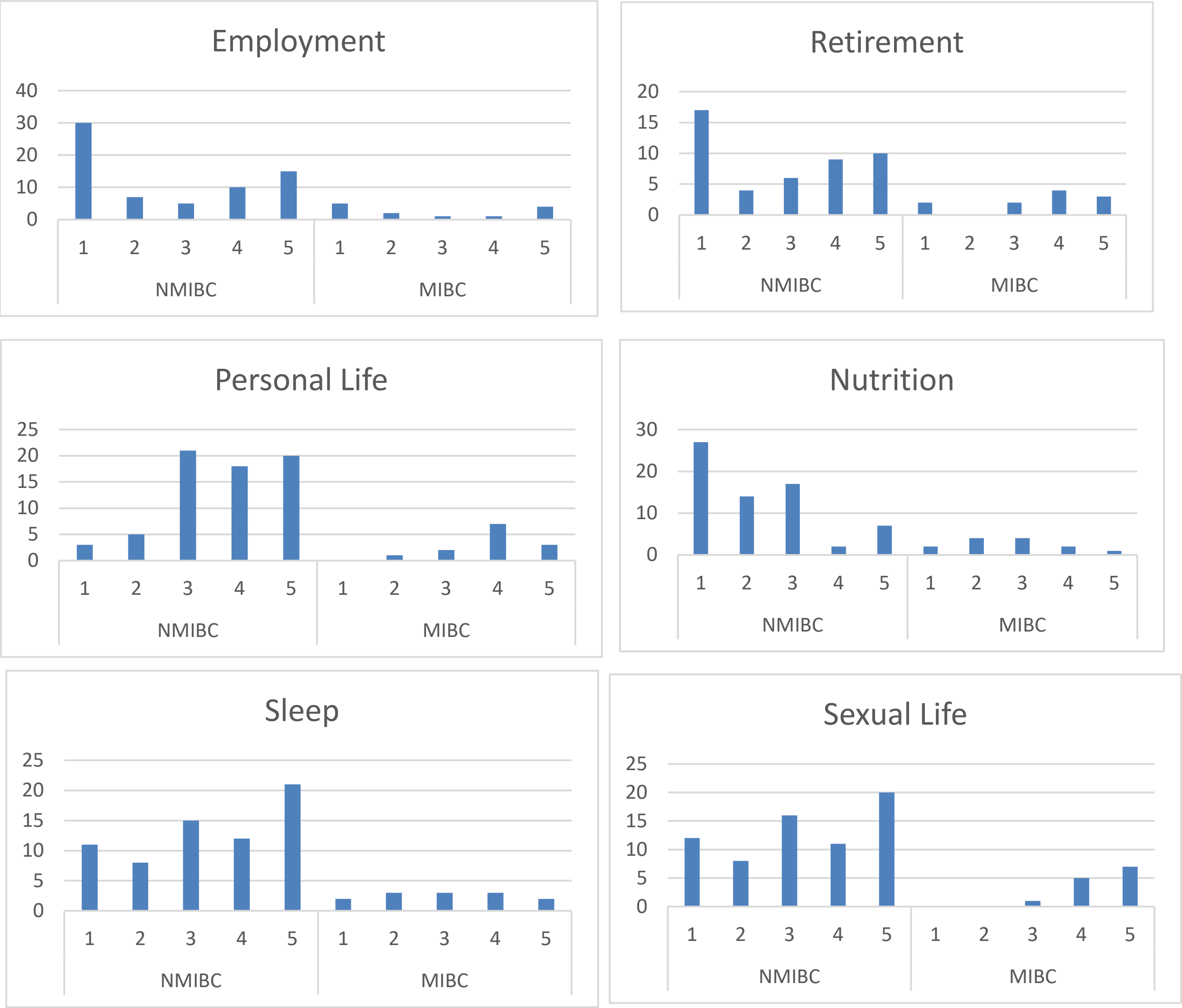
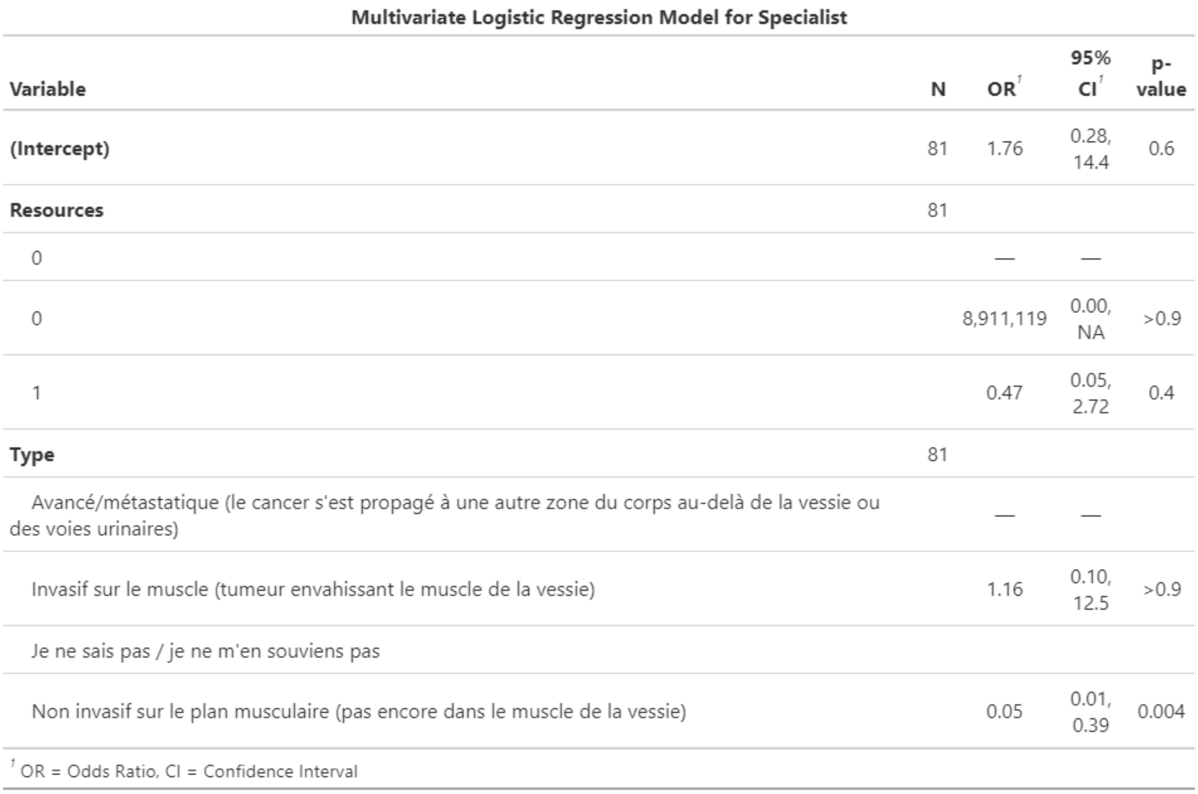


