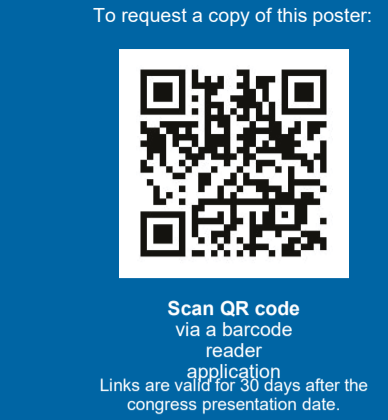


Oncologists' consideration of Health related quality of life in clinical practice for Immune-Checkpoint Inhibitors-treated patients: an online patients community research

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Introduction

- Preserving the health related quality of life (HRQoL) of cancer patients is a major goal of clinicians and health authorities [1]. Routine monitoring of PROs in daily clinical practice has demonstrated improvements in symptom management [2], patient satisfaction with care [2], levels of supportive care use [2], clinician/patient communication [3], HRQoL and overall survival [4,5,6].
- HRQoL management in routine clinical practice using various patient reported outcomes (PROs) has become the subject of many studies [7,8].
- By providing patients with a survival benefit [9] and a better tolerance profile compared to therapeutic standards [10], Immune-Checkpoint Inhibitors (ICI) treatment has become a therapeutic alternative in many tumor types.
- ICI treatments have specific HRQoL profiles.
- While the feasibility of collecting ICI-related symptom and HRQoL data is the subject of various studies [11,12], to understand patients' and healthcare professionals' (HCPs) behaviors and expectations regarding HRQoL management in routine clinical practice becomes essential and remains poorly documented.

- The study objective was to describe patients' experience and expectations regarding HRQoL, in particular in their relationship with oncologists/radiotherapists.

Methods

Online survey

- A cross-sectional web-based survey of patients treated with ICI for cancer was conducted using the French platform of an online patient community: Carenity.
- Volunteer patients were recruited from September 2018 to January 2019.
- Inclusion criteria:
 - patient or caregiver of patient living in France and suffering from cancer
 - patient or caregiver of patient treated or who has been treated with ICI: atezolizumab, durvalumab, nivolumab, pembrolizumab or ipilimumab

Questionnaire

- Areas of exploration on the questionnaire include patients' experience and expectations regarding:
 - HCPs' involvement in HRQoL monitoring
 - discussion time and dimensions of HRQoL discussed between HCPs and patients
 - importance of nine HRQoL dimensions were measured with a visual analog scale (VAS; 0-10 [low-high])
 - patients' satisfaction with the handling of their HRQoL.

Respondents' profile

- 82 patients (44% women), mean age 57 years old (y/o) (Figure 1) successfully completed the questionnaire directly or with a relative's help (10 out of 82).
- Patients suffered mainly from lung cancer (41%), lymphoma (15%), skin cancer (15%), renal cell carcinoma (6%) (Table 1).

Figure 1. Gender and age distribution of patient (n=82)

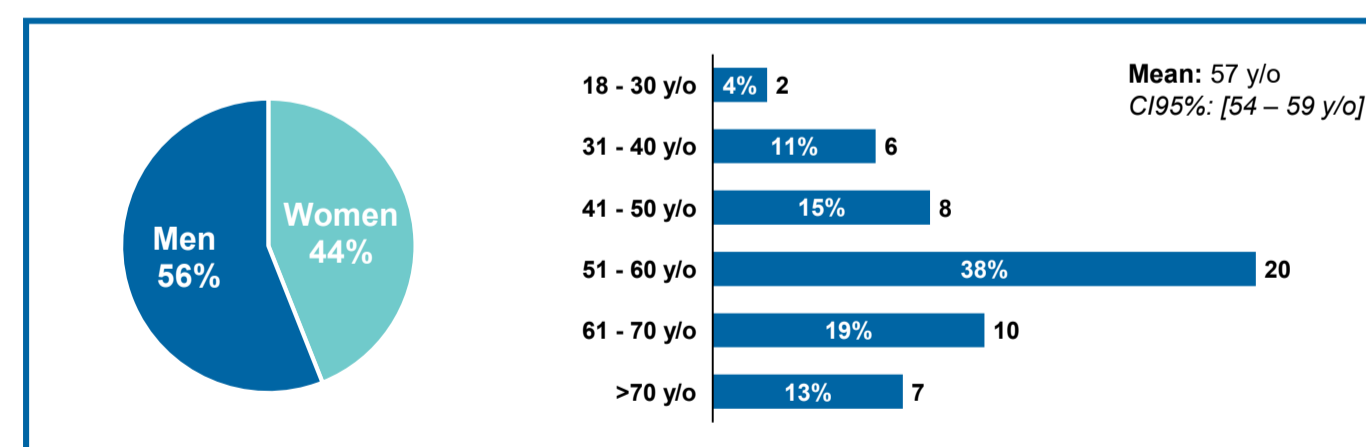


Table 1. Type of cancer of patient (n=82)

