

Health-related quality of life (HRQoL) in clinical practice for immune-checkpoint inhibitors (ICI)-treated patients: what are French patients' experiences and expectations?

Results from an online patient 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 symptoms' 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 (PRO) 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], ICI treatment has become a therapeutic alternative in many tumor types. While the feasibility of collecting ICI-related symptom and HRQoL data is the subject of various studies [11,12], to understand patients' and HCPs' behaviors and expectations regarding HRQoL management in routine clinical practice becomes essential.
- The study objective was to describe ICI-treated patients' experiences and expectations regarding HRQoL consideration in cancer management.

Results

- 82 respondents (44% women), median age 57 years (CI 95%: 54 – 59) successfully completed the questionnaire directly or thanks to the help of a relative (10 out of 82). Patients suffered mainly from lung cancer (41%), lymphoma (15%), skin cancer (15%), renal cell carcinoma (6%), other cancer types (23%).

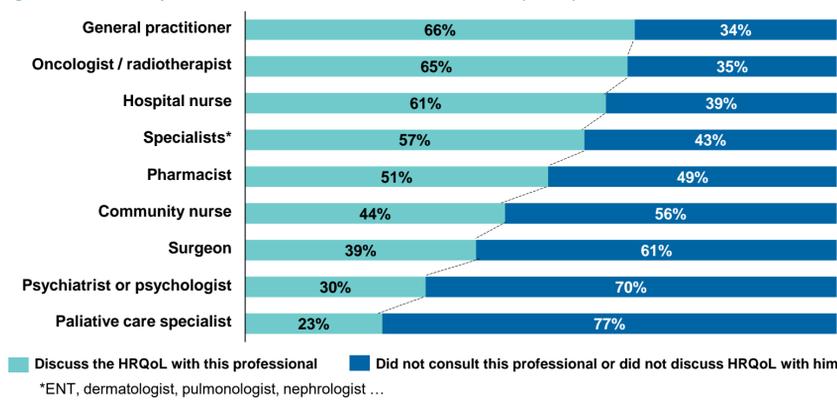
Discussion of quality of life with healthcare professionals – Experience and expectations

According to a majority of the 82 patients, HRQoL remains insufficiently integrated into clinical practice (Figure 1):

- 76% of patients (62/82) discussed their HRQoL with a HCP at least once.
- 55% of patients (45/82) were satisfied with the discussion they had with a HCP.
- 35% of patients (29/82) reported that they felt their HCP listened when they discussed HRQoL.
- 31% of patients (26/82) did not have a discussion with HCPs on their HRQoL but would have liked to or were not satisfied with the discussion they have had.
- 70% of patients think it is very important to discuss HRQoL with their HCP, and 20% think it is quite important.

- Patients mentioned a HRQoL discussion at least once with HCPs, mainly general practitioners (GPs) (66%), oncologists (65%), and hospital nurses (61%) (Figure 2). According to patients who discussed their HRQoL, discussion were only occasional or rare with all HCPs for nearly or more of half of patients (47% to 73% depending on HCP type). Discussion with oncologists/radiotherapists are most often at patients' initiative (64%). In terms of expectations, two-thirds (54/82) of the patients confirmed that oncologists are one of the most important HCPs to discuss HRQoL, half (44/82) reported this for the GPs (Figure 3).

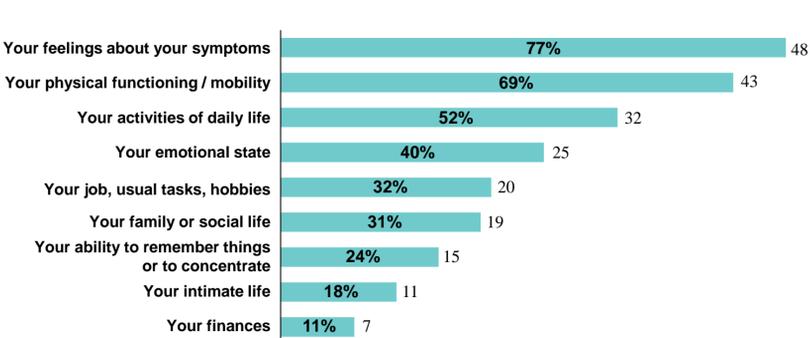
Figure 2. Healthcare professionals involved in HRQoL discussions (n = 82)



Quality of life related topics of discussion with healthcare professionals – Experience and expectations

- Among the 62 patients who discussed at least once their HRQoL, the most discussed topics were symptoms (77%), physical fitness (69%) and daily activities (52%) (Figure 4). The most discussed topics are also considered as the most important to be discussed by all patients (82). However, all topics are considered as important to be discussed (means $\geq 5.5/10$) (Figure 5).

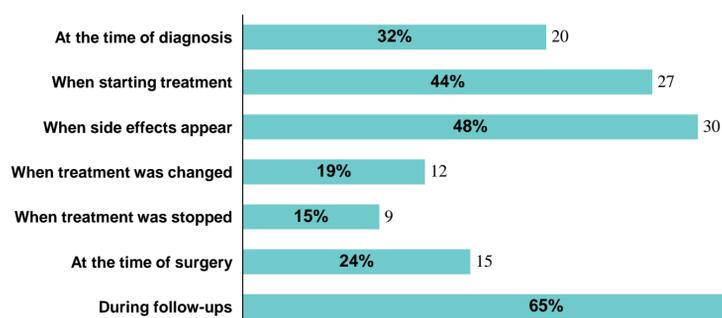
Figure 4. Quality of life related topics discussed with healthcare professionals (n = 62)



Moments of discussion of the quality of life with healthcare professionals – Experience and expectations

- The follow-up consultations, the appearance of side effects and the initiation of a new treatment are the moments of the care pathway during which the HRQoL was the most often discussed (respectively according to 65%, 48% and 44% of the patients) (Figure 6). However, most of patients considered that it was important to discuss this at the time of diagnosis and to maintain a dialogue throughout their treatment (>77%), particularly when changes were made to treatment (Figure 7).