Figure 12. Detailed results for the impact of the disease on the following aspects of patient lives: employment, retirement (if applicable), personal life, professional life, nutrition, sleep, sexual life (1="No/little impact", 5="A lot of impact")

Appendix 5. Results of the multivariate logistic regressions performed

Table 5. Results of the multivariate logistic regression for Type of Specialist (dependent variable) versus Type of BC and satisfaction with the resources received (independent variables), with the associated Odds Ratios, Confidence Intervals, and p-values.

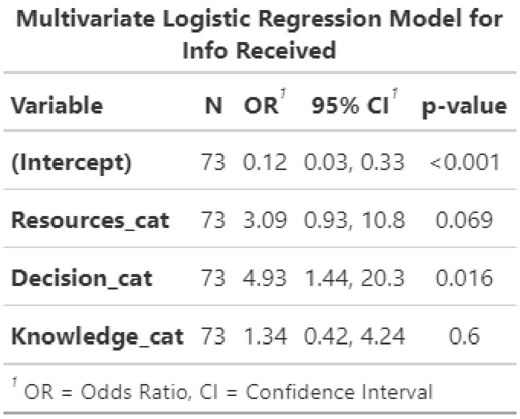


Multivariate Logistic Regression Model for Specialist

Variable	**N**	**OR**[1]	**95% CI**[1]	**p-value**
(Intercept)	81	1.76	0.28, 14.4	0.6
Resources	81			
0		—	—	
0		8,911,119	0.00, NA	>0.9
1		0.47	0.05, 2.72	0.4
Type	81			
Avancé/métastatique (le cancer s'est propagé à une autre zone du corps au-delà de la vessie ou des voies urinaires)		—	—	
Invasif sur le muscle (tumeur envahissant le muscle de la vessie)		1.16	0.10, 12.5	>0.9
Je ne sais pas / je ne m'en souviens pas				
Non invasif sur le plan musculaire (pas encore dans le muscle de la vessie)		0.05	0.01, 0.39	0.004

[1] OR = Odds Ratio, CI = Confidence Interval

Table 6. Results of the multivariate logistic regression for levels of Information Received (dependent variable) versus Location, Implication in the treatment decision-making process, and Knowledge Levels before diagnosis (independent variables), with the associated Odds Ratios, Confidence Intervals, and p-values.

