

STANDARDISATION OF SYMPTOM MONITORING METHODS REQUIRED TO IMPROVE COLLABORATION IN MASCC SYMPTOM PROJECTS

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INTRODUCTION

- Patient-reported symptom monitoring is increasingly used in clinical practice to report a broad range of symptoms, to provide early recognition, enable earlier intervention and to assess patient outcome to improve health-related quality of life (HRQoL).
- Worldwide many initiatives exist to electronically monitor these symptoms during and after treatment, in studies but increasingly also in routine clinical care.
- However, there is no international consensus on core symptom subsets, introducing large variation in questionnaires and methods.
- A MASCC Working Group on symptom monitoring has started to explore possibilities for standardization of methods.

MATERIALS AND METHODS

- An online survey was developed and send to 23 Working Group members.
- Available patient-reported symptom datasets were investigated
- The goal was to explore their currently used methods in studies investigating the use of electronically gathered patient-reported symptoms.

RESULTS

- 16 Working Group members from 10 countries returned the survey (Australia, Belgium, Denmark, Netherlands, New Zealand, Portugal, Serbia, Switzerland, UK, USA)
- 12 Working Group members conducted/ are conducting symptom monitoring studies involving patients with cancer. Sample sizes ranged from 30 to 841. The cancer types were: breast, head and neck, hematological, lung or any/several cancer types.
- Several symptom questionnaires were used in the studies ([Table 1](#)).
- Various HRQoL questionnaires were used in addition to symptom monitoring and these were cancer-, organ- and/or symptom specific. Also HRQoL surveys include symptom questioning.
- Priorities for the Working Group to improve symptom monitoring were mentioned in open questions ([Table 2](#)).

DISCUSSION

- MASCC Working Group members use different methodologies for symptom monitoring, i.e. type of patient-reported questionnaires and frequencies.
- Standardization would allow pooling the symptom data and research e.g., creation of statistical and/or Artificial Intelligence models to predict symptom severity, trajectory, impact and outcomes of interventions.
- Another solution is mapping (i.e., transform concepts into a single code with a same/similar meaning) of separate questionnaires. However, different scales introduce loss of information.
 - Example: how to map PRO-CTCAE (severity: none, mild, moderate, severe, very severe) and ESAS (severity 0-10)?
- There is no insight in the use of symptom monitoring methods over the continents as only Working Group members from high income countries participated in the survey.

CONCLUSION

“Standardisation of symptom monitoring methodologies would improve optimal use and sharing of data in collaborative MASCC projects”

Table 1 Symptom monitoring methods among studies of Working Group members

Type of Symptom Questionnaire
• Patient-Reported Outcomes Common Terminology Criteria for Adverse Events (PRO-CTCAE) • Daily Chemotherapy Toxicity self-Assessment questionnaire • Symptom Inventory • Edmonton Symptom Assessment System (ESAS) • Problem checklist
Symptom Questionnaire Frequency
• Ranging from daily to 3-weekly

Table 2 Ideas for collaborative projects

Research topics
• Patient-Reported Outcomes related to: • Symptom severity and burden • Objective data collected using monitoring devices • Heath-related Quality of Life • Survival • Financial toxicity • Patiënt engagement and (long-term) compliance
Development
• Easily accessible digital tools for symptom monitoring • Decision algorithms for health care professionals to respond to monitoring • Prediction models for symptom evolution, longitudinal trends • Integration of symptom reporting in daily clinical practice • Symptom management integration in after care • Position paper on implementation of symptom monitoring • Recommendations on good clinical practice: quality, safety, interoperability

References

Recent symptom monitoring publications with Study Group members involved

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9. Patient-centered care – transforming the healthcare system in Vietnam with support of digital health technology. Dang et al. J Med Internet Research. 2021
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