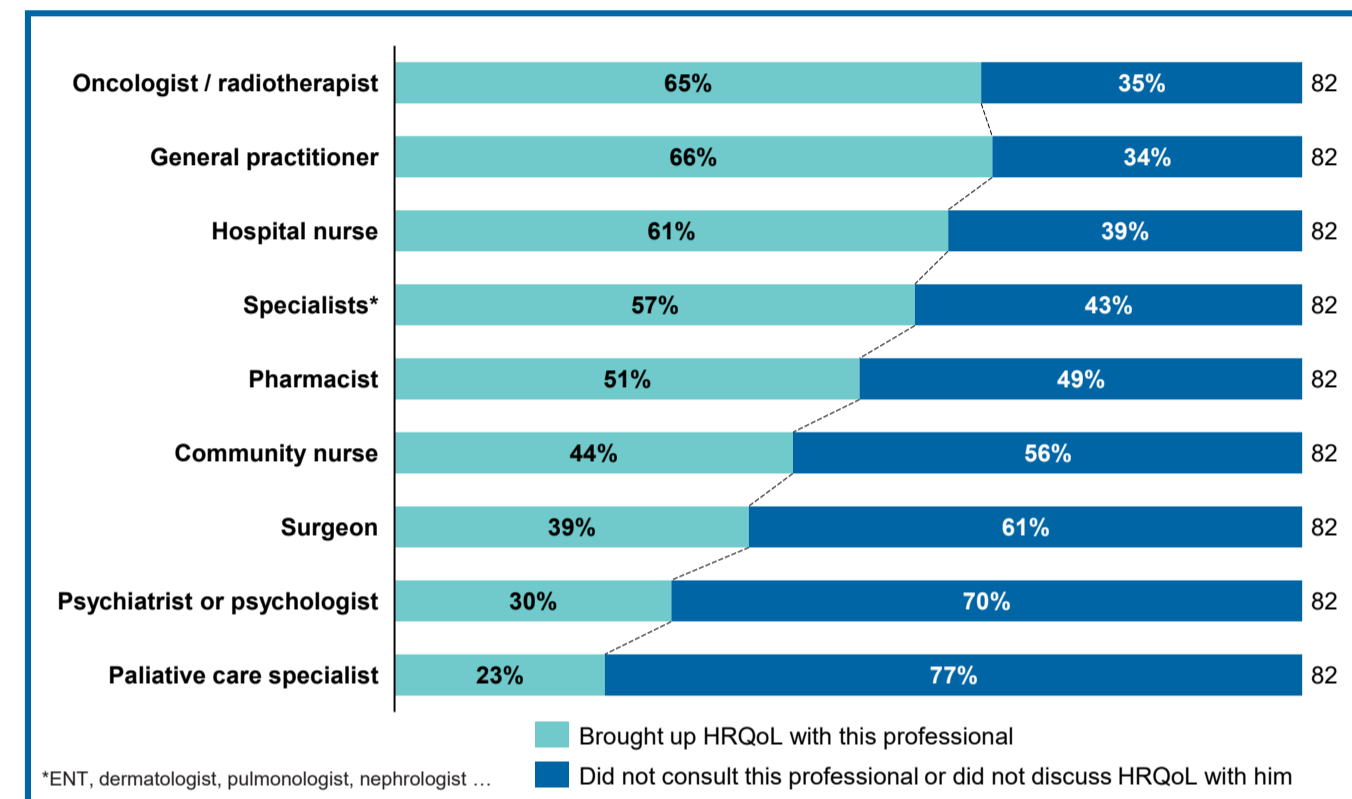
Type of cancer	n (%)
Lung cancer	34 (41%)
Lymphoma	12 (15%)
Skin cancer	12 (15%)
Renal cell carcinoma	5 (6%)
Prostate cancer	3 (4%)
Ovaries cancer	3 (4%)
Leukaemia	3 (4%)
Other	10 (11%)

Oncologists and radiotherapists are key professionals to discuss quality of life

A. Patients' experiences: oncologists/radiotherapists are one of the key professionals with whom HRQoL is discussed

- Among the 82 patients, 53 (65%) mentioned a HRQoL discussion at least once with an oncologist/radiotherapist, 54 (66%) with a general practitioners (GPs). They are the two main groups of HCPs with whom patients brought up HRQoL (Figure 2).