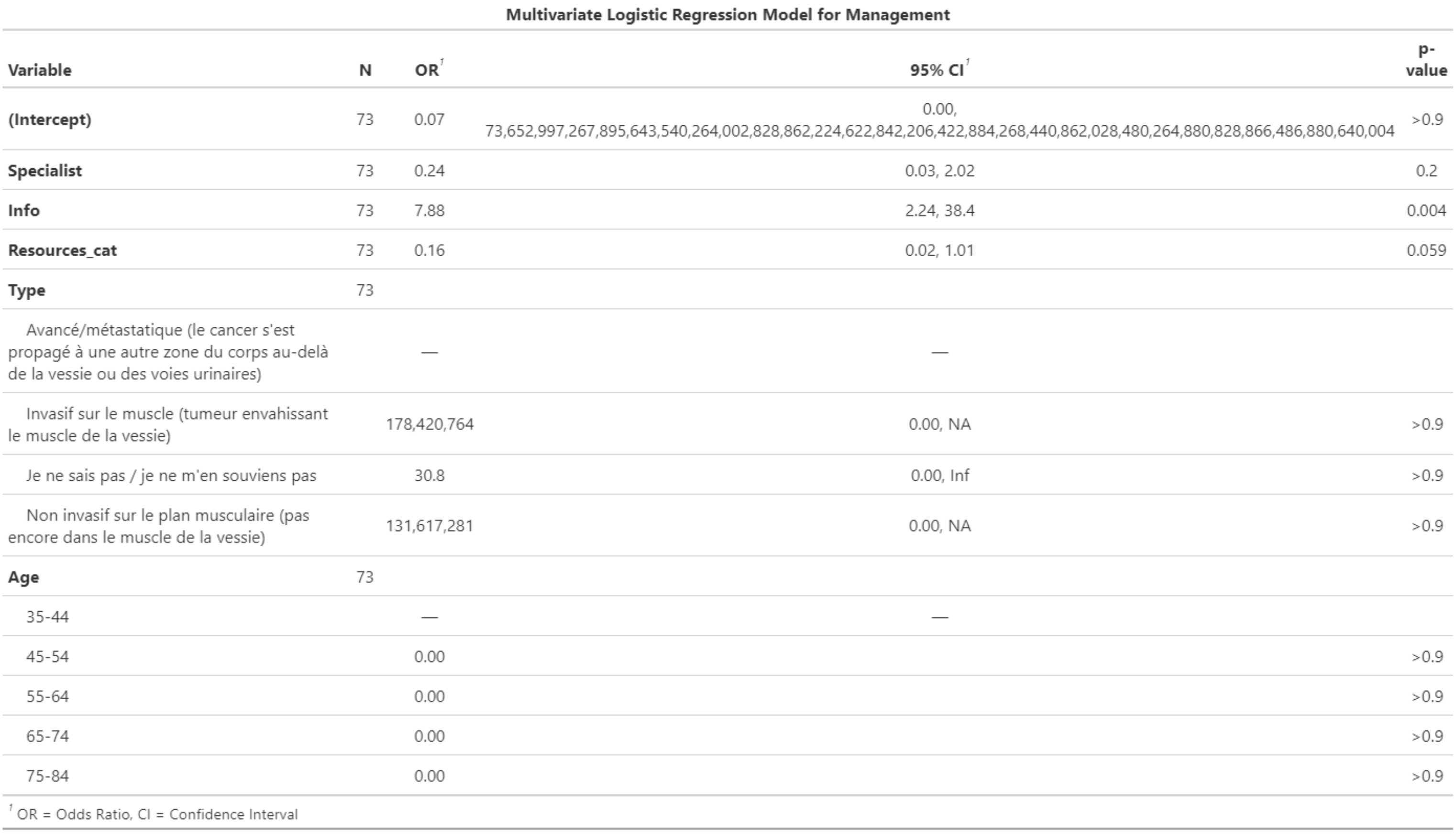


Multivariate Logistic Regression Model for Info Received

Variable	**N**	**OR**[1]	**95% CI**[1]	**p-value**
(Intercept)	73	0.12	0.03, 0.33	<0.001
Resources_cat	73	3.09	0.93, 10.8	0.069
Decision_cat	73	4.93	1.44, 20.3	0.016
Knowledge_cat	73	1.34	0.42, 4.24	0.6

[1] OR = Odds Ratio, CI = Confidence Interval

Table 7. Results of the multivariate logistic regression for Satisfaction with the Management of their Disease (dependent variable) versus Type of Specialist seen, Levels of Information received, Type of BC and Age (independent variables), with the associated Odds Ratios, Confidence Intervals, and p-values.