Figure 6. Moments when quality of life has been discussed with a healthcare professional (n = 62)



Methods

- A cross-sectional web-based survey of patients treated with ICI for cancer was conducted using the French platform of an online patient community: Carecity.
- Volunteer patients were recruited from September 2018 to January 2019.
- Inclusion criteria:
 - patient or caregiver of patient living in France and suffering from cancer
 - treated or who has been treated with ICI: atezolizumab, durvalumab, nivolumab, pembrolizumab or ipilimumab
- Areas of exploration of the questionnaire include patients' experience and expectations regarding:
 - HCPs' involvement in HRQoL monitoring
 - discussion time and dimensions of HRQoL discussed between HCPs and patients
 - patients' satisfaction with the consideration of their HRQoL
- Respondents had to answer 53 questions including multiple choice questions (7), Likert scales or digital visuals (9) and open questions (4).

Figure 1. Level of satisfaction and discussion with taking QoL into account (n = 82)

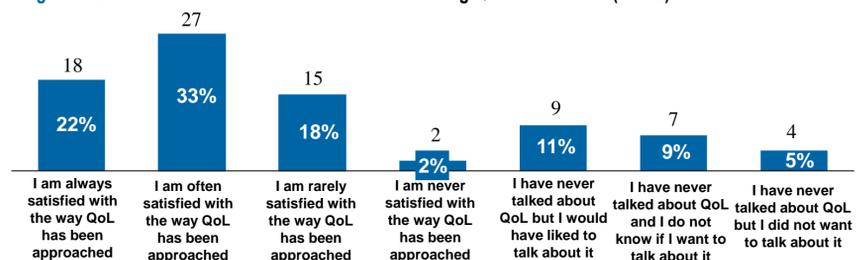


Figure 3. Healthcare professionals with whom it is important to approach HRQoL (n = 82)

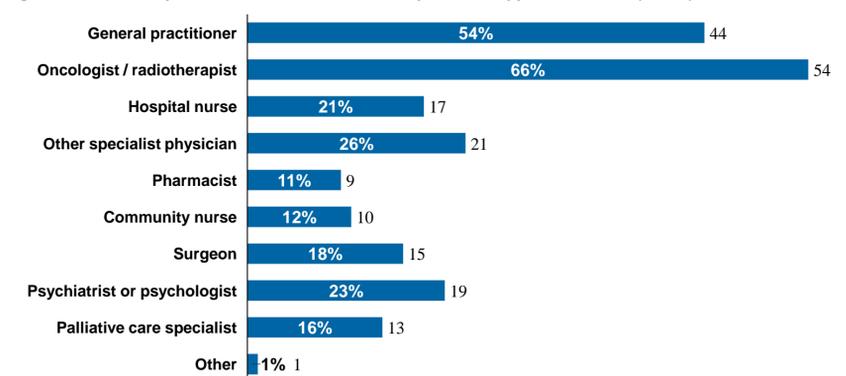
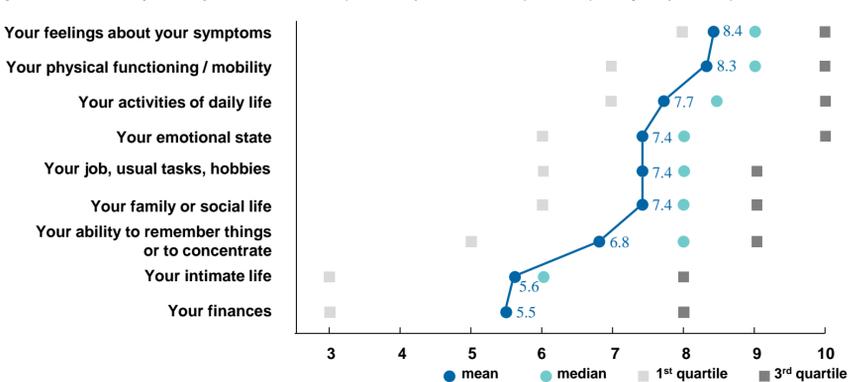


Figure 5. Importance of quality of life related topics to discuss with healthcare professionals (n = 82) Cursor from 0 (=not important at all) to 10 (=very important)



Measures to improve quality of life management and dialogue

- Listening, customizing the relationship with HCPs, increase of support / orientation and information are the three main topics spontaneously mentioned by patients to improve HRQoL management. Among specified listed measures that could improve dialogue about their QoL, the most frequently retained by the patients were: better follow-up of side-effects of treatment (38%), provision of consultations specifically devoted to HRQoL (37%) and better coordination of care within the health team (34%).

Conclusions

- In this survey, only 55% of cancer patients treated with ICI were satisfied about HRQoL discussions with the key stakeholders of their care pathway. Given the gap outlined between patients' expectations and experiences in terms of HRQoL management, a stronger integration of HRQoL into routine clinical practice is a critical lever to improve care outcomes.
- Even if this study remains based on a web community of patients and if the patients' point of view should be confronted to the practitioners' one, this study clearly reveals that the integration of HRQoL into routine clinical practice relies fundamentally on two key stakeholders: oncologists and GPs. The HRQoL integration into clinical practice should happen at every step of the care pathway on a continuous basis from diagnosis to palliative care. It could operationally be facilitated by specific organisations, such as the deployment of dedicated HRQoL consultations. All HRQoL dimensions must be taken into account to meet patients' expectation. That requires to even better understand why some of them important for the patients (ie. intimate life, finances, ...) are still rarely addressed.

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