Figure 2. Healthcare professionals involved in HRQoL discussions (n=82)

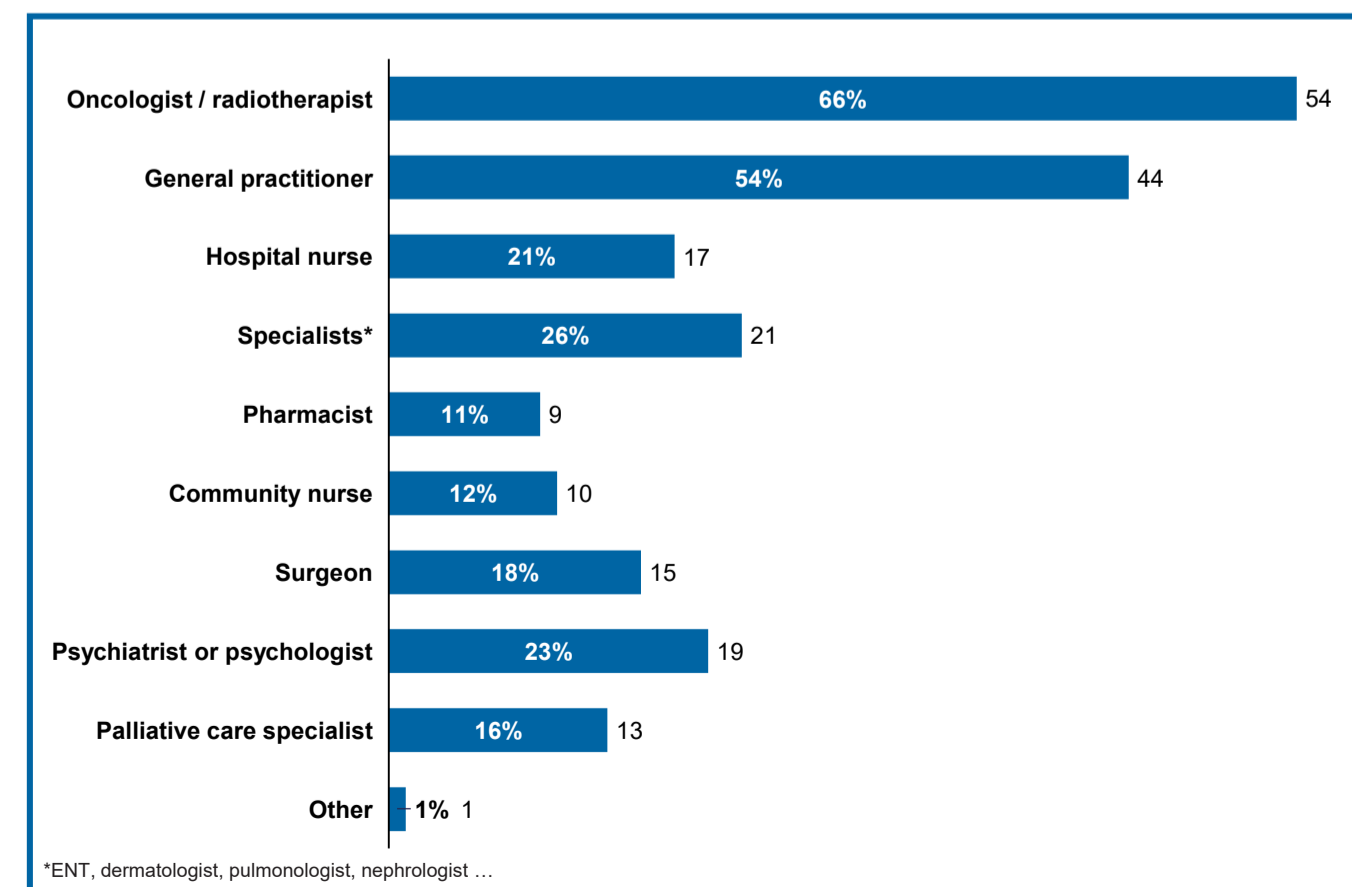


- 73% of patients (39/53) who discussed HRQoL with oncologists/radiotherapists were mostly satisfied with this interaction.
- 51% of patients (27/53) reported that they felt their oncologists/radiotherapists listened when they discussed HRQoL.
- Discussion with oncologists/radiotherapists are most often at patients' initiative (64%).
- 83% of patients who discussed HRQoL with oncologist/radiotherapist think it is very important to discuss HRQoL with their HCP and 15% think it is quite important.

B. Patients' expectations: oncologists/radiotherapists are the most important HCP to discuss HRQoL

- When asked about which professionals it is important to bring up HRQoL, two-thirds (54/82) of patients confirmed that oncologists/radiotherapists are one of the most important HCPs to discuss HRQoL with, half (44/82) reported this for GPs (Figure 3).