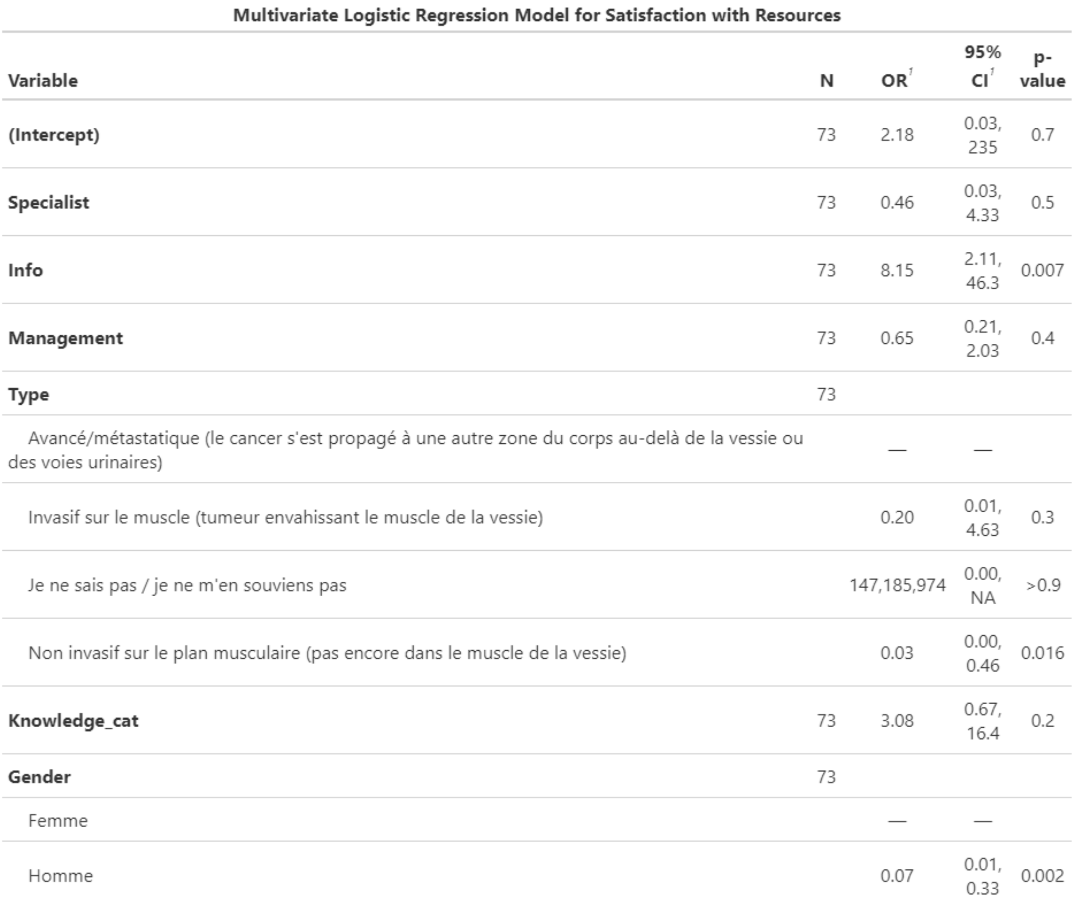


Multivariate Logistic Regression Model for Management

Variable	**N**	**OR**[1]	**95% CI**[1]	**p-value**
(Intercept)	73	0.07	0.00, 73,652,997,267,895,643,540,264,002,828,862,224,622,842,206,422,884,268,440,862,028,480,264,880,828,866,486,880,640,004	>0.9
Specialist	73	0.24	0.03, 2.02	0.2
Info	73	7.88	2.24, 38.4	0.004
Resources_cat	73	0.16	0.02, 1.01	0.059
Type	73			
Avancé/métastatique (le cancer s'est propagé à une autre zone du corps au-delà de la vessie ou des voies urinaires)		—	—	
Invasif sur le muscle (tumeur envahissant le muscle de la vessie)		178,420,764	0.00, NA	>0.9
Je ne sais pas / je ne m'en souviens pas		30.8	0.00, Inf	>0.9
Non invasif sur le plan musculaire (pas encore dans le muscle de la vessie)		131,617,281	0.00, NA	>0.9
Age	73			
35-44		—	—	
45-54		0.00		>0.9
55-64		0.00		>0.9
65-74		0.00		>0.9
75-84		0.00		>0.9

[1] OR = Odds Ratio, CI = Confidence Interval

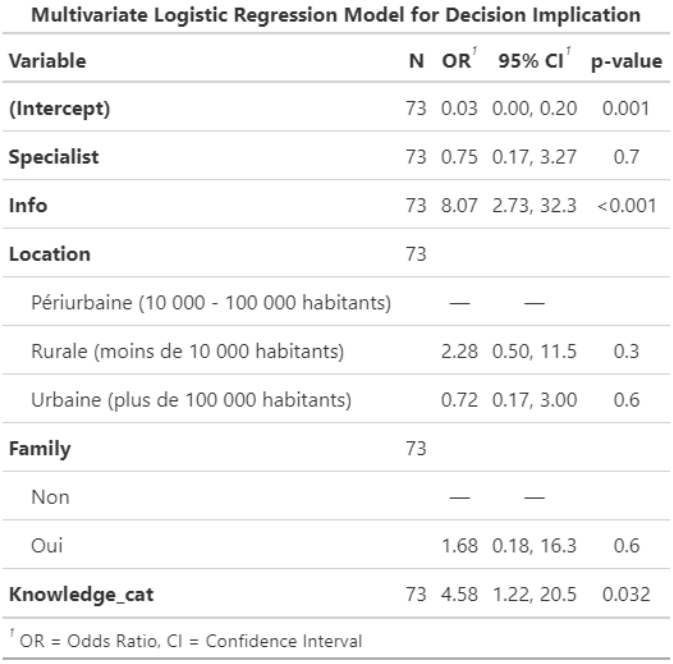
Table 8. Results of the multivariate logistic regression for Satisfaction with the Resources received (dependent variable) versus Type of Specialist, Levels of Information Received, Type of BC, satisfaction with the Management of their disease, Gender, and Knowledge Levels before diagnosis (independent variables), with the associated Odds Ratios, Confidence Intervals, and p-values.



Multivariate Logistic Regression Model for Satisfaction with Resources

Variable	**N**	**OR**[1]	**95% CI**[1]	**p-value**
(Intercept)	73	2.18	0.03, 235	0.7
Specialist	73	0.46	0.03, 4.33	0.5
Info	73	8.15	2.11, 46.3	0.007
Management	73	0.65	0.21, 2.03	0.4
Type	73			
Avancé/métastatique (le cancer s'est propagé à une autre zone du corps au-delà de la vessie ou des voies urinaires)		—	—	
Invasif sur le muscle (tumeur envahissant le muscle de la vessie)		0.20	0.01, 4.63	0.3
Je ne sais pas / je ne m'en souviens pas		147,185,974	0.00, NA	>0.9
Non invasif sur le plan musculaire (pas encore dans le muscle de la vessie)		0.03	0.00, 0.46	0.016
Knowledge_cat	73	3.08	0.67, 16.4	0.2
Gender	73			
Femme		—	—	
Homme		0.07	0.01, 0.33	0.002