Figure 3. Healthcare professionals with whom it is important to bring up HRQoL (n=82)

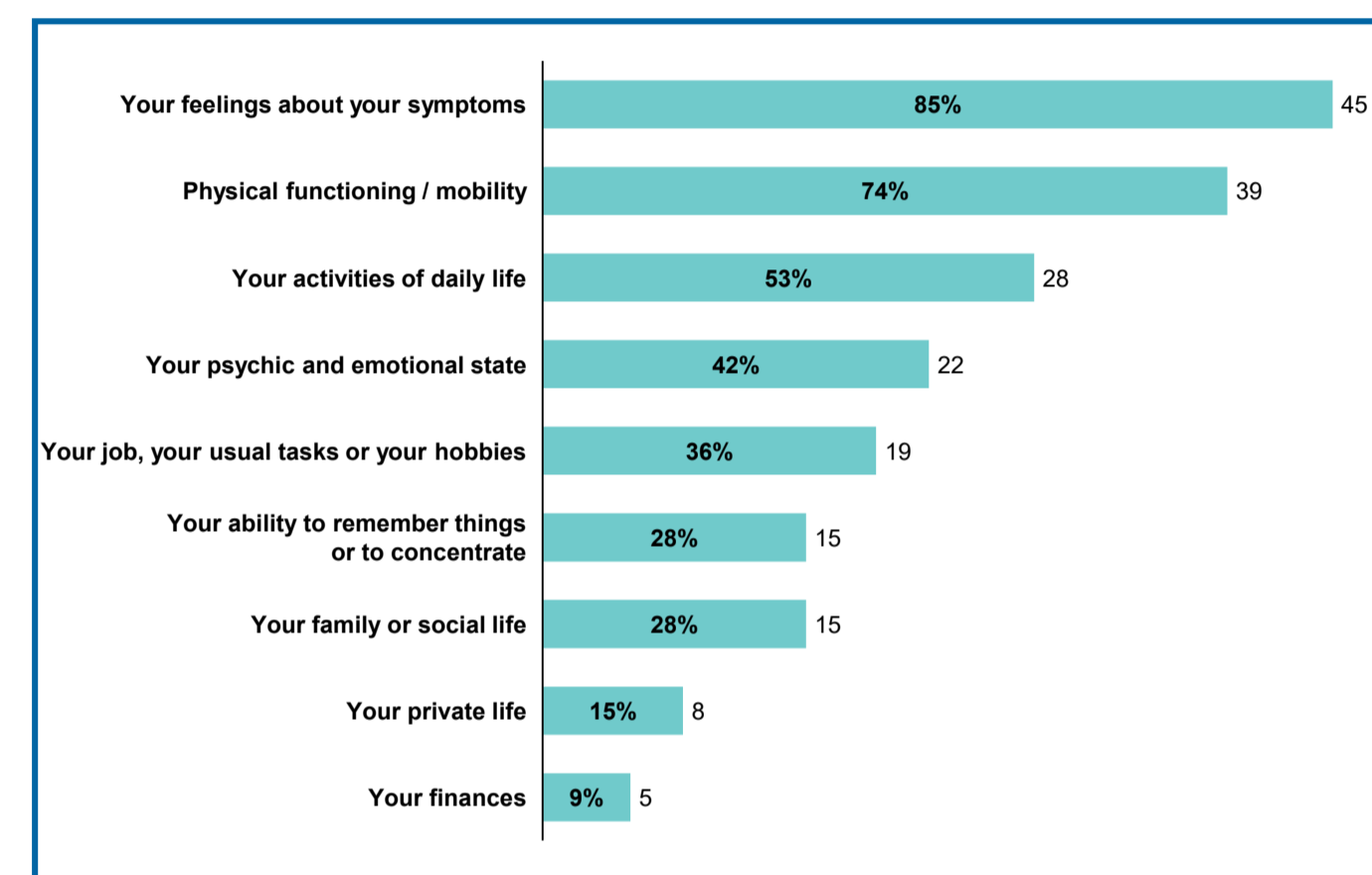


Quality of life related topics of discussion with oncologists and radiotherapists

A. Patients' experiences: topics discussed by patients who already brought up HRQoL with their oncologist/radiotherapist

- Among the 53 patients who discussed their HRQoL at least once with their oncologist/radiotherapist, the most discussed topics were symptoms (85%), physical functioning / mobility (74%) and activities of daily life (53%) (Figure 4).
- The least discussed topics are private life (15%) and finances (9%).