Table 9. Results of the multivariate logistic regression for Implication in medical decisions (dependent variable) versus Type of Specialist, Levels of Information Received, Location, Family History, and Knowledge Levels before diagnosis (independent variables), with the associated Odds Ratios, Confidence Intervals, and p-values.



Multivariate Logistic Regression Model for Decision Implication

Variable	**N**	**OR**[1]	**95% CI**[1]	**p-value**
(Intercept)	73	0.03	0.00, 0.20	0.001
Specialist	73	0.75	0.17, 3.27	0.7
Info	73	8.07	2.73, 32.3	<0.001
Location	73			
Périurbaine (10 000 - 100 000 habitants)		—	—	
Rurale (moins de 10 000 habitants)		2.28	0.50, 11.5	0.3
Urbaine (plus de 100 000 habitants)		0.72	0.17, 3.00	0.6
Family	73			
Non		—	—	
Oui		1.68	0.18, 16.3	0.6
Knowledge_cat	73	4.58	1.22, 20.5	0.032

[1] OR = Odds Ratio, CI = Confidence Interval

***Titre :** « Une étude à méthodes mixtes des besoins non satisfaits et du fardeau de la maladie des patients atteints d'un cancer de la vessie en France »*

Résumé

Introduction : Le cancer de la vessie est l'un des dix cancers les plus fréquemment diagnostiqués dans le monde, avec un rapport d'incidence entre hommes et femmes de 4 : 1 et un âge médian au diagnostic de 73 ans. Le cancer de la vessie se manifeste part de tumeurs urothéliales parmi lesquelles on distingue les tumeurs qui n'infiltrent pas le muscle (TVNIM) et celles qui l'envahissent, dites infiltrantes (TVIM). Le taux de mortalité en France est l'un des plus élevés d'Europe de l'Ouest. La maladie représente un fardeau important en raison des taux de récidive élevés et des options de traitement limitées, notamment pour les TVNIM, pour lesquels de nouvelles immunothérapies sont à l'étude. Bien qu'il représente l'un des coûts de prise en charge les plus élevés de tous les cancers, le financement de la recherche sur le cancer de la vessie reste faible, impactant le niveau de connaissances.

Méthodes : Une approche mixte a été utilisée, par le biais d'une enquête auprès des patients et d'entretiens avec des médecins. Au total, 81 patients (52 hommes, 29 femmes) ont répondu au questionnaire et 7 médecins (4 oncologues et 3 urologues) ont été interrogés.

Résultats : En pratique, les patients TVNIM sont pris en charge uniquement par des urologues, souvent dans des cliniques privées, et les patients TVIM sont traités à la fois par des oncologues et des urologues. Les patients TVNIM reçoivent ainsi moins de ressources de soutien et leurs besoins sont également sous-estimés. L'un des plus grands besoins non satisfaits identifiés était l'obtention d'informations complètes et compréhensibles. Il s'est révélé être un facteur prédictif significatif de la satisfaction à l'égard de la gestion de la maladie (OR=7,88), de la satisfaction à l'égard des ressources reçues (OR=7,91), ainsi que comme niveaux d'implication dans les décisions de soins (OR = 8,07). En ce qui concerne la manière dont l'organisation des soins devrait évoluer pour mieux répondre à ces besoins, notamment face aux nouveaux traitements potentiels du TVNIM, aucun consensus n'a pu être atteint, mais l'implication des oncologues semble probablement nécessaire, en raison de l'inexpérience des urologues avec de telles thérapies.

Conclusions : Des politiques fondées sur des données probantes doivent être mises en œuvre pour garantir l'accès des patients du TVNIM aux soins de support et relever les défis organisationnels actuels. De plus, un examen approfondi des ressources informatives dont bénéficient les patients est nécessaire.

Mots-clés : Cancer de la vessie, organisation des soins, soins de support, perspectives des patients