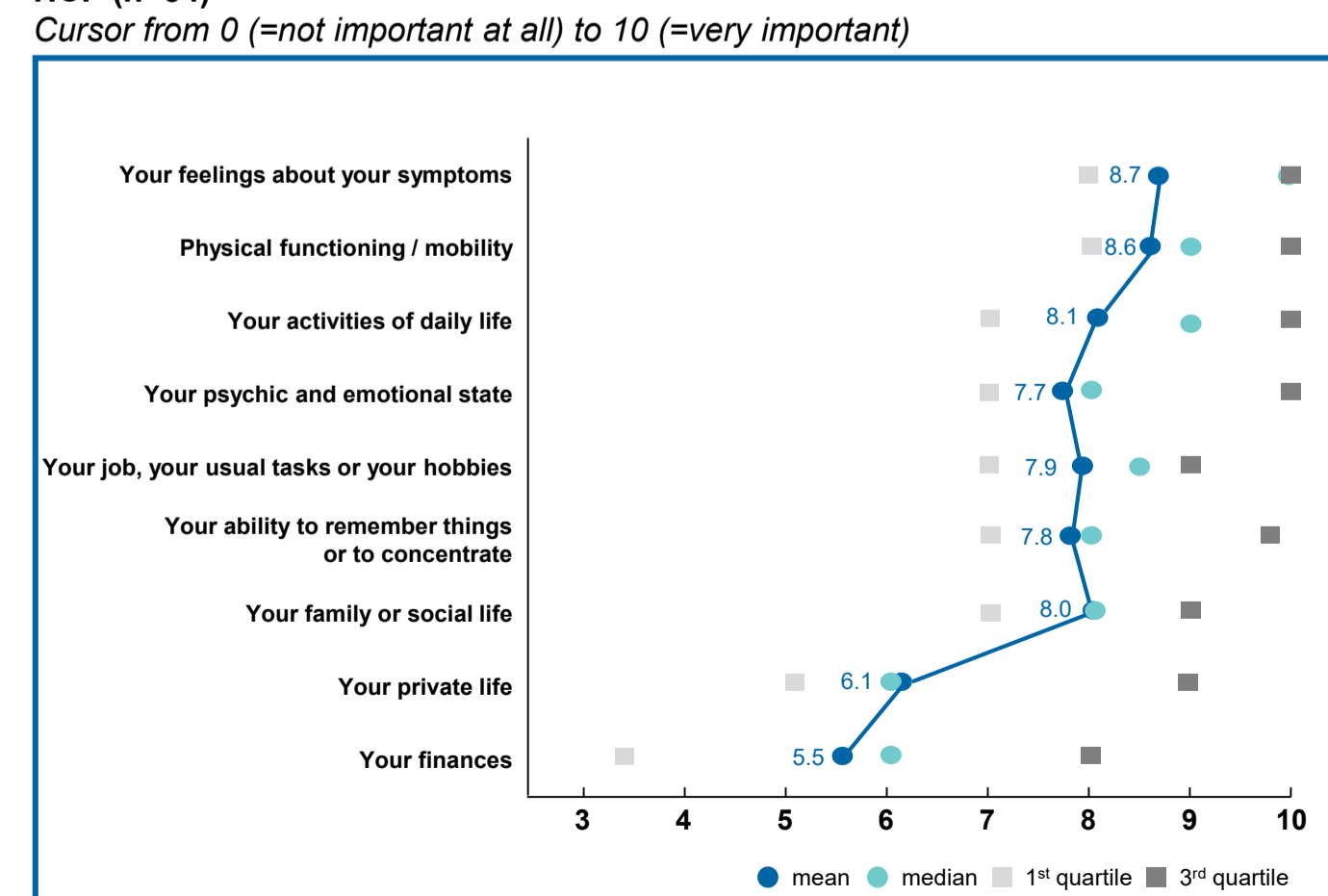
Figure 4. Quality of life related topics discussed with healthcare professionals by patients who discussed HRQoL with their oncologist/radiotherapist (n=53)



B. Patients' expectations: the most important discussion topics for patients who considered oncologists/radiotherapists as one of the most important HCP to talk to about HRQoL

- Among the 54 patients who considered oncologists/radiotherapists as one of the most important HCP to discuss HRQoL with, the most important topics to be discussed are symptoms (8.7/10 SD ± 2.0), physical functioning / mobility (8.6/10 SD ± 1.8) and activities of daily life (8.1/10 SD ± 2.2) (Figure 5).
- The most discussed topics are also considered the most important ones to bring up by patients who considered oncologists/radiotherapists as one of the most important HCP to talk to about HRQoL.

Figure 5. Quality of life topics which are important to discuss according to patients who think that oncologists/radiotherapists are one of the most important HCP (n=54)

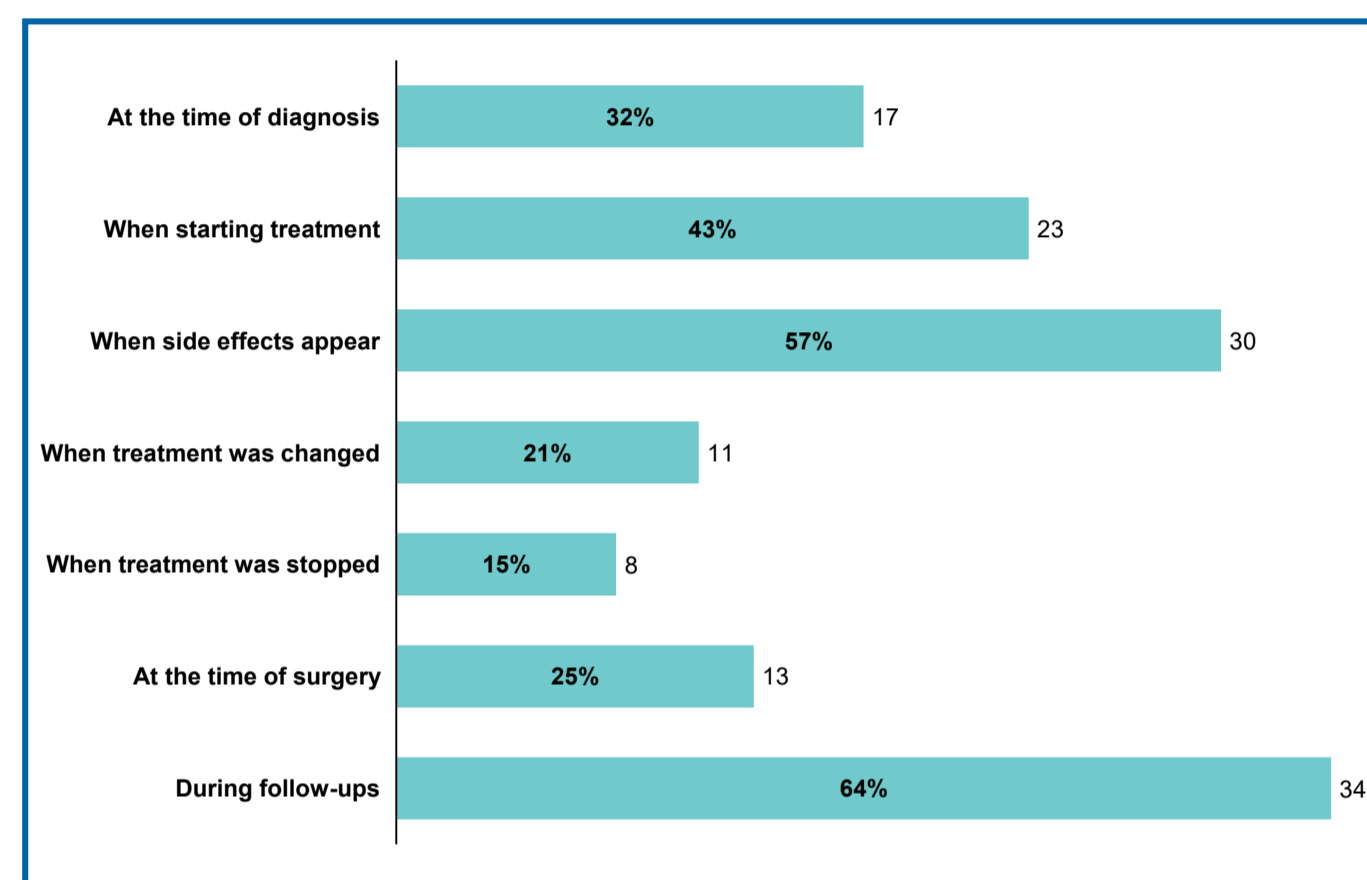


Moments of discussion on quality of life with oncologists and radiotherapists

A. Patients' experiences: moments of discussion on HRQoL of patients who brought it up with their oncologist/radiotherapist

- Among the 53 patients who discussed their HRQoL with their oncologist/radiotherapist at least once, follow-up consultations (64%), the appearance of side effects (57%) and the initiation of a new treatment (43%) are the care pathway moments during which HRQoL was most often discussed (Figure 6).

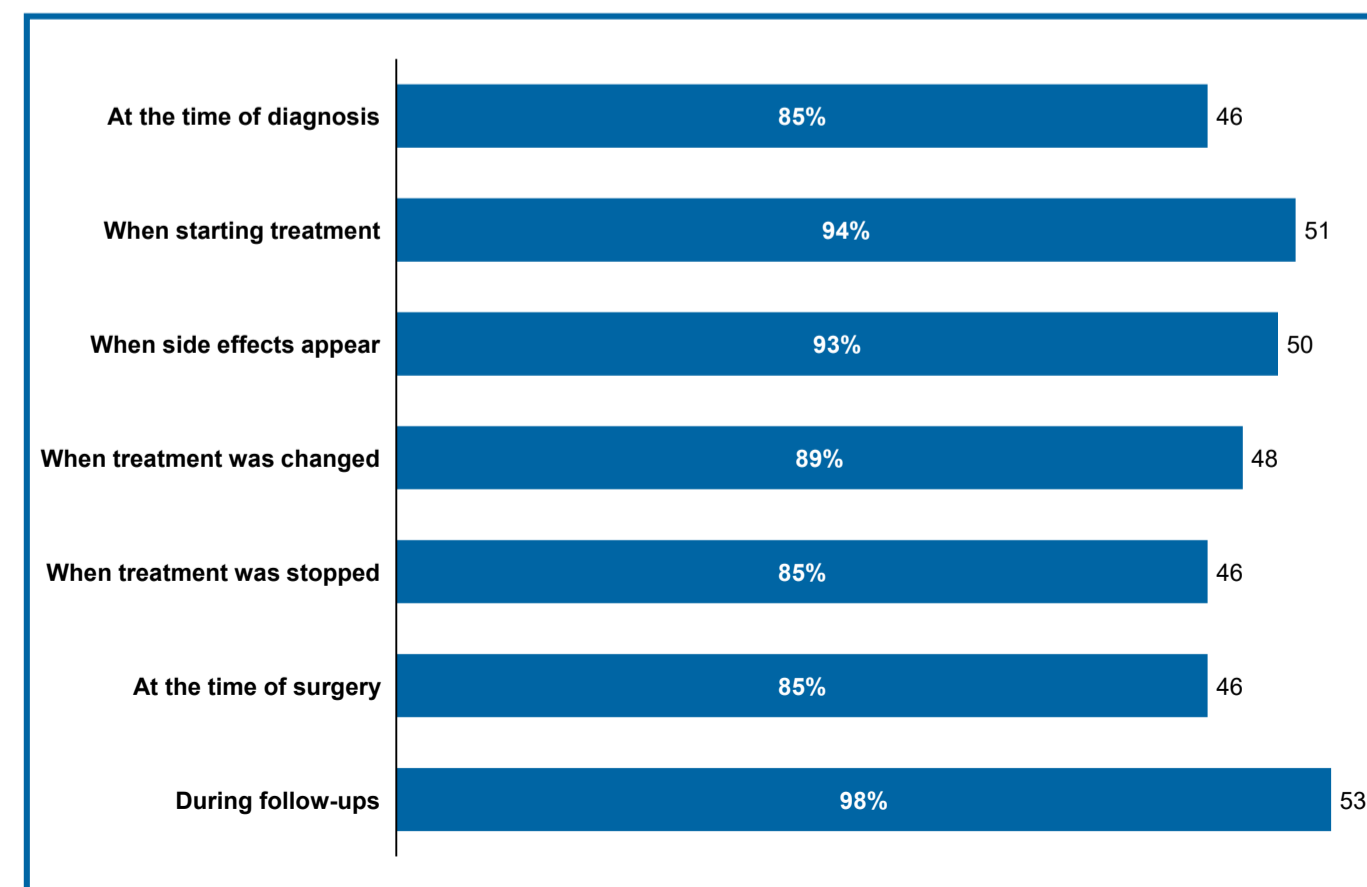
Figure 6. Moments when quality of life was discussed by patients who discussed HRQoL with their oncologist/radiotherapist (n=53)



B. Patients' expectations: the most important moments to discuss quality of life for patients who considered oncologists/radiotherapists as one of the most important HCP to approach about HRQoL

- Among the 54 patients who considered oncologists/radiotherapists to be one of the most important HCP to discuss HRQoL with, 85% to 98% considered that discussing HRQoL was important at all times of care considered in the study from diagnosis to palliative care (Figure 7).
- There is a gap between patients' experiences and patients' expectations in terms of moments to discuss HRQoL with their oncologist/radiotherapist.

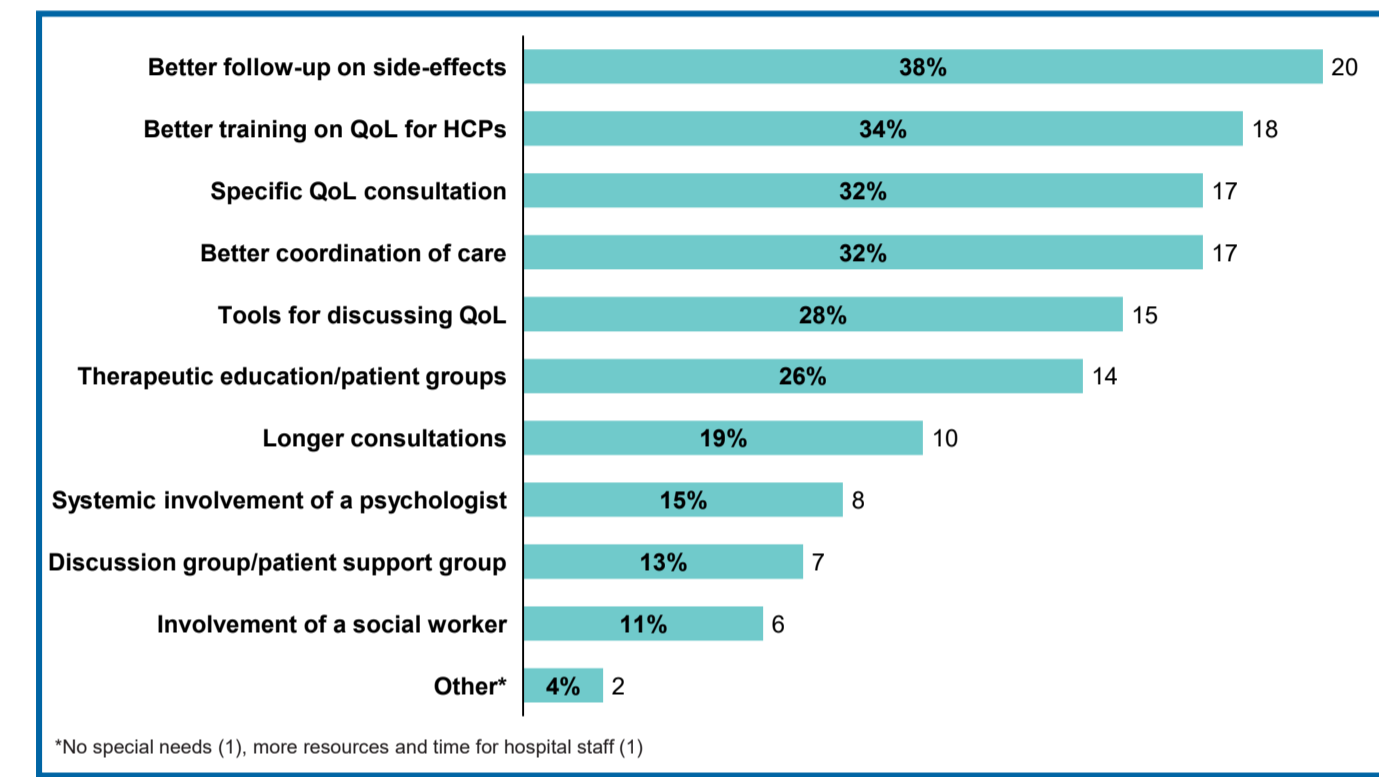
Figure 7. Moments when it would be important to discuss quality of life according to patients who think that oncologists/radiotherapists are one of the most important HCP (n=54)



Measures to improve quality of life management

- Listening, customizing the relationship with HCPs, increase of support / orientation and information are the three main topics to improve HRQoL management spontaneously mentioned by patients who discussed their HRQoL with their oncologist/radiotherapist at least once.
- Among specified listed measures that could improve dialogue about their QoL, the most frequently retained by the patients who discussed their HRQoL with their oncologist/radiotherapist at least once were: better follow-up on side-effects of treatment (38%), better training on QoL for HCPs (34%), provision of consultations specifically devoted to HRQoL (32%) and better coordination of care within the health team (32%) (Figure 8).

Figure 8. Specific measures for improving dialogue about quality of life according to patients who discussed HRQoL with their oncologist/radiotherapist (n=53)



Conclusions

- This study clearly reveals that the integration of HRQoL in routine clinical practice mostly relies on oncologists/radiotherapists. According to patients' point of view, they are and must remain the key HCP for discussion HRQoL.
- In this survey, 73% of cancer patients treated with ICI who discussed HRQoL with their oncologist/radiotherapist are satisfied with this discussion but only 51% felt listened to.
- Given the gap between patients' expectations and experiences in terms of HRQoL management, a stronger integration of HRQoL into clinical practice is a critical lever to improve care outcomes.
- The integration of HRQoL into oncologists/radiotherapists' clinical practice should happen at every step of the care pathway on a continuous basis from diagnosis to palliative care.
- All HRQoL dimensions must be taken into account to meet patient expectations. That requires an even better understanding of why some dimensions which are important for the patients (i.e. intimate life, finances, ...) are still rarely addressed and to extend discussions to these dimensions.
- Patients who have experienced at least one HRQoL discussion with oncologists/radiotherapists expect to improve quality of life management, better follow-up on side-effects of treatment, better training on QoL for HCPs, provision of consultations specifically devoted to HRQoL and better coordination of care within the health team.
- This study is based on a web community of patients, it could also be interesting to confront the patients' point of view to the oncologists' and radiotherapists' one.

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- All authors contributed to and approved the